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ABSTRACT

The Personal Futures Planning Project created a person-centered planning model for developing and implementing individually designed transition services for 30 secondary-age youths with deaf-blindness in Kentucky. Project activities included: providing training and consultation in personal futures planning, providing consultation in planning and developing services based on outcomes of the individual's "dreams," providing training to specific parents and professionals who could assist local teams, disseminating the model to other parents and local teams, and developing a method of evaluating the outcomes. The project developed and implemented strategies to increase the involvement of individuals with deaf-blindness into integrated school and community settings, to help others see the strengths of the individual, and to encourage active listening to the individual and/or the family. This was accomplished by developing a futures vision for the life of the person based on his/her preferences. The process appeared to refocus the efforts of those involved to better match their efforts with what the individual wanted. This report discusses project goals and objectives, the project's conceptual framework, evaluation findings, and project impact. Appendices provide numerous project documents, such as a description of the Summer Institute on Community Integration, evaluation summaries of project training activities, participant observation summaries, project newsletters, and a 67-page facilitators training manual. (JDD)

ABSTRACT

Personal Futures Planning Project for Individuals with Deaf Blindness (H086L00001)

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The Personal Futures Planning Project was designed to create a person-centered planning model in developing and implementing individually designed transition services for 30 secondary age youths (ages 15 -21) with deaf-blindness in Kentucky. A total of 30 youths and their families were served by the project over the three years, though six students were under 15 years of age.

The objectives and the activities of the PFP project included:

1. *Providing training and consultation in personal futures planning to participants and other interested people.*
   Activity 1: Orientation Training
   Activity 2: Individual Meeting
2. *Providing consultation in planning and developing services based on outcomes of the individual's "dreams."*
   Activity 3: Local ITP Consultation
3. *Providing training to specific parents and professionals who could assist local teams.*
   Activity 4: Mentor Team
4. *Disseminating the model to other parents and local teams.*
   Activity 5: Process Manual
   Activity 6: Newsletter
5. *Developing a method of evaluation of the outcomes.*
   Activity 7: Outcome Evaluation

The PFP project developed and implemented strategies to increase the involvement of individuals with deaf-blindness into integrated school and community settings; to help others see the strengths of the individual; and to encourage active listening to the individual and/or the family. This was accomplished through developing a futures vision for the life of the person based on his/her preferences. This process often created a vision that exceeded the capacity of present human service agencies to provide it, and

thus the process continually challenged participants to collaborate in highly creative ways to make the vision a reality.

The PFP process required an extended personal commitment by team members above and beyond the typical efforts made in developing the IEP, ITP, or other individual plans. In most cases, personal futures planning did have an impact on the education and the life of the individual after school (see Evalatuation Section and individual PFP team summaries). The process appeared to re-focus the efforts of those involved with the individual to better match their efforts with what he/she wanted. The members of the team became a source of support for the family. Lastly, as a result of the process, the individual and/or the family were better able to advocate for the individual with deaf-blindness.

PERSONAL FUTURES PLANNING PROJECT FOR INDIVIDUALS WITH DEAF-BLINDNESS
(H086L00001)

PROJECT FINAL REPORT
OCTOBER 1, 1990 - SEPT. 30, 1993

TABLE OF CONTENTS

Narrative

Appendices

Appendices for *Conceptual Framework* (Section V)

Appendices for *Evaluation Findings* (Section VIII)

Appendices for *Project Impact* (Section IX)

Personal Futures Planning Project Facilitators Training Manual

IV: Goals and Objectives of the Project

The goal of the Personal Futures Planning Project was to enhance the community participation, integration and quality of life for 30 transition age youth with deaf-blindness through the Personal Futures Planning process with these students, their families, service providers and community network. The principal objective of the Project was to provide technical assistance to these local personal futures planning teams to enable them to envision, plan and provide appropriate, personalized transitional services in an effort to create and support post-school outcomes reflecting the integration, independence and productivity of these young adults.

The Project implemented the following objectives in providing technical assistance to the local teams to enable them to accomplish the above goal:

1) To provide training and consultation in personal futures planning to project participants and other interested persons

2) To provide consultation in planning and developing services based on personal futures plan outcomes

3) To provide training to a core of parents and professionals who can assist other local teams in utilizing the personal futures planning model

4) To disseminate the model to other parents and local teams

5) To develop and utilize a method of outcome evaluation regarding the model and project activities

Each of the participants in the Project were to receive the following benefits from their involvement:

- The development of a vision for his or her "ideal" life upon exiting school, mapped for and/or with the individual
- The development of an I.T.P. to implement steps to make the vision a reality upon exiting school
- Transitional services based on the I.T.P.
- A life upon exiting school that approximates the vision

The 30 parents and families participating in the project (estimated 90 individuals total) were to receive the following additional benefits:

- Increased status as consumers who have significant input in defining service outcomes
- Strengthened relationships with families, students and other professionals and other parents who are working toward a common vision for the individual

- Increased independence in articulating and advocating for their son or daughter

The 140 educational and the 160 adult service providers participating in the project were to receive the following benefits:

- Redirection of efforts into activities which generate positive support from parents and families
- Strengthened relationships with families, students and other professionals
- Increased confidence and skills in carrying out innovative strategies

Through various dissemination efforts, the potential benefits to other children and youth not directly involved in the project were to include:

- Potential services from a cadre of key professionals in educational and adult service agencies who have a commitment to the transitional planning process, based on involvement with the project
- Potential services from a cadre of providers who *themselves* have raised expectations about adult life for individual youth, a life with emphasis on preferences, strengths and real consumer choices rather than skill deficits and limited options
- Potential transitional services based on creative strategies which have been identified by the project (i.e., strategies to help find and develop adult options when few exist currently)
- Potentially improved quality of adult life through parent advocacy fostered by the mentor team

Because of the logistical issues encountered in the Project related to the recruitment of 30 youths with deaf-blindness between the ages of 15 to 21 and parents to serve as personal futures planning facilitators, the Project sought and obtained permission to work also with children who were deaf-blind who were younger school-aged and to utilize parents in the mentor role whose children were multiply handicapped but not necessarily deaf-blind. In training done by the PFP Project for the PASSPORTS program at Seven Counties Services and the Family Connections Project of IHDI, several parents were trained as PFP facilitators and these parents did provide a mentorship role for other families in the PFP project by attending PFP meetings as participants.

V: Conceptual Framework for the Project

As stated in the original proposal, students with deaf-blindness are at great risk for segregated schooling, institutionalization, and limited opportunities upon graduation. At that time, the 17 individuals ages 22-25 years who had already "aged-out" from the Kentucky Deaf-Blind Registry had the following situations:

Kentucky Youth Who Have "Aged Out"
1989 data
Ages 22-25 years; N = 17

Where the individual lives
- 3 on his/her own (independent, minimal support)
- 1 with an alternative family (community living program)
- 2 in a state-operated facility (ICF/MR)
- 9 with parents, no service
- 2 unknown, presumably unserved

How the person is occupied during the day
- 2 in competitive employment
- 3 in sheltered work programs
- 2 in a sheltered workshop
- 3 in a day activity center
- 3 are unemployed, unserved
- 4 unknown, presumably unserved

Neither these Kentucky statistics, nor the national trend data, suggest that students who are deaf-blind are making smooth transitions to an adult life integrated into the community.

Typical Educational Solution: The ITP Model

With the passage of amendments to P. L. 101-476, and the renaming of the historic legislation to the Individuals with Disabilities Education Act in 1990, transition planning must be initiated by the school by the time the student reaches the age of 16. In the development of an Individual Transition Plan, or ITP, the local education agency takes on the responsibility of coordinating interagency efforts with various adult service agencies before the student exists the school program. The ITP, which is to be developed by this group, outlines the objectives for student skills so that the student is prepared for the life outside of school.

The ITP should also outline the steps to be taken by representatives of each agency (appropriate referrals and tests completed, etc.), so that there is no lag in services when the student exits school. The process also includes the identification of a "lead agency" for the student upon exiting school who would be willing to contact and coordinate inter-agency efforts for adult services.

The Personal Futures Planning Project proposal was written in 1989, prior to the year when the amendments to P. L. 94-142 were written and passed which required mandated transition planning. In 1989, transition planning was recommended in Kentucky, but was not mandated. Therefore, the Personal Futures Planning Project was initiated simultaneously with extensive efforts in Kentucky to implement the mandated ITP planning process. This was both positive, but also negative, in that the majority of schools, adult service providers, and even parents in the first two years of the project were themselves learning about transition planning and were, at times, unprepared and unwilling to participate meaningfully in the extra efforts required by both personal futures planning and the newly required transition component.

Despite the recognized value of the ITP concept, there are some inherent weaknesses in the model. First, the model is based on the status quo: that is, on whatever adult services are available. Transition is viewed as a "hand-off" between the school and the adult service agencies, with existent adult services reviewed and selected for the student. The model thus does not address two major issues in adult services in Kentucky and the United States today:

1) QUANTITY: the lack of sufficient adult services and the fact of long waiting lists for what does exist; and
2) QUALITY: a service delivery system which, like most others, is designed to provide specific programs (e.g., sheltered workshops, supervised apartments) rather than being designed for an individual person, reflecting his or her choices and preferences.

Both of these issues are paramount in Kentucky given that the state ranks 47th and 48th in expenditures for adults who are disabled. (reference from David Braddock, State of the States)

Second, the general approach to transition planning has little emphasis on, or impetus for, consumer direction. Of course, parents and students are invited to participate in the interagency meetings, and their input is welcome. However, real parent/student direction is not found in the details of implementation. Even when consumer direction is initially sought in determining what outcomes will be, parents and students are still left with making forces choices between extremely limited adult service options, of which few if any are ideal or even preferred. Such limited and limiting options may lead to apathy alternating with anger, a situation similarly found in individuals in the poverty cycle.

Despite the state and local level efforts made in Kentucky, the limited transitional planning and services which have occurred have not resulted in adequate outcomes for youth with deaf-blindness as documented by the data presented earlier. The following are the needs which the Personal Futures Planning Project was to address:

- Need for services which reflect real consumer choices, rather than a forced choice between limited options
- Need for creative strategies in finding and developing adult options, when few exit currently
- Need for raising expectations about adult life for individual youth, emphasizing preferences and strengths rather than skill deficits and limited options
- Need for local commitment to the transitional planning process, especially by families and key professionals in community, educational and adult service agencies

Personal Futures Planning

The primary focus of the project was to utilize a person-centered planning model called Personal Futures Planning (PFP) (Covert and Carr, 1988; Mount, 1986) to guide in the development of transition plans for youth with deaf-blindness. This conceptual framework is illustrated in the graphic in **Appendix V-A** which was designed by Paul Bates with Southern Illinois State University. The personal futures planning is the cornerstone upon which the high school curriculum and inter-agency collaboration should be based in order to maximize the likelihood that transition planning really leads to something meaningful for the student.

A description of Personal Futures Planning, written by Jane Wells who was a training consultant to the Project, is included in **Appendix V-B.** The key steps include the identification of people who would be willing and able to commit to the planning process, the development of a personal profile based on the person's interests, gifts and capacities, and a series of planning meetings led over time by a person skilled and trained in the he process. The process demands personal investment by team members and creative action - a personal futures plan is only as good as the people who come to the meetings. Such demands are well beyond the mandated participation for IEP's and, in fact, were in addition to the normal efforts expended in developing the IEP and ITP.

Personal Futures Planning is not a values-free process. It is based on the "five accomplishments" as described by John O'Brien in his chapter entitled "A Guide to Life-Style Planning" (Wilcox & Bellamy, 1987). These five accomplishments are as follows:

- Community presence
- Choice
- Competence
- Respect
- Community participation

Personal Futures Planning can be most effective when the person who is the focus of the planning, or someone who is committed and closely aligned to that person, desires change in the direction of these accomplishments. If the person, or his or her family, is satisfied with the current situation, or does not desire change in this direction, then futures planning may not be effective and, in fact, may elicit fear and hostility from people as their values conflict with the values of the planning process.

The Project utilized the Personal Futures Planning process as designed by Beth Mount, Ph.D. and as detailed in the Manual written for the Project by Dr. Mount. The Associate Project Director and one of the Parent Coordinators, who was hired on a part-time basis, provided the bulk of the personal futures planning facilitation for the project over the course of the three years.

Given the demands of facilitating a personal futures plan are well beyond the mandated participation for IEP's and ITP's, the assumption was made that a person outside the school system and the family would have to initiate the personal futures planning process on behalf of youth with deaf-blindness. The Personal Futures Planning Project was an initiative of the Deaf-Blind Intervention Program as the assumption was also made that staff of this program could not take on the additional responsibilities and workscope with their resources and staff. Additional resources and personnel would be required to initiate and sustain such an endeavor.

Integrated Program Collaboration and Effort

In addition to the utilization of personal futures planning, the project was conceptualized to be an integrated effort of and for person with deaf-blindness, their parents and families, and the following entities:

- Interdisciplinary Human Development Institute, Univ. of KY
- Deaf-Blind Intervention Program (DBIP), Univ. of KY
- KY Department of Education
- Kentucky School for the Blind

This person and family-centered focus could not be developed or sustained without the cooperation and enablement of these organizations as together they provided administrative, technical, and fiscal support to the Personal Futures Planning Project. This integrated effort modelled effective inter-agency collaboration and individualized support for this particular project in numerous ways throughout the project's existence.

The Project also provided leadership and staff involvement in the development of a shared advisory committee, which subsequently emerged as the "Expanding Horizons Committee for Youth and Adults with Deaf-Blindness" with the Deaf-Blind Intervention Program and the Helen Keller National Center Affiliateship sponsored by the Department of Vocational Rehabilitation. The concept of working together to develop and share resources to facilitate personal futures plans as well as systemic change was a major component in both the design and particularly in the implementation of the Personal Futures Planning Project. Examples of this include:

- The 1991 Family Forum, co-sponsored by the DBIP, the PFP Project, and the HKNC Affiliate in which funds from two of the projects enabled people to attend the forum, PFP staff provided the training in futures planning at the forum, and several personal futures planning teams for young children and adults who are deaf-blind were initiated as a direct result;

- The development of a joint DBIP and PFP newsletter, "Insight" which went to people not only on the DBIP registry, but also to people on all the PFP teams; combining resources enabled a larger newsletter which could be sent to a larger number of people;

- Co-sponsorship of two consumer conferences for youth and adults who are deaf-blind with the subsequent development of a Kentucky Chapter of the Association for the Deaf-Blind; staff worked together from the PFP Project, the DBIP, and the HKNC Affiliateship to garner funds from outside sources as well as utilizing their resources jointly to enable these events;

- Co-sponsorship, with the OUTREACH Project and the KY Systems Change Project, a two-day workshop with Marsha Forest and Jack Pearpoint in May of 1991; no single project could have afforded to do this alone and members from four PFP teams were able to attend;

- Co-sponsorship, with a number of other organizations, of a Summer Institute on Community Integration in June of 1993 with a strand on person-centered planning attended by 25 people from across the state of Kentucky (see **Appendix V-C**); and

- Direct leadership provided by the Associate Project Director in the development of a Supported Living initiative in Kentucky and direct work with a Task Force of the Kentucky Disabilities Coalition to write and advocate for passage of Supported Living legislation and an appropriation of $1.5 million for the 92-94 biennium budget

This concept of inter-agency collaboration, cooperation and networking is illustrated as well in the graphic drawn by Beth Mount at the conference organized at the end of the first year of the Project (see project's *Person-Centered Planning Manual* in final appendix of this report). The commitment and participation of other people with shared values were a crucial element in the implementation of this Project.

VI: Description of the Model and Participants

The participants in the Personal Futures Planning Project were predominantly young adults between the ages of 16-21 years of age who were deaf-blind and their families. Six of the 30 individuals were school-age between the ages of 5 and 12 years of age. The model of Personal Futures Planning was utilized to guide the development of Individualized Transition Plans and also Individual Education Plans for these students.

Of the thirty participants, the following summarizes their school and post-school placements at the during and at the end of the project:

	Years 1, 2, & 3	End of Year 3
Homebound instruction (parents would not consent to child attending school; 3 only completed profiles and didn't continue with process)	5	4 (1 child died)
Residential School with no regular education inclusion	7	4
Residential school with regular education inclusion	1	2
Segregated School	3	1
Segregated classroom in regular school with no regular education inclusion	9	0
Segregated classroom in regular school with regular education inclusion	2	9
Regular class with support services	0	4
Integrated pre-school program	3	0
Transitioned from school to the community	0	4
Transtion to Helen Keller National Center Rehabilitation facility; did not work out and returned to residential facility in late summer		1
TOTAL	30	29

The Project participants represented a wide range of abilities and disabilities as is typical of the deaf-blind population. From a deficit perspective, eighteen of the participants had no formal communication system, were labelled as severely/profoundly disabled or multiply handicapped and required extensive systems of support for daily living. Of the individuals who were over the age of 18, all had been adjudicated and had full guardians appointed for them.

Five of the individuals were able to communicate either orally or through sign language, but still required extensive supports to have their daily needs met and to be safe. The seven remaining individuals had no significant cognitive limitations, but six had limited social and environmental experiences. A common characteristic of all these individuals was isolation.

The primary focus of the project was to utilize a person-centered planning model called Personal Futures Planning (PFP) (Covert and Carr, 1988; Mount, 1986) to guide in the development of transition plans for youth with deaf-blindness. This conceptual framework is illustrated in the graphic in **Appendix V-A** which was designed by Paul Bates with Southern Illinois State University. The personal futures planning is the cornerstone upon which the high school curriculum and inter-agency collaboration should be based in order to maximize the likelihood that transition planning really leads to something meaningful for the student.

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VII: Methodological or Logistical Problems

1. Recruitment of participants who were deaf-blind between the ages of 15-22

    a. Only 30 people from this target population were identified on the deaf-blind registry; when contacted about the Project, a number of families did not wish to participate;

    b. Three families agreed to participate through the profile part of the personal futures planning process and then decided not to continue; this took staff time and project resources which could not be recaptured.

Resolution: Project officer agreed to "lower" the age to include school age students who were deaf-blind; six participants were younger than 15; the inclusion of these younger children was tremendously useful to the development of a futures planning model by the staff of the Deaf-Blind Intervention Program for young children which they have subsequently utilized in trainings with families of these children.

2. Even with expenses paid, families would not travel to "orientation meetings." Orientation opportunities were coordinated each year of the project per the original proposal.

Resolution: Project staff met individually with each potential participant in their home. This required additional travel and time.

3. Time is a critical factor in the achievement of outcomes in futures planning teams. Teams which were convened the first year of the project accomplished more than those convened the third year.

Resolution: Efforts were made by Project staff to identify someone on the team who would continue to serve in the role of facilitator once the Personal Futures Planning Project was completed; the person identified was always a professional whose role on the team had been affirmed through the process and who had the time to commit to this activity.

4. Staff spent an **average** of 10 hours/week simply driving to and from meetings. Entire days could be spent in travelling to a futures

planning meeting and then back home (a number of 12 to 16 hour days were logged by the two staff who did the futures planning on the project). The availability of a state car in Louisville was also determined to be non-existent.

Resolution: The Project Director was able to negotiate a long-term lease of a state car for the Louisville-based staff for the last 16 months of the Project. This was extremely helpful to staff as the car was both reliable and available.

5. The outcomes of the personal futures planning on behalf of the focus person were highly dependent on the willingness of circle members, especially parents, to take risks, to experience change, and to obtain resources to support the dream/vision for the person. The mere existence of a plan does not guarantee the dream will become a reality. Project staff were challenged in each planning circle with numerous obstacles related to these issues (risk-taking, change, and resources) and experienced success to varying degrees in moving toward the dream in the majority of situations. Please see the review written by Beth Mount at the end of Year 2 for further elaboration and clarification of these issues found in **Appendix VIII-C.**

6. There were many factors which negatively affected the outcomes or of the personal futures planning which were beyond the Project's control. These included:

   - Health of the person
   - Health of other key family members
   - Family circumstances, e.g., divorce, unwillingness of both parents to participate, children being raised by grandparents without parental support, etc.
   - Family dynamics - how family members got along, how they dealt with the disability of their family member, and how supported they felt by others
   - Lack of investment in or commitment to the values inherent in the personal futures planning process by key people, i.e., parents, teachers, special education coordinators, rehab counselors, etc. as applied to the focus person because of the severity of that person's disability

7. Even with support, no parents whose children were deaf-blind would agree to be personal futures planning facilitators for other families. In retrospect, this result is very understandable. PFP facilitation not only required extensive meeting time; in most instances, PFP facilitation also required considerable efforts in coordinating the schedules of the other participants, contacting needed resources, and long hours 'on-the-road'. These demands are doubly difficult for

parents with substantial family and child-care commitments, as is always the case with parents of children with severe disabilities.

Resolution: Parents did serve in a variety of "mentor roles" on futures planning teams, but not in the role as facilitators. Project officer agreed to parents whose children were multiply disabled serving in this role, and these parents were quite effective and helpful.

While no parents of children who are deaf-blind served in the role of Personal Futures Planning facilitator, the Project did train three parents in other related projects and provided some support to their involvement.

There are a number of advantages to parents as facilitators:

- Parents can often bring perspective to other parents about possible educational or recreational options. Not only can the parent facilitator do this for the family of the focus person, but the parent facilitator can gain new ideas for his/her own son or daughter;
- Building support networks for the parent facilitator, including both professionals, community members, and other parents/ families with similar needs and challenges;
- Meetings lots of 'important' people, which is to say, persons who have the power to direct and influence service systems for the focal person, and therefore the facilitator's own son or daughter;
- Learning about other programs and services, increasing one's awareness of what is available in the community, including funding sources, etc.
- If the parent facilitator's child is younger than the focal person, the parent facilitator may gain valuable information and perspective about 'what comes next' for his/her own child; if the parent facilitator's child is older than the focal person, the facilitator is able to use her knowledge and experiences about her own child's transition in envisioning and facilitating dreams and opportunities for the focal person; this may, in turn, lead to refinements in the dreams for their own son or daughter.

Even for parents who have attained a balance for their own son or daughter - who have developed at least an approximation to the dream for their child - the role of being a personal futures planning facilitator may not be possible. Facilitation requires a great deal of time and energy, and these demands increase with physical distance from the focal person, with the extent of needs of that focal person, and with the extent of community isolation of the focal person's own family.

Families who have achieved successful community and educational integration for their own son or daughter with severe disabilities may have "little left over" to invest in the needs of their other family members, let alone the needs of other families. In these situations, parents can still play an invaluable role in the realization of the dream for another family's son or daughter by serving in the role of **parent mentor.** In this role, the parent mentor can share with the focal person's family their experiences and knowledge in achieving a more positive quality of life for their son or daughter (e.g., more inclusive education, work, friends, etc.) and how the focal person may "get there" as well.

A parent mentor offers the focal person's family a chance to share their fears and dreams with a parent who has had similar experiences, and who has had success in dealing with many of the same obstacles and challenges. Parent mentors can say things to the focal person's family that service providers, and even friends and relatives, cannot - including exhortations to face current challenges, to realize the future is not going to go away - in ways which are forceful but not judgemental. They, too, have been there, and their perspective has much greater credibility and authenticity.

VIII: Evaluation Findings

The following represents a summary of the project evaluation activities, carried out under *Activity #8: Outcome Activities.* As indicated in the project's Evaluation Plan specified in the original proposal and expanded in the Year II Continuation Proposal, a multi-tiered evaluation process was used. *Level I* evaluation included all teams participating in the project, and included information from each team's Personal Futures Planning document, the Personal Profile conducted with the family of each focus person, the TIPS Family Survey Form, the Helen Keller Personal Futures Planning Baseline Questionnaire, and the facilitator log for each team. *Level II* evaluation activities included structured telephone interviews with ten of the PFP teams over the course of the project. Key members of each team were interviewed twice: the first round of interviews were conducted after the team had been functioning approximately six months and the second round near the completion of each team's work. *Level III* evaluation activities were designed to focus more indepth upon *six* of the teams identified in Level II. These indepth interviews were to be in-person, and at Level III, up to five team members were to be interviewed for each team. As it became apparent during the course of the interview process that the telephone interviews conducted for Level II were as in-depth (and sometimes more so) as the 'in-person' interviews for Level III, we collapsed Levels II and III into a single evaluation level of ten teams. By the end of the project, 71 interviews had been conducted across the ten teams. Typed transcripts for each interview averaged 14 pages in length; and the cumulative transcripts for all ten teams were 1064 pages in length. Finally, the *Level IV* evaluation focused on participant observations for the focal persons in *two* teams. At this level, we were interested in how that person's life 'looked', i.e., how Personal Futures Planning had resulted in daily, observable life changes.

A summary of evaluation findings will be reported for each of these Levels: Level I, Level II/III (combined), and Level IV. At the end of these findings, we will discuss the implications of our results, including differing perceptions of family members and professionals of the PFP process, and directions for further work using Personal Futures Planning with youth and young adults with deaf-blindness.

Level I: Evaluation of Project Training Activities and Component Analyses Conducted with All Teams

The Level I evaluation component included both the evaluation of *general* project training and awareness activities (PFP training sessions, orientation sessions, and annual conferences) as well as an outcome analysis for all of the teams that participated in the Personal Futures Planning Project. For the individual student outcome analysis, the following sources were included in the Level I evaluation: information from each team's Personal Futures Planning document, the Personal Profile conducted with the family of each focus person, the TIPS Family Survey Form, the Helen Keller Personal Futures Planning Baseline Questionnaire, and the facilitator log for each team. In this section, each component of the Level I analysis will be considered in turn.

Evaluation of Project Training/Orientation Sessions and Annual Conferences. Evaluation summaries of project training activities and conferences that occurred early during the project have been reported in previous reports (Year II and III Continuation Applications). Evaluation summaries of training activities not yet reported are included in **Appendix VIII-A.**

The total numbers of persons in attendance at conference training activities over the course of the project totaled 665. This includes people trained in three workshops in Indiana, Alabama, and Tennessee The total number of persons involved in Personal Futures Planning teams included 285, not counting the number of people involved in groups facilitated by people trained by the Project. The combined total is 950 people. The original proposal had an objective that 300 educational and service providers would be involved with the project and 90 individuals and their families would be involved. The Project well exceeded this objective.

Most significantly, the total number of new Personal Futures Planning facilitators trained through the project totaled 29 in Kentucky, 4 in Indiana, 2 in Tennesse, and 3 in Alabama for a grand total of 38. To the Project's knowledge, all but 6 of these people have actually facilitated personal futures planning teams. For the six people trained but who have not facilitated PFP groups, all six have incorporated aspects of the planning process into their work and have been involved as members of teams.

Finally, the project coordinated, in concert with two other projects, two consumer conferences for youth and adults with deaf-blindness, a direct result of its efforts to enable young adults with deaf-blindness to become self-advocates through the Personal Futures Planning Process. This was in addition to the original workscope as outlined in the proposal. Agenda and evaluation results from these two conferences are included in **Appendix VIII-B**

Evaluation of PFP Documents and the Congruence between the Personal Futures Plans and Individual Transition Plans.

This component of the evaluation plan was to be conducted by Dr. Barbara Wilcox. Because of a new appointment for Dr. Wilcox that occurred late in the project, she was unable to complete this portion of the evaluation component, and project staff were not able to find a suitable replacement for her. In addition, due to the 'checklist structure' of the Kentucky Department of Education's recommended Individual Student Transition Form and the difference in format and imagery between that instrument and the typical PFP plan, project staff found that an analysis of the *congruence* between the PFP and the ITP would have been problematic at best.

In order to achieve the intent of this component of the evaluation plan and to broaden its original scope, project staff contracted with Dr. Beth Mount, founder of Personal Futures Planning, to interview three of the project's facilitators concerning their involvement and perception of the process and its outcomes for four specific focal persons and their teams. In addition, Dr. Mount reviewed the interview transcripts from other members from these four teams, as well as the Personal Futures Plans developed by these teams. Her analysis of these interviews and documents are included in **Appendix VIII-C**, and provide an in-depth analysis of the processes and accomplishments for these teams.

Further, in order to determine if the *outcomes* of the Personal Futures Planning process (and not just the PFP plans themselves) reflected O'Brien's five accomplishments of Community Presence, Choice, Competence, Respect, and Community Participation, project staff have included an analysis of how the outcomes for *each* PFP team relate to O'Brien's five accomplishments. This analysis is included in the individual team summaries in **Appendix VIII-D** of this report.

This evaluation component was measured by several of the *predictor* statements generated by project staff. In general, these predictor statements served as indicators of the extent to which the Personal Futures Planning process resulted in greater levels of integration in school and community settings for the focal student, greater access to services for the focal student and his/her family, more options or choices for the focal student and family, etc. A total of 20 predictor statements were generated (see **Appendix VIII-E** for a complete list of the predictor statements and the cumulative results from the analysis of the predictor statements). Project staff used data from multiple sources, including the Personal Profiles, Personal Futures Planning Baseline Questionnaires, facilitator logs, IEPs/ITPs, etc., to analyze the results of the 20 predictor statements for each of the participating focal students and their teams. Specifically, three of the 20 predictor statements addressed this component of the evaluation:

- *Predictor Statement #8: The IEP/ITP is more reflective of value-based, peer-centered planning around the themes of the five accomplishments.* This predictor statement was judged as true for 75% (18) of the 24 teams analyzed, and *not* true for only 25% (6) of those teams.

- *Predictor Statement #16: The family (parents/siblings) of the student/focal person is helped to visualize a more positive future for the student/focal person as described in terms of the five accomplishments.* This predictor statement was judged as true for 62.5% (15) of the teams, not true for 16.7% (4) of the teams, and not applicable or scoreable for 20.8 % (5) of the teams.

- *Predictor Statement #18: The family of the student/focal person is assisted to look at the future of their son or daughter with regards to life planning.* Again, this statement was judged as true for 62.5% (15) of the teams, and as not true for 37.5% of the teams.

PFP Participant Satisfaction with PFP Process. Participant satisfaction was measured in a number of significant ways. First, *parent/family* satisfaction was evaluated through two of the predictor statements:

- *Predictor Statement #7: Parents evidence greater satisfaction for the school program of their son/daughter.* This statement was rated as true for 66.7% (16) of the teams analyzed, not true for 29.2% (7) of the teams analyzed, and not applicable or scoreable for 4.2 % (1) team.
- *Predictor Statement #13: The family of the focal person/student experiences less stress as a result of the PFP process.* This statement was rated as true for 70.8% (17) of the teams analyzed, and not true for 29.2% (7) of the teams.

Family satisfaction with the process was also measured through the Family TIPS Instrument (Transition Status and Family Satisfaction Form) which was administered to family members at the start of the PFP process and near its completion. This instrument asks parents to indicate the status of the student's residential, day-time, social, and health situations, and their relative satisfaction with those situations. Significant increases from the pre- to the post- measure in family satisfaction ratings were noted in four areas: *the number of friends without disabilities, the number of integrated activities*, and *overall social life* (all significant at the .01 level of significance) and for the *role of the family in leisure/friend activities* (significant at the .05 level). Differences between pre and post satisfaction measures for the other items were not significant.

Finally, the project's extensive interviews with parents/guardians and other team members for ten of the teams directly asked participants to comment about their satisfaction with the PFP process overall and to what extent they felt that the specific PFP tasks assigned to members of the team were evenly distributed among those team members. Again, almost all respondents felt that the process was valuable for developing and creating a vision for the future, and at a more 'pragmatic' level, for evenly distributing the work among the team members and thereby using the personal expertise and the resources of the full team. The most common points of dissatisfaction centered on the difficulty of including significant numbers of nonpaid or nonprofessional team members (i.e., friends, extended family members, other community persons) for at least some of the teams; the extent to which at least some parents and/or guardians felt that ultimately the 'onus' for the change process would fall upon them; and a sense of frustration that the resources were not always there to make the dreams happen.

Perhaps the most difficult element to measure is the satisfaction of the *focal person* with the PFP process and outcomes. This is true in that the majority of the students involved had very limited formal communication skills, and teams did not always find it even possible to include the focal person directly in the planning. There are, however, at least two indirect measures of focal person satisfaction with the process. First, *Predictor Statement #9: The student/focal person has more control and choice-making in his/her life*, indirectly assesses satisfaction through changes in the degree of personal control over one's life. For 79.2% (19) of the 24 teams, this statement was rated as true; for 16.7% (4) of the teams, the statement was rated as not true, and for one team, the statement was rated as not applicable or scoreable. Second, as a direct result of the Personal Futures Planning process, a consumers group of young adults with deaf-blindness was formed and two annual conferences were held. Again, this sense of empowerment and a continuing desire to shape one's own future indicates that for the students in this group, Personal Futures Planning was a powerful force in how *they* perceived their own lives.

Personal Profile (initiated with the family and completed with the entire team, usually at the first meeting). The Personal Profile was not really an instrument per se, but is part of the Personal Futures Planning process, and typically included the Relationships, Background (History), and Places Maps, Personal Preferences, Respect Issues, Communication and Health Issues Maps as needed, and the Dream Map. This profile was completed for each participating focal person, and served as one of the baseline measures for evaluating PFP outcomes, for organizing these outcomes into O'Brien's five accomplishments (Community Presence, Choice, Competence, Respect, and Community Participation), and for rating the truth of each of the predictor statements for that focal person. Thus the data from this component were used throughout the other evaluation components to substantiate change.

Professional Attitudes Towards Persons with Severe Disabilities (and Individuals with Deaf-Blindness) Before and After the PFP Process. Though a specific attitudinal instrument was not used in a pre/post format, this evaluation component was indirectly measured in several ways. First, *Predictor Statement #20: Professionals participating in PFP circles have extended collaborative efforts for persons with disabilities beyond the circle and the focal person* indicated that in nearly half of the teams, participating professionals had increased their collaborative efforts for *other* persons with disabilities as a direct result of participating in the PFP process. This predictor statement was rated as true for 41.7% (10) of the participating teams, and rated as not true for 58.3% (14) of the teams. While this predictor statement does not directly measure professional *attitudes*, it does measure changes in professional *behaviors*, and an increased sense among participating professionals of what is possible for persons with severe disabilities.

Second, a change in professional attitudes can be directly inferred from the numbers of professional staff who underwent the project's intensive facilitators' training, so as to increase their own capacity to facilitate person-centered planning for individuals with disabilities, including children and youth with deaf-blindness. A total of 29 persons were trained as facilitators through the project's efforts, and the majority of these persons *do* work in a professional capacity with individuals with severe disabilities. It should be emphasized that the project's facilitator training was wholly voluntary, and those professionals who undertook this training did so *in addition* to their regular job responsibilities.

Finally, professionals interviewed in Levels II and III indicated that one of the ripple effects of the PFP process was raising their expectations not only for the focal person, but for other persons with severe disabilities with whom they work. Indeed, high professional expectations is one of the most critical variables related to *any* student achievement.

Helen Keller Personal Futures Planning Baseline Questionnaire (pre and post measure). A final instrument used to measure changes in the focal person's level of participation in home and community activities is the *Helen Keller Personal Futures Planning Baseline Questionnaire*, which was administered by the facilitator to the parent/guardian at the beginning of the PFP process, and then mailed to and completed independently by the parent/guardian near the completion of the PFP process. Overall, the cumulative pre/post changes evidenced by this instrument are very inconclusive. None of the items evidenced statistically significant change in either a positive or negative direction. A 'hand-calculated' analysis revealed that, as a group, family members rated 19 items as indicating more positive participation, 8 items as actually indicating *less* participation, and 4 items as having no change. It is also interesting to note that in at least one area in which *both* the predictor statement analyses and the parent satisfaction survey form (TIPS) indicated significant positive life changes (i.e., meaningful relationships with peers) the pre/post baseline questionnaire actually indicated a (statistically insignificant) *decrease*. Perhaps the single most likely reason for this inconsistency lies in the fact that parents filled out this baseline form initially with the facilitator's assistance, and in the post-evaluation, filled it out independently and returned it by mail. It should be noted that, on those Helen Keller questionnaire items in which family members had actually noted decreases in levels of community and home participation from the baseline levels, these decreases were not in evidence in the other measures of life change impact. Since the Helen Keller Questionnaire is essentially a checklist instrument, these results may indicate the difficulty in using 'one-shot' checklists more than the status of changes in the focal person's life resulting from the PFP process.

A second explanation for the discrepancy is that life changes that professionals judge as significant may not be seen in the same light by family members. While this explanation is certainly possible, as was noted above, the two instruments administered to family members to indicate their perceptions of life changes (the *TIPS Survey* and the *Helen Keller Baseline Questionnaire*) actually resulted in contradictory family responses within similar items, so these results remain rather puzzling.

Analysis of Predictor Statements. As indicated above, staff constructed a set of 20 'predictor' statements concerning probable outcomes for each of the focal persons and their families as a result of their involvement in the project. The full set of these predictor statements are included in **Appendix VIII-E**. Using all of the data sources available, project staff then rated each predictor statement as having occurred (true), not having occurred (false), or as being not applicable or scoreable. All 20 statements were rated for each of the project's participating students and teams. The results for a number of these predictor statements have been included above. In this section, we summarize the analysis of the 20 predictor statements as a whole, and highlight some of the predictor statements previously not mentioned.

Among the most significant findings are the percentages of 'true' or 'yes' responses for the following items (percentages are calculated in terms of the numbers of focal students for whom each item is applicable):

Changes for the Student Him/Her Self:

- The student has more weekly opportunities for interactions with nondisabled peers in the school setting: 60.9% true or yes responses.
- The student participates in more frequent, systematic community-based training experiences: 52.6% yes responses.
- The student participates in more frequent vocational community-based training experiences: 52.6% yes responses.
- The student participates in a greater number of age-appropriate activities in the community in non-school hours: 58.3% yes responses.
- The student/focal person participates in a greater range of age-appropriate recreation/leisure activities at home and in the community: 73.9% yes responses.
- The student attends a greater number of integrated classes with nondisabled peers: 30.4% yes responses.

Changes for the Focal Student's Family:

- The family of the focal student has more choices/options: 66.7% yes responses.

- The family initiates more contact with service providers for the focal person: 79.2% yes responses.

- The family of the student/focal person is helped to gain all medical, SSI, and/or SSDI financial assistance to which the person is entitled: 78.9% yes responses.

Adult and/or Community Services:

- Adult services (vocational rehabilitation, vocational education, comprehensive care) are contacted as a result of the PFP process: 95.0% yes responses.

Levels II/III: Round I and Round II Interviews with Key Participants from Ten Teams.

As indicated above, Levels II and III of the Evaluation Plan were collapsed into a single pool of interviews (some via telephone and some in person) with key, representative participants from ten of the project's teams. From three to five members of each team were interviewed through a set of structured questions developed by Dr. Diane Ferguson (see **Appendix VIII-F**); and in all cases, one of the parents or the guardian of the focal person was included in those interviewed. Each person was interviewed twice (after the team had been functioning approximately 6 to 8 months) and then near the end of the PFP process. A total of 71 interviews were conducted, with an average transcript length of 14 pages; and a cumulative transcript length of 1064 pages. All of the interviews were conducted by the same person, one of the project's Parent Coordinators.

While it is difficult to succintly summarize such a volume of data, there are at least three functions that these extensive interviews have served. First, they have provided a rich source for drawing out conclusions about each of the predictor statements for the ten focal persons involved. Second, these interviews have provided a confirmation of the impact or life changes for these focal persons, as seen through the eyes of the different team persons, and they give evidence of how the various roles of team members may influence their perceptions of both the changes and the barriers in the focal person's life. Finally, from the volume of these transcripts emerge several themes about the *continuing* issues in the lives of persons with deaf-blindness and their families. Each of these evaluative roles of the interviews will be discussed in turn.

First, interview transcripts provided a rich source of information (along with the facilitator logs, Personal Profile, and TIPS Survey and Baseline Questionnaire) for rating each of the 20 predictor statements for the ten focal students whose teams were interviewed. As noted above, predictor statements were rated as '+' (true), '-' (not true), or NA (not applicable or scoreable) by project staff for *every* student who was included in the project. For the ten students whose teams were interviewed, the transcripts thus provided an additional layer of data not available from all teams, and allowed for a more detailed analysis of impact.

Second, the interviews confirmed significant life changes that had been noted in other ways, and provided a method for examining how one's role as a parent, professional, or friend/neighbor/relative may influence one's perceptions of these changes. Interviews asked team members to voice how they felt about the life changes (e.g., a student working for the first time in an after school or summer job, attending a regular high school for the first time, or speaking out about their own educational program). In general, professionals viewed such changes more positively than family members (though this was not always the case); parents and/or guardians tended to view these changes more cautiously. From their 'long-term' vantage point, parents wondered if the changes could be maintained, if the support that had made these changes possible would continue to be there, and they considered how these changes might affect *their* lives. These responses are typical, of course, for *all* parents; yet they provide insight into why very positive changes in the life of the persons with deaf-blindness are not always met with equal enthusiasm by families and professionals.

Third, these transcripts provided voluminous data about continuing issues in the lives of the focal students and their families. In order to categorize these interviews into major themes, the project asked an outside evaluator, Dr. Carol David, to read a subset of the interviews and identify a probable set of categories for developing an analysis. The nine categories identified were:

- Participation of the focal person at the PFP meetings
- Participation in the process by the family and community
- Support for the family and/or caregiver
- Coordination of school and other programs
- Resources with the focal person involved
- Resources available for the focal person in the community
- Life changes and/or new experiences for the focal person
- Empowerment of the focal person and/or family
- Ripple effects from the Personal Futures Planning.

Ms. Brenda Pezzarossi conducted an extensive sorting of interview quotes into these nine categories, and then further coded quotes by family members, focal persons, and other persons (professional, community member, facilitator, etc.). Her complete analysis is included in **Appendix VIII-G**.

What follows is a summary of some of the most significant findings and continuing issues within the above themes.

Participation of the focal person at the PFP meetings.

One of the most critical processes in Personal Futures Planning, and one intrinsically related to O'Brien's five accomplishments, is the empowerment of the focal person to dream about their own life, to speak out for themselves, and to make substantial choices. Perhaps the single greatest issue in Personal Futures Planning for individuals with deaf-blindness, especially persons with deaf-blindness and additional multiple disabilities, is that for many of these individuals, communication is problematic at best; and when students *are* able to communicate, that communication has typically extended only to matters of immediate daily needs and preferences. Thus, for a number of teams, those interviewed expressed that they did not feel that it was feasible to fully include the focal person in the actual meetings. However, team members also expressed regret about that lack of focal person participation, and wondered, in hindsight, if more could have been done to *interpret* the individuals' nonverbal communicative behaviors. For those students who *were* able to participate fully in the meetings, other team members noted increased confidence in those students' ability to speak out and to advocate for their needs.

The lack of a 'true voice' for the focal person means that this crucial self-advocacy function falls more to the family or to the facilitator. This, in itself, may lead to conflict between the facilitator and/or other professionals and family members as to who speaks most clearly to the needs of the focal person and to the desirability of a particular 'future'. This tension (which is certainly not always unhealthy) was in evidence in a number of teams. Yet, in several of these instances, professionals and parents moved to a more of a shared vision, with parents recognizing new capabilities in their son/daughter and professionals acknowledging and addressing the long-standing obstacles in the lives of the focal persons and their families.

Long-Term Family Support

Several important themes emerged around this category. First, *family structural* changes *outside* of the life of the focal student can have a profound affect on the family's reaction to and capacity to respond to the needs of the focal student. Siblings going off to college or getting married, close family friends who used to provide support developing health problems themselves, can significantly affect the capacity of the family. A second prevalent theme is the *social isolation* of the parents/caregivers themselves (as distinct from the social isolation of the focal student). Parents may have even *rejected* overtures from other relatives or community members on the basis that *they* should be able to care for their own son or daughter; or they may feel that since they have cared so long for their son or daughter's needs themselves, they don't really need anyone else now. Some parents seemed to accept their sense of isolation passively; others reflected more anger. Another parent who had sought outside help, had seen positive outcomes, and been relieved still felt somewhat ambivalent: "When it gets back down to the nitty gritty, it all falls back onto the shoulders of the parents." A third, related theme around family support is the concern of the long-term future of those *parents and caregivers who are aging.* Parents or guardians reflected the difficulty of managing important changes in their life of their son or daughter as they themselves age, concerns of who will care for their child when they are no longer able, and of the exhaustion that comes from fighting life-long battles to provide for the needs of their child. Clearly, parents were thinking *beyond* the Personal Futures Planning process; as they welcomed the positive changes in the life of their son or daughter and expressed relief that 'everything was 'no longer falling to them', they voiced concerns of the future and the permanency of those positive changes.

PFP as a Coordination Tool

A 'ripple' effect of Personal Futures Planning that emerged from the data is the value of this process in assisting parents through the myriad of services and systems with which they must interact, and the value of PFP as an 'organizer' for coordinating these services. Parents continually voiced their frustrations with dealing with multiple services, with long-standing battles over particular services, and with no one having the 'big picture' of their son or daughter's life. Parents and professionals both noted that the Personal Futures Planning Process often provided the first real opportunity for those persons integrally involved with the focal person's life to sit down and plan together and to understand what *each* was doing. One professional observed that the frequency of Personal Futures Planning meetings allowed for the resolution of long-standing problems that otherwise might have gone unresolved until the next annual IEP or ITP meeting. At the same time, facilitators indicated that much of this coordination necessarily fell to them, and that this role was both complex and time-consuming. Nevertheless, it is unlikely that complex service systems would have been coordinated around that student's needs - or at a more basic level, if new services would have been successfully accessed - without the Personal Futures Planning process. This is born out by at least two of the predictor statements: *the family of the student is helped to gain all medical, SSI, and/or SSDI financial assistance to which the person is entitled* (true for 78.9% of the teams for which this situation was applicable); and *adult services are contacted as a result of the PFP process* (true for 95.0% of the teams for which this statement is applicable).

Level IV - Participant observation of the focal person's life - to be conducted in the third year of the project:

The people chosen to be involved in this phase of the project began the futures planning process in the first year of the Project. Summaries of these observations are included in **Appendix VIII-H.** These observations were conducted as part of the Project's involvement with these particular individuals and were not "set-up" for purposes of this observation. In other words, these observations were made in the context of getting to know the person's situation better and in implementing steps from the action plan.

This was a conscious decision on the part of Project staff for two reasons:

1) A belief that telling people that someone was coming to observe as part of the evaluation component of the Project would create a false set of circumstances; and

2) Adding an additional trip for this purpose did not seem a wise use of Project resources.

For both individuals who were part of this final level of evaluation, increased amounts of community presence and participation (e.g., for one student, working for the first time in a community job and interacting effectively with coworkers; for the second student, interacting with nonhandicapped age-peers in regular high school classes and meaningfully participating in course projects) were observed. As noted in the observation reports included in Appendix VIII-H, this was consistent with their personal futures plan and resulted from the advocacy and technical assistance provided through the PFP process.

IX: Project Impact

Systemic Change:

1) The Associate Project Coordinator Served on Supported Living Task Force and provided leadership for the development (wrote portions of the legislation) and passage of Supported Living Legislation (HB 447) which was funded at a modest amount(in collaboration with the Kentucky Disabilities Coalition); was appointed to the State Supported Living Council and served as Chairperson from 10/92 to 10/93; without this resource, dreams developed by teams would not have resources to implement them; see **Appendix IX-A** for legislation;

2) In collaboration with Beth Mount, Ph.D., the developer of Personal Futures Planning, the Project has developed a Manual and a training model which has been used in training both professionals and parents in Kentucky, Alabama, Tennessee, and Indiana; the training manual was sent to the original Project Officer; training was also provided to three State-wide projects (PASSPORTS, Family Connections and the Bluegrass IMPACT program) which were funded by the KY Developmental Disabilities Planning Council and resulted in a number of other futures planning teams (at least 20) being initiated in Kentucky in addition to those initiated by the PFP Project. The manual is enclosed as the final appendix in this report.

3) Louisville-based Parent Coordinator provided impetus and technical assistance to the development of a School to Work Transition Program at Kentucky School for the Blind; and

4) Lexington-based Parent Coordinator provided leadership and organization to the development of "Parents Confronting Dual Sensory Impairments," a new state-wide support group for parents of children who are deaf-blind; assisted in the group applying for and receiving a grant to provide computers for 30 families who have children who are deaf-blind as well as additional resources for their newsletter (see Appendix IX B for newsletters not previously provided with continuation grants).

Leveraging resources

1) In collaboration with the Deaf-Blind Intervention Program and the Helen Keller National Center Affiliateship, wrote and received a grant from the KY Developmental Disabilities Planning Council for the first consumer conference; used these funds to leverage funds from TRACES and TAC (two national projects) which paid for speakers and other resources for this event;

2) Wrote and presented request to KY Developmental Disabilities Planning Council for two young adults with deaf-blindness to attend the first National Conference on Deaf-Blindness in ten years (requested approved);

4) For the second consumer conference, obtained funding from the Kentucky Disabilities Training Network (KY DD Planning Council funds) and the Center for Accessible Living to enable consumers to attend and to pay for interpreting expenses;

4) In concert with the Helen Keller National Center, facilitated the training of a KY team of four people including a parent, at Personal Futures Planning training in Atlanta (the project paid the air fare and partial expenses for one person to attend who was targeted as one of the project's additional facilitators) with Beth Mount and teams from nine other states;

5) Collaboration across numerous agencies (Comprehensive care centers, Vocational Rehabilitation, Home Health agencies, Protection and Advocacy) resulted in greater individualized program planning and allocation of resources for some PFP participants or the accessing of opportunities available in the community (e.g., summer job at a day care center)

6) Assisted in leveraging $1.5 million for the initiation of the Supported Living Program in Kentucky, which is serving several individuals who are deaf-blind and provides hope for thousands of children and adults in Kentucky with severe disabilities;

Consumer Impact

1) For students who are deaf-blind, the efforts of their futures planning groups have resulted in:

    * More meaningful involvement on the part of the person and family members in decision-making which has led to both family and person empowerment;

    * Increased Inclusion in regular education classes and activities;

    * Investment in vocational training and job development in integrated settings;

    * Accessing existing services (Dept. of Vocational Rehabilitation, SSI, Home and Community-Based Waiver, AIS/MR services, Supported Living resources, etc.) to support the person's

presence and participation in their home communities at present and after high school;

- Additional educational services, i.e., vision/hearing itinerant services, orientation/mobility, school to work transition programs, augmentative communication devices and functional assessments usually related to communication;

- Effective inter-agency collaboration on behalf of persons who are deaf-blind, in which agencies have demonstrated flexibility and commitment, over time, to work toward a desirable future for the individual;

2) Families have stated in interviews, which are part of the evaluation process, that they (in most cases) have felt more supported and empowered to act on behalf of child; consumers who are themselves active participants have shown personal growth and increased self-confidence;

3) The initiation of the KY Chapter of the Association for the Deaf-Blind (see Appendix IX -B for their mission statement) and

4) The involvement of the Helen Keller National Center Technical Assistance Center in the development of a transition planning focus specifically for students who are deaf-blind (Kentucky is one of eight states chosen to participate) which will continue the futures planning process for at least 3 students; appointment to the Kentucky Inter-Agency Transition Council of the State Coordinator for the Deaf-Blind Intervention Program, which will bring the needs of the students to the attention to numerous administrators of state agencies; and

5) The development of a training workshop and materials by the Deaf-Blind Intervention Project, entitled "Reach for the Stars" for families with young children who are deaf-blind.

Implications of the Project:

1) Futures planning for children with disabilities, especially those with severe disabilities, needs to start when the children are young; by the time a child reaches transition age, parents' attitudes are often very set, they may be worn out, and it is more difficult to imagine a positive future for their son or daughter;

2) Despite the existence of the transition planning mandate in IDEA, there is tremendous variation in the quality of its implementation across school districts, particularly for students with deaf-blindness; some districts are actively involved in planning for

these students, some are passively involved, and some are uninvolved;

3) Transition planning must include more than referring people to adult agencies or even having a "case opened;" because of the tremendous demand on limited resources, coordination of people who can commit these resources toward a vision is essential and typically requires more time and energy than most teachers have available to them; this implies the need for someone in addition to the teacher to help coordinate the transition planning who is knowledgeable about the ways of the adult service system;

4) The futures planning effort was most effective in the following situations:

   - Facilitator lived in the same community as the focal person and was familiar with the local resources;
   - People committed to the focal person wanted change in that person's life in a direction consistent with the values of futures planning;
   - At least two years were invested in the process;
   - The parent(s) or person was/were willing to ask other people to the meetings in addition to service providers;
   - Refreshments were provided at the meetings and people felt a sense of community and fellowship with one another;
   - The student's teacher **and** an adult service provider were both committed to the futures planning process; and
   - The facilitator felt supported in his/her role by the futures planning group.

5) In many groups, there was still work remaining to be done, even though the three years of the Project had been completed. We did not have one group where "natural leadership" emerged within the group where someone else would take on the role except in instances where one of the members, usually a professional, was trained by the project as a faciltitator. The project raised several "moral dilemmas" about starting something that really never ends - which may explain why some parents felt limited benefit from their involvement - they will still be there even when projects such as these have ended.

Appendices for Conceptual Framework (Section V)

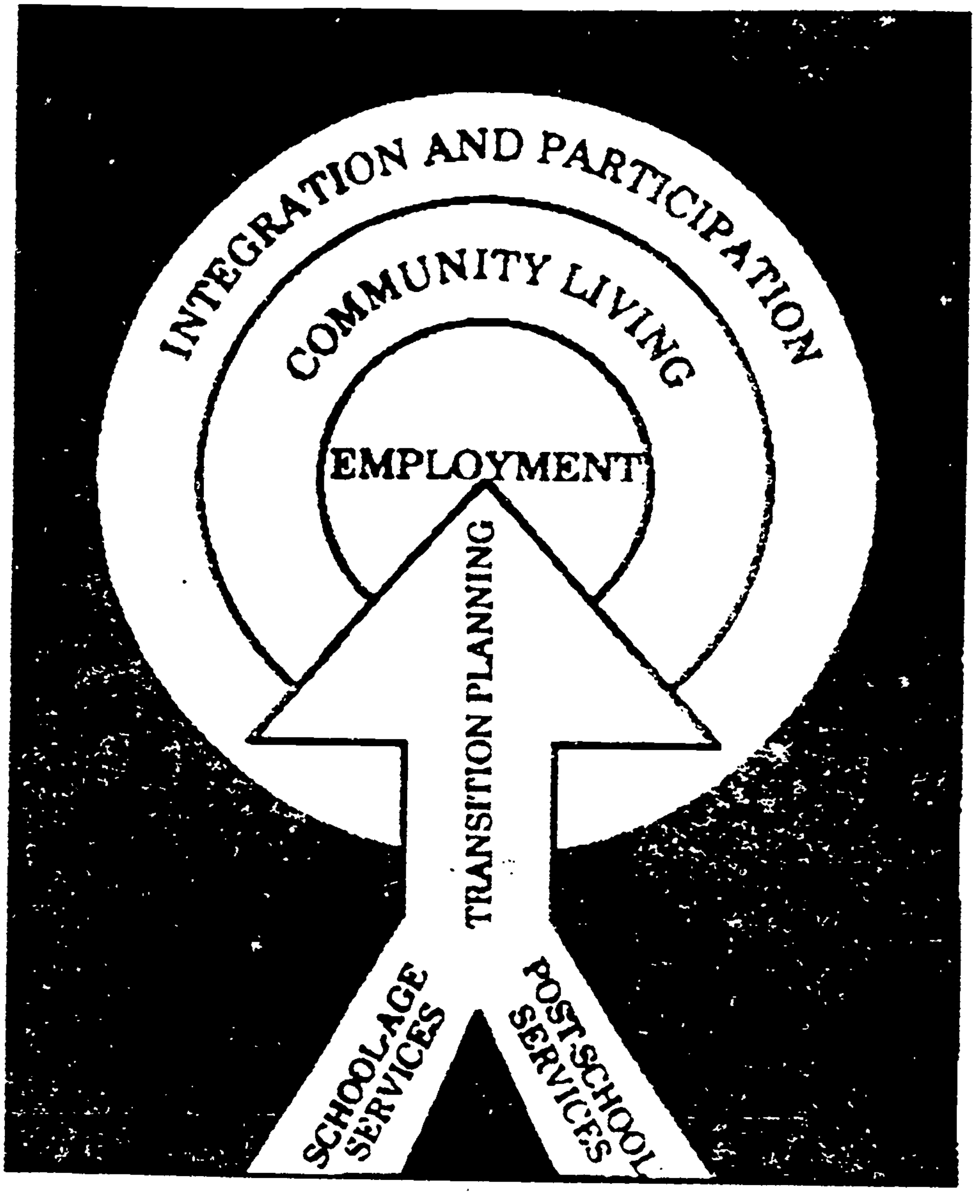
A: Conceptual Relationship Between Personal Futures Planning and Transition Planning (diagram designed by Dr. Paul Bates, consultant to the project)

B: Personal Futures Planning Description (developed by Jane Wells, consultant to the project)

C: Summer Institute on Community Integration

Appendix V-A

Conceptual Relationship Between Personal Futures Planning and Transition Planning (diagram designed by Dr. Paul Bates, consultant to the project)



Process and Outcome Accountability: A Data-Based Approach to Transition Planning at the Individual, Community and State Level

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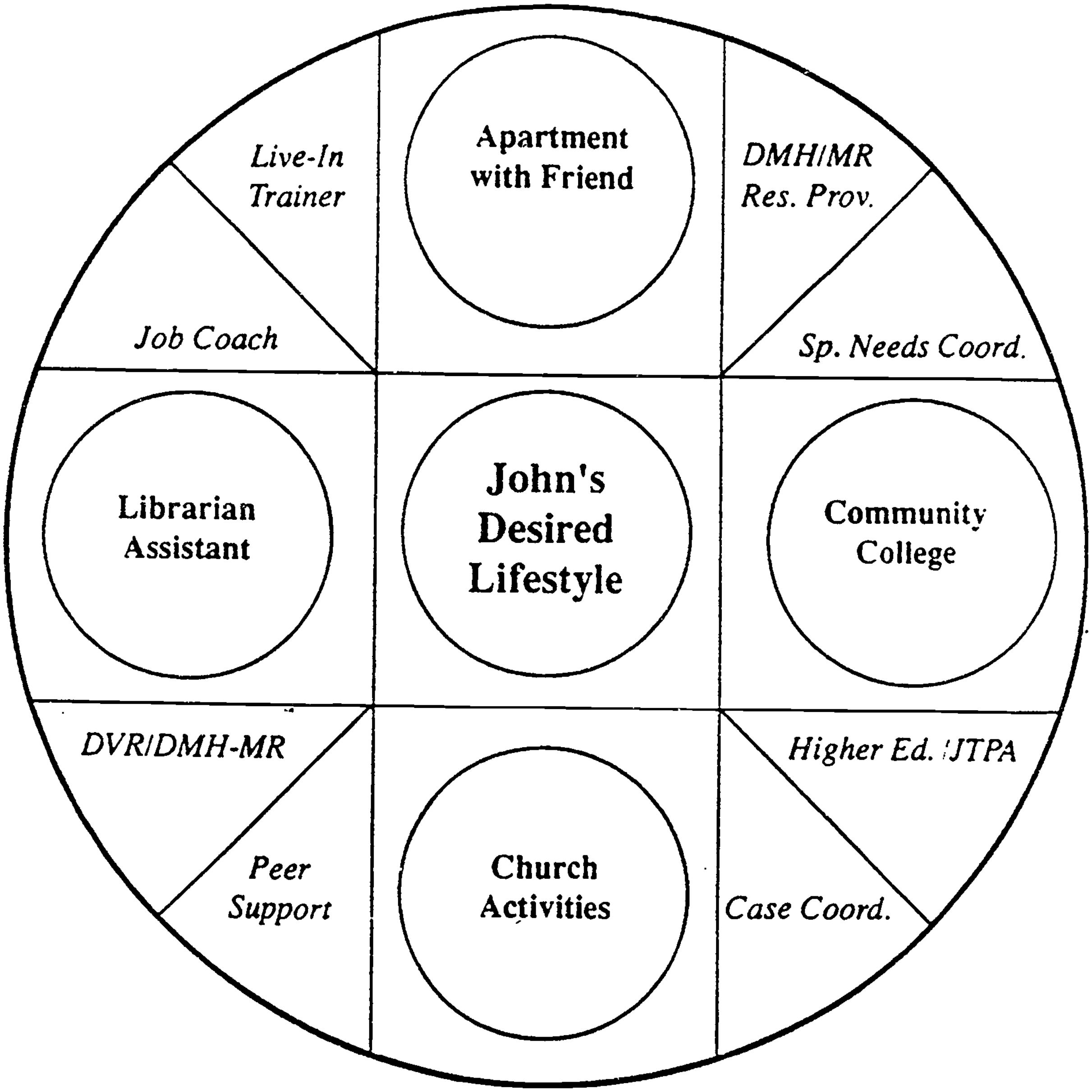

Personal Futures Planning
↓
Collective Vision
↓
Relevant High School Curriculum
↓
Interagency Cooperation/Collaboration
↓
Personalized Post-School Supports

Appendix V-B

Personal Futures Planning Description (developed by Jane Wells, consultant to the project)

Personal Futures Planning[1]

Introduction

Personal Futures Planning is a process that focuses on the capacities and strengths of an individual in order to create a vision of a desirable future. Personal Futures Planning involves much more than the development of a written plan; it is *an ongoing problem solving process.* Desired changes come about through the efforts of a small group of people who voluntarily agree to meet over time for mutual support, brainstorming and strategizing. This circle of support is committed to taking action to ensure that changes will be accomplished for the individual.

Personal Futures Planning differs radically from typical human service planning. Traditional planning meetings tend to focus on deficits and problems. Too often team meetings are held because there is a crisis, a problem is about to become a crisis, or the crisis has just ended and it's time to assess the damage. In some instances, team members get together because an outside source has determined that it is time to do so; if the rules say the team needs to meet, then the team meets. Rarely do people come together because they want to; people attend because it is required. Meetings, regardless of who is on the team or why the meeting is being held, are usually not described as positive, energizing, or exciting.

Personal Futures Planning, however, is a process that builds on capacity rather than on deficits; people who have participated describe it not only as "fun" but also as "empowering, exciting, and life-changing." People participating in Futures Planning come together to discover an individual's gifts, talents, and interests in order to create a shared vision of a more desirable future. Participation is voluntarily; Futures Planning is not likely to succeed if it is imposed on a group of people who have no personal investment in the outcome.

Personal Futures Planning is a process built on inclusion, and special care is taken to include the person whose life is being focused upon. The process is guided by a skilled facilitator who works to ensure that each participant is given an equal opportunity to contribute. People participate as equals; each person's contribution is valued and an important part of the process. Because the process focuses on discovery rather than documentation, participants are not required to bring "paperwork" (such as case files, annual reviews, social histories, or monthly data summaries) to the meetings.

Although Personal Futures Planning has most often been discussed in the context of individuals with developmental disabilities, the process could be useful to anyone with a committed desire for change. Personal Futures Planning can be used to plan with people of any age or life situation. It can be useful for very young children and their families, as well as with older people facing major life-style changes related to the need for assistance or support.

Developing the Personal Profile

The first step in Futures Planning is to create a personal profile through a group "interview," sometimes referred to as a capacity search. The participants include the individual whose life is being focused upon (the "focus person"), a few other people who care about and know the person well, and a facilitator. Because the profile is based on personal knowledge of the individual, it is important for those who spend the most time with the person on a daily basis to participate in the interview. The facilitator is a neutral, unbiased individual who is trained in Personal Futures Planning. The role of the facilitator is to lead the group through the process, assure that everyone has an equal opportunity to participate, to handle conflict if

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[1] This summary was prepared by Jane Wells, Creative Community Options, 4209 Oakmede Lane, White Bear Lake MN 55110, 612-426-9263. It is based on materials from a variety of sources, including *It's Never Too Early, It's Never Too Late* (Mount and Zwernik), *Framework for Accomplishment* (O'Brien and Lyle O'Brien), and unpublished materials by Beth Mount and Connie Lyle O'Brien.

make a commitment to action on behalf of the individual. There are seven basic steps to developing a Personal Futures Plan:

- Review the personal profile. As the facilitator reviews the profile, the group has the opportunity to make additional comments and observations.

- Review trends in the environment. Trends in the environment are ongoing events that are likely to have an effect on the person either in a positive or negative way. They may be specific to the individual or part of the larger environment.

- Finding desirable images of the future. The group begins to share their ideas about the future. Through brainstorming about where the person might live, job possibilities, friends, and opportunities for fun and relaxation, the group begins to form a vision of a future. It is essential that the group be encouraged to think creatively and imaginatively and not limit their ideas to only what is known now. Ideas are shared until something concrete emerges and the group agrees on the practicality of the envisioned future.

- Identifying obstacles and opportunities. While the group is describing images of the future, the facilitator clusters ideas together in major areas. There are typically one to three such clusters, usually around home, work or school, community activities, and relationships. The group decides which area of life is the most important to work on first and then begins identify both obstacles and opportunities that may be encountered in making the vision a reality.

- Identifying strategies. Making the vision a reality requires action. The strategies are action steps for implementation; they need to be both specific and concrete. Members of the group should be able to recognize each strategy as something that is possible to accomplish in a short period of time. Global statements, such as "investigate alternative living arrangements," are likely to produce few results. Strategies such as "contact Mary Beth Peterson to schedule a time to visit her agency and learn about what they are doing to support people where they live" are concrete, specific, and more likely to result in action.

- Getting started. The group identifies up to five action steps they will commit to completing within a short period of time. It is essential that these first steps be ones that can happen quickly and that the group meets again soon to move ahead. Before the meeting adjourns, individuals volunteer to complete one or two specific action steps and set a time to meet again. Unless at least a few members of the group will voluntarily agree to continue meeting over time, the likelihood of positive change is minimal.

- Identifying the need for system change. Focusing on the gifts and capacity of an individual often leads to a new understanding of the limitations of the existing service system. If the group members feel that the plan cannot be implemented because of problems with "the system," the likelihood of positive change for the focus person is decreased. In order to get past this tendency to "freeze" at the thought of dealing with systems issues, the group concludes the Futures Planning meeting by making a list of these issues. During the follow-along meetings, group members can begin to develop strategies for changing organizational structures.

Perhaps the most important part of Personal Futures Planning happens *after* the plan is developed. Real change comes about because people who care are willing to commit their time and energy. This network of personal support can be a group of friends, neighbors, family members, and others who care about the focus person. When these individuals are deeply rooted in the community, this kind of group is called a "circle of support." If the people who are willing to commit voluntarily to the focus person are generally human service workers and other professionals, the group is called a "person-centered team." Regardless of its composition, the network of support is a key element to making the vision real.

Implementation Issues

In our work with Personal Futures Planning, we have learned a variety of things:

- Participants have consistently reported that the process is empowering. Because the process is guided by a neutral, skilled facilitator, participants report that they felt that someone was *really listening* to them and that what they said actually did matter.

- In addition, the process provides a way for people to explore complex issues in a non-threatening situation. The presences of a third party as the facilitator helps to break down any existing "turf" issues.

- Because Personal Futures Planning is focused on discovery, the wisdom of the group is highly valued. One person cannot know everything there is to know about a person. Each person's contribution is valued.

- The use of the wall charts, symbols, colors, and maps to represent the thinking of the group provides an excellent "equalizer." Individuals with disabilities who would not be expected to sit through a meeting become engaged and sometimes enchanted by watching the facilitator use markers to write on paper taped to the wall. It is so much out of our ordinary experience that people become engaged in the process beyond their own, or others, expectations.

- There are a number of components of the Futures Planning process that may be similar in content to the development of Individual Services Plans, Individual Habilitation Plans, Individualized Education Plans, and other mandated written materials.

- Personal Futures Planning is a process that encourages participants to think creatively, lends itself to a great deal of flexibility, and may be seen as easily "adaptable" to meet the needs of a variety of situations.

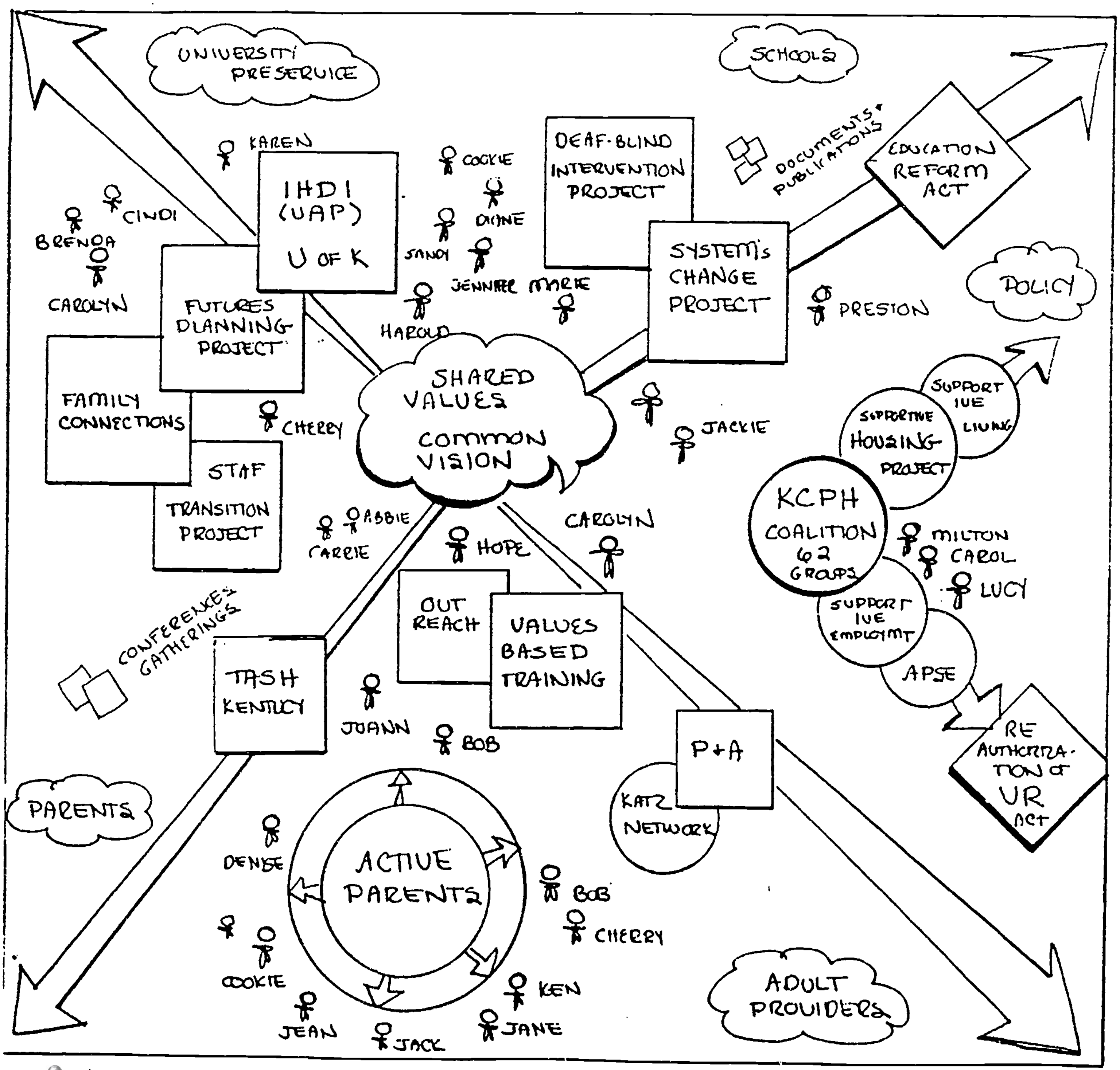
- Personal Futures Planning cannot be successfully imposed on the "system;" success depends on the voluntary commitment of the participants. Futures Planning is not a panacea.

Because of the "user-friendly" nature of Personal Futures Planning, there may be a tendency to use only what is most appealing from the process, or to change the format to fit a particular situation. However, the likelihood of positive long-term results is related to a number of factors. Those who have worked with Personal Futures Planning over time have come to realize that *it is more than the sum of its parts.* The "power" of the process is directly related to its roots as a search for capacity, its holistic approach to life planning, and the energy that is generated by the ongoing circles of support. Taking the process apart and using only what fits a particular situation significantly diminishes the effectiveness of Personal Futures Planning.

Futures Planning is first and foremost an ongoing problem-solving process. It is not an assessment. It is not the basis for a new set of forms to fill out. It cannot successfully be super-imposed on top of bureaucratic requirements. It may at times conflict with standard operating procedures. It will challenge people to think in a different way about the needs of persons with disabilities and the ways that the system responds. It takes time and energy and a willingness to go the extra mile. It can open new doors to new possibilities. And for some people, it could make all the difference in the world.

A Network of Support that Nurtures Support Circles

In addition to the 20 circles we directly or indirectly support, we also collaborate with a growing network of people to sponsor workshops, produce publications and newsletters, and learn together ways to stimulate and implement our ideals. As a result of this network, we are developing a collective vision that nurtures the personal visions of individuals and families, and the dreams and experience of individuals then informs and influences the collective vision. The following graphic summarizes the emerging leadership of these overlapping networks.



Appendix V-C

Summer Institute on Community Integration

APPLICATION FORM

Please print clearly all information.

Name:

Address:

Telephone:

Role/job:

WORKSHOP OFFERINGS Please indicate your first and second choices:

Workshop I	Workshop III
Workshop II	Workshop IV

HOUSING On-campus housing accommodations must be made for all four evenings: Monday, June 21 - Thursday, June 24:

- I do not require on-campus housing
- Register me for double occupancy housing arrangements at a total cost of $44.00
  If you are planning to room with a specific person, please provide their name:
- Register me for single occupancy housing arrangements at a total cost of $60.00
- Register me for a room that is fully handicapped accessible (single occupancy only).

SPONSORSHIP

- I am a consumer or family member and I am applying for sponsorship to cover the cost of registration and housing.

CREDIT

- I do not plan to take the workshop for college credit
- I plan to take the workshop for undergraduate credit
- I plan to take the workshop for graduate credit

Please describe any special needs you may have and accomodations which would help you participate fully:

How to Apply

1. Complete the attached application form (duplicates are acceptable) indicating your first and second workshop choices. Each workshop has limited space which will be filled on a first come, first serve basis. Register early to insure your 1st workshop choice!

2. Registration and housing fees are required at the time of application. A space will not held until your registration fee is received. Make checks payable to R.E.A.C.H. of Louisville, Inc.

3. Mail the application form with payment for registration and housing NO LATER THAN MONDAY, JUNE 7TH, 1993 to:
R.E.A.C.H. of Louisville, Inc.
428 West Oak Street
Louisville, KY 40203

4. You will receive confirmation of your registration within two weeks of receipt of application. Additional information, including a map and recommended course materials, will be also forwarded.

5. If you are interested in registering for college credit contact Debbie Cotton at 502-588-6411.

For more information, contact:
Carolyn at 502-894-9366.

R.E.A.C.H.

OF LOUISVILLE, INC.

Summer Institute on Community Integration

University of Louisville,
Shelby Campus
Louisville, Kentucky
June 21-25, 1993

For people interested in bringing individuals with challenging needs into full participation in community life.

1993

R.E.A.C.H.

O F L O U I S V I L L E, I N C.

1993 Summer Institute on Community Integration

June 21 - 25, 1993

University of Louisville, Shelby Campus

Louisville, KY

R.E.A.C.H. of Louisville, Inc., and the Kentucky Developmental Disabilities Planning Council are sponsoring a 1993 Summer Institute on **Community Integration**. The Institute is a unique and innovative one week immersion focusing on strategies for the inclusion of people with challenging needs into the community.

The Institute brings together an internationally recognized faculty to teach four workshops that provide participants with exposure to and information about integration, along with the opportunity to develop strategies relevant to their own lives and work. The Institute offers something for everyone, including consumers, family members, service providers, administrators, advocates, consultants, clinicians, teachers, university students and community members. Participants will choose one of the four workshops listed below.

The 1993 Summer Institute on Community Integration will be held at the Shelby Campus of the University of Louisville which is fully accessible. The Institute begins at 1:00 p.m. on Monday, June 21st and concludes at 11:00 a.m. on Friday, June 25th. Registration for the Institute is $55 for KY residents and $95 for out-of-state residents. Housing is available in the dormitories on campus for $11 per evening (double) or $15 per evening (single).

The Institute can be taken for one to three undergraduate or graduate credits through the University of Louisville School of Education. Extra fees are required.

For more information, call Carolyn at 502-894-9366.

kshop I

Moving Toward Supported Living: Issues for Support Agencies

Joel D. Yeager

This workshop will focus on issues related to quality of life for people who live in the community and rely on support from human service agencies. Topics will include integrated living situations, friends and family, personal finances and choice, opportunities for learning, and social standing in the community. "Real life" problems and challenges encountered by persons with developmental disabilities and the agencies that serve them will be discussed. Stories of people who Residential, Inc. has assisted in living on their own will be used to illustrate how an agency can be involved in supporting community life. Participants will benefit from Residential, Inc's. dedication to the thoughtful and timely integration of persons with developmental disabilities into the community.

*Instructor. **Joel D. Yeager** currently serves as Executive Director of Residential, Inc. in New Lexington, Ohio. Residential, Inc. is a support agency serving 22 individuals that believes that individuals regardless of disability can thrive living in the community if they are well-supported in all areas of their lives. Mr. Yeager has been directly involved in the provision of support services which focus on quality of life in the community*

Workshop II

Understanding One Another's Behavior To Create More Responsive Services

Herb Lovett and
Susannah Joyce

Service organizations sometimes have traditions and practices that can get in the way of their stated goals. We want to provide lives of satisfaction and opportunity for people and yet we often find ourselves dissatisfied and frustrated, and puzzled by interactions with coworkers, volunteers, and people we support.
This workshop will examine some of those practices within human service agencies and the complexities of the relationships involved. During the institute we will look at:
•how we can understand one another's "difficult behavior" in order to work together more co-operatively •strategies to de-mystify systems so they become resources, not obstacles •our goals and beliefs about service and what our practices are in fact •how we can bring our ideals and reality into greater concordance •what the behavior of people we support can teach us about the effectiveness of our service systems.

*Instructors: **Herb Lovett** is highly acclaimed throughout North America, and in Britain, Ireland and Europe for his innovative work for people who have challenging behavior and for his lectures and writings on creative service delivery. He is president of the Autism National Committee and author of* Cognitive Counseling and Persons with Special Needs. ***Susannah Joyce** does training and consultation on innovative approaches to human services. She has authored manuals on individual planning and quality service and is currently writing a book on the changing roles and relationships involved in supporting people with disabilities.*

Workshop III

The Challenge of Changing Systems

John O'Brien

This workshop provides a unique opportunity for participants to reflect on their own work situations and to generate new and creative directions. The instructors will lead a variety of individual, one to one, and small and large group processes for problem solving. This approach is intended to assist participants in developing their consultation, facilitation, and problem-analysis skills. A reflective thinking model will be discussed and demonstrated, helping participants to develop innovative ways of approaching their own job challenges. This workshop is designed to help create confident leaders who can assist families, schools and communities in their efforts to implement change.

*Instructors: **John O'Brien** has consulted extensively with human service systems throughout the United States, Canada, the Republic of Ireland, the United Kingdom, and Australia. The focus of his work has been that of helping people plan for change which will result in innovative and responsive supports to improve the quality of life and social position of people with disabilities. **Connie Lyle O'Brien** focuses on helping people become part of the community with the help of "circles of support." She is currently involved with an Inclusive Schools' project in Georgia and with helping two men move out of a nursing home.*

Workshop IV

Community-Building: Making Good Things Happen

George Ducharme and
Pat Beeman

This workshop will focus on practical information related to realizing the dreams held by people with disabilities. In recent years, many human service providers have embraced new person-centered approaches to planning with people who rely on their service. The development of plans which reflect the importance of authentic relationships and life rich with community experiences has resulted. Many families and human service providers continue to struggle with how to actualize such plans. The success of person-centered planning strategies depends largely on our ability to "make things happen out there". This workshop will encourage participants to explore the meaning and complexity of community and develop strategies for effectively creating new community opportunities for people with disabilities.

*Instructors: **George Ducharme** and **Pat Beeman** are co-founders and coordinators of North Spring Consulting and Communitas, Inc. in Manchester, Connecticut. Both small groups are dedicated to the full inclusion and participation of children and adults with disabilities into community life. George and Pat spend most of their time walking with people as they struggle to become part of their community.*

1993 Summer Institute

The 1993 Summer Institute on Community Integration is a unique and innovative week-long learning opportunity focusing on strategies for the inclusion of people with disabilities into the community. The Institute brings together an internationally recognized faculty to teach four workshops that provide participants with exposure to and information about integration, along with the opportunity to develop strategies relevant to their own lives and work. The Institute is a must for all leaders in the inclusion movement!

Who Should Attend

Anyone interested in the full participation of people with disabilities in our communities, including consumers, family members, human service providers, advocates, consultants, administrators, teachers, university students, and community members.

Co-Sponsors

The REACH of Louisville 1993 Summer Institute on Community Integration is co-sponsored by:

- The Kentucky Developmental Disabilities Planning Council
- The Kentucky Disabilities Coalition
- The Personal Futures Planning Project at the Interdisciplinary Human Development Institute, University of Kentucky
- The University of Louisville School of Education.

Important Information

Dates: 1:00 pm Monday, June 21 through 11:00 am, Friday, June 25.

Place: University of Louisville Shelby Campus, 9001 Shelbyville Road, Louisville, KY.

Registration Fee: The registration fee is $55 for Kentucky residents; $95 for out-of-state residents.The registration fee includes tuition and lunch on Tuesday, Wednesday and Thursday. Because the registration fee is absurdly reasonable, no group discounts will be granted.

Housing: Affordable housing is available in the dormitories on Shelby Campus. Fully accessible rooms are available. Rooms are arranged suite style with a private bath for every two rooms. The dormitories are air conditioned. Double rooms are $11 per person per evening; single rooms are $15 per person per evening.

Sponsorship: Scholarships which cover the cost of registration and housing are available for consumers and family members. If applying for sponsorship, mark the appropriate box on the registration form and do not send the fees. You will receive to confirmation of your sponsorship.

Credit: Participants may apply to receive 1-3 hours of undergraduate or graduate credit through the University of Louisville. Tuition is $112 per credit hour for Kentucky residents. Contact Dr. Sherry Moore at 502-588-6421 with questions concerning coursework.

Schedule

Monday	
11:00 a.m. -1:00 p.m.	Registration/Check-in
1:00 a.m. -3:00 p.m.	Opening address: John O'Brien
3:30 p.m. -5:00 p.m.	Individual workshops
5:30 p.m. -7:30 p.m.	Barbecue social
Tuesday	
9:00 a.m. -3:00 p.m.	Individual workshops
3:30 p.m. -5:00 p.m.	Keynote address: Pat Beeman and George Ducharme
7:00 p.m. -8:30 p.m.	Videotapes/Discussions
Wednesday	
9:00 a.m. -3:00 p.m.	Individual workshops
3:30 p.m. -5:00 p.m.	Keynote address: Joel D. Yeager
7:00 p.m. -8:30 p.m.	Videotapes/Discussions
Thursday	
9:00 a.m. -3:00 p.m.	Individual workshops
3:30 p.m. -5:00 p.m.	**Keynote address**: Susannah Joyce and Herb Lovett
6:00 p.m. -9:30 p.m.	Site seeing excursion
Friday	
9:00 a.m. -11:00a.m.	Closing session
11:00 a.m. -Noon	Check-out

Special Features

● Intensive workshop instruction (18 hours) in a small group setting lead by faculty highly respected in the field.

● Community seminars each day which provide participants the opportunity to hear each workshop instructor share their experience and ideas about inclusion.

● Nationally recognized videotapes shown on Tuesday and Wednesday evenings followed by discussions.

● Organized and informal opportunities to socialize and network with others interested in integration.

Appendices for Evaluation Findings (Section VIII)

A: Evaluation Summaries of Project Training Activities

B: Consumer Conference Agendas and Evaluation Summaries

C: Update and Reflections on the Kentucky Personal Futures Planning Project at the End of Year II (written by Dr. Beth Mount, consultant to the project)

D: Individual PFP Team Summaries of Accomplishments

E: Predictor Statements and Summary of Results

F: Structured Interview Questions for Rounds I and II

G: Interview Perspectives of Family Members and Other Participants

H: Participant Observation Summaries

Appendix VIII-A

Evaluation Summaries of Project Training Activities

PERSONAL FUTURES PLANNING PROJECT
IHDI - UNIVERSITY OF KY

Facilitator Training
May 21 - 22, 1992

Thursday, May 21, 1992

8:30 am Registration/Coffee
Derby B

9:00 am Welcome, Introductions & Overview of the Personal Futures Planning Project

Carolyn Wheeler
Associate Project Director
Personal Futures Planning Project
IHDI/University of Kentucky

9:45 am **Overview of Persons with Dual Sensory Impairments**

Marie Ruf
Transition Specialist
Deaf-Blind Intervention Program
University of Kentucky

10:30 am Break

10:45 am Overview of Personal Futures Planning as One Tool For Change - Values and Assumptions

Jane Wells
Creative Community Options
Minneapolis, MN

12:00 pm Lunch
Holidome

1:15 pm **Examples of Personal Futures Plans - The Challenge and the Opportunity**

Cindi Vaughn and Hope Leet Dittmeier
Personal Futures Planning Project
OUTREACH Project
REACH of Louisville, Inc.

2:00 pm The Personal Profile - Building Capacity
Derby B

1.) Relationship Map - who are the people in this person's life?

2) Places - Where does this person spend his/her time?

3) Background - What are the important life events, accomplishments, celebrations?

Jane Wells & small group work

3:00 pm Break

3:15 pm

4) Personal Preferences - What activities, people, opportunities motivate, encourage, are important to the person (what works) and what are activities, people, things, etc. to avoid?

5) Dreams Map: Hopes and Fears - How do people feel about the opportunities and obstacles they see to making things happen?

6) Optional Maps:
Choices
Health
Respect
Skills/ Gifts & Contributions

Hope Leet Dittmeier & small group work

4:30 pm Break

6:30 pm Communication Map
Genuine Risk

Carolyn Wheeler & Marie Ruf

7:00 pm Creating a Vision of the Future

Jane Wells & small group work

8:30 pm Adjourn for the day

Friday, May 22, 1992

8:30 am	Coffee
9:00 am	The Planning Meeting - Getting Started and Maintaining Momentum Jane Wells & Hope Leet Dittmeier
10:15 am	Break
10:30 am	Role Play of an Initial Planning Meeting and Feedback
12:00 pm Holidome	Lunch
1:00 pm	Transition Planning in Kentucky Ron Harrison & Beth Maquire State-wide Training and Facilitation Project IHDI/University of Kentucky
3:00 pm	Break
3:15 pm	Integrating the Personal Futures Planning into the IEP/ITP Process Carolyn Wheeler & Cindi Vaughn
4:00 pm	Personal Futures Planning Project and Facilitators' Roles and Responsibilities
4:30 pm	Adjourn

FACILITATOR'S TRAINING
PARTICIPANT TRAINING
MAY 21-22, 1992

CONFERENCE ORGANIZATION

1. Comfort of setting and services of hotel	3.67
2. Communication concerning event	4.44
3. Number of participants involved	4.82

PROGRAM

1. Relevance of the topic in your work	5.0
2. Usefulness of information presented	4.94
3. Format of workshop	4.61
4. Use of audio-visual materials	4.24
5. Amount of material covered	4.72
6. Hand-out material	4.71
7. Likelihood that I will perform my job differently	4.75

In your opinion, what were the most valuable aspects of the workshop?

Role play

I was encouraged to hear that our agency is really on the right track. I appreciate knowing that the human services department is viewing our families the way we do.

Philosophy of program as presented by a variety of people. Opportunities to work through (or observe) process number of times & situations.

Examples were great - I think the role play worked well. Cindi's example this afternoon was great too.

All

How to plan a future for my child.

Demonstration, hand-outs & notebook.

Actually going through a PFP with a group.

The information received from participants from other agencies etc. that could be passed along to the group.

Drawing maps.

Small group work was helpful. I enjoyed hearing personal experiences of what did & didn't work with PFP. Background info on communication issues with person with dual sensory impairments was helpful.

The hands on experience to "practice". The variety of experienced people who were at the event & able to give input & ideas.

Quality of presenters. Knowledge of program/workshop organizers. Small group & application exercises/opportunities.

Mixture of lecture & small group format. As usual, very well done! I learn things each time I hear this information presented. Thanks for inviting me.

That the person was viewed holistically past, present, future. That the wants and needs of person came first. That the person was not made to "fit" into "existing" services but services were made to "fit" the person. That the focus is individualized. That a meaningful life is wanted be all - is deserved to be had by all. That persons with disabilities can have a meaningful life and their future as well as present life situations can be rewarding and fulfilling. That a network of friends and relatives are extremely important to enhance life experiences and provide support.

Becoming familiar with the process. Learning about people needing services.

In your opinion, what could have improved the quality of the workshop?

Handout on material discussed by Jane Wells on System Centered/Person Centered, etc.
Maybe a less hectic time of year (May apply only to me).
A little more structure. Maybe being assigned to a group & staying with them throughout the event.
I thought the group activities were excellent. Maybe increase that component of your training program.
Better facility.
Had more time.
Evening sessions probably are a challenge for many.
The setting was the most distracting (temperature/noise).
The only part of the presentation that was slow was the role play. I felt I knew the piece fairly well by the second day.
It was excellent

If you are going to be a facilitator with the Project, do you feel reasonably prepared for this role? If not, what kinds of information/preparation do you need?

Yes
Yes
Somewhat!
Reasonably. Would benefit form some quick phone contacts to review before each step/mtg., etc.
Yes, but I'm not familiar with IEP meetings but this may prove to be an advantage.
Yes. I'll let you know.
Yes. It's been very helpful.

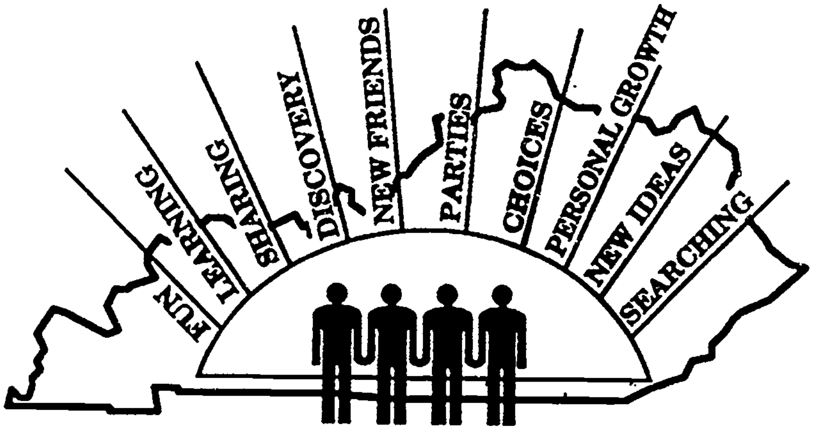
Appendix VIII-B

Consumer Conference Agendas and Evaluation Summaries

Expanding Horizons

April 24 - 26, 1992

Holiday Inn Hurstbourne Lane
Louisville, Kentucky



Sponsored By:

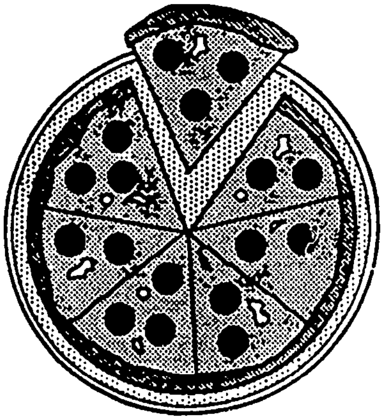
Helen Keller National Center Affiliateship
University of Kentucky Deaf Blind Intervention Program
Personal Futures Planning Project

EXPANDING HORIZONS
April 24 - 26, 1992
Holiday Inn Hurstbourne
Louisville, Kentucky

AGENDA

Friday, April 24, 1992

6:30 p.m. Parlor C	Registration
7:00 p.m. Parlor C	Welcome and Introductions Janis Friend Helen Keller National Center Affiliateship Department of Vocational Rehabilitation Marie Ruf Deaf-Blind Intervention Program University of Kentucky Dale Snellen Deaf-Blind Transition Subcommittee University of Kentucky
7:15 p.m.	Art Roehrig National Academy Gallaudet University Washington. D.C.
9:00 p.m. Presidential Suite	**Pizza Party**



Saturday, April 25, 1992

9:30 a.m. Presidential Suite	Do We Want A Support Group? Kathleen Monroe Coordinator of Information and Referral Retinitis Pigmentosa Foundation
10:30 a.m.	**Break**
10:45 a.m. Presidential Suite	Do We Want A Support Group? (continued)
12:00 p.m.	**Lunch**
1:00 p.m. Presidential Suite	Personal Futures Planning: One Way to Expand Personal Horizons Carolyn Wheeler Personal Futures Planning Project University of Kentucky Dale Snellen Deaf-Blind Transition Subcommittee University of Kentucky
1:30 p.m. Presidential Suite	An Adventurer in Washington - A Report on the National Conference on Deaf-Blindness Dale Snellen Deaf-Blind Transition Subcommittee University of Kentucky
2:00 p.m. Presidential Suite	Helen Keller National Center and Resources Monika McJannet-Werner Southeast Regional Representative Helen Keller National Center

2:30 p.m. Presidential Suite	Kentucky Helen Keller Affiliateship Deaf-Blind Transition Subcommittee Janis Friend Helen Keller National Center Affiliateship Department of Vocational Rehabilitation Marie Ruf Deaf-Blind Intervention Program University of Kentucky
3:00 p.m.	**Free Time**
	Dinner (On your own)

7:00 p.m. Presidential Suite	**Make Your Own Sundae**

Sunday, April 26, 1992

9:00 a.m. Parlor C	**Breakfast**
10:00 a.m.	What I Need To Know About Retinitis Pigmentosa Steven J. Lichtenstein, M.D. Louisville Children's Eye Specialists, P.S.C. Louisville, Kentucky
11:30 a.m.	Evaluation of the Weekend and Good-byes

HAVE A SAFE TRIP HOME!

EXPANDING HORIZONS
PRESENTER'S

Art Roehrig
National Academy
Gallaudet University
800 Florida Avenue NE
Washington, DC 20002-3625

Janis Friend
Department of Vocational Rehabilitation
627 W Fourth Street
Lexington, KY 40517

Dale Snellen
1419 Tollview Road
Shepherdsville, KY 40165

Carolyn Wheeler
Personal Future's Planning Project
c/o Kentucky School for the Blind
1867 Frankfort Avenue
Louisville, KY 40206

Monika McJannet Werner, Regional Representative
Helen Keller National Center
1065 Virginia Avenue Suite 104
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SPECIAL THANKS FOR:

FUNDING:

Helen Keller National Center
Technical Assistance Center
Sands Point, NY

TRACES
Atlanta, GA

Kentucky Developmental Disabilities Planning Council

Interdisciplinary Human Development Institute

Deaf Blind Intervention Program

DONATIONS:

Steven J. Lichtenstein M.D.

Parent's Confronting Dual Sensory Impairments

Pepsi, Louisville, KY

Nita Kauffman, Graphics

7/3/92

TRACES SUMMATIVE EVALUATION REPORT

CONSUMER SUPPORT AND ADVOCACY CONFERENCE

April 24-26, 1992

Report submitted to:
Jennifer Leatherby

Report submitted by:
Anita C. Briggs, Ph.D.
South Central Regional Coordinator
TRACES Project

SC-630-KY

PROGRAM DESCRIPTION

TITLE OF TA: Consumer support and advocacy conference

FOCUS OF TA (unit of analysis): system components

KEY SERVICE BEING ADDRESSED: 307.11 (a)(2)(i) Provide special education and related services, as well as vocational and transitional services, to children with deaf-blindness....

ADMINISTRATIVE LEVEL BEING ADDRESSED: state

OTHERS CONTRIBUTING TO PROVISION OF THE TA: Deaf-Blind Project, Personal Futures Planning Project, HKNC-TAC, Helen Keller Affiliateship.

TA FORMAT: meeting/retreat

VISITS: One two day meeting in Louisville, KY April 24-25, 1992

CONSULTANT: Art Roehrig

RECIPIENTS: 5 individuals with Usher's syndrome

TA CONTENT: Characteristics of Usher's syndrome

GOAL: To facilitate development of a consumer support and advocacy network.

OBJECTIVES:

1. To provide information on characteristics of Usher's syndrome (both sensory and psychological/emotional).

2. To facilitate discussion on future options and dreams for participants.

3. To facilitate development of a support and advocacy network for participants.

4. To facilitate development of an Action Plan for the group.

EVALUATION MEASURES

A Meeting Satisfaction Form (developed by the Kentucky DBIP) was administered to six participants as a measure of consumer satisfaction. The TA Evaluation Form was completed by the Project transition consultant as a measure of consumer satisfaction.

RESULTS

Six participants completed a Meeting Satisfaction form as a measure of consumer satisfaction. The overall mean score was 3.8 on a scale of 1-4. Comments indicated that recipients were generally satisfied with the retreat. The Deaf-Blind Intervention Project transition consultant completed the technical assistance evaluation form as a measure of consumer satisfaction. The overall mean score was 5.0 on a scale of 1-5. Comments indicated that the recipient was well satisfied with the services provided.

DISCUSSION

There was a perceived need in Kentucky to facilitate development of a consumer support and advocacy network for individuals with deaf-blindness. It was felt that this could best be accomplished by beginning with individuals with Usher's syndrome. Therefore, over the weekend of April 24-26, 1992 a retreat was held in Louisville, Kentucky. The stated objectives were: 1) to learn more about Usher's Syndrome, 2) to meet a consultant from Gallaudet University who has Usher's Syndrome, 3) to learn about the Personal Futures Planning Project in Kentucky, and 4) to discuss beginning a support group.

Five individuals with Usher's Syndrome met with the consultant and other interested participants (i.e., staff from the Kentucky Deaf-Blind Intervention Project, the Personal Futures Planning Project, and the Helen Keller Affiliateship) from Friday evening until Sunday noon. The format of the meeting alternated between formal presentations and semi-structured times to socialize and network.

As can be seen from the results of the data, the recipients felt that the speakers were informative and provided them with information about Usher's Syndrome that will help them in the future. Several also expressed a desire to help share this information. It is hoped that this TA began a process which can be continued by the supporting agencies to assist these consumers in developing a shared agenda and any needed Action Plans.

BEST COPY AVAILABLE

MEETING SATISFACTION SUMMARY
(per Kentucky Deaf-Blind Project)

TAN#: 90-630-KY
Site: Louisville, KY
Date: April 24-26, 1992
Topic: Usher's Consumer Conference

1. Did the training meet your expectations?

	agree			disagree	mean rating
range:	4	3	2	1	3.8
number:	5	1			

2. Were the speakers well prepared, informative, and understanding of your needs?

range:	4	3	2	1	4.0
number:	6				

3. Has your knowledge of Usher's Syndrome increased because of this workshop?

range:	4	3	2	1	4.0
number:	6				

4. What is your reaction to the information you received at this workshop (will share with others, good to know, will never use this information)?

range:	4	3	2	1	3.8
number:	5	1			

5. Do you think this information will help you in the future?

range:	4	3	2	1	4.0
number:	6				

6. Was this session too advanced, about right, or too elementary?

range:	4	3	2	1	3.0
number:		5			

TOTAL OVERALL MEAN = 3.8

TOTAL N = 6

BEST COPY AVAILABLE

MEETING SATISFACTION SUMMARY
(per Kentucky Deaf-Blind Project)

TA#: 9C-E30-KY
Site: Louisville, KY
Date: April 24-26, 1992
Topic: Usher's Consumer Conference

1. Did the training meet your expectations?

	agree			disagree	mean rating
range:	4	3	2	1	3.8
number:	5	1			

2. Were the speakers well prepared, informative, and understanding of your needs?

	agree			disagree	mean rating
range:	4	3	2	1	4.0
number:	6				

3. Has your knowledge of Usher's Syndrome increased because of this workshop?

	agree			disagree	mean rating
range:	4	3	2	1	4.0
number:	6				

4. What is your reaction to the information you received at this workshop (will share with others, good to know, will never use this information)?

	agree			disagree	mean rating
range:	4	3	2	1	3.8
number:	5	1			

5. Do you think this information will help you in the future?

	agree			disagree	mean rating
range:	4	3	2	1	4.0
number:	6				

6. Was this session too advanced, about right, or too elementary?

	agree			disagree	mean rating
range:	4	3	2	1	3.0
number:		5			

TOTAL OVERALL MEAN = 3.8

TOTAL N = 6

BEST COPY AVAILABLE

TECHNICAL ASSISTANCE EVALUATION FORM
SUMMARY DATA

TA#: SC-630-KY
TA Site: Louisville, KY
Date: April 24-26, 1992
Consultant: Art Roehrig

	Agree			Disagree		Mean
A. The TA objective was met and the outcome achieved.						
range:	5	4	3	2	1	5.0
number:	1					
B. The TA provider was prepared to deliver the TA.						
range:	5	4	3	2	1	5.0
number:	1					
C. The TA provider possessed the necessary expertise to deliver the TA.						
range:	5	4	3	2	1	5.0
number:	1					
D. The TA provider kept the focus of the TA on the intended objective.						
range:	5	4	3	2	1	5.0
number:	1					
E. The TA was delivered at a desirable time during the project year.						
range:	5	4	3	2	1	5.0
number:	1					
F. Overall, project staff were well satisfied with the TA provided.						
range:	5	4	3	2	1	5.0
number:	1					

TOTAL OVERALL MEAN = 5.0

TOTAL N = 1

BEST COPY AVAILABLE

SC-630-KY
TA EVALUATION COMMENTS:

2. Any additional TA needs identified? No.

Not at this time, but this has led to an on-going consumer support network and more TA may be identified in the future.

3. Would you recommend this TA provider to another project with the same designated objective? Definitely.

4. Anything you wish had been done differently? No.

It was perfect!

SC-630-KY
TA EVALUATION COMMENTS:

2. Any additional TA needs identified? No.

Not at this time, but this has led to an on-going consumer support network and more TA may be identified in the future.

3. Would you recommend this TA provider to another project with the same designated objective? Definitely.

4. Anything you wish had been done differently? No.

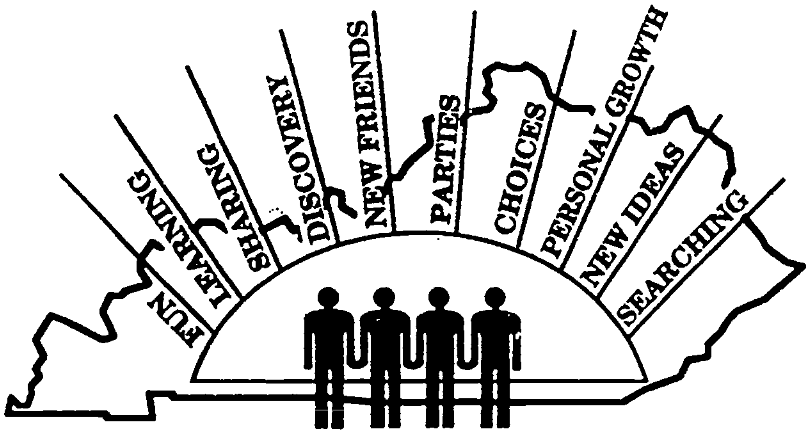
It was perfect!

2nd Annual

Expanding Horizons Conference

July 30 - August 1, 1993

Kavanaugh Life Enrichment Center
Crestwood, Kentucky



Sponsored By:

* Helen Keller National Center Affiliateship
* University of Kentucky Deaf Blind Intervention Program
* Personal Futures Planning Project
* TRACES (Teaching Research Assistance to Children Experiencing Sensory Impairments)
* Developmental Disabilities Planning Council

Expanding Horizons
July 30 - August 1, 1993
Kavanaugh Center
Crestwood, Kentucky

Friday, July 30, 1993

4:00 pm **Foeman Lodge**	Registration in Robertson Room
6:00 pm **Dining Hall**	Dinner
7:00 pm **Robertson Room** **Foeman Lodge**	Opening Session Dr. Jeffrey Bohrman, President American Association of the Deaf-Blind
8:30 - ???? **Robertson Room** **Foeman Lodge**	Social

Saturday, July 31, 1993

8:30 am **Dining Hall**	Breakfast
9:30 am **Robertson Room** **Foeman Lodge**	What is AADB?

Saturday, July 31, 1993, continued

10:30 am	Break
10:45 am	How to set up a State Chapter of AADB
12:00 pm **Dining Hall**	Lunch
1:00 pm **Robertson Room** **Foeman Lodge**	What I Need to Know About Retinitis Pigmentosa & Other Eye Conditions
3:00 pm	Swimming/Free Time
6:00 pm **Dining Hall**	Dinner
7:30 pm - ???? **Robertson Room** **Foeman Lodge**	Games and Social

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Sunday, August 1, 1993

8:30 am	Breakfast
9:30 am **Robertson Room** **Foeman Lodge**	Working session about starting a KY Chapter of The American Association of the Deaf-Blind
10:45 am	Evaluation & Wrap-up
11:15 am	Check-out (no lunch provided)

Appendix VIII-C

Update and Reflections on the Kentucky Personal Futures Planning Project at the End of Year II (written by Dr. Beth Mount, consultant to the project)

Update and Reflections on the
Kentucky Personal Futures Project
at the end of Grant Year Two: October, 1992
By Beth Mount

Overview: This report summarizes my impressions and reflections on the Kentucky Personal Futures Project based on phone interviews with the three project facilitators and a review of many of the journal notes and futures plans of people involved in the project.

Project staff are now directly or indirectly involved in the personal futures plans of 24 people, while the three facilitators are directly involved in about half (a total of 13) of these situations. My impressions of project outcomes are based on informal accounts of change in the lives of these 13 people.

This report reflects the pattern of responses in Year two, , the diversity of ways that facilitators are responding to the interests of the people and their families, the current challenges to the project staff, and the capacity of project staff to manage the tensions caused by the complexity of this work.

Background

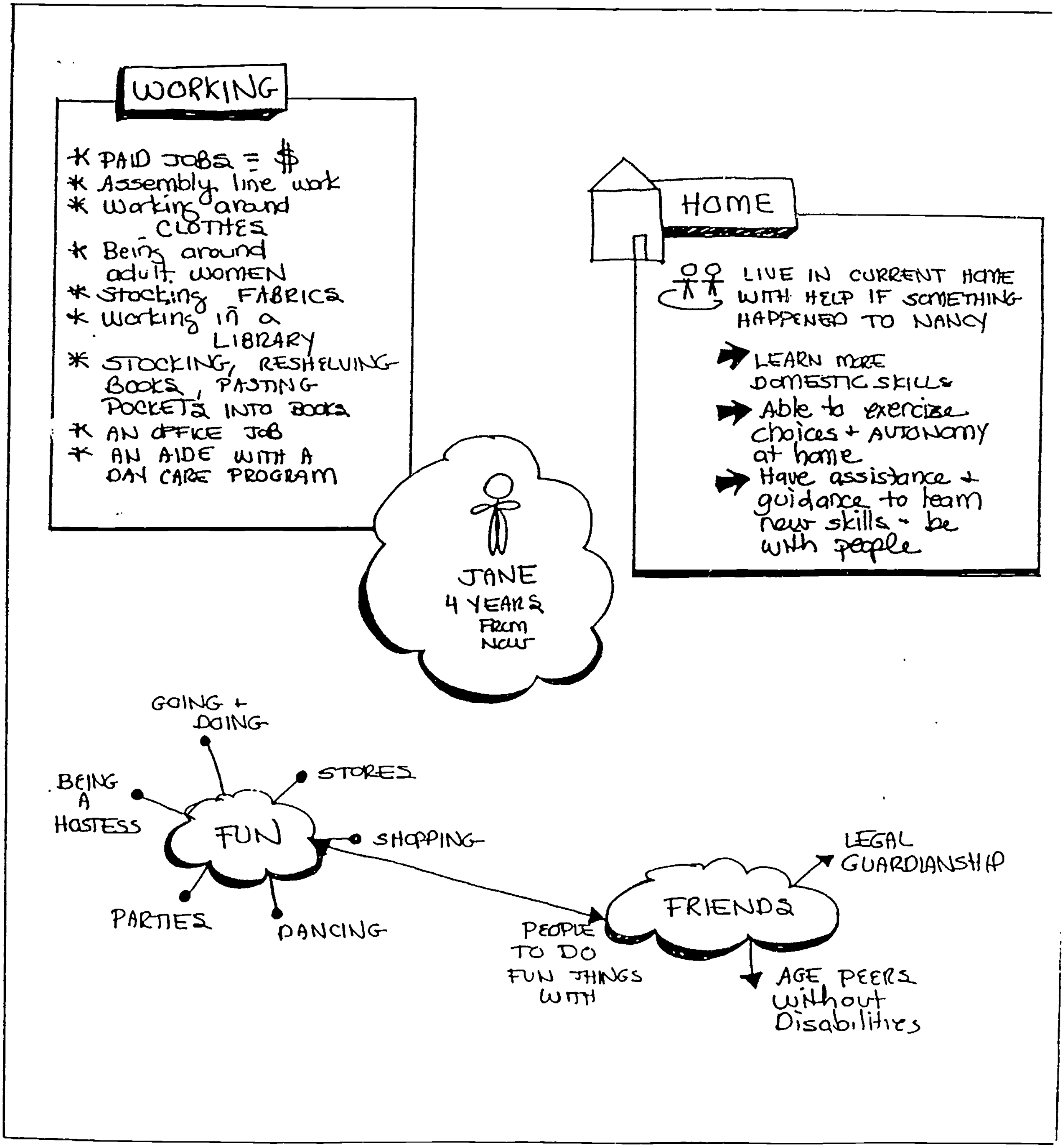
This overview is loosely tied to "An Analysis of the Strengths and Challenges to the Personal Futures Planning Project," a summary of my impressions of the first year of project development. In this analysis, I identified the strengths of the Kentucky Project, as well as the challenges to the project as it develops, and I also provided a number of specific recommendations.

In year one, the focus of the grant was personal change in the lives of the young people with developmental disabilities. Project staff spent lots of time getting to know the people and their families, bringing together interested people, and developing visions for the future and plans for implementation. Jamie's plan helps remind us of the focus of her futures plan during year one (Figure 1).

In year two, Project staff continue to meet the challenges identified in year one. Their on-going responsiveness to the mandates created by each personal futures plan reveals a fascinating pattern of investments that extend far beyond changing the lives of the focus people.

Figure One

A POSITIVE FUTURE FOR JANE



Benefits of the project in Year Two:

The stories of change in Year two of the grant reveal not only minor and major changes in the lives of the focus people, but also significant changes in the supports available to families, changes in local school systems, changes in community attitudes and perceptions, and increased organizational change and flexibility. An update of the developments in Jamie's life helps to illustrate the complexity of changes required to implement her ideals.

AN UPDATE OF JAMIE'S LIFE IN 1992

Jamie dreamed of working, but no one really believed in her capacity to work. Without the intervention of the futures planning process, she would have finished school at the School for the Deaf, and then graduated to her grandmother's living room. As a result of the planning process, Jamie obtained a job at K Mart working in the stock room, tagging and hanging clothes and other items. She makes minimum wage, and is thrilled with her work; a strong example of personal change that clearly matches the preferences she and others expressed as a result of the planning process.

Jamie's grandmother, who lives with the threatening question, "What's going to happen to Jamie when I die?" has been supported to go through the complex guardianship process. A member of Jamie's support group agreed to be the successor guardian, and the grandmother put her house into a life estate for Jamie. Jamie's support group provided the emotional and technical support to help the grandmother negotiate these complex issues. Project staff worked very hard to provide life planning and personal support to the family as a whole.

During this process, Jamie's teacher at school expressed an interest in learning to be a job coach, and she began to leave her traditional role in the classroom to learn new roles and skills. Project staff worked with the teacher and the school system to help her renegotiate her role outside of the classroom.

Several weeks after Jamie began her job at K Mart, a number of fellow employees from K Mart attended a sign language class offered by the School for the Deaf. They voluntarily attended this class based on their interest in learning to communicate with Jamie. Jamie's personal future is clearly changing the attitudes and perceptions of people in the larger community.

Finally, as a result of the grant, project staff were able to hire an independent job developer who could see beyond the limited stereotypes and preconceptions of the people who had little vision for Jamie. This job developer imagined a challenging job and design one to fit Jamie. The capacity to hire an independent job developer sets a precedent for additional potential changes in the system. The VR counselor also accepted a functional assessment from the job developer in order to open the case. These developments are examples of organizational change and flexibility.

Multiple sources of change

Jamie's life illustrates that real change in the lives of the focus person depends greatly on influencing the agenda's of many other people. For example, the changes reported in the lives of 12 people indicate that staff have responded in a variety of ways to consider the needs of families, and negotiate the interests of many people. The following section describes benefits to the focus people, families, communities and schools, and increased organizational capacity and flexibility.

Benefits to the Focus People

The benefits of the project to the focus people must be weighed in comparison to where people would be without the intervention of the grant. The focus people involved in this grant are most at risk of segregation and institutionalization because of the complexity of their disability. Most focus people have been in totally segregated school programs for all of their school life, and most people live at home and are completely dependent on their mothers or other family care givers for total support. Many of the primary care givers have health problems, and they live with the chronic fear and fatigue of the question, "How long can I provide the day to day support needed by my child, and what will happen to them if anything happens to me?"

Without the intervention of this project, the focus people will finish their student careers in totally segregated classrooms, and they will remain lonely and disconnected from the larger community. They will have very limited options when they graduate, and consequentiy place even more demands for care and support on their already depleted parents, Some people do not even have even the most basic adaptive equipment and communication systems that enable them to relate to others. Just having an image of the future that offers an alternative to these bleak outcomes is a critical outcome of the project.

Project staff have worked to develop a vision for the future that includes many areas of life, and they have instilled a hopeful attitude that they can make some things happen for people. They have responded immediately by working on short term ideas while maintaining a long term vision. The benefits to the focus people include the following:

Examples of Benefits to the Focus People:

New Opportunities for Work Experience

Sean was not even considered to have the skills needed to attend the sheltered workshop. He obtained a summer job making minimum wage at a local rest stop. While his job only lasted 3 weeks, people learned a lot about potential job opportunities and supports needed for Sean.

Jamie obtained a job at K Mart tagging and hanging items in the stock room.

Jason may become involved in the school to work program.

Eric is exploring job options as an alternative to the sheltered workshop.

Stephanie has a part-time job at a day care center,.

For the first time in his life, Jayson is having experiences in the community with someone other than his mother. He is going to community settings ten hours a week with an escort whom he really likes. He has been introduced to lots of new people.

Increased Mobility and Communication

Jayson, Jason and James are obtaining new communication systems and devices.

Increased numbers of family and community members are having the change to see Tommy differently, and learn to relate to him. He has a new wardrobe that gives him a chance to be cool.

Michael spent his lifetime up to now in bed. He is getting a new wheelchair, and possibly a placement in school.

Darrah Joe is expressing her dreams and preferences for the first time. People have taken the time to listen and communicate with her and it has clarified her cognitive potential and gifts to many other people.

Opportunities to Develop Friendships at School

Sean went to the high school prom with his cousin.

Twenty five high school students in Jackie's high school took a sign language course, and now more kids communicate with him. He eats lunch with the football team. Two students from the high school have joined his support circle.

Stephanie is involved in regular education classrooms for home ec, and art. She is going to dance classes at the community collage.

For the first time, Jason attends regular education classes in the high school for half of his day.

Kelly auditioned to attend the high school for drama and the performing arts, which she now attends for half her day.

Benefits and Additional Support to Families

The tension of working toward personal change for the focus person while balancing the needs and concerns of families is expressed in the summary of challenges faced during year one:

> "Family attitudes can be difficult sometimes. We have high ideals we want to work for and we can feel the tension between these high ideals and the day to day realities families face; the stress, the rejection, the isolation, the responsibility, and the fears they live with. Also, because of their history with negative service systems as well as their isolation, they may have poor or negative predictions about the future, they may overprotect their children, and be afraid of taking risks, or they may trust in and promote segregated options which differ from the hopes we have for people. How do we manage these tensions?"

Staff were challenged in year one to find a "common ground" with families where the work of change could begin. Staff were faced with the difficult tension of working toward an ideal while working with families AND professionals who missed opportunities to see people differently, consequently, they had very different expectations for the future of these children.

In Year Two, project staff are finding a variety of ways to respond to the concerns of parents, primarily by assisting mothers to meet some of their own needs. It seems essential that staff work as much or even more with moms on whom the focus people are completely dependent. When these mom's feel someone listening to them with respect and representing their interests, then they are more likely to have the trust and energy needed to work with staff to support more challenging experiences and situations for their children.

It seems that staff are finding a balance in working toward a personal future for the focus people and listening to and supporting parents. This is a delicate balance. In the past, professionals in human services thought they knew what was best for people and basically controlled families and focus people with their demands. Person-centered work does not just reverse this power trip to say, "the families and focus people now know best and now control workers with their demands." Person-centered work attempts to shift the pattern of power-over to a relationship of power-with people in which people involved develop common agendas and work together to affect both day to day realities and long term futures.

This alternative "power with" relationship is complex because it challenges all parties to listen to each other, respect differences, and find a mutual meeting place that expresses the interests and values of everyone involved. The effectiveness of a "power-with" relationship depends on trust, mutual respect, compromise, and negotiation which is hard work. I think staff have resisted the tendency to over-power parents with their ideals by taking the time, interest, and concern to walk with parents through their own dilemmas. This does not mean that staff should be "blank slates" on which parents write demands, but that there is healthy respect for the needs of parents in addition to idealistic hopes for the children. The following examples indicate many efforts to respond to parents:

Examples of Benefits to Families

What will happen to my child if something happens to me?

Jamie's grandmother has been assisted through the guardianship process to become Jamie's guardian and arrange her will to put her house in a life estate for Jamie. A member of her support circle agreed to be the successor guardian if anything should happen. This rigorous process required many decisions and members of the support circle assisted in many ways.

Jackie's mom has multiple health problems and has to take him with her when she is hospitalized. She was assisted to "jump the waiting list" for the AISMR program which provides her with additional respite care now, and residential support in the event that she could no longer care for Jackie.

Tommy was about to be institutionalized because his family was completely exhausted by the total care required. They are working to jump the 200 person waiting list for the AISMR program so that they will have more respite care and additional assurances if anything happened to them. They have obtained some immediate respite relief, and a summer support program that provides assistance five days a week during the summer months.

Personal and respite support to primary care persons:

Jayson's mom has benefited from her own support circle which has helped her find part-time work, and look into buying a home. Her meetings are a refuge for many people who benefit by talking about the issues and challenges in their own life.

Stephanie moved to a group home in the community, and her mother had the energy to work really hard to create a classroom for her in the local high school.

Michael's parents are looking into the possibility of purchasing a home after a life time of renting a home in a very rural, isolated setting.

Jason's mom was not to sure about the idea of school inclusion. She was linked to another parent who has already negotiated the complexities and fears of such a decision and found a lot of encouragement from this mom.

Changes in Community and Public School Attitudes and Perceptions

During Year One, project staff were also challenged to compose and maintain **effective support circles**, and to develop and strengthen relationships in the local community. Building relationships was challenging because many of the focus people lack the tangible and immediate forms of relating such as eye contact, language, and other basic sensory responses. Project staff were challenged to invent many ways for people to cross these communication barriers. The following examples indicate changes in the attitudes and perceptions of community members the deepening and strengthening of new and existing relationships.

Benefits in Developing and Strengthening Relationships

Jamie's school teacher wanted to leave the classroom to learn to be a job coach. A large number of employees from K Mart, where Jamie is employed attended a community sign language course to increase their capacity to communicate with Jamie.

Jackie's success in high school is due to the collaboration between the high school teachers and the teachers in the deaf community. 25 high school students went to sign language course to improve their ability to communicate with him. Two students joined his support circle.

Jason's mom has a strong and powerful support circle of community members and professionals who are also nurtured by the support circle. A growing number of people have a deep appreciation of the issues and concerns of the family.

Sean's circle has included about 20 aunts and uncles and members of the church. A growing number of people are involved in thinking about the complex challenges to supporting his future.

Stepanie's mom helped create a new classroom in the high school for her, and increased a general awareness and openness to the needs of her daughter throughout the school district. Stephanie has the potential for friendships now that she is in the school.

Tommy's deaf-blind teacher is much more involved with his family and has really helped them see him differently and communicate more. There is a strong sense of community in meetings and family and church members are trying to get the Governor to intervene for needed supports. Tommy's dad is now president of a parent support group.

More people are involved in exploring school placement for Michael.

Other children are learning Jason's communication system. His 6-C coordinator is determined to support real integration for him.

Eric's circle is now determined that he will not go to a sheltered workshop, and they have become staunch advocates for him in favor of supported work.

Organizational Change

In Year One, the project was challenged to find ways to link the scarce resources connected with innovation to the requirements of people with intense needs for support. The project was also challenged to find and develop **adult service agencies that are committed to change.**

Year Two reveals a pattern of increased organizational flexibility and change by increasing the level of collaboration between various providers such as VR counselors, high school teachers, deaf-blind teachers, and MR case workers and program directors. The project is promoting innovation by directly paying for independent job coaches. Project staff have also facilitated communication and functional vocational evaluations that were previously non-existent.

Significant organizational changes just take time, and the small examples of innovation in year two will hopefully establish expectations for organizational change leading to larger scale change and innovation in the future.

Summary of Benefits During Year Two

The dreams and ideas developed during year one of the grant are taking shape during year two. The focus people are having new work experiences and new opportunities to develop relationships in public schools. Some people are benefiting from new communication systems and increased mobility. The focus people are being empowered to define their interests and work toward alternative futures. These experiences provide a striking contrast to the bleak futures facing people prior to the beginning of the grant.

Families are being empowered to speak out and to ask for help. The most striking benefits in year two are the ways that mothers are getting direct support and assistance in order to maintain and strengthen their capacity to shape the future of their children.
It appears that most families feel that more people are helping them negotiate the complexities of their life and therefore, they have the emotional support and energy to expect more for their children.

As a result of the project, the transition and IEP planning process is much more functional and meaningful, and resources of the system are being used creatively to support new ideas. Professionals are collaborating and going out of their way to work together. The gatherings and meetings are relaxed, voluntary, and people seem invested and willing to be creative.

The project is driving the way people think about planning in general. Increasing numbers of people are interested in person-centered planning and individualized supports. The individual futures of the focus people are strengthening the case for individualized supports for people with complex needs in Kentucky.

Challenges to Staff in Year Two

The developments in year two invite new challenges. Staff are challenged to balance the needs of parents with their ideals for the focus people, they continue to confront the powerful stereotypes and biases that reinforce segregation, and they are searching for ways to define personal boundaries for this work.

It seems that some individual dreams feel blocked because parents and/or professionals are willing to settle for less. Familiar segregated options still dominate people's thinking. Supportive living or supportive work options are just beginning to happen in Kentucky, so there are few models to point to, especially for the people who need intensive support. It seems hard to find the most constructive ways to influence people's values.

Staff are facing these tensions by taking the time to develop constructive, trusting relationships with other professionals and families. Responding to families and finding a middle ground with professionals may seem to "slow down" the outcomes in the lives of the focus people, but building these relationships lays the foundation for powerful change in the future.

The outcomes of many support circle projects reveal that significant benefits for the focus people do not occur until the third year of our work together. While this rate of change can feel painfully slow, the significant changes in people's lives during the first two years set the stage for greater change in the future.

Staff struggle with their fear that they overwhelm care people with big ideals that immobilized them. Consequently, they are taking the time to listen to parents and respond to their concerns, while also promoting idealistic options for their children. These dilemmas are not simple either/or situations--"do we listen to parents, or push for ideals for the children; do we work on long-term, big dreams, or day to day realities?" The challenge to staff and parents is to find inclusive strategies that balance investments in all these areas. There are many examples in year two that indicate that staff are using their judgement to find such a balance.

Another pressing challenge in year two relates to the issue of establishing personal boundaries for this work. This question challenges staff as they get more personally and emotionally involved with families while they seek to maintain a personal life.

Setting personal boundaries with support circles is an agonizing challenge. We are effective when we let down the barriers that distance professionals and people, and when we open ourselves to the pain and complexity of people's lives. When we work this way, we are at risk of losing a personal center from which we are effective, renewed and sustained over time. We can become broken down by needs and complexity that render us helpless.

The issue of personal boundaries does not lend itself to either/or solutions--"Am I detached, or involved, is this a job, or my personal life." Traditional job descriptions prescribed external boundaries and reinforced a simple either/or response--"I am detached and this is my job." Person-centered work supports a more flexible response in which we can be personally involved and affected while maintaining a self that can respond with both empathy and optimism. We can love people and become friends and also respond to our own families and personal needs. We have to find an internal thermostat for involvement instead of a job description that prescribes our activity. This requires a lot of inner awareness, and the support of others. This is another challenge that staff are processing and finding individual ways to manage.

The complexity of these challenges leads us to a discussion of the supports that seem essential to people who want to do this work. The dilemmas of year two require time for reflection, personal support, and the personal strength to maintain a vision and respond to multiple interests, agendas, and demands.

The Supports that Sustain People To Do this Work

Person-centered work requires commitment and integrity by the people who offer their support. It seems that effective workers have both inner qualities and attitudes that sustain them over time, as well as concrete strategies for self-renewal. We cannot instill the inner qualities needed, we can only nurture them and invite their growth over time. We can invest in support strategies that encourage the personal strength that effective people who do this work seem to have.

This project benefits from the involvement of three facilitators who share a calling to do this work. The calling may be expressed differently for each person, but their collective calling reflects an optimistic attitude that communicates these powerful messages:

> "This work is the right thing to do--it has act validity, even if you don't accomplish what you set out to do. It is a good fit for me personally--to align myself with oppressed people and use my values training, my direct service experience, and my administrative experience and connections to help build a better life for people."

> "This work has meaning to a lot of other people I care for and respect. I am part of cadre of people who are all shaping a movement. We can look to a lot of things that have changed, and believe we are on the right track."

> "This is a calling for me. It is part of my faith. I believe there is a tie that binds us that is larger than ourselves. It certainly helps when people share faith and a sense of optimism. I have a gift of helping people, of seeing the best in others and encouraging them. I believe there is a plan for my life, so there must be a plan for others. It is part of my path to clarify the path in others. I have a strong belief that when people work together that positive results are possible. I'm not easily discouraged by failure--I see failure as a lesson."

> "This work is about people being real, families being really able to say what they want, what's important to them, and our being honest, more real and genuine. I really love people. I love being in their homes, getting with people where they are and being humble so I can hear them. This work is not about changing people, it is about relationship. Who am I to say what they need? It is up to me to listen to them and learn. I feel a social responsibility to respond. The only logical reason for being here is to find ways to live here together better. "

Clearly, the internal beliefs and qualities of the facilitators bring a dimension to the work in which mysterious and powerful change is possible. One of the unspoken benefits of the project is the way that these positive qualities have been strengthened in the facilitators and in the lives of the people, and that little by little, faith and hope displace the fear and despair that challenges people.

The facilitators are supported in concrete ways through their friendship, mutual respect, and history of cooperation and team work. It seems essential for people involved in this work to have the time to process their struggles and conflicts and to trust each other enough to process deep feelings, the experiences that feel like failures, and other challenges. It seems almost impossible to do this work alone, or in an environment of low trust or misunderstanding.

Conclusion

The following comments summarize the challenges to project staff at the end of year one:

> In the coming years they will be challenged to find a common ground with parents and professionals who are struggling with day to day realities and other limitations. They will need to find many creative ways to build relationships in support circles and in local communities. They will also face the difficult task of linking service dollars and policy to their vision.

There is certainly ample evidence to indicate that staff are meeting these challenges and paving the way for even more significant changes in the lives of the focus people and their families. Their efforts to be responsive to mothers is one of the most impressive outcomes of year two, while adding another level of complexity and additional challenges to the project as a whole.

Given that there are virtually no models in the country of effective transition planning for people with dual-sensory impairments, the Kentucky project continues to reveal both the challenges and complexities of planning a community future for this group of people, as well as creative approaches to responding to and voicing the interests, needs, and dreams of people and their mothers who would otherwise live in isolation and silence.

RSON	SITUATION	NEW - Transition EXPERIENCES	SUPPORT TO CAREGIVERS	SCHOOL CHANGES	COMMUNITY ATTITUDES & PERCE	ORGANIZATIONAL FLEXIBILITY
* REAN AGE 20		• Summer job for 3 weeks rest area • went to the prom w/ his cousin			• 20 aunts + uncles in the room for his plan	• UR funded a personal job coach • Lots of collaboration to make 1 idea work
JAMIE AGE 18	• JAMIE DREAMED OF WORK, BUT NO ONE BELIEVED WOULD HAVE GONE TO SCHOOL FOR THE DEAF + THEN GONE H.M.I. • Grandma	• OBTAINED A JOB AT K MART 1:00 - 3:00 AT MINIMUM WAGE - STOCK ROOM, TAGGING + HANGING ITEMS	• CHANGING ATTITUDE TO SUPPORT THE ROLE OF WORK • SUPPORT GRAD TO HELP GRANDMA THRU GUARDIANSHIP • WILL - estate	TEACHER WANTED TO LEARN TO BE A JOB COACH	1/2 PEOPLE FROM KMART WENT TO COMMUNITY SIGN LANGUAGE COURSE • SHE IS RADIENT	HIRED AN INDEPENDENT JOB DEVELOPER - used flexible! • UR COUNSELOR ACCEPTED FUNCTIONAL ASSESSMENT TO OPEN THE CASE
JACKIE AGE 18	• Mom has multiple health problems + has to take Jackie w/ her when she goes to hospital	• MORE KIDS COMMUNICATE WITH HIM: HE EATS LUNCH WITH THE FOOTBALL TEAM	• MOM OBTAINED AISMR, JACKIE CAN HAVE RESPITE, IF SHE DIED, HE WOULD HAVE RESIDENTIAL SUPPORT - JUMPED 200 Person waiting list	• LOTS OF COLLABORATION BETWEEN TEACHERS + DEAF COMMUNITY	• 25 HIGH SCHOOL STUDENTS WENT TO SIGN LANGUAGE COURSE • 2 KIDS CAME TO LAST CIRCLE MEETING	• MR Director came to the meeting to explain program • Providers agreed that mom could hire workers
JASON AGE 23	• Was home all day w/ mom, family was completely isolated	• He is going somewhere! 10 hrs a wk thru the family support grant • He has been introduced to lots of people • Arranging a communication device	• the meetings are a refuge for a lot of people, esp mom • Mom has done some part-time work • Started a sp. support gp for mom • looking into	• NA interests in being an artist, landscaping, getting driver's licence	• Deep appreciation of this family + their issues + concerns	• Commitment of many diverse providers even if they don't know what to do

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SON	ORIGINAL SITUATION	NEW · LEARNING + TRANSITION EXPERIENCES	SUPPORT TO CAREGIVERS	SCHOOL CHANGES	COMMUNITY ATTITUDES + PERCE	ORGANIZATIONAL FLEXIBILITY
STEPHANIE age 16	• Lived out in trailer in the cunty • At age 18 went to middle school in seg. classroom	• Going to Dance class at commy collage • Involved in regular ed classrooms- home ec - art	• Moved to a group home in a commy closer to resources. • Mom created classroom in high school	• New classroom in local high school openness in school district, • in	• opportuny for more friendships	• openness of school district
Tommy age 15	• About to be institutionalized • total physical assistance, seizure disorder - famy exhausted • School trying to send him home	• New clothes - a chance to be cool • If there was a crisis, there are alternatives to nursing home" - encouraging placemt in reg. nursing home	• Lots of adapt. equipment • work w/ respite program • medical Waiver Program - got medical card • summer sup. funded - 4/5 days wk. mo	• Deaf-Blind teacher more involved with famy	• Dramatic changes in perceptions of famy • Strong sense of commuy in meetings - • Parents - Dad is president of Parent Supp GO	• Famy + church commuy trying to get to Governor to jump waiting list for AISMR program
Michael Age 16	• Lived in rural setting, spent his whole life in bed • Dad has cancer; what will happen if mom gets sick?	• Trying to explore school placement • Finally getting a new wheelchair	• Looking into option / abity to buy them a home		• Helping others' see possibilities in him	• Got a local caseworker to come to meetings -
JASON AGE 18	• Was in a really silly middle school spc ed program	• Attending regular classes in high school next door - ½ day • Art • PE • Music • Home E • Exploring school to wk training program	• Mom wasn't too sure about this - invited another Mom to her meetings + they really connected	• 6-C coordinator determined to support real integration	• Other kids are learning his communication system -	• Paid for evaluation for communication system + obtained system

PERSON	ORIGINAL SITUATION	NEW - Leading to transition EXPERIENCES	SUPPORT TO CAREGIVERS	SCHOOL CHANGES	COMMUNITY ATTITUDES & PERCE	ORGANIZATIONAL FLEXIBILIT
 Darrah Joe	• Lots of confusion re her cognitive abilities	• Taking a really long time to listen to her + clarify her cognitive abilities	• Interpreting her experiences + dreams to Family		• People took her a lot more seriously	
 kelly age 14	• was attending K.S. for the Blind	• Attending 1/2 day program at high school • Auditioned for high school for drama + performing arts - 2 drama + bio		• Integrated high school		
 ERIC age 20	• was headed for a sheltered workshop	• Bought a house • working on a job	•		• His circle has become staunch advocates for him • won't have to go to sheltered wksp	• Hired indep job coach
 James age 19	• Mom conservative about his options	• Developed consistent communication system • obtained services for auditory trainer				• KSB agreed to pay for job coach program

Appendix VIII-D

Individual PFP Team Summaries of Accomplishments

In Wilcox, B. & Bellamy, G.T. (1987). A comprehensive guide to the activities catalog: An alternative curriculum for youth and adults with severe disabilities. Baltimore: Paul Brookes.

Table 11.1. Questions to describe life-style outcomes

Community presence

What community settings does the person use regularly (daily, weekly, occasionally)?

To which of these places does the person go alone? as part of a group of two or three? as part of a larger group?

Does the person have any significant problem using any of these places?

What other community settings would it be in the person's interest to use, or to use more independently?

What would it take to increase the number of community settings the person uses completely? (Consider changes in the person's skills, changes in available assistance, negotiating changes in the setting, or changes in service patterns.)

Choice

What decisions are regularly made by the person?

What decisions are made for the person by others? For which of these could decision making be transferred to the person himself or herself?

What are the person's strongest interests and preferences that make him or her unique?

What would it take to increase the number, variety, and importance of the decisions the person makes?

What would it take to increase others' knowledge of the person's interests and preferences?

Competence

What skills could the person develop that would offer the most opportunity for increased presence, choice, respect, and participation?

What strategies for instruction and assistance have been most effective for the person?

Are there more efficient strategies than instruction, such as environmental modification or provision of additional personal assistance?

Are there any health-related threats to the person's continuing development? How can these be managed effectively with minimal disruption of good quality life experiences?

What would it take to increase the person's competence in more valued activities?

Respect

What are the valued community roles the person occupies and what percentage of time is spent in each?

Which community roles offer the person the best opportunity to express individual gifts and talents?

What would it take to increase the amount of time the person spends in a valued community role? in roles that express the person best?

What images and ideas about a desirable future are available to the person?

Does the person display any characteristics that reinforce stereotyped perceptions of people with severe handicaps?

Are there any characteristics of the person's environment that reinforce stereotyped perceptions of people with severe handicaps? (Consider the images projected by activities, schedules, expectations, and the way the person is spoken to or about.)

What would it take to decrease the stigma the person experiences?

Community participation

With whom does the person spend the most time on a daily and weekly basis? How many of these people are other clients/students in the same program? How many are program staff? How many are people without apparent handicaps?

Are there other important people in the person's social network with whom the person spends time occasionally?

Who are the person's friends and allies? Who knows the person intimately? Who will act as an advocate for his or her interests?

What would it take to provide better support for the person's present network of relationships?

What would it take to develop more friends or allies?

What would it take to increase the number of nonhandicapped people, including age-peers, who know and spend time with the person as an individual?

PERSON	MAJOR ACCOMPLISHMENTS	LIFE-STYLE OUTCOMES	KEY PEOPLE
S.M. Louisvillle Yr. 1	School program at Binet Supported employment provider Supported living provider & application HKNC application & attendance Vocational experiences at school & summer Collaboration between school & ICF-MR Video for Alternative Portfolio Mom involved in PCDSI group; attended WS in Atlanta on PFP, Supported Living WS	Competence Respect Choice	S.M. Mom HKNC Affiliate, DVR DBIP Transition Consultant School Counselor ICF/MR Social Worker ICF/MR Unit Leader DVR Counselor Teaching Asst., School Teaching Asst., School Cousin & Husband PFP Facilitator
T.S. Mt. Washington 1 hr. Yr. 1	More + view of T.S. Adaptive equipment - lift, bathchair, bed Home & Community-based waiver - Medicaid card Communication evaluation Family involved in Family Forum, PCDSI	Respect Choice Competence Presence	T.S. Parents SCS Rurual Respite Coord. Teacher Aunt Pastor & wife Grandparents DBIP Consultant PFP Facilitator

PERSON	MAJOR ACCOMPLISHMENTS	LIFE-STYLE OUTCOMES	KEY PEOPLE
J.A.	High school classes	Presence	J.A.
Stanton	Voc. Rehab. case	Choice	Mom
5 hrs.	Supported living $	Respect	DBIP State Coord.
	Parents seeing Jason	Participation	Employment Consultant
Yr. 1	having a future	Competence	HKNC Affiliate, DVR
	Communication evaluation		PFP Facilitator
	Work transition program		Parent Mentor
S.G.	High school sp. ed. class	Presence	S.G.
Morganfield	Adaptive switches	Choice	Mom
6 hrs.	Mom attended workshops & conferences	Competence	DBIP State Coord.
			Case Manager
Henderson	Orientation & Mobility evaluation -		PFP Facilitator
5 hrs.	less time in wheelchair, more walking		
Yr. 1	Calendar box in school/home		
	Supported move to group home		
	Provided training & TA to new HS teacher		
	Eating in cafeteria with other students		
	Efforts to provide more choices		
	Community-based instruction		

PERSON	MAJOR ACCOMPLISHMENTS	LIFE-STYLE OUTCOMES	KEY PEOPLE
J.B. Madisonsville 5 hrs. Yr. 1	O & M evaluation HKNC Reg. Rep. visit Sign language class AIS/MR resources Staying at current school Voc. trng. in school Program of the year award Braille instruction - Cathy Johnson from KSB	Choice Competence Presence	J.B. Teacher Mom Teaching Asst. Peer tutor Biology teacher W. KY Coop. evaluator Case manager Program Director Pennyroyal Center DBIP State Coord. PFP Facilitator HKNC Affiliate, DVR
--J.R. Danville 4 hrs. Frankfort 2 hrs. Yr. 1	Transition back to Franklin Co. HS Job at K-Mart Guardianship Estate planning CONTACT connection Teacher took sign language class prior to J.R. transitioning to her class	Presence Choice Competence Respect	J.R. Grandmother Employment Consultant Parent Mentor KSD Program. Coord. KSD Teacher Franklin Co. HS Teacher HKNC Affiliate DVR Counselor PFP Facilitator Family friends

PERSON	MAJOR ACCOMPLISHMENTS	LIFE-STYLE OUTCOMES	KEY PEOPLE
J. M. Yr. 1	Profile completed at '91 Family Forum Family started to think differently about school program	Family unwilling to continue with planning process	Mom & Dad PFP Facilitator
K.S. Radcliffe 2 hrs. Yr. 1	Profile information Family committed to coming to Family Forum in 1991 but did not Connected with HKNC affilifate, DVR	Parents decided not to participate K.S. has since passed away	
J.S. Louisville Yr. 1	DVR acceptance School to work program Hearing-Support Services-Auditory Trainer O & M evaluation Coordination of services between JCPS and KSB	presence competence respect	PFP Facilitator KSB Counselor HKNC Affiliate, DVR Vision Itinerant Coordinator, JCPS DBIP Transition Consultant KSB Speech Therapist Mom J.S.

PERSON	MAJOR ACCOMPLISHMENTS	LIFE-STYLE OUTCOMES	KEY PEOPLE
J.B. Louisville Yr. 1	Community Resource Developer Presence in the Community Supported Living Funds More independence for Mom-Driver's License-Studying for GED	presence choice competence participation respect	PFP Facilitator Neighbors, who were also service providers with very postive values Seven Counties Services PASSPORTS Coordinator DBIP Transition Consultant HKNC Affiliate, DVR Mom & Dad J.B.
M.B. Paducah 8 hrs. Yr. 1	Profile information completed	Mom unwilling to continue	DBIP Consultant PFP Facilitator
M.C. Shelbyville 1.5 hrs Yr. 2	Got people to think about the future KY Housing Corp. person Case manager with SCS Mom to think about school Encouraged to come to Family Forum	None - Mom unwillng to act at present; Health concerns of M.C. & Father	Respite provider Mom SCS Rural Respite Coord. Former homebound teachers Parent Mentor PFP Facilitator Current homebound teacher

PERSON	MAJOR ACCOMPLISHMENTS	LIFE-STYLE OUTCOMES	KEY PEOPLE
L.M. Lexington 3 hrs. Yr. 2	Vision for the future outside the nursing home Involvement in local church Supported living application completed & funded	presence respect	L.M. Parents PFP Facilitator Friends of parents
W.L. London 3 hrs. Yr. 2	Reg. Kindergarten !!!!!! Mom's empowerment IEP goals & objectives which mean something Transition from pre-school to reg. education Mom called P & A	presence choice competence respect	W.L. Mom DBIP State Coord. as PFP Facilitator DBIP Early Childhood Consultant
L.B. Florence 4 hrs. Yr. 2	IEP goals & objectives which mean something Brenda's empowerment Training of additional school personnel at SHIPP Involvement of other family members Leadership role with PCDSI	presence choice competence respect	L.B. Grandmother DBIP State Coord. DBIP Early Childhood Consultant as PFP Facilitator

PERSON	**MAJOR ACCOMPLISHMENTS**	**LIFE-STYLE OUTCOMES**	**KEY PEOPLE**
W.W. Louisville Yr. 2	Vision as a capable young man Artistic abilities recognized Integrated into regular classes in middle school with supports	presence competence respect choice	W.W. Parents PFP Facilitator DBIP School-age Consultant
K.P. Louisville Yr. 2	Integrated school setting -half-day Class schedule arranged for college acceptance Attended 1st consumer conference and met other young people with Usher's Syndrome	presence competence participation	DBIP Transition Consultant Mom PFP Facilitator K.P. KSB Teacher
--E.C. Jenkins 8 hrs. Yr. 2	Regular home--out of PC home Guardianship more positively focused 2 strong advocates part-time job More fun things to do Catalyst for School to Work Transition Prog.	presence choice competence respect	PFP Facilitator Protection & Advocacy Teacher Teacher's husband HKNC Affiliate,DVR E.C.

PERSON	MAJOR ACCOMPLISHMENTS	LIFE-STYLE OUTCOMES	KEY PEOPLE
S.H. Louisville Yr. 2	Self-advocate Interpreter at school Independent Dorm More positive self image Summer job of her choice Voc. Rehab. Eval.	presence choice competence respect	PFP Facilitator KSB teacher DBIP Transition Consultant S.H.
K.C. Nicholasville 4 hrs. Yr. 3	SSI New hearing aid Supported employment provider in Lexington Info re diabetes support group Info re Bluegrass Technology Center K.C. invited to consumer conference	choice competence	K.C. PFP Facilitator DVR Counselor for the Deaf Mom & Dad Sister Grandmother
M.H. Owensboro 5 hrs. Yr. 3	Supported living funding for after 12/93 Greater family involvement of extended family Lift for the van	presence participation	M.H. PFP Facilitator Mom & Dad Friend of the family

PERSON	MAJOR ACCOMPLISHMENTS	LIFESTYLE OUTCOMES	KEY PEOPLE
D.G. Jackson 3 hrs. Yr. 3	Community-based Peer involvement	presence participation	PFP Facilitator Regular ed teacher HS students in one class
D.J.L. Danville 5 hrs. Yr. 3	Adaptations for voc. eval. JTPA for senior yr.? Vision consultation from Cathy Johnson Thinking about future Visited KSB Transition planning	choice competence respect	D.J.L. Parents KSD Counselor DBIP Transition Consultant HKNC Affilifiate, DVR Rehab. Counselor for the Deaf Computer instructor PFP Facilitator
T. P. Erlanger 3 hrs. Yr. 3	Thinking about work options Exploring resources in N. Kentucky re work, further training	choice presence competence	T.P. Mom Fiance

PERSON	MAJOR ACCOMPLISHMENTS	LIFESTYLE OUTCOMES	KEY PEOPLE
C.R. Lexington 3 hrs. Yr. 3	Supported living funded Facilitated communication is being explored Looking at work issues & job development	presence competenc respect choice	C.R. Mom PFP Facilitator Employment consultant
S.C. Morehead 7 hrs. Yr. 3	Transition planning at KSB Involvement of peers/ family in Morehead Vision for the future Getting home earlier on some Fridays Participation in HKNC/TAC	choice competence respect participation presence	S.C. DBIP Transition consultant (served as PFP facilitator) Mom KSB Curriculum Director
A.U. Louisville Yr. 3	Mom to attend meetings Voc. Rehab. Involved Supported Employment provider	presence competence respect	Teachers HKNC Affiliate Rep., DVR Mom DBIP Transition Consultant A.U.

PERSON	MAJOR ACCOMPLISHMENTS	LIFESTYLE OUTCOMES	KEY PEOPLE
C.D. Louisa 8 hrs. Yr. 3	Different vision More Choices Dressing more age appropriately DBIP In-service	choice competence respect	PFP Facilitator Special Education Coordinator Mom and Dad C.D.
W.S. Louisville Yr. 3	Integrated with children with no disabilities	competence presence respect	Mom and Dad Vision Itinerant Coordinator, JCPS VIPS staff W.S.
J.T.B. Bardstown 3 hrs. Yr. 3	Grandmother to agree to do PFP More of a vison for him Next school year to address more choices	choice competence	Special Ed. Coord. PFP Facilitator Teacher Grandmother Aunt J.T.B. Protection & Advocacy

Key to abbreviations:

PFP = Personal Fuures Planning
DBIP = Deaf-Blind Intervention Program
HKNC Affiliate = Helen Keller National Center Affiliate, Dept. of Vocational Rehabilitation
HKNC/TAC = Helen Keller National Center Technical Assistance Center
KSB = Kentucky School for the Blind
KSD = Kentucky School for the Deaf
VIPS = Visually Impaired Pre-School Services
JCPS = Jefferson County Public Schools
8 hrs = Round trip travel time
Yr. 1, 2, 3 Project year when Futures Planning began

Appendix VIII-E

Predictor Statements and Summary of Results

Through participation in Personal Futures Planning, the following predictor statements should result for the focal person (student), his/her family, or other involved Circle Members

PREDICTOR STATEMENTS:	DATA SOURCES
1) The student attends a greater number of integrated classes with nondisabled peers (for students who are being served in a regular high school setting). (STRONG)	IEP; TIPS Survey; Facilitators Log; Parent Interview
2) The students has more weekly opportunities for interactions with nondisabled peers in the school setting as measured by: a) eating lunch at the same table with nondisabled peers; b) participating in regular school breaks, homerooms, assemblies, etc,; c) participation in other school activities (extracurricular activities, school sports events, etc.). (STRONG)	IEP; TIPS Survey; Facilitators Log: Parent Interview
3) The student participates in more frequent, systematic community-based instruction in general community settings (as measured in minutes per week in systematic CBI). (STRONG)	IEP; TIPS Survey; Facilitators Log; Parent Interview
4) The student participates in more frequent community-based vocational training experiences (as measured in minutes or times per week). (STRONG)	IEP; TIPS Survey; Facilitators Log; Parent Interview
5) There are more persons (both typical peers and staff) in the school setting who are have been trained specifically in the use of that student's communication system. (MEDIUM)	Facilitators Log; Parent Interview
6) The student participates in a greater number of age-appropriate activities in the community in non-school hours: a) with nondisabled peers; b) with extended family members and friends. (MEDIUM)	TIPS Survey; Facilitators Log; Parent Interview
7) Parents evidence greater satisfaction with the overall school program for their son/daughter. (MEDIUM)	TIPS Survey; Parent Interview
8) The IEP/ITP is more reflective of value-based, person-centered planning around the themes of the "five accomplishments". (MEDIUM)	IEP and/or ITP; Analysis of IEP/ ITP by B. Wilcox

9) The student/focal person has more control and choice-making in his/her life. (MEDIUM)	Helen Keller Baseline Quest.; Parent Interview
10) The student/focal person participates in a greater range of age-appropriate recreation/leisure activities at home and in the community. (MEDIUM)	TIPS Survey; Parent Survey
11) The transition-age student has a written ITP. (MEDIUM)	ITP
12) The IEP for the transition-age students will include a "statement of the needed transition services for students beginning no later than age 16 and annually thereafter, including a statement of the interagency responsibilities or linkages or both before the student leaves the school setting. (STRONG)	IEP/ITP
13) The family (parent/siblings) of the student/focal person experiences less stress as a result of the PFP process. (MEDIUM)	Parent Interview
14) The family (parent/siblings) of the student/focal person has more choices/options in their own lives as evidenced by the actual number of persons upon whom the family can rely to do what they had previously been responsible for doing for the student/focal person; and by more "fun" things in their own lives. (MEDIUM)	Parent Interview TIPS Survey
15) Empowerment: the family initiates more contacts with service providers for the focal person. (WEAK)	Parent Interview Facilitator Log
16) The family (parent/siblings) of the student/focal person is helped to visualize a more positive future for the student/focal person as described in terms of the "five accomplishments". (STRONG)	Parent Interview Personal Futures Plan
17) The family of the student/focal person is helped to gain all medical, SSI, and/or SSDI financial assistance to which the person is entitled. (MEDIUM)	Facilitators Log Parent Interview
18) The family of the student/focal person is assisted to look at the future of their son/daughter with regards to life planning (i.e., wills, trusts, and/or guardianships). (MEDIUM)	Facilitators Log Parent Interview

19) Adults services (vocational rehabilitation, vocational education, comprehensive care) are contacted as a result of the PFP process. (STRONG)	Facilitators Log Parent Interview
20) Professionals participating in PFP circles have extended collaborative efforts for persons with disabilities beyond the circle and the focal person. (WEAK)	Interviews with Other Circle Members

PREDICTOR STATEMENTS

1. The student attends a greater number of integrated classes with nondisabled peers.

	Frequency	%	Valid %
Yes	7	29.2	30.4
No	16	66.7	69.6
NA	1	4.2	

2. The student has more weekly opportunities for interactions with nondisabled peers in the school setting as measured by ...

	Frequency	%	Valid %
Yes	14	58.3	60.9
No	9	37.5	39.1
NA	1	4.2	

3. The student participates in more frequent,systematic community-based vocational training experiences

	Frequency	%	Valid %
Yes	8	33.3	61.5
No	5	20.8	38.5
NA	11	45.8	

4. The student participates in more frequent community-based vocational training experiences.

	Frequency	%	Valid %
Yes	10	41.7	52.6
No	9	37.5	47.4
NA	5	20.8	

5. There are more persons (both typical peers and staff) in the school setting who have been trained specifically in the use of that student's communication system.

	Frequency	%	Valid %
Yes	11	45.8	61.1
No	7	29.2	38.9
NA	6	25.0	

6. The student participates in a greater number of age-appropriate activities in the community in non-school hours...

	Frequency	%	Valid %
Yes	14	58.3	58.3
No	10	41.7	41.7

7. Parents evidence greater satisfaction for school program of son/daughter.

	Frequency	%	Valid %
Yes	16	66.7	69.6
No	7	29.2	30.4
NA	1	4.2	

8. The IEP/ITP is more reflective of value-based, peer-centered planning around the themes of five accomplishments.

	Frequency	%	Valid %
Yes	18	75.0	75.0
No	6	25.0	25.0

9. The student/focal person has more control and choice-making in his/her life.

	Frequency	%	Valid %
Yes	19	79.2	82.6
No	4	16.7	17.4
NA	1	4.2	

10. The student/focal person participates in a greater range of age-appropriate recreation/leisure activities at home and in community.

	Frequency	%	Valid %
Yes	17	70.8	73.9
No	6	25.0	26.1
NA	1	4.2	

11. The Transition-age student has a written ITP.

	Frequency	%	Valid %
Yes	18	75.0	81.8
No	4	16.7	18.2
NA	2	8.3	

12. The IEP for the transition-age student will include a statement of needed transition services...

	Frequency	%	Valid %
Yes	19	79.2	90.5
No	2	8.3	9.5
NA	3	12.5	

13. The family of the focal person/student experiences less stress as a result of the PFP process.

	Frequency	%	Valid %
Yes	17	70.8	70.8
No	7	29.2	29.2

14. The family of student/focal person has more choices/options...

	Frequency	%	Valid %
Yes	16	66.7	66.7
No	8	33.3	33.3

15. Empowerment: the family initiates more contact with service providers for the focal person.

	Frequency	%	Valid %
Yes	19	79.2	79.2
No	5	20.8	20.8

16. The family (parents/siblings) of the student/focal person is helped to visualize a more positive future for the student/focal person as described in terms of the five accomplishments.

	Frequency	%	Valid %
Yes	15	62.5	78.9
No	4	16.7	21.1
NA	5	20.8	

17. The family of the student/focal person is helped to gain all medical, SSI, and/or SSDI financial assistance to which the person is entitled.

	Frequency	%	Valid %
Yes	15	62.5	78.9
No	4	16.7	21.1
NA	5	20.8	

18. The family of the student/focal person is assisted to look at the future of their son/daughter with regards to life planning.

	Frequency	%	Valid %
Yes	15	62.5	62.5
No	9	37.5	37.8

19. Adult services (vocational rehabilitation, vocational education, comprehensive care) are contracted as a result of the PFP process.

	Frequency	%	Valid %
Yes	19	79.2	95.0
No	1	4.2	5.0
NA	4	16.7	

20. Professionals participating in PFP circles have extended collaborative efforts for persons with disabilities beyond the circle and the focal person.

	Frequency	%	Valid %
Yes	10	41.7	41.7
No	14	58.3	58.3

Appendix VIII-F

Structured Interview Questions for Rounds I and II

PFP Project: Family Member Interview Guide

Date: Which family member(s):

Time of interview: Individual: Length of interview:
Location of interview:

SETUP: Interview family members either individually or together. Try to make sure that you subsequent interviews involve the same, or at least some of the same family members.

Identify yourself as working with the Personal Futures Planning Project and remind the family member that you want to talk about their thoughts and reactions to the planning process and results. Remind them that your interview will take about an hour or so and that they can stop or reschedule at any time. Ask their permission to tape the conversation, reassuring them that only you will hear the tape and that it will be transcribed using pseudonyms.

INITIAL INTERVIEW: EXPECTATIONS

Let's talk about how you get involved in the project.

Probes:

How did you hear about the PFP Project?

Had you ever heard of futures planning before? Had any experiences with it?

Why did you decide to get involved?

What did you expect would happen when you got involved in the project?

INITIAL INTERVIEW: PROCESS

So. Let's talk about how the futures planning went.

How was it like what you expected?

How were the arrangements for the first meeting made? was that okay with you? could it have been better for you in some way?

Were there any parts of the meeting that you especially liked? didn't like? wish had happen differently?

How did [person's name] seem to feel about the meeting? was his/her involvement in the meeting okay with you? how might it have been better?

What are two or three adjectives that you might use to characterize the meeting?

INITIAL INTERVIEW: MEETING OUTCOMES

Let's talk about the actual plans that were made.

What did you think of them? were they things you hadn't thought about before? tried before?

How did you feel about the way the group strategized about the plans? were the ideas reasonable and likely to get done from your point of view?

How did you feel about the tasks that were outlined? did they seem to be reasonably distributed among the people present? did you feel like the "right" people accepted the appropriate task?

How about your tasks? enough? too many? possible for you? do you need any other assistance or support to go ahead with them.

INITIAL INTERVIEW: CLOSURE

Suppose I come back in two months, or three months, what would I see in [individual's name] life that will be different?

What will be different in your life?

Do you have any suggestions for us about the futures planning project?

Would you be willing to talk with us again?

SUBSEQUENT INTERVIEW: SUMMARY UPDATE

Let's see. Last time we talked, some of the things you and the group had planned were: [summarize some of the tasks and strategies from the previous meeting].

Catch me up. What's been happening?

*Identify which tasks and strategies implemented. Probe for those not mentioned.

*Identify why tasks and strategies <u>not</u> tried were dropped, if possible.

*For those tasks and strategies "in progress," try to determine their status and make notes about whether or not the interviewee thinks the status is reasonable or things are being unduly delayed or dragged out.

PFP Project: Other Participants Interview Guide

Date: Who/Relationship:

Time of interview: Individual: Length of interview:
Location of interview:

SETUP: Interview other participants either individually or together. In at least some situations, try to interview all the other participants in the futures planning meeting. In others, try to interview those members that strike the facilitator as "key" in some way. Finally, try to either interview other participants at different times in the PFP process, or try to select a few groups to interview some members several times so that you get a picture of how other participants feel about the outcomes and ripple effects of the PFP process.

Identify yourself as working with the Personal Futures Planning Project and remind the family member that you want to talk about their thoughts and reactions to the planning process and results. Remind them that your interview will take about an hour or so and that they can stop or reschedule at any time. Ask their permission to tape the conversation, reassuring them that only you will hear the tape and that it will be transcribed using pseudonyms.

INITIAL INTERVIEW: EXPECTATIONS

Let's talk about how you get involved in the project.

Probes:

How did you hear about the PFP Project?

Had you ever heard of futures planning before? Had any experiences with it?

Why did you decide to get involved?

What did you expect would happen when you got involved in the project?

INITIAL INTERVIEW: PROCESS

So. Let's talk about how the futures planning went.

How was it like what you expected?

How were the arrangements for the first meeting made? was that okay with you? could it have been better for you in some way?

Were there any parts of the meeting that you especially liked? didn't like? wish had happen differently?

How did [person's name] seem to feel about the meeting? was his/her involvement in the meeting okay with you? how might it have been better?

What are two or three adjectives that you might use to characterize the meeting?

INITIAL INTERVIEW: MEETING OUTCOMES

Let's talk about the actual plans that were made.

What did you think of them? were they things you hadn't thought about before? tried before?

How did you feel about the way the group strategized about the plans? were the ideas reasonable and likely to get done from your point of view?

How did you feel about the tasks that were outlined? did they seem to be reasonably distributed among the people present? did you feel like the "right" people accepted the appropriate task?

How about your tasks? enough? too many? possible for you? do you need any other assistance or support to go ahead with them.

INITIAL INTERVIEW: CLOSURE

Suppose I come back in two months, or three months, what would I see in [individual's name] life that will be different?

What will be different in your life?

Do you have any suggestions for us about the futures planning project?

Would you be willing to talk with us again?

SUBSEQUENT INTERVIEW: SUMMARY UPDATE

Let's see. Last time we talked, some of the things you and the group had planned were: [summarize some of the tasks and strategies from the previous meeting].

Catch me up. What's been happening?

- Identify which tasks and strategies implemented. Probe for those not mentioned.
- Identify why tasks and strategies not tried were dropped, if possible.
- For those tasks and strategies "in progress," try to determine their status and make notes about whether or not the interviewee thinks the status is reasonable or things are being unduly delayed or dragged out.

SUBSEQUENT INTERVIEW: OUTCOMES

Talk to me about [individual's name] life right now. How has it changed?

Are these changes okay with you?

Did the changes turn out like you had imagined?

During the futures planning meeting we talked about different aspects of [individual's name] life including:

home life
work life
financial security
health/fitness
fun and friends
community membership and involvement

How are you feeling now about these aspects of [name]'s life?

How are your feeling about your role in [name]'s life? too much? okay? not enough?

Are there things that you think need to be re-planned? have you talked to the PFP facilitator about your concerns?

SUBSEQUENT INTERVIEW: RIPPLE EFFECTS

Sometimes things occur that the planning process doesn't even anticipate. Have there been any of these kinds of changes in [name]'s life that didn't even come up at the meeting?

What about your life? or others who were at the meeting?

Can you think of things that have happened because of the PFP meeting that not one could have guessed?

SUBSEQUENT INTERVIEW: CLOSURE

Suppose I come back in two months, or three months, what would I see in [individual's name] life that will be different?

What will be different in your life?

Do you have any suggestions for us about the futures planning project?

Would you be willing to talk with us again?

Msc\OthrGuid.PFP 2/92 m:

SUBSEQUENT INTERVIEW: OUTCOMES

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Are these changes okay with you?

Did the changes turn out like you had imagined?

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Can you think of things that have happened because of the PFP meeting that not one could have guessed?

SUBSEQUENT INTERVIEW: CLOSURE

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What will be different in your life?

Do you have any suggestions for us about the futures planning project?

Would you be willing to talk with us again?

Personal Futures Planning for Transition Age Young Adults with Dual Sensory Impairments

Interview Perspectives of Family Members and Other Participants

by Brenda M. Pezzarossi
Interdisciplinary Human Development Institute
University of Kentucky
Lexington, Kentucky

Personal Futures Planning Project
Qualitative Analysis
Evaluation Component
September 30, 1993

CONTENTS

Personal Futures Planning for Transition Age Youth with Dual Sensory Impairments

Interview Perspectives of Family Members and Other Participants

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Introduction

Overview

This final evaluation component report summarizes this interviewer's interpretative analysis formed in the duration of a three year Personal Futures Planning Project grant. The formation of personal futures planning teams, surrounding thirty transition age young adults, listed on Kentucky's state deaf/blind registry, was the purpose of the Personal Futures Planning Project, Interdisciplinary Human Development Institute, University of Kentucky. Telephone and in-person interviews, conducted by this interviewer, included a sampling of family members and many other participants after each planning team was in progress. The following is a documentation of the results of a qualitative analysis interpretation by this interviewer.

History

By the end of the third year of the project, seventy one interviews had been coordinated, set up, conducted, taped, and transcribed by this interviewer. Interviews, after being transcribed into written format, averaged fourteen type-written pages. Transcriptions, audio taped from standardized interview questions, averaged over one hundred pages for each of the ten teams interviewed. The final volume of material for the evaluation component of the Personal Futures Planning meetings data was one thousand and sixty four pages of documented information which was used in the final qualitative analysis.

This report reflects the continuation of the last two years of the Personal Futures Planning Project, during which the majority of the interviews were conducted. Each team surrounded the focal person from one family; each team must have already met several times before interviews were conducted. Therefore, family members and participants were not usually contacted by this interviewer until the second year of the project. The majority of the first rounds of interviews were conducted from October of '91 through September of '92. The consecutive second rounds were conducted from approximately six months to one year later, with the majority taking place from October of '92 through August of '93.

Purpose

The purpose of qualitative research is to come to understand the experience from the perspective of the individual involved (Biklen & Mosely, 1988). For this analysis, ten teams agreed to participate in the interview process after the formation of their Personal Futures Planning teams. Using qualitative research techniques, this interviewer conducted family member interviews in order to learn of the experiences and perspectives of families, whose transition age children were deaf/blind (dual sensory impaired). Interviews with other participants were conducted with the same question format in order to find out the perspectives of facilitators, neighbors, community members, and professionals. Team members interviewed initially were, for the most part, on Personal Futures Planning teams which had been formed, were already meeting regularly, and were actively involved in the process. In order to better evaluate the outcomes of forming the Personal Futures Planning teams around individuals with dual sensory impairments, this interviewer set up individual meetings.

Method

The final evaluation component of the Personal Futures Planning Project falls under the research best known as qualitative analysis techniques. Qualitative research methods study perspectives. The techniques used in qualitative research are not efficient ways to produce predictive, generalizable statements about how to better control designated outcomes (Ferguson , Ferguson, & Jones). Rather, this technique can document the patterns of people's lives and reveal how research subjects construct meaning around these patterns. The participants' own interpretations of their lives assume a prominent place. Qualitative data take the form of narrative rather than numbers. Qualitative methods are labor intensive because in order to accumulate valid data, the researcher must gain the informants' trust and understand the individuals' lives (Biklen & Moseley, 1988). This study did use "qualitative" techniques to inteview a select group of family members and other participants who were members of the Personal Futures Project teams.

Participants

Participants from ten teams were contacted for private interviews at the convenience of those being interviewed. Each participant was interviewed two times in the interest of more accurate accounts, based on the interviewer's familiarity, with the families and the process involved. Rationale for conducting two interviews with each participant centered around establishing a baseline of the need for changes and eliminating extraneous variables in order to gauge which outcomes could be attributed solely to the personal futures planning process. Conducting the first interview soon after a few team meetings had been conducted was thought to be one way to better evaluate outcomes which could be directly attributed to the personal futures planning meetings.

Ten teams, perceived to be a fair sampling of the teams, were selected by project staff members to represent the totality of teams formed by the project. Actual participants interviewed ranged in number from three to six, with most teams having four or five members interviewed.

The types of people interviewed ranged from the actual facilitators employed by the project to volunteers who were long time friends of the family. Others who agreed to be interviewed were siblings, vocational rehabilitation counselors, employment consultants, school admissions coordinators, itinerant hearing and vision teachers, parents, grandparents and guardians. The focal person, using an interpreter, was interviewed for one of the teams and a pastor and his wife agreed to be questioned for another team.

Data Gathering Procedures

The names of specific team members were given to this interviewer, after being determined by the facilitators as ready for a first interview to proceed. As part of the evaluation component, this interviewer was instructed to contact specific team members for their interview participation. Team members were called by telephone in order to set up and conduct taped audio interviews. When contacted, each participant was asked about scheduling a convenient time for either a telephone or in person interview. Many participants, especially those who were paid providers of services, were very difficult to schedule and often had to be contacted repeatedly before being able to set up an interview. For the parents and guardians contacted, almost all were called at night and/or on weekends. Of the ten teams, for which parents were to be interviewed, all agreed to the initial interview upon the first telephone contact.

In order to acquire a working knowledge of the expertise required to conduct the interviews, this interviewer conducted initial interviews with three parents. During the latter part of the first year of the project, when a few teams had been formed, this interviewer used differing interview techniques to determine the best method for the most accurate data collection. Contacts with these three parents consisted of interviews with note taking conducted in person and without a tape recorder, by telephone using a computer for dictation, and in person using a tape recorder. Two of these original interviews were not used in the evaluation component of the final report. An interview guide format was set up on a computer template for repeated use. Depending upon the size of the transcript, the reproducible form of the interview guide was able to be expanded to any length. Verbatim tapes and transcriptions were determined to be the most accurate method of recording data, both in person and by telephone.

An "interview guide" formulated by Dr. Diane Ferguson, a consultant to the project, was constructed for the greatest degree of freedom in the comments of those interviewed (see appendix). Some of these original questions were later reformulated by this interviewer, after being field tested with three practice interviews. A family member guide along with a guide for the other participants, including two sets of open-ended questions, were used. Round one questions focused more on the process of the Personal Futures Planning meetings and the expectations of family members and other participants. Round two questions detailed specific outcomes and summarized other participants' involvement in the life of the focal person and family.

Some of the major issues discussed in the first round interviews are listed on the interview format in Table 1. Second round interview topics followed a more open ended format, which allowed for more general answers with less structure in the questions. The setup for questions for both round one and round two were described in this identification process as given below.

Table 1
Interview Topics

Interview Format for Round I and Round II

ROUND ONE INTERVIEWS

Specific Expectations
Meeting Process
Meeting Outcomes
Permission Request (followup interview)

ROUND TWO INTERVIEWS

Outcomes
Summary Update
Ripple Effects
Closure Suggestions

In order to retrieve as much relevent information as possible from the many interactions of participants involved with the personal futures planning process, interviews took place in an informal manner. The most difficult interview to conduct, transcribe, and interpret was conducted with one of the focal persons who needed an interpreter. This particular focal person had great difficulty with the abstract quality of many of the open ended questions which had been constructed and standardized prior to the interview.

Data were collected over a period of about one year and ten months, primarily through the use of in-depth, semi-structured interviews. Many respondents took this as an opportunity to share their history of involvement with the focal person, as well. Most interviews lasted at least one and one half hours. In duration, they were from two hours and twenty minutes for one grandparent/guardian to the most brief interview which was completed in fourteen minutes with one facilitator.

All of the interviews were conducted by the author. The actual interview guide consisted of prompts to elicit the identification of the interviewer, a description of the interview process, and the pursuit of receiving permission to tape the conversation. The interview setup was designed as follows:

Interview Setup

The setup of the interviews included instructions concerning the taping procedure. The title and job description of the interviewer, background, and purpose of the interviews were given. The interviewer asked permission to tape the conversation and offered reassurance that only project staff would hear the tape unless their story would be used for the Insight Newsletter. If their story was to be used for publication, the participants would be contacted by telephone and read the entire dictated interview and asked to give verbal permission for the printing of their interview. During the 'in person' interviews, each participant was given full control of the tape recorder; the interviewer demonstrated the pause button, and encouraged participants to pause when answers to questions *became uncomfortable. The participant was also told that any part of the interview could be reviewed and erased if unsuitable to the participant at that time. Participants, interviewed 'in person', also had a copy of the questions to follow throughout the interview, if so desired.*

Data Analysis Procedure

Other than one team, whose interviews consisted of first round interviews only, all the other major family members, other participants, and focal persons, where appropriate, were involved in both first and second round interviews. All discussions were recorded on tape and verbatim transcriptions were developed. In order to determine categories, two of the first teams interviewed with participant's comments from the entire team, including first and second rounds, were transcribed by this interviewer. These two completed teams were given to Dr. Carol David, an outside consultant, who noted nine themes which emerged. With these nine categories in mind, each transcription was scanned by this interviewer for reflective quotes, which appeared to match each of the nine categories. Table 1 includes the nine categories which emerged from the interviews.

Table 2
CATEGORIES FROM INTERVIEWS
Organized into Nine Emerging Patterns

1. Participation of the focal person at PFP meetings.
2. Participation in the process by the family and community.
3. Support for the family and/or caregiver.
4. Coordination of school and other programs.
5. Resources with the focal person involved.
6. Resources available for the focal person in the community.
7. Life changes and/or new experiences for the focal person.
8. Empowerment of the focal person and/or family.
9. Ripple effects from the Personal Futures Planning.

Using the old fashioned cutting and pasting technique to locate each matching category, verbatim quotes were highlighted using color coded markers. Appropriate color coded descriptions were placed on numerous 5X7 note cards which were used for each participant and for each category. The previously transcribed verbatim quotes were attached to the cards under each of the appropriate headings for the nine categories. These quotes were grouped under categories across the span of the many participants' comments derived from the ten teams interviewed. These quotes were then either separated by category title, focal person, family member, other participant. Initials of the focal persons involved were placed on each card. Pseudonym names, to safeguard confidential information, were selected for use in the publication of the final report.

Table 3

PFP PARTICIPANT DESCRIPTIONS

	Pseudonym	Gender	AGE (beginning PFP)	INTERVIEW(S) First	INTERVIEW(S) Second	Home/School Arrangements
1.	Jack Andrew	male	18	91	92	home/local high school
2.	Sam Marshall	male	20	91	93	institution
3.	Jake Stephens	male	18	91	92	state school for the blind
4.	Joe Burton	male	21	91	92	home
5.	Jeff Bradshaw	male	17	91	92	home/high school
6.	Terry Sweeney	male	14	92	93	home/middle school
7.	Jennifer Russell	female	16	92	93	home/high school
8.	Sharon Green	female	17	92	93	group home/high school
9.	Sally Hall	female	18	92	(-)	state school for the blind
10.	Donna Jean Lane	female	16	93	93	state school for the deaf

Source: Personal Futures Planning Project, PFP Evaluation Component Interview(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

Data Analysis Procedure. Themes, selected after quotes were placed on notecards, appeared repetitively throughout the volumes of interview data. Each of the nine categories was listed on a separate card upon which applicable quotes from the various participants were placed. Two methods of organizing the quotes into easily recognizable themes were used.

1.) **Quotes arranged by themes.** The quotes were arranged by the themes and grouped under the appropriate category. These quotes appeared the most frequently across all the teams and were arranged under a particular theme irrespective of the focal person or the team from which it was derived. These examples appear throughout the quotes centered around one particular focal person's team and immediately following the interpretative description of each category.

2.) **Quotes arranged by focal person's team.** The quotes were arranged by the focal person's team and grouped onto each card. These quotes, which centered about one particular focal person's team, were selected to fit the most prevalent themes of one category. An example for each team was listed under the most appropriate category. These examples appear throughout the following interpretative descriptions after each theme for each category.

Results

CATEGORY I: Participation of Focal Person at the PFP Meetings

Several themes warranted the most attention in the observations of the focal person's participation in the Personal Futures Planning process. The value of inclusion in the meetings, communication related to participation, and the effects of the severity of the disability upon participation in the planning process were equally represented.

THEMES
Of the Focal Person's Participation

1. The Value of Inclusion
2. Communication
3. Severity of the Disability

The value of inclusion was viewed differently for several participants involved. Many prefaced their remarks with, "I am not sure." Some felt it would have been nice to include the focal person, while others were not sure how much the focal person would understand. One professional with the state's Deaf/Blind Intervention Program recognized that the inclusion opportunity had already passed and commented.

> ***Maybe we should have made a more conscious effort of asking him questions about specific things and used his motor communication so he could express himself more.***

Communication, which was constantly mentioned in the interviews, was seen as the major block toward any focal person's ability to be able to participate in the family, school, meetings, or the community. His mother commented about one meeting held at Jake Stephen's home, "He doesn't communicate . . . he just greeted people and went on back to his room." Concerning a meeting held at the school for Jake, his vision teacher made her own observation. "I think a lot of things in the communication area are confusing to him." One parent explained why her son did not attend a meeting held where he lived. "Because of his sensory impairment, he isn't able to communicate with you."

The severity of the disability was interconnected with communication and cognition. "She's not capable of judging right or wrong . . . people have to make all these decisions for her." Participation of the focal person appeared to hinge upon the focal person's level of comprehension for some of participants interviewed. One service provider related the severity of the disability to the focal person's participation.

> ***Due to the severity of his disability, he isn't able to provide direct input other than through demeaner and gestures and those kinds of things.***

CATEGORY II: Participation in the PFP Process by Community Members and Family

Closely related to the focal person's participation in the personal futures planning meetings was the participation process involving the family and the community. Most apparent in the themes of the quotes were those which dealt with the involvement needed from friends, including peers, activities, and simply more people included in the life of the person with the disability. While mentioned the most as an area of need, this area was also listed as one in which the least amount of success was achieved. "We talked about more socialization for Jake, such as getting him out more to basketball games . . . I don't think that ever got off the ground."

THEMES

In the Process of Participation by Family/Community

1. Positive Involvement
2. Experiences in Problem-Solving
3. Involvement from Friends

Problem solving experiences were constant themes in the interviews, since the end result of a better quality life for the focal person was often the goal of Personal Futures Planning meetings. However, many times there was no road map to follow about how to arrive at that particular outcome. "The planning was . . . to have him assimilate into our community as best he could, and we didn't know in what direction it was

THEMES: PFP PARTICIPATION
Observations of Focal Persons' Participation
Sample Quotes

VALUE OF INCLUSION AT PFP MEETINGS

"I am not sure how much he would understand of what is going on; but, I am not sure those are reasons to include or exclude him. I think a lot of things in the communication area are confusing to him." . . . vision program director

"Maybe we should have made a more conscious effort of asking him questions about specific things and used his motor communication so he could express himself more." . . . Deaf-Blind Intervention program director.

"I know he is deaf and blind; but, I think it would have been nice to have someone to interpret to him what was going on." . . . case manager.

COMMUNICATION AND PFP PARTICIPATION

"He doesn't communicate, but you can look at his facial expressions and tell how he feels. If he has a glum look on his face then I know he wants to leave the room. He just greeted the people and went on back to his room." . . . mother.

"Because of his sensory impairment, he isn't able to communicate with you." . . . mother.

SEVERITY OF THE DISABILITY AND PFP PARTICIPATION

"I'm not sure that he could (participate). I think the decisions that we made for him, I feel like we felt they were best and I feel like if all those things were carried through and accomplished that it would be for his benefit." . . . friend of the family.

"Due to the severity of his disability, he isn't able to provide direct input other than through demeaner and gestures and those kinds of things, so he hasn't been able to provide input." . . . Helen Keller Affiliateship service provider.

"She's not capable of judging right or wrong or danger or not danger, you know, going in and out. People have to make all these decisions for her." . . . mother.

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

PFP PARTICIPATION

by Focal Person

Sample Quotes

FAMILY MEMBER

"Some people put things on the wall saying nice things about me. Every time, it was like a contest . . . to the interpreter and I would get . . . my eyes would really hurt. I would get . . . I wouldn't know what they were talking about, a little bit." . . . focal person

"She got frustrated because her eyes would get tired and the interpreter would keep going on with everything that was going on." . . . interview interpreter.

FACILITATOR

"Sally still has a real hard time in being confident in voicing what she wants, but like I said, over the last year or so that has become. . . she has become more confident and I am pleased with that, but at the first meeting, she just had a lot of fear." . . . facilitator.

PROFESSIONALS AND OTHER PARTICIPANTS

"I know it was really hard on them (Sally and her mother). I guess I felt in an awkward position in being the first one to have to present the idea to them that Sally is eighteen and these are things we need to look at because mother was totally unprepared for that. It was a painful growing process, I think, but I think everyone did really well. Sally came along very quickly, I think, in terms of trying to figure out, "What does this mean for me?" Mother wasn't able to come along quite that quickly. In the end, I think everyone has grown a lot." . . . school admissions coordinator

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

THEMES: PFP PARTICIPATION
Observations of Family and Community Participation
Sample Quotes

POSITIVE INVOLVEMENT

"Sharon moved into our **group home** in June of 1992 and since then she has adjusted very well, as far as she has made a lot of friends, you know at the home." . . . case manager.

"I feel like that any time they have needed us we have been glad to have helped them out and will continue to do so. It's just that you feel so limited. You feel like you're doing it for the **family** because I don't think, as far as I feel, Terry ever knows anything about it, really." . . . pastor.

EXPERIENCES IN PROBLEM-SOLVING

"I took Joe out one day myself and we got out on the sidewalk and he was afraid and he became very, very difficult to know how to **support.** He was screaming and hitting his head real hard and biting himself and refused to move and wouldn't do anything. It was the first time I really understood that this is not as simple as just introducing somebody new to him." . . . facilitator/neighbor.

"The planning was simply to help Jeff as best we could and develop his potential as best we could and to have him assimilate into our community as best he could, and we didn't know in what **direction** it was going to go." . . . high school biology teacher.

INVOLVEMENT NEEDED FROM FRIENDS

"Jake doesn't have much of a social life and we all agree that he should get out more with his **peers**, deaf and blind children like himself, or just deaf children or just blind children whichever, instead of just staying home." . . . mother.

"My friend came and a young lady who grew up with Jenny and was her friend for all those years. She used to be her **friend.** We don't ever see her anymore except to babysit for me if she comes home. She grew up and is going to college and working and dating. Jenny won't be able to do that ever. Jenny didn't grow up. She is still Jenny." . . . guardian/grandmother.

"We talked about more **socialization** for Jake, such as getting him out more to basketball games or even paying somebody to accompany him to certain activities. I don't think that ever got off the ground. I guess that is one aspect we really didn't address as much." . . . hearing itinerant teacher.

"I just wish there had been, there could be more **people** involved and that there would have been more consistent involvement from his peers." . . . Deaf Blind Intervention specialist

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

PFP PARTICIPATION
by Family Members and Community
Sample Quotes

FAMILIES

"At Sam's first meeting, we had family members and friends. That gave us a big range of ideas that parents alone would not have come up with." . . . mother.

"It almost seems like maybe it could be more of a harm to someone simply because they have now gotten all of these people involved in their life and . . . some of them have fallen through. There has been a lack of commitment from the family as well as other members in school also". . . case manager

FACILITATOR

"My expectations were that we would be able to get some of his vast, extended family more involved in his life. The expectations formed more after I heard more about his story and what had happened in the past year or two. I had hoped we would be able to get the family more involved." . . . facilitator.

PROFESSIONALS AND OTHER PARTICIPANTS

"Just thinking of future planning, I did expect the extensive planning that was laid out on paper. I did expect there would be more of a commitment. It seemed like the people that had been involved in the planning. . . it seemed to be really good and adequate; but, I felt that there was a lack of committment." . . . case manager

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

going to go." An experienced facilitator commented, "It was the first time I really understood that this is not as simple as just introducing somebody new to him." One aspect of Personal Futures Planning was the problem solving required to integrate persons with the most severe, multiple disabilities into participatory activities in the community.

CATEGORY III: Support for the Family and/or Caregiver

The third category and most frequently mentioned quotes fell into the category which represented the support for the family and/or caregiver. It included the themes listed below:

THEMES
In Support of Family/Caregiver

1. Family Support that Feels like Support
2. Family Structural Changes
3. Social Isolation of Parents/Caregivers
4. Transition Process Changes
5. Aging of Parents/Caregivers
6. Positive Professional Views

One parent humorously checked her pulse and said, "What is family support? Perhaps the best answer is what it is *not*. Family support is not support until it *feels* like family support." Several parents, whose transition age young people, were involved in personal futures planning had their own ideas of family support. Jack Andrew's mother valued having someone who would just simply listen. Knowing someone was close by, who could stay with their family member, while routine chores were done ranked high on the list of support by another parent. Since one of the outcomes of Terry Sweeney's personal futures planning meetings was a nurse, his mother identified the end result of their family support. She said, "I'm just not as tired as I was before."

THEMES: PFP FAMILY SUPPORT

Observations of Support for the Family and/or Caregiver

Sample Quotes

FAMILY STRUCTURE CHANGES: EFFECT UPON FAMILY

"I got married and moved out of the house. That was the most hectic thing and the most fun. I don't get to see him as much as I used to, and I do miss him a lot." . . . sister.

"I did have a few friends that used to keep Jamie. They're having health problems now and can't anymore." . . . guardian/grandmother.

"Since his brother's been home from college, he helps me out with him. Like if I want to go to the store, his brother will watch him." . . . mother.

SOCIAL ISOLATION OF PARENTS/CAREGIVERS

"Close friends, I guess I'm a different kind of person from other people, I've found I don't need them. . . the less you visit, the longer you'll stay friends. So that is me. I took that to heart. I don't have coffee with anybody." . . . mother

"No one has paid me for nineteen years to take care of my child and I do it because I love her and I want her to be happy and I want the best for her." . . . mother.

"I don't involve my relatives in anything that concerns my personal life. They're not interested! I feel that they know Jake is here and if they were interested, I wouldn't have to ask them." . . . mother

"I really haven't needed anyone to come. I haven't asked anyone to come. I feel that if I can't do it and I'm his mother, then how can I expect other outside people to do it? That's the way I've always felt." . . . mother

"I'm doing quite a bit, helping around the house, moving Terry around. I'll stay at home while she's (wife) out shopping, or stay with him." . . . father.

"A lot of things I have had to do before on my own, other people started doing it for me, so it sort of relieved me of some of it, really; but basically, when it gets back down to the nitty gritty, it all falls back onto the shoulders of the parents." . . . mother

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993). Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

THEMES: PFP FAMILY SUPPORT

Observations of Support for the Family and/or Caregiver

Sample Quotes

TRANSITION PROCESS: CHANGES DUE TO FOCAL PERSON'S TRANSITION

"She (her mother) said, "I just felt like you were all hitting me with so much at one time and I have done this and I have done that." . . . school admissions coordinator.

"Some of them were . . . people who take care of a handicapped person that are doing it for a job, it's different than a person that has raised them and given birth to them. There's a different kind of intent on working than doing it because you love them." . . . mother

"It was obvious that Mom was not real comfortable and I think she was beginning to get on the defensive a little bit and get somewhat upset, not quite understanding about it." . . . school admissions coordinator.

AGING PARENTS AND CAREGIVERS

"I had a hard time getting her in there. I don't want to have to go through that again because I am getting too old. I am too old to go through all of that.". . . guardian/grandmother.

"Any meeting, like the meetings with the school system, I am exhausted when I leave. You are emotionally exhausted just trying to hold it together, trying to get done what you're supposed to get done." . . . mother.

"You wonder what will happen to Terry when my mother and father aren't around any longer." . . . sister

"You have someone else to do the foot work for you, some of the phone calling. As a parent, you don't have the emotional strength to do it all. All you can do, especially if your child is still at home, is take care of the day to day needs you child requires." . . . mother.

"All these meetings are just very stressful. It is just because you have to go back and relive all the things that have happened to your child. You do become emotional about it." . . . mother.

"So now it is just Grandma. Now it is just she and I and she doesn't have any brothers or sisters. That makes a difference." . . . guardian/grandmother.

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

THEMES: PFP FAMILY SUPPORT
Observations of Support for the Family and/or Caregiver
Sample Quotes

POSITIVE SUPPORT: PROFESSIONAL VIEWS

"Donna Jean has very good support from her family and her parents. Her parents are really supportive and that helps a great deal." . . . vocational evaluator

"I would think that . . . the group, Jenny, her grandmother, and I will have figured out . . . what the support will look like and it will be happening." . . . employment consultant.

"She (his mother) is a very shy individual and it is hard for us to get her out and get her going. I think my team has shown her so many things Jeff has learned." . . . high school teacher.

"I feel Sam is fortunate to have so many people to support him and the family support, as well, which a lot of our other residents here do not have." . . . case manage-

FAMILY SUPPORT THAT FEELS LIKE "SUPPORT"

"I'm not as tired like I was before. I've got respite and I've got a nurse to help me more with him. I'm just not as tired as I was before." . . . mother.

"We've been friends for five or six years now and they live real close, so if she needs to run to the store or something, I have to pop over and sit with Jack."
. . . friend of mother

"They know any time that they need us . . . for such minor things like taking him to the doctor or picking him up at school. We feel good about our involvement."
. . . pastor.

" Many times after a meeting, we'd talk. If she wants advice, I am the type of person that would state my opinion, whatever I thought was in Jack's best interest."
. . . friend of mother.

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

SUPPORT
For the Family and/or Caregiver
Sample Quotes

FAMILY MEMBER

"I feel like when they are here, I have God's hand in my hand. I feel like they listen to me and there is no criticism and they really go out of their way for me. They really want to get somewhere for Joe and for themselves, too. They want to accomplish it both ways. I think they protect me and Joe. They made me feel like it was okay to cry when I did. I didn't feel alone. When I cry with family, it is just like . . . well, what are we going to do? We are to see what we can do." . . . mother.

FACILITATOR/NEIGHBOR

"I have become friends with Joe's mother and she is not necessarily a person that I would have had the chance to become friends with, otherwise. I appreciate the opportunity to meet her. She is a different person than a lot of my friends are. She is an amazing woman. I have a lot of respect for her and I have learned a lot from her about being positive in the face of adversity, about being a gentle person, not being angry, about just hard work and being humble. All this sounds corny, I know, but honestly she is a woman that I look to for strength because I just think she is an amazing lady. I also enjoy them." . . . facilitator/neighbor.

PROFESSIONALS AND OTHER PARTICIPANTS

"There were so few people involved with Joe and in Joe's family's life, outside of the school system. When Joe exited school, there was the fear that with life outside of the school system, the people who could be involved in Joe's life would be extremely limited. All the people participating were professionals with the exception of the parents of the young man."
. . . Deaf-Blind Intervention Program transition specialist.

"I think some things that we didn't expect was the difference it made in Joe's mother's life, in that it has given her the courage to go out and do some things that she lacked either the courage or means to do previously, such as taking driving lessons to get her driver's license and to start looking at some training for herself with maybe some work potential in her future. . . things that she couldn't even consider before, due to her commitment to Joe and the time that he required in her caring for him."
. . . Helen Keller Affiliateship vocational rehabilitation service provider.

Source: Personal Futures Planning Project, PFP Evaluation Component Interview(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

Transition of the young adult with the disability is not the only change which can have an effect upon the family and the caregiver. Changes in the structure of the family itself can be due to *other* life events which occur routinely in most other families. Terry Sweeney's sister got married and moved out of town, which meant the family lost their main contact for Terry to be able to attend any after-school events. Since all friends of Jenny's guardian are getting older and having health problems, they can no longer be available to offer respite. Mrs. Burton cherished the time Joe's brother could help her out with Joe when he was home from college; but, when he left again it made the adjustment more difficult. Whether a family member is disabled or not, changes do occur in the structure of all families. However, coping with the routine along with the unexpected may cause a reaction similar to the one made to her daughter's school admission coordinator by Sharon Green's mother.

> ***I just felt like you were all hitting me with so much at one time and I have done this and I have done that.***

Social isolation of parents and caregivers of young people with more severe disabilities appeared time and time again in the quotes from the interviews. Some parents seemed tc have passively accepted their plight of being alone. "I really haven't needed anyone to come." Other parents reacted to the isolation with a passive sort of anger. "No one has paid me for nineteen years to take care of my child." A question asked by one parent seemed typify her own contribution to the social isolation she felt. "I feel that if I can't do it and I'm his mother, then how can I expect other outside people to do it?" Another parent who had sought outside help, had seen positive outcomes, and been relieved still felt somewhat isolated. "When it gets back down to the nitty gritty, it all falls back onto the shoulders of the parents."

Professionals' views of family support leaned more toward generic statements of the focal person's support in comparison with others for whom they were responsible. "Sam is fortunate to have so many people to support him and the family support, as well, which a lot of our other residents here do not have." From this professional's perspective, the notion of family support was relative when compared to the lack of support some people on her case load at the institution experienced throughout their life time.

Service providers, often with large case loads, wondered why other people with whom they worked could not receive the support of the personal futures planning process for their lives. "There is another student in Jake's class that I work with, who is trainable mentally handicapped and also hearing impaired, but not visually impaired. She isn't as high functioning as Jake and would benefit tremendously from something like this. .... I asked my supervisor because I wondered how Jake was chosen for this. She thought it was strictly for deaf and blind children." A service, without being limited to one specific type of disability, appeared to be the foundation for comments by many professionals. Most professionals, who shared huge case loads, wanted the same support process for all people with disabilities with whom they were involved.

CATEGORY IV: Coordination of Schools and Other Programs

The theme titles below exemplify the issues involved in the coordination of schools and other programs.

THEMES
In the Coordination of Schools and Other Programs

1. The Magnitude of Programs
2. Coordinated Programs: The Need for Enhancement
3. Weariness of Efforts of Other Participants
4. Family Fatigue and Resignation in Coordination

The magnitude of the service system seemed to cause the greatest desire for a concerted effort to produce coordinated end products for the focal persons involved in the planning meetings. The themes, noted in the

THEMES: PFP COORDINATION
Observations of Coordination of School and Other Programs
Sample Quotes

THE MAGNITUDE OF PROGRAMS

"Maybe somehow. . . you'll just have to list everybody who is involved, but then it gets so big and confusing." . . . itinerant hearing teacher.

"The channels you go through, that kind of amazes me. Some things are federal, some things are state programs. . . just the different places you go. It's just kind of overwhelming, all the different agencies." . . . high school teacher.

"My concern is . . . do I use both programs or is it just if he's in a new program, he don't get the other any more? I'd just like to know where I stand when he's offered these programs." . . . mother.

"I still didn't know what to expect in terms of how the meeting would be conducted because what we did was combine it with her IEP and her ITP meeting. . . not knowing how all of that was going to fit together and tie in together." . . . school admissions coordinator.

A STRONG NEED TO PRODUCE COORDINATED PROGRAMS

"I think things will be changed a lot for her and I think that it's going to take a coordinating effort to make everything work." . . . vocational evaluator

"The same school personnel who earlier had expressed some really sincere reservations about whether it was even reasonable to proceed, gave me names . . . to contact." . . . employment consultant.

"It is extraordinarily difficult to coordinate meetings across professionals and families, all of whom have very busy schedules, so I think that is where I feel that I take on a disproportionate amount of tasks, which probably isn't true." . . . facilitator

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

THEMES: PFP COORDINATION

Observations of Coordination of School and Other Programs

Sample Quotes

WEARINESS OF EFFORTS IN COORDINATION: OTHER PARTICIPANTS

"I mean we've been around and around with those people to get him physical therapy and it just doesn't seem to be working." . . . sister

I have worked with systems to demand that they provide an adequate education for Jenny, simply because there was nothing here and the child needed more." . . . friend of grandmother.

"When we get to the school issues, I felt that a lot of the weight and burden for all of that figuring out fell on me . . . and that is not to take an ego investment. I felt very alone when it came to strategizing about how do we get this thing to work." . . . facilitator.

FAMILY FATIGUE AND RESIGNATION IN COORDINATION

"I talked to the therapist once. Every time I tried to talk to her about the wheelchair . . . seems like she kept turning me off." . . . mother

"I could do it, but it'd be real hard on me. I'll have to get her ready . . . be on call to pick her up." . . . guardian/grandmother.

"I spend all day Monday making long distance phone calls to find out what is going on. It makes it kind of hard to find out whose job is what, what my job still is." . . . mother.

"I think . . . they were things I had thought about, but realized they were not in my reach to be able to do. You think about this is what you would like for your child and this is what you want, but you just don't have the capability of pulling it all together." . . . mother

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

COORDINATION
SCHOOL AND OTHER PROGRAMS
Sample Quotes

FAMILY MEMBER

"When he was at the other school, they would always discuss and ask what I wanted for the future for Jake. I'd always say, "whatever comes, whatever happens . . . we'll just take one day at a time. You can't plan on a whole lot for the future because it might not go right. We mostly just plan 'one day at a time' and see how that works out and we go on from there." . . . mother.

PROFESSIONALS

"My expectation was that there would be family members and professionals and that this would occur in either a neutral location or a place like the family's home or something along that line, but it turned out to be very different because all of the people Mom invited were professionals. She was the only nonprofessional attending the meeting. The meeting was held at a segregated facility." . . . Deaf Blind Intervention Program.

OTHER PARTICIPANTS

"I know he gets speech therapy at KSB, but he also gets speech therapy one day a week through the public school and one wasn't aware that the other one was doing therapy. Even with speech, it would have been nice if maybe the speech goals could have been similar. My language goals should be similar to her language goals. We should be reinforcing and be working somewhat on the same thing." . . . itinerant hearing teacher. *(In discussing improved coordination through the Personal Futures Planning process.)*

"I have a lot more confidence in the outcome than if it is only once a year. When it is only once a year, you say, "Well, so & so didn't do her part, or this was a dead end, or we couldn't follow through on that because of ta da." Where as, this way, *(in the PFP process)* you know that in another six weeks or so that you are going to be meeting again and it is going to be right out there again on the table and you can get right on it." . . . vision program coordinator *(In discussing improved coordination through the Personal Futures Planning process.)*

Source: Personal Futures Planning Project, PFP Evaluation Component Interview(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

observations which dealt with the coordination of schools and other programs, appeared to cause the greatest degree of weariness among both parents and professionals. The size of the service systems and their programs were confusing to parents and professionals as well. This was summarized best by a regular education high school teacher.

> ***The channels you go through, that kind of amazes me. Some things are federal, some things are state programs, just the different places you go. It's just kind of overwhelming, all the different agencies.***

Joe Burton's mother, who recently received supported living services for her son as a result of being involved in the Personal Futures Planning process, expressed confusion over the many programs which involved Joe. "Do I use both programs or is it just if he's in a new program, he don't get the other any more?" The itinerant hearing teacher for Jake Stephens thought everybody should be listed for the school meetings. "You'll just have to list everybody who is involved, but then it gets so big and confusing." Since she did not understand at the beginning how everything was going to fit together and tie in together, a state school coordinator commented:

> ***I still didn't know what to expect in terms of how the meeting would be conducted because what we did was combine it with her IEP (Individual Education Program) and her IITP (Individual Interagency Transition Plan) meeting.***

A sense of parents and professionals working together on the same level was noted in the interviews when both expressed similar degrees of exhaustion in dealing with the coordination of the myriad levels of service systems. "I have worked with systems to demand that they provide an adequate education for Jenny." was a comment from a long-time friend of the grandmother for Jenny Russell who advocated a long time ago to make a difference in Jenny's school program. One personal futures planning facilitator expressed her feeling of isolation when it came to strategizing how to get something to work. "When we get to the school issues, I felt that a lot of the weight and burden for all of that figuring out fell on me." While some parents and professionals may have noticed an increase in their tasks, most personal futures planning meetings enabled a greater coordination of services to work in the best interests of the focal person.

CATEGORY V: Resources with the Focal Person Involved

Community acceptance, independence, and activities available for the focal person were all themes found within the category of resources with the focal person involved. These themes are found below:

THEMES
Observations of Resources with the Focal Person Involved

1. Community Acceptance of Focal Person
2. Independence of Focal Person
3. Activities Available for the Focal Person

While members of the personal futures planning teams worked to make resources available for the focal person of the team for which they were a part, community acceptance did not occur spontaneously. Resource development of providers with job titles such as a 'leisure companion' and/or 'recreational therapist' were created as a vehicle for social involvement for several of the focal persons. However, funding for paid service providers continued to be a problem which limited available resources. When the focal person was able to become more involved in school and community resources, just the act of getting involved did have some positive benefits upon their independence.

CATEGORY VI: Resources Available for the Focal Person in the Community

Resources in the community fell into four themes such as supported living, supported employment, availability, facilitators and service

THEMES: PFP RESOURCES

Observations of Resources with the Focal Person Involved

Sample Quotes

COMMUNITY ACCEPTANCE OF FOCAL PERSON

"He had some old friends from years ago that are in college now. That's the first place they go is to go in and visit Jeff. He's developed a pretty wide circle of friends out at the high school." . . . high school teacher

"She has a lot of community outings and going, doing things like the swimming and stuff, but as far as being accepted or considered a part of the community, I don't think she has that yet." . . . mother

"To me, it looks like a little seizure when he snatches his head. You're out in the street and people see that with this big tall man and they have a tendency to be a little leary or afraid of him. This is the reaction you get from people and I am sure Sam feels some of this." . . . family relative

INDEPENDENCE OF FOCAL PERSON

"On Wednesdays, we do community based education where the teacher (for the mentally handicapped) takes them down to the public libray and checks out books, ride the TARK, work with bus fares, must know where to get on and off. I meet them on Wednesdays at the gallery, a shopping mall downtown and work on ordering food, counting money. Jake is becoming more independent." . . . hearing itinerant teacher.

"Sally had been through a lot of meetings about one thing or another. Getting her auditory trainer, she had to meet with people. The neatest thing is that Sally realized that she could do some of these things she had wanted to do." . . . school admissions coordinator

ACTIVITIES AVAILABLE

"There's a recreational therapist that come in and takes her (Sharon) out swimming and takes her to the park and takes her bowling, stuff like that that's fun." . . . mother

"They take him (Terry) out at school. Once a week they go around maybe to a restaurant or a store. They take them different places to get them a Coke or take them shopping." . . . father

"He's out just in the mornings, like Monday, Tuesday from 9:00 AM to 1:00 PM, and then Wednesday, Thursday from 9:00 AM to 11:30 AM. for his leisure service. After that, he's with me, looking after my mother, shopping. I mean he goes everywhere with me." . . . mother

"On a Sunday morning when he's in church, I always make a point to speak with him as though he understood everything that was going on." . . . pastor's wife

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

RESOURCES
Involving the Focal Person
Sample Quotes

FAMILY MEMBER

"She has very few just friends. Her people around her are mainly people that do stuff for her. Sharon has not made that bond with a friend. I mean, she's very friendly with everybody, but as far as having somebody that comes to see her just because they're her friend or just because they like her or they've met her at school and they've formed a bond, she doesn't have that. It's the people that work with her, it's family, you know." . . . mother.

PROFESSIONALS

"She's involved with all the activities they have there (group home) we do. She has a YMCA membership. She goes out on recreation through our program once a week. She's involved in any of the extra activities that we might have. If we have dances or picnics, Special Olympics, you know all that, she's involved with through us. I think that's increased even more since she's moved into the group home as well." . . . case manager.

OTHER PARTICIPANTS

"She lives in the group home setting and she does have access to other young people in that setting and I understand that she gets along with them quite well. She does have other persons who visit her room and she does interact with people in the group home situation. I understand she's participating in her school fairly actively and I think that's good. I also understand they're doing community based programming with Sharon at school and I think that's good. I think she participates in other community activities through the group home situation on a regular basis, as well." . . . educational consultant

Source: Personal Futures Planning Project, PFP Evaluation Component Interview(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kertucky.

THEMES: PFP RESOURCES
Observations of Resources Available for the Focal Person in the Community
Sample Quotes

SUPPORTED LIVING ARRANGEMENTS: MORE NEEDED FOR FOCAL PERSONS

"The dream has to do with him living outside the facility. I think that is reasonable for Sam. I don't know that it is possible given the limitations of resources." . . . facilitator

"I know several years ago when the father thought they might have to put Terry in a home, I know he would just cry because he didn't want to put him somewhere. If her (his mother's) back gives out I don't know what will happen." . . . pastor's wife.

"The long range goal for my son is to have him living outside of the institution in a supported living situation. I know I can not do that alone." . . . mother

SUPPORTED EMPLOYMENT: MORE NEEDED FOR PEOPLE FOR FOCAL PERSONS

"Sally did get employment this summer working with young children in a day care. She did get counseling." . . . school admissions coordinator

"I want Jack to be as productive as he can in his future. I don't want him just sitting around watching T.V. for the rest of his life. I won't always be here to take care of Jack." . . . mother

"I hope that we can have Sam, if not out in an apartment out of the institution, then definitely out looking into some area sites for him and also a job for employment" . . . case manager

FUTURE CONCERNS OF AVAILABILITY OF RESOURCES

"I know she's very concerned about Jack's future. As she is, as we are getting older, I think that is a big concern." . . . teacher friend of mother

"I just hope, I just worry about her. That is what is wrong with me now. What is going to happen to Jennifer after I am gone? I know it willl be a group home or something like that, but I want someone to love her." . . . grandmother/guardian

MORE PFP FACILITATORS AND/OR HUMAN SERVICE PROVIDERS NEEDED

"I have looked high and low for help and for people to come in and break it down step by step into what they expect of Joe. It was so discouraging for six years, but now I feel he has a future." . . . mother

"It is good to get other people's ideas because you (as a parent) are limited in how you see (your child) because of your limited resources." . . . mother

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

RESOURCES
Available for the Focal Person in the Community
Sample Quotes

FAMILY MEMBER

"He don't understand commands or what to do. She (Goodwill) told me he'll always have to have custodial care. That's just the way she put it. You know, they closed the book on him in vocational rehabilitation. There's nothing more they can do. Okay now, Joe gets out four days a week. The leisure therapist drops me off at school and Joe goes to restaurants, . . . museums, . . . the zoo. I'm trying to get him in a swimming program and I'm looking for a fitness club or another place if it's open in the morning." . . . mother.

FACILITATOR/NEIGHBOR

"Clearly, no one expected Joe to be out in the community three days a week. I think the process yields wonderful surprises that happen and that's been true with Joe. Nobody ever dreamed that Joe's parents would be as supportive of him being out in the community and cared for by other people as they are now. The clincher of it all was that they now want other people to be involved in Joe's life and see other people being able to care for him and participate in making that happen" . . . facilitator/neighbor.

OTHER PARTICIPANTS

"There was a supported living application filled out and Joe was approved. We had the meeting that we brain stormed about different activities and we met with the gentleman . . . who will be Joe's companion and instructor. We also had a communication evaluation done on Joe which was something the group wanted to have done which made various suggestions to add to his communication which would help facilitate communication with his companion and family and something on which to base some instruction that could be done with him in communication." . . . Helen Keller Affiliateship service provider.

"It took months and months and months of trying out different people in Joe's life before the right match was found. My little part . . . was to provide some funds to renumerate those people. The team worked together to write a supported living proposal and it was all based on the work we'd done in locating a companion and embedding him in Joe's life. To make a long story short, the supported living council liked what had been put together and provided perpetual funding for the companion to stay in Joe's life." . . . comprehensive care system provider.

Source: Personal Futures Planning Project, PFP Evaluation Component Interview(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

providers. Below are the themes listed for the category of resources available for the focal person in the community.

THEMES
Observations of Resources Available for the Focal Person in Community

1. Supported Living Arrangements
2. Supported Employment Availabilty
3. Future Concerns of Availability of Resources
4. PFP Facilitators and/or Service Providers Needed

The greatest need for resources of young adults, as they transitioned out of high school, was for support to be able to live in their own community. Being supported in employment in order for young adults to become contributing members of society was also important. Parents' comments centered around the concern of what would happen to their children after they could take care of them no longer. Since most parents never before had a plan for the future of their child, more Personal Futures Planning facilitators and/or more human service providers trained to continue to help parents plan futures were seen as necessary for outcomes to endure.

CATEGORY VII: Life Changes and/or New Experiences

School objectives, adult service goals, and community plans, which included supported employment and supported living were all themes observed in the life changes and new experiences categories of the interviews.

THEMES
Of Life Changes and/or New Experiences

1. School Objectives
2. Adult Service Goals
3. Community Plans
4. Supported Employment
5. Supported Living

THEMES: PFP LIFE CHANGES/NEW EXPERIENCES
Observations of Life Changes and New Experiences for the Focal Person
Sample Quotes

SCHOOL OBJECTIVES

"We were determined to increase his [Jeff] circle of friends, make him more aware of his surroundings, more comfortable. He's more mobile now and both of those have been done." . . . high school teacher.

"It's like when he [Jack] went from the middle school to high school . . . we saw that it did work very well with the couple of classes." . . . teacher friend of mother.

ADULT SERVICE GOALS

"It's better for him to have a community resource developer to take him out in the community and they'd (the task force and Supported Living) pay for that. I know who he's with and I know where he's going, and he's getting out and I'm getting out, too." . . . mother

"Some of them I didn't think would get done because if it depended upon my resources and what I could get done, then it wouldn't; but, you have this pool of people to pull from and to help you do the work. Most of the goals for Sam have been accomplished." . . . mother *(Goals included such things as relatives visiting, a summer job, and training at HKNC, Helen Keller National Center)*

COMMUNITY PLANS

"She [Sharon] moved into a group home. She's going to a different school . . . in a summer program, attends an adult day program. She's got recreation, swimming at the Y, a music therapist once a week, and she gets music." . . . mother

"The auditory trainer is a major benefit to him [Jake] and something that had not been fully explored. Now it will help his expressive communication. He will become more of an independent traveler and feel more comfortable about going out." . . . hearing teacher.

SUPPORTED EMPLOYMENT:

"They did a wonderful job up there by getting her [Jenny] a job and getting the meetings, getting everybody together; but, it's not their fault that it didn't work out and it's not the fault of the people that attended." . . . grandmother/guardian

SUPPORTED LIVING

"In Joe's life, I think the changes are pretty well stated. More involvement, more life outside the home, more independence from his family, these kinds of things." . . . vocational rehabilitation counselor.

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

LIFE CHANGES/NEW EXPERIENCES
Sample Quotes

FAMILIES

"Before we had these kind of meetings, we didn't have any hope that there could be a productive future for Jack." . . . mother.

PROFESSIONALS

"I hoped that Jack would have been out of the middle school very quickly after we started convening and that there would be a lot of people that felt the same way about that so that could happen. The only thing I don't like is that we can't get more people involved, the more people you can assign duties to which means that more's going to get done." . . . Deaf-Blind Intervention program. *(In discussing the amount of time it took for Jack to move from the age inappropriate middle school placement to the high school.)*

OTHER PARTICIPANTS

"I think with some of the plans, it's just a bit hard to tell sometimes. You just have to get in there and try a little bit. It's just like when he went from the middle school to high school, I think we wanted that for him, but we didn't know exactly how that transition would work. I think we saw that it did work very well with the couple of classes he did take last year over there." . . . teacher friend of mother.

"People would come up to his mother and make the statement that they've seen a lot of changes in him and that they've felt the situation was good for him and there were professional people. These people were like the occupational therapists and people who could just see that the fellowship and everything was a good environment for Jack and they just made comments to such." . . . long time friend of the family.

Source: Personal Futures Planning Project, PFP Evaluation Component Interview(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

According to team members interviewed, increasing friends, mobility, personal advocacy, and integration were the greatest needs for which school objectives had been established and, in most cases, these met with a moderate degree of success. However, adult service and community plans were more nebulous and less striking in the finality of specific goals accomplished. Since adult and community systems cover the span of the rest of the focal person's life after his/her exit from school at age twenty-one, these plans will need to be addressed over the focal person's life-span.

Many participants interviewed hoped the changes and experiences which had occurred through personal futures planning would continue. Most participants, especially parents, stated that they would continue to need support and assistance to facilitate life changes for the focal person. Sam Marshall's mother said it this way.

> ***It is not all straightened out. That is what we're working on. No, it is just like you go from on thing to another. Then, there is a nice quiet period and you rest. Then, you get all geared up for the next thing.***

CATEGORY VIII: Empowerment of the Focal Person and/or Family

As a category exemplifying outcomes of forming personal futures teams around focal persons, empowerment was a very difficult, yet potentially significant outcome.

THEMES
Empowerment: Focal Person and/or Family

1. Parents and Caregivers Speak Out
2. Parent/Caregiver Advocacy on Behalf of Child
3. Advocacy on Behalf of Focal Persons
4. Self Advocacy in the Focal Person

THEMES: PFP EMPOWERMENT

Observations of Empowerment of Focal Person and Family

Sample Quotes

PARENTS/CAREGIVERS SPEAK OUT

"Being outspoken is better than standing back waiting and listening." . . . mother

"Well, after awhile you get tired of getting run over, too. If you get run over enough, you start fighting back." . . . father

PARENT/CAREGIVER ADVOCACY ON BEHALF OF THEIR CHILD

"The mother met with the people in the central office . . . and things were back in force as we had originally planned." . . . friend of family.

"We were one of the first. . . everybody else was learning from us . . . learning from our mistakes and how to handle the situation to get what they needed for their handicapped child." . . . father.

"I'm getting somewhere. You have to work for your answers, you've got to work for your rewards. You really do. It's hard work, but you can do it." . . . mother

ADVOCACY ON BEHALF OF FOCAL PERSONS

"I have spent a great deal of time over the past year and a half advocating for Sam, so I guess I have an advocacy relationship." . . . facilitator.

"I didn't agree with everything. I spoke up, but I don't know at which meeting, about it." . . . guardian/grandmother.

SELF ADVOCACY IN THE FOCAL PERSON

"They're telling her you have to go here and you have to go now and she is telling them, "I don't want to go here and I'm not going to go here. If we're going to go, you're going to have to make me go." . . . mother.

"This is a new experience for her to be able to voice what she wants and voice some things in trying to make decisions. She has come a long way since the first meeting." . . . facilitator

"She hasn't been given choices. . . I think people are still making choices and they're still wanting Sharon to do what they want her to do. It's not what she wants to do." . . . mother.

"That is one of the main reasons that we have gotten into this is to learn better ways to communicate with him." . . . high school teacher

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

EMPOWERMENT
PFP FOCAL PERSON/FAMILY
Sample Quotes

FAMILY MEMBER

"I've been pretty independent all my life and I hate to ask people to do things for me. I know now, all they can do is say no and it might hurt my feelings; but, it's not for me, it's for Jack." . . . mother.

PROFESSIONALS

"I had been working with Jack about a year before and had gotten to know his mother and knew what some of her concerns were, and I had some concerns about Jack's school placement, and so I saw this as an opportunity to really try to make some changes in his life, so I guess that's the reason I wanted to be involved." . . . Deaf Blind Intervention Program. *(In discussing the role of the PFP process in empowering the mother to voice her concerns with the school system.)*

OTHER PARTICIPANTS

"It is my understanding that his mother did go talk to some people at the central office about some of the things that were supposed to be done and that had been carried out for a short period of time, but had sort of deviated back to the old method. After she met with people in the central office, I understood that those were back in full force as we had originally planned." . . . long time friend of the family.

"I just think we have to always keep in mind and we need to reach out for the ultimate and top of everything. . . using common sense through it all, too." . . . retired teacher friend of mother.

Source: Personal Futures Planning Project, PFP Evaluation Component Interview(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

One parent, the mother of Sam Marshall, had grown tired of the all the efforts required in making a life for her son and for herself. She expressed her feelings about empowerment in this way:

> *I don't have a problem with allowing other people to do things for me. I don't ever want to get to the point where I just wear myself out. I have been to that point before where I have almost been totally worn out. So I don't have a problem with allowing other people to do anything for me. You know, I have learned that lesson.*

Feeling enough power to have the confidence to make their own choices is one outcome of encouragement and support to focal persons and their families. Personal Futures Planning kinds of empowerment were evident in the interviews because of the social circles formed for encouragement of the focal person and family. Advocacy by parents and caregivers on behalf of their child, advocacy by others on behalf of the focal person, and self advocacy exhibited by the focal person were all themes running through the empowerment category.

Becoming a self advocate, the last type of empowerment, is recognized as the highest form for which all should strive. This self advocacy was not only found in one of the most capable young adults interviewed, but also in a young lady with some of the most severe and challenging disabilities. After her daughter's move to a group home, this exemplary form of self advocacy was noticed by Sharon Green's mother.

> *I think people are still making [her] choices and it's not what Sharon wants to do. She sits down and refuses to get up. You have to keep talking to her and you have to physically get her up. She can be pretty stubborn when she wants to be.*

CATEGORY IX: Ripple Effects

Although ripple effects were noted by family members, the greatest number of benefits, mentioned in the interviews, was with professionals who had been either facilitators or members of the planning teams. Ripple effects of the Personal Futures Planning Project were divided into five main themes.

THEMES

Observations of Ripple Effects

1. Attitude Changes about Disabilities
2. Referrals to Help Others with Disabilities
3. Financial Gains and/or Opportunities for Families
4. Benefits to Professionals and Team Members
5. Future Careers in the Helping Professions

Observations of attitude changes were made mostly by professionals working in the field. Unusual themes, found in the quotes, included financial gains for families, referrals of team members to assist other persons with disabilities, and the future career possibilities for people involved in the process. Due to the lasting impact the focal person appeared to have upon the young people with whom they came in contact, either as peer tutors or as a members of the Personal Futures Planning teams, this last career theme was the most futuristic benefit of all.

Summary

The number of quotes about the participation of the focal person in the actual meetings and the quotes about participation in the process by the family and the community were closely related. Support for the family and caregiver was linked in many ways because of the complexity of services involving coordination of the school and other programs. Resources, both for the focal person and in the community, were constrained by very limited formal resources in most communities. Since empowerment depended upon so many variables, it was a difficult category to attribute

THEMES: PFP RIPPLE EFFECTS

Observations of Ripple Effects of PFP Meetings

Sample Quotes

ATTITUDE CHANGES

"The process has helped people think about Jenny in other ways." . . . employment consultant.

"It taught me. . . there is a whole world outside that this person is a part of and how to include them in it as another human being and not to treat them as an invalid." . . . family relative

"I don't think that up until this time anybody had ever thought about Sam in this way. I think it was radical . . . I think that for his mother." . . . facilititator.

REFERRALS TO HELP OTHERS WITH DISABILITIES

"Our brother's youngest granddaughter . . . sounds a lot like Terry. I thought of this program because they have helped Terry so much." . . . pastor's wife.

"We've had something similar for another student who is not deaf/blind just because of her needs and I feel much better about the plan." . . . vision program director

FINANCIAL GAINS AND/OR NEW OPPORTUNITIES FOR FAMILIES

"A lot of Terry's health care costs have gone down." . . . sister

"Sharon's mom now sometimes works as a parent consultant to other parents" . . . consultant

BENEFITS TO PROFESSIONALS AND TEAM MEMBERS

"Its raised my expectations . . . for a lot of the other kids I work with and I think seeing the positive effects of his inclusion . . . carries over." . . . Deaf/Blind Intervention specialist

"They're neighbors, they're friends. I'm not sure when I first got involved that I expected to have an on-going friendship with them." . . . facilitator/neighbor.

"I'm helping families secure really significant things that can make a difference in their lives, and without this process, I don't see it." . . . comprehensive care employee.

"It would . . . to my caseload . . . distribute responsibilities so I do not have to put extensive time and energies into the entire family." . . . Deaf/Blind Intervention specialist.

FUTURE CAREERS IN HELPING PROFESSIONS

"One young lady attended one meeting and has kind of carried this with her . . . as a springboard for other things." . . . vocational rehabilitation counselor.

"The peer tutors. We added two peer tutors during the year and I think it has opened their eyes and broadened their horizons a great deal." . . . high school teacher

Source: Personal Futures Planning Project, PFP Evaluation Component Interviews(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

RIPPLE EFFECTS
Sample Quotes

FAMILY MEMBER

"Through this, we have met a lot of caring people. It makes us seem more apart of something instead of having to go through this by ourselves. We don't have to be alone." . . . mother.

PROFESSIONAL

"One of the nice things about my involvement with him is that it has been more frequent than with many of the kids I'm involved with and it has raised my expectations for him and hopefully for a lot of the other kids I work with. I think that seeing the positive effects of his inclusion, I hope that carries over, because I am a person that has had reservations about the inclusion of some kids and I hope that the things I've learned from working with Jack carry over to some of the other kids I work with." . . . Deaf-Blind Intervention project.

OTHER PARTICIPANTS

"You know I see them doing more things together as a family. With the school, I'm assuming that a lot of the things that we had decided prior to next year will be in force." . . . teacher friend of the mother.

"I will always remain a friend of that family and I'll always be considered a supportive person in any way I can help him or the goals that are for his mother and to be supportive to her and her family." . . . long time friend of the family.

Source: Personal Futures Planning Project, PFP Evaluation Component Interview(s), (1993), Brenda Pezzarossi, Parent Coordinator, Interdisciplinary Human Development Institute, University of Kentucky, Lexington, Kentucky.

solely to the personal futures meetings. Finally, ripple effects were seen in a great variety of themes as a result of the Personal Futures Planning Project.

Nine major categories were gleaned from the interviews of family members and other participants included in the Personal Futures Planning Project. Those interviewed nearly always gave a history of the circumstances surrounding the focal person with whom they were involved. When placed into the volumes of interview transcriptions, this history was sometimes difficult to decipher from the current events in the life of the focal person. With parents, the past seemed to be 'only a step away' from the Personal Futures Planning progress of the present. While wondering about the future of her twenty-one year old son living elsewhere, outside of an institution, one parent talked about the past.

> *You know you want to do it, but you are not sure you want to take that chance. There is always the chance that it is not going to work. You don't want to feel like then you'll have to start all over again.*

Conclusion

It is appropriate to conclude this exploration of interpretations with a comment from one of the parents involved in the three year Personal Futures Planning Project. There were life changes and new experiences with all the family members and focal persons sampled in areas such as inclusion, communication, transition, family support, advocacy, supported employment, coordination of schools, and other resources. However, underlying these many positive outcomes were pervasive fears of the future. Sam Marshall's mother expressed it this way.

> *Our children are not going to be here for just two or three years and it is not going to be just our children. Every day there are new clients to serve . . . new families to serve. As parents, we get older and we are not able to do everything that we think we would like to do for our child. We are going to need the assistance for our child's entire life or find people who can do that if something might happen to us.*

The conflict that families often felt was not so much that they disagree with the process of the planning meetings to dream and design a future for their family member. It was more often than not due to the implications these future plans had for their *own* lives. For them, the struggle would never be over. For many of these families, there was always the apprehension that the future would negate the successes they had achieved. This represents the continual struggle of parents, professionals and community members in maintaining and enhancing the life outcomes of youth with dual sensory impairments.

References

Biklen, S.K., & Moseley, C.R. (1988). "Are you retarded?" "No, I'm Catholic": Qualitative methods in the study of people with severe handicaps. *Journal of The Association for Persons with Severe Handicaps, 13*, 155-162.

Brady, S.J. (1992). *Focus groups interviews interpretive comments for families of children with special developmental needs and early intervention professionals.* unpublished manuscript, University of Kentucky, IFSP, Lexington, KY.

Downing, J., Shafer, M.S., Brahm-Levy, A., & Frantz, M., (1992). Supported employment for individuals with dual sensory impairments and mental retardation: current practice and future challenges. *Journal of Vocational Rehabilitation, 2*, 28-38.

Everson, J.M., & Burwell, M.S., (1991). Transition to work: addressing the challenges of deaf-blindness. *Journal of Vocational Rehabilitation, 4*, 39-45.

Everson, J.M., & Goodall, D., (1991). School-to-work transition for youth who are both deaf and blind. *Journal of The American Speech-Language-Hearing Association, 11*, 45-47.

Ferguson, D.L., Ferguson, P.M., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult Life. *The Journal of The Association for Persons with Severe Handicaps, 13*(3), 177-187.

Giangreco, M.F., Cloninger, C.J., Mueller, P.H., Yuan, S., & Ashworth, S., (1991). Perspectives of parents whose children have dual sensory impairments. *The Journal of The Association for Persons with Severe Handicaps, 16*, 14-24.

Morgan, D.L. (1988). *Focus groups as qualitative research.* (Qualitative Research Methods series, *16*) Newbury Park, CA: Sage Publications.

Stainback, S., & Stainback, W., (1984). Methodological considerations in qualitative research. *The Journal of The Association for Persons with Severe Handicaps, 9*(4), 296-303.

Wolcott, H.F. (1990). *Writing up qualitative research.* Qualitative Research Methods series, *20*, Newbury Park, CA: Sage Publications.

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Brenda Pezzarossi
Lexington, KY

Appendix VIII - H

Participant Observation Background For Jason:

Jason was 18 years old when the Personal Futures Planning process began with Jason and his family. The profile information and first meetings were held in the spring of 1991. At that time, Jason was placed in a severe-profound handicapped, self-contained classroom housed in the middle school. Jason had been in this classroom since returning from the at the age of 12.

In April of 1991, the Associate Project Director observed the following in Jason's classroom over a period of two hours:

"Jason sat in his wheelchair with one of the teaching assistants sitting next to him. There was no instruction which took place during this time. Jason initiated communication with the assistant by reaching out to touch her and also vocalizing. There were four other students in the classroom with one special education teacher and another aide (3 adults and 5 students). While there, one of the teaching assistants took two of the students to the library and returned. There were no non-handicapped students who served in the role of peer tutors and there were no opportunities for interactions with non-handicapped students other than at lunch time."

By the fall of 1991, Jason was enrolled in the home economics class at the high school which was located next door to the middle school. The Associate Project Director observed March of 1992, the following in his home economics class:

"Jason was seated in his wheelchair at a table with three other students. All of the other students in the classroom were young women. They were talking with Jason prior to class starting, and he was smiling and maintaining eye contact with them, especially Julie, one of the students whom I had been told had taken a particular interest in Jason. Julie is an attractive young lady who is a senior and will be graduating in the spring. She planned to attend the training which was to take place that afternoon on Jason's communication system.

The class for the day was in lecture format. Jason was given paper and a pen by one of his peers, and he did make marks on the paper while they were taking notes. I was told by his home economics teacher that during activity oriented classes she attempts to include Jason, as much as possible, in the activity. He sets the table, hands things to other students out of the dishwasher, receives hand over hand assistance in food preparation lessons, and is asked his preference if there is one when the students have prepared several different kinds of food and there is a choice.

While welcoming Jason into their class, it did seem as though he was treated in somewhat of a childish fashion by the other students. A more age appropriate view of Jason might be encouraged if he were in the high school all day, as opposed to only one class period."

Milton Tyree, who provided technical assistance to the PFP Project around the issue of work for Jason, visited the high school in 1993. The attached "Initial Work Considerations" paper which he wrote reflects some of these issues. He also observed in Jason's classroom and many of the same issues which the Associate Project Director observed in April of 1991 were still there. This illustrates the limitations of the Personal Futures Planning process when key people, such as the teacher, do not "buy into" or commit to the dream or vision.

Extensive technical support was provided both the PFP Project and the Deaf-Blind Intervention Program to the teacher, but the observations would indicate that little was implemented even though many of these objectives were included on the Jason's IEP. Jennifer Leatherby, the State Coordinator of the Deaf-Blind Intervention Program, provided extensive technical assistance to Jason's special education teacher and wrote his IEP objectives, in concert with his Mother, for two of the three years of the Project. Problems continued to be encountered with implementation issues, as illustrated in the letter written to his teacher following a day she spent observing Jason in his school program.

Participant Observation Background For Jamie:

When the Personal Futures Planning process was initiated with Jamie, she attended school during the week at the in a self-contained "multi-handicapped" classroom and lived on campus. Jamie lived in a dormitory by herself with house parents and had no meaningful interaction with other deaf students on campus. She was picked up on Friday afternoon by her Grandmother and they travelled back to where they lived. This is about an hour's drive each way.

Jamie was one of five students in this class. There was no community-based instruction or vocational training in the community in integrated environments. Jamie did wrap silverware in the school's cafeteria and occasionally went to the and did piece work when there was work.

Copies from Milton Tyree's observations of Jamie in her classroom in a letter to on 11/22/91 and notes from his involvement as an Employment Consultant in helping staff at find her a job in the community are attached. Mr. Tyree provided extensive technical assitance to the in the areas of job development and job coaching as staff there had never iniatiated this kind of activity on behalf of their high school aged students. The observations would indicate that positive interactions were occurring on the job site where Jamie was employed and that positive benefits had resulted from this effort.

Initial Work Considerations for Jason

compiled by Milton Tyree

5/26/93

I. **Background** - In January, I met Jason and began spending time with him in order to help think about how he will spend his day following high school graduation. Even thought Jason still has some time remaining in school, now is not too soon to be planning for the future. Current efforts, including Jason's Personal Futures Planning group and his Supported Living arrangement, will play a critical role in fostering positive post-school realities. Indeed, without such concerted planning efforts, people having disabilities such as Jason's often find themselves with little to do following graduation. (In other words, unless we do something, things won't "just happen".) Essentially, I will serve in conjunction with positive efforts that have been initiated on Jason's behalf.

In order to get to know something about Jason's life, I have (1) visited with Jason and his family in their home; (2) observed Jason's school program at . including his classes at the high school; and (3) worked in conjunction with on developing a trial for Jason as an office aide at the high school.

My primary responsibility involves generating "work" ideas for Jason. Some type of employment or work is realistic to consider for Jason. However, Jason needs to be appreciated and known for more than his productive capacity since his ability to "produce" (at least in the traditional sense) is not a particular area of strength. Therefore, questions related to how Jason will spend his day must extend beyond issues of work. I am beginning with this question: What is it that will provide Jason with a genuine sense of purposefulness, contribution, belonging and acceptance within his community? Of the many aspects involved in answering this question, I will focus on types of people, place and activity characteristics that seem to be a good fit for Jason. (Issues of work and employment are subsumed here.)

II. **People Considerations** - Many have commented on Jason's desire to imitate the actions of others. Since Jason is going to imitate what it is that he observes, it is especially important the Jason have good role models. These role models need to be competent in areas of life that Jason needs to learn. Additionally, models need to be people with whom Jason will identify (as well as people who will identify with Jason). For example, next year Jason will learn about being a high school senior. So it is essential that he be involved with other high school seniors in the context of senior activities including (a) classes that can be suitably adapted for his involvement, and (b) other senior stuff like class meetings, preparing for graduation, etc. (Recalling that Jason can imitate both enhancing behaviors as well a the unfavorable kind, Jason needs to spend time with seniors who are competent in modeling positive conduct.) Likewise, for other-than-school associations (including work), it is important that Jason be with people who are in the same general age range as Jason and who have skill and interest in what they are doing. For instance, Jason will learn to take pride in his work when he works with others who are conscientious about their work. In summary, I suspect that Jason has a great deal to learn about his identity as a young adult. The "models" with whom Jason spends time will either help him learn about adulthood or prevent him from learning about this important aspect of his life.

Jason needs to be understood, and he needs to spend time with people who want to understand him. Two interrelated aspects of understanding are important here: (1) Jason needs people who will understand that the essence of his personhood is not consumed within his disability. In other words, Jason's disability is one part of his identity, but there are many other important aspects about him as a person. For instance, Jason is a young adult and as such he needs to be taken seriously. Establishing understanding and balanced relationships is often difficult, because many people have not known a person who has a disability outside of the role of "their helper". (Of course being a helper is fine, but being the one who is always "the helped" is not so positive.) (2) Jason wants to understand communication from others. (He taught himself to read lips.) And, he wants others to understand him. (He has learned a few signs and symbols for communicating.) Yet clear communication with Jason is not easy. There are a couple of relevant "people implications" here. Jason needs to be with people who want to take the time to communicate with him (in terms of being understood and understanding Jason). Also, the number of people Jason spends time with (for instance in a job) should be manageable. If Jason works with a few people (at least initially), then it is more likely that these people will invest the time to learn about communicating with Jason. On the other hand, if he works with too many people initially, then he may get lost in the shuffle with no one really taking time to converse with him. One related note of responsibility for Jason (and the rest of us) to figure out: Many people seem to know Jason and will say "Hi" when passing by. However, Jason does not acknowledge their greeting. (Perhaps he cannot see them well enough to read their lips in addition to being unable to hear.) At any rate, he needs a way to communicate HI and BYE as I believe that this will significantly affect others getting to know him.

Finally, Jason's "status" within school and community (the way that he is perceived by others and self) will be significantly influenced by the social standing of people with whom he associates. Therefore, Jason should spend time with people who are valued for their character, competence, personality, etc. In other word, if Jason spends time with people who others want to know, then this will increase the likelihood that more people will get to know Jason in a positive way.

III. **Activity Considerations** - We might begin by asking the following questions: How do other high school seniors and young adults in spend time? Which of these activities makes sense for Jason? What types of adaptations and/or supports may be needed for Jason to be involved in a meaningful way?

Selection of the proper activities and supports is critical. We will not want to exclude Jason from involvement in an activity just because his involvement looks somewhat different from typical involvement. On the other hand, Jason's involvement must look and be "real". (It should not seem to be contrived or as though Jason is "just hanging around".) For example, if Jason is in the role of employee, then he needs to be working. If he is in the role of a student then he needs to be receiving instruction and learning. But if Jason is "just there" (physically present) with no planning or supports for his genuine involvement, then he will be in the role of "a project". (Of the many roles that may be beneficial for Jason, being someone's project is not one of them.)

In addition to considering tasks that are typical for young adults of similar age, we need to consider the public perception of the tasks that Jason is performing. In other words, Jason needs to do things that would be seen by the public at large as desirable in contrast to being involved in tasks that would convey beliefs such as, "I wouldn't want to do that, but it's OK for him."

Some degree of interdependence should be built into Jason's work tasks. We need not be so concerned about Jason working independently if he is working on tasks that are interrelated or part of the tasks that others are performing. (This is consistent with the previous recommendation that Jason work initially with a small group/team of people.) Team work will promote Jason being known by others, while providing good work models, and alleviating the need for long-term external support (i.e, "job coaching").

Jason will do best with objective jobs that have clear parameters - where the task is clearly done or it is clearly not done. This is so that Jason can see what it is that he is accomplishing. For instance Jason liked sorting silverware in the classroom. However, Jason would have been less successful if he had been asked to perform tasks such as washing the silverware or wiping tables since these jobs have a much broader range of correctness. One related point to consider is that the "realness" of tasks will affect Jason's perception of self as well as affecting the perceptions of others. For example, sorting silverware that needs to be sorted is far preferable to sorting silverware will be mixed -up again and sorted the next day as a work sample. (A related note about Jason's satisfaction with completion of work: Jason takes pride in a job well done. However, he seems to be quite dependent on the praise of others. If Jason is presented with tasks where he can see his accomplishment, I believe that he can find increasing levels of intrinsic satisfaction from completing work and rely less on the opinions of others.)

It is important that tasks and activities presented to Jason have a suitable level of intensity and challenge. Jason will loose interest in an activity that is too easy (one that can be learned in 10 minutes) or one that is too difficult (a task where he cannot reach success in a reasonable period of time). Also, Jason needs to have opportunities for learning progressively more difficult tasks (e.g., job advancements).

Some obvious considerations specific to Jason's disability include a lack of emphasis on mobility although some mobility is desirable for exercise. Likewise the tasks should not depend on academic demands yet some such requirements (e.g., recognition of letters/symbols, and perhaps counting) will provide a functional way for Jason to further his academic skills. Work or tasks that focus on the need for a high degree of fine motor control should be avoided. Finally, care must be taken to know that activities will be safe given Jason's visual, hearing and mobility limitations.

Of course, Jason's areas of interest will provide some guidance for what it is that he should be doing. However, I suspect that Jason will like doing tasks and activities that are carefully selected and structured for his involvement and success. In other words, there are a lot of activities that Jason can potentially enjoy that are not part of his current experience.

IV. **Place Considerations** - The places that other meet Jason will influence their perception and expectations for him. As with activities, places he spends time should be perceived as desirable and should also fit Jason's identity as a young man. For example, since Jason is already vulnerable to being seen as younger than he is, it is especially important that he attend the high school. The more Jason is treated as being younger than his age, the more he will conform to these expectations and act younger than his age - which will in turn confirm others negative expectations and perpetuate his dependence, and on and on... "Place" is only one part of the formula, yet it is an important part in terms of increasing possibilities for people to know Jason in a positive way.

Obviously, places of work or other community activities need to be accessible and safe for Jason.

V. **What's Next?** - Planners need to "fine-tune" the characteristics in this report and then seek people, places and activities that match the desired characteristics. For example what types of work, or affiliations in the Stanton area offer opportunities for genuine (not contrived) involvement? What types of places for volunteer work or employment will likely have small teams of workers, and jobs that are interrelated? How might we foster ways for people to look beyond Jason's disability and get to know him as a person? What will supports and adaptations look like?

Of course, plans will change as Jason grows, and we will not always be right the first time. What it is that we must do is always work with the best information available to us in order to establish a sense of purposefulness and belonging for Jason within the community.

September 2, 1993

Dear Brenda,

Thank you for allowing me to spend a day with you last week. I realize it was hectic with school just beginning. Throughout the course of the day, I made some notes of suggestions that would perhaps facilitate Jason's inclusion into the classes he is attending. I have listed those below as well as an explanation of how to use the Meyer Johnson pictures I have included. Margarita has asked that I observe Jason's classes again when I come for the meeting on the 27th of September. I will probably be there late in the morning. I would appreciate it if you would let the principal know I am coming.

SUGGESTIONS:

1) DYCEM: This summer Angie started using dycem to secure things for Jason on a table top. She used it during mealtimes to secure his bowl and glass and during his job at the library to secure books to the table he was cleaning. I have enclosed a catalog where you can order Dycem. Also, Angie used a substitute material that is used by Recreational Vehicle (R.V.) owners to secure dishes in place when the R.V. is in motion.

2) SECURE PAPERS BY TAPING THEM TO TABLE: During art class or any class where Jason will be writing, I would suggest that you secure his papers to the desk by taping them. The dycem may work in this regard as well.

3) TAPE PAPER TO CHALK OR BULLETIN BOARD: Due to the fact that Jason does drool quite a bit, I would suggest that you allow him to produce some of his artwork on the bulletin or chalk board. This would reduce the likelihood that he would dampen his paper with drool. said that the next activity they will be doing is painting. I would suggest that you use chart paper and tape it to the wall or board and allow Jason to paint on it in that manner.

4) FACILITATE INDEPENDENCE: I still see things being done too much for Jason. Given the fact that Jason may not be able to do all parts of the class lesson, it is important to consider ***set-up and clean-up*** activities as opportunities for instruction. Jason should be given the opportunity to retrieve and return his own materials instead of someone doing those things for him. Doing those things gives him the opportunity to practice many of his IEP objectives such as wheeling his wheelchair, using bilateral coordination, and focusing on objects. In addition, I think you can build in clean-up activities that involve your other students in the class routine more. For example, if the art class is making a project that requires throwing away trash at the end or cleaning paintbrushes, perhaps Jason or Daniel or another student who has finished their work early could assist with that clean-up. Jason is a very capable young man, as I am sure you are aware, and should be allowed to do as many things for himself as possible. He takes great pride in these responsibilities. Further, an observation Milton has made relates to this matter. Often, when Jason completes an activity on his own, everyone claps for him. This is not necessarily age-appropriate and also does not teach Jason that the ***completion*** of an activity is what should be motivating. (I hope I am making sense on this point.)

5) SEPARATE STUDENTS: While this suggestion relates to other students in you class other than just Jason, I think it is a valid point. Part of the goal of inclusion of students with disabilities is that natural supports emerge through the student's participation in regular classes. When your students are all sitting at the same table (e.g. Art Class), it does not give other students the opportunity to get to know your students. Placing one at each table might result in one of the students without disabilities offering assistance to one of your students. It might be possible,as the year goes on, that your staff may be able to leave for brief breaks if natural supports present themselves. I also really believe that your students will be less

dependent on you and your staff if you are not in sight during some of these classes.

6) WRIST BANDS FOR DROOLING: I have suggested for some time to try athletic wristbands as a method for Jason to wipe his drool. While I can't verify it, I would suggest that Jason's drooling may be a deterent to interactions between he and his peers. It has worked successfully with other students I know.

7) PICTURE COMMUNICATION SYSTEM: All three of Jason's communication objectives on his IEP center around the combined use of picture symbols and sign. If you re-read language evaluation you will note that she felt that pictures should be used *receptively and expressively* with Jason. I think that unless they stay with him at all times, they will not be used. I spoke with Margarita about getting Jason pencils and a notebook like the rest of the students. She said she would get him a backpack just for school supplies. Jason's communication binder should stay in there at all times. I have included pictures that relate to all of the classes that Jason will be involved with this year. The pictures should be used in combination with speech to: ***tell Jason*** what he will be doing in class that day; to ***give him instructions*** of what to do to prepare for class (e.g. show pictures of paintbrush and paper to indicate that he needs to retrieve those from his tray in Art class); and to ***allow him to express what he wants*** (e.g. In lunch, you may not get his drink and expect him to request it through his communication system). These are important foundations of Jason's IEP and are high priorities for Margarita. I will be anxious to see how he is doing with this system when I come later in the month.

If you questions about any of these suggestions, please do not hesitate to contact me at

Sincerely.

Jennifer Leatherby
Coordinator, Deaf-Blind
Intervention Program

cc: Margarita

Observation by Milton Tyree
Jason

February 3, 1993

(time frames are approximations)

8:45 - 9:20 Middle School - special ed. class - watch video in classroom with other class members - cannot hear audio portion - attention to video minimal

9:20 - 10:20 - Home Ec. class at High School with Vicky, classroom aide - involved in same activity as other class members (cutting, pinning and sewing patterns) - Vicky assisted Jason with all sewing hand-over-hand - Jason sat with 2 other students from his special ed. class when students sat at tables - interaction with other students minimal but friendly

10:20 - 11:20 - Art class at High School with Vicky - involved in different activity than other students (Jason played with "Etch-o-Sketch" while other students worked on clay carvings) - Jason shared a table with (only) 2 other students from his PCMS special ed. class (and Vicky) - interaction with other students minimal but friendly

11:20 - 12:30 - lunch at PCMS classroom (other students ate lunch at 10:20) - Watched news with classmates

12:30 - 12:40 - sit in class activity dealing with current events

12:40 - 2:00 - sat on mat with Allison, a classmate - both had wooden blocks - others watched Sesame Street and did desk work

2:00 - 2:30 - (on my request to see a work-type task) Brenda gave Jason silverware to sort and towels to fold while other students observed

Saw physical integration, but nothing done to support social integration; issue of age-appropriate activities.

Because so little was going on, day was tedious and seemed very long.

Milton Tyree
Employment Consulting

November 22, 1991

Dear Mr.

I want to thank you, Robin, Sherry, and Patsy, for your hospitality during my visit to on 10/30. The day was most enjoyable, and I appreciate the ideas and insights offered about Jaime's future.

The information below is a summary of planning impressions based on my visit and our meeting last week with Nancy, Carolyn and Marie. I hope that these considerations can serve as a starting point for planning when we get together at on 12/6.

Jaime's Schedule

8:10 - 9:00	reading group (language experience - copying from board, group reading, individualized signing of phrases an a work sheet)
9:00 - 9:15	make cool-aid with other class members (structured group activity)
9:15 - 10:15	workshop (stuff envelopes, count a set of envelopes using a jig, and count the number of completed sets using a counter)
10:15 - 10:40	drink cool aid - break
10:40 - 10:50	vacuum classroom
10:50 - 11:15	make Halloween cards
11:15 - 11:30	walk to lunch
11:30 - 1:30	lunch in cafeteria
12:30 - 1:30	clean tables and carts in cafeteria
1:30 - 2:00	game in cafeteria (not observed)
2:00 - 3:00	gym class
3:00 - 5:00	watch TV in dorm (not observed)
5:00 - 6:00	dinner in cafeteria (not observed)
6:00 - ?	dorm - watch TV go for walks, etc. (not observed)

Information & Impressions (based on observation & interviews)

- Jaime knows many signs, but rarely initiates communication with others. Also, she seldom acknowledges the other students in her class, and is more likely to interact with adults.
- Jaime occasionally communicates (frustration?) by "yelling".
- She was friendly, and patient with visitors.

- Jaime is attentive to detail in her work (e.g. placement of salt and pepper shakers on cafeteria tables). "She will do work perfectly when she knows what to do."

- She has a good memory.

- Jaime learns well by watching others and modeling their actions.

- She needed a great deal of guidance in order to vacuum. [Perhaps Jaime will do better with more objective sorts of tasks which are easier to define and structure. i.e., Cleaning tasks require varying degrees of discrimination and decision-making. Vacuuming/sweeping are probably among the most difficult in this regard. "Where do I start?" Where do I stop?" "When is it clean (enough)?" Also, Jaime's visual impairment may further complicate performance of judgement in cleaning tasks.]

- She wiped off tables and carts with minimal guidance. [Even though this is a cleaning task, it is much more "objective" than vacuuming. i.e., The task involves wiping a relatively small defined area (table or cart) with a "marked area". (It's wet or it's not.)]

- Jaime did not maintain any significant level of engagement with the envelope work sample. [Possibly because real work (as above) is preferable to work samples.]

- Jaime "cut out" and folded her Halloween card without assistance. [She decided/inferred "the next step" and had good fine motor control.]

- Jaime and the other students in her class are (generally) not accepted by other students. [Possibly this is due to the deaf students' vulnerability to being perceived as "mentally retarded" simply because they are deaf; their fear that the association with students who are mentally retarded will intensify this vulnerability; and their understanding that people who are mentally retarded are perceived very negatively by people in our society.]

Needs

- CHALLENGING WORK - Jaime needs work which will have an appropriate level of stimulation, intensity and demand (not too easy and not too difficult). The presentation of challenging work will also communicate to Jaime that others have high expectations for her achievement.

- HIGH EXPECTATIONS - As "products" of today's society, we all have a relatively limited range of experience related to positive societal involvement of people who are mentally retarded. Unfortunately, our lack of positive "reference points" will significantly impact the services and "realities" experienced by the individuals we serve. Creativity and high expectations are critical: To a large degree, that which we expect to happen, probably will.

- INTRINSICALLY MEANINGFUL TASKS/WORK - This is an aspect of work which will effect Jaime's personal sense of achievement, pride, and getting something (perceived by self) to be significant accomplished.

- TASKS/WORK WHICH MATCHES JAIME'S PERSONAL COMPETENCIES, AND INTERESTS - Jaime has many abilities and interests. It is our job to help her refine and discover related skills and think of ways for skill application in jobs. For example, since Jaime is attentive to detail (quality), but may have difficulty with pace (production), work tasks will need to be those where quality is more important than production. Since Jaime has developed few academic skills, the job will not be one which emphasizes such skills. (However, it need not be a job which totally avoids the need for academic skills. A job is an excellent place to acquire "functional academic" skills.) Also, Jaime's "likes" need to be considered: Since Jaime likes clothes, may she like working in a stockroom pricing/labeling/steaming clothes?

- BEING "UNDERSTOOD" - Of course Jaime has the need (which we all have) for acceptance and accepting environments. Jaime needs to be in places where she will be appreciated for "who she is". (e.g. Jaime needs places which will be challenging and which will foster her growth and development. But, she also needs places which do not feel compelled to "change" her and places which will treat her with respect - not make her a "project", etc.)

  Also, Jaime's need to communicate is relevant here: We all understand the disappointment and frustration which is experienced when we are "misunderstood". (We become angry, depressed, perhaps "act out", and maybe even become physically ill.) Now, we might consider what it is like to be mentally retarded (and therefore, immediately misunderstood by most members of society) in addition to having limited communication (with a limited number of people who understand sign). Since communication will be a problem for Jaime and co-workers, the ideal job will possibly have a relatively small, stable work force (e.g., 6-8 immediate co-workers in the business or "department") so that these people can get to know Jaime, and learn her method of communication. At least initially the job would not deal with the public, but would involve close interaction with the co-workers, perhaps a business which uses a "team approach".

- GOOD MODELS - Since Jaime learns well by modeling others, the ideal job will have at least one other person who does the same job as Jaime, at the same time, and in the same vicinity. A sort of "self-fulfilling prophecy" will significantly influences Jaime's achievements and self-expectations. For example, if Jaime is surrounded by other individuals having competency impairments, then the (external and internal) expectation is that she will be (or become) incompetent. On the other hand, if Jaime works along-side competent workers and is expected to become a competent worker herself, then the odds of such occurring are greatly increased

- INCREASED OPPORTUNITIES FOR OF SOCIAL INTEGRATION - In addition to the advantages of social integration regarding modeling, Jaime can benefit greatly from increased opportunities to know non-disabled people. Also, non-disabled people benefit greatly from opportunities to know Jaime.

- STRUCTURE - Since Jaime does not like change and since she has limited work (job) experience, an ideal job will be a structured job, with an objective starting/finishing point, specific quantity/quality standards, etc. (A job where the work "comes to Jaime" rather than a job where Jaime needs to initiate work.) Also, since Jaime is not accustomed to requirements of working long periods on a task, the ideal job will begin with 2-4 hours of work a day with the opportunity to work more hours.

- WORK WHICH IS PERCEIVED TO BE IMPORTANT BY THE LARGER SOCIETY - Adults in our society are expected to work. Other than individuals of the "wealthy/leisure class", those who do not work are viewed as burdens of society, lazy, or incompetent and therefore are not likely to be readily welcomed. Also, one's type of work (employment status) will significantly effects one's status in society, and will to a large degree determine one's treatment by other members of society. Therefore, to the extent possible, we must seek work for Jaime which will be positively perceived by others. (Note: This is not to deny the virtue & value nor the pride & challenge which may be derived from jobs which are perceived by the "public at large" to be undesirable jobs. Rather, the issue here is this: the systematic relegation of people with disabilities to jobs which the majority of community members do not want will perpetuate prevailing negative attitudes. e.g., That's all "they" can do. "They're" happy to do it. That's all "they" deserve.)

- DEVELOPMENT OF HER IDENTITY AS A YOUNG WOMAN - Jaime needs as many activities/associations as possible which will promote her seeing herself (and others seeing her) as a young woman. This will significantly influence Jaime's potential for positive life opportunities. Most important, this will help Jaime to understand "who she is" and hopefully avoid confusion over her identity. (i.e., "Am I an adult or a child?")

- INDIVIDUALIZED PLANNING - As an individual who has many and complex needs, Jaime will often "fall between the cracks" in regard to having her needs met by available human services. (This is not intended as an indictment of human services, but rather as a consideration for effective planning of Jaime's future.) "A clean sheet of paper" is indicated. This approach may likely use existing services; however, the plan for Jaime must be developed first. This way Jaime (and those providing the service) will have an increased chance for success. In other words, it is suggested that prospective human service providers be approached in this manner, "This is what Jaime needs. Will you work with us?" As opposed to this approach, "We need help. What do you do?"

On the 6th I would like you, Robin, Nancy, Sherry, and Patsy to respond to these considerations, and then I would like for us to think about a framework for planning. As we discussed in the meeting last Friday, perhaps it will make sense to look at establishing a job during a portion of the day in during this school year. (Regardless of Jaime's school assignment next year, it seems to be a good idea for Jaime to begin working with the support of those who know her best. Then if appropriate supports are developed for Jaime within . schools, there will already be an established foundation for work supports. i.e., "What will this look like in the real world?")

I look forward to meeting with you, other : personnel, Nancy (and possibly Marie .) at 1:00 on 12/6. Of course, I will be pleased to talk to you (and others) prior to then. Just give me a call.

Sincerely,

Milt

Milton Tyree

cc: Nancy
Robin
Sherry
Patsy
Marie
Carolyn
Mary

Patti for their analysis and for guidance regarding relevant communication/training strategies. (K-Mart staff are planning on providing the majority of tasks training for Jamie.)

8/28/92 Confirmation letter sent to K-Mart - copies to , and . Also, I called Frank and Patti. We will meet at prior to going to K-Mart on the 11th (≈ 12:15).

9/11/92 Patti , Frank and I went to K-Mart where we met with Kim to plan for a positive introduction for Jamie. Functional sorts of communication were discussed. We decided that the best way for Jamie to understand the job during her introduction on Monday, will be for her to be introduced to Kim, Anita, and Ideana and then perform a short work task.

We determined that an aide from the transition program (Sherrie or Patsy) Frank, and I will accompany Jamie on her interview. Sherrie of Patsy will provide initial assistance by helping Jamie learning her job primarily by assisting other K-Mart personnel in knowing Jamie and in knowing the best ways to organize instruction for her.

After Jamie's interview/introduction, the aide, and I will stay to work for a period of time in order to perform the types of tasks that Jamie will be doing. Also, Patti will come to K-Mart following Jamie's interview to practice the job as well. The three of us will determine the best ways to Jamie to do the clothes-hanging tasks.

9/14/92 Jamie's interview and introduction went very well. Kim showed Jamie the apparel receiving area and showed her how to hang women's sweaters. (Jamie liked the sweaters, but was not distracted from doing the work.) Jamie was quite comfortable with Kim and I believe that she will enjoy working here. Robin did an excellent job of encouraging Kim and Jamie to work together. I believe that Robin will do an excellent job of facilitating training for Jamie.

We agreed that Jamie will begin next Monday and will work from 1:00 to 3:00 M-F. Robin completed necessary personnel work for K-Mart so that Jamie cold get on the payroll. Frank took Jamie back to . Robin and I stayed to work on the job to organize instruction for Jamie next week. Patti joined us shortly thereafter.

9/15/92 I sent a letter to Mrs. describing the effect of Jamie's wages on her SSI check. (copy to Robin)

9/24/92 I called Robin to learn how Jamie's job is progressing and to see if I might visit this afternoon. She said that Jamie is working very well with Ideana and Anita. Ideana seems to be taking a particular interest in Jamie. Apparently, Robin has been successful in fostering a good working relationship between Jamie and her peers. Robin will plan on cutting her time on-sight in half next week. (This is fine with Jamie and K-Mart.)

The only problem which was noted involved Jamie working in the stock room with Robin folding towels and placing the towels on shelves. This task was apparently awkward for Jamie and she "hollered" for the first time.

Later when I visited, Jamie was taking stock to the floor with Anita. (The apparel shipment had not come in, so Jamie was reassigned.) I watched for a while as they worked together putting up purses. Very impressive - Jamie is working hard, seems very happy (never quit smiling) and she looks great in the K-Mart smock and name tag. Also, I learned that a number of K-mart employees are taking sign classes at . Robin continues to be an great encourager and has very high expectations for Jamie.

I must admit that Jamie has exceeded my expectations given her accomplishments in short period of time which she has worked at K-Mart. She will be paid this Friday and I believe that some clothes have already been set aside for a discount purchase.

Appendices for Project Impact (Section IX)

A. Developed/Impacted Legislation

B. Project Newsletters Not Previously Submitted

C. Mission Statement for the Kentucky Chapter of the Deaf-Blind

Appendix IX-A

Developed/Impacted Legislation

92 RS BR 1018/GA

GENERAL ASSEMBLY

COMMONWEALTH OF KENTUCKY

REGULAR SESSION 1992

HOUSE BILL NO. 447

TUESDAY, MARCH 17, 1992

The following bill was reported to the Senate from the House and ordered to be printed.

AN ACT relating to supported living services for persons with a disability.

Be it enacted by the General Assembly of the Commonwealth of Kentucky:

SECTION 1. A NEW SECTION OF KRS CHAPTER 210 IS CREATED TO READ AS FOLLOWS:

As used in Sections 1 to 6 of this Act, unless the context otherwise requires:

(1) "Mental impairment" includes mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities;

(2) "Person with a disability" means someone with a physical or mental impairment and includes individuals who have a record or history of an impairment, or are regarded as having a physical or mental impairment that substantially limits one (1) or more major life activities;

(3) "Physical impairment" means any physiological disorder or corrective, cosmetic disfigurement, or an anatomical loss affecting one (1) or more of the following body systems: neurological, musculo-skeletal, special sense organs, respiratory including speech organs, cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin and endocrine;

(4) "Substantial limitation of a major life

activity" includes limiting such things as walking, talking, seeing, hearing, caring for oneself, or working;

(5) "Supported living" means a broad category of highly flexible, individualized services designed and coordinated in such a manner as to provide the necessary assistance to do the following:

(a) Provide the support necessary to enable a person who is disabled to live in a home of the person's choice which is typical of those living arrangements in which persons without disabilities reside;

(b) Encourage the individual's integrated participation in the community with persons who are members of the general citizenry;

(c) Promote the individual's rights and autonomy;

(d) Enhance the individual's skills and competences in living in the community; and

(e) Enable the individual's acceptance in the community by promoting home ownership or leasing arrangements in the name of the individual or the individual's family or guardian;

(6) "Supported living" does not include the following housing arrangements:

(a) Segregated living models such as any housing situation which physically or socially isolates people with disabilities from general citizens of the community;

(b) Congregate living models such as any housing situation which groups individuals with disabilities as an enclave within an integrated setting;

(c) Any model where the individual, as an adult, does not have maximum control of the home environment commensurate with the individual's disabilities; and

(d) Any single living unit where more than three (3) people with disabilities live;

(7) "Supported living council" means a supported living council appointed by the Governor and recognized by the commissioner of the Department for Mental Health and Mental Retardation Services to approve individual supported living plans;

(8) "Supported living services" include, but are not limited to:

(a) Supported living community resource developers;
(b) Homemaker services;
(c) Personal care services;
(d) In-home training and home management assistance;
(e) Start-up grants;
(f) Monthly stipends;
(g) Transportation;
(h) Home modifications;
(i) Adaptive and therapeutic equipment; and
(j) An individual plan by an independent and trained facilitator; and

(9) "Regional Supported Living Council" means a

regional supported living council created under Section 4 of this Act.

SECTION 2. A NEW SECTION OF KRS CHAPTER 210 IS CREATED TO READ AS FOLLOWS:

(1) There is hereby created the State Supported Living Council for services to persons with a disability and their families.

(2) (a) The State Supported Living Council shall be composed of ten (10) members. The commissioner of the Department for Mental Health and Mental Retardation Services and the executive director of the Kentucky Housing Corporation or their designees shall be ex-officio members.

(b) Eight (8) of the members shall be volunteers and shall be appointed by the Governor from a list of nominees in the following manner:

1. Three (3) of the appointed members shall represent family members of persons with a disability. One (1) member shall be selected from each of three (3) lists containing two (2) nominees submitted by each of the following associations: the Kentucky Association for Retarded Citizens, the Association for Persons with Severe Handicaps, and the Mental Health Coalition;

2. One (1) of the appointed members shall represent family members of persons with a disability who reside in an intermediate care facility for mental retardation or

developmental disabilities. The nominee shall be selected from a list containing two (2) nominees submitted by each of the following associations: Concerned Parents of Hazelwood, Parents and Relatives of Oakwood Facility, and Concerned Parents of Outwood;

3. Two (2) of the appointed members shall be persons with a disability. They shall be selected from a list containing two (2) nominees submitted by each of the following associations: the Kentucky Campaign for Personal Attendant Care, the Kentucky Association for Retarded Citizens, the Mental Health Coalition, and the Kentucky Coalition for People with Handicaps;

4. One (1) of the appointed members shall represent professionals and providers of services to persons with a disability. The nominee shall be selected from a list containing two (2) nominees submitted by each of the following associations: the Kentucky Association of Private Residential Resources and the Kentucky Association on Mental Retardation; and

5. One (1) of the appointed members shall represent advocates for persons with a disability. The nominee shall be selected from a list containing two (2) nominees submitted by each of the following entities: the Division of Protection and Advocacy and the Kentucky Developmental Disabilities Planning Council.

(3) The appointed members may serve on the council

for three (3) years. Members may be reappointed for a maximum of two (2) consecutive terms. The Governor shall fill any vacancy occurring in the council in the manner prescribed in subsection (2) of this section.

(4) The Department for Mental Health and Mental Retardation Services shall provide staff assistance to the State Supported Living Council.

(5) The chairman of the State Supported Living Council shall be elected from among the members. A majority of the members shall constitute a quorum.

(6) The State Supported Living Council shall meet as often as necessary but no less frequently than every other month.

SECTION 3. A NEW SECTION OF KRS CHAPTER 210 IS CREATED TO READ AS FOLLOWS:

(1) Upon the appointment by the Governor of all members of the State Supported Living Council, the council shall recommend to the Department for Mental Health and Mental Retardation Services:

(a) A budget and priorities for fund allocations for supported living services for persons with disabilities within the Commonwealth;

(b) Standards for quality assurance for persons with a disability who receive supported living services in accordance with Sections 1 to 6 of this Act.

(2) The provisions of paragraph (b) of subsection

(3) of this section shall be effective upon the members' appointment, and for two (2) years after the effective date of this Act, at which time the provisions of subsection (2) of Section 4 of this Act shall apply.

(3) The State Supported Living Council shall be responsible for:

(a) Disseminating information about supported living services available under Sections 1 to 6 of this Act;

(b) Reviewing, approving, and recommending expenditures for individual plans for supported living services submitted by the consumers and providers of supported living services to a regional community mental health-mental retardation board;

(c) Encouraging the creation of new providers of supported living services; and

(d) Hearing grievances and providing due process for consumers and providers of supported living services.

(4) The State Supported Living Council shall not impose an individual service plan on any applicant who objects to the plan.

(5) The State Supported Living Council may recommend necessary administrative regulations under KRS Chapter 13A to carry out the purposes of Sections 1 to 6 of this Act.

SECTION 4. A NEW SECTION OF KRS CHAPTER 210 IS CREATED TO READ AS FOLLOWS:

(1) There are hereby created fourteen (14) regional

supported living councils which shall represent regions as established by KRS 210.370 to 210.460. Each regional supported living council shall be composed of eight (8) members who shall be volunteers and shall be appointed by the Governor. The method of submission of the list of nominees, composition, and the representation of the regional supported living council shall be the same as for the appointed members of the State Supported Living Council.

(2) At the beginning of the third year after the effective date of this Act and every year thereafter, each regional supported living council shall have the authority and duty to review, approve, and recommend expenditures for individual plans for supported living services submitted by any person with a disability and eligible providers of supported living services to a regional community mental health-mental retardation board.

(3) No individual service plan shall be imposed by a regional supported living council on any person with a disability who objects to the plan.

SECTION 5. A NEW SECTION OF KRS CHAPTER 210 IS CREATED TO READ AS FOLLOWS:

(1) Only a person with a disability who is a resident of Kentucky or whose family or guardian is a resident of Kentucky is eligible for supported living services. The person may be living with a family member,

independently, or be in a congregate setting and be eligible for services.

(2) Any eligible person with a disability who wants to apply for supported living services may design and request a set of services in the amount, kind, frequency, and duration which is dependent upon the person's individual needs, and is consistent with the definition of supported living under Section 1 of this Act.

(3) Payments for supported living services may be made directly to the person with a disability to enable the person to purchase a service, or to the guardian of the person with a disability, or to the local service provider or to any combination of these parties.

(4) A license shall not be required for any supported living housing arrangement provided on a contractual basis.

SECTION 6. A NEW SECTION OF KRS CHAPTER 210 IS CREATED TO READ AS FOLLOWS:

(1) The Department for Mental Health and Mental Retardation Services in cooperation with the State Supported Living Services Council shall establish standards for quality assurance for eligible persons who live in the community in supported living arrangements as defined in Section 1 of this Act. The purpose of these standards is to ensure that a person with a disability receives supported living services in a manner that

empowers the person to exercise choice and enhances the quality of that person's life. These standards shall promote the following:

(a) Control over where and with whom a person with a disability lives;

(b) Opportunities to meaningfully participate in activities in the community with members of the general citizenry;

(c) Enhancement of health through on-going medical and dental care;

(d) Flexible services that change as the person's needs change without the individual having to move elsewhere for services;

(e) Use of generic options such as home health aids, homemaker services, live-in roommates or staff, community counselors, neighbors, family, and friends in the development of a supported living plan;

(f) Well planned and proactive opportunities to determine the kinds and amounts of support desired, with the meaningful participation of the individual, the individual's family or guardian where appropriate, friends, and professionals; and

(g) Home ownership or leasing with the home belonging to the person with a disability, that person's family, or to a landlord to whom rent is paid.

(2) The individual supported living plan shall be

developed by the person with a disability and that person's family or guardian where appropriate, and, as appropriate, the proposed or current provider.

(3) The individual supported living plan shall document assistance and support required by the person with a disability in the following eight (8) areas:

(a) Choice and options;

(b) Personal income;

(c) Housing;

(d) Health;

(e) Safety;

(f) Appearance and hygiene;

(g) Relating to others; and

(h) Activities.

(4) The Department for Mental Health and Mental Retardation in concert with the State Supported Living Council shall promulgate administrative regulations under KRS Chapter 13A, if necessary, to establish the methods of monitoring the quality of service delivery.

CABINET FOR HUMAN RESOURCES
COMMONWEALTH OF KENTUCKY
FRANKFORT, KENTUCKY 40621

CONTACT: Kim Saylor (502) 564-6786
or Brad Hughes (502) 564-7130
Office of Communications

STATEWIDE AND PRESS ROW

DEPARTMENT FOR MENTAL HEALTH AND
MENTAL RETARDATION SERVICES
An Equal Opportunity Employer - M/F/H

State Program Gives People with Disabilities More Living Arrangement Options

FRANKFORT, Ky. (April 2, 1993) -- Kentucky's supported living program is giving 93 Kentuckians with disabilities the opportunity to live with their families or independently in their communities.

The recently implemented program enables people with disabilities to stay in their communities by getting flexible services, such as home modifications, equipment and personal care.

"This is another option for people with disabilities, so they can have more choices about how and where they live their lives," said Dennis Boyd, commissioner of the Department for Mental Health and Mental Retardation.

"This program covers a wide range of services that can be tailored to the individual and it is open to anyone who qualifies under the Americans With Disabilities Act as having a disability. Like other Kentuckians, people with disabilities should have as many choices about how they live their lives as possible," he said.

In 1992, the Kentucky General Assembly provided $1.5 million during the 1992-94 biennium to implement the Supported Living Bill and establish the State Supported Living Council. During the first application phase in November and December last year, 178 Kentuckians applied for funds. New applications are currently being accepted until April 16.

People who were not approved for money during the first application phase will be considered along with new requests.

"Our first obligation is to serve the first group of applicants and then other people may be helped if money permits," said Doug Riddell of the Division of Mental Retardation. "At this point, we don't know how much money will be left after we take care of the first group of people."

Riddell said about a fourth of the approved applications are for one-time expenses, such as home modifications, equipment and furniture. Other applications are for recurring costs, such as a personal care assistant or in-home training. The most common requests were for respite care, therapy and equipment.

"The council tries to distribute the money across the state and to people with various disabilities. The money is not limited to people with mental retardation or developmental disabilities, but covers other disabilities as well," Riddell said.

Among the applications, funds were requested to assist people with mental retardation, head injuries, multiple sclerosis, cerebral palsy, Alzheimer's disease, developmental disabilities and mental illness, and people who are blind and deaf.

Eligibility for funds is determined by the State Supported Living Council, which is composed of 10 people across Kentucky with various backgrounds. Funds can be given to a Kentuckian with a disability, a family member or guardian of a person with a disability living in Kentucky or an agency that wants to provide supported living services. Eligibility is not based on income.

"We have seen by the first application response that these services are needed in our communities and many people can benefit from them. Deciding who receives funding is very difficult, but knowing that people who need these services are out there may help us secure more funding in the future." Riddell said. "This program not only helps the person with a disability, but also the family."

To find out more about supported living or to get an application, contact your local Mental Health and Mental Retardation Center or the Division for Mental Retardation in Frankfort at (502) 564-7700.

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STATEWIDE AND PRESS ROW

New Law Assists Kentuckians with Disabilities To Live Independently

FRANKFORT, Ky. (July 17, 1992) -- Kentuckians with disabilities can now receive support services which will allow them to live independently or to continue to live with their family and also be assured that those services will be quality ones.

House Bill 447 -- The Supported Living Bill -- allows for flexible services to persons with disabilities and their families to enable the person to live independently and be integrated into the community.

"The glory of this new law is its flexibility; various services that individuals need in order for them to live in the place of their choice can now be made available," said Dennis Boyd, commissioner of the Department for Mental Health and Mental Retardation Services.

"For instance, many persons with disabilities can live alone or with their family if they have personal care services or if their home is modified to fit a wheelchair or if transportation is provided," said Boyd. "This legislation will allow money to be spent in areas that enable a disabled person to live alone or with up to two other people."

The General Assembly provided $500,000 during the first year of the biennium and $1 million the second year to implement the new law.

The legislation also establishes a State Supported Living Council which will set up standards to assure quality of services to Kentuckians with disabilities.

"Not only will this population receive needed support but the services rendered will be caliber services that empower the person to exercise choice and improve the quality of life," said Boyd.

(over)

"By choice, I mean these individuals, along with their family members and the state council, will play a major role in deciding what support services they receive and where they live and with whom," he said.

Doug Riddell of the Division of Mental Retardation said supported living is a lifesaver.

"Parents of people with disabilities want their offspring to find a safe place to live, especially as the parents get older. They want their children to remain or become a real part of a community, to have a real chance of being like everyone else and supported living is a way to do just that.

"It's important to point out that this financial support cannot assist any housing situation which isolates people with disabilities from the general public or groups more than three people with disabilities in a single residence.

"The goal is to integrate persons with disabilities into the community and enhance the individual's skills in living on his or her own or with their families," said Riddell.

The state already provides residential-related services for Kentuckians with disabilities such as daily and periodic supervision, group homes and in-home support services like personal care and training in social and self-help skills. Supported living services will pick up where these services leave off.

"Money appropriated for supported living will pay for services that cannot be gotten through other programs," said Riddell. "We are excited to be able to offer such assistance.

"Kentuckians with disabilities have the same right to live independently as Kentuckians without disabilities."

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Appendix IX-B

Project Newsletters Not Previously Submitted

INSIGHT

Volume 3 Number 1
Jennifer Leatherby, Editor
Brenda Pezzarossi, Parent Coordinator
Spring 1992

National Deaf-Blind Bulletin Board Available to Kentuckians

Using a computer, modem, and communications software, anyone can now call SpecialNet, a national computer access reached by subscription by calling 1-800-927-3000. The fee for private membership is a $35.00 setup fee and an annual fee of $25.00 plus any long distance charges. If you only call toll free numbers, there are no additional charges; however, you will also need the gadgets mentioned in the opening line before you initiate this process.

Since the third week of January, personnel with the above hook-ups have been able to begin interactive communications by asking for announcements, training, collaboration, resources, and reviews across many state deaf-blind projects and federal sponsoring and operating agencies. The bulletin board is titled **DEAFBLIND** and you may sign on by placing "che" in front of the board title. The new board is sponsored by TRACES in Oregon with the editor located at the California Deaf-Blind Services.

On a more local level, at U.K.'s Interdisciplinary Human Development Institute, we have been able to add this new bulletin board to the weekly readings done by the (MSRRC) MidSouth Regional Resource Center. We can then access the readings through our own MacIntosh computer and relay to you any thing of interest. Please contact Brenda Pezzarossi for more information at **1-800-365-1258** or 606-272-1992 or 606-257-3586.

The following quote was used by Mike Meyers, Ohio's advocate for persons with significant disabilities living "on their own" at a Supported Living Workshop held in Lexington, KY.:

> "the sin in NOT in setting the goal too high and missing, but in setting it too low and hitting." by Jesse Jackson

RALLY TO SUPPORT PROGRAMS FOR INFANTS AND TODDLERS WITH DISABILITIES IN KENTUCKY

On Tuesday, February 25 at 1:30 p.m. there will be a rally in Frankfort to support infant toddler programs for children with disabilities in Kentucky. Parents who support the idea of early intervention are urged to attend. The rally will be on the Capitol steps on Capital Avenue in Frankfort. (The rain-out location is the Capitol Rotunda.) The purpose of the rally is to raise legislators' awareness of the importance of infant toddler programs and to support funding during the next fiscal year, in the amount of $10 million, to continue these programs. If your child benefitted from such programs, this is a wonderful opportunity to let others know how important such programs were to you and your child. If you are unable to attend, please contact your legislator and let them know how important these services are. You can reach them at: 1-800-372-7181. Leave a message with whomever answers and tell them how you feel. ***YOUR INPUT MAKES THE DIFFERENCE!!!!***

Parent Testimony Impacts Professionals and Other Parents

The following speech is taken from the testimony given to the Deaf-Blind Intervention Project's Parent Advisory Board Meeting on January 15, 1992 at the Breckinridge Inn in Louisville, Ky.

Continued on Page 2

Continued from Page 1

"Hello, I'm Sharon Cole, the one that sent the letter out inviting you all to join us here today. The reason for this meeting is to begin organizing a state wide support system for and by parents and/or family members who have deaf and blind sons and daughters. I'm sure that most of you have experienced difficulty and frustration in coping with the problems facing us and our deaf-blind child.

We, as parents are no different than any other parent in wanting the best for our children. Who knows better than us, as parents, what our childrens' needs are? We do have many needs! Needs such as identifying and reaching out to families, particularly those in rural areas with small children. There is the need for resources and training to assist with stress management, the need for training to develop advocacy and leadership skills. There is the need for accessible and current information, including medical, respite care, and financial assistance. There is a great need for increased employment and community living options for those with the greatest disabilities. There is also the need for sharing our concerns and experiences with each other and the need for sharing the expertise of those who have succeeded.

If we do not address these needs while our children are still young and in the school system, our child will fall through the cracks, and many do any way due to lack of public awareness, knowledge, and communication skills. People with vision and/or hearing loss have been very neglected. We need to make the public aware that such disabilities exist and that we have needs to be met. We can't do this alone! We can't expect the professionals to do this alone. We need to work as partners with professionals towards becoming a more powerful source in establishing services to improve the quality life for our sons and daughters.

I'd like to share with you my personal testimony of what life was like when I learned of my daughter Kelly's disability. Kelly was three years old when she started having ear infections. Her father and I had just recently divorced, and it seemed that when we divorced he just disappeared from our lives. I was receiving some financial assistance from the State. Kelly had a medical card which really didn't seem to do any good. When she had an ear infection I'd have to take her to the emergency room because there weren't any doctors in Owensboro who would see her with a medical card. We fought with ear infections off and on for quite some time.

Then I remarried and my husbands' insurance would not cover stepchildren. I could not get insurance for Kelly after we learned that she had asthma and this hearing disability. We were very fortunate to meet Dr. Cohen at the hearing clinic in Louisville. He sympathized with us and he knew that Kelly had a permanent and progressive hearing loss. He fought very hard to get her into the program with the Commission for Handicapped Children. We were very fortunate in being accepted into this program and we made some very good friends there. Three ladies, who worked for the Commission, seemed to fall in love with Kelly and they became very close personal friends of ours over the years.

During this time I had developed ulcers, my new marriage was on the rocks, and I had a nervous breakdown and was hospitalized. Then, when I could see that Kelly was functioning. . . she would turn the television set on. She would enjoy watching T.V. even though she couldn't hear anything and she was still enjoying life. I decided it was time that I overcome some of my problems and started enjoying life again also.

We were on the road to recovery, I thought, until Kelly was diagnosed with Ushers Syndrome at the age of 10. They called me at home and told me that Kelly needed to be seen in Louisville. It was a month before we would get an appointment. I knew something was wrong, but they really didn't want to tell me. Being the kind of person I am. I wouldn't let them hang up until they would tell me what it was that they suspected. They did tell me that they thought Kelly would lose her sight, but I was not allowed to tell Kelly because they hadn't made this diagnosis and didn't want to upset her. I had to go for a month pretending that nothing was wrong. Kelly knew me well enough to know that something was wrong. We came to Louisville, had the tests done, and the diagnosis was correct. Kelly had Ushers Syndrome.

They thought that I should send her away to the Kentucky School for the Deaf for her education. This was very difficult for me. I could not send Kelly and she did not want to go in the

Continued on Page 3

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beginning. Then, she made the decision on her own to go. She was there for two years. Greg Whittington, a psychologist at the U.L. School of Medicine, stayed in touch with Kelly to let her know he cared after she went away to school. However, we had problems at the School for the Deaf. They knew that Kelly had Ushers, but they were not allowed to talk about it. They had never informed the teachers or anyone else there that Kelly had Ushers. She had many accidents there.

During this time I got a call from Marie Ruf, with the Deaf-Blind Intervention Project, who was a life saver at this point. There were times when Kelly was first diagnosed with Ushers that I even considered suicide. Then I thought that I couldn't do something like this and leave my daughter behind. I thought that maybe it would be best if neither Kelly nor myself either one lived. . . that we couldn't have much of a life and I couldn't enjoy seeing Kelly suffer.

Kelly, again, made me realize that this is not the way it should be. She was a very happy little girl. Kelly loved life. She enjoyed life to the fullest. We were on our way to recovery again. Marie had made me understand. I had mentioned to her about . . . death. She made me realize that I had to think of Kelly as dead . . .the Kelly that I had wanted was dead, and I had another Kelly and we should go on from there. She got me involved in this Kentucky Deaf-Blind Program.

Since then Kelly and I have grown a lot. Kelly appreciates me caring enough about her to be involved. She knows that standing here in front of your telling all of these things is very difficult for me. She appreciates that I am here telling you about our experiences and hoping that other parents who are going through the same difficulties will finally realize that life does go on and that we can still have a quality life."

PROJECT UPDATE:

Personal Futures Planning for Individuals with Deaf-Blindness

A process manual is in the final stages of development with the assistance of Beth Mount, Ph.D., New York, who is nationally recognized for her efforts in helping individuals and families plan quality futures.

Dr. Barbara Wilcox, Indiana University, is assisting the project in the evaluation of the P.F.P.'s (Personal Futures Plans) developed thus far and the impact these plans have on student's I.E.P., especially transition services.

Orientation training, through a combination of approaches has reached 410 persons. Approximately half or 195 of these persons have directly participated in PFP teams and have applied their knowledge in activities of direct benefit to the participants in this project. Personal Futures Planning team meetings have been facilitated with nine teams. Seven of these teams, presently functioning, have received local consultation in the development of the IEP, especially the transition aspect. A minimum of two consultants has been used for five of these seven teams. Consultants are chosen on the basis of their expertise in specific areas of the Personal Futures Plans.

As a part of the parent mentoring aspect, we have contacted and set up parent alliances when possible. For example, one parent agreed to share her vision with another family who had never seen persons with significant disabilities working in the community. A skeptical family member was able to ask questions and visit community work places which included persons with disabilities. Changes in values, based on being exposed to more integrated community settings, helped this family to believe that their young adult could have a quality life in a positive location in the community for his future.

MARK YOUR CALENDARS!!!

The (now) Annual Family Forum for families of children with dual sensory impairments will be August 14-16 at the Kavanaugh Center in Crestwood Kentucky (35 miles from Louisville). All families of children with dual sensory impairments are invited to this wonderful weekend of fun and learning. Expenses are paid for each family to attend through the Hilton/Perkins National Program. Watch for additional information in the next issue of Insight.

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RESOURCES FOR PARENTS

ASSESSMENT FOR CHILDREN WITH DISABILITIES - Kaye Langer (606)257-4644, Pat Berdine (606)257-1254.

ACCESS for link with services for developmental disabilities & M.R. Nelda Stephans, (606)233-0444.

ADVOCATE FOR DEAF-BLIND PERSONS - Cherry King (502)839-7556.

COMMISSION ON THE DEAF AND HEARING IMPAIRED - William Rogers 1-800-382-2907.

CONSULTATION FOR ATTENTION DEFICIT DISORDERED CHILDREN, Bobbie Burchan (606)257-7372.

DIRECTIONS - information about services for the disabled. Karen Stone & Dawn Jacobs. Parents: 1-800-234-0497.

INFANT TODDLER PROGRAM for infor. birth - 2 years, Marge Allen (502)564-7700.

KY COALITION FOR PEOPLE WITH HANDICAPS - Ann Hancock (502)875-1871, Gail Lincoln (606)784-7580.

KY. SPECIAL PARENT INVOLVEMENT NETWORK - KY-SPIN Paulette Logsdon, parent information 1-800-525-SPIN or (502)589-4717.

KY TALKING BOOK LIBRARY for service information 1-800-372-2968.

NATIONAL ASSOCIATION FOR PARENTS OF THE VISUALLY IMPAIRED. Beloit, Wisconsin Barbara Auletta 1-800-562-6265.

NATIONAL PARENT NETWORK ON DISABILITY (NPND). Alexandria, Virginia. Help to apply, in behalf of your child, for Supplemental Security Income (703)684-6763.

PAWS WITH A CAUSE - newest unfunded model program to train companion dogs for disabled. Kim Rosenberg (606)873-4271.

PRESCHOOL - KY DEPT OF ED for ages 3 - 5 Debbie Schumacher, (502)564-4970.

PROTECTION & ADVOCACY - Help with legal rights of disabled children and adults 1-800-372-2988.

SKI-HI Help for parents with young hearing impaired children Andy Hensley (606)357-7939.

PARENT DIRECTORY

Included within this issue of INSIGHT is a directory of parents who have children with dual sensory impairments and have consented to having their names and numbers disseminated to all families with children on the Deaf/Blind Registry. Take a few moments to glance through it and locate other families in your area. Perhaps, you may want to contact these families if you have concerns or issues that you need to discuss with another family.

CRISIS LINE

NEW! HELP! TOLL FREE!

Call 1-800-365-3586 and "call forwarding" will take your call directly into the home of another parent who may or may not be in crisis also. We probably will not have the answers, but we have most likely had a similar crisis.

Beware! The following is an advertisement.

Attention! All Parents
In Attendance At
Last Year's Family Forum

For those of you who, along with your son or daughter attended our Otter Creek Family Forum, we have a 10 minute video treat for you.

If your son or daughter participated and you would like a copy of this event on VHS for eternity, Brenda Pezzarossi is able to make copies of the original "Spontaneous Integrated Adapted Kickball Game" that occurred on Saturday evening at Otter Creek's Family Forum.

Send $5.00 along with your name and address to Brenda Pezzarossi, 3428 Crimson King Ct., Lexington, KY 40517, who is willing to make copies of the tape, at your expense, of course. You may contact Brenda at 606-272-1992 at home or 1-800-365-1258 or 606-257-3586 at work.

FYI CORNER

Deaf Blind Intervention Program
Jennifer Leatherby
UK Special Education Department
229 Taylor Education Building
Lexington, KY 40506-0001
(606) 257-7909 *

Diane Haynes,Sandi Baker, and Marie Ruf
1867 Frankfort Avenue
Louisville, KY 40206
(502)897-1583 *

Helen Keller Affiliateship
Janis Friend
Dept of Vocational Rehabilitation
627 W 4th St
Lexington, KY 40408
(606)255-1431

Systems Change Project
Dr. Harold Kleinert or
Jacque Farmer
UK Interdisciplinary Human Development
114 Mineral Industries Building
Lexington, KY 40506-0051
(606)257-3045 *

Amy Reber
Associate Director
501 Farrell Drive
Covington, KY 41011
(606)331-7742 (wk) - (513)231-8454 (hm)

Personal Futures Planning Project
Carolyn Wheeler or
Cynthia Vaughn, Parent Coordinator
1867 Frankfort Avenue
Louisville, KY 40206
(502)894-9366 *

Brenda Pezzarossi, Parent Coordinator
UK Human Development Institute
114 Mineral Industries Building
Lexington, KY 40506-0051
(606)257-3586 or (606)272-1992 *

*Answering machines located on these phones.

The Monitors Came!
The Monitors are Coming Again!

The United States Department of Education, Office of Special Education and Rehabilitative Services (OSERS), is responsible for visiting each state approximately once every five years to "monitor" whether or not the state education agency is meeting the requirements of federal law. A part of this process is to invite parents and disability/advocacy organizations to make comments that will alert the federal monitors to issues concerning implementation in their state.

Kentucky's two public meetings, held in Bowling Green and Lexington, were well attended in spite of severe weather warnings on the evenings of January 14 and 15. Many parents, representing a multitude of groups for persons with disabilities, were in attendance at the federal monitoring meetings. The OSERS staff person, Dr. Gregory Corr, 202-732-1027, seemed to value parent participation, and was extremely interested in the comments.

Protection and Advocacy, 1-800-372-2988, submitted the largest written documentation of noncompliance which addressed issues of "no school" with no services for school age children with special needs, "homebound" with minimal services for children with special health care needs, and instruction time being less for children with disabilities than for regular students.

Parents addressed many other educational issues, which occur even though P.L. 94-142 was enacted in 1975 and IDEA is the new law of the land. Concerns of parents, taken from federal oral testimony, are listed below:

* Children with disabilities being placed in one location because of administrative convenience, rather than their educational needs.

* Lack of training of principals, teachers, and guidance counselors in integration and equal rights leads to outright discriminatory practices against children with disabilities in many school systems.

* Children with disabilities being placed in "what is available" rather than basing the placement on the individual child's educational goals and objectives.

* Regular classroom modifications or adaptations not being offered to ensure success for the child with disabilities in the least restrictive environment.

Continued on Page 6

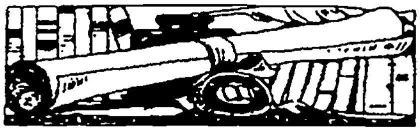
Continued from Page 5

- Related services such as occupational therapy, physical therapy not being provided, not considered educationally relevant, and not being placed on the IEP.
- School systems' continued refusal of parental requests for IEP goals or services.
- Parents not being encouraged, or actively discouraged, by the school system to be actively involved in writing Individualized Education Plans for their son or daughter.
- The lack of mandatory Interagency Individual Transition Planning for students with disabilities after they reach age 14.
- The lack of Assistive Technology services for students with documented communication needs for these services.
- Proper implementation of school services depending upon parent contacting P & A; consequently, unequal service delivery for students with disabilities across the state, across districts, across local systems, and even among students in the same local school system.

During the week of February 24, 1992, the monitors will be making on-site visits to five local school districts in Kentucky. Results will return to Kentucky in the form of a report which will reflect the issues and comments brought to the attention of the monitors by the parents throughout the state. Parents and children with special needs will begin to notice some positive changes.

Parents, your comments may be sent directly to:

Dr. Gregory Corr
Office of Special Education Programs
US Department of Education
400 Maryland Avenue, SW
Washington, DC 20202-2722
Tel: 202-732-1027



ATTENTION!!!

YOU MAY RECEIVE A COPY OF **THE AMERICAN DISABILITIES ACT** FROM THE AMERICAN PRINTING HOUSE FOR THE BLIND BY CALLING 502-897-1583.

NEEDS ASSESSMENT

Attached is a needs assessment that has been developed for parents to let us know what information you need regarding your son/daughter's disability. Please take a few moments to complete this needs assessment and return it in the postage paid envelope that is included. The intent of the newsletter is to assist families in attending existing trainings specific to your needs. Information from the Needs Assessment may also be used to plan this year's Family Forum.

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TOLL FREE NUMBER

The Kentucky Support Network for parents confronting dual sensory impairments now has its own 800#. The new phone line is located in Jennifer Leatherby's office at U.K. There is an answering service on the line, so if Jennifer is unavailable, please leave a message and she will return your call. Feel free to leave messages for other staff of the Deaf/Blind Intervention Program on this number, as well. The number is **1-800-999-4910**.

CALENDAR OF EVENTS

If you want to know more about the CONFERENCES listed, please call the contact person listed below.

2/19 - 2/21: Social Role Valorization Workshop in the awareness of life's value, Lake Cumberland Leadership Training Center, Carrie Stith 606-257-5389.

3/1 - 3/6: PASSING, A week long workshop of training to evaluate services for persons with disabilities, contact Carrie Stith, 606-257-5389.

3/13 - 3/15: Parent/Professional Conference, $20 due to NKCES (Northern Kentucky Cooperative for Educational Services), Holiday Inn, Erlanger, KY. Contact: 606-525-8121, Sandy Teeters, 3573 Ridgewood Dr, Erlanger, KY, 41018. **THE DEAF/BLIND INTERVENTION PROGRAM CAN PAY EXPENSES FOR PARENTS TO ATTEND THIS CONFERENCE** contact Jennifer Leatherby 1-800-999-4910.

3/21 - 3/25: National conference on Deaf Blindness, Washington, D.C., contact Jennifer Leatherby 1-800-999-4910.

3/26 - 3/28: State of Kentucky C.E.C. (Council for Exceptional Children) Conference, contact Linda Elford, Campbell County Schools 606-635-2173.

4/24 - 4/26: Consumer Conference Adolescents and Young Adults with Ushers Syndrome, Holiday Inn at Hurstborne Lane in Louisville, KY. for additional information, contact Marie Ruf 502-897-1583 or Janis Friend at 606-255-1431 ext. 373. 4/25: (in conjunction with Consumer Conference) Parent Advisory Board Meeting 1:00 to 3:00 p.m.

5/15: Consumer Workshop, Cincinnati, Ohio: contact Patty Conway, ext. 7475 at Support Services for the Deaf, Vocational Rehabilitation, 1-800-372-7172.

8/14 - 8/16: Family Forum, Kavenaugh Center, Crestwood, KY, contact Jennifer Leatherby 1-800-999-4910 or 606-257-7909.

Usher's Syndrome Toll Free Information Resource

Usher's Syndrome is an inherited disorder characterized by hearing loss, present at birth or shortly thereafter, and a progressive loss of vision. The loss of vision is caused by (RP) retinitis pigmentosa, a degeneration of the retina. The retina lines the inside of the eye and acts like the film in a camera, receiving and processing what you see.

Many people with Usher's syndrome are born with profound deafness, while others have a mild hearing loss. In the overwhelming majority of patients, it appears that the hearing loss usually does not progress. One of the earliest visual symptoms is difficulty seeing at night and in dimly lit places. Later there is a loss of side vision, resulting in "tunnel vision". The visual symptoms of RP generally worsen over a period of years. Usher's Syndrome is often diagnosed in children and young adults. By then, the individual has been dealing with the hearing loss for some time.. Some may experience complete loss of sight later in life; however. many retain at least some residual vision, but have "legal blindness".

While there is currently no way to halt the degeneration of the retina or to restore normal hearing, some individuals with Usher's benefit from cochlear implants. Individuals should consult a neuro-otologist to determine whether or not they are candidates for this procedure. Those who have any degree of usable hearing with hearing aids are typically not candidates for the cochlear implant.

An accurate diagnosis of the hearing and vision loss is important. It should include audiometric tests, as well as special electrodiagnostic tests of retinal function, visual field and a thorough ophthalmological examination. A person with Usher's Syndrome can learn to cope with the vision problems by using a wide variety of low vision aids, reading machines, sunglasses, and talking computers. Dealing with the hearing loss may involve learning sign language or other communication skills and using hearing aids.

Information about Usher's Syndrome and resources for individuals with hearing and vision losses can be obtained from:

R. P. Foundation
1401 Mt Royal Ave., 4th Floor
Baltimore, MD 21217
1-800-683-5555 or 410-225-9409 (TDD)

Brothers and Sisters

Hints for Parents

The presence of a child with a disability in the family does not necessarily have a negative effect on siblings. This is according to Dr. Peggy Ogle and Dr. Thomas H. Powell in their book titled Brothers and Sisters. Children adjust well to the extra responsibilities and inconveniences that can occur when there is a child with a disability in the family, if given the opportunity to live in an open, honest and nurturing atmosphere. In fact, there is some evidence that siblings of children with disabilities who have been raised in an understanding environment demonstrate greater maturity, sensitivity, and resilience than the general population. Many eventually enter helping professions like medicine, teaching, and counseling.

Here are some suggestions for supporting siblings:

1. Encourage brothers and sisters to observe their sibling with a disability in therapy or special education class.
2. Don't overindulge siblings without disabilities in order to make up for the fact that they have a sibling with a disability.
3. Don't expect children to accept adult roles, particularly in caring for the child with a disability.
4. Set reasonable expectations for all of the children in the family and don't expect the children without disabilities to excel in order to compensate for the child with a disability.
5. Expect sibling rivalry. . . there will be jealousy and that is normal.
6. Do your best to integrate the whole family into activities early such as church, sports, music groups, and civic organizations.
7. Don't imply that children without disabilities have a lifetime responsibility to care for their brother or sister with a disability.
8. Network with another family who has a child with disabilities and whose siblings you admire.

For information, write to the following:

Siblings Understanding Needs (SUN)
Department of Pediatrics
University of Texas, Medical Branch
Galveston, TX 77550

Siblings for Significant Change
823 United Nations Plaza, Room 808
New York, NY 10017

Sibling Information Network
Department of Educational Psychology
Box U-64 University of Connecticut
Storrs, CT 06268

This newsletter is supported, in part, by the Hilton/Perkins National Program of Perkins School for the Blind, Watertown, Massachusetts. The Hilton/Perkins National Program is funded by a grant from the Conrad N. Hilton Foundation of Los Angeles, California.

The following quote, which can apply to all persons with significant disabilities, was taken from a book written by a native Kentuckian:

> "No joy runs deeper than the feeling that I have helped a youth stand on his own two feet, to have courage and self reliance, and to find himself when he did not know who he was or . . . . where he was going." by Jesse Stuart

I N S I G H T

Volume 3 Number 2
Jennifer Leatherby, Editor
Brenda Pezzarossi, Parent Coordinator
Summer 1992

It's Fathers Day!

More Fathering When You Are The Father of a Child with Disabilities

What is it like to be the father of a child with disabilities? Is this experience different because you are male? Why is it so demanding? What feelings are associated with drastic changes? Why is it so difficult? These questions can only be answered individually by each father and are probably different for each, but history and society have made many experiences more difficult.

The ways men approach the demands of parenting has changed incredibly during the past 20 years. Fathers are now present in the birthing room and during delivery on a routine basis. The family breadwinner was once the only role of the father. Roles of fathers, once limited, now extend to child caretaking tasks and responsibilities. Glenn Dearing must constantly balance his full-time job with his wife, Linda's job so someone can stay home to keep Chad, one of the youngest children on the state's Deaf/Blind census. Increasing numbers of men are choosing to stay at home while their wives pursue full-time employment.

Society instills in almost all men the notion that they must be strong, in-control, protective, competitive, rational, and be able to solve all problems. Their stories differ, but all share the theme of the strong man's craving to feel more dominant. We still read about it in the newspaper story lives of sports heros like Magic Johnson, and Muhammad Ali, and the late Lyle Alzado.

There may be nothing inherently evil about the role of the male as strong man, however it does not work well when you have a child with a disability. Research indicates that the divorce rate hovers around 85 percent when the family must cope with chronic disability of any kind. The pressure of concealing pain and weakness ultimately crushes the soul of even the strongest man. Dads can no longer protect their family from problems or control outcomes. A father's self-sufficiency often means they do not know what to do with the powerful feelings that rage inside them.

The intense stress in the family of a child with a disability can leave a father depressed, weak, guilty, powerless, and very angry. A father's self esteem may be at risk. The man's dreams of namesake, ego fulfillment, athletic, and career achievement, are all threatened. Even fathers who are quite uninvolved with their children will feel the loss more profoundly than men two generations ago.

The needs of all family members are in balance with each other. These needs are complicated, interdependent, and in constant change. Having a child with a disability changes the balance and places extreme constant pressure on the family. Communication becomes strained and finances may be reduced. Outside help and even assistance from relatives may be limited. All family members may feel isolated and neglected. Research indicates that fathers of children with disabilities have universal feelings of failure and guilt. For many men, it is difficult to accept the reality of the situation. Men who may have gotten pleasure from athletics, may be embarrassed by their child's physical appearance or lack of development.

Many fathers of children with disabilities are discovering they don't need to be limited by what they "should" be. They gain an understanding of the importance of bonding with all their children. Cheryl, the daughter of Ruldolph Spinks, believes that her close relationship with her father is due, in part, to her brother's severely handicapping condition.

Some men still have limited perceptions of the roles they can play regarding their children.

Continued on Page 2

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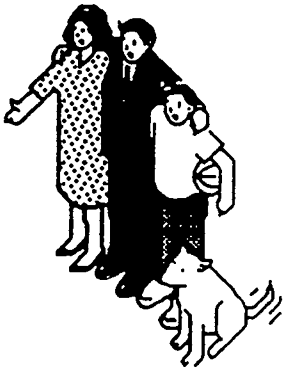
However, these roles take on new meaning if the child has a chronic illness or a disability. Bob Moore, whose 10 year old son has Cerebral Palsy, mental retardation, and chronic health-care needs, has redirected his life into making legislative changes. Being the father of a child with disabilities may dramatically change your philosophy of life if you choose to recognize its value. A father may choose to accept the realities of the problems at hand, and become an active problem-solver for their child's needs.

Changes are made, but not without stress and confusion. Men are being confronted with inadequate role models, a lack of child-rearing information and education, and a set of values needing change. Fathering is an old game, now played with new rules. When you are the father of a child with disabilities, there has to be more fathering. The fathers that stick with this really find the true meaning of being a father. Congratulations, fathers!



Advice from Famous People

"The greatest thing a parent can give their child is freedom. . . . "**Stevie Wonder**

"While they were saying among themselves, 'it can not be done, it was done'. . . "**Helen Keller**

"Keep your face to the sunshine and you won't see the shadows. . . "**Helen Keller**

"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 capabilities. . . "**Helen Keller**

REMEMBER....
MARK YOUR CALENDARS!!!

The Annual Family Forum for families of children with dual sensory impairments will be August 14-16 at the Kavanaugh Center in Crestwood, Kentucky (35 miles from Louisville). All families of children with dual sensory impairments are invited to this wonderful weekend of fun and learning. Expenses are paid for each family to attend through the Hilton/Perkins National Program. See enclosed registration form and return it as soon as possible.

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Different Is Good!

by Brenda and Arby's

After buying a soft drink last week, I had one of my rare profound thoughts. Apparently, the Arby's high corporate executives must now be the parents of a child with disabilities.

Arby's new plastic cups say, "DIFFERENT IS GOOD". They count the ways you can eat different fast foods. They ask, 'How to be different'? Their plastic cup lingo says, 'burgers are the same - Arby's is different. Hey! Different is Good!'

As the parent of a child who is viewed as different, maybe I should go into advertising. There is certainly a need to sell my product to the public schools, where my child needs to be successful at learning differently.

Businesses definitely have a long way to go before my product can be equally employable.

Continued on Page 3

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Maybe I need to sell my product, with a catchy slogan, to the business world, where this aspiring young adult will need to be viewed differently. Let's advertise. Hey! Different is Good! Who has the patent for this? Don't we? We were different first!

Excerpts from A Personal Futures Planning Project Interview conducted by Brenda Pezzarossi

Words of Wisdom

by Sylvia Shacklette

"To tell about James, it'd be a long story. It'd be a book. I think I could write a couple of books, a book on nursing and a book on this. People should really know what 'supposedly educated professionals' say to parents when they have a handicapped child. They might not do it now, but I know they have done it before."

"I've been told things like, 'He's retarded!', 'Put him in a home.', 'He'll never be able to put his clothes on.' 'He'll never be able to tie his shoes.' 'He'll never be able to do anything.' 'He'll just be a vegetable.' 'You'll get a check for him, so you shouldn't worry about trying to educate him and send him to school.'"

"I've been through all kinds of stuff like that, from the time he was a little baby, by and from educated, professional people."

"I'll never forget when he was a little eighteen month old baby, sitting in the middle of the floor, playing . . . with whatever he could touch because he couldn't see anything then either. One of them told me and I'll never forget it (she was going to be a professor at the University of Louisville) and she said, 'Oh, Oh, he's retarded!' James couldn't see or he couldn't hear and he was sitting in the middle of the floor. What is he going to do? Get up and write a book? I thought, 'this woman is crazy!' She didn't even touch him, didn't examine him or nothing. . . just told me he's retarded. 'He's going to have to be put in a home. He will never do this and he'll never do that.'"

"If you take a child who is not retarded and put him in an environment. . . with only children who are retarded, he is going to do just what the other children doing. I said, 'no, James is not retarded! He is a deaf and blind child.' I want to forget about it. I just want to forget about it. At least, that's the way I feel!"

"We've always tried to treat James just like anybody else. He's not handicapped to us and he isn't handicapped to himself, because he doesn't know it any different. When he needed a spanking, he got it. When he needed to sit in a corner, he got it . . .just like the other children. I didn't make different care or treatment for him. Because of that, he is like he is."

"I don't feel that I could do any more, any better than what I have already done. I brought him along doing things when they told me he was a vegetable. There is nothing anyone can say about what I did for him because I have already done it. . . me alone. What I do for him or what I do with him is a continuation of what I have have been doing. There are no extras. It is just what I have been doing all along."

"James doesn't communicate, but you can look at his facial expressions and tell how he feels. If he has a glum look on his face then I know he wants to leave the room. If you're going to go with me, you have to accept James. I never let anybody say a 'poor little this or poor little that' about him. When he can't go, I say, 'This time we'll watch it on television, pop some popcorn, and make some punch and maybe next time you can go.' James understands. He is very independent. That's a good way to raise him, as independently as possible."

"When I was younger and kind of shy, I wouldn't speak out. But now, I don't care what it is. . . if he has a fingernail broken and I don't know how it happened I say, 'Hey, come here, James got his fingernail broken, could you tell me how this happened?' Being outspoken is better than standing back waiting and listening."

"It's a lot better now. They're doing a good job with him. Now he is just leaping! I want what is best for James. Whatever comes, whatever happens . . . we'll just take one day at a time. You can not plan on a whole lot for the future because it might not go right. We mostly just plan 'one day at a time' and see how that works out and we go on from there."

Personal Futures Planning Meetings

(Some of Sylvia's thoughts)

"Each time we go, they (the meetings) get better and better. All his teachers are there and everyone who works with James is there. We just have good meetings. I can't find any fault with them right now at all. It couldn't be any better. We enjoy each others' company. We all get along.

Concerning other meetings, very few meetings are pleasant. You dread going and you dread being there and you're glad to leave. With our futures meetings, we all communicate with each other. There is something **"alike"** there. You have to be there to feel it and see it to know what's going on. It is just nice and I look forward to going to them. I look forward to seeing all the teachers and greeting each other. It is just pleasant.

We suggest different things that we feel will be beneficial to James. They are written on the board and we either agree or disagree with them. We all finally agree on them; if we don't agree then they're erased off. We don't plan a whole lot of things. It is just a few things at a time that we feel James can accomplish.

Each person has their own thing that they do. They communicate between each other about what you are doing and what they are doing and what I am doing. so that everyone knows what everyone else is doing. Let them continue working as they are with me because I think it is beautiful."

* * *

Selected Parent Quotes

"Parents are the first teachers of their children."

"Parents are the long lasting resource and the only consistent persons who continually have their child's interest at heart throughout their lifetime."

"Carry a brief case, have a list of questions and dress like you are going to an interview even though it's an IEP."

"There is no right or wrong way to teach your child independent living skills."

"Feelings of anger and frustration may never go away, but you can find a different and rewarding focus."

SOURCE: NAPVI, 2180 Linway Dr., Beloit, WI 53511

CRISIS LINE

NEW! HELP! TOLL FREE!

Call 1-800-365-3586 and "call forwarding" will take your call directly into the home of another parent who may or may not be in crisis also. We probably will not have the answers, but we have most likely had a similar crisis.

LETTER TO PARENTS

by Stephanie Hallum

Dear Parents,

I am hard of hearing and my left ear is deaf and my right ear is good with a hearing aid and not without it. When I am wearing my left ear hearing aid, I can hear some, but I can't understand people who are talking. I am going to tell you how a deaf parent can raise hearing kids.

When I have a baby, how would I hear the baby cry at night or during the day? During the day, I will use a monitor with high volume. At night, it is easy because the cry alarm and the light will flash on and off. It will wake me up.

How could kids know how to talk? When the baby turns one year old, ask some family member who will work with the kids. When you take them to day care, the day care worker will work with them. Ask someone who can talk and sign. For example, I have a great aunt who is deaf and she had a hearing daughter. My aunt's mom and my aunt worked with my cousin (my aunt's daughter). My aunt's mom taught her to talk and my aunt taught her to sign.

Continued on Page 5

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There are many people asking me, "Can deaf people drive? Yes, people who are deaf can drive. But they can't hear? All they have to do is to use their eyes and they have to look at the car mirror all the time to see the car behind. What is the police came and the light is on? Deaf people have to look at the car mirror lots more than hearing. But they can't hear and must use their eyes.

How do deaf people communicate with people? They had to write me on paper and give it to people who they are talking with on the paper. Deaf people have to write with good English.

Deaf people can get jobs, drive, do many things. I would like to show you how I can know my deaf friends. Before I learned the sign language, my friend's name was Dara. She and I had to write because I couldn't sign yet. Here is what Dara and I were talking on paper.

Hi! My name is Stephanie. What is your name?

My name is Dara and I'm glad to know you. I will teach you to sign. I know lots of it. So do you want to learn?

Sure, I would like to because lots of my friends are deaf. I don't want to write all the time.

I agree with you.

See, that is so easy to write unless you know the signs. I started going to KSD when I was seven years old and didn't know the sign language until I was nine years old. But my speech was not very good. Now I am eighteen years old and I am improving my speech because I am in KSB now. I am very happy here at KSB, but I do miss KSD.

Well, if you have any questions about deaf people, please let me know. I will be happy to answer your questions. But I may not know all the questions. I will try to answer. Well, bye for now.

Sincerely,
Stephanie Dawn Hallum

FYI CORNER

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UK Special Education Department
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(606) 257-7909 *

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Helen Keller Affiliateship
Janis Friend
Dept of Vocational Rehabilitation
627 W 4th St
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(606)255-1431

Systems Change Project
Dr. Harold Kleinert or
Jacque Farmer
UK Interdisciplinary Human Development
114 Mineral Industries Building
Lexington, KY 40506-0051
(606)257-3045 *

Amy Reber
Associate Director
501 Farrell Drive
Covington, KY 41011
(606)331-7742 (wk) - (513)231-8454 (hm)

Personal Futures Planning Project
Carolyn Wheeler or
Cynthia Vaughn, Parent Coordinator
1867 Frankfort Avenue
Louisville, KY 40206
(502)894-9366 *

Brenda Pezzarossi, Parent Coordinator
UK Human Development Institute
114 Mineral Industries Building
Lexington, KY 40506-0051
(606)257-3586 or (606)272-1992 *

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PARENTS, YOU CAN HELP MAKE SCHOOL DECISIONS!

Welcome to the team! Educators have known for a long time that children do better in school when parents are involved. Now KERA, Kentucky Education Reform Act of 1990 makes parents full partners in the improvement of education. Your local school will become the place where most school decisions will be made.

This new KERA management process is referred to as 'School-Based Decision Making'. It is also called a school council and/or site-based team management. By June 30, 1991, each school district must have at least one school using this team management. All schools in our state must be managed by school councils by July 1, 1996.

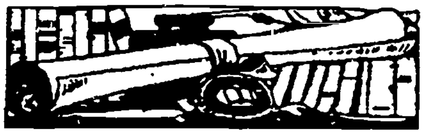
The Kentucky Education Reform Act sets each school council membership at six: the principal, three teachers (elected by teachers) and two parents (elected by parents). Schools can design a different structure for their council membership, but only with permission from the state department. For example, a larger school might choose to double their council to twelve members.

Parents, especially those of children with disabilities, must be involved so the school doesn't leave them off the team. There are only two parent openings for each school council. No spot is designated on the council for parents of children with disabilities.

Parents of children with disabilities can help make school decisions. In order to be eligible to be elected to the local school council, parents of children with disabilities must become active in their local PTA. What if you're too tired? Find respite care and set aside the PTA night to make your school better at offering a good education for your child.

For more information, contact Bill Stearns, Division of School-Based Decision Making, 18th floor, Capital Plaza Tower, Frankfort, KY 40601, (502) 564-4201

SOURCE: FOCUS on Diverse Learning Needs, Feb. 1992



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✉ ✉ ✉ ✉ ✉ ✉

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Parents Confronting Dual Sensory Impairments (PCDSI)

The Founding Committee includes the following individuals: Sharon Cole, Marna Miller, Jennifer Leatherby, Brenda Pezzarossi, Cecelia Snellen, Bob Moore, Glen Dearing, Margarita Arnett and Greg K. Whittington.

For further information call 1-800-999-4910.

CALENDAR OF EVENTS

If you want to know more about the **CONFERENCES** listed, please call the contact person listed below.

June 4-5: **Best Practices Annual Conference** - "Supporting People in the Community", Campbell House, Lexington, KY, contact Carrie Stith 606-257-1714.

July 13-17: **Summer Institute** - "Issues Regarding Students with Dual Sensory Impairments", Springs Inn, Lexington, KY, contact Jennifer Leatherby 1-800-999-4910 or (606) 257-7909.

August 14, 15, & 16: **Family Forum,** retreat location near Louisville, contact Jennifer Leatherby 1-800-999-4910 or (606) 257-7909.

Sept. 17 & 18: **KAAMR/KY TASH** Fall Conference, Holiday Inn South, Louisville, KY, contact Carolyn Wheeler (502) 894-9366.

Sept. 24 - 26: **Aging/MR SIG Annual Conference**, Lexington, KY, contact Jim Stone (606) 257-5244

HAPPY 4TH OF JULY

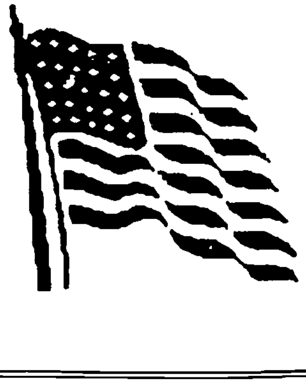
Kentucky Early Intervention System April Update

The Secretary of the Cabinet for Human Resources, Leonard Heller, spoke at the March 31st meeting of the Infant-Toddler Interagency Coordinating Council in Frankfort. He voiced his support and encouragement for interagency coordination and collaboration for services for Kentucky's children and their families.

A resolution sponsored by Senator Gerald Neal in the Senate and Representative Tom Burch in the House supporting Early Intervention was signed by the Governor March 31st. Anyone interested in that can get copies by calling 502-564-8100 ext 323 and asking for Senate Joint Resolution #67 and/or House Joint Resolution #94.

The Extended Participation Application is expected to be out for public comment April 15th. Your Regional MH/MR Board office will have copies. Please let state staff know if there's any problem accessing this application (502-564-7700). Hearings will be held to allow input.

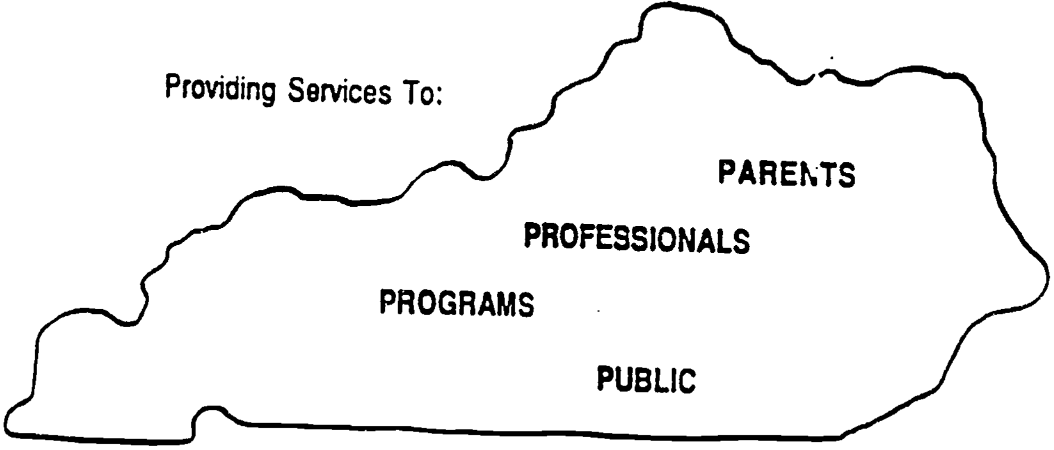
This newsletter is supported, in part, by the Hilton/Perkins National Program of Perkins School for the Blind, Watertown, Massachusetts. The Hilton/Perkins National Program is funded by a grant from the Conrad N. Hilton Foundation of Los Angeles, California.



Deaf-Blind Intervention Program
229 Taylor Education Program
Department of Special Education
University of Kentucky - 00010
Lexington, KY 40506-0001

THE DEAF-BLIND INTERVENTION PROGRAM

Providing Services To:



REMOVE AND POST FOR YOUR INFORMATION AND AVAILABILITY

AREA RESOURCES

ACCESS, 350 Elaine Dr., Suite 203, Lexington, KY 40504, (606) 281-2106 or (606) 233-0444

AER, Association for the Education and Rehabilitation of the Blind and Visually Impaired, Darlene Middleton, (502) 897-1583

ARC/KY, Bluegrass Association Association for Retarded Citizens, 898 Georgetown St., Lexington, KY 40511, (606) 233-1483 or Marie Allison (502) 564-8006

Bluegrass Regional Mental Health-Mental Retardation Board, Inc., 1351 Newtown Pike, Lexington, KY (606) 253-1686

Bluegrass Technology Resource Center for People with Disabilities, 894 Georgetown St., Lexington, KY 40511, (606) 255-9951

Partnerships for Productivity, 1664 Brentmoor Dr., Lexington, KY 40515, (606) 271-3482

PUNCH, Parents Understanding the Needs of Children with Handicaps, Keith Adams, (502) 554-5006

Rehabilitation Engineering, Barney Fleming, Department of Special Education, University of Kentucky, 229 Taylor Building, Lexington, KY 40506-0001, (606) 257-4269

YWCA-Lexington, Activities for Persons with Disabilities, Tanya Supplee, (606) 276-4457

STATEWIDE RESOURCES

Compliance Monitoring in Education, Kentucky Department of Education, Charlotte Kirk, (800) 252-7776

Employment Consulting, P.O. Box 22638, Louisville, KY 40252, (502) 426-3261

KATS (Kentucky Assistive Technology Service) (800) 327-5287

Kentucky Commission on the Deaf and Hearing Impaired, Bill Rogers, (800) 372-2907 or (502) 564-2604

KDC, KY COALITION FOR PEOPLE WITH HANDICAPS - Ann Hancock (502)875-1871, Gail Lincoln (606)784-7580.

KY. SPECIAL PARENT INVOLVEMENT NETWORK - KY-SPIN Paulette Logsdon, parent information 1-800-525-SPIN or (502)589-4717.

KY TALKING BOOK LIBRARY for service information 1-800-372-2968.

PCDSI (Parents Confronting Dual Sensory Impairments), Sharon Cole (502) 276-3306, Brenda Pezzarossi, (606) 272-1992 or (800) 365-1258

Parent Resource Centers, Community Education/Family Support Branch, Kentucky Department of Education, Frankfort, KY 40601, Jacque Hukill and Linda Miller, (800) 252-7776

PRESCHOOL - KY DEPT OF ED for ages 3 - 5 Debbie Schumacher, (502)564-4970.

PROTECTION & ADVOCACY, 1264 Louisville Rd., Frankfort, KY - Help with legal rights of disabled children and adults 1-800-372-2988.

Prichard Committee for Academic Excellence, P.O. Box, 1658, Lexington, KY 40592-1658, (800) 928-2111

TASH, The Association for Persons with Severe Handicaps, Carolyn Wheeler, (502) 894-9366

VIPS, Visually Impaired Preschool Services, Sharon Bensinger, (502) 636-3207

NATIONAL RESOURCES

APSE, Association for Persons in Supported Employment, 5001 W. Broad St., Suite 34, Richmond, VA 23230, (804) 282-3655

HKNC-TAC, Helen Keller National Center-Technical Assistance Center, 111 Middle Neck Road, Sands Point, NY 11050-1299, (516) 944-8900 (Voice/TDD)

National Camps for Blind Children, 4444 S. 52nd St., Box 6097, Lincoln, NE 68506, (402) 488-0981

National Father's Network, 16120 NE Eighth St., Bellevue, Wash. 98008, (206) 282-1334

NAPVI, National Association for Parents of the Visually Impaired, 2180 Linway Dr., Beloit, WI 53511, Barbara Auletta (800) 562-6265

NICHCY (National Information Center for Children and Youth with Disabilities) 1-800-999-5599.

NPND, NATIONAL PARENT NETWORK ON DISABILITY, Alexandria, Virginia. Help to apply, in behalf of your child, for Supplemental Security Income (703)684-6763.

OTHER RESOURCES FOR PARENTS

ASSESSMENT FOR CHILDREN WITH DISABILITIES - Kaye Langer (606)257-4644, Pat Berdine (606)257-1254.

ADVOCATE FOR DEAF-BLIND PERSONS - Cherry King (502)839-7556.

CONSULTATION FOR ATTENTION DEFICIT DISORDERED CHILDREN, Bobbie Burchan (606)257-7372.

DIRECTIONS - information about services for the disabled, Karen Stone & Dawn Jacobs, Parents: 1-800-234-0497.

INFANT TODDLER PROGRAM for infor. birth - 2 years, Marge Allen (502)564-7700.

PAWS WITH A CAUSE - newest unfunded model program to train companion dogs for disabled, Kim Rosenberg (606)873-4271.

SKI-HI Help for parents with young hearing impaired children Andy Hensley (606)357-7939.

INSIGHT

Volume 3 Number 3
Brenda Pezzarossi, Parent Coordinator
Jennifer Leatherby, Editor
Fall 1992

In Celebration of Grandparents Day!
September 13, 1992
by Brenda Pezzarossi
Parent Coordinator

A GRANDMOTHER'S STORY
told by Brenda Browning
Winchester, KY

Leslie is a beautiful, loving, and gentle child who is now six years old. At two months of age, doctors stated the medical facts and said, "She will not live past one year." Since Leslie required 'round the clock" care, the hospital would not let us bring her home. Leslie was placed in a nursing home for eight days. She nearly died several times, but they brought her back.

By three months, Leslie was sent to the Children's Hospital in Cincinnati where a gastrotomy tube was inserted because she can not swallow. A tracheostomy tube was inserted to help her breathe. This helped us to get the secretions out of her lungs. Leslie's medical history describes Leslie as being a quadriplegic who is deaf and blind.

We describe Leslie as being able to move her arms and legs, not as being paralyzed. Leslie does have some head and trunk control, but tires easily. Of course, she can not crawl or walk, but 'she moves'! We describe Leslie as having some vision and hearing which is limited, not as being totally deaf and blind.

Doctors told us Leslie would be a "vegetable" mentally. We know Leslie understands when people talk to her. She can discriminate between people and things she knows and likes and those which she does not like. We see Leslie answering questions and making choices between two objects by using her eyes to blink. Leslie tells us, by the movements she makes, when she wants to get up.

She does not like for you to talk about her and lets you know it. Leslie loves music, except for classical violin. She enjoys riding the school bus and going to school, but she gets bored easily. She has a school bus aide and a classroom aide of her own and we send her suction machine to school for them to use.

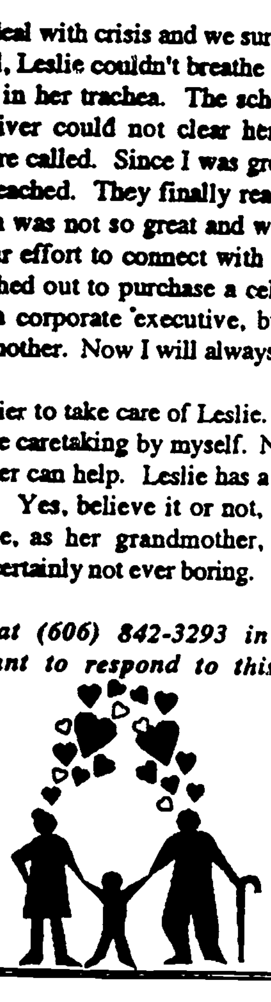
Leslie does not require constant care and attention. Life with Leslie is a challenge, but dealing with an inhuman suctioning machine is even more of a challenge. I have had to pick Leslie up at school several times because her suction machine has gone dead. When the suction machines goes dead on the bus, it scares everyone.

Besides calling me Leslie's Grandmother, just call me the Chief Mechanical Engineer for Suctioning Machines. Four years ago, I couldn't fix anything, but this past weekend, I managed to rig up an adapter which will run off a cigarette lighter. It has now been installed on Leslie's school bus to keep her suctioning machine working. My next invention will be a fan, which can run off the cigarette lighter, to keep Leslie cool because the school bus stays too hot for her.

We routinely deal with crisis and we survive! The second week of school, Leslie couldn't breathe because of a plug (dried mucus) in her trachea. The school bus aide and school bus driver could not clear her trachea, so the paramedics were called. Since I was grocery shopping, I could not be reached. They finally reached me, but the communication was not so great and we wasted a lot of time during our effort to connect with each other. The next day, I rushed out to purchase a cellular phone, not because I am a corporate executive, but because I am Leslie's Grandmother. Now I will always be within reach.

It is getting easier to take care of Leslie. Four years ago, I did most of the caretaking by myself. Now, my thirteen year old daughter can help. Leslie has a stepmother who helps out a lot. Yes, believe it or not, it is easier now. Life with Leslie, as her grandmother, is challenging, rewarding, and certainly not ever boring.

Call Brenda at (606) 842-3293 in Winchester, KY if you want to respond to this article.



Change in the System by and for Parents

The Commission for Handicapped Children, when conducting eligibility requirements for children with medical needs, no longer has to consider step-parents income in their eligibility formula for services. The income of step-parents is no longer considered because a mother named Sharon Cole litigated for her daughter, age three at the time, to be eligible. A parent was responsible for getting these Kentucky state guidelines changed!

Contact Sharon at (502) 276-3306 for details.

* * *

It's Whitney's First Day of School!

September 14, 1992

told by Paulene Lewis, Mother
written by Brenda Pezzarossi, Parent Coordinator

I got up and started getting everything ready for Whitney to go to school. I was hoping the morning wouldn't be too cool, and it was a warm morning. I went to get Whitney and she was laughing and seemed really happy. Sometimes she cries when she gets up, but she didn't this morning and she did not go to bed until 10:00 PM the night before. Whitney was happy! It was 8:00 AM and we had to be there at 9:00 AM. I fed her, got her all ready, and dressed her in pink. Whitney looked really pretty. She always looks good in pink. We were all ready by 9:00 AM. Whitney's Pa & Ma Lewis came and picked us up to take her to Head Start in Pittsburg, Kentucky.

When we got there, the teacher, Ms. Morgan, and her aid, Mary, met us at the door. The class was filled with boys and girls all having fun. It was a few minutes and then we had to get Whitney's picture taken. We did and went back to the classroom to start the day. Monica is one lady who worked with Whitney for awhile. Whitney was listening to all the sounds all around and having a time.

The boys and girls had wondered, "Who is Whitney?" They were coming around her, seeing her, laughing, and talking away. Even though they saw that Whitney was in a wheelchair, the kids knew she could still have fun. They rubbed her hands and talked to her. The teacher, Ms. Morgan, told the class that Whitney is their new classmate. She said for them to watch her and to try not to be so loud. She explained it is because Whitney gets scared sometimes. She also said, "Sometimes Whitney needs to rest and lie down for a bit." One little boy asked, "Why is Mary feeding her with a bottle?" She said, "You know how you have muscles in your mouth to help to drink and eat? Well, Whitney's muscles are not very strong right now and she drinks from a bottle." That was okay!

The teacher got everybody into a circle and played some music. She told them about what happens when you go see the doctor and what they do. The boys and girls were full of all kinds of ideas. Soon it was time for recess. They wanted to go out and play, but workers were putting a fence around the playground. The children could not play that day, so they played inside. Mary, her aid, just took Whitney for a walk. Whitney loves it when you walk her around.

It was getting time for everybody to go to lunch. Whitney had been so excited, but now she was getting sleepy. The boys and girls went to lunch and we started out on our way back home. Whitney was asleep by the time we drove out of the parking lot, but she did have a very good day. This was a very happy little girl. That was Whitney's first day of school at Head Start.

* * *

The Americans with Disabilities Act A Glance at Effective Dates of Federal Law

SERVICES

Effective Date: January 26, 1992

Key Requirement: Public services, programs, or activities including state and local governments and Amtrak, cannot discriminate on the basis of disability. Almost all community services available to the nondisabled public must now be equally available to individuals with disabilities.

Comment: Section 504 of the Rehabilitation Act originally covered recipients of federal funds; however, this section of the ADA broadens coverage to include government facilities, services and communications, even if they are not recipients of federal funds. Local and state government is required to ensure that emergency telephone numbers to police and fire departments can be used by people with speech and hearing impairments.

Key buzzword: "Title II"

ACCOMMODATIONS

Effective Date: January 26, 1992

Key Requirements: Public accommodations, such as restaurants, theaters, hotels, stores, museums, libraries, doctor's offices, parks, zoos, video libraries, auditoriums and day care centers, can not discriminate on the basis of disability. Auxiliary aids and services must be provided to individuals with vision or hearing impairments so that they can have an equal opportunity to participate in or benefit from services.

Key buzzword: "readily achievable."

Condensed by Brenda Pezzarossi from a handbook from the *Texas Young Lawyers Assoc., P.O. Box 12487, Austin, Texas, 78711, (512) 463-1446*, for more ADA glances, call (606) 257-3586, (800) 356-1258

AREA RESOURCES

ACCESS, 350 Elaine Dr., Suite 203, Lexington, KY 40504, Sue Hicks, Director; Nancy Chesser, Assistant Director (606) 281-2106, connects services with people with disabilities in 17 KY counties.

ARC/Bluegrass, 898 Georgetown St., Lexington, KY 40511, Roger Hartner, Director (606) 233-1483

BET, Bluegrass Employment & Technology, supported employment/assistive technology, (606) 281-2106

Bluegrass East, 201 Mechanic St. Lexington, KY, 40407, crisis intervention & counseling (800) 928-8000

Bluegrass Regional Mental Health-Mental Retardation Board, Inc., 1351 Newtown Pike, Lexington, KY 40511, Joe Toy, Executive Director (606) 253-1686.

Bluegrass Technology Resource Center for People with disabilities, 169 North Limestone St., Lexington, KY 40507 (606) 255-9951

Center for Independent Living for the Visually Impaired, 620 South Third St., Betty Gissoni, (502) 595-3143

Department for the Blind, 201 Breckinridge Lane, Louisville, KY, Mike Becker, Manager (502) 897-9475

PUNCH, Parents Understanding the Needs of Children with Handicaps, Western Kentucky Region, Keith Adams, (502) 554-5006

Rehabilitation Engineering, Barney Fleming, Department of Special Education, University of Kentucky, 229 Taylor Building, Lexington, KY 40506-0001, (606) 257-4269

YWCA, Lexington, KY, Activities for Persons with Disabilities, Tanya Supplee, (606) 276-4457

STATEWIDE RESOURCES

AER, Association for the Education and Rehabilitation of the Blind and Visually Impaired, Kirsten Schmidt, Vocational Evaluator/Orientation & Mobility Instructor, Work (502) 595-4861, Home (502) 456-4758

ATUG, Assistive Technology Users Group, Dianna Jenkins, Rick Roderick, Jim Lepping, Louisville, (502) 893-0211,Bulletin Board Numbers (800) 242-0490, (502) 896-0022. (502) 894-0393

Commission for Handicapped Children, 982 Eastern Parkway, Louisville, KY 40217-1597, (502) 588-3264

Department for the Blind, Central Office, 427 Versailles Rd., Frankfort, KY, Priscilla Rogers 40601, (502) 564-4754, FAX 502-564-3976.

Developmental Disability Planning Council, Leestown Square, Frankfort, KY, Prudence Reilly, Executive Director, (502) 564-7700; for Grants Dept. MH/MR, contact Mr. Robin Sims (502) 564-7841

Early Childhood Division, Programs for Children with Disabilities: Ages 3-5, Capitol Plaza Tower, 12th Floor, Frankfort, KY 40601, (502) 564-7056

Educational Compliance Monitoring, Kentucky Department of Education, Frankfort, KY, Charlotte Kirk, (800) 252-7776

Employment Consulting, Milton Tyree, P.O. Box 22638, Louisville, KY 40252, (502) 426-3261

KATS, Kentucky Assistive Technology Service, 427 Versailles Rd., Frankfort, Ky 40601 (800) 327-5287.

KDC, Kentucky Disability Coalition, 859 E. Main, Frankfort, KY 40601, Ann Hancock (502) 875-1871; Gail Lincoln (606) 784-7580

Kentucky Commission on the Deaf and Hearing Impaired, Bill Rogers, (800) 372-2907

Kentucky Rehabilitation Center for the Blind, 1900 Brownsboro Rd., Louisville, KY, H.D. Wilson, (502) 895-5489

KY Easter Seal Society, 233 East Broadway, Louisville, KY 40202, Becky Dausman, Director (502) 584-9781

KY/Speech-Language-Hearing Association, P.O. Box 4098, Lexington, KY 40544, (606) 277-2446

Parent Training Information Project, KY/SPIN, Kentucky Special Parent Involvement Network, 318 West Kentucky St., Louisville, KY 40203, Paulette Logsdon, (800) 525-7746, (502) 589-5717, (502) 584-1104

Parent Resource Centers, Community Education/Family Support Branch, Kentucky Department of Education, Frankfort, KY 40601, Jacque Hukill and Linda Miller, (800) 252-7776

PCDSI, Parents Confronting Dual Sensory Impairments, Sharon Cole, President (502) 276-3306, FAX (502) 276-9516, Rudolph Spink, Vice President (502) 538-7578, Brenda Browning, Sec. (606) 842-3293, Marna Miller, Treas. (502) 459-1227, Brenda Pezzarossi, Parent Coordinator, (800) 365-1258

Prichard Committee for Academic Excellence, P.O. Box, 1658, Lexington, KY 40592-1658, (800) 928-2111

Protection & Advocacy, 1264 Louisville Rd., Frankfort, KY 40601, (800) 372-2988 or (502) 564-2967

SKI-HI, Help for parents of young hearing impaired children, Andy Hensley (606) 257-7939

TASH, The Association for Persons with Severe Handicaps, Cynthia Bayes, (502) 459-5292 or (502) 241-1637

NATIONAL RESOURCES

APSE, Association for Persons in Supported Employment, 5001 W. Broad St., Suite 34, Richmond, VA 23230, (804) 282-3655

Family Consortium Project, Division of Residential Services, 35 E. Chestnut St., 5th Floor, Columbus, Ohio 43266-04125, (614) 466-3814 to find out how to create a place to live in your own community.

Hadley School for the Blind, 700 Elm St., P.O. Box 299, Winnetka, IL 60093-0299, (708) 446-8111 for tuition free home study courses accredited by the North Central Association of Colleges since 1978.

HKNC-TAC News, Helen Keller National Center-Technical Assistance Center, 111 Middle Neck Road, Sands Point, NY 11050-1299, Jane Everson, Director, (516) 944-8900 (Voice/TDD)

JAN, Job Accommodation Network, President's Committee on Employment of People with Disabilities (800)-JAN-7234 or (202) 376-6200 (voice), (202) 376-6205 (TDD), (202) 376-6219 (Fax)

NAPVI, National Association for Parents of the Visually Impaired, 2180 Linway Dr., Beloit, WI 53511, (800) 562-6265

NATIONAL PARENT NETWORK, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050, write c/o Nancy O'Donnell or call (516) 944-8900 to be placed on newsletter mailing list.

NICHCY, National Information Center for Children and Youth with Disabilities, Interstate Research Associates, 7926 Jones Branch Drive, Suite 1100, McLean, Virginia 22102-3364, (800) 999-5599

***Please call Brenda at (606) 257-3586, (606) 272-1992, and/or 1-800-356-1258 to update.**

The Parent's Role in the Interagency Individual Transition Planning Team

by: Ron Harrison and Brenda Pezzarossi

Young adults who are deaf and blind (hearing impaired and visually impaired) need options after high school. They need assistance to plan for their desired outcomes during their high school years. These students need integrated community employment and community living choices. Transition is a lifelong process. The goal is to obtain the highest quality and dignified life style for an individual with a disability. This article will address the school to work phase of that process, bridging the gap between when school services end and when "getting a life" in the adult world begins.

Who can initiate an interagency team?

Legally, the Admissions and Release Committee is required to initiate the transition teams; however, parents can and should be active initiators of these efforts also. Parents are long term advocates focused on the individual needs of their son or daughter. Parents need to recognize the potential of an interagency planning team to address the future of their child. Parents can effect quality adult outcomes! An interagency team can identify existing services and plan and develop more or new individualized services and supports for the child.

Once again, it is true that the 'early bird gets the worm.' Education is an entitlement, but adult services are not. Adult services are not mandated by a law which states that each person with a disability shall receive free and appropriate services according to their need. Access to adult services can take years of simply waiting at home while the name of your son or daughter climbs to the top of service provider lists. Your son or daughter may 'fall through the cracks', if transition planning does not occur.

Who should be on the team for your son or daughter?

It's like baseball. You'll need someone to cover home (food, clothing, shelter), someone else to keep pitchin' (calling meetings), people on at least three bases (out there lookin' and catchin'), a couple of people at short stop (tutors or job coaches), and big people in the field (usually left field has more money). Be thinking of who can substitute and invite them if attendance drops off. For a positive outcome, you must have representatives from many creative forces that could play a role in reaching transition goals.

Try to find agency professionals who have a positive vision of winning. Invite school professionals who have been the most supportive for you and your son or daughter. Invite the administration from your school. An interagency team might have any of the following members as needed: the school guidance counselor, the principal, a couple of special and/or regular education professionals, therapists (O.T., P.T., Speech, Auditory, Vision), a vocational rehabilitation professional, a supported employment specialist, a vocational/ technical schools professional, an independent living specialist, a college disability specialist, a community employer, and/or a work adjustment counselor. Most importantly, the individual transition team includes the focus person, his or her family, and any relatives or significant others in his or her life.

How will the actual invitations be issued?

The school typically issues the invitations. If your young adult is already in his/her last years of school, you may inquire to see if the school needs your assistance in order for the team to be formed. You may also suggest that the school could telephone or meet with department heads, directors, specialists, or other leaders of identified programs and agencies to discuss the most convenient time and location for them. Nice hand written letters to the key decision-makers, with a signature of the person for whom the meeting is being held, is a great idea. Most professionals appreciate personal invitations.

What will the letter of invitation say?

Briefly describe the interagency transition meeting, need, and why it is important to your son or daughter. Give the meeting date, time, and location with directions, and a contact person for responding or for more information. If possible, enclose a copy of the specific agenda.

Sample Agenda - INTERAGENCY INDIVIDUAL
TRANSITION TEAM MEETING

Welcome by Team Initiator
Introductions (Round Robin)
Rationale for Involvement of all Team Members
Description of Individual's Need
Description of Community Needs to Meet Desired Outcomes
Information Sharing
Group Discussion: Local need & issues
Discuss and Summarize Desired Outcome, Persons Responsible, Action Steps to be taken with Time Lines for Completion

****

ONE FREE COPY TO PARENTS TRANSITION INFORMATION

"It's MY Choice. . . Read My Lips", please contact the Minnesota Governor's Planning Council on Developmental Disabilities State Planning Agency, 300 Centennial Office Building, 658 Cedar St., St. Paul, MN 55155, (612) 296-4018, (612) 296-9962 (TDD)

"Kentucky Model for Interagency Transition Planning for Students with Disabilities", please contact Jeanna Mullins or Preston Lewis, Dept. of Education, Capital Plaza Tower, 8th floor, 500 Mero St., Frankfort, KY 40601, (502) 564-4970 ***Quantity is limited!***

Kentucky Directory, Your KEEP Sake Directory of Advocacy, Leisure and Residential Programs and Resources for Persons with Mental Retardation/ Developmental Disabilities and their Families, Division, 275 E. Main Street, Frankfort, KY 40621,
call (502) 564-7700

"Options After High School for Youth with Disabilities", NICHCY Transition Summary, Number 7, Sept., 91,
call (800) 999-5599

NOT FREE, BUT WORTH THE SUBSCRIPTION COST

EXCEPTIONAL PARENT magazine is published 8 times per year (Jan, Mar, Apr, June, July, Sept, Oct, Dec) by the Psy-Ed Corporation. The rate is $18.00 per year to an individual family. To place a new order, call 1(800) 247-8080

Exciting News Parents!

We now have our own support group. We call it "Parents Confronting Dual Sensory Impairments" or PCDSI for short. Parents decided to incorporate at this years' Family Forum at the Kavanaugh Center in Crestwood on August 16. Greg Whittington from the University of Louisville "Lions Eye Foundation", acting as the group's agent, was very helpful in this process. Interim officers for the new

PCDSI were volunteers and duly approved by those in attendance. New officers are as follows:

President	**Sharon Cole (502) 276-3306** **FAX (502) 276-9516** **Fordsville, KY**
Vice President	**Rudolph Spink** **(502) 538-7578** **Mt. Washington, KY**
Secretary	**Brenda Browning** **(606) 842-3293** **Winchester, KY**
Treasurer	**Marna Miller** **(502) 459-1227** **Louisville, KY**

We decided the purpose of PCDSI will be to advocate, network, support, and raise funds for persons with dual sensory impairments. We agreed that any individual concerned about people with dual sensory impairments could become a member. These concerned individuals could become eligible to be members of the Board of Directors after serving as a PCDSI member for one calender year. The board will meet quarterly unless there is a need for additional meetings. The board will consist of nine parents, 3 professionals, and 3 community representatives.

The meeting location, time, and date will be announced in the INSIGHT newsletter to invite all who are interested. Respite services will always be provided to families at the location of the meeting or the family will be reimbursed at $20.00 for the meeting day when a special care attendant is needed at home. Travel mileage will also be reimbursed and if meetings include lunch, you will be reimbursed for that also. Our meeting was held:

Date: Saturday, November 7, 1992
Time: 11:00 AM to 3:00 PM
Place: KY School for the Blind, Hauser Hall, Conference Room, Louisville, Ky
Directions: The first turn on the left, past the main KSB entrance, turn left at the light by the Dairy Mart and church, go to the first and second gate on Haldeman Avenue, Hauser Hall is off of Haldeman Avenue. If the circle is full, go back out on Haldeman Ave, turn left again, go down a hill to the lower lever parking lot.
Number: 1-800-999-4910 to leave a message that you are coming!

We need to know! Please come!! We need your input. This is your PCDSI support group! Without your interest and help, we can accomplish nothing. With your active support, we can and will accomplish everything!! Our children need you!!! See you there.

Brenda Browning, Secretary PCDSI
Brenda Pezzarossi, Parent Coordinator
(800) 365-1258

SUPPORTED LIVING

Persons interested in applying for the newly created Supported Living Program can contact Jennifer Leatherby at 1-800-999-4910 or Doug Riddell at (502) 564-7700 for an application. Applications should be available in early November and due back to the Department of Mental Health/Mental Retardation by mid-December. Families or agencies may apply on behalf of specific individuals for an array of services to help support the person remaining in the family's home or to live in a home of their home. The funds are available to purchase support services (personal care, in-home training, respite, roommates, etc.) but not to pay for the cost of housing. A limited amount of funding is available, but families are encouraged to apply to demonstrate not only the need but also the interest in this kind of approach to assisting people with disabilities to live in the community.

The following is an advertisement from the Personal Futures Planning Project.

Hear Ye, Hear Ye!!

The Personal Futures Planning Project
invites you to participate!
If you would like help with
your son or daughter's
future planning
(school, what to do after school,
help in your home,
more friends, adaptive equipment)
and your son or daughter is
between the ages of 14-21
Please call Carolyn Wheeler at
1-800-925-3013

FYI CORNER

Deaf Blind Intervention Program
Jennifer Leatherby
UK Special Education Department
229 Taylor Education Building
Lexington, KY 40506-0001
(606) 257-7909 *

Diane Haynes, Sandi Baker, and Marie Ruf
1867 Frankfort Avenue
Louisville, KY 40206
(502)897-1580 *

Helen Keller Affiliateship
Janis Friend
Dept of Vocational Rehabilitation
627 W 4th St
Lexington, KY 40408
(606)255-1431

Systems Change Project
Dr. Harold Kleinert or
Jacque Farmer
UK Interdisciplinary Human Development
114 Mineral Industries Building
Lexington, KY 40506-0051
(606)257-3045 *

Personal Futures Planning Project
Carolyn Wheeler or
Cynthia Vaughn, Parent Coordinator
1867 Frankfort Avenue
Louisville, KY 40206
(502)894-9366 *

Brenda Pezzarossi, Parent Coordinator
UK Human Development Institute
114 Mineral Industries Building
Lexington, KY 40506-0051
(606)257-3586 or (606)272-1992 *

*Answering machines located on these phones.

Who is Disabled?

by Daniel Scott Hance

Two years ago, I left the halls of my old familiar Shelby County High School for my college venture into the unfamiliar lecture auditoriums at the University of Kentucky. Like any other freshman, I experienced many things, good and bad, for the first time in my life.

While playing in the Wildcat Marching Band, I became acquainted with another college student whose brother had a disability. Many new experiences had been mine up until then, but this was the first time I had ever been close to anyone with a disability. It has changed my life, to say the least!

My alma mater did indeed have kids with disabilities, but they were not really in the mainstream of things. The only contact I had with them was when, on occasion, I looked over and wondered what was wrong with them. Never before was I aware of the incredible experience missing in my high school course of study, until I got to really know a person with a disability.

Nobody realized or had pointed it out to me that persons with disabilities are people, too. They are more like me than not. It seems to me that while I had been so busy learning my college prep. classes (advanced placement reading, writing, and arithmetic), someone forgot to teach me to understand life and to understand people who may look or act differently. I lost out because I did not understand!

Now that I have come to the university, I have made many friends who happen to have disabilities. Some of the best moments of my life have been spent around these friends and their families. I have witnessed impossible situations they experience on a daily basis. While so few recognize their accomplishments, I respect them for their courage. I can only hope to achieve half as much as most children and adults with disabilities have already overcome just to survive.

Yes, since my old high school days, I have learned a lot. However, the greatest thing I have learned was taught to me by some very special teachers - the kids with disabilities and their families I have been graced to meet. They taught me the greatest lesson of all, a lesson about myself and the rest of the "non-disabled" society. Are we too BLIND to see through their disabilities? Are we too DEAF to hear their cries for help? Now in this society of ours, sometimes I wonder who is really disabled?

TOLL FREE NUMBER

The Kentucky Support Network for parents confronting dual sensory impairments now has its own 800#. The new phone line is located in Jennifer Leatherby's office at U.K. There is an answering service on the line, so if Jennifer is unavailable, please leave a message and she will return your call. Feel free to leave messages for other staff of the Deaf/Blind Intervention Program on this number, as well. The number is **1-800-999-4910.**

Definition of Deaf-Blindness

A person is considered to be Deaf-Blind when varying degrees of combined visual and auditory impairment cause the individual to be unable to utilize services developed for the visually impaired or for those with hearing impairments. Some Deaf-Blind people with dual sensory impairments have residual hearing and residual vision, and may also be labeled visually impaired and hearing impaired, while still others are totally deaf and blind.

The Federal guidelines state that a child who has a vision and hearing loss to the degree to which he/she cannot be served appropriately by one service or the other; therefore, such a child would be better served with a wider range of services. The child needs something of both services in order to receive the most appropriate education. Services vary by states, but some states set 20/70 (in the best eye) as the vision criteria. In addition, there may be a field loss. The visual field must be less than twenty degrees. Hearing losses are harder to identify. For example, a child may qualify if there are inconsistent responses to auditory and/or visual stimuli in the environment and/or if supported by a medical description.

Extreme difficulties with regard to communication, education, social life, training, working life, cultural activities, and information processing are encountered by persons who have Deaf-Blindness. This may further reduce their chances of taking the best advantage of any residual vision or hearing.

Deaf-Blindness can, therefore, be regarded as a separate disability. Individuals who are registered on the State Deaf-Blind Census, and their families, are eligible for the services of the Deaf Blind Intervention Program. Also, he/she can benefit, past the mandated school age of 21, from adult services such as the Kentucky Helen Keller Affiliateship Program. For additional information regarding the referral process please call **1-800-999-4910.**

Condensed by Brenda Pezzarossi from the following sources: Steve Perreault's taped talks to PCDSI, 10/10/92 and the Canadian Deaf-Blind and Rubella Association Intervention magazine, Intervention, Vol. 17, No.1, 1992

Quote by Joyce Ford - Idaho

Parent/Chairperson for National Parent Network (for Parents & Families with Individuals who are Deaf-Blind

I realized that "I could not reach out beyond myself (and help others) until the partnerships close to me were stable".

Taken from speech delivered to the State deaf-blind coordinators at Project Directors Meeting - Washington D.C. Oct. 27, 1992. For additional information about the National Parent Network call: (516)944-8900.

CALENDAR OF EVENTS

KENTUCKY

Dec. 2-4	Social Role Valorization Workshop, Ashland, contact Carrie Stith (606) 257-5389
Jan. 6	1993 Kentucky Legislative Breakfast, Farnham Dudgeon Civic Center, Frankfort, call Ann Hancock or Gail Lincoln at (502) 875-1871
Feb. 11-13	KY CEC Conference, Teresa Wasson, (606)271-3939
Feb. 17-19	Social Role Valorization Workshop, Bowling Green, call Carrie (606) 257-5389
2/28 - 3/5	PASSING 1993, week long training after completion of Social Role Valorization workshop, call Carrie (606) 257-5389

NATIONWIDE

Nov. 20-21	Youth with Disabilities: Preventing Drug and Alcohol Abuse, Sheraton Hotel-Westport Plaza, St. Louis, MO., call Linda Birenbaum (314) 889-3429 or (314) 889-3425 (TDD)
Nov. 19-21	National TASH Conference, Marriott Hotel, San Francisco, (206) 361-8870
Nov. 26	Thanksgiving Day
Dec. 25	Christmas Day

Please send your calendar events to: 3428 Crimson King Ct., Lexington, KY 40517 or call Brenda at (606) 257-3586 or (606) 272-1992

HELEN KELLER SCHOLARSHIP FUND FOR DEAF/BLIND COLLEGE STUDENTS
A program from the American Foundation for the Blind provides financial assistance, including help to pay for equipment, for deaf/blind students in college. The amount of assistance varies between $1,000 and $3,000 per academic year. For more information, call (212) 620-2000, (800) 232-5463, or (212) 620-2158.

Personal Futures Planning Project

- **A young man gets his first summer job; it wasn't a total success; but how many 20 year old's make it on their first job!?**
- **A young man in Powell County now attends home economics, art, shop and physical education in regular education classes and his IEP now includes community-based instruction.**
- There is a new work study employee at the K-Mart in Danville - a young woman is starting a 10 hour per week job there as part of her education program through Kentucky School for the Deaf.
- A family in Mt. Washington now has a medical card, personal care assistance, a visiting nurse, Ensure and diapers provided through the Home and Community Based waiver; in addition, respite services.
- A teaching assistant for a young man in Nortonsville was able to provide instruction on a weekly basis this past summer through extended school services resources made available.
- It's moving day (pretty soon) for a young man in Jenkins who will be leaving a personal care home to move into a "real home" with two other individuals who are disabled.
- A day care center in Henderson had a capable child care worker this past summer.
- Neighbors and concerned service providers, while getting to know a young man in Louisville, are helping the family find more people to be involved in his life, providing respite; and helping Mom obtain her driver's license, GED, and information related to low-interest loans for purchase of a family home.
- Henderson County High School now has a class for teenagers with significant disabilities and the new teacher has a lot of positive ideas for including students in the mainstream of high school life.

These are just some of the "outcomes" for participants in the Personal Futures Planning Project through the collaborative efforts of Project facilitators, the individual, parents, teachers, service providers, and other interested community members. Yes, all of the people described above are deaf-blind, and most have other disabilities as well.

Through the efforts of the Project, personal futures planning has been initiated for nineteen individuals of

Through the efforts of the Project, personal futures planning has been initiated for nineteen individuals of transition age (14-21) and five individuals of school age below the age of 14. In addition, facilitators trained through the Project have also convened personal futures planning teams for an additional seven individuals (not using Project resources) who are either deaf-blind (but are out of school) or handicapped through some other disability.

This newsletter is supported, in part, by the Hilton/Perkins National Program of Perkins School for the Blind, Watertown, Massachusetts. The Hilton/Perkins National Program is funded by a grant from the Conrad N. Hilton Foundation of Los Angeles, California.

People Concerned with

Dual Sensory Impairments

A Public Directory

Published by

Parents Confronting
Dual Sensory Impairment

To add your name to this public directory, write, call, or fax your name, address, phone number, and reason for wanting to be included to:

PCDSI
Route 2, Box 15A
Fordsville, KY 42343
(502) 276-3306
FAX: (502) 276-9516

Merry Christmas

INSIGHT

Volume 3 Number 4
Brenda Pezzarossi, Parent Coordinator
PCDSI, Inc. Officers, Editors
Winter 1993

"The focus . . . is on building CONFIDENT parents and SENSITIVE professionals . . . conducive to building positive partnerships between parents and professionals." *a quote from "Wings for Success", the 7th Annual KY Parent/Professional Conference on Children with Educational Disabilities, coordinated by the Kentucky Parent Resource Centers and other Kentucky agencies.*

A Word of Encouragement

from the President of PCDSI, Inc.

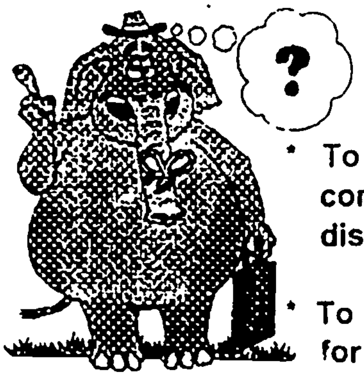
"I encourage you to be a part of these activities as this will help bring about empowerment to our families on the Deaf/Blind Registry of Kentucky." *. . . Sharon Cole*

Help Parents Be Informed!

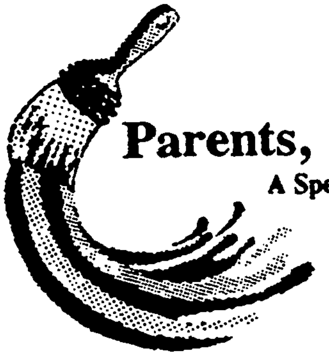
Everyone can benefit from being informed. PCDSI, Inc. (Parents Confronting Dual Sensory Impairments) would like to encourage all agencies and projects serving or working with deaf/blind persons and/or their families to keep them informed of past, present, and future happenings, including information concerning upcoming conferences, trainings, and workshops and to allow consumers and their families the opportunity to determine whether or not they would benefit or be interested in participating. Many times parents do not hear about such events until they are over or it is too late to register, find child care, and make arrangements to attend. This practice defeats all purposes, for both parents and professionals, who want to help persons with disabilities. PCDSI, Inc. would be grateful for your cooperation in this effort.

PCDSI, Inc.
New Plans and New Ideas!

from the officers and the advisory members



- To provide an opportunity for families to write in, ask questions, make comments, publish the questions and answers and have this information disseminated to all parents.
- To network and be able to tell other concerned parents about your child; for example, if someone in your family is having surgery, in the hospital or experiencing any kind of crisis, or if you would like to tell other parents about a good experience or event, we would like to know.
- To design and print a brochure describing PCDSI, Inc. and to distribute it nationwide.



Parents, This is YOUR Newsletter!

A Special Message from a New Parent Group

***Feel free to call.**
***Feel free to participate.**
***Feel free to voice your opinion.**

PCDSI, Inc. has gotten off to a great start seeking, setting, and accomplishing certain goals:

1. Becoming incorporated which was accomplished at 2:05 P.M. on November 23, 1992.

2. Obtaining a nonprofit corporation 501-3-c status for our parent group in order to do some serious fund raising. Please call us with ideas for your area!

3. Collecting names, addresses, phone numbers, birthdates, disability diagnosis, along with some family history, such as the names of siblings in order to distribute this information, by way of a directory, to all families on the Deaf/Blind Registry.

4. Continuing quarterly newsletters to serve as an update on PCDSI, Inc. happenings as well as events in Kentucky and conferences workshops being offered across the country.

PARENTS SEARCH

Parent to Parent Connection

Insight will publish letters from parents searching for other parents with similar experiences and/or information about rare problems needing specific resource information for individuals registered on the Kentucky Deaf/Blind census only with explicit parent consent from those parents requesting help.

PETERS ANOMALY

Kimberly is eleven years old and born with Peters Anomaly. For vision, she has light perception; but is profoundly deaf. Kimberly attends Maryville School in Bullitt County. Her parents, who both work, have difficulty finding and keeping babysitters and would like some help with that. Their main concern at this time is related to how to increase communication with Kimberly. She has been biting others and it is felt that this behavior is related to Kimberly's inability to communicate. Kimberly's mother would like to network with other parents and families who are experiencing some of these same frustrations. You may contact Kimberly's family by calling (502) 957-2800 or you may wish to write to them. Their address is as follows:

James & Andrea Sipes
127 Abundance Drive
Shepherdsville, Kentucky 40165

[illegible]

PROFESSIONALS SEARCH

A cute little three year old was brought to a rehabilitation facility for outpatient therapies. The social worker case manager for the child called in hopes of finding another parent with similar issues. One of the mother's concerns is related to transitioning her child from early intervention services into the school system. She has visited the school and is afraid they will not know what appropriate special services her child should have because of the dual sensory, both hearing and vision, losses. She does not want any time to be lost in obtaining the necessary educational services. The mother would like to be matched with another parent whose child is the same age and who is going through a similar experience.

Names have been withheld due to confidentiality; however, if you are a parent who could offer resource information to this family and would give permission for your name and number to be given to this family, please call the toll free statewide parent hotline number 1-800-365-1258.

PUBLIC PARENT DIRECTORY

Parents, we are in the final complilation process of our Public Parent Directory. We have received written permission from three-fourths of the families listed on the state Deaf/Blind census. We still want to hear your story about your child in order to print the summary following your name. We know how hard it is to respond to all the stuff that comes in your mail. Therefore, unless you tell us NOT to print your name, address, and phone number in our Public Parent Directory, the final version will be going to print with only this information, but not the detailed story about your child. You still have time, however, to add your child's story, the most important part, to our final version of this first Public Parent Directory. Please write, fax, or call your information to:

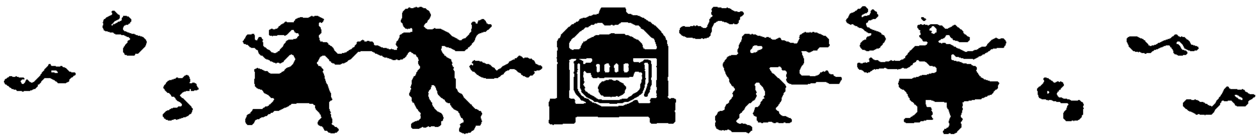
PCDSI, Inc.
Route 2, Box 15A
Fordsville, KY 42343

Phone: (502) 276-3306
FAX: (502) 276-9516

Kentucky Disabilities Coalition

A New Group Member

PCDSI, Inc. has become a new group member of the Kentucky Disabilities Coalition. Dues for disability groups are $100.00, but this has been waived until PCDSI, Inc. is financially able to pay. Single membership to parents of persons with disabilities is available for as little as $10.00 per year. Through this coalition, A great variety of disability advocacy groups band together to make their united voices heard in Frankfort. The Kentucky Disabilities Coalition holds two full group membership meetings each year. Their biggest annual project is the Legislative Breakfast held in Frankfort. Their third annual event was held January 5, in conjunction with the Kentucky Assistive Technology Service conference. The KDC Spring meeting is Saturday, April 17th at 10:00 AM at 1351 Newtown Pike, Lexington, KY.



KERA Supports PARENTS of PCDSI, Inc.

News from the Kentucky Department of Education

Active parents of PCDSI, Inc. submitted a grant proposal in January of 1993 to the Kentucky Department of Education, Division of Exceptional Children Services. Parent groups are more important, with KERA, and can be assisted through the state family resource centers. Funds were requested for printing and mailing two parent newsletters, preparing a brochure, printing and dispersing a Public Parent Directory. PCDSI, Inc., was funded, for the first time, from this source and intends to accomplish these goals using the funds for helping parents by June of 1993.

Hilton Perkins National Foundation

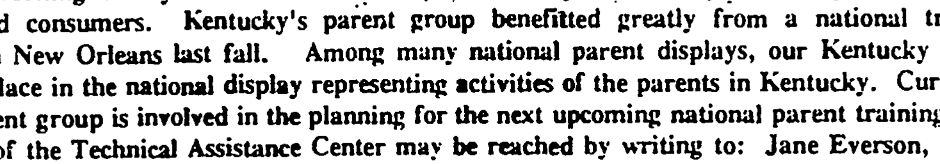
The newly incorporated parent group, PCDSI, Inc., is funded with sponsorship by the Hilton Perkins National Foundation in the amount of $5,000.00. The funding is used primarily for the annual Family Forum, held each August and to cover expenses such as telephone, travel, speakers, respite, interpreters, printing/mailing newsletters, newsletter coordinator, and brochures.

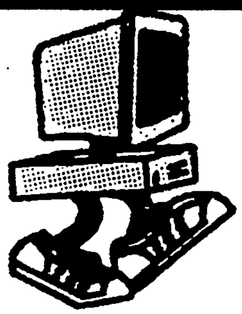
Helen Keller National Center

PCDSI, Inc. is working closely with this national center to acquire training workshops for parents, professionals, and consumers. Kentucky's parent group benefitted greatly from a national training workshop held in New Orleans last fall. Among many national parent displays, our Kentucky parent group won first place in the national display representing activities of the parents in Kentucky. Currently, the statewide parent group is involved in the planning for the next upcoming national parent training. The Project Director of the Technical Assistance Center may be reached by writing to: Jane Everson, Ph.D., LSU Medical Center, 1100 Florida Avenue, HDC Building 119, New Orleans, LA 70119. Send a FAX to (504) 942-8305 or call (504) 942-8188. The Helen Keller National Center address is: 111 Middle Neck Road, Sands Point, New York 11050-1299. Send a FAX to (516) 944-8751 or call Kathy McNulty at 1-800-255-0411 for more information.

NEWEST GRANT AWARD

Notification of the award was first received in the form of a letter on February 25, 1993 with final approval being confirmed March 12, 1993. This grant money, in the amount of $17,400.00, can now be used to connect families of children on the Deaf/Blind Registry with other families through technology. The grant proposal, written by PCDSI, Inc., was submitted to the the Kentucky State Developmental Disabilities Planning Council on December 4, 1992.

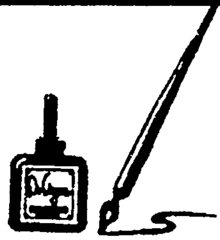




Innovative PCDSI, Inc. Parents

Created, Designed and Received

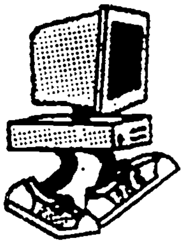
A big funding news bulletin by Brenda Pezzarossi

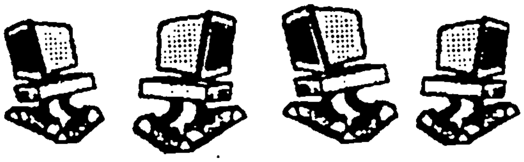


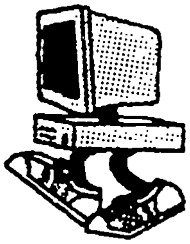
Parents involved with PCDSI, Inc. received the final good news on March 12, 1993! Their dream vision will be coming true. It is the dream of being able to connect parents of children whose children have dual sensory impairments, often with multiple disabilites, and chronic health care needs. Many of these families may live is isolated areas of the state, are scattered around the state in small towns, and are often unable to attend parent meetings.

You may wonder how such an impossible task could be accomplished. The answer is through technology . . . computer hardware with modems in the homes of the families where the child with the disabilites is living. Bulletin board services on computer modems can often be accessed free of charge with toll free numbers which go to system operators (Sysops) at the Kentucky Assistive Technology Services, the Assistive Technology Users Group, Central Kentucky Computer Society, Bluegrass Technology for People with Disabilities, or the Department for the Blind.

How does this work? What do you want to know? Do you want to ask a question about which eye doctor is best for your child? Where should you take your child to get an augmentative communication evaluation? Does anyone offer transportaion from your house to the next parent meeting? Just turn on your computer, with the modem hooked to your phone line, and ask it to dial the toll free bulletin board system. Next ask your question by typing in your message to the Sysop. You won't get an instant reponse, but it is faster than the U.S. Mail. After you leave your message, you are finished until the system operator has time to read your message and reply to your question or send back a referral source with the correct information. Later, probably the next day, you will simply turn on your computer and read your messages.







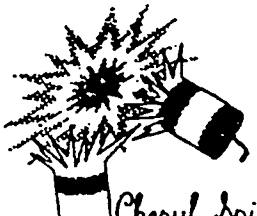
For more technology information and the specifics, please call the Parent Hotline Number at (800) 356-1258 or (606) 272-1992 for Brenda Pezzarossi, call Bob Moore at (606) 255-1922, or call Sharon Cole at (502) 276-3306.

INSIGHT Special Parent Edition 3/93

Just a Little Quote from Tommie's Sister

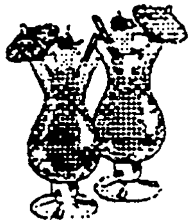
"You don't normally get to know the brothers and sisters of other kids with disabilities, especially when you live in a small town, you just never seem to run into them, and if you do you don't usually find out about their brother or sister. It was really nice to be able to get together at the Family Forum with others close to my age, to just hang out and talk about what it has been like for us."

by Cheryl Spink



It is the Spink Family News!

Cheryl Spink, daughter of Rudolph and Cindy Spink of Mt. Washington, KY. is getting married March 20, 1993.



A Time of Sharing

At the Annual Family Forum

by Rudolph Spink

Parents sharing ideas and helping each other obtain ideas to help their own children. That is really what it is all about! It is a time to get away from the city, be with your own family, and connect with other families who have similar situations. This year's Family Forum will held again at the Kavenaugh Center in Crestwood, Kentucky. Swimming, fishing, games, volleyball, movies will all be all ready for fun for kids with disabilities and their brothers and sisters.

Respite care, including registered nurses, will be provided while parents attend workshops. Let us know, in advance, what special foods your child may need. Overnight lodging and food will be provided. Keep a record of your mileage if you want to be reimbursed for travel expenses.

Because of last year's experience, the new PCDSI, Inc. officers voted to change the rules concerning reserving rooms. This year your family will be required to make a small deposit. Unfortunately, at last year's forum, some families signed up, but did not show up to use the reserved rooms being held for them. Since the rooms were paid in advance, the money was lost. Therefore, a small deposit, to hold the rooms, will be required for each person. If, however, your family does let us know soon enough in advance, your deposit will be refunded. We hope this will ensure that all our rooms are used.

Parents Confronting Dual Sensory Impairments
PCDSI, Inc.
AUGUST '93 FAMILY FORUM

Our FAMILY FORUM will be held August 13, 14 and 15, 1993. We need to know your needs for special accomodations now in order to be better able to plan for a successful event. PCDSI, Inc. will be paying your travel expenses, meals, overnight accomodations and respite care. If you have any other needs or questions in order to be able to attend this FAMILY FORUM, please let PCDSI, Inc. know by writing the address above or on the reverse of this form. You may call Sharon Cole at (502) 276-3306 or (502) 276-9516.

_____Yes _____No I am interested in attending this year's FAMILY FORUM. If you answered No, please return this form anyway and please let us know your reasons for not being able/interested in attending. Thanks!

_____Yes _____No We have a form of transportation.

_____Yes _____No We will need an interpreter.

_____Yes _____No We will need braille or large print materials.

_____Yes _____No We have special diet needs for someone in our family who will be attending. Please explain, if you answered yes to this question.

============================FOLD THIS SHEET IN HALF============================

_____Yes _____No We have special needs (crib, bed rails, air conditioning, equipment, wheel chair accessible rooms) for respite care. Please explain, if you answered yes.

CHILD'S NAME (on Deaf/Blind state registry or in referral process) AGE

CHILD'S WEIGHT CHILD'S HEIGHT CHILD'S T-SHIRT SIZE

SIBLING(S) AGE T-SHIRT SIZE

SIBLING(S) AGE T-SHIRT SIZE

SIBLING(S) AGE T-SHIRT SIZE

YOUR CHILDRENS' FAVORITE FORMS OF RECREATION OR ENTERTAINMENT

Please take a few minutes to mail this form back if you think your attendance at this year's FAMILY FORUM is possible. You may simply fold, tape shut, and add a stamp to return this form. Please return as soon as possible to this address and/or on the reverse side of this sheet.

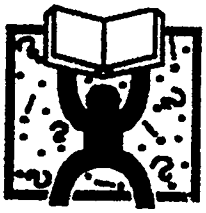
Family Forum Registration
PCDSI, Inc. President
PO Box 60, 2428 State Hwy. 54
Fordsville, KY 42343

Stamp

Family Forum Registration
PCDSI, Inc. President
P.O. Box 60, 2428 State Hwy. 54
Fordsville, KY 42343

Public Parent Directory

Please complete the information below and return to:
PCDSI, Inc., PO Box 60, Fordsville, KY 42343



This information will be published in a directory and distributed to other families of children on the Deaf/Blind Registry. This will serve as a means of helping families to connect with other families and to share ideas or information with others who may be experiencing similar situations. For your benefit and to help others, we encourage you to participate in this Public Parent Directory. **Please mail to the address on the reverse side.**

NAME STREET ADDRESS

CITY STATE ZIP

HOME PHONE WORK PHONE NEIGHBOR OR FRIEND PHONES

NAME OF CHILD ON DEAF/BLIND REGISTRY BIRTHDATE OF CHILD ON REGISTRY

MEDICAL DIAGNOSIS OF CHILD ON DEAF/BLIND REGISTRY

SIBLINGS AND THEIR BIRTHDATES

=======Fold Here==========================Fold Here================================Fold Here==============

CHILD'S HISTORY (Please give as much information as you would like by adding pages.)

CHILD'S HISTORY continued

PLEASE SIGN ABOVE SIGN IF YOU WOULD LIKE A STORY ABOUT YOUR CHILD IN OUR NEWSLETTER.

EXAMPLE OF A CHILD'S FAMILY HISTORY

NAME: Sharon Cole ADDRESS: P.O. Box 60, 2423 State Hwy. 54, Fordsville, KY 42343
TELEPHONE: (502) 276-3306 FAX: (502) 276-9516
NAME OF CHILD ON DEAF/BLIND REGISTRY: Kelly Corinne Phelps BIRTHDATE: 3/14/77
MEDICAL DIAGNOSIS OF CHILD ON DEAF/BLIND REGISTRY: Usher's Syndrome
SIBLINGS AND THEIR BIRTHDATE: William Phelps 6/28/68

HISTORY: Kelly was diagnosed with a hearing impairment at age three, which was permanent and progressed as she grew older. She attended public school in Ohio County until fifth grade. She was then diagnosed with Usher's Syndrome, as her vision impairment was detected. At this time, she became a residential student at Kentucky School for the Deaf and was there two years. She is now a residential student of Kentucky School for the Blind and in the tenth grade She is studying drama in hopes of having a career in acting. She has been on the teams of track, swimming, and cheerleading. When she graduates from high school, she plans to attend Gallaudet University. Her brother, William has no disabilities and he lives and works in Dearborn Heights, Michigan. As Kelly's mother, I serve as the President of the PCDSI, Inc. or Parents Confronting Dual Sensory Impairments. I also operate my own promotional advertising business from my home and am the wife of Norman Cole, Plumbers and Pipefitters Union CEO, Owensboro, Kentucky.

INSIGHT Special Parent Edition News Insert 3/93

STAMP

Public Parent Directory
PCDSI, Inc. President
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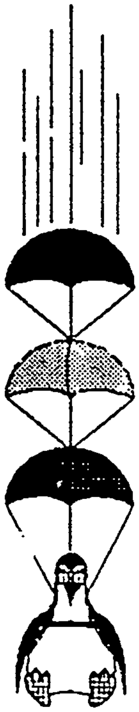

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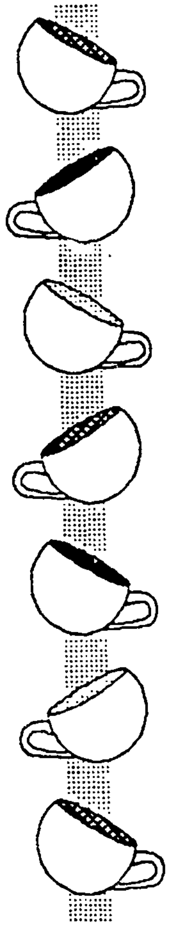
Cups For Sale!



Parents, drink from a PCDSI, Inc. cup silk screened in red and black with PARENTS CONFRONTING DUAL SENSORY IMPAIRMENTS.

Comfort yourself with the warmth of a hot drink in a shiny white mug and take part in this parent network.

Drink from a beautiful ceramic 10 oz.cup with our REACH FOR THE STARS logo silk screened in red and black.

Sip from a shiny white mug for only $6.00. Shipping and handling is included in this price and all money is to remain in the PCDSI, Inc. account.

Invite yourself to call (502) 276-3306 to place your order and make a contribution to all parents.

The opinions expressed herein do not necessarily reflect the position or policy of the KDE, Kentucky Department of Education, [illegible], Helen Keller Affiliateship, Systems Change, PFP, and no official endorsement should therefore be inferred.

INSIGHT Journal Parent Edition 3/93

SPECIAL PARENT EDITION
INSIGHT NEWSLETTER
PCDSI, Inc.
P.O. Box 60, 2428 State Hwy. 54
Fordsville, KY 42343

Stamp

Except for these
I am just like you.
My ears don't hear
And my eyes don't see,
But that should not alienate
You from me.
I can feel a soft gentle breeze
On my face.
And fresh homemade cookies
Are good to my taste.
I love to feel
A new baby's skin,
A soft kitten's fur,
The hug of a friend.
I can tell by your touch
If you really care.
Remember, my feelings
Are not impaired.
I can think, I can learn,
I can play and have fun.
I can cry, I can laugh
Just like anyone.
I can pray, I can worship
The Lord up above.
I can share and be your friend,
I can love.

-Bonnie Richards

I N S I G H T

Volume 4 Number 1
Brenda Pezzarossi, Parent Coordinator
Jennifer Leatherby, Editor
Spring 1993

FOCUS ON EARLY CHILDHOOD

An Early Start Toward Legislative Change

An Interview with Linda Dearing, Mother
by Brenda Pezzarossi, Parent Coordinator

It was 7:00 AM on January 6, 1993. Chad Dearing and his parents were in the State's Capitol city as Chad attended his first Legislative Breakfast.

"Chad had his head kind of turned sideways because he will turn his head, if he thinks you are going to take a picture with a flash." ..... Linda Dearing

"This little school, ECDC, Early Childhood Development Center, is really good for Chad. They do really good with Chad and I think this is one of the best schools around. We have a parent meeting on Monday night at the end of each month. The people at the school are trying to teach Chad to use a spoon. That is still in the workings because he won't hold a spoon here at home; but, they have some kind of a little special spoon at school. I am going to see if they can get us one of those spoons. They are working on it. If he would just try to get the spoon to his mouth; that would be progress! He still uses his fingers here at home and he just eats certain things. He won't eat vegetables and the only kind of fruit he will eat is a banana. Grilled cheese, french fries, peanut butter, and toast are about the only things I can get him to eat. He does love pizza and sandwich ice cream."

Chad's Progress Report

Mid-Year Update on Chad's I.E.P.
Summary Results and Changes
Early Childhood Development Center

Chad is making good progress on physical therapy goals. He will hold his head up with a verbal prompt and is beginning to belly crawl, standing up with support, and beginning to reach and grasp. Chad is able to finger feed himself independently and is continuing to work on using a spoon with guidance. Chad can choose between two objects. He is beginning to show that he can choose between two pictures as well. He also uses a switch to activate a toy.

Chad will continue to work on skills and imitation of oral motor movements. He will continue to work on eating a wide variety of foods and textures. He will continue to work on his imitation skills. He is currently using a patterned behavior to indicate his desire for more of a certain activity. He does use a switch to activate items. He will play with a toy for up to twenty minutes.

"It used to be that Chad did not have any interest in the toys, but his interest span is increasing. There is another thing Chad does now here at home. I have books for him in his room where he is lying in the floor and he has certain books that he likes better than the others. He will look at that book forever. He will just lay there on his stomach, hold that little head up, and look at that book. I would like to have a little movie showing him doing that." . . . Linda Dearing

To respond to this article, call or write to:

(606) 745-6901
Glen and Linda Dearing
110 Gary Court
Wincnester, KY 40391

(606) 744-3183
Jo Ann Dove, Director
Early Childhood Development Center
Winchester, KY 40391

First Steps

Kentucky's Early Intervention System

by Germaine O'Connell

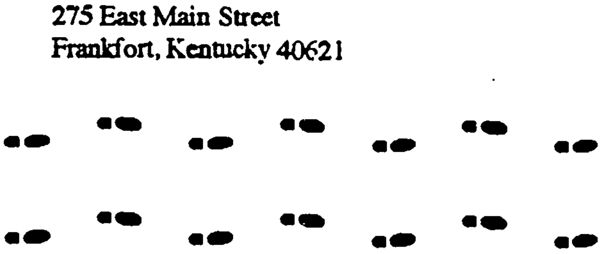
The first three years of life are the most critical developmental years. If there is a sensory impairment, a neurological disorder, or some other condition that may cause a delay in development, early intervention should be provided.

The Kentucky Cabinet for Human Resources is responsible for Early Intervention Services as provided by Part H of P.L. 99-457. All children ages birth to three for whom there is a concern regarding their development may receive, at no cost to the family, screening and evaluation to determine eligibility for Early Intervention Services. Once eligibility is established, the children and their families have the right to further assessment, service coordination and service planning called the Individual Family Service Plan (IFSP).

Kentucky's participation in Part H, hopefully will expand in 1994. The Cabinet for Human Resources is preparing to fully participate in Part H by Fall 1994. This would mean that all eligible children ages birth to three would be entitled to all needed early intervention services. Unlike the present; where only evaluation, assessment, service coordinator and IFSP development is available, the fall of 1994 will ensure that all early intervention services such as physical therapy, speech therapy, developmental intervention, etc, will be available and at no cost to the family.

It is critical to identify children with a delay or a condition that might cause a delay as soon as possible. The earlier the intervention is provided, the more effective it will be. If anyone suspects that a child is not developing in a typical way, some type of screening and/or evaluation should be done. Please contact the child's physician, the local health department, or your local mental health/mental retardation center. Check the yellow pages under Mental Health Center for the location and telephone number. If you are not sure where to call in your community, please call: (502) 564-7700

First Steps: Kentucky's Early Intervention System
Division of Mental Retardation
275 East Main Street
Frankfort, Kentucky 40621



REACH FOR THE STARS.... PLANNING FOR THE FUTURE

TRAINING FOR FAMILIES OF CHILDREN TRANSITIONING TO PRESCHOOL

By Jennifer Leatherby, Coordinator
Deaf-Blind Intervention Program

The Deaf-Blind Intervention Program has developed a new training for parents of young children (birth to 3 years) with dual sensory impairments. The focus of this training is on issues related to the transition from infant/toddler to preschool programs. Some of the questions answered at this training include:

- Will my child go to preschool with children without disabilities?
- What supports will my child receive in preschool?
- What is the difference between an IFSP and an IEP?
- What rights do I have when my child enters public school?
- What does a "quality" preschool program look like?

This training, which lasts two days, is very individualized for each family. The Personal Futures Planning process has been modified so that families may dream about their child's future and about what they want preschool to look like. Family members also are given the opportunity to think about what they want their child to learn in preschool and what information they want service providers to know about their child. All of this information is collected in a colorful, beautifully illustrated binder that families can take to their child's initial IEP meeting. (Thanks to Nita Kaufman for her assistance in developing the binder!!!)

The first training was conducted in Corbin, Kentucky on March 9 and 10. Nine families participated. The local Comprehensive Care Center provided a delicious lunch each day and respite for the children. KY-SPIN assisted with the conference by providing families with reimbursement for their mileage. At future trainings, they may also provide respite care. **We appreciate KY-SPIN's support!!!** The next *Reach for the Stars. . . Planning for the Future* training will be **May 5 and 6** at the PUSH Early Childhood Development Center in Frankfort. DBIP is attempting to take the training to all areas of the state where there are young children on the Deaf-Blind Census. Parents are welcomed to attend any of the trainings, however. At each location, the training is also opened to other families served by the host agency.

For additional information about this training, please contact **Jennifer Leatherby at (800) 999-4910 or Diane Haynes at (502) 897-1583**.

Give Our Kids A Head Start!

A Little Talk with Rena Hallam, Head Start Coordinator
by Brenda Pezzarossi, M.Ed., M.S.

Kentucky's Head Start and Parent Child Center programs are increasing their capacity to serve children with severe disabilities. The objectives of this new collaborative project are to:

1. Provide training and technical assistance to parents and staff;
2. Develop regional interdisciplinary professional resource and support networks;
3. Develop family intergenerational support networks.

Currently, this project is involved in Owsley and Grayson counties. New counties from both central and northeastern portions of Kentucky will be in the next phases of this effort.

Please call toll free to 1-800-288-2173 if you would like to know more about the possibility of this project being available for your children in your Head Start.

This project is being implemented through the Head Start Collaboration Project in coordination with the Interdisciplinary Human Development Institute-University Affliated Program (IHDI-UAP) at the University of Kentucky. Lexington, KY.

Whitney Lewis Attends Head Start

* * * * *

Parents, You Can be State Advisors!

State Councils to be Selected

Condensed by Brenda Pezzarossi, M.Ed., M.S. from appropriate sections of Title I and Title VII

Before President Bush left office, the Rehabilitation Act amendments were signed into law on October 29, 1992 following much debate by those interested in vocational rehabilitation. Months of advocacy, testimony, and changes initiated by individuals with disabilities and national consumer organizations preceded the amendments being signed into law.

New amendments require all states to establish two advisory councils for all Departments of Vocational Rehabilitation. These councils are a Statewide Independent Living Advisory Council and a Department of Vocational Rehabilitation State Advisory Council.

The law contains more specific language for council members. Representatives who may serve on the councils must meet very specific requirements and must not be employed by the state unit. Parents, family members and representatives of disability advocacy groups can serve. One P.T.I. (Parent Training and Information) center representative must serve. Current and former applicants or recipients of vocational rehabilitation services may also be individuals with disabilities and the Governor must make the appointments. For more information, please call Kathy Williams (502) 564-4440 or write to:

Sam Serraglio, Commissioner
Department of Vocational Rehabilitation
Capital Plaza Tower, 9th Floor
500 Mero Street
Frankfort, KY 40601

TOLL FREE NUMBER

The Kentucky Support Network for parents confronting dual sensory impairments now has its own 800#. The phone line is located in Jennifer Leatherby's office at U.K. There is an answering service on the line, so if Jennifer is unavailable, please leave a message and she will return your call. Feel free to leave messages for other staff of the Deaf/Blind Intervention Program on this number, as well. The number is **1-800-999-4910.**

Kentucky Administrative Regulations Preschool Education Program for Children with Disabilities

707 KAR 1:150

Interpreted by Brenda Pezzarossi, M.Ed., M.S.

"Free" and **"appropriate"** are still the most important and powerful words for parents to know in order to obtain the best educational services for their children with disabilities. **Each local school district shall make available a free appropriate preschool education and offer related services to all eligible children with disabilities.** New regulations, amended after a Hearing, were to become effective in Kentucky by the Fall of 1991. .

Preschool education means programs which:

1) Focus on the physical, intellectual, social, and emotional development of the child.
2) Include student learning activities to assist the child with intrapersonal, interpersonal and socialization skills development.
3) Meet the **"unique"** needs of a child with disabilities.

Related Services means:

1) Related services includes **PARENT EDUCATION** and **SERVICE COORDINATION** to "assist the parent" in coordinating services for the child with disabilities.
2) Transportation and any developmental or supportive services required to assist the child to benefit from preschool education.

Identifying Children

For those children who have been referred to the school district **PRIOR TO THE CHILD'S THIRD BIRTHDAY:**

Referral Procedures Shall:

1) Include district **collaboration** in the development of the IFSP, or Individual Family Service Plan, prepared by the early intervention agency "if the child is receiving early intervention services".
2) Allow preschool services to begin upon the child's third birthday.
3) Allow eligible children all **rights and protections** afforded to all children with disabilities.
4) Include members from early childhood or early intervention services in the ARC (Admissions and Release Committee).

Confidentiality

The school district shall:

Obtain the **PARENT'S CONSENT** before collecting information about the child from other agencies about services provided prior to age three.

Criteria for Identification of Your Child

A preschool child can be identified as having a "developmental delay" if the child:

1) Is under age six.
2) Has delays in one or more areas of development (i.e self-help/adaptive behavior, cognition, communication,social-emotional or motor development.)
3) Has a discrepancy between current performance and expected performance for the child's chronological age.

Evaluation of Your Child

The School must:

1) Assure an **INTERVIEW** with the **PARENT**, legal guardian, or parent's designee to obtain current functioning levels of their child as part of the evaluation process.
2) **Contact** other intervention services and/or any other early childhood agency if services have been provided by any agency other than the public school.

Placement for Your Child

Preschool children with disabilities:

1) Shall be educated with children without disabilities.
2) Shall not be routinely placed in settings serving only other children with disabilities.

Services for Your Child

The school district shall make services to eligible children available through a VARIETY of program OPTIONS such as:

1) Parent-child programs
2) Itinerant programs
3) Preschool class programs
4) A combination of the above options

Integrated Services for Your Child

When preschool children with disabilities are placed in classes where the majority of children do not have disabilities:

1) Six is the maximum number of children with disabilities recommended for one room.
2) One adult shall be available for each three children with disabilities in one classroom. (These vary according to severity of disability).
3) Instructional staff, including a lead teacher and teaching associate, must meet 704 Kentucky Administrative Regulations.
4) Related services personnel must also meet specific licensing requirements.

Selected portions of these regulations were highlighted by Debbie Schumacher, Kentucky Department of Education, Head Start Coordinator (502) 564-3010. You may obtain a copy of these regulations by calling your request to the Department of Education Information Line 1-800-252-7776 or by calling Brenda Pezzarossi at 1-800-365-1258.

Getting Involved In Early Intervention A Conference for Families of Young Children with Special Needs

Saturday, April 17, 1993
9:00 AM to 5:00 PM

Holiday Inn South (I-75 at Exit 104)
Lexington, Kentucky

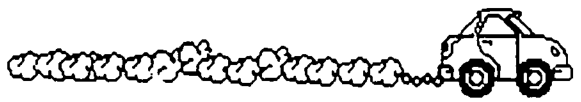
Kentucky is presently in the midst of implementing Part H of the Individuals with Disabilities Education Act (IDEA). This new law focuses on a state and national effort to meet the needs of children, ages birth to three, with developmental disabilities and delays and their families. In Kentucky, eligible children and families are now entitled to receive, AT NO COST TO THE FAMILY, the following:

(1.) Multidisciplinary evaluations
(2.) Multidisciplinary assessments
(3.) Service Coordination
(4.) An Individualized Family Service Plan or IFSP

Come join this important conference to discuss such topics as: Getting into the KY Early Intervention System, Understanding Your Rights Under Part H of IDEA, Evaluation and Assessment, Service Coordination, Individual Education Plans (IEPs) vs. Individualized Family Service Plans (IFSPs), Issues for Family Involvement in Early Intervention.

Come hear the experts share their state and community experiences and expertise. FAMILIES of young children, ages birth to three, with developmental disabilities and delays, will benefit from attending the conference. Also, family members representing STATEWIDE PARENT and FAMILY ADVOCACY and PARENT SUPPORT groups are encouraged to attend.

Space is limited on a first-come, first-serve basis, Priority will be given to those families who have a child with a disability between the ages of birth and three. You are encouraged to pre-register as soon as possible. There is no conference registration fee, but you must present your confirmation notice the day of the conference. If you have any questions, need a conference pre-registration form or need additional information, please call Michele Searcy at (606) 257-3098.



"WHAT IS IT?" AND "WHO QUALIFIES?"

By Sandi Baker
Curriculum Consultant
Deaf/Blind Intervention Program

The questions "just what does dual sensory impairment, or deaf-blindness, really mean?" have recently arisen. I will attempt to answer both questions in a clear and concise manner.

As defined by Kentucky for certification on the Deaf/Blind Census a child has a dual sensory impairment if he has "the combined handicaps of deafness and blindness and is eligible for special education and related services if the combination of handicaps prevents him or her from profiting satisfactorily from educational programs provided for the blind child or the deaf child". There are conditions, within this definition, which qualify a student as having a hearing impairment:

- a hearing loss of 25 decibels or worse (with a hearing aide); and/or cortical deafness; or
- a medically diagnosed condition of progressive hearing loss; or
- a functional hearing loss

And there are conditions, within this definition, which qualify a student as having a vision impairment:

- visual acuity (with prescribed lenses) is 20/70 or worse in the better eye
- a medically diagnosed progressive loss of vision
- a visual field of 20 degrees or worse
- a medically diagnosed condition of cortical blindness
- a loss of functional vision

As most of you are aware persons with dual sensory impairments usually have some residual vision and/or hearing, and therefore can sometimes be taught to use the vision and/or hearing that they have along with input from other senses (sensory integration).

This is where the terms functional vision and functional hearing apply. For the purpose of the Kentucky Deaf/Blind Census, functional vision refers to a child's visual performance during daily routines within the five life domains: home. school. community, vocational and recreation/leisure. Functional hearing refers to a child's auditory performance while performing daily activities and routines within the five life domains: home, school, community, vocational and recreation/leisure.

Two check-lists (one each for vision and for hearing), adapted from DEAF-BLIND INFANTS AND CHILDREN (Mc~Innes and Treffry, 1982), are frequently used by Deaf/Blind Intervention Program consultants to determine functional vision and hearing losses. A sampling of items from these checklists are as follows:

Functional Vision:

- Does the child occasionally attempt to locate objects visually?
- Does the child respond to lights or sunlight with flicking of fingers before his eyes, or any other specific behavior?
- Is one color preferable to another? Which?
- How does the child examine an object?
- Does the child move his eyes, head, to follow lights, objects, people?
- Will the child make eye contact with you?

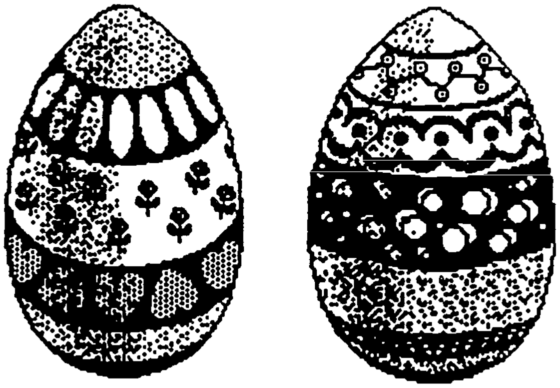
Functional Hearing:

- Do loud or strange noises startle or interest your child?
- Does child turn head toward sound? Tense his body? Stop what he's doing? Show other responses?
- Does child change activity, become fussy, stop crying, show excitement when mother speaks?
- Does child attempt to investigate sound sources nearby? At a distance?
- Does child make a variety of sounds?
- Does child attempt to imitate sounds?

As you can see, there is no simple definition of deaf/blindness and no single description of a person with a DSI. Each individual with a DSI is unique and has different strengths, challenges and circumstances surrounding his vision and hearing impairments.

In closing, I would like to share with you the words of Robert J. Smithdas (1982) as he reminds us of the severe challenges and the psychological impact of having a DSI:

> "The senses of sight and hearing are unquestionably the two primary avenues by which information and knowledge are absorbed by an individual, providing a direct access to the world in which he lives. These two senses account for the great majority of experiences by which one learns through observation and conscious imitation the activities and mores that are most acceptable to society and that develop intelligence, maturity, and social habits. When these senses are most or severely limited, the individual is drastically limited to a very small area of concepts, most of which must come to him through his secondary senses or through indirect information supplied by others. The world literally shrinks; it is only as large as he can reach with his fingertips or by using his severely limited sight and hearing, and it is only when he learns to use his remaining secondary senses of touch, taste, smell, and kinesthetic knowledge.
>
> The immediate consequence of the severe limitations of sight and hearing, or their total absence, is that the deaf/blind individual must depend on secondary sources for information, gained either through observation, through lesser avenues of sensation, or through rapport with other people on a one-to-one basis."



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Helen Keller Affiliateship
Janis Friend
Dept of Vocational Rehabilitation
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(606)255-1431

Systems Change Project
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Jacque Farmer
UK Interdisciplinary Human Development
114 Mineral Industries Building
Lexington, KY 40506-0051
(606)257-3045 *

Personal Futures Planning Project
Carolyn Wheeler or
Cynthia Vaughn, Parent Coordinator
1867 Frankfort Avenue
Louisville, KY 40206
(502)894-9366 *

Brenda Pezzarossi, Parent Coordinator
UK Human Development Institute
114 Mineral Industries Building
Lexington, KY 40506-0051
(606)257-3586 or (606)272-1992 *

*Answering machines located on these phones.

Personal Futures Planning 1993 Project Update

Carolyn Wheeler, PFP Associate Director

As of February, 1993, Project staff are working with 20 futures planning groups with an additional 10 groups having been facilitated by people who have been trained by the Project. Significant accomplishments on the part of these young people, who are deaf/blind, through the Futures Planning process are as follows:

1) Greater meaningful involvement on the part of the person and family members in decision -making which has led to both family and person empowerment;

2) Increased Inclusion in regular education classes and activities;

3) Investment in vocational training and job development in integrated settings;

4) Accessing existing services (Dept. of Vocational Rehabilitation, SSI, Home and Community-Based Waiver, AIS/MR services, Supported Living resources), etc. to support the person's presence and participation in their home communities at present and post high school;

5) Additional educational services, i.e., vision/hearing itinerant services, orientation/mobility, school to work transition programs, augmentative communication devices and functional assessments usually related to communication;

6) Effective inter-agency collaboration on behalf of persons who are deaf-blind in which agencies have demonstrated flexibility and commitment, overtime, to work toward a desirable future for the individual;

7) In concert with Deaf-Blind Intervention Program and the Helen Keller National Affiliateship through Dept. of Voc. Rehab., the initiation of consumer support groups for adults with deaf-blindness;

8) Greater parent and consumer participation in parent support groups and state-wide advocacy initiatives;

9) Attendance at conferences on supported living, assistive technology, and parent/professional collaboration;

10) Motivating some families to engage in estate planning to help reduce the vulnerability of their family member with a significant disability and as part of the answer to the question of "What happens to my child when I die?"

Not all of these outcomes have happened for each person; no individual's life is now ideal or without challenges or problems. We have been involved with some families where nothing has changed except that people now have a few more folks to call on. The process is not magic; it provides a way for people to come together and work toward a common goal and direction and is effective only to the extent that people, particularly the person him/herself and important family members, want to work toward the dream.

What are the barriers to change? I bet you thought I'd say money. Well, surprise! The answer is fear. Fear of change, of the unknown, of risk, of effort, of commitment, of inconvenience, of new roles for me (if my child has a life maybe I will have to get one, too), etc. If people want something badly enough, resources can be found, developed, or advocated for.

I have yet to work with a family where they or the person desired the dream more than I did. Parents are often tired and worn out by the time their children with disabilities are teenagers. Well, I have some other surprising news - the majority of parents are worn out by the time their children are teenagers!!!!!! Parenting is hard work regardless of whether or not the child is disabled. What probably makes it harder is the sense of responsibility that parents of children with disabilities feel will never end. With economic times being what they are, I would venture to say that many parents experience this sense of "relentless parenting" with no end in sight.

Personal Futures Planning, or any kind of person-centered planning, is only as good as the people involved want or are able to make it to be. The process provides a means to think about people positively, to work together instead of in isolation, and to bring about change. And only people can turn ideas on wallpaper into reality.

Facilitator Transformed
Into Neighbor and Friend
VIA PERSONAL FUTURES PLANNING PROJECT

by Brenda Pezzarossi, M.Ed., M.S.

In the beginning of Jayson's Personal Futures Planning meetings, nothing beemed to be working out, but people kept coming back. Consequently, the facilitator felt that they had tested the PFP system and succeeded because people were willing to stay involved even though nothing seemed to be working out and progress was not easy nor fast.

Were there parts of the meetings that you didn't like or you wish had happened differently?

I wish that . . . you know, hindsight is 20/20. I wish that earlier in the process we would have better understood how closely tied Jayson's future is to his mother's future. That in the beginning, when we began to see the truth of the matter, was that unless we helped Charlotte and addressed some of Charlotte's issues and lifestyle and that kind of thing. . . that nothing was going to happen for Jayson. When we saw that, it really scared us and we thought we were doing something wrong. We thought that we were denying Jayson somehow because this is (the PFP) is supposed to be about him, not about Charlotte. So we really struggled with that and different members of the group felt like we should pay more attention to Charlotte. Some people thought we should pay less attention to Charlotte. Some folks thought, "Boy, we need to try to balance it." There was a lot of confusion about that.

In the end, I think we have learned that because of their family, because of their lifestyle, and because of Jayson's needs and their lifetime history together, you can not separate Charlotte and Jayson's needs. They are one and the same or they have to be understood in that context. I remember the point at which I wish we had understood that earlier because I think we could have been more productive; but as a group we had to evolve over several meetings with a lot of discussion. For instance, we even broke out and started having separate meetings for Charlotte because we saw that as a way of protecting Jayson's meetings. . . that is, if we have separate meetings for Charlotte with a separate group of people, then we can say to her, "Well, that is stuff for your meeting. Let's talk about Jayson." We did everything we could to separate the two and thought we were doing that in behalf of Jayson and that was what we were supposed to be doing. I think that was our "perversion"of it, myself. I think we got real confused about what was really right and that when we finally got to the point that we pulled it all back together and realized this is about

Jayson and his family as one that we were on better track. That is not meant as a criticism but just. . . that was the point at which I thought, "Boy, we have wasted some time here trying to figure this whole thing out."

You said there was a point at which you realized this. Do you have a specific example of anything that really lit up the sky for you?

We had already broken up into a separate Personal Futures Planning group for Charlotte that met at a separate time with a separate facilitator to work on some of Charlotte's things and then we came back to the group and back to Jayson's kind of dreams and goals, which in all honesty, because we have such difficulty communicating with Jayson and his experience has been so limited, his dream is to a great extent, his **"mom and dad's dream"** for him. Because of that, there was this meeting where we were talking about a provider who was going to be more involved with Jayson, some neighbor folk, who we were working on trying to come and take a walk with Jayson and do that kind of thing and Mom was real worried and resistant to that. That was the meeting at which it dawned on me that "these are not separate things". There is not like, Charlotte's meeting about Charlotte and Jayson's meeting about Jayson. They have been **"twenty four hours a day for twenty two years"** together and we are not going to separate them now. Working with them is really the same thing. It clicked with me when Charlotte's own fears became evident as we talked about Jayson's plans. . . that they were not separate, we had to do them together and that we had to 'listen' to Charlotte. We had to quit saying that it SHOULD be like this or we want it to be like this. We had to be better at listening to what Charlotte's concerns and fears were and in figuring those things out. In other words, paying attention to them instead of trying to come up with some scheme to try to divert her.

Have there been any ripple effects that have occurred in your life?

Absolutely. I have become friends with Charlotte and she is not necessarily a person that I would have had the chance to become friends with, otherwise. I appreciate the opportunity to meet her. She is a different person than a lot of my friends are. She is an **amazing woman.** I just have a lot of respect for her and I have learned a lot from her about being positive in the face of adversity, about being a gentle person, not being angry, about just hard work, and being humble. All of this sounds real corny I know; but honestly, she is a woman that I look to a lot for strength because I just think she is an **amazing lady.** I also just enjoy them. We brought this baby home last week and three days later, Charlotte, Jason, and Richey were at my door coming in, hugging and wanting to hold the baby. I am not sure when I first got involved that I expected to have an ongoing friendship with them so much, so for me that has been a ripple.

The other thing, in all honesty, professionally, I have learned a bunch about how hard we have to try as professionals; how much effort it takes to **really** understand and listen to families. Again, Charlotte and Richey would not say to us, "We're not comfortable with that." They would just go along with it and unless we listened really carefully and respected where they were and what they wanted; it was more about what we wanted, otherwise. I have learned a lot about respecting their lifestyle. For instance, Charlotte doesn't have a desire to have a Saturday night where somebody would provide respite for Jayson and she and her husband would go out on the town. They have never done that. They are not interested in that. That doesn't sound like fun to them. That is just not their lifestyle. I just have had to learn a lot about respecting different priorities and lifestyles and listening better and not imposing. That would be the **professional ripple effect** for me.

Do you have any suggestions for the people who work with the Personal Futures Planning Project?

My suggestion, which has already been discussed a lot, is that somehow, somebody, whether it is them or somebody else figure out how to make this service available to the people who want it versus trying to talk some families into doing it simply because they are eligible for it. Do you know what I mean? I think it has been real unfortunate that some of the folks with the Personal Futures Planning Project have been eligible because their child has deaf/blindness and they are not really interested; they have been kind of talked into doing it, whereas, other families out there are dying for somebody to do that. It would be nice if the service could be made available on a less categorical kind of framework in terms of eligibility. I understand why that was the way the grant was written; that is who the funding source is, and so forth and so on, but if they could broaden either the disability criteria or the age criteria or something so that it could be available to more people who really want it and are requesting it. It would be a better use of the resources.

The above Personal Futures Planning Project interview was conducted, transcribed, and published in INSIGHT by Brenda Pezzarossi, PFP Evaluation Component Interviewer, with permission from the family of Jayson Baugh, and Facilitator/Neighbor Hope Leet Dittmeier. Please contact them for permission to print in other publications.

A FACILITATOR'S REFLECTIONS

As the end of the Personal Futures Planning Project comes quickly to an end (September 30, 1993), I find myself reflecting on the past 3 years. I have been in the helping profession for nearly 20 years now. However, I've never been involved in such a rewarding process as the Personal Futures Planning. Rewarding for me but more so for the individual and the family.

This unique process gave the opportunity for the person's voice to be heard and an opportunity to made some choices about the future. It was an avenue for the parents to express their "dreams" for their child. I witnessed professionals, family members, and others who were involved in the group taking time to look at the person in a different way. They seemed to recognized the person's abilities and focused on his/her capabilities.

I was thrilled to see the results of those who developed into advocates for an individual. Some of the "dreams" of the person were reached. Of course, not all "dreams" were attained. There were many challenges along the way. It is not a perfect process - - people are the process and none of us are perfect. However, through the collaborative efforts of those involved in the group, effective changes were made in the lives of individuals with deaf/blindness.

It has been an humbling experience for me and one I shall remember always. One very important thing I have learned, when a group of people get together, form a commitment, look at one's abilities and not the disabilities, listen to that particular individual's "dreams", things happen!!

Cindi Vaughn
Parent Coordinator

CALENDAR OF EVENTS

KENTUCKY

Apr. 24	ARC of Kentucky, Galt House, Louisville, 8 - 5:30, $35 Fee, Speaker: Wolf Wolfensburger from Syracuse University. Contact Patty Dempsy (502)875-5225.
May 5 & 6	Reach for the Stars . . . Planning for the Future, Frankfort, KY. Call Jennifer Leatherby at 1-800-999-4910.
July 30 - Aug. 1	Expanding Horizons Consumer Conference. Location to be announced. Contact Janis Friend at 224-1272.
Aug. 13-15	Fourth Annual Family Forum, Parents Confronting Dual Sensory Impairment at Kavenaugh Life Enrichment Center - Contact Sharon Cole (502)276-3306.

Please send your calendar events to: 3428 Crimson King Ct., Lexington, KY 40517 or call Brenda at (606) 257-3586 or (606) 272-1992

HELEN KELLER SCHOLARSHIP FUND FOR DEAF/BLIND COLLEGE STUDENTS
A program from the American Foundation for the Blind provides financial assistance, including help to pay for equipment, for deaf/blind students in college. The amount of assistance varies between $1,000 and $3,000 per academic year. For more information, call (212) 620-2000, (800) 232-5463, or (212) 620-2158.

Parents Seek & Fund Technology

by Brenda Pezzarossi, M.Ed., M.S.

Parent Coordinator (606) 272-1992 or (606) 257-3586

* PCDSI, Inc. prepared an exciting grant proposal to connect, via computer modems, families whose children are listed on the state Deaf/Blind registry throughout the state. The grant was awarded by the Developmental Disabilities Council on 3/12/93.

* Since December of '93, the technology grant proposal has resulted in networking, word of mouth, and through-the-grapevine donations of 126 computers and equipment offered to PCDSI, Inc., an active statewide parent group.

* On December 23, 1992, the PCDSI, Inc. parent advisory director, traveled to Dayton, Ohio and returned with a large truck load of computers, monitors, printers, and computer parts, at no cost to the parent group or affiliated projects.

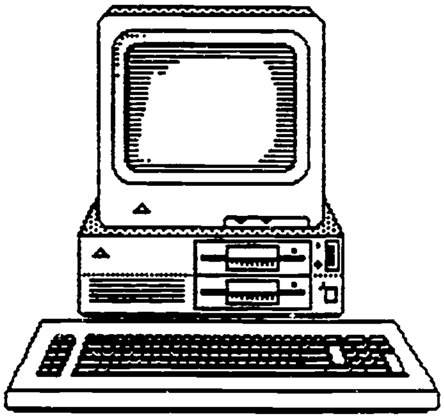
* The PCDSI, Inc. group is continuing its exploration of "recycling" in the field of computer technology and some computers and parts have already been recycled for use by consumers with disabilities.

* Local exploration by the PCDSI, Inc. group has begun a move to address the national issue of transition and computerized devices. PCDSI's position has been to advocate for allowing "transition" of equipment with the person who is disabled as the individual transitions from school systems into the rehabilitation systems.

* Computer businesses and private enterprise organizations have either volunteered repair services or offered to repair computer equipment at cost. The business community views this "computer recycling" idea as something which will benefit their business and which will capture the imagination of the public.

* PCDSI is collaborating with the Central Kentucky Computer Society, the Kentucky Assistive Technology Service Network, the Department for the Blind, the Assistive Technology Users Group, and Bluegrass Technology for Persons with Disabilities.

* The Central Kentucky Computer Society has submitted a nomination for the PCDSI group to receive a national prize from their national computer volunteer network. If selected, the prize money will go directly to benefit the PCDSI, Inc. parent group.



This newsletter is supported, in part, by the Hilton/Perkins National Program of Perkins School for the Blind, Watertown, Massachusetts. The Hilton/Perkins National Program is funded by a grant from the Conrad N. Hilton Foundation of Reno, Nevada.

PERSONAL FUTURES PLANNING PROJECT
Brenda Pezzarossi, Parent Coordinator
Interdisciplinary Human Development Institute
University of Kentucky
114 Mineral Industries Building
Lexington, KY 40506-0051

INSIGHT

INSIGHT

Volume 4 Number 2 PCDSI, Inc. Editors, Brenda Pezzarossi, Parent Coordinator Summer 1993

Our Family Forum

by Rudolph Spink

This year's 1993 Family Forum will be held again on August 13, 14, and 15. For the second year in a row, it will be at the Kavenaugh Center in Crestwood, Kentucky. Swimming, fishing, games, volleyball, movies will be ready for fun with all kids with disabilities and their brothers and sisters.

Parents sharing ideas and helping each other. That is really what it is all about! It is a time to get away from the city, be with your own family, and connect with other families who have similar situations. Respite care, including registered nurses, will be provided while parents attend workshops. Let us know, in advance, what special foods your child may need. Overnight lodging and food will be provided. Keep a record of your mileage if you want to be reimbursed for travel expenses.

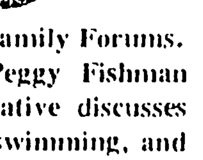
Teenagers Having Fun!

Jason Is . . . Where the Action Is
Bert Pushes and Karla Dribbles

* * *

LAST CHANCE! DEADLINE NEAR!
HURRY! HURRY! HURRY!

Parents, This is your last chance! Our deadline has passed and we only have a few spaces left for the 1993 Family Forum information. Mail in the Family Forum Registration form found in this summer issue of the INSIGHT news.



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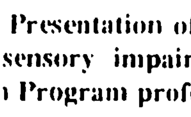
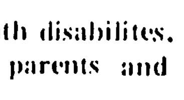




Family Forum Agenda

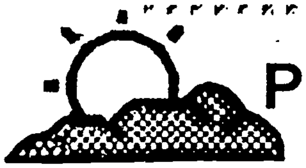
FRIDAY EVENING: Hot dogs, hamburgers, homemade ice cream; slides from previous Family Forums.

SATURDAY: Presentation on self esteem, Katie Beckett "medicaid waiver", Dr. Peggy Fishman discusses "vision loss", Burton Cohen discusses "hearing loss", governmental representative discusses politics, Karen Edwards Hunter, theatre specialist provides entertainment, movies, food, swimming, and games for the kids.

SUNDAY: Presentation of what is good and happening for and with people with disabilites, individuals with dual sensory impairments, and their families given by PCDSI, Inc. parents and Deaf/Blind Intervention Program professionals.

Parents Meet Governor!

PCDSI. Inc. President, Sharon Cole, arranged for Governor Brereton Jones to celebrate his birthday with the parents of children with disabilities and with consumers. Kentucky's Governor was born on Helen Keller's birthday and shares some of the same values for implementing change for persons with disabilities. The Governor signed a Proclamation declaring the last week of June as Helen Keller Week for Kentucky. Another parent, Brenda Pezzarossi, brought a cake decorated with American flags for Governor Jones' birthday. She also worked with the Governor's Office to obtain Dana Parker as the interpreter for the deaf. PCDSI. Inc. parent, Bob Moore shared the program with Governor Jones by awarding the Father of the Year Plaque to Rudolph Spink of Mt. Washington, KY. Bob also explained the latest PCDSI, Inc. project which consists of providing used home computers to parents to network through a toll free bulletin board system across Kentucky. News coverage from several television stations and the Corbin Times focused on the families of children with disabilities who were in attendance along with over fifty people. The signing of the Proclamation took place at 11:45 AM on Monday, June 28, 1993 in the Governor's office of the Capitol in Frankfort.



Parents Making A Difference!

Margarita Arnett, acting on behalf of Jason Arnett, received their first supported living assistance June 21, 1993. She is excited about Jason going to the beach, being out for lunch, and having other people in his life.

Sharon Cole has assumed management of a grant received from the Kentucky Department of Education in order to offer more communication among parents across the state. Sharon has been selected to serve on the National Parent Network Advisory Board which will hold its first meeting in July of 1993.

Paulene Lewis has received word directly from President Clinton. Paulene thought the new President should know more about her daughter, Whitney. Paulene wrote a nearly ten page letter in long hand informing President Clinton about what her hopes and dreams are for Whitney. Paulene received a very nice letter from the White House with President Clinton's own signature.

Marna Miller and son, Sean, will be leaving for Sands Point, New York on June 29. Sean will be undergoing a job training effort at the Helen Keller Center.

Bob and Cherry Moore received a supported living grant to create a community living environment for their son, Lew Moore. Bob, a major spokesman for health reform, won the primary election in Lexington and will be standing his ground in the November elections. Bob is starting technology connections for families through a grant funded by the Developmental Disabilities Council.

Jay Pezzarossi, son of Brenda Pezzarossi, was selected for a supported living grant to receive training to operate a networking business called ORCCA, Inc., Online Resource for Communication, Computers, and Assistance Technology, for his own independent living. Brenda and Jay were selected by Scotty Baesler to attend the Presidential Inauguration Ceremonies in January. In March, they attended the National CloseUp Foundation's Week in Washington where Senator Wendell Ford's office selected Brenda and Jay to help plan the next Inauguration according to ADA guidelines.

Lions Club Honored

by Parent Group's Transportation Request

At first Paulene Lewis was excited when she found out her daughter might get to meet the Governor this year. However, Paulene, who does not drive or own a car, had resigned herself to staying home rather than trying to get her daughter to Frankfort. Public transportation is limited in eastern Kentucky where the Lewis family lives. They were unable to attend last year's signing of the Helen Keller Proclamation at the state's capitol due to their lack of transportation. Paulene voiced her wishes to another parent, Brenda Pezzarossi, who recalled efforts of locating transportation for parents over the past two years.

Back in 1991, long before PCDSI, Inc. became a separate and active parent group, parents recognized the transportation barrier. Parents realized that before a statewide parent group could assist other families, they must be able to meet other active parents. Transportation of families with children who have multiple health care needs was recognized as the first step toward forming a statewide parent group. Without transportation, many families in sparsely populated areas, across the state would never be able to meet other parents.

A professional, Greg Whittington, who volunteered to help this group of parents, became interested in the parents' needs and transportation. Greg, who later became the incorporating agent for PCDSI, Inc. invited Kay Lutes, Executive Director of the Lions Institute, to one of the earlier meetings. After meeting with parents, Ms. Lutes offered assistance in providing transportation to and from events. She contacted Lions Clubs across Kentucky and the National Lions Club who recognized the need. Corbin Lions Club member, Cleland Thorpe, a member of the Shriners, who also volunteers for the American Red Cross and the Adult Literacy Program, responded by offering to transport the Lewis family to Frankfort.

Parents alone have a difficult time making connections, but when a parent group undertakes awareness, they find supportive and caring people like Mr. Thorpe. Many people benefit and find strength from offering their help and genuinely care about people with disabilities and their families. After visiting the Governor's office with the Lewis family, Cleland Thorpe was full of praise for all the families he met at the Helen Keller signing. "I think they are very courageous people", said Mr. Thorpe. "Since Whitney's birth, their family has been in many hospitals dealing with her handicap. She seems to be able to cope well with it when alot of people probably would have given up."

*P*arents *C*onfronting *D*ual *S*ensory *I*mpairments, Inc.

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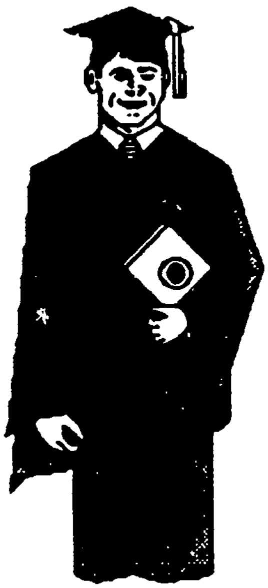

Parent Changes Large School System

by Removing Graduation Barrier

It had always been done that way. Kentucky's second largest school district is called Fayette County. Four of its large high schools have been holding their graduation ceremonies at Rupp Area for many years. Their 1993 plans, like past years, called for all graduates to take their diplomas and use the stairs to exit from the front center of the stage. That meant a student in a wheelchair, on crutches, using a walker, or having any mobility restrictions could not exit from the front of the stage. Instead, such a student would have to leave down a back ramp, the same way he entered the stage --- or not go up on the stage at all.

This plan was unsatisfactory to Jay Pezzarossi who wanted to receive his diploma just like everyone else. A birth injury, which caused hypotonic, ataxic cerebral palsy, has made walking and talking difficult for Jay. Like his sister, Karla, and other graduating seniors, Jay wanted to exit from the center of the high stage. According to Jay's mother. "The schools' existing arrangements would have deprived graduating seniors with physical disabilities from their few short, extra minutes to bask in the glory of their graduation." Jay's sister, Karla said, "I just wanted my brother to get through the ceremonies without any more barriers to overcome."

While other families of most graduating seniors were thinking about new clothes for their graduation, Jay's family was focusing on lowering the stage, building ramps, and adding handrails. Phone calls, advocating Jay's request, were made by Jay's mother to the principals, school superintendents, and Rupp Arena corporate executives. These were followed up with a letter from Jay's family to the school superintendent with copies to all the principals and Rupp Arena's executive directors.

Other contacts helped to raise the awareness of the school administrators and arena corporate executives. A convincing letter was sent from an ADA representative with the governor's office. The school and Rupp Arena personnel received a copy of the 1990 accessibility requirements of ADA (Americans with Disabilites Act) as helpful reading material. A citizen advocate, in contact with the Governmental Affairs office for UCP in Washington, DC called in Jay's behalf. By the time Rupp Arena and the school administration were contacted by a local newspaper reporter, architectural changes were already in progress.

Ramps with handrails appeared at the side and front center of a lowered stage. Marching in the graduation ceremonies was easier for everyone. One person's family did change things by getting a barrier removed. The highlight of the end of school became more beautiful and included all seniors. Many others will continue to benefit because one person did make a difference. One parent advocated for a better way for everyone.

For more details, please call Brenda at (606) 272-1992 (h) or (800) 356-1258 (w) at the U.K./U.A.P. Human Development Institute, 307 Mineral Industries Bldg., Lexington, KY 40506-0051 or write to Brenda Pezzarossi, 3428 Crimson King Court, Lexington, KY 40517.

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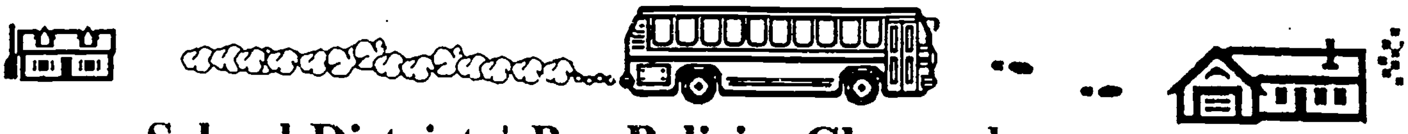
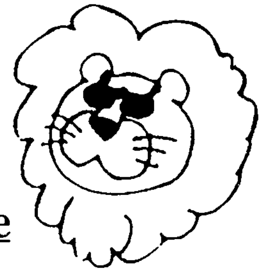


School Districts' Bus Policies Changed by a Parent from PCDSI, Inc.

Residential students at the Kentucky School for the Blind in Louisville travel hundreds of miles across the state to their homes on weekends. Two school districts would not allow the students to eat or drink during this lengthy traveling time. Some of these school children, with multiple disabilities, also have secondary conditions such as diabetes, seizure disorders, and hypoglycemia. Many students' medical conditions depended upon regular scheduled diets. One first grader cried all the way from home to the school when cookies were taken away. Some students, while riding the bus, were denied the comfort of holding their stuffed animals. Emotional stress for some students, caused by being sent away to school, worsened when they could not keep their familiar possessions from home.

After listening to these horrifying reports from Kelly, her daughter, Sharon Cole was prompted to take action. After inquiring at the local school district level, she was told these bus rules were the state law. Hearing a rule quoted did not stop Sharon for she knew instinctively what is right, fair, and just. She called the Kentucky State Department of Education and learned, in fact, it was not a state law. It was simply a local individual school district policy. Armed with her new found knowledge of the state's educational law, Sharon made phone calls, wrote letters, and began an awareness campaign for the bus drivers. She distributed flyers explaining the disabilities and handicapping conditions of the students riding their buses. Residential students, who travel long distances on Friday and Sunday, are now allowed to eat and drink. Yes, the school districts have agreed that it was not a state law and have changed their school bus policy.



Kentucky Lions Eye Research Institute

What is it?

The current Lions Eye Research Institute building in Louisville was completed in 1969. The new addition (23,000 square feet) will cost approximately $4.1 million dollars when completed. As a result of many hardworking Lions Clubs, generous contributions of $3.1 million dollars have been raised. The Kentucky Lions Eye Institute is expanding to better serve the patient care and eye research needs of Kentucky.

The Kentucky Lions Eye Foundation was founded as a non-profit organization in 1954 to assist those in need of eye care and to expand vision conservation in Kentucky. Check with your nearest Lions Club to see if you qualify for their assistance with your child's or your eye care needs.

[illegible] at [illegible] (w) [illegible] 69(h) or [illegible] East [illegible] Louisville [illegible]

INSIGHT Newsletter PCDSI, Inc 6 93

PROFESSIONAL TO PARENT CONNECTION

How To Identify and Assess Students

With Dual Sensory Impairments

July 12-15, 1993
Jim Durkel from the Texas Deaf-Blind Outreach Project will speak at a three day workshop called the SUMMER INSTITUTE at the Springs Inn, 2020 Harrodsburg Road, Lexington, KY. The program covers assessment INCLUDING FAMILIES and gives useful information to the educational team. Students with deaf-blindness are often assessed using instruments that do not give a "true picture" of the child's capabilities. Families can be reimbursed by the Deaf-Blind Intervention Program for mileage and/or lodging and meals. Call (800) 999-4910 for Jennifer Leatherby if you have additional questions.

How To Have A Supportive Community

After Transition From School

July 30 - August 1, 1993
Consumers, Parents, Guardians. Interested Persons will want to hear Dr. Jeffrey Bohrman, president elect of the American Association of the Deaf/Blind at A CONSUMER CONFERENCE called "Expanding Horizons" at the Kavanaugh Life Enrichment Center, Crestwood, Kentucky. After transition from school of persons who are deaf/blind, there is a need to have a supportive community with which they can identify. The American Association of the Deaf/Blind can help provide that community. Call (502) 897-1583 to Contact Marie Ruf, Deaf/Blind Intervention Program or call (800) 999-4910 about your desire to receive more information.

How to Offer Future Direction

for Best Practices in Natural Environments

August 26-27, 1993
A two day conference for professionals working with infants/toddlers (birth through three years) will be held at the Radisson Plaza Hotel, Lexington. Kentucky. The focus is on best practices, natural environments, future direction, and mandated services. Call (502) 564-7700 for Germaine O'Connell at the Cabinet for Human Resources, Frankfort, KY.

Grant Proposal Submitted to the Federal Government

In May, 1993, Jennifer Leatherby of the Deaf-Blind Intervention Program applied for another three-year Personal Futures Planning Project to support 24 teams who would work toward better educational services in integrated settings for children on the Deaf-Blind Census. Training would be provided to families and facilitators to develop each child's planning group. Families would assist in the selection of their facilitator who would convene and conduct each meeting. Families involved in the previous Personal Futures Planning Project wrote letters of support in hopes of obtaining this person centered process for other families.

TO LIST YOUR WORKSHOPS, CONFERENCES, AND PROFESSIONAL ACCOMPLISHMENTS, FOR PARENT CONNECTIONS, PLEASE CALL BRENDA PEZZAROSSI AT (606) 272-1992 OR (800) 365-1258.

PARENTS SEARCH

Parent to Parent Connection

***INSIGHT** will publish letters from parents searching for other parents with similar experiences and/or information about rare problems needing specific resource information for individuals registered, referred, or suspected of being diagnosed with a dual sensory impairment only with explicit parent consent from those parents requesting help.*

Andrea was born on October 4, 1989. She will turn four on her next birthday. Andrea has been seen by a neurologist and hospitalized several times for non-controlling seizures, but the doctors knew nothing they could do to help her. It was very frustrating for everyone. An MRI showed that Andrea has a thin corpus callosum which means her left and right sides of the brain are not communicating. Andrea was also diagnosed with cerebral palsy. It is stressful at times to care for her and to accept everything that comes with a special child.

Andrea's family would like to hear from others who are experiencing some of these same frustrations. You may contact Andrea's family by calling (606) 744-9318 (h) or (606) 624-9077 (w). Their address follows:

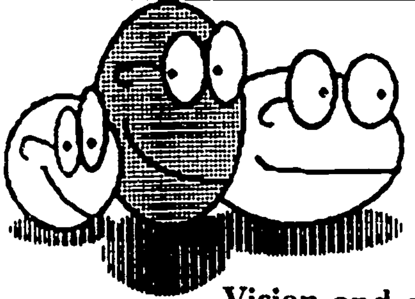
Billy & Wanda Coomer
156 Quickshop
Winchester, KY 40391

* * *

Joshua Millwood, our grandson, was born on August 19, 1986. He will be seven this summer. Joshua has grown quite a bit in the last year. As our grandson gets larger, we are concerned about getting him in and out of the bathtub. We are also concerned about who will take care of Joshua when we are no longer able to provide care. We are Joshua's guardians, but have not become his permanent legal guardians. Right now we have the right to sign papers for medical purposes and to send him to school, but not to do estate planning.

Sam and Diane would like to talk to others with some of the same issues. Their phone number is (606) 269-5509. Their address is as follows:

Sam & Diane Sears
247 Bassett Avenue
Lexington, Ky 40502



Know Your Eye Doctors!

Which Eye Doctor is for What?

by Greg Whittington

Vision and eye care is very important to all of us. It is essential for our eye care professional to be interested and specially trained in the care of deaf and blind children and adults.

There are several kinds of doctors that provide care for our eyes. Ophthamologists are Medical Doctors (M.D.'s just like your family doctor or pediatrician) that treat diseases of the eye, prescribe medicine, eyeglasses, and perform eye surgery.

Pediatric ophthamologists are Medical Doctors (M.D.) that are trained to treat infant's and children's eye problems and eye disease. In addition to the training to become an opthalmologist, these eye doctors spend an additional one or two years (residency) studying diseases and surgeries specifically affecting children's eyes.

Doctors of Optometry (Optometrists) are not Medical Doctors. They have received training in eye care and can prescribe eyeglasses, contact lenses and some eye medicines; but, do not perform surgery. After completing their educational training, they do not have the specialized educational training (Internship, Residency, or Fellowship) to examine infants and children. Optometrists attend schools of optometry. Some schools are affiliated with state universities such as Indiana University and Ohio State University. Schools of optometry require at least two years of college (some four years) prior to admission. Students of optometry then spend four years studying the eye and receive degrees as Doctors of Optometry (O.D.).

* * *

Parent to Parent Connection

My name is Brenda Browning and I'm the grandmother and caregiver for a special needs child. As caregiver, I have come into contact with many professionals, doctors, nurses, therapists, case managers, and consultants, from different fields. Most of these people are caring and concerned individuals, but they have so many cases or "clients", they don't have time to become involved with our family. We hear from them a few times a year, or sometimes only once a year, to see what we need them to do for us. This is usually a waste of time because I seldom know what we need or if their organization can do it, so I'm usually told they can't help me.

Imagine my surprise and delight when a consultant with an organization actually told me what we needed and told me they would help us get it, if we wanted to participate in their program. It has been a wonderful and educational experience for us. Our granddaughter has benefitted from her association with this program more than any other we have seen over the last seven years. Her acceptance at school and their willingness to work with us on her educational planning and even her progress can be directly attributed to their help and interest. They are not only professional people, they are also loving, caring people who have become friends of our entire family. I can call them and discuss my problems with them at any time.

If you would like the same services for your child, as mentioned above, you may reach people like this by calling the Deaf/Blind Intervention Program at 502/897-1583 in Louisville or 502/257-7909, or 800-999-4910 in Lexington.

INSIGHT Newsletter PCDSI, Inc 6-93

Parent to Parent Connection

Dear Brenda,

Today is June 16, 1993 and it was Whitney's second I.E.P. meeting for kindergarten. Today's meeting would cover the whole school year for kindergarten starting this fall. There weren't as many people at this meeting. They had been having their own meetings about Whitney. They agreed to work with her this summer. So many different people had goals and things they wanted to do with Whitney. She will have physical therapy and a special skills teacher and each one will be one day a week. They will bring things Whitney can learn to use.

For this next school year, the school decided that Whitney should not go to Sublimity Grade School. They thought she should go to Cold Hill Grade School instead. Sublimity School is really close to where we live and I thought it would be nice to be able to walk there since I don't drive. But the school people thought Sublimity School would not be best for Whitney. They said Cold Hill has many more things to offer her.

I visited Cold Hill Grade School and the classrooms are what I liked, too. The building was all on one level and everything was all bright and cheery when I walked in. The staff seemed really nice and it made me feel good just to be there. I guess they will be able to offer more for Whitney. I really don't know if I will let her ride a school bus, but I will think about that when the time comes. We just have to take one thing at a time.

Paulene Lewis

---

20 Year Old Policies Changed

by a Committee Formed Because of One Student's Parent

One student's parent can make a difference! Outdated dorm rules and old policies in effect for twenty years were causing conflict and frustration among students, parents, and staff at Kentucky's residential school for the blind. Conflicts were arising on a daily basis over some of the current needs of students who live in the dorms of the residential school. Students felt the dorm staff enforced rules that were no longer needed due to changes in society. Other students felt that there were strict rules for some, but none for others. Some students felt that the residential staff was only interested in their academic needs, but not in them personally. Several students complained to one parent who took their comments seriously and wrote letters on their behalf.

Prior to the 1992-93 school year, group meetings between families and the staff of the institution had never been attempted. At the insistance of one student's mother, who wrote letters on behalf of the students, a committee was formed to take into consideration the current and changing needs of all individuals. Excitement among all the students, parents, and residential staff was evident at the first meeting when this new committee was formed. Students, believing the staff and parents were becoming interested in their personal feelings, ideas, and rights as individuals, have begun to voice their concerns. Relationships with each other and among students in the dorms where they live is beginning to improve. Staff members commented they have seen some interesting and positive attitude changes from the staff as well as the students. One student's parent did make a difference!

NSIGHT FOCUS, Inc., Edition 6 93

Receive a Free Computer for Your Home

Parent Group Makes This Possible!

PCDSI, Inc.

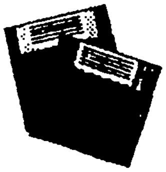
These are the amazing days in which we live. Technology changes rapidly and improves our opportunities for better lives for our children. Opportunities to communicate across great distance are now available through the use of computers by families of children with deaf-blindness. You may want to explore these opportunities. The number of people using computers for telecommunication is expected to increase rapidly within the next few years.

Families with children who are deaf-blind must apply directly to PCDSI, Inc. for participation in this project. The requirement is that their deaf-blind child be under age 22 and on the Kentucky Deaf-Blind registery (or otherwise certified as having a dual sensory impairment). See the application form in this issue of INSIGHT.

PCDSI, Inc. volunteers will provide those families who are accepted into the project with a computer, modem, telecommunication software, and operating system. We will provide training and support to begin the use of the equipment we provide. We will also be available to assist families if problems develop during the course of the project.

Families who receive computers accept one obligation - - - to become regular participants in the Assistive Technology User's Group Bulletin Board System (ATUG-BBS). This is a community of people interested in blindness and other disabilities who interact using telecommunication. The BBS is accessible statewide by means of a toll-free 800 number.

The purpose of the project is to use telecommunication as a means of overcoming the social isolation of families who have children with deaf-blindness.



Please complete the computer application in this issue of INSIGHT and return by the deadline of August 1, 1993. You may call Bob Moore at (606) 233-5760 (w) or (606) 255-1922 (h) or write to him requesting an application form.

Bob Moore
929 Wolf Run
Lexington, KY 40504

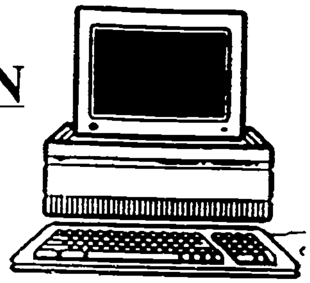
WE ARE [illegible] A VOLUNTEER NON PROFIT CORPORATION AND PARENT GROUP. To help with our costs, we encourage parents and [illegible] help us seek businesses that would like to donate to PCDSI, Inc. (Parents Confronting Dual Sensory Impairments, Inc.) by sending [illegible] donations to the above address. Note: Parents of children with only visual and hearing impairments may wish to contact Sharon Cole [illegible] 502 276-9516. Parents of children with multiple handicaps and/or other additional handicapping conditions may wish to contact [illegible] at 3428 Crimson King Ct., Lexington, KY 40517, or call 606 2[illegible] 1992, 606 257-3586, or 800 365-1258.

[illegible] Newsletter PCDSI, Inc. [illegible]

FREE COMPUTER APPLICATION

Made Possible by PCDSI, Inc.

Parents Confronting Dual Sensory Impairments



MAIL BY AUGUST 1 TO: Bob Moore
Parent and Computer Advisor
929 Wolf Run
Lexington, KY 40504

PLEASE TAKE TIME TO ANSWER THE FOLLOWING QUESTIONS:

[ ] YES. I want to connect by computer modem with other parents and do give permission for my name to be shared with another parent in a like situation.

[ ] NO. I do not want to connect by computer modem at this time, but I want to be on the mailing list and will send my ideas for helping our family in the future.

Name: ____

Address: ______________________________ (zip code) __________

Phone Number: (with area code) ______________________________

Age of Child: ____

- - - - - - - - - - - - - - *FOLD IN HALF HERE FOR MAILING PURPOSES* - - - - - - - - - - -

Tell us a little about your child: ______________________________

Is your child registered on Kentucky's state deaf/blind registry (census)? ________

Is your child in the referral stage for the registry (census)? ______________

If so, how long has it been since the referral was made? ______________

Do You have a computer? ______ If so what kind? ______________

If you have a computer, do you use it? ______ If not, why? ______________

Do you have a modem for your computer? ____ if so, what kind? ______________

If you have a modem, do you use it? ______ If not, why not? ______________

If so, what communication software are you using? ______________

PCDSI, Inc. is an ALL VOLUNTEER nonprofit parent group. To help defray costs, we encourage parents who can afford it and who want to receive information from PCDSI, Inc. (Parents Confronting Dual Sensory Impairments, Inc.) to send tax-deductible donations to the above address. *Note: Parents of children with only visual and hearing impairments may wish contact Sharon Cole at 502 276-3306 or 502-276-9516. Parents of children with multiple handicaps and/or other additional handicaps may wish to contact Brenda Pezzarossi at 3428 Crimson King Court, Lexington, KY 40517 or by calling 606/272-1992, 606/257-3586, or 800/365-1258.*

Free
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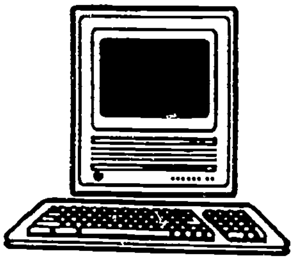
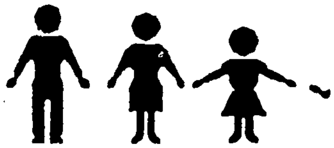
for the
BLIND



Bob Moore, Parents for DEAF/BLIND Children
Parents Confronting Dual Sensory Impairments, Inc.
Computer & Modem Networking Advisor
929 Wolf Run
Lexington, Kentucky 40504

SURVEY about NEEDS of PARENTS and FAMILY SUPPORT



WHAT PARENT/FAMILY SUPPORT ARE YOU RECEIVING? (CHECK BELOW!)

☐ I feel that nobody understands my particular situation.
☐ I have nobody with whom I can discuss my personal needs or who understands.
☐ I feel the need to help other parents going through a similar situation.
☐ I have a close family member who understands what I am going through.
☐ I have someone else I can reach by telephone who understands what I am going through.
☐ I have a relative with whom I can discuss my situation and who understands.
☐ I do not have relatives with whom I can discuss my situation.
☐ I have another parent of a child with disabilities who understands my situation.
☐ I have a professional person I can call during their working hours.
☐ I have a professional person whom I can call day or night and on weekends and holidays.
☐ I would like to hear success stories of parents with children similar to mine.
☐ My child's school service providers have not received any or enough training.
☐ My child's school service providers do not feel adequately prepared to teach my child.
☐ My child's school service providers are confident they can offer the best for my child.
☐ I am concerned about the future for my child, but have no dependable resources.

We are an ALL VOLUNTEER separate parent group operating as a non-profit corporation. To help meet our costs. we urge anyone who wants to receive information from PCDSI, Inc. (Parents Confronting Dual Sensory Impairments, Inc.) to give to our cause and/or to help us seek donations. Tax-deductible gifts should be mailed to PCDSI. Inc., Rt. 2, Box 15A, Fordsville, KY 42343.

- *-fold here to return by mail* -

Parents of children with only visual and hearing impairments may wish contact Sharon Cole at 502/276-3306 or 502/276-9516. Parents of children with multiple and/or additional handicaps may wish to contact Brenda Pezzarossi at 3428 Crimson King Court, Lexington, KY 40517 or by calling 606/272-1992, 606/257-3586, 800/365-1258.

DO YOU WISH TO NETWORK WITH OTHER PARENTS?

☐ YES. I wish to network with other parents. Please send me the name & address of a parent in a like situation. I also give permission for my name, address, and phone number to be shared with another parent in a like situation.
☐ NO. I do not wish to network at this time, but I do wish to be on the parent's mailing list. Please add a page and mail your comments or suggestions. You may fill out the survey above and leave off your name below.

Parent/Guardian Name: ____________________

Address: ____________________

City: ____________________ State: __________ Zip: __________

Telephone: (with area code) HOME- ____________________ WORK ____________________

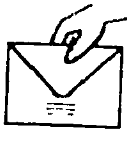
Child's Name: ____________________

Date of Birth: (Month, Day, Year) ____________________

Siblings: (Name, Date of Birth) ____________________

Mail to :

Brenda Pezzarossi, Parent Coordinator
3428 Crimson King Court
Lexington, KY 40517



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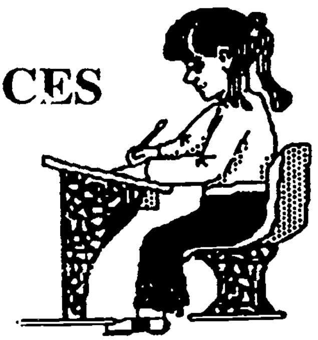
Parent Coordinator for DEAF/BLIND Children
STATEWIDE PARENTS' NEEDS SURVEY
Parents Confronting Dual Sensory Impairments, Inc.
3428 Crimson King Court
Lexington, Kentucky 40517

QUESTIONNAIRE about SERVICES for our CHILDREN



Mail to : Sharon Cole, PCDSI, Inc. President
P.O. Box 60, 2428 State Hwy. 54
Fordsville, KY 42343

We are an ALL VOLUNTEER **organization and parent group.** To help with our costs, we encourage parents to help us seek **businesses** that would like to donate to PCDSI, Inc. (Parents Confronting Dual Sensory Impairments, Inc.) by sending **tax-deductible** donations to the above address. *Note: Parents of children with only visual and hearing impairments may wish to contact Sharon Cole at 502/276-3306 or 502/276-9516. Parents of children with multiple handicaps and/or other additional handicaps may wish to contact Brenda Pezzarossi at 3428 Crimson King Court, Lexington, KY 40517 call 606/272-1992, 606/257-3586, 800/365-1258.*

Parent GuardianName: ______________________

Address: ______________________

City: ______________ State: ______ Zip: ________

Telephone: (with area code) HOME- ____________ WORK- ____________

Child's Name: ______________________

Date of Birth: (Month, Day, Year) ______________________

- - - - - - - - - - - - - **FOLD HERE AND MAIL TO ADDRESS ON BACK** - - - - - - - - - - - - -

Where is Your Child & What Services is Your Child Receiving? (CHECK BELOW!)

- ☐ Public School (mainstreamed with no itinerant or special education teacher)
- ☐ Public School (mainstreamed with itinerant or special education teacher)
- ☐ Public School (resource room and mainstreamed combination)
- ☐ Public School (resource room/self-contained only and not mainstreamed)
- ☐ Private or Parochial School (for children with disabilities)
- ☐ Private or Parochial School (for children without disabilities)
- ☐ Either State School for the Deaf or Blind (with integration into Public School)
- ☐ State School for the Blind (without integration into Public School)
- ☐ State School for the Deaf (without integration into Public School)
- ☐ Institution care provided by the state (along with public school services)
- ☐ Institution care provided by the state (without any public school services)
- ☐ Home care (with home-bound school services)
- ☐ Home care (without any school services)
- ☐ Protection & Advocacy (P&A) has advocated for more services for my child.
- ☐ Out of school (due to age)
- ☐ Out of school (for other reasons) Please list reasons: ______________________

____

____

DO YOU WISH TO NETWORK WITH OTHER PARENTS?

☐ YES. I wish to network with other parents. Please send me the name & address of a parent in a like situation. I also give permission for my name, address, and phone number to be shared with another parent in a like situation.

☐ NO. I do not wish to network at this time, but I do wish to be on the parent's mailing list. My comments or suggestions are as follows. Please write in the space below or add a page and mail to the PCDSI, Inc. president at the addresss on the back of this questionnaire.

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BLIND
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PCDSI, Inc. for DEAF/BLIND Children
CHILDRENS' SERVICES QUESTIONNAIRE
Parents Confronting Dual Sensory Impairments, Inc.
P.O. Box 60, 2428 State Hwy. 54
Fordsville, Kentucky 42343

DEADLINE NEAR!

LAST CHANCE!

Parents Confronting Dual Sensory Impairments
PCDSI, Inc.
AUGUST '93 FAMILY FORUM

Our FAMILY FORUM will be held August 13, 14 and 15, 1993. We need to know your needs for special accomodations now in order to be better able to plan for a successful event. PCDSI, Inc. will be paying your travel expenses, meals, overnight accomodations and respite care. If you have any other needs or questions in order to be able to attend this FAMILY FORUM, please let PCDSI, Inc. know by writing the address above or on the reverse of this form. You may call Sharon Cole at (502) 276-3306 or (502) 276-9516.

_____Yes _____No I am interested in attending this year's FAMILY FORUM. If you answered No, please return this form anyway and please let us know your reasons for not being able/interested in attending. Thanks!

_____Yes _____No We have a form of transportation.

_____Yes _____No We will need an interpreter.

_____Yes _____No We will need braille or large print materials.

_____Yes _____No We have special diet needs for someone in our family who will be attending. Please explain, if you answered yes to this question.

================================FOLD THIS SHEET IN HALF================================

_____Yes _____No We have special needs (crib, bed rails, air conditioning, equipment, wheel chair accessible rooms) for respite care. Please explain, if you answered yes.

CHILD'S NAME (on Deaf/Blind state registry or in referral process) AGE

CHILD'S WEIGHT CHILD'S HEIGHT CHILD'S T-SHIRT SIZE

SIBLING(S) AGE T-SHIRT SIZE

SIBLING(S) AGE T-SHIRT SIZE

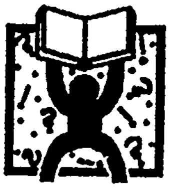
SIBLING(S) AGE T-SHIRT SIZE

YOUR CHILDRENS' FAVORITE FORMS OF RECREATION OR ENTERTAINMENT

Please take a few minutes to mail this form back if you think your attendance at this year's FAMILY FORUM is possible. You may simply fold, tape shut, and add a stamp to return this form. Please return as soon as possible to this address and/or on the reverse side of this sheet.

Family Forum Registration
PCDSI, Inc. President
PO Box 60, 2428 State Hwy. 54
Fordsville, KY 42343

Cochlear Implant Information Requested



Catherine Schlasinger will be three on her next birthday which is October 19, 1993. She is a new addition to our family after being recently legally adopted on May 14. Catherine has cerebral palsy and has made an eighty per cent recovery from cortical blindness due to her previous brain trauma. On Catherine's behalf, we are going through the cochlear implant evaluation at the Children's Hospital in Cincinnati, Ohio. Cochlear implants are currently only done on children who are cognitively on target. I am interested in being contacted by another parent who has a child with multiple physical disabilities and has gone through the cochlear implant. I would also welcome information from any professional who has information about any multihandicapped disabled child who has been through a cochlear implant.

You may talk to Pat Schlasinger at (606) 441-2740. Her address is:

Pat Schlasinger
156 Park Place
Ft. Thomas, KY 41075

Respite Care!

Entertainment and Music!

Activities and Fun!

It's the Family Forum!

Once a Year Experience

ATTENTION: Parents, you must mail your $10.00 NOW to reserve a room at the Kavenaugh Center Crestwood, Kentucky. This was decided by the PCDSI, Inc. board as a way to be sure all the reserved rooms are occupied. Please mail to the address on the enclosed Family Forum registration form.

INSIGHT

Reach for the Stars

INSIGHT PARENT NEWSLETTER
PCDSI, Inc./PFP Parent Coordinator
P.O. Box 60, 2428 State Hwy. 54
Fordsville, KY 42343

Stamp

UNITY

I dreamed I stood in a studio
And watched two sculptors there.
The clay they used was a young child's mind
And they fashioned it with care.

One was a teacher; the tools she used
Were books and music and art;
One a parent with a guiding hand
And a gentle loving heart.

Day after day the teacher toiled,
With touch that was deft and sure,
While the parent labored by his side
And polished and smoothed it over.

And when at last their task was done
They were proud of what they had wrought.
For the things they had molded into the child
Could neither be sold nor bought.

And each agreed he would have failed
If he had worked alone.
For behind the parent stood the school,
And behind the teacher the home.

Author Anonymous

This newsletter is published and mailed with funds obtained through a grant obtained by PCDSI, Inc. from the Kentucky Department of Education. It was written, designed, and edited by Brenda Pezzarossi, Parent Coordinator.

Appendix IX-C

Mission Statement for the Kentucky Chapter of the Deaf-Blind

MISSION STATEMENT
OF
KENTUCKY ASSOCIATION OF THE DEAF-BLIND

We believe that we have the right to live, work, play, worship, and FULLY experience life in the community of our choice with supports as needed. We believe that we have the right to contribute our talents and gifts to the community of our choice. We have the right to make our own choices and to receive services that will increase our abilities. We have the right to be treated with dignity and respect. We can be strong self-advocates when we get support from our family, friends and professionals and work together with them.

Personal Futures Planning Project Facilitators Training Manual

PERSON-CENTERED PLANNING
For People with Dual Sensory Disabilities

FINDING DIRECTIONS FOR CHANGE USING PERSONAL FUTURES PLANNING

A Sourcebook of Values, Ideals, and Methods to Encourage Person-Centered Planning for People Who are Deaf and Blind

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has."

Margaret Mead

By: Beth Mount
With: Carolyn Bardwell Wheeler
October, 1991

Supported by a Grant Through the Interdisciplinary Human Development Institute
University Affiliated Program of the University of Kentucky
Funds Are Available to this Project From the Office of Special Education Services

PERSON-CENTERED PLANNING
For People with Dual Sensory Disabilities

By: Beth Mount
Graphic Futures, Inc.
25 West 81st Street, 16-B
New York City, NY 10024

With: Carolyn Bardwell Wheeler
Personal Futures Planning Project
1867 Frankfort Avenue
Louisville, KY 40206

Production of this material was made possible by a grant from the Office of Special Education Services through the Interdisciplinary Human Development Institute (IHDI), University of Kentucky.

The stories, examples, and sections specific to the challenges of planning with people with dual-sensory impairments and their families have been provided by Carolyn Bardwell Wheeler as a result of her work with the Personal Futures Planning Project for Individuals with Deaf-Blindness, IHDI, University of Kentucky. Permission for use of these materials cannot be reproduced without the written permission of Carolyn Bardwell Wheeler. The names of people have been changed in respect for their privacy.

Acknowledgements: We are grateful to the people with dual-sensory disabilities and their families who are participating in the Personal Futures Planning Project. Their lives, struggles, hopes, and dreams have informed and directed our work.

We appreciate the support of Dr. Harold Kleinert, who has promoted this project from the beginning. Special thanks to Kathy McNulty and the staff at the Helen Keller National Center who helped develop the Communication Map described in this manual, and have informed our work and inspired families to work toward new possibilities.

PERSON-CENTERED PLANNING

Contents

CHAPTER 1: VALUES AND PHILOSOPHY OF PERSON-CENTERED DEVELOPMENT

This is a challenging time for those of us working with people with disabilities in human service settings. We are learning more about listening to people with handicaps and shaping services to support valued lifestyles for each person, which we will call PERSON-CENTERED development. However, many of us work in human service settings which are organized to be SYSTEM-CENTERED instead of person-centered. We face a turning point in human services today as we learn to let go of system-centered thinking and practice, and learn new ways of thinking and practice which focus on quality of life for everyone.

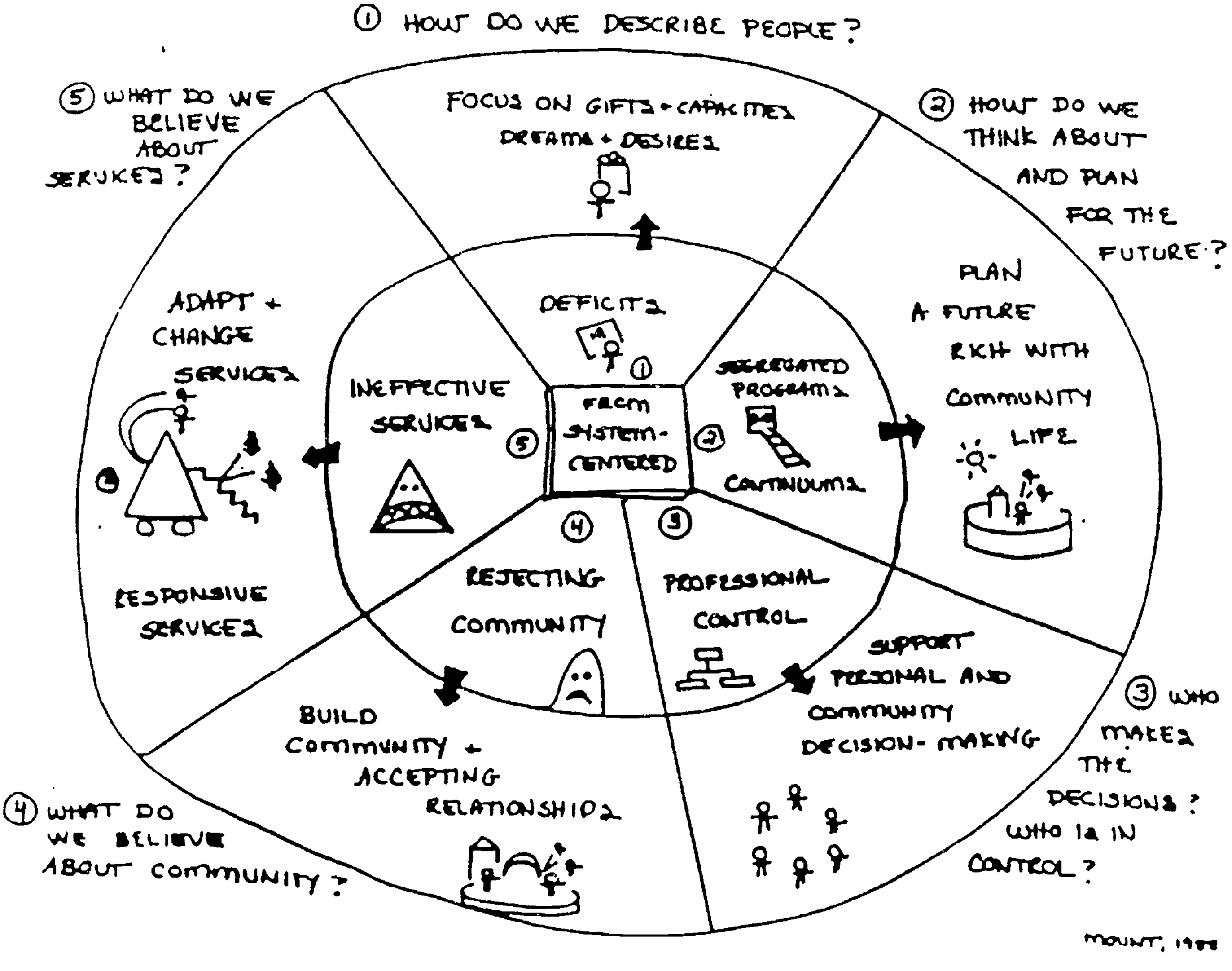
This section provides an overview of the values of person-centered development in contrast to the assumptions and practices of system-centered development. Personal Futures Planning is then described as a tool that can help people implement the ideals of person-centered development. Personal Futures Planning is both a planning tool and a different way of seeing and thinking about people with disabilities. This new way of thinking is vividly illustrated by telling the story of Tom throughout this section from a system-centered perspective in contrast to an alternative person-centered view.

Why is person-centered development so important? The common experiences of people with handicaps reveal that they often suffer from rejection, isolation, poverty, and discrimination as a result of their difference. System-centered practices often reinforce these painful experiences by further stigmatizing, segregating, and distancing people with disabilities from their local communities.

Person-centered development seeks to reverse these painful realities by working to support the contribution of each person in local community life. Person-centered development invites us to 1) find and develop the gifts of each person, 2) to develop a vision that expresses these gifts, 3) to build a support group to make these ideals happen, 4) to build a community network of acceptance, and 5) to change services to be more responsive to the interests of people. Each of these ideals is discussed in the following section.

THE TURNING POINT IN HUMAN SERVICES:

Contrasting System-Centered and Person-Centered Assumptions



MOUNT, 1988

HOW DO WE DESCRIBE PEOPLE?

Person-centered change challenges us to value each person as unique, filled with gifts and possibilities, to find ways to discover our common experience and work together to build a life where these gifts can be shared with others.

From **SYSTEM-CENTERED**	Toward **PERSON-CENTERED**
* Focus on labels.	* See people first.
* Emphasis on deficits, needs.	* Search for capacities, gifts.
* Invest in standardized testing and assessments.	* Spend time getting to know people.
* Depend on professionals to make judgments.	* Depend on people, families, and direct service workers to build good descriptions.
* Generate written reports.	* Gather folklore from people who know people well.
* See people in the context of of human service systems.	* See people in the context of their local community.
* Distance people by emphasizing difference.	* Bring people together by discovering common experience.

The deficiency description of Tom summarizes the dominant view of him taken from written evaluations compiled by professional specialists who see him mostly by how he is different from other people. The contrasting capacity view tells another story of Tom based on the folklore and descriptions of people who know him well. This capacity view emphasizes his interests, gifts, and contributions, which will have a significant impact on how people also think about the future.

CONTRASTING A DEFICIENCY/CAPACITY DESCRIPTION

WHO IS TOM? A DEFICIENCY VIEW

Mr. Smith is a 17 year old male.
His disability includes deafness from birth, also blindness.
They cannot repair his detached retina because of his self-abuse and tendencies for autism and uncontrollable behavior.
It was said that his behaviors at school are sometimes very violent.
Before his blindness, he was known to be very violent, and his behaviors to be sporadic with autistic tendencies.
He still has tendencies to show disruptive behavior.
People are afraid of him.
He has problems staying on tasks, he angers quickly, and will throw himself backwards.
Mental Retardation, probably severe to moderate.
He has never had a job. Vocational evaluation is very difficult.
When he did sit for more than five to ten minutes, he would become very tired and lazy, he would lean over and try to sleep.
It is very difficult to work with Mr Smith.
He demonstrates very poor physical mobility.
On tasks that involve sitting down, and working with very routine tasks, he becomes very bored, very quickly.
He is very hesitant to trail (walk) independently.
He is nonverbal.
His weaknesses include oral expression, listening comprehension, written expression, reading comprehension, math reasoning, inability to have satisfactory interpersonal relationships, and the ability to learn at the expected rate.
His abilities range from the 3-year level to above the 9-year level.
The Vineland Adaptive Behavior Scales show his adaptive skills to be very weak.

Some positive qualities buried among negative statements:

When Mr. Smith is challenged on a task such as simulated assembly he tries to use his problem solving ability to solve tasks to the best of his ability. He may benefit from vocational training using tools.
He responds appropriately to praise by smiling.
He is very independent. He picks up a routine quickly and follows a schedule.
He is completely independent in self-help skills.
He is able to write his name and words as well as acquiring other academic skills.
No problems have been noted when he is in the community.

WHO IS TOM? A CAPACITY VIEW

He is lovable.
He has a sense of humor and will laugh with you.
He is playful.
He has good self-help skills and can take care of himself.
He is the member of an extended family and a brother to Marty.
He is smart.
He is not abusive to other people.
He entertains himself.
He likes to please other people.
He likes music, to feel the speakers and vibrations.
He likes swimming and being in the water.
He is interested in shopping, trying on clothes, and going to the grocery store.
He is interested in video games.
He is fascinated with cars, he started one when he was six years old.
He is mechanical. He figured out how to keep a washing machine going with the top up! He can make the TV picture go fuzzy and then fix it.
He likes riding in the car, and windshield wipers.
He likes going out to church, restaurants, walking in the park, going to the mall, and horseback riding, and swimming.
He likes drawing, markers, puzzles and his communication book.
Being with his family is important to him.
He knows when people don't like him, when they are rejecting.

Ways that Tom challenges people to accept him:

He has a long history of self-abusive behavior.
He is deaf and blind and has difficulty communicating with others.
He is a large young man and he scares people with his size and awkwardness.
He has been bored a lot and gets frustrated.
He is frustrated when people don't make the effort to communicate with him.
He doesn't like certain activities such as an exercise bicycle.

HOW DO WE THINK ABOUT AND PLAN FOR THE FUTURE?

Person-centered change challenges us to discover and invent a personal dream for people; to craft a pattern of living that increases people's participation and belonging in community life.

From SYSTEM-CENTERED	Toward PERSON-CENTERED
* Plan a lifetime of programs.	* Craft a desirable lifestyle.
* Offer a limited number of usually segregated program options.	* Design an unlimited number of desirable experiences.
* Base options on stereotypes about people with disabilities.	* Find new possibilities for each person.
* Focus on filling slots, beds, placements, closures.	* Focus on quality of life.
* Overemphasize technologies and clinical strategies.	* Emphasize dreams, desires, and meaningful experience.
* Organize to please funders, regulators, policies and rules.	* Organize to respond to people.

The deficiency future for Tom summarizes the negative predictions about his future generated in the traditional program planning process. This deficiency future suggests segregated options that emphasize the reduction of negative behaviors. The contrasting capacity future tells another story of possibility for Tom. This alternative future emphasizes increased community experience and community life through inclusion, meaningful work, a real home, and friendships.

A DEFICIENCY FUTURE

Limited predictions about Tom's future:

A Trainable Mentally Handicapped classroom in a **segregated** classroom.

He needs direct services from a speech clinician, itinerant teachers of the hearing and vision impaired, an orientation specialist, and an occupational therapist.

He needs individualized Orientation and Mobility Instruction.

Improve receptive/expressive language skills in signs.

Improve math skills, improve postural/ocular skills, and increase physical endurance and coordination.

Psychotropic **medication**.

A behavior management plan to **reduce** self-injurious behavior, property destruction, and aggression toward others.

Control of inappropriate self-abusive behavior by continuing with Navane and Cogentin as prescribed. Evaluations of medications to be done every 60 days through medication review.

Sheltered employment where he would be very familiar with one task such as assembly tasks.

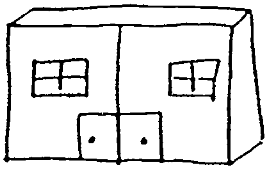
He **could not live in the community** because of his behaviors.

He requires a very stable and predictable environment. At the present time it seems that this might best be met in **a facility**.

He needs 24 hour close supervision with **on-sight medical** capabilities.

He needs integrated/augmented services for the hearing and visually impaired with appropriately trained staff, structured emotional support, psychological follow-up, medical monitoring, family access and involvement, vocational training, structured day habilitation activities, and domestic skills training.

A CAPACITY FUTURE
A Positive Vision of Tom's Future:



SCHOOL

• *FRIENDS* •

- HIGH SCHOOL NEAR WHERE TOM LIVES
- TO BE WITH KIDS HIS OWN SIZE + AGE
- WORKOUT, EXERCISE IN GYM, SWIMMING POOL
- A ROLE WITH THE FOOTBALL + BASKETBALL TEAM
- TO HAVE FRIENDS WITH OTHER STUDENTS
- A FULL DAY

• *GOOD INSTRUCTION* •

- LEARNING IN:
  - Domestic
  - Computers
  - Leisure
  - Vocational
- 1 to 1 INTERPRETER
- CONSISTENCY
- ACTIVE, NOT BORING

COMMUNITY LIFE

- MEMBERSHIP AT AMERICAN FITNESS CENTER – HEALTH CLUB
- FAMILY LIFE: SUPPORT FAMILY MEMBERS TO VISIT, GO TO DINNER, GO SWIMMING, OR TO LAUNDRY MAT 1 A MONTH.
- GOING OUT TO EAT, GOING TO CHURCH
- RECREATION: ACTIVE, PHYSICAL:
  - ➔ WALKING ➔ SWIMMING
  - ➔ HOURSEBACK RIDING
  - ➔ BOWLING ➔ SHOPPING
  - ➔ GOING TO THE MALL
- ART EXPLORATION
  - ➔ DRAWING, PAINTING, CLAY, EXPLORE DIFFERENT MEDIUMS
- VOCATIONAL EXPLORATION
  - ➔ WASHING CARS / DISHES
  - ➔ ELECTRICAL
  - ➔ PUTTING THINGS TOGETHER

"HIS HOME"

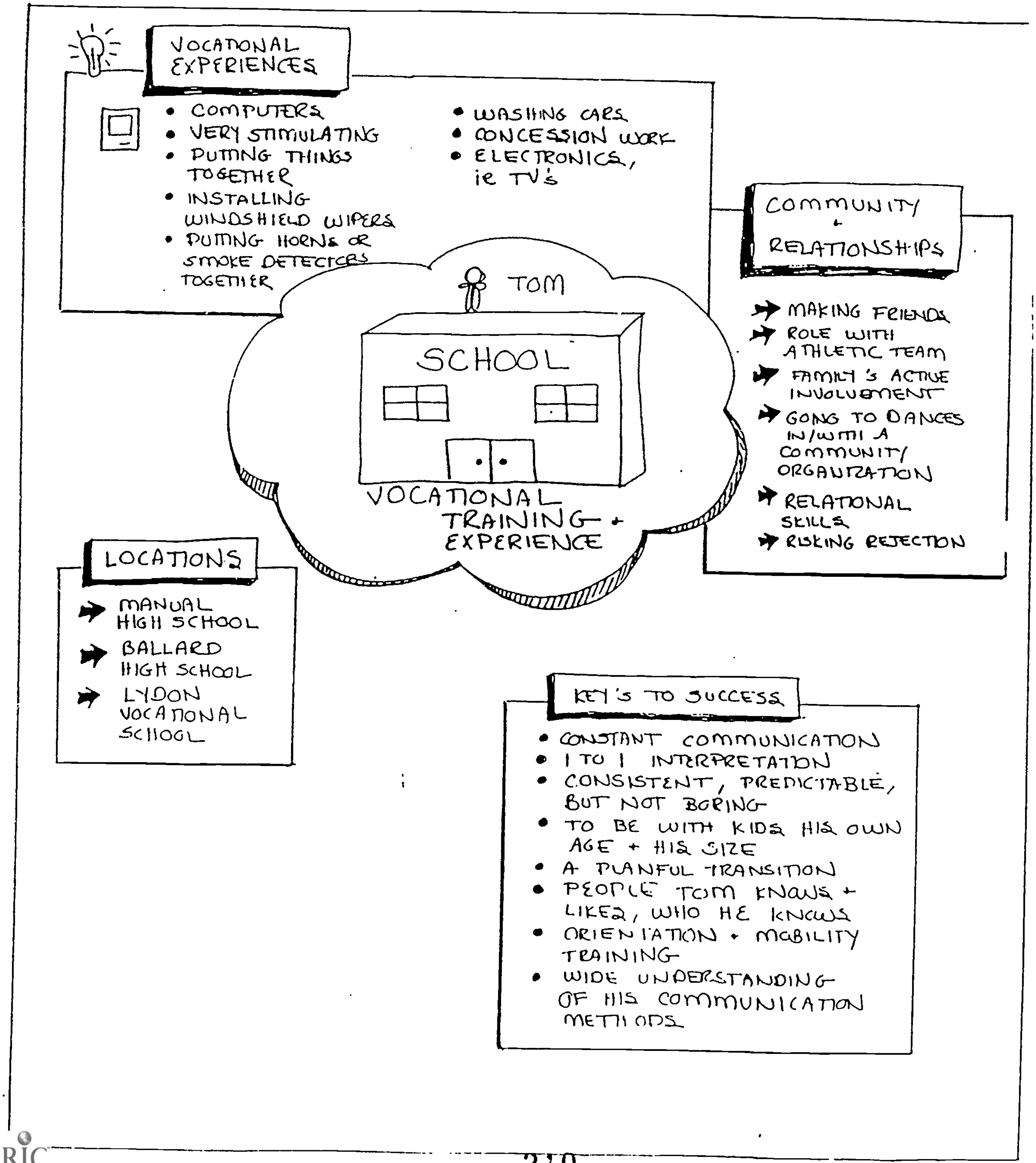
HOME

- CLOSE TO PARK + THE MALL, RESTAURANTS, BOWLING, SWIMMING POOL

- HOUSE WITH A YARD
- ROOMMATE: someone he knows maybe Walter
- CLOSE TO FAMILY – (but not next door)

- DOMESTIC SKILLS
  - ➔ COOKING
  - ➔ LAUNDRY
  - ➔ GROCERY SHOPPING

More Images for Tom's Future:



VOCATIONAL EXPERIENCES

- COMPUTERS
- VERY STIMULATING
- PUTTING THINGS TOGETHER
- INSTALLING WINDSHIELD WIPERS
- PUTTING HORNS OR SMOKE DETECTORS TOGETHER
- WASHING CARS
- CONCESSION WORK
- ELECTRONICS, ie TV'S

COMMUNITY + RELATIONSHIPS

- MAKING FRIENDS
- ROLE WITH ATHLETIC TEAM
- FAMILY'S ACTIVE INVOLVEMENT
- GOING TO DANCES IN/WITH A COMMUNITY ORGANIZATION
- RELATIONAL SKILLS
- RISKING REJECTION

VOCATIONAL TRAINING + EXPERIENCE

LOCATIONS

- MANUAL HIGH SCHOOL
- BALLARD HIGH SCHOOL
- LYDON VOCATIONAL SCHOOL

KEY'S TO SUCCESS

- CONSTANT COMMUNICATION
- 1 TO 1 INTERPRETATION
- CONSISTENT, PREDICTABLE, BUT NOT BORING
- TO BE WITH KIDS HIS OWN AGE + HIS SIZE
- A PLANFUL TRANSITION
- PEOPLE TOM KNOWS + LIKES, WHO HE KNOWS
- ORIENTATION + MOBILITY TRAINING
- WIDE UNDERSTANDING OF HIS COMMUNICATION METHODS

WHO MAKES THE DECISIONS? WHO IS IN CONTROL?

Person-centered change challenges us to learn together with people how to solve problems over time to make meaningful change happen.

From	Toward
SYSTEM-CENTERED	**PERSON-CENTERED**
* Professional control. Professionals know best.	* Shared decisions with person, family, and friends.
* Delegate work to direct service workers.	* Empower direct service workers to make good decisions.
* Rely on standardized interdisciplinary teams to generate plans.	* Create person-centered teams to solve problems over time.
* Organize efforts in conference rooms for the convenience of professionals.	* Organize efforts in community to include person, family, and direct service workers.
* Take action to follow rules and regulations.	* Reflect together as a basis for setting priorities.
* Spend lots of time planning with little time to take action.	* Spend lots of time taking action, with regular times to reflect.
* Respond to need based on job descriptions.	* Respond to people based on shared responsibility and personal commitment.
* Create distance through process.	* Share struggle by working together.

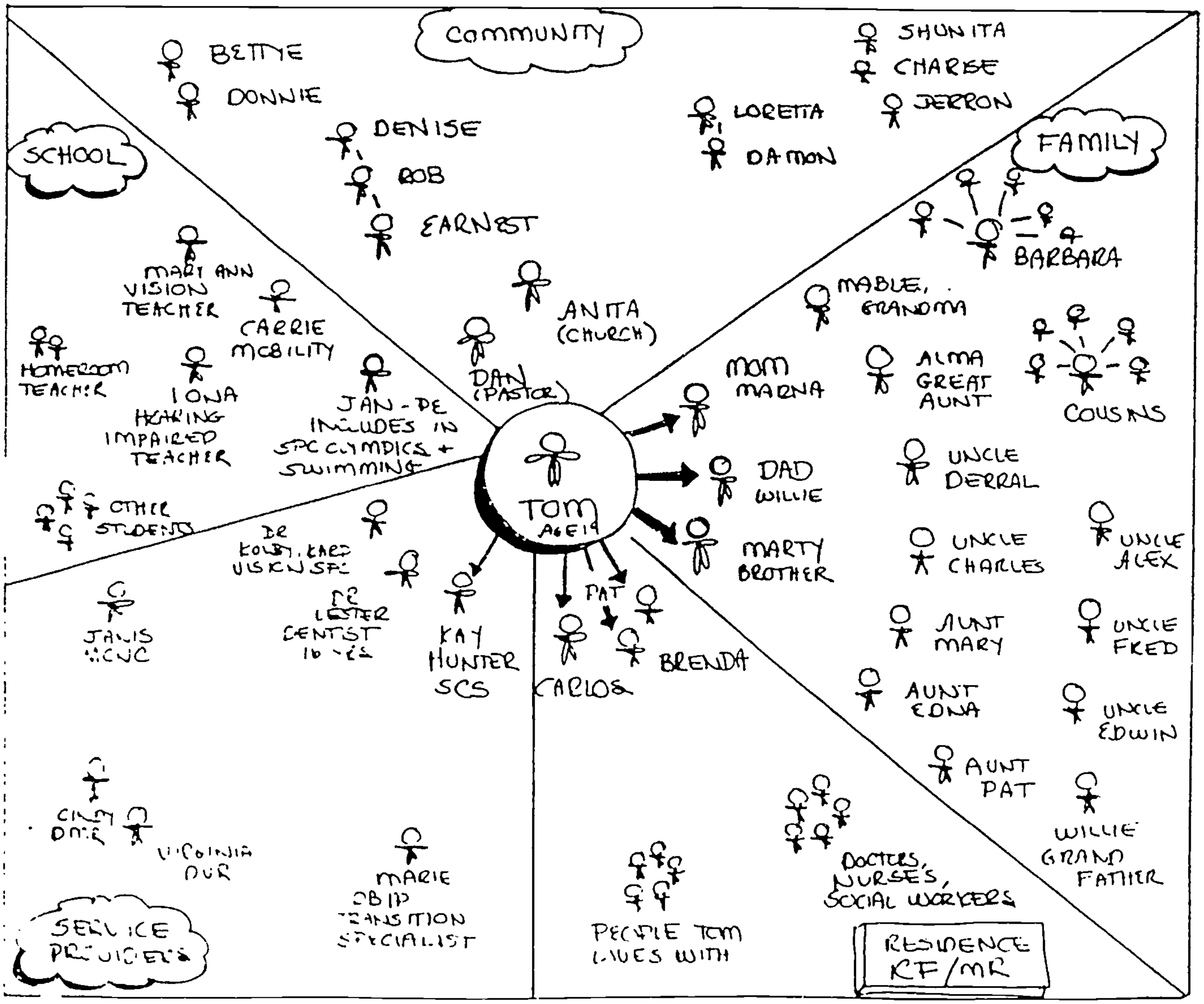
Tom's deficiency future depends on the coordinated efforts of a number of specialized staff. While these professionals may make important contributions to Tom's future, his relationship map reveals a much larger group of people who can participate in shaping the quality of his life.

CONTRASTING AN INTERDISCIPLINARY/INTERVISIONARY TEAM

The Interdisciplinary Team for Tom

- Vocational Counselor
- Certified Orientation and Mobility Specialist
- Educational Examiner
- School Psychomotrist
- Nurse
- Recreation Therapist
- Registered Dietician
- Social Worker
- Physician
- Occupational Therapist
- Pharmacist

The Intervisionary Team for Tom



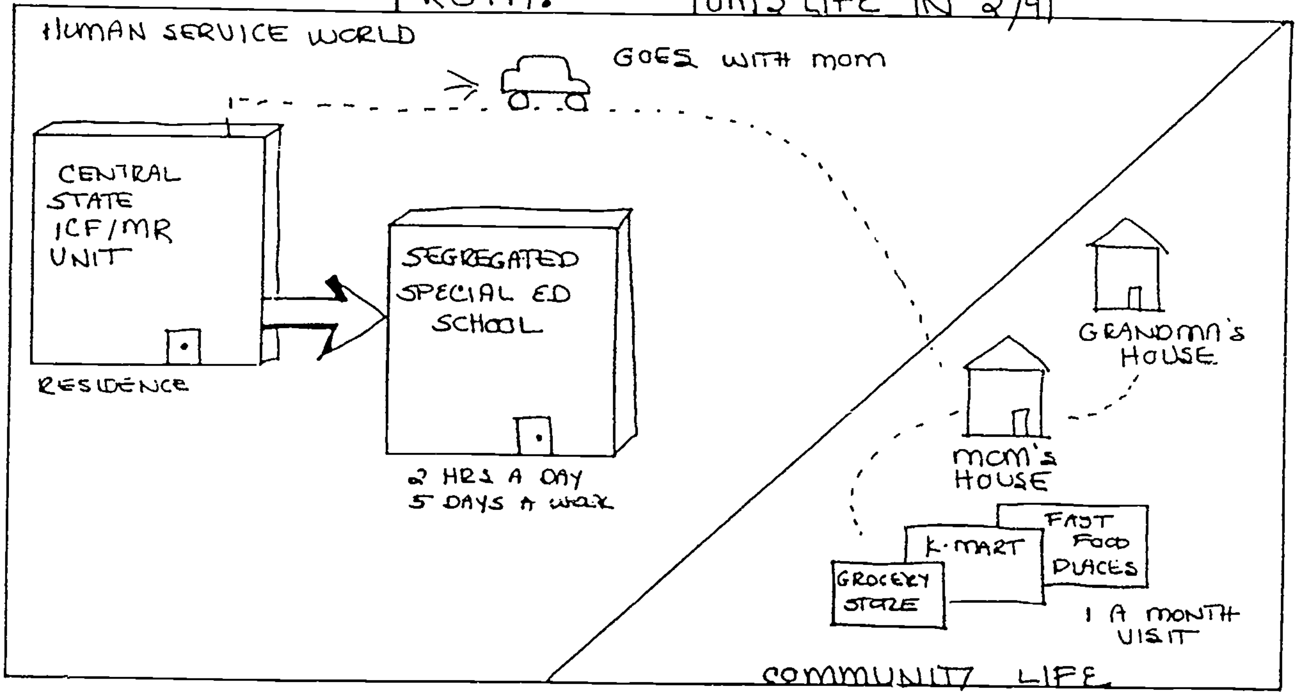
WHAT DO WE BELIEVE ABOUT COMMUNITY?

Person-centered change challenges us to learn new ways to build relationships, to find welcoming spaces in community life, and to invent new forms of community experience.

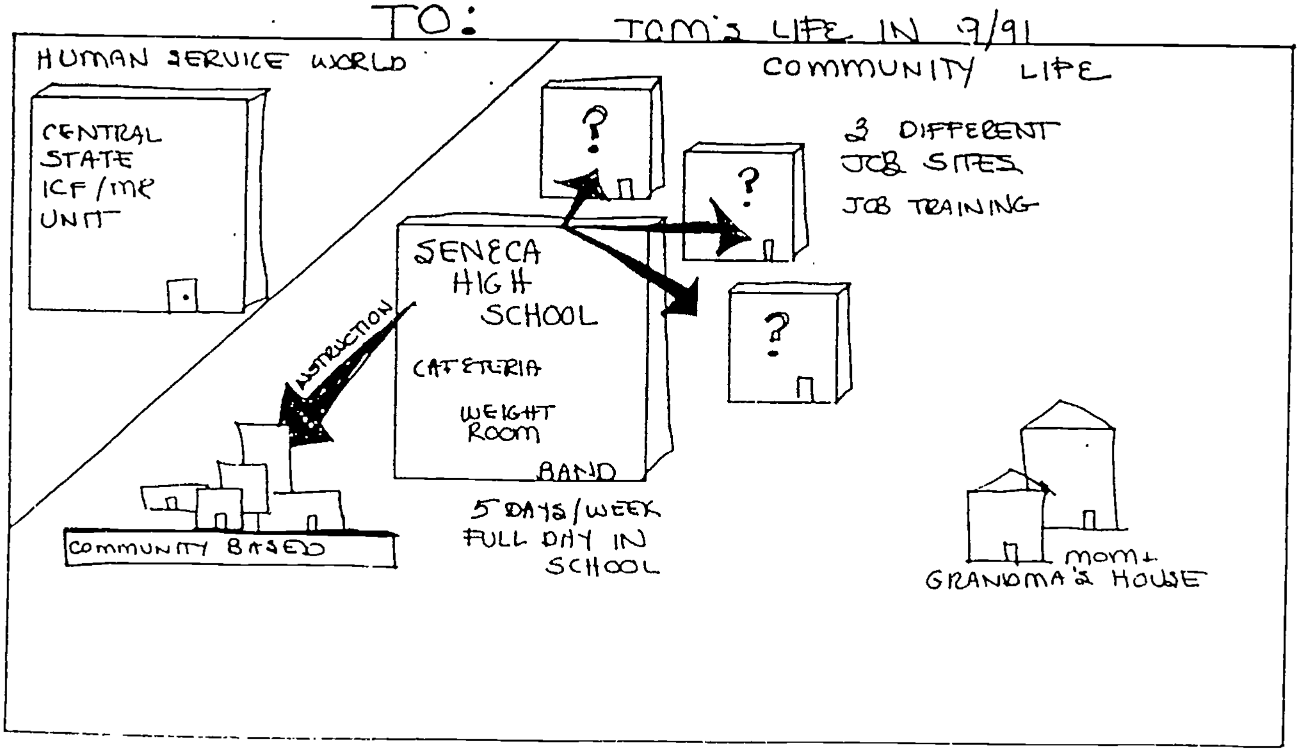
From	To
SYSTEM-CENTERED	**PERSON-CENTERED**
* Community is rejecting.	* Community can be welcoming.
* Protect and congregate people with labels.	* Negotiate acceptance by building relationships.
* Focus on fearful, dangerous, and exploitative side of community.	* Find safety and build trust networks.
* Simulate safety in segregated settings.	* Find associations, settings, and people who facilitate new experience.
* Avoid prejudice by reinforcing segregation.	* Invite involvement by finding and building open spaces.
* Seek quick-fix solutions that reinforce rejection.	* Invest in long term commitment to build openness in local community life.

PERSON-CENTERED CHANGE ENCOURAGES EXPLORATION IN COMMUNITY ASSOCIATIONAL LIFE:

FROM: TOM'S LIFE IN 2/91



TO: TOM'S LIFE IN 9/91



WHAT DO WE BELIEVE ABOUT SERVICE SYSTEMS?

Person-centered change challenges us to make dramatic changes in the structure and processes of service delivery.

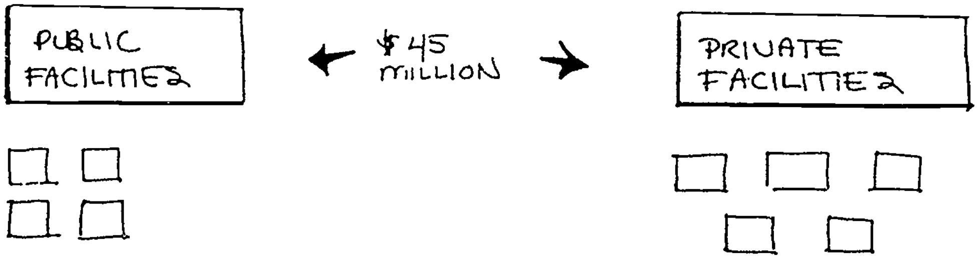
From	Toward
SYSTEM-CENTERED	**PERSON-CENTERED**
* Services are not responsive to individual need.	* Services can adapt and respond to people.
* Services exist to maintain the interests of professionals.	* Resources can be distributed to serve the interests of people.
* Budgets are structured to maintain investments in buildings and property.	* Budgets can be structured to provide individualized packages of support to people.
* Services are hopelessly entangled by bureaucratic complexity.	* People paid by service systems can be supported to respond to people.
* Services are impersonal.	* People paid by service systems can provide caring, personal support.
* Services hurt more than they help.	* Services can provide support that people find helpful.
* Quality depends on bureaucratic safeguards.	* Quality depends on good information and creativity.
* New initiatives are only worthy if they can be quickly implemented on a large scale basis.	* Initiatives are worthy if they must start small and develop over time.

WHAT WOULD IT TAKE TO TRANSFORM THE DUAL SYSTEM OF SERVICES IN KENTUCY

to Reallocate the Money Spent on System-Centered Options so That People Would Have the Support to Live in Their Own or Family Homes?

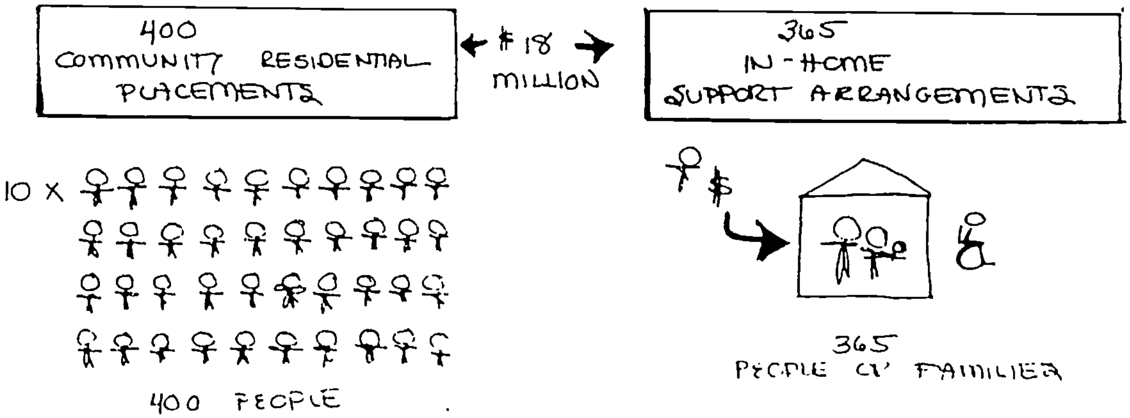
FROM: SYSTEM-CENTERED : INSTITUTIONAL

$45 WHAT WOULD IT TAKE TO TRANSFER
MILLION DOLLARS SPENT FOR 1200 PEOPLE
USING ICF-MR MEDICAID + STATE FUNDING



TO: PERSON-CENTERED : COMMUNITY BASED

$18 TO INCREASE THE
MILLION DOLLARS SPENT FOR 765 PEOPLE
USING ALTERNATIVE INTERMEDIATE SERVICES FUNDING
WHICH NOW LEAVES 10,500 ADULTS UNSERVED
IN KENTUCKY



CHAPTER 2: FINDING CAPACITIES

The first challenge of a person-centered approach to planning with people is to learn to develop a capacity view of people. A capacity view does not deny or ignore the real limitations that challenge people on a daily basis. A capacity view does require us to see past the critical messages that surround people in the form of labels, negative predictions, and stereotypes so that we can see the whole person, a person full of gifts, potential, dreams, and a life to be lived.

The facilitator of a Personal Futures Plan must accomplish two tasks that can help uncover often hidden capacities. The first task is to **establish a relationship** with the person and those who know the person well, and the second task is to **develop a capacity description** of the person which we call the Personal Profile.

Getting to Know People

Person-centered planning begins with getting to know the person who is the focus of the planning process. Getting to know the person is a time to develop a relationship, to understand how people are living now, and to learn about or imagine their dreams. In learning about the person, we discover seeds and possibilities to nurture in the future. Getting to know the person gives us a chance to break through our stereotypes, professional roles, and impersonal approaches to find a new way to see people and feel the passion to work for change.

A person-centered approach to learning about a person enables us to learn about the person's life; friendships, favorite places to go, life stories, personal preferences and capacities, and dreams and fears. Learning about these things is often best done in an informal manner, by spending time with the person and the people who know them well. We've learned that the most interesting information about people is contained in the folklore of the people who have spent the most time together, and we rarely find this rich folklore in written reports and evaluations.

Sometimes people have lived a long time with little support and/or their capacities lie deeply buried under labels, negative reputations, and personal and organizational failure. We may need to spend a long time getting to know these people and developing some positive relationships for them before we can develop a capacity-based profile.

The Personal Profile

The facilitator of a personal futures planning process must design the best approach for getting to know the focus person, and building a description of their life and dreams from which other people can plan. The Personal Futures Planning process provides a specific tool, the Personal Profile, which is like an Atlas describing different areas of a person's life.

The facilitator begins the planning process by deciding the best method for gathering the information that forms the Profile. The facilitator selects the pieces of the Profile that will help others develop a common understanding of the person. The facilitator then develops a strategy for collecting the folklore and experiences that will complete the Profile. The Personal Profile process is a creative and informative process when it is adapted to fit each person and the people who will plan with them.

The Personal Profile provides an opportunity for the facilitator, the person who will be the focus of the plan, and invited friends and guests, to create an overview description of the current life of the person. The Personal Profile process can help the facilitator and others:

1. Get to know the person and listen to them.
2 Develop a shared appreciation of the gifts and capacities with this person, as well as the barriers and struggles they face.
3. Value and include, the perspectives of family members, direct service workers, friends, and other people who may often be excluded from a planning process.
4. Strengthen the voice of the person by clarifying their interests and desires, and naming the things that prevent them from expressing their capacities.
5. Establish a record of how things are now for future reflection.
6. Translate human service jargon by finding a common language.
7. Discuss values, options, and feelings in an informal situation.

It is often helpful to bring together a small group of people who work together to create the Personal Profile. The focus person and the people who know the person well are the most important people to include in this session. A lot of groundwork must go into preparing the Profile session to insure that the focus person is comfortable, the most helpful people are included and the most helpful frameworks are completed. The Personal Profile process lays the foundation for the planning meeting that follows.

Conducting a Personal Profile Session

Meeting frameworks help facilitators and groups organize information. In the Personal Profile process, the facilitator uses a number of frameworks, sometimes referred to as "maps" to help describe a person's life. The **basic** maps of the Personal Profile provide a fundamental description of the key areas of one's life; relationships, places, background, preferences, and dreams, hopes and fears. These basic maps often reveal opportunities and provide clues to build on in the future.

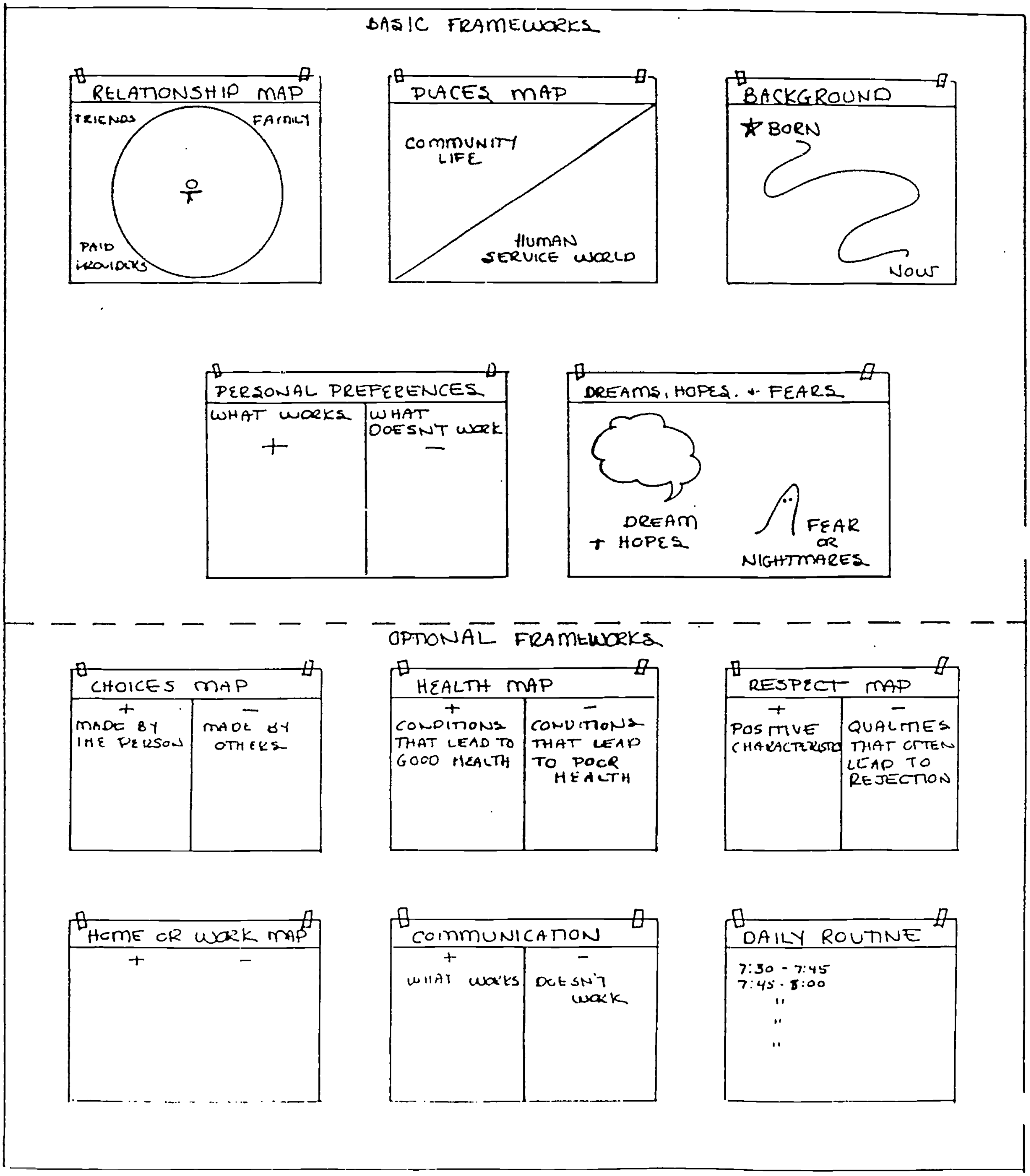
The Personal Profile includes **optional** maps to provide additional information when needed. These optional maps help us understand a person's life in more detail, particularly in areas of complexity such as health, autonomy, respect, and communication. For example, when the focus person has a number of sensory impairments that effect their capacity to communicate, we want to be sure to complete the communication map. A detailed description of information we could obtain from a communication map is provided in this section.

The facilitator of a Personal Futures Plan can use group graphics and meeting frameworks to aid the process of group dialogue and reflection. Group graphics help people organize information by color coding their experience, for example information about capacities is recorded in green, and information about difficulties in recorded in red. Meeting frameworks help people organize information and provide a focus for the group. These visual aides can help a group see and name patterns in the opportunities and barriers that are present in a person's life. An example of a complete personal profile is included in the appendix.

In summary, the meeting frameworks, the color coding, and graphics are all tools that can help us put the pieces of a person's life together to see new patterns and possibilities. The profile process is interactive and creative, and can evoke a new and deeper understanding of the person; their struggles, dreams, fears, and hopes.

These meeting techniques can help people make sense of their situation so they feel more competent to do something about it. However, if these meeting formats and tools get in the way, don't use them. Regardless of techniques, effective facilitators help people focus on capacities and opportunities, they help people describe a dream, they help people take action to make it happen, they never deny obstacles, and they help people get excited and engaged in the process of working together.

A FRAMEWORK FOR EXPLORATION: THE PERSONAL PROFILE



THE PERSONAL PROFILE:

BASIC FRAMEWORKS for getting to know the focus person.

Relationship Map:	*Identifies opportunities for personal support and assistance.* Helps to illustrate the most important people in the focus person's life. People interested in planning together over time, and opportunities for building relationships.
Places Map:	*Describes the pattern of current daily life.* Helps to illustrate how the focus person spends her time. How much time is spent in segregated or community settings, and existing opportunities for building community.
Background Map:	*Provides an overview of the life experience of the person and family.* Helps to illustrate positive experiences from the past to build on. Appreciation of the traumas, loss, and grief in life. Celebration of accomplishments, and opportunities now as a result of the past.
Preferences Map:	*Describes personal preferences, gifts and interests, as well as conditions to avoid.* Helps to illustrate patterns in the gifts, potential, and unique contributions of the person. Describes patterns in conditions that challenge development.
Dreams Map: Hopes and Fears	*Describes ideas about personal dreams and desires for the future. Describes how people feel about the opportunities and obstacles they see to making things happen.* Helps to understand inner images about desires, and both the hopes and fears about the future through the eyes of the focus person.

OPTIONAL MAPS TO USE IN THE PERSONAL PROFILE PROCESS

Choices Map:	*Describes decisions made by the person and decisions made by other people.* Helps to illustrate the degree that the focus person has control over life decisions, and the degree to which decisions are made by other people. Helps clarify the need for personal assistance.
Health Map:	*Describes the conditions that promote or threaten the health of the person.* Helps to illustrate real limitations and constraints imposed by health concerns, medications, therapies, and other conditions and routines that assure or threaten good health.
Respect Map:	*Describes personal characteristics that can create barriers to community acceptance as well as remembering qualities that will be a contribution in relationship life.* Helps to illustrate the personal characteristics, behaviors and social roles that may lead to rejection by others as well as positive qualities that can be strengthened in personal relationships.
Other Optional Maps:	Other maps can be invented by the facilitator to help them understand life as it is experiences through the eyes of the focus person. For example, for people who live with visual and auditory impairments, it is important to understand methods and channels of communication. In this section, we will outline some optional maps that focus on **communication**.

An Optional Map: Describing Communication Capacities

The purpose of the Communication Map is to describe the collective knowledge concerning the focus person's capacity to receive information and express themselves. There are thousands of variables, both overt and subtle, that convey an accurate description of the communication capacity of each person with sensory impairments. The following questions are simply a guide for discussing many of the fine and critical details of the person's history, receptive communication habits, expressive communication abilities, and environmental supports and clues. This description should also include the best of what we know about establishing relationships between the person with a sensory impairment and others.

History

Has this person been blind or deaf since **birth**?
Or, did they lose their vision or hearing **later**?
How much life **experience** did the person have before they lost their vision or hearing?
In general, what are the person's cognitive and language capacities and what are their primary modes of communication?

Receptive Communication: How does this person receive information: Can the person:

Hear? How much, how loud? What environmental cues can they perceive (i.e., bells, doors opening, the sound of walking).
Read **written** material? What size type is required?
Read **Braille**? What degree/size of type?
Translate by **lip-reading**? How close must the person talking be?
Read **sign language**? If so, what system of sign? Are there regional differences (ASL, English, native American , etc.)
Identify **pictures** or symbols by sight or touch.
Hold, give, receive, or point to **objects** to communicate needs.

How can you tell how much the person **understands**? Can you ask questions to determine understanding? How reliable is head nodding, yes or no?

Expressive Communication: How does this person express needs, feelings, desires, and instructions? Can the person:

Speak, make sounds; what do different sounds and inflections mean?
Use **signs**, both formal and informal. How much does one sign generalize to communicate about many things? What are the regional differences in sign. What "private" signs does the person use? Who understands them.
Use **pictures**, point, hand objects, or touch to communicate needs?
Use **mime**, or role playing to express what they need/want?
Use **body language**, gestures, and facial expressions.
Use **behavior** to express likes, dislikes, fears, pain, needs, desires.
Touch, move, or signal to others to express needs.
Change **routines** to express needs (i.e., not getting out of bed).

Environmental Supports and Clues:

Is an **interpreter** required? What skills and capacities are needed for the interpreter? How close or far away must the interpreter be? Should the interpreter be in front of the person or in the periphery?

What **lighting** is required?
What background colors will reduce **glare**?

How much do **landmarks** in the environment provide clues? Which landmarks are permanent (i.e., light fixtures, furniture) and which landmarks come and go (i.e., smells, movement and activity).

What are the **expectations** of a place (i.e., kitchen, bathroom, bedroom). What roles and activities usually occur in these places. How much do the **smells** of people (perfume, lotions, cigarette smoke) or the **sounds** of Jewelry, or the length of nails, bother or help people?

Getting to Know People and establishing relationships:

What do we know about the most effective ways to initiate contact with this person?

1. What are the best ways to make contact with a person in the first place? People have different ways to **establish intimacy** and create the permission and safety to communicate. What are they? Things to consider include:

   Gently tap the person on the shoulder or hand.
   Don't interrupt the person if they are conversing with others.
   Immediately indicate who you are, and who else has entered the room.
   Speak or gesture directly to the person.
   Find many ways to communicate with the person beyond just "giving directions." Relate, don't just instruct.
   Convey the mood of a speaker including emotions such as humor, sarcasm, etc.
   Find out who know this person best, and observe them in conversation.

2. Allow **time** for the person to process information, for example:

   Leave your hand there until people find you.
   Watch and **observe** others to learn about the best modes of communication.
   Be very careful about how you touch. Are your hands cold? Are your hands filled with anger or anxiety?

3. Pay attention to entrances and exits by others, for example:
   Let the person know someone else has entered the room, and they now hear things that are being communicated.

4. Know when the person is most receptive, for example:
   Perhaps mealtimes may not be the best time to converse.
   Perhaps there are other "private times" to be aware of.
   Perhaps it is best to communicate during certain functions.

5. Above all else, think of the person as yourself. What would feel respectful, courteous, and gracious? Imagine what other gestures might be meaningful if you were in the other person's shoes.

COMMUNICATON MAP

Use the following chart to summarize what is known about what works and what doesn't work to support effective communication between the focus person and others. Consider the issues related to the person's history, receptive communication, expressive communication, environmental supports, and establishing relationships.

What Works	What Doesn't Work

CHAPTER 3: CREATING A VISION FOR THE FUTURE

The planning meeting provides an occasion for people to gather to clarify a vision for the future, choose a focus for getting started, and organize to make it happen.

The planning meeting provides the opportunity for a group of people to develop a powerful positive future that inspires people to work hard over time to implement this vision. A positive future is simply a summary of the experiences we want to increase, making the most of the opportunities and capacities we found to work with in:

- The life of the focus person,
- The resources and richness of the local community,
- The connections and support of family, friends, and staff, and
- The resources and opportunities in service supports.

Developing the positive future provides an opportunity for people to use their imagination to generate the most creative ideas possible. These ideas are inevitably shaped by the barriers and obstacles of reality, but it is critical to begin the journey of change with the *highest* vision possible. This initial vision provides a menu of possibilities from which the planning group can choose a long term focus (the main course), and an immediate priority (an appetizer) to start with.

The facilitator's values significantly shape the development of the dream. The values of the facilitator and the group members are revealed in the richness, detail, and creativity of the vision.

In this section we provide guidelines for the development of a dream by describing characteristics of a positive future worth working for and the five accomplishments that guide the development of a dream. Several examples of positive futures are included to illustrate desirable futures worth pursuit. We conclude this section with a summary of the steps of the personal futures planning meeting.

CONTRASTING IMAGES OF THE FUTURE

CHARACTERISTICS OF TRADITIONAL PROGRAM PLANS:	**CHARACTERISTICS OF A POSITIVE FUTURE WORTH WORKING FOR:**
Goals focus on specific negative behaviors of the focus person to change or **decrease**.	Images of the future contain specific, concrete examples of positive activities, experiences, and life situations to **increase**.
The plan identifies program categories and **service options** that are often **segregated**.	Ideas and possibilities reflect specific **community** sites and settings and valued roles within those settings.
Many goals and objectives reflect potentially **minor** accomplishments that can be attained within existing programs without making any changes.	Some ideas will seem far out, unrealistic, and impractical, and will require **major** changes in existing patterns such as: funding categories, service option, how people (and staff) spend their time, shared decision making, where people live and work, etc.
These plans will **look similar** to the plans and ideas written for other people.	These plans will really reflect the **unique** interests, gifts, and qualities of the person, and the unique characteristics, settings, and life of the local community.
These plans will probably not even mention personal relationships or or community life.	These ideas will emphasize creative ways to focus on the development and deepening of **personal relationships** and community life.

THE FIVE ACCOMPLISHMENTS* PROVIDE A GUIDE FOR THE DEVELOPMENT OF A PERSONAL VISION

By John O'Brien and Connie Lyle

The five accomplishments provide a framework for assessing our ideas about the future. Will our ideas reinforce old patterns of isolation, rejection, powerlessness, and poor reputations? Or will our choices lead to inclusion in community life, relationships, dignity, choice, and real contribution. Increasing opportunity in these five areas of life is clearly the intended outcome of the Personal Futures Planning process.

Moving away from a past characterized by:	**Toward daily experiences which include:**
* Isolation, seclusion, separation	* COMMUNITY PRESENCE: How can we increase the presence of a person in local community life?
* Rejection, loneliness always on the outside, ignored.	* COMMUNITY PARTICIPATION: How can we expand and deepen people's friendships?
* Old stories, bad reputations labels	* DIGNITY: How can we enhance the reputation people have and increase the number of valued ways people can contribute?
* Limited voice, restriction lack of representation, no power	* PROMOTING CHOICE: How can we help people have more control and choice in life?
* Unproductive, severely ignored undeveloped, no resources	* SUPPORTING CONTRIBUTION: How can we assist people to develop more competencies?
These experiences often led to broken people with wasted lives, who have suffered from physical and/or psychological hurt.	These experiences can lead to developing people with lives of contribution who are valued in community life.

CONTRASTING VIEWS OF A POSSIBLE FUTURE FOR JANE

Jane's Personal Futures Plan helps illustrate the characteristics of a desirable positive future in contrast to a traditional program plan. The traditional plan defines segregated settings as desirable, decreases problem behaviors, and is written in generalities that can apply to almost anyone in a similar situation. In comparison, Jane's Personal Futures Plan is rich with specific examples of job opportunities to pursue in her local community. The plan emphasizes friendships and having fun. The ideas reflect her unique interests and gifts, and a number of enhancing roles that enable her to contribute in community life.

TRADITIONAL PROGRAM PLAN FOR JANE

The student will improve her skills and competencies in the areas of: reading, language arts, mathematics, spelling, science, social studies, communication skills, P.E./Health, Pre-vocational skills.

Jane will improve in self help skills in doing laundry, preparing simple meals, and grooming skills.

Jane will participate in a sheltered workshop approximately 2 hours a day. This will be based on work availability.

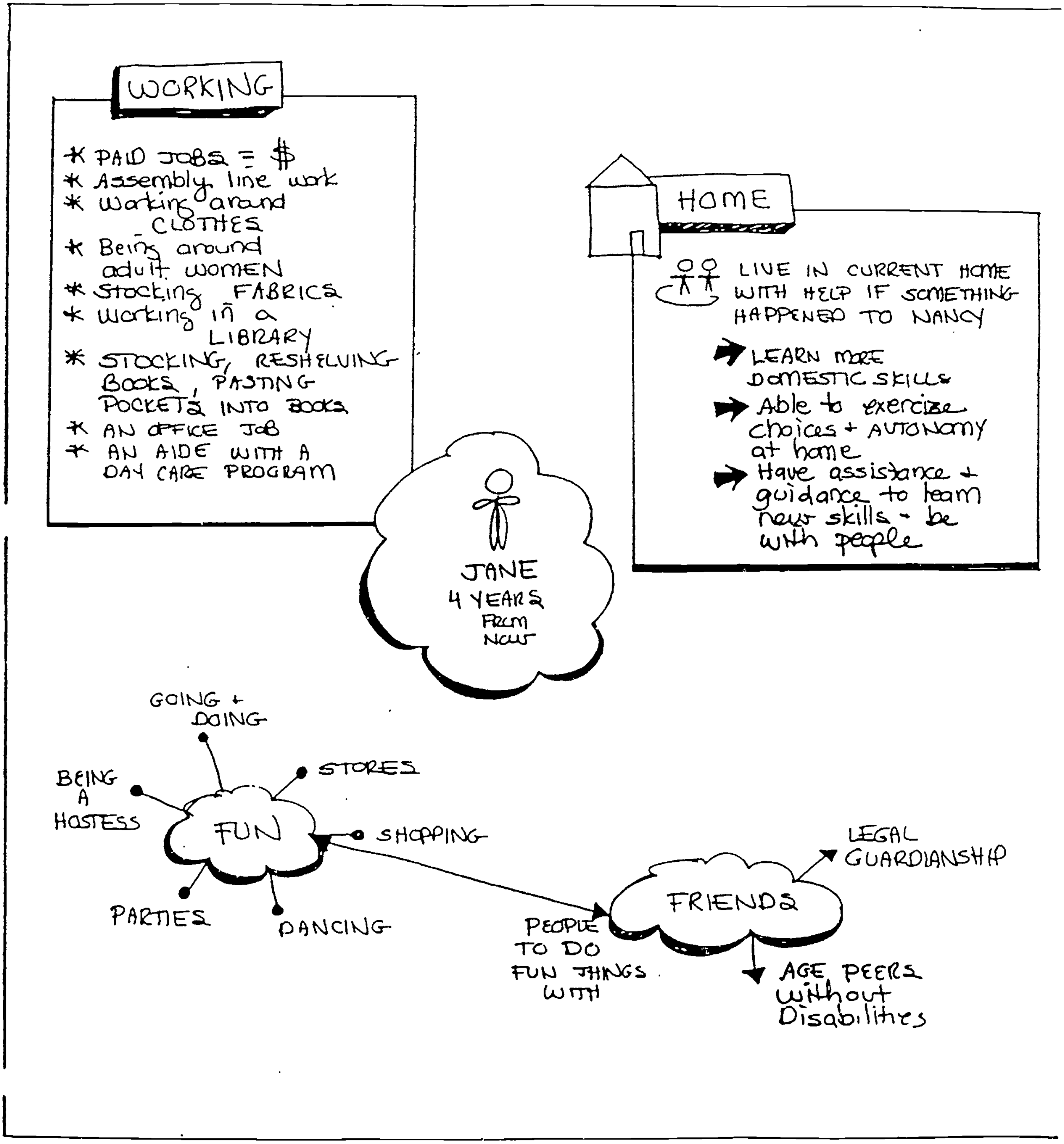
Jane will develop more socially acceptable behavioral skills in expressing her displeasure.

Jane will decrease her vocal outbursts when upset by 50%.
A behavior modification program will be established.

Jane will improve math skills in the areas of counting, time, and money.

Jane will demonstrate increased skills in communication by increasing vocabulary, reading comprehension and expressive language.

A POSITIVE FUTURE FOR JANE



CATEGORIES, PRIORITIES, AND TIME FRAMES FOR DEVELOPMENT

One distinctive aspect of a Personal Futures Plan is the diversity of each plan. Each vision of the future is a unique expressive statement of possibility for the focus person. Plans vary greatly in the categories, priorities, and time frames for development.

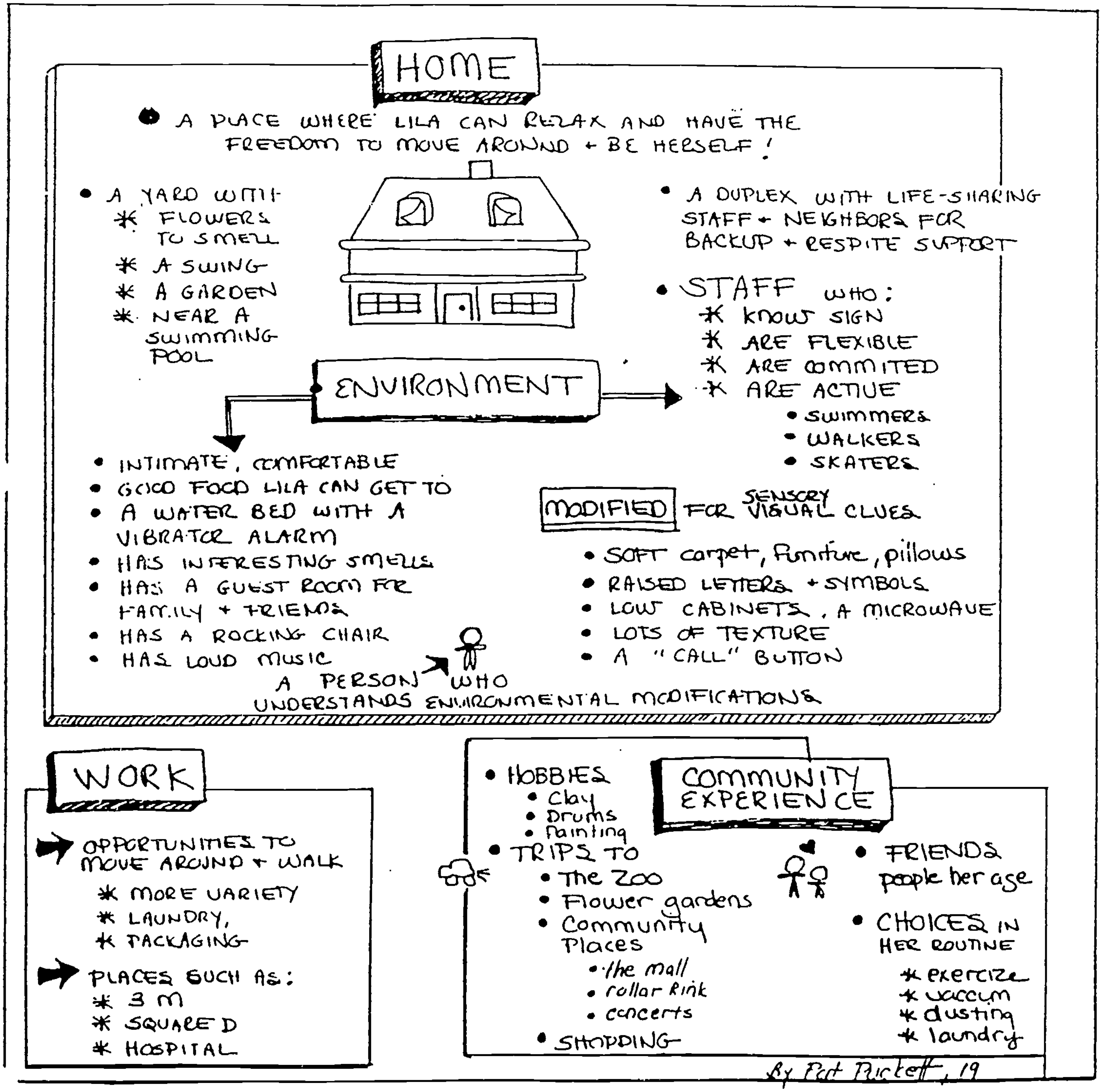
An effective futures plan will reflect several **categories** for development, and common categories for development are listed below. The choice of categories will reflect the interest of the person, life stages and transitions, and interests of the facilitator.

Home
Home Ownership
Homemaking
Hospitality
Work
Transition to Work
Work Experience
School
Adult Education
Spiritual Life
Choice
Mobility/Transportation
Sports
Friends
Fun
Community Life
Community Participation
Community Experience
Love Life
Family Life
Vacations and Travel
Beauty
Communication
Self-advocacy
Artistic Expression
Etc.

Often, one category emerges as the **priority** for development. For example, Jane's plan reflects an emphasis on working, and the transition to work, while Lila's plan reflects an emphasis on home, an alternative to the nursing home which had been her only choice of residence. For all of us, priorities change over time, so also we expect the priorities of the futures plan to evolve.

FINALLY, **time frames** of each futures plan will also vary from two months to five or more years. It helps to choose one priority that may take several years to accomplish, and another priority can be realized within several months. Balancing both a long range and short range priority helps the group work toward an ideal requiring many years to implement, while working on immediate changes that can change the quality of life of the focus person right now.

A POSITIVE FUTURE FOR LILA



HOME

- A PLACE WHERE LILA CAN RELAX AND HAVE THE FREEDOM TO MOVE AROUND + BE HERSELF!

- A YARD WITH
  * FLOWERS TO SMELL
  * A SWING
  * A GARDEN
  * NEAR A SWIMMING POOL

- A DUPLEX WITH LIFE-SHARING STAFF + NEIGHBORS FOR BACKUP + RESPITE SUPPORT

- STAFF WHO:
  * KNOW SIGN
  * ARE FLEXIBLE
  * ARE COMMITED
  * ARE ACTIVE
    - SWIMMERS
    - WALKERS
    - SKATERS

ENVIRONMENT

- INTIMATE, COMFORTABLE
- GOOD FOOD LILA CAN GET TO
- A WATER BED WITH A VIBRATOR ALARM
- HAS INTERESTING SMELLS
- HAS A GUEST ROOM FOR FAMILY + FRIENDS
- HAS A ROCKING CHAIR
- HAS LOUD MUSIC

MODIFIED FOR SENSORY VISUAL CLUES

- SOFT carpet, furniture, pillows
- RAISED LETTERS + SYMBOLS
- LOW CABINETS, A MICROWAVE
- LOTS OF TEXTURE
- A "CALL" BUTTON

A PERSON WHO UNDERSTANDS ENVIRONMENTAL MODIFICATIONS

WORK

- OPPORTUNITIES TO MOVE AROUND + WALK
  * MORE VARIETY
  * LAUNDRY,
  * PACKAGING
- PLACES SUCH AS:
  * 3 M
  * SQUARE D
  * HOSPITAL

COMMUNITY EXPERIENCE

- HOBBIES
  - Clay
  - Drums
  - Painting
- TRIPS TO
  - The Zoo
  - Flower gardens
  - Community Places
    - the mall
    - rollar Rink
    - concerts
  - SHOPPING
- FRIENDS people her age
- CHOICES IN HER ROUTINE
  * exercize
  * vaccum
  * dusting
  * laundry

By Pat Puckett, 19

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THE PERSONAL FUTURES PLANNING MEETING

The personal futures planning meeting provides the occasion for people to gather to clarify a vision for the future, choose a focus for getting started, and organize to make it happen. This meeting has seven basic steps which can vary to fit the situation. Each step is described below.

STEP 1: Review the personal profile.
Describe trends in the environment; conditions in the community or service system working with and against us.

STEP 2: Find desirable Images of the Future

STEP 3: Brainstorm a number of strategies for bringing the ideas discussed during the vision session into reality.

STEP 4: Identify opportunities and acknowledge obstacles in implementation process (this is an optional step).

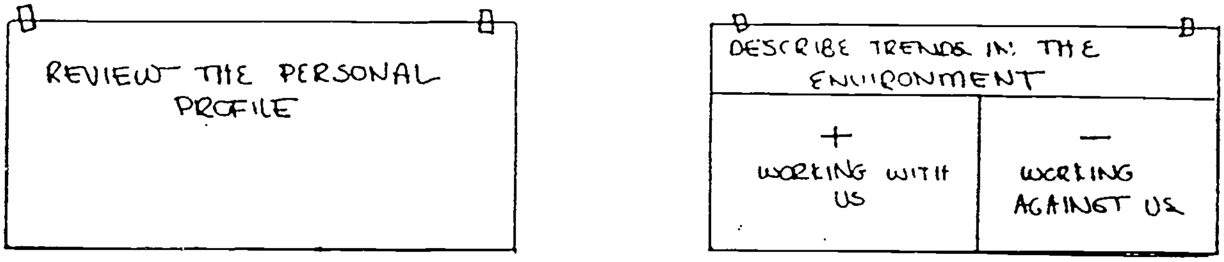
STEP 5: Establish a small number of priorities to start with and help group members make commitments to action.

STEP 6: Set the next meeting time and date.

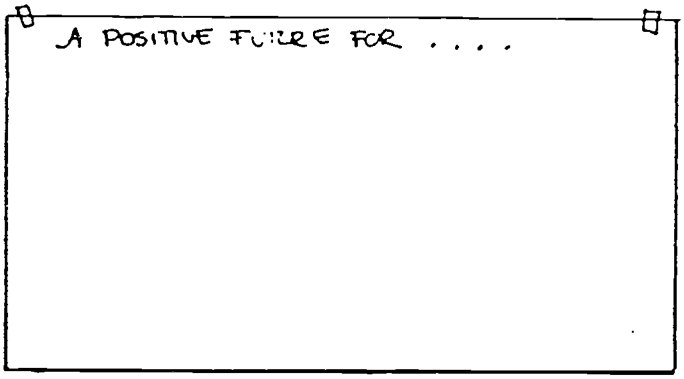
STEP 7: Identify the need for system change (this is an optional step).

The planning meeting defines a road map for a journey which is only the beginning of the process of change. The journey really begins when a small group of people agree to work over time to turn the ideas discussed in the vision into reality. In the following section we discuss the hardest task of all; developing commitment to the focus person and the implementation of the plan.

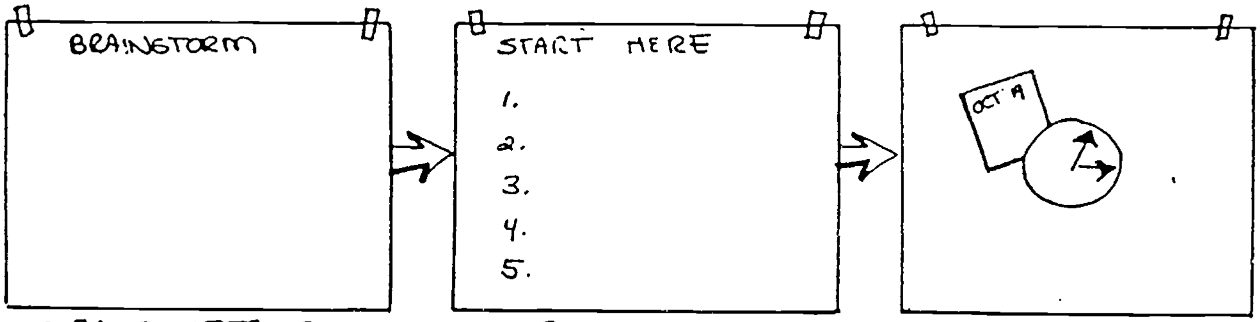
STEPS OF THE FUTURES PLANNING MEETING



STEP 1: DESCRIBING WHAT IS: REVIEW PROFILES



STEP 2: IMAGES OF THE FUTRE

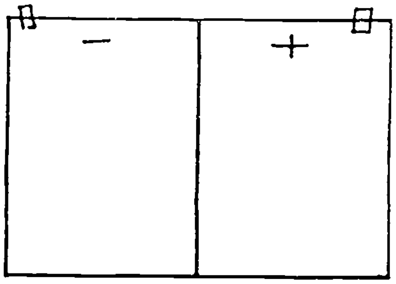


STEP 3: STRATEGIES

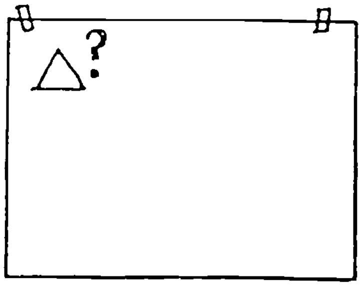
STEP 5: PRIORITIES + COMMITMENTS

STEP 6: SET NEXT MEETING TIME

OPTIONAL STEPS



STEP 4: OBSTACLES + OPPORTUNITIES



STEP 7: ISSUES FOR ORGANIZATIONAL/SYSTEMS CHANGE

CHAPTER 4: SUPPORTING PEOPLE OVER TIME

Now that a powerful positive future has been created, the focus person, the facilitator, and the planning members **face the hardest task of all**: developing commitment to the focus person and the implementation of the plan. In many ways, finding capacities is fascinating and creating a positive future is exciting. The long-term benefits of implementation are rewarding but the process of solving problems over time is just plain hard work. There's no way around it.

We know now that the implementation process is smoother when group members want to be involved, they care for the person, they are engaged in the process, and they enjoy each other as much or more than they get frustrated. The facilitator plays a critical role in shaping the composition of the group, and nurturing the participation of people over time.

The facilitator is constantly seeking to compose a group that can provide both emotional and instrumental support to the focus person. In this section we will outline an ideal person-centered planning group with the understanding that most groups fall far short of this ideal. The purpose of sketching an exemplar group is to observe what we have working with us, and where we will need to develop additional capacity within the group.

The facilitator must also find many ways to renew the work of a group over time. In this section we also outline a format for follow-along meetings, a strategy for follow-along, and ideas for nurturing the group process over time.

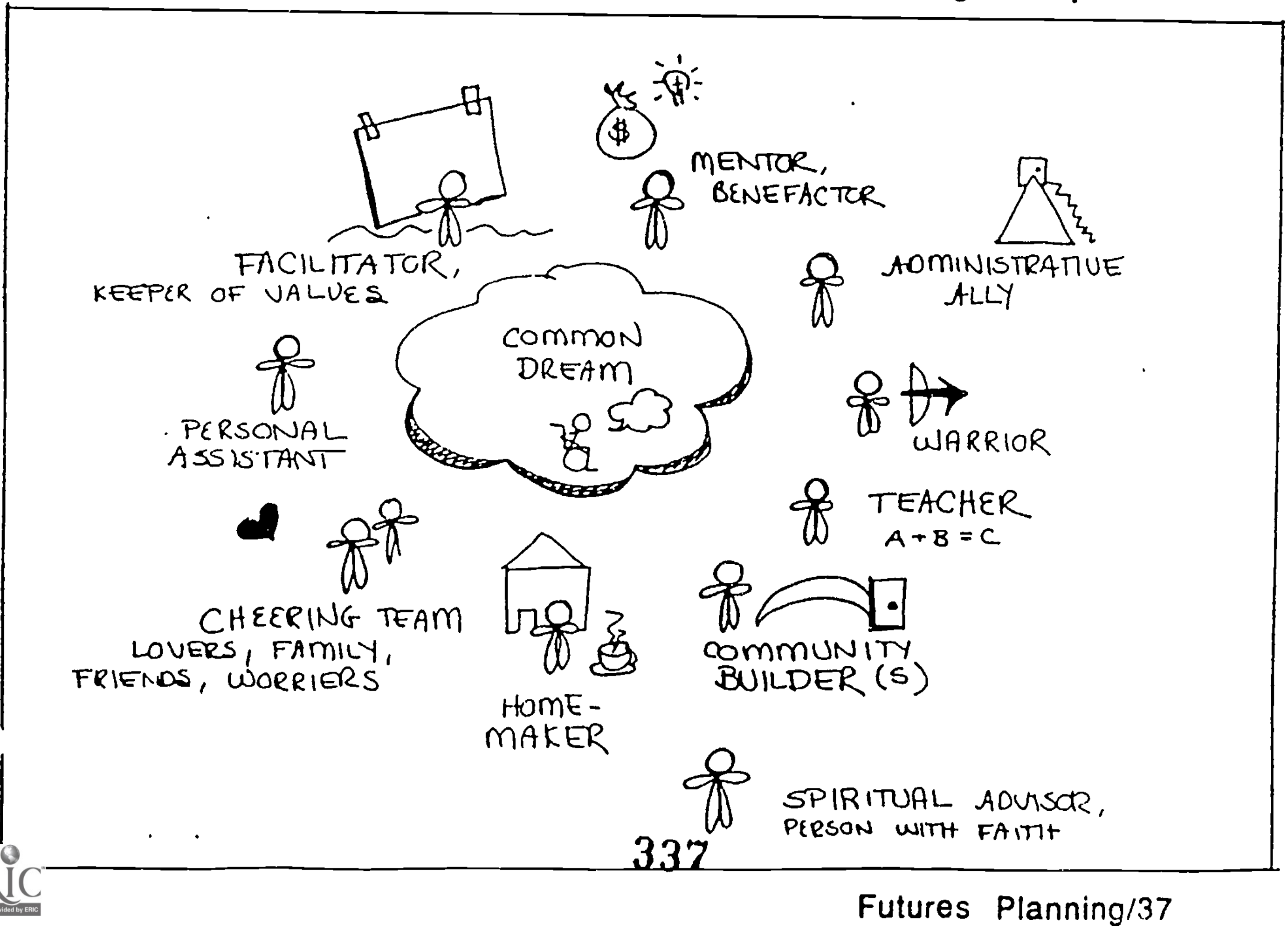
We've learned that heartfelt commitment and caring between people is central to facilitating change over time. While there is no way to mandate, control, or contrive these feelings, we can invite their development through the spirit and attention to the entire planning process.

CRITICAL ROLES OF THE INTERVISIONARY TEAM

Traditional interdisciplinary teams are defined by standards and professional roles. In contrast, person-centered groups are composed of people who contribute their time and interest to the planning process because they feel personally engaged in working for change.

An ideal person-centered group includes a variety of people who assume various roles during the planning and implementation process. Some members, such as family members, homemakers, and personal assistants, may focus more on day-to-day responsiveness to the person. The warrior, teacher, or community builder, may focus more on immediate action to help implement the plan. Administrative allies, mentors, or benefactors may pave the way for long-term change. Finally, the facilitator keeps the process going by providing a focus and a time for structured reflection. In a similar way, the spiritual advisor seeks to renew the faith of the person and the group over time.

A Profile of an Ideal Person-Centered Planning Group



EXPLORING THE ROLE OF THE FACILITATOR

1. Does the person, parents, or a committed advocate want life to be different somehow? Do people **feel stuck** in their current situation, and do they have the energy to change things?

2. Are a few people willing to **meet on a regular basis** to solve problems over time? Are they willing to contribute their time to the process if necessary? Are you, the facilitator able to meet with this group on a regular basis?

3. Does the planning group include at least one person with a **strong commitment** to act on behalf of the person? If not, are you the facilitator, willing to assume this role?

4. Does the planning group include at least one person who can act as a **facilitator?** A facilitator must take the lead in recording ideas, keeping a focus, and helping others follow through on commitments. If a facilitator does not emerge, are you, the initiator of the plan, able to stay in the group until internal leadership develops?

5. Does the planning group include at least one person who is well **connected to the local community**? If not, can you find someone who can assist in building bridges to the local community?

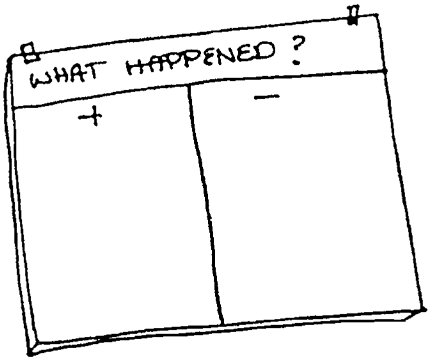
6. Is the group, focus person, or family **connected to other people** who face similar obstacles and/or are involved in a similar process? If not, can you connect them to other groups or people as a source of renewal and support?

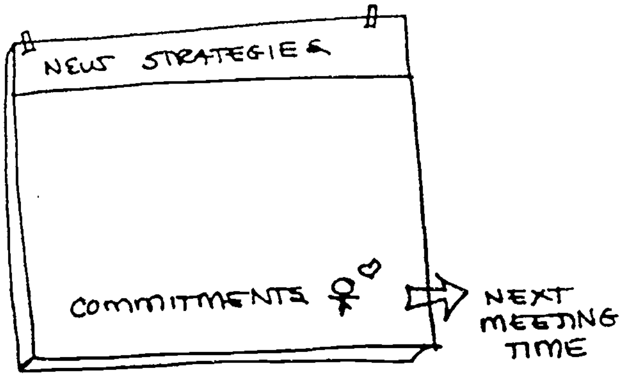
7. Is at least one involved **agency committed to organizational change** as a result of what is learned from this process? Does this agency support the time and commitment required of staff? If not, can you develop and interest within an existing agency to listen to the results and implications of the planning process?

8. Are **resources available** for flexible, individualized supports required to implement a personal plan? If not, can you identify or create this type of support within existing systems, as a pilot program, or by seeking local grants or other forms of support.

FOLLOW ALONG MEETINGS AND RENEWAL

The follow-along meetings help planning groups learn form the process of implementation. An effective agenda for follow-along meetings is to begin by helping groups review actions taken since the last meeting, both successful and less successful efforts. An important renewal strategy is simply reviewing positive actions and outcomes on a regular basis. Following this review the group then brainstorms new strategies for action. The facilitator concludes this meeting by setting a date and time for the next meeting.





The follow-along meetings provide repeated occasions for group members to solve problems over time. The meeting format can be varied to help renew the actions and commitments of the group. Every planning group is different, and every group requires a strategy for follow-along that fits the energy, commitment, and developmental stage of the group. Most planning groups also just run out of energy and new ideas and need to be nurtured and renewed A variety of follow-along and renewal strategies are listed on the following pages.

Facilitators need to remember that **maintaining the commitment of a group of people over time is one of the most challenging requirements of the futures planning process.** Do not underestimate the hard work required to bring a group of people together to solve problems again and again over time. Do recognize that inviting people to work together in a constructive manner toward a positive vision is one of the most important responsibilities of an effective facilitator.

Design a Strategy for Follow-Along

From the start of the planning process, the facilitator looks for people who agree to meet regularly to solve problems over time. The method for follow-along may vary from group to group as long as some continuity and commitment to the process is planned. The facilitator should consider these questions when designing a follow-along process.

1. What is the best method for follow-along for this group?
2. How often should people meet to gain momentum in the process of change?
3. How often should the facilitator meet individually with the focus person and/or family between meetings?
4. Should there be subcommittees or smaller brainstorming groups around certain issues? Can someone else lead these groups?
5. Who can facilitate the group over time? Who can learn to facilitate the group in time? Are there two people who can work as partners to facilitate the group?
6. What would it take to support the focus person to lead his or her own group. Who could be their partner in such an effort?
7. Who will keep a record during the meeting?

Nurturing the Vision and the Commitment of a Group over Time.

Even the strongest groups run out of energy and new ideas over time. Facilitators can nurture the group by finding ways to help group members celebrate, and receive recognition for their work and contributions. Groups can also be renewed by finding new ways to inform their vision such as attending conferences, networking, and visiting others. The following list provides some concrete suggestions for renewal.

1. Plan celebrations to recognize important accomplishments, birthdays, holidays, and other meaningful events.

2. Meet in a comfortable place and provide refreshments.

3. Plan an occasion to revision or refocus the group. Find a way to recognize the contributions of each group member.

4. Help group members attend conferences and workshops. Find opportunities for the focus person and group members to tell their story to others; in newsletters, meetings, and conferences.

5. Find other advocacy or consumer groups for people to join. Help people attend these groups.

6. Help group members visit other people who face similar challenges. Help group members visit other places where people have found solutions to similar problems.

7. Help all group members find opportunities for self-development even if they are not the focus of the group.

8. Find newsletters, publications and books that reflect the interests and challenges in the group.

9. Help group members write proposals to obtain critical resources needed to implement their ideas.

10. Find people to serve as mentors or advisors to the group even if they are not regular members. Invite new people to meetings just to explore new ideas.

CHAPTER 5: GETTING STARTED: Empowering Families and Developing Facilitators

Once people are interested in the ideals of person-centered development, then comes the question, "How do I get started?" "What is the best way to begin a personal futures plan and a circle of support?" This section is addressed to the concerns of the **people** most central to the Futures Planning Process; the focus person, families, facilitators, and agency executive directors.

A person-centered approach to development requires that as many people as possible become leaders of change on behalf of another person. Therefore, we assume that people with disabilities can be the leaders in their own development, families can be empowered to make things happen, and facilitators can assist people in making ideals real. There is no one "Knight in Shining Armor" in this process. Real change depends on everyone's capacity to recognize and build leadership abilities while working as partners toward a common goal.

The Critical Role of People with Disabilities and Their Families

People with disabilities and their family members or loved ones play a central role in the development of a Personal Futures Plan. Many parents are very engaged in the personal futures planning process, and they make the greatest contribution to shaping the future of their child. Time and time again, parents are the strongest champion of their child's future, and they are the stakeholder whose interests and concerns must be taken seriously. Their stories of change and hope provide the greatest sources of hope and inspiration for others.

Sometimes facilitators feel that they are persuading families or people with disabilities to get involved in a personal futures plan when the people seem resistant. Many people will be skeptical of this process and they should be! These (wise) people see many fads come and go and they endure much disappointment. They hear many unfilled promises from well-meaning workers, and they live with the daily responsibilities and challenges that make "positive futures planning" seem like a day dream. Why would they trust another well-meaning facilitator, bright eyed with ideals of finding capacities and a vision for community? We need to work very hard to change the pattern that leads people to feel such skeptism and disappointment. The following suggestions may ease some of the tensions of getting started.

Suggestions for Getting Started for People with Disabilities and/or Family Members

1. Facilitation of your own group can be very challenging. Most people with disabilities or parents prefer to work with a facilitator that they like and trust to at least get the process going. Once a support circle is "rolling" you may want to facilitate your own group, or someone else's group. Like many things in life, it's hard to do this for yourself and may be easier to facilitate for other people.

2. The personal futures planning process is designed for you, to assist other people listen to your desires, hopes, and fears, and then to learn to solve problems together to bring these hopes into reality. The process should constantly be adapted and modified to reflect your preferences.

3. Be cautious about the reality that some people who initiate a personal futures plan on your behalf may actually use the process as another way to get you to do what they want. Now other people do have good insights and suggestions that can help you clarify and focus your issues. But if it seems that others are using the process to serve their agenda, then call a "time out" and talk about it. Ask to have individual meetings with your facilitator.

4. Make your day-to-day needs as clear as your long term hopes, and find a way to work on both. Once you've thought about all the dreams you have for yourself, and asked other people to add their views, it really helps to pick a focus. Pick one issue you want to change right away, and one issue you want to change that may take a long time.

5. Most people feel that they lack people to invite to help them plan, and/ or they agonize over asking people to help. Keep in mind that most people do have people to ask, it just may be really hard to ask for help, or it may be hard to trust people. Work with your facilitator to find ways to invite people into your support circle. Let the facilitator run the actual meetings and ask people for commitments to action. People may not know how to help at first. Give the group and facilitator time to learn about ways they can help.

6. It may help to begin with the people you know you can trust, who are open to listening, and who may be easiest to ask. The size of the group is not as important as your comfort level. Remember that it is an honor for most people to be asked to get involved. Perhaps you will be able to return the personal support to group members in the future.

7. Be open to the inclusion of people you may not know well, when people you trust recommend their involvement in your group.

8. When people really do begin to "come through" for you, find some ways to thank them for their support. Find ways to support them in their own journey.

9. Find another person who has been through this process who can serve as a guide and a sounding board. Compare notes, invite them to your meetings, listen to their advice, fears and hopes. Modify your own planning process based on what you learn from them.

10. Constantly adapt the process to fit your needs. Take vacations from planning for a while. Confront your facilitator and ask for changes. Stop whatever practices feel intrusive or uncomfortable and renegotiate.

The Critical Role of an Effective Facilitator

The Personal Futures Planning process is most effective when organized by an effective facilitator. Effective facilitators bring a number of qualities and skills, such as respect, clear values, and the capacity to manage a lot of information, to the planning process. Many of these qualities are hard to describe and difficult to transmit. For this reason, we find that facilitators are most competent when they learn from and work with another experienced facilitator.

An effective facilitator is a healer of sorts, and the skills, qualities, and characteristics of a healing person are often subtle and complex. For example, an effective facilitator communicates a deep sense of respect for the focus person and others. Somehow they avoid the professional trap of the need to establish superiority, and their earnestness comes through whatever other system-centered quirks they may bring with them!

Effective facilitators have often themselves been wounded, and they have had to live with these wounds, illness, mistakes, or personal pain, so that they approach the vulnerabilities of others as if it were their own. This seems to increase the likelihood that people will struggle together as equals, and avoid the arrogance of professionalism. This quality of shared vulnerability and respect brings a lot of power into the circle process.

Another important capacity of a facilitator is her basic values and assumptions about people, people with disabilities, and the process of change. These values and attitudes emerge in our language, our vision, our creativity, our commitments, and our interactions with people. These qualities are also hard to describe, therefore they are best transmitted in a mentor-apprenticeship relationship.

An effective facilitator also learns to manage a lot of information, and run an effective and lively meeting. There are many meeting tools such as group graphics and meeting formats that can help facilitators empower, inform, and motivate a group to take action. An apprentice can obtain many of these tools by watching more experienced facilitators plan, improvise, and energize a group.

In summary, effective facilitators learn best from others with more experience, who are respected for their capacity to lead change. The following suggestions for interested facilitators can help one get started.

Suggestions for Getting Started for Facilitators

1. If you are interested in facilitating a Personal Futures Plan then find someone who has experience and is recognized as an effective facilitator. Work with them for a while. Ask that person to help you start your first Personal Futures Plan.

2. Start small. Choose one person who compels you to get involved and allow yourself to become personally involved with at least one person. Allow yourself to make commitments far beyond those expected of a facilitator. Allow yourself to be moved, changed, and affected by your intense involvement with at least one person.

3. Obtain as much freedom and unstructured time away from system-centered work to enable you to learn to listen, to begin to respond, and to take action on behalf of the person.

4. Allow the "bigness" of your hard work with one person to "spill over" to other people. This inevitably happens when one powerful vision is realized.

5. Do not try to combine this process with other standardized planning requirements, particularly if you are just learning the process.

6. Learn more about the Personal Futures Planning process and the underlying values through many different values-based workshops, publications, and apprenticeship. Effective facilitators are always learning and deepening their involvement through a variety of professional and personal growth experiences.

7. Find a style of facilitation that suits you; your gifts, skills, and interests. Don't feel obligated to copy the approach of other facilitators, but do learn what you can from effective facilitators.

8. Work with the tensions of person-centered development and try not to run from them. System's-centered work can distance you from these tensions and can seem like a relieving replacement. Only through feeling the tensions of person-centered work do we experience the empathy, compassion, and determination to work for change.

9. Work with a partner. It makes the process of facilitation more manageable, and the struggles with the tensions more bearable.

10. Create boundaries for yourself and your involvement. Respect your own limits and avoid making promises you can't keep. Safeguard the time you need to nurture your own family and personal life.

11. Get to know the local community in which the focus person lives. Learn about the community together--visit restaurants, churches, etc. Journey together into the life of the community.

12. Establish a relationship with at least one human service agency that administers needed resources. Build personal alliances within the agency and work toward constructive outcomes. Make personal calls to people in authority to represent the interests of the person you are facilitating.

The Role of an Executive Function

While the Personal Futures Planning process does not depend on the support of human service organizations, the planning process is certainly strengthened when organizational support is available.
The following suggestions are for people in executive roles who are interested in promoting and sheltering person-centered development.

1. Think big, but start small. Encourage innovation by selecting a small number of focus people, and a small number of staff who are really interested in these ideas. Let them try out all kinds of innovative ideas. Let the creativity and innovation that arises from these situations "spill over" to other staff and individuals.

2. Choose a focus for exploration using the futures planning process. For example, you may want to learn more about community building, or supportive living, or home ownership, or family support, etc. Begin the planning process by choosing 2 or 3 people with disabilities who will inform you of creative possibilities in the focus area you choose.

3. Don't try to change your whole agency all at once, train everyone, and standardize these ideas. Allow them to exist outside of the formal organization for as long as you can. Shelter these innovative efforts and give them intensive support and consideration. Develop a plan for expansion later as the initial efforts gain strength and momentum.

4. Develop a leadership group of creative, energetic facilitators who crave autonomy and freedom. Relieve them of other duties so they have more free space in which to work. Support facilitators to work in teams, even if it seems inefficient.

5. Provide flexible money for small-scale inventions. Encourage the planning groups to submit brief proposals or presentations stating their needs for moving forward. Help people get pilot projects or grants to test out new service arrangements.

6. Support diversity. Allow planning groups to pursue very different ideas and possibilities. Help people use existing money and funding categories in a more flexible and creative way. Support ideas that increase the personal wealth of people with disabilities, and their direct control over their own supports.

7. Encourage planning groups to go outside of traditional channels to express needs and pursue change. Bend rules and regulations to fit what people are doing.

8. Create a project advisory group to nurture these planning groups. Include people with disabilities and/or family members in this group. Create regular times to listen to what people are doing and learn from them.

Hopefully, these suggestions for getting started will inspire and inform people instead of restrict people who are interested in these ideas. There are a growing number of resources related to the ideals and implementation of person-centered development. A number of these references are listed in the appendix.

APPENDIX A

References Related to Person-Centered Development

Center on Human Policy. Annotated Bibliography on Community Integration. Available from Syracuse University, 200 Huntington Hall, 2nd Floor. Syracuse, NY 13244-2340. 1990.

Forest, Marsha and Snow, Judith. The MAPS Process. Available from Frontier College, 35 Jackes Ave., Toronto, Ontario Canada m4T 1E2.

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

McKnight, John. Valuable Deficiencies. Co-Evolution Quarterly, 6, 1977.

McKnight, John. Capacity Inventory. A Capacity-Oriented Strategy for Neighborhood Development. Center for Urban Affairs and Policy Research, Northwestern University, 1988.

Mount, Beth. Personal Futures Planning: Finding Directions for Change. UMI Dissertation Service, 1987.

Mount, Beth and Zwernik, Kay. It's Never Too Early, It's Never Too Late: an Overview of Personal Futures Planning. (Available from Minnesota's Bookstore, 117 University Ave, Ford Building, St. Paul, Minnesota 55155.), 1988.

Mount, Beth, Beeman, Pat, and Ducharme, George. What are We Learning from Circles of Support, Available from Communitas, Inc., P.O. Box 374, Manchester, CT 06040, 1988.

Mount, Beth. Imperfect Change: Managing the Tensions of Person-Centered Work. Available from Communitas, 1990.

Mount, Beth. Dare to Dream: An Analysis of the Conditions Leading to Personal Change for People with Disabilites. Available from Communitas, 1991.

Mount, Beth, Ducharme, George, and Beeman, Pat. Person-Centered Development: A Journey in Learning to Listen to People with Disabilities. Available from Communitas, 1991.

Mount, Beth. Making Futures Happen: A Facilitators Guide to Personal Futures Planning. Available from Minnasota's Bookstore. 1991

O'Brien, John and Lyle, Connie, Framework for Accomplishment. Responsive Systems Associates, Atlanta, Georgia, 1987.

O'Brien, John. A Guide to Lifestyle Planning. A Comprehensive Guide to the Activities Catalog. Baltimore: Paul Brookes Publishing Co., 1987.

O'Brien, John and Mount, Beth. "Telling New Stories: The Search for Capacity Among People with Severe Handicaps." In Meyer, Peck and Brown, Eds. Critical Issues in the Lives of People with Severe Disabilities. Baltimore: Paul Brooks Publishers, 1991.

O'Connell, Mary. The Gift of Hospitality: Opening the Doors of Community Life to People with Disabilities. Center of Urban Affairs and Policy Research, Northwestern University and Department of Rehabilitation Services, State of Illinois, 1988.

Perske, Robert. Circles of Friends. Nashville, TN: Abingdon Press, 1988.

Snow, Judith and Forest, Marsha. Support Circles-Building a Vision. Downsview, Ontario: G Allan Roehr Institute, 1986.

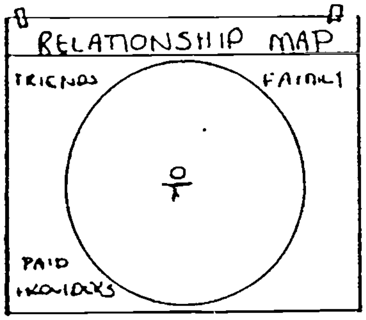
Wetherow, David. The Whole Community Catalog. Available from Communitas, Inc. P.O. Box 374, Manchester, CT., 1991.

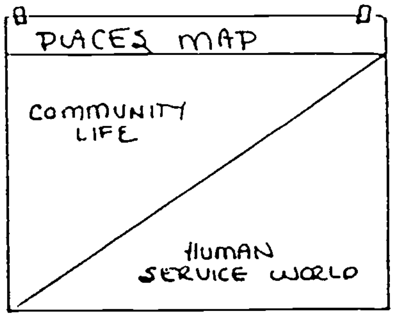
Wolfensburger, Wolf. Social Role Valorization: A Proposed New Term for the Principle of Normalization. Mental Retardation, 21(6), 234-239. 1983.

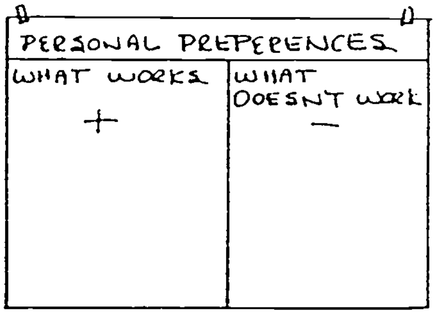
APPENDIX B: AN EXAMPLE OF A PERSONAL PROFILE

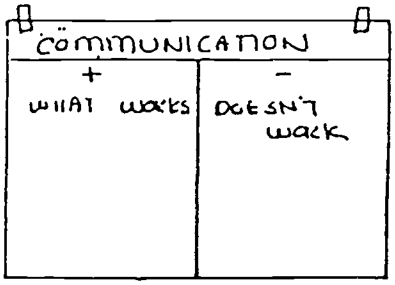
The following Profile of Tom is provided to illustrate a number of the maps included in a typical Profile. Tom's profile includes almost all of the basic maps and one optional map, the communication map. Facilitator tips for developing each map are also included in this section.

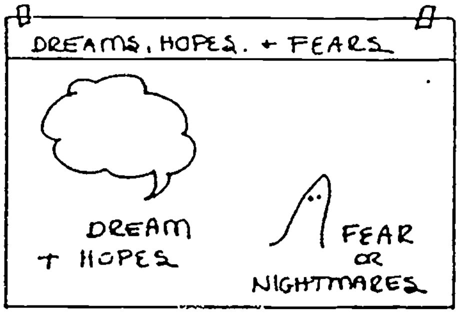
Tom's Profile Illustrates the following Maps:



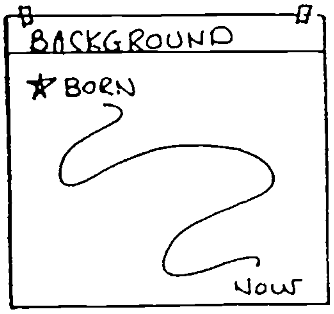


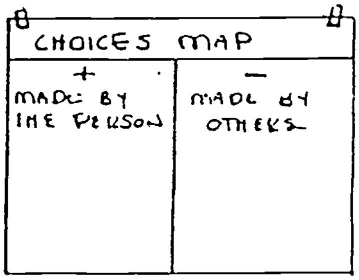


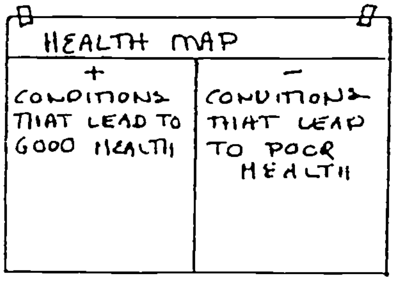


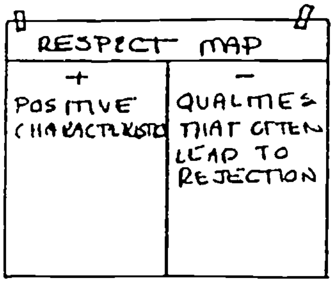


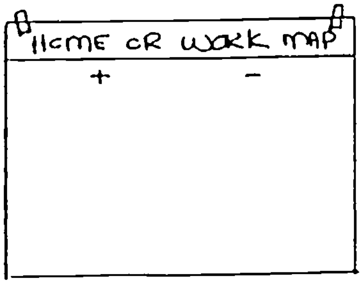
Facilitator Tips are Included for these Additional Maps:

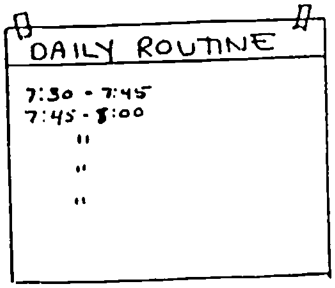








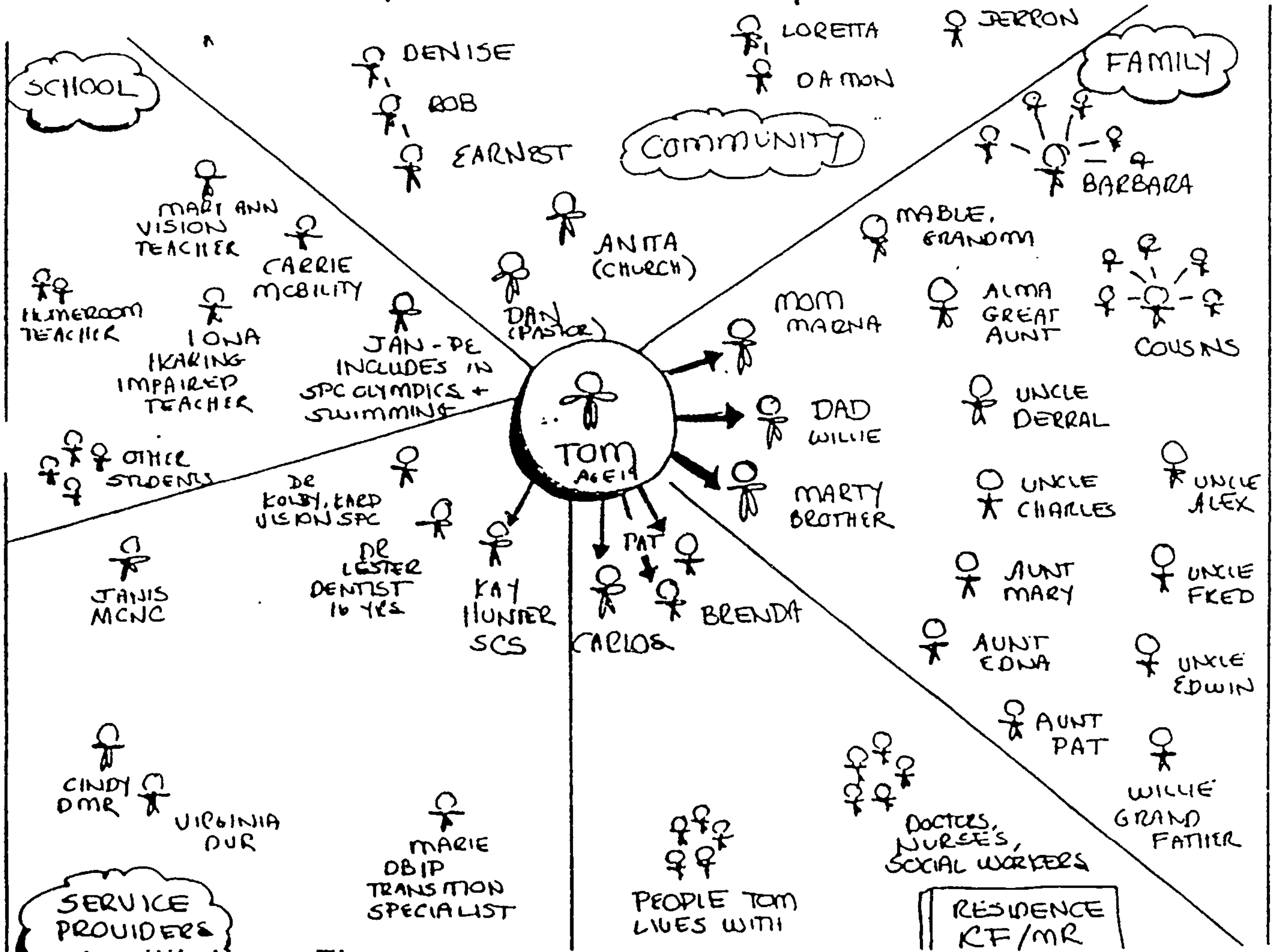




RELATIONSHIP MAP

Purpose: To identify personal support, the most important people in the focus person's life, and people who may be interested in planning together over time.

Example: Tom's Relationships



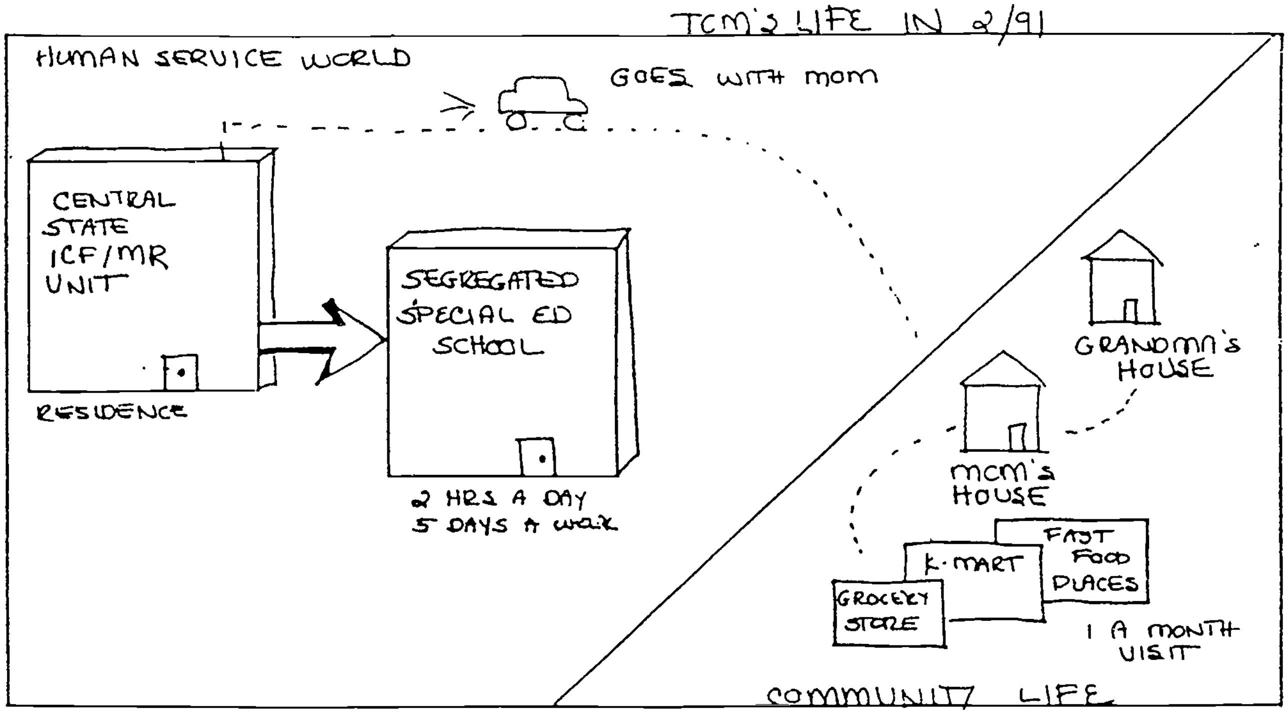
Facilitation Tips:

1. Divide the circle into at least three categories: family, friends, and paid staff members.
2. Put each person on the map with a symbol of a person and their name. Indicate the nature of the relationship and how long they have known each other.
3. Put the people who are closest to the person, who are most important toward the center of the circle. Indicate intensity and strength of the relationship with heavier lines.
4. Highlight in yellow people who might be involved in the support circle.

PLACES MAP

Purpose: To describe the pattern of daily life to help illustrate how the focus person spends his or her time. To gain an understanding of the community life of the person compared to the amount of time spent in segregated human service settings.

Example: Tom's Life in the Community



Facilitation Tips:

1. Make a picture of the places used by the person. Indicate the amount of time spent in each place and the frequency of contact. Include home, work and community settings.
2. Draw a diagonal line or a triangle on the map and put segregated human settings and activities below the line or in the triangle. Put community settings above the line.
3. Indicate in green the places the person most enjoys, places where he or she has positive experiences, and places that the person may want to increase their involvement and contact. Record in red the places where the person has the least success and note the reason why.

IDENTIFYING PERSONAL PREFERENCES

Purpose: To discover capacities to build on and conditions to avoid when planning experiences in the future. This exercise can help us find patterns in the gifts, potentials, interests, and unique contributions of the person. This list also helps to identify patterns in the conditions that block or challenge development which should be avoided in the future.

Example: Personal Preferences for Tom

Things that "work"
That create interest, aliveness engagement, and motivation:

- Music: feels the speakers, likes the vibrations.
- Likes swimming and water.
- He likes shopping, trying on clothes. Going to the grocery store, and picking out one item.
- He is fascinated with cars. He started one when he was 6 years. He likes riding in the car.
- Tom is mechanical. He figured out how to keep the washing machine going with the top up. He made the TV go fuzzy and then fixed it.
- He likes church, restaurants, doing to the mall. He likes walking in the park and the mall.
- His communication book.
- He loves being with his family.

Things that "don't work"
That create boredom, upset, depression, and frustration:

- Not being able to communicate
- When people don't or won't make the effort to relate or communicate with him.
- When Tom perceives that people don't like him.
- When Tom is inactive, he is really bored.
- He doesn't like music when he's in the car.
- He doesn't like going thru the car wash.
- His cane didn't work.
- The exercise bicycle.
- He doesn't like sticky stuff.

Facilitation Tips:

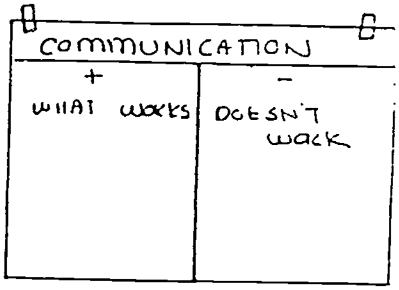
1. Record things that work in green and things that don't work in red.
2. List everything people can think of. Decipher all clinical jargon and technical language into common language. Look for patterns in the things that engage and interest people and the things that do not.

COMMUNICATION MAP

Purpose: To develop a detailed understanding of the communication strategies and abilities that work. To identify both receptive and expressive skills, as well as environmental supports that work, and helpful strategies for building relationships.

Example: Communication Strategies that Work for Tom?

- Tom is very responsive to touch. The first thing to do when you approach him is to touch him gently. Then identify who you are with a tactile sign he associates with you. Then spell your name.
- Tom can write his name perfectly. He can write other words when they are fingerspelled.
- Slip your hand into his palm to tell him you want to sign or fingerspell a message to him. Fingerspell in Sean's hand. Emphasize your thumb. His hand should be cupped over your signing hand.
- To sign "toilet" wave "t" and fingerspell.
- Practice fingerspelling in the mirror.
- Tom can smell and identify a lot that is going on by smell. He can also feel your face or body to know who you are.
- Remember Tom is very capable! He has good problem-solving and mechanical skills.
- Tom really likes choices. Give him lots of choices.
- Tom's mother has a communication book containing the sign's he knows. A copy is being made for family members.



COMMUNICATION	
+	–
WHAT WORKS	DOESN'T WORK

Facilitation Tips:

1. Tom's list focuses on "things that work" and does not include "things that don't work. It helps to list out both things to gather the most reliable folklore.
2. Once again, record things that work in green, and things that don't work in red. USE ENGLISH. A lot of the information about communication is hidden in fancy technical jargon. Translate it!
3. Use the lists on Pages 23-26 to provide clues for communication signs and symbols to look for.

IMAGES OF THE FUTURE: DREAMS MAP

Purpose: To explore inner images about desires and dreams for the future. It helps to illustrate the experiences the person or the family wants to have more of, including dreams for a home, a job, community life, and personal life. The difference between this map and the "vision" map developed during the Futures Planning meeting is that this map expresses the images and hopes of the person and those who know them best. The vision map may include many other ideas contributed by lots of other people.

Images of the Future for Tom

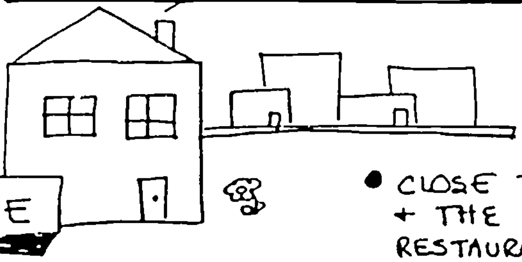
SCHOOL

• *FRIENDS* •
- HIGH SCHOOL NEAR WHERE TOM LIVES
- TO BE WITH KIDS HIS OWN SIZE + AGE
- WORKOUT, EXERCIZE IN GYM, SWIMMING POOL
- A ROLE WITH THE FOOTBALL + BASKETBALL TEAM
- TO HAVE FRIENDS WITH OTHER STUDENTS
- A FULL DAY

• *GOOD INSTRUCTION* •
- LEARNING IN ;
  - Domestic
  - Computers
  - Leisure
  - Vocational
- 1 to 1 INTERPRETER
- CONSISTENCY
- ACTIVE, NOT BORING

COMMUNITY LIFE

- MEMBERSHIP AT AMERICAN FITNESS CENTER — HEALTH CLUB
- FAMILY LIFE: SUPPORT FAMILY MEMBERS TO VISIT, GO TO DINNER, GO SWIMMING, OR TO LAUNDRY MAT 1 A MONTH.
- GOING OUT TO EAT, GOING TO CHURCH
- RECREATION: ACTIVE, PHYSICAL:
  - WALKING
  - SWIMMING
  - HOURSEBACK RIDING
  - BOWLING
  - SHOPPING
  - GOING TO THE MALL
- ART EXPLORATION
  - DRAWING, PAINTING, CLAY, EXPLORE DIFFERENT MEDIUMS
- VOCATIONAL EXPLORATION
  - WASHING CARS / DISHES
  - ELECTRICAL
  - PUTTING THINGS TOGETHER



"HIS HOME"

- CLOSE TO PARK + THE MALL, RESTAURANTS, BOWLING, SWIMMING POOL

HOME

- HOUSE WITH A YARD
- ROOMMATE: someone he knows maybe Walter
- CLOSE TO FAMILY - (but not next door)

- DOMESTIC SKILLS
  - COOKING
  - LAUNDRY
  - GROCERY SHOPPING

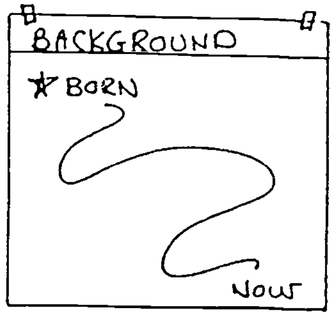
ADDITIONAL MAPS AND FACILITATOR TIPS

Tom's Personal Profile illustrates most of the basic profile maps, and one optional map, the Communication Map. Facilitators must design each Personal Profile process, choosing to use the most informative maps. The following facilitator tips relate to additional maps.

BACKGROUND MAP

Basic Map--BACKGROUND MAP: The purpose of the background map is to understand the life experience of the focus person and his or her family. The background map can reveal positive experiences from the past to build on. The background map also provides an opportunity to appreciate traumas, loss, and grief in the person's life, as well as the celebration of accomplishment.

Facilitation Tips:

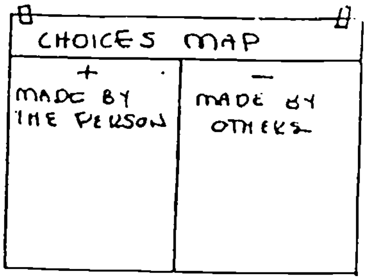


1. Identify when and where the person was born. Identify places the person has lived and highlight major life changes and/or milestones.
2. Indicate the patterns in crises and problems in red. Use green to record positive experiences.
3. Summarize opportunities from the past to build on.

CHOICES MAP

Optional Map--CHOICES MAP: This map helps illustrate both personal autonomy as well as needs for assistance. This map can help us understand the degree to which the focus person has control over life decisions in contrast to the degree to which other people make decisions for the person.

Facilitation Tips:



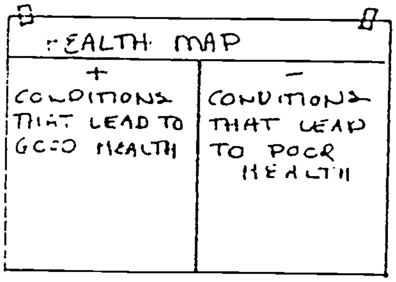
1. Indicate how much choice the person has in defining such things as a place to live, roommates, work, money, etc.
2. Also indicate how much choice the person has in everyday decisions, such as dressing, grooming, and meal preparation.
3. Notice opportunities for transfering the decisions made by others to the person.

HEALTH MAP

Optional Map-Health Map: The purpose of the Health Map is to describe conditions that promote or threaten the health of the focus person. This is a good map to do when people have complex health, therapy, or medication issues that must be considered in the development of a plan.

Facilitation Tips

1. Note the conditions and indicators of good health in green, and the symptoms or problems of poor health in red.
2. Note special physical care needs, needed equipment and health routines, and issues such as diet and exercise.



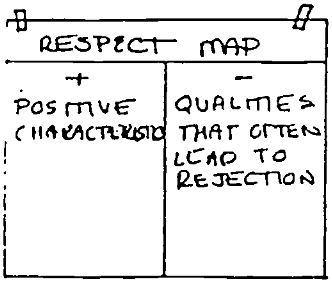
HEALTH MAP	
+	–
CONDITIONS THAT LEAD TO GOOD HEALTH	CONDITIONS THAT LEAD TO POOR HEALTH

RESPECT MAP

Optional Map-Respect Map: The purpose of the Respect Map is to identify personal characteristics that create barriers to community acceptance, and that may lead to rejection by others, in contrast to the positive personal characteristics that help the focus person gain respect by others and develop relationships. This is a helpful map when people have complex characteristics and behaviors that challenge others.

Facilitation Tips:

1. Record respected characteristics and roles in green. These are qualities and characteristic that other people admire, value, and appreciate.
2. Record the odd or unusual behaviors that can lead to rejection or alienation by typical community members.
3. Clarify the frequency and context in which these behaviors occur.



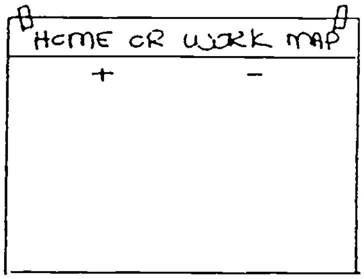
RESPECT MAP	
+	–
POSITIVE CHARACTERISTICS	QUALITIES THAT OFTEN LEAD TO REJECTION

HOME OR WORK MAP

Optional Map-Home or Work Map: The purpose of a home or work map is to explore in more detail the conditions in the home or in the work site that work and don't work. This is a helpful map when people are frustrated with their living or work environments, and we want to understand more about the specific conditions that help or hurt. The Home Map can be particularly helpful when working with families.

Facilitation Tips:

1. When describing the home describe conditions such as the physical space, roommates, staffing patterns, family dynamics, etc.
2. When describing work conditions indicate conditions such as the environment, job duties and tasks, co-workers, income, frequency of pay checks, effective job supports, etc.

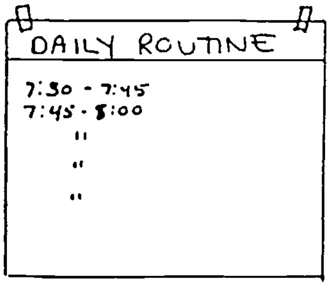


DAILY ROUTINE MAP

Optional Map-Daily Routine: The purpose of the Daily Routine Map is to describe the daily schedule in detail to find opportunities to build meaningful activities in community life. A detailed analysis of the daily routine helps reveal gaps, down time, boredom, frustration, and times of segregation which can be reorganized to include meaningful activities and contributions. This is a helpful map when people have complex behaviors, and/or they life in segregated institutional-like settings that offer few opportunities for meaningful stimulation.

Facilitation Tips:

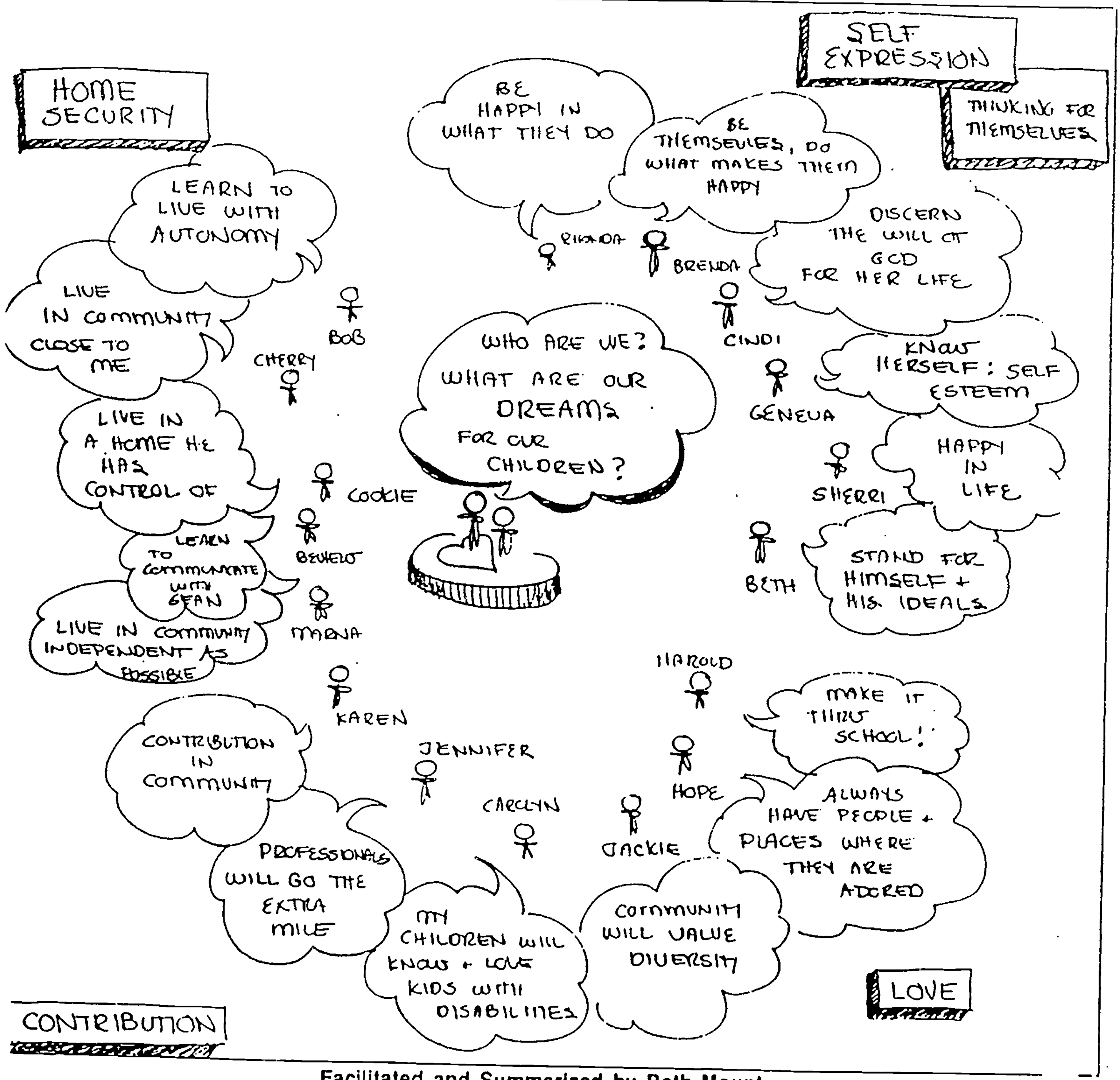
1. Starting with the typical time of waking up, record the person's typical day in 5 to 15 minute increments.
2. Describe the degree of personal assistance needed to help the person accomplish each segment.
3. Note in green the times and activities that are most successful. Note in red the times and activities that are least successful.



APPENDIX C

Reflections on our Experience with Personal Futures Planning During 1991

The proceedings from a conference held September 27 and 28, 1991 Involving a number of people involved in the Personal Futures Planning Project who have the following dreams for their children:



Facilitated and Summarized by Beth Mount

Overview

On September 27 and 28, a number of people involved in the Personal Futures Planning Project in Louisville, Kentucky gathered to review and reflect on the first year of the project, the outcomes, lessons learned, and challenges of doing this work. We spent much of the time discussing the challenges and frustrations resulting from implementation, and many of these implementation strategies are captured in Part 4 of the manual, "Getting Started." This brief review highlights accomplishments and challenges identified during our discussion, and concludes with an analysis of the strengths and challenges to this project written by Beth Mount.

Initial Outcomes:

In the first year, we have become directly involved with **nine** families and provide direct assistance and support to these nine circles.

In addition, we sponsored a family forum in which we stimulated the development of another **eleven** support circles, and identified 11 additional facilitators to work with each new circles. We provide on-going support and consultation to these circles and facilitators.

Finally, we are becoming the source of other person-centered planning efforts beyond the people in transition on our project. We have started other circles, and provided consultation and assistance to agencies interested in person-centered thinking.

What's Going Well? What is encouraging, moving, promising, hopeful?

1. The process has given people the hope, vision, and courage to work for a lot of wonderful things, and the personal support to do so.
2. It has opened people's minds to really get to know people and see them differently. For several people, the family relatives or service providers were able to see the person in a new way.
3. The process helps the family or the person voice their dreams and feel that other people really believe in them.
4. Some concrete, positive change has happened for every person.
5. Many people have learned about listening with respect by watching the facilitators manage the process with respect and sensitivity.
6. Many interesting and hopeful things have happened when people had a chance to take off their professional hats and be creative.

Challenges, Frustrations, and Issues for Discussion

1. Asking people for help and inviting people to the (initial) meetings is always difficult.

2. How do we get other people to come to meetings and participate over time? What else do we need to do to help people participate?

3. Some groups have only professionals in them. How do we widen the composition to include others?

4. Preconceived attitudes of professionals can get in the way of seeing people and their potential.

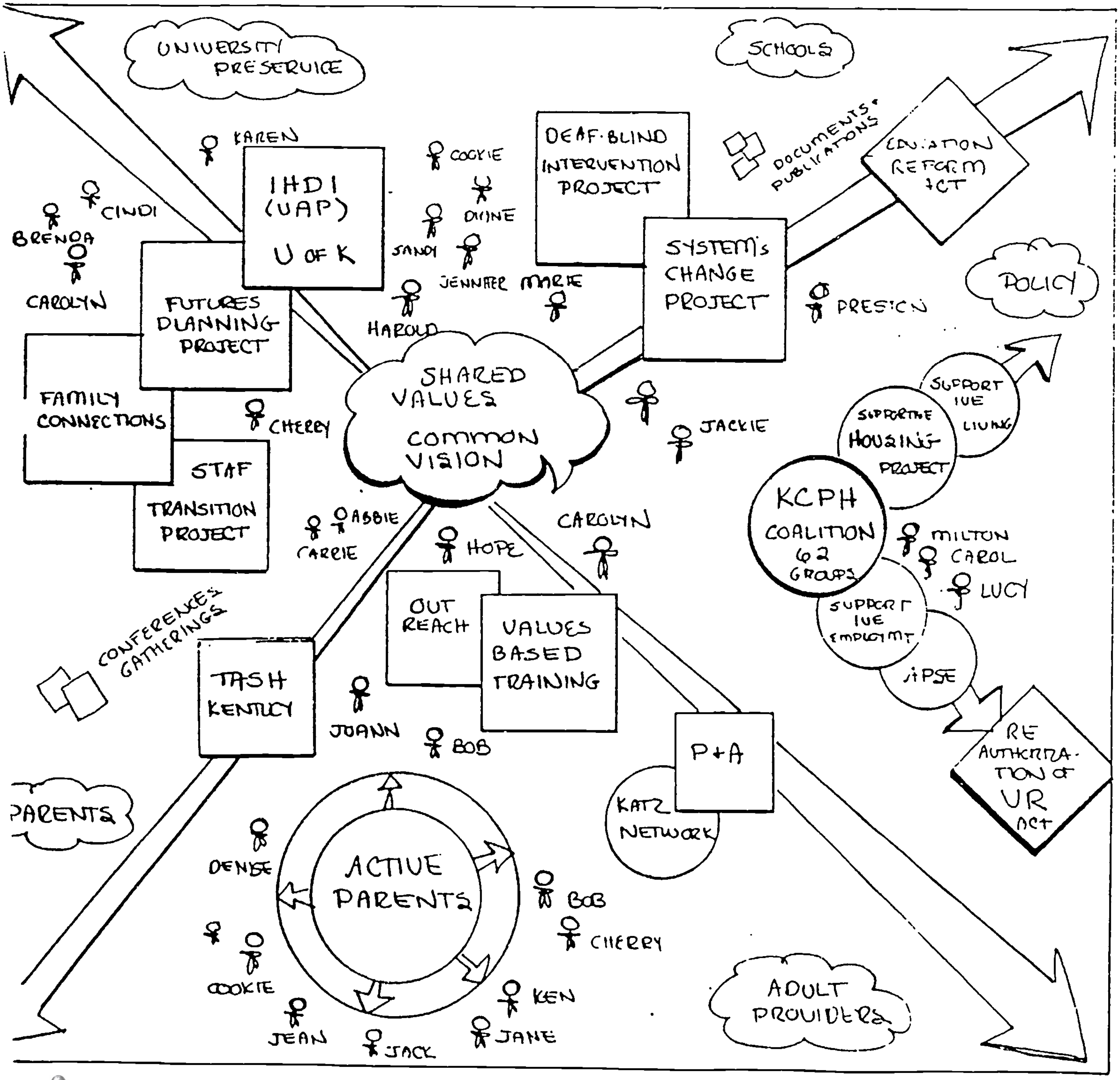
5. Family attitudes can be difficult sometimes. We have high ideals we want to work for and we can feel the tension between these high ideals and the day to day realities they face, the stress, the rejection, the isolation, the responsibility, and the fears they live with. Also, because of their history with negative service systems as well as their isolation, they may have poor or negative predictions about the future, they may overprotect their children, and be afraid of taking risks, or they may trust in and promote segregated options which differ from the hopes we have for people. How do we manage these tensions?

6. What is our role when people cannot speak for themselves, and they have trouble reciprocating in relationships in general? How do we trust our interpretations of the messages they send us in other ways? How do we enhance the warmth, comfort, and ease of relating when people have many barriers to communication? How do we help people reciprocate?

7. How do we manage the tension between needing to talk people into becoming involved in a futures plan and the voluntary nature of the process?

A Network of Support that Nurtures Support Circles

In addition to the 20 circles we directly or indirectly support, we also collaborate with a growing network of people to sponsor workshops, produce publications and newsletters, and learn together ways to stimulate and implement our ideals. As a result of this network, we are developing a collective vision that nurtures the personal visions of individuals and families, and the dreams and experience of individuals then informs and influences the collective vision. The following graphic summarizes the emerging leadership of these overlapping networks.



An Analysis of the Strengths of and Challenges to the Personal Futures Planning Project

The first year of a person-centered development project is difficult because many years are required to realize significant outcomes in the lives of the focus people. There are however, several major strengths of the Kentucky Personal Futures Planning Project which are immediately apparent and warrant recognition. In this section, I will describe some of these assets as well as the ways the project staff are challenged in their implementation efforts.

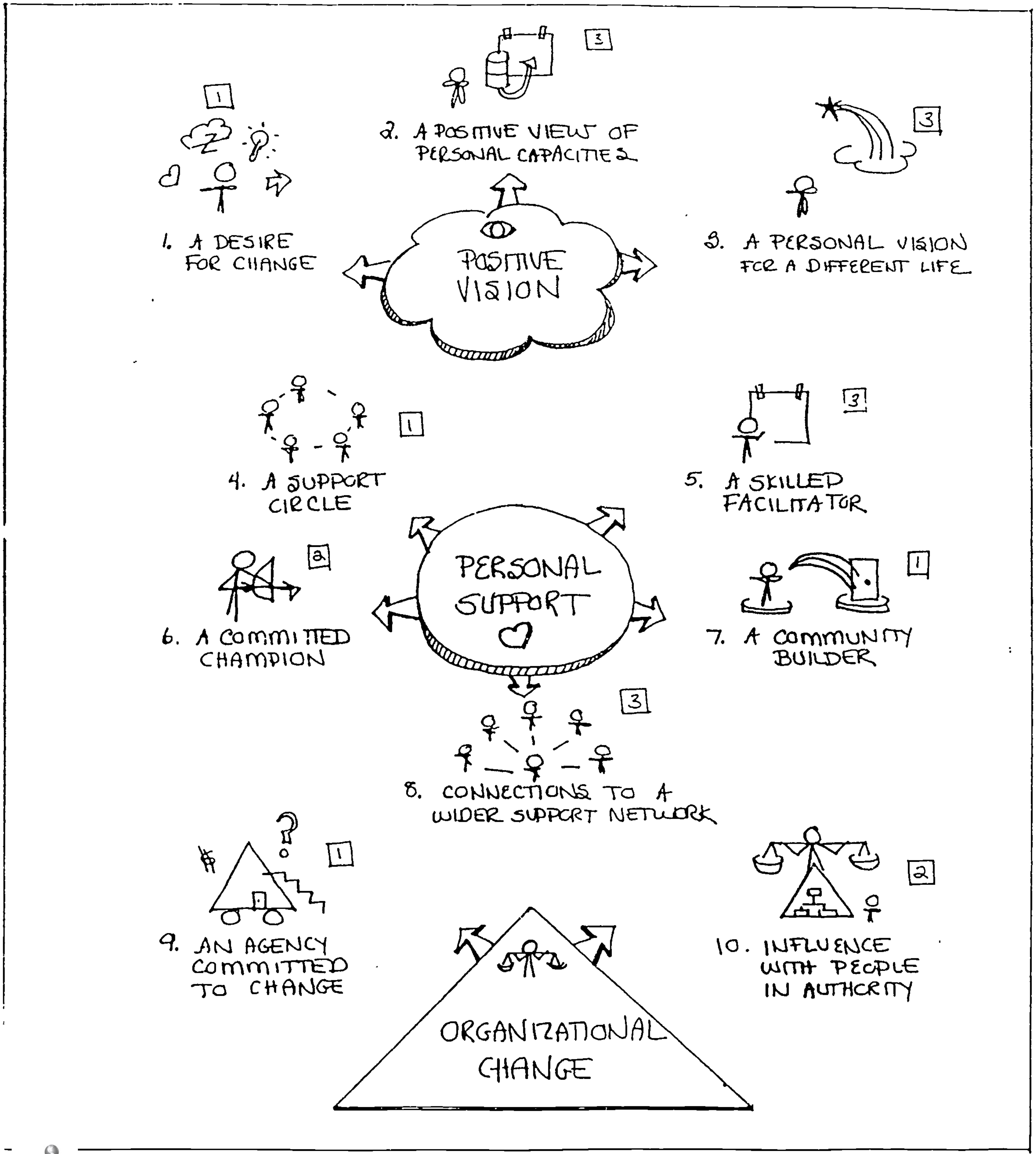
The framework for this analysis is from the monograph, "Dare to Dream: An Analysis of the Conditions Leading to Personal Change for People with Disabilities (1991)."* In this document we identify ten conditions that increase the likelihood that a positive future will be implemented. A summary graphic of these ten variables is included on the following page.

The greater the ability of a project to develop capacity in each of these ten areas, the more likely we are to see significant changes in the lives of the people who are the focus of a Personal Futures Plan. This development process takes time, and cannot be short-changed. Therefore, in the first year of a project, we look for evidence that project staff are at least planting the seeds and laying the foundation to nurture each of the ten conditions.

I will review each of the three major clusters of development as they relate to the Kentucky project, and describe the strengths and challenges in each area. As an overview, each of the ten conditions on the following page is rated with a (3), indicating a major strength, the development of a condition to be really excited about, or a (2), indicating a good start, a condition with lots of potential, or a (1), a condition that presents major challenges to development. The Kentucky project began with a number of favorable conditions because of the project design and the capacities of staff. Project staff are busy laying good foundations in many of the areas presenting the greatest challenge.

*Dare to Dream: An Analysis of the Conditions Leading to Personal Change for People with Disabilities. By Beth Mount (1991). Available from: Communitas Communications. P.O. Box 374, Manchester, CT 06040 (203-645-6976).

Positive Change is More Likely
Under these Conditions:



Positive Vision

The impact of this project is most evident in the powerful way that the focus people are now seen and described as people with strengths, gifts, and vision instead of people whose lives are dominated by labels and stereotypes with no future in sight. The capacity of project staff to **see the gifts of people** and inspire a **positive vision** is most clearly evident in the contrasting descriptions and visions of the people featured in the manual. The revisioning of the people who are deaf and blind is a significant contribution because these are the people who are most at risk of living hidden lives with bleak futures and little hope.

The challenge to project staff in the area of personal vision is to find a "common ground" with families where the work of change can begin. Staff are faced with the difficult tension of dreaming and working toward an ideal while working with families and professionals who missed opportunities to see people and possibilities differently, consequently, they may experience little **desire for change**. There are at least three implementation strategies that may help staff manage this tension.

1. Support families and professionals to see people differently and have a desire for change by working intensely with several focus people and telling their story in many ways as their vision unfolds. Staff may want to invest in the development of a short video featuring inspired family members and professionals who feel really hopeful about their experiences. The newsletter is another helpful way to communicate vision, and amplify the voice of parents speaking to other parents.

2. Be sure to balance work on immediate, short term changes that are most important to family members, with the more abstract work toward long-range ideals. This is one way to build a common ground.

3. Additionally, it may be important for project staff to find "compromise" visions which creates an opportunity to start working with families in a common direction. In view of a compromise, staff should continue to maintain their high ideals, and find as many ways as possible to encourage parents and professionals to see additional possibilities.

Personal Support

This project has several strengths in the area of building personal supports. Of primary importance, staff are taking the time to develop effective **facilitation skills**, and develop the values essential to person-centered planning. The training design for facilitators emphasizes a good mix of skills, values, and commitment. Consequently, many facilitators are also becoming **"champions"** which is appropriate at this stage in the project. Facilitator development is designed to insure intensity of involvement of a number of facilitators in almost one-to-one relationships with focus people (In contrast with the common mistake of training a few facilitators to work with many focus people). Spreading the facilitator role to a number of people who concentrate with a few focus people increases the likelihood that facilitators remain involved and committed over time, which is one of the most important implementation variables.

Another major strength of the project is the involvement of project staff in **wider support networks**, coalitions, and interest groups working toward common ideals, innovation, and policy change (This network is illustrated on page 4). The connection to wider support networks will influence the outcomes of the project in many ways. The vision, values, and commitment of facilitators, families, and professionals will be inspired and deepened over time by the collective activities of this network. Many needed organizational changes will also be influenced by the activities of this network. Staff should be commended for their time and attention given to this values-driven, informal network.

Project staff are particularly challenged in the area of personal support to compose and maintain **effective support circles**, and to develop **community builders**. The concept of reciprocity is a critical in this project because many of the focus people lack the tangible and immediate forms of relating such as eye contact, language, and other basic sensory responses. These personal characteristics create barriers to building relationships, therefore, project staff will have to invent many ways for people to cross these barriers. The following strategies may be helpful in the area of building support circles and building community.

1. Create strength in fragile circles by supporting the involvement of several facilitators. Team work can help in lots of ways to strengthen the power of a "professionally loaded" or otherwise imbalanced or difficult circle.

2. Find a number of ways to strengthen the involvement of local community members. Involving facilitators who live close to people is one way to build local community ties. Engage facilitators in a brain-storming session just in the area of community building. You may want to invite Cathy Bartholomew to help with some problem solving. You may also want to keep some "spare-change" money in the budget to pay some local people by the hour to help facilitate community involvement.

3. Bring facilitators together for a brainstorming session regarding reciprocity. Discover ways facilitators are already increasing interactions between people, and generate a number of strategies for increasing the warmth, novelty, creativity, and depth of meetings and other interactions so that difficult barriers are crossed.

Organizational Change

The good news in the area of organizational change is that a number of small innovations, such as supportive living, supportive employment, and education reform, in Kentucky are gaining support and expanding. The leadership involved in these policy changes are gaining momentum through the informal network of people who share common vision and values. Fortunately, this network has the potential to become the **"people in authority,"** those who can make the money and policy match new person-centered initiatives on a wider scale.

The project is challenged to find ways to link the scarce resources connected with innovation to the requirements of people with intense needs for support. The project is also challenged to find and develop **adult service agencies that are committed to change.** The following strategies may help in the area of organizational change:

1. Consider sponsoring a search conference in year 2 or 3 to frame the organizational challenges emerging from this project. The purpose of a search conference is to bring critical people in authority together to hear the stories of individuals and develop a common understanding of new directions that can address individual situations.

2. Ideally, the project would have an implementation budget which could be used to fund pilot projects or even small inventions that can help people get needed paid supports immediately. This kind of very flexible and accessible money can keep people going in the interim while they wait for long term changes to occur.

Conclusion

An effective person-centered development project begins by focusing on developing positive vision and personal support for development. These are the conditions that sustain people over time as they work toward long-term organizational changes that take many years to accomplish. In summary, the Kentucky project has many strengths in the areas of finding capacities, and developing positive vision, and teaching many people to do this.

The Kentucky project is investing now in the development of competent and committed facilitators who will stick with the process of change over time. Many of the facilitators feel the passion of a champion, and they are working in many ways to develop other circle members who feel similarly invested. The project staff are outstanding in their capacity to keep the values of this work clear, communicate with others, and organize and motivate people to get involved. The emerging person-centered network in Kentucky is filled with hope and the leadership capacity to make their ideals happen.

In the coming years they will be challenged to find a common ground with parents and professionals who are struggling with day to day realities and other limitations. They will need to find many creative ways to build relationships in support circles and in local communities. They will also face the difficult task of linking service dollars and policy to their vision.

In conclusion, people throughout Kentucky and the United States will have much to learn from this project. If we change the way we see and respond to the most unseen, unknown, and misunderstood members of our communities, then it is possible to do so for anyone with a label or a reputation that has prevented them from having a dream. This is a source of great hope.

> *"In an atmosphere of hope there is a reason for being, there is a reason for doing, there are people to share the journey. Hope provides the strength to continue. It is the nourishment for the journey toward any dream, vision, or goal."*
>
> Pat Beeman and George Ducharme