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ABSTRACT

This compilation brings together various conference papers and a working group report on health and psychosocial aspects of transition for people with deaf-blindness and other profound disabilities. The title paper by Sharon Hostler focuses on health service needs of the individual, including health planning, a transition health assessment, and an adult care plan. Psychosocial service needs of the family and needs of the health care system are also discussed. A response by Mary O'Donnell, titled "A Medical Service Delivery System for Clients in New Jersey," describes the health service program of a state-funded community residence for deaf-blind young adults. A response by Hank Bersani, titled "Principles and Practices of Community Integration for Persons with Severe and Profound Disabilities," addresses the issue of social change toward community integration, which occurs in three spheres (ideology, practice, and legal initiative). A report of the Working Group on Health/Psychosocial Issues and Services outlines issues and recommendations for five levels of care provision: individuals, families, groups, health care providers, and agencies. (JDD)

SECTION III. HEALTH AND PSYCHOSOCIAL ASPECTS OF TRANSITION

Youth with Profound Multiple Handicaps of Deaf-Blindness: Health Issues in Their Transition

Sharon L. Hostler

Introduction

During the 1964-65 rubella epidemic, 30,000 infants were born with congenital rubella syndrome (CRS) (Cooper, 1975). In 1969, the rubella vaccine was licensed. In 1985, only two infants with congenital rubella syndrome were reported to the Center for Disease Control (Morbidity and Mortality Weekly Report, Volume 35:9, March 7, 1986). In 1986, 6,023 profoundly multiply handicapped, deaf-blind survivors are aging out of the educational system into the community. What are the health care needs of these survivors and their families? What are the needs of the health care system? Where are the models of excellence in practice or in concept to meet the needs of survivors, families, and health care systems?

On the 24th of July, 1974, a conference on the future of deaf-blind children was conducted by the John Tracy Clinic and funded by the former Bureau of Education for the Handicapped. The title of that conference was 1980 IS NOW. The stated purpose was to stimulate planning to meet the individual and social needs of a projected 5,000 plus deaf-blind children from the 1964-65 rubella epidemic who would be maturing by 1980. The final five recommendations of the conference were as follows:

1. immediate initiation of planning efforts for services by 1980,
2. development of accurate definitions of "deaf-blind" and "rubella-child,"
3. call for a continuum of services from childhood through adulthood,
4. training of personnel,
5. development of a spectrum of model living and working styles for individuals who are deaf-blind (Lowell, 1974).

We are all aware that the projected continuum of services is not in place as of today, the seventh of April, 1986.

Health care was mentioned only briefly in the proceedings of that conference: hospitals were not good places for children to live (Rieger, 1974), and projected services should include premarital genetic counseling and rehabilitative therapy (Lowell, 1974). Why so little emphasis on health? By 1974, the morbidity and mortality peaks had passed. The emphasis legitimately shifted from medical to developmental concerns. The critical need to preserve residual functions of children with CRS was not fully appreciated in practice. The late sequelae of CRS did not appear in the published pediatric literature until 1975 (Cooper), although the 25-year experience of the 1940 epidemic in Australia had been reported elsewhere (Menser, Dods, & Harley, 1967). Issues of adolescence unique to special-needs teens became increasingly evident with the implementation of Public Law 94-142 guaranteeing education for all handicapped children from 3 to 21 years of age in the least restrictive setting. Today, not only does the implementation of Section 504 of the amended 1973 Rehabilitation Act ensure equal access to health care services, but our current concept of health promotes physical and psychological well-being, not just the absence of disease.

Service Needs of the Individual: Health

Planning

The individual's self-care strengths, his communication mode, and his social characteristics are primary determinants of his adult living situation. The intensity and frequency of required medical services will influence this decision. The health component of transition planning incorporates the individual's life experiences, his medical history, his current medical status, and a reasonable prediction for his future health needs. A wheelchair, a feeding gastrostomy tube, an intermittent catheterization program or an intractable seizure disorder contribute increasing degrees of restriction on the choice of residential setting.

Although health issues may not be the primary concern for the successful transition

of the person with profound multiple handicaps of deaf-blindness or the primary concern of his family, the following four areas need to be addressed:

1. lifelong promotion of physical and psychological wellness;
2. continued management of the manifestations of CRS:
   a. impaired hearing,
   b. impaired vision secondary to glaucoma or cataracts,
   c. mental retardation,
   d. heart disease,
   e. cerebral palsy,
   f. the associated communication, learning and behavior disorders;
3. timely diagnosis of late onset sequelae of CRS (Sever, 1985):
   a. diabetes mellitus (Cooper, 1975; Shaver, 1983),
   b. thyroid dysfunction (Clarke, 1984; Cooper, Shaver, Bright, Rogol, & Nance, 1984),
   c. ocular damage (Boger, 1980),
   d. cardio-vascular disease (Sever, South, & Shaver, 1985),
   e. encephalitis (Townsend et al., 1975; Weil et al., 1975; Waxham & Wolinsky, 1984),
   f. others;
4. successful completion of the physical and psychological tasks of transition:
   a. reconciliation of one's hopes and the relevant realities,
   b. modification of realities when possible,
   c. change of setting, program and team members,
   d. changing social and sexual roles of the young adult,
   e. obligatory grieving of the losses inherent in even positive change (Wheelis, 1973).

Today I would like to propose a process to identify the individual's health needs. The process includes four stages: (a) planning or needs assessment, (b) health assessment, (c) development of an adult health care program, and (d) family consultation. The time requirement for completion might vary from 6 to 12 months. In addition to family members, the specific disciplines and agencies involved will reflect the unique history of the youth and the community systems involved in his past and future.

Ideally, the transition planning would be initiated early in childhood so all intervention would be directly focused on adult outcome. Such a plan would necesarily be modified on a periodic basis as a result of changes in the child, his family, and his eventual community. In reality, the stress of managing immediate crises and coping "one day at a time" negates this ideal.

Transitions to a new stage in life are the periods of the greatest stress (Terkelsen, 1980). Families experience increased vulnerability during periods when their child enters or leaves school. Planning for transition necessitates clarification of family values. One intervention program identified these planning tasks for families: (a) identifying the quality-of-life criteria that are important, (b) identifying preferences of their son or daughter, (c) conducting ecological inventories of community programs, (d) evaluating alternatives against quality-of-life criteria, and (e) establishing priorities (Turnbull & Summers, 1985). Families are richly diverse and not all may value or participate in transition planning!

Transition Health Assessment

In preparation for the transition health assessment, a complete health record is compiled. Information gathering includes

1. all past health documents such as private office and clinic records, dental records, hospital discharge summaries, operative reports, lab results, x-rays, EKGs, audiograms, school records, emergency room records, mental health/behavioral psychology reports;

2. a current health profile including information on communication, mobility, feeding, self-care, medications, behavioral programs, therapy plans, the communication system, mobility devices, bowel and bladder programs, and updated family medical history;
3. a review of symptoms and concerns of caretaker, school and family.

Information gathering may be performed by any one of the team, for example, public health nurse, school nurse or case manager. The actual assessment process includes a review and summary of the information gathered; additional history-taking as indicated; the complete physical examination; appropriate work-up as indicated by the history and physical examination such as blood studies, audiograms, x-rays, or a subspecialty consultation; and a final document which summarizes all the above and projects future medical needs.

The health assessment is performed by the primary pediatrician who is committed to the care of this youth and his family. Although the primary pediatrician may have cared for the young adult from birth, it is doubtful that he or she has systematically reviewed all of his documentation or had access to a complete set of records. The process of review and summarization is very time-consuming, as we discovered in our own adolescent project. For example, the time required to review all the complex documentation of an 11-year-old girl with cerebral palsy was nine hours. This is an important procedure, no matter how well coordinated he health care delivery may have been. Appropriate incentives need to be provided to ensure its completion.

Attention is addressed to the progression and patterns of illness. Accidents, injuries, and behavioral changes need to be assessed in light of physical or sexual abuse. Immunizations may need to be updated. The medication profile is evaluated for the potential of drug elimination or simplification, reduction of side effects or long-term risks, cost reduction, a less intrusive schedule, an alternate route of administration, and abuse/dependency prevention. The family's medical history is reviewed for risk factors pertinent to the young adult's future health. For example, a family history of early onset coronary artery disease or rectal carcinoma would alter the projected medical screening.

The physical evaluation of the young adult has added value and efficiency when preceded by a thorough historical review. The specific content of a physical examination is dependent on the patient, the presenting issues, the examiner and their historical relationship. However, I believe the uniqueness of this health assessment dictates special attention to at least the following areas.

General Wellness

Height, weight, nutrition:
sleep and eating patterns;
adequate growth;
unexplained changes in the growth curve;
complete secondary sexual development;
onset menses, cycle pattern;
adequate dietary intake;
increased fiber to eliminate laxative use;
need for nutritional consultation;
need for supplementation such as iron or calcium;
immunization needs;
indication for hemoglobin, hemocrit, and white blood cell count.

Two cases of growth hormone deficiency have been reported in CRS with the onset at 12 years in one boy (Preece, Kearney, & Marshall, 1977). Persistence of some growth slowing is indicated in the 1985 description of a CRS cohort of adolescents as

"small and light" (Desmond, 1985) although well proportioned weight for height. Obesity, on the other hand, is an issue reported in group homes for the severely mentally retarded (Green & McIntosh, 1985).

Dental examination:
- oral hygiene;
- eruption complete, status of wisdom teeth;
- adequate occlusion for speech, feeding, and attractiveness;
- need for restoration or operative procedures;
- does bruxism indicate need for protective device

Skin care:
- hygiene, corns, infected nails;
- decubiti, could acne care be improved;
- evidence of self-stimulation or physical abuse.

Aspects Pertinent to the CRS

Hearing
- evidence of excessive cerumen, ear infection, foreign body;
- audiological assessment including review of aid appropriateness;
- otologist referral.

The hearing loss associated with CRS may worsen as a complication of conductive problems and progresion of the sensorineural damage (Desmond et al., 1985). The latest age for progression documented is 10 years (Sever et al., 1985).

Vision
- acuity; if glasses, an appropriate prescription;
- if glasses, are they still intact;
- intraocular pressure;
- conjunctivitis;
- retinal changes or injury;
- ophthalmologic consultation.

Boger reports additional ocular damage in nearly 10% of children followed with CRS. The diagnosis of late onset glaucoma has been documented up to 22 years of age (Boger, 1980). A decrease in central vision has been related to subretinal neovascularization and reported to occur during years 8-17 (Frank & Purnell, 1978).

Communication:
- current method, functional level;
- with whom does he routinely communicate;
- who is his interpreter in his current setting;
- interpretive source in medical setting;
- indicators of pleasure and pain;
- most effective comfortconsoling measure;
- appropriateness of communication system.

Feeding:
- self; assisted or adapted;
- intake adequate;
- time requirement acceptable;
- progress socially acceptable, in the community;
- nasogastric or gastric tube feeding;

vomiting, self-stimulation;
drug side-effect;
aspiration pneumonia.

Mobility:
level of ambulation, injuries;
full range of motion at all joints;
special attention to the hips and knees of chair sitters;
more than 20 degrees of scoliosis;
patterns of spasm, need for continued medication;
orthoses still functional;
reduction in size or weight as appropriate;
updated adaptive devices;
electric or sport-weight chairs;
leisure and exercise;
therapeutic recreation;
medication; therapy needs;
orthopedic surgery.

Cardiac status:
activity level;
blood pressure;
history of risk factors;
change in history or physical findings.

Although congenital heart disease was a prominent concern during the early life of children with CRS, only one adolescent with functional heart disease was identified in a follow up study of 36 CRS teens with congenital heart disease as infants (Desmond et al., 1985). A second longitudinal study did not list cardiac disease as a long-term problem (Appell, 1985). Ligation of the patent ductus arteriosus has not been associated with late onset sequelae. If there is pulmonic valvular disease, one might consider an EKG and chest x-ray. If there is evidence of right ventricular hypertrophy, a cardiology consultation is indicated (H. P. Gutgesell, personal communication, 1986). Late appearance of hypertension has been described and concern stated that the vascular lesions of rubella may cause coronary, cerebral, and peripheral vascular disease in adulthood (Sever et al., 1985).

Diabetes Mellitus:
weight change;
increased thirst;
increased voiding;
bed wetting;
urinalysis;
hemoglobin A_1.

The association of diabetes mellitus with CRS was first reported in 1967 (Menser et al.) and confirmed in a 1975, ten-year follow-up of youngsters with CRS from New York (Cooper, 1975). The follow-up studies of the 1941 rubella epidemic in Australia indicated up to 20% had overt or latent diabetes mellitus by age 35 (Menser, Forest, Bransby, & Hudson, 1982). A current study of young adults with CRS is finding the occurrence of diabetes mellitus to be 1-2% with autoimmunity as the probable mechanism. There is not, to date, a clear pattern with respect to insulin dependence or age of onset. (Shaver, 1983; Clarke et al., 1984).

Thyroid function:
serum for thyroid antibodies;
if positive, then full thyroid function studies

In a study of adymptomatic adolescents with CRS between the ages of 15 and 18, 25% had demonstrated thyroid antibodies and 5% had thyroid dysfunction (Clarke et al., 1984).

Neurological evaluation:
vision, hearing, mobility as above;
change in frequency or form of seizures;
appropriate blood levels of anticonvulsants;
EEG;
fine tuning of medications: simplification, reduction;
side effects;
injuries secondary to seizure activity;
change in mental status, loss of skills;
deterioration on neurological exam.

In 1975, progressive panencephalitis was reported in four patients with CRS with onset during adolescence and leading to death in two patients (Townsend et al., 1975; Weil et al., 1975). In total, 12 cases of fatal progressive rubella panencephalitis have been reported. All were boys who experienced the onset in their second decade with progressive neurological deterioration over 8 to 10 years (Waxham & Wolinsky, 1984).

Behavioral disorders:
attention-seeking behavior;
autism;
temper-tantrums, self-stimulation;
aggression;
known aversive stimuli;
eating or sleeping disorders;
what is the behavior management strategy, does it generalize;
are behaviors related to medication, time of day, activity.

Issues Related to Transition

Body image:
need for visible devices;
grooming level;
family, staff or community concerns;

Socialization:
friends, communication, conversation;
preferred person, favorite object;
roommate preference;
recreation and leisure activity;
possible lifting of outdated medical prohibitions;
dress or undress alone, toilet independently;
seductive behavior.

Sexuality:
review of family values;
level of sex education;
body parts, relationship issues;

history of sexual activity;
private vs. public behaviors;
personal hygiene;
masturbation, sexual activity, other;
personal hygiene ability;
pregnancy and veneral disease prevention;
behavioral or pharmacologic prevention;
sterilization.

The incidence of sexual activity in a group of 108 moderately to severely physically disabled adolescents of ages 13-18 was 17% (Hostler & Linden, 1981). Depo-Provera, 150-250 mg every three months, usually prevents ovulation. Sterilization using federal funds since the moratorium of 1973 is prohibited. Sterilization is available with adjudication of the youth as incompetent in most states with the assignments of a guardian ad litem for the youth and legal representation for the parents.

Examination:
breast exam, pelvic exam, Pap smear;
vaginal discharge, infection;
foreign body, hernia, phimosis;
testicular masses.

Safety:
accident pattern;
self-abuse;
drug overdose;
molestation, rape, physical abuse;
environmental requirements;
supervision requirements.

In a 1970 report, 29% of the 6,000 abused children had developmental disabilities prior to abuse (Gil). A survey of Parents' Anonymous members revealed that 58% of their abused children had "developmental problems" (Chotiner & Lehr, 1976). The 1979 data fo the National center on Child Abuse and Neglect indicated that 16.3% of all substantiated reports involved children with special charateristics as opposed to the incidence of 7-10% of children with disability (Mattsoon, 1972). Episodes of sexual molestation and rape of the disabled are discussed among parents in quiet desperation, although the incidence of sexual abuse is not known. Concern about the incidence of sexual abuse is not known. Concern about the incidence of accidents and suicide was noted in two recently published longitudinal studies of the CRS population (Desmond et al., 1985; Appell, 1985).

Separation:
family members' reaction to anticipated change;
projection of youth's awareness of setting, structure, and caretaker change;
immediate need for intervention or counseling referral for any family member;
how else can the physician be helpful;
timely report, support;
legal or funding help;
identification of community resources;
competent and caring health professionals;
is the physician "letting go" successfully.

Independence:
rehabilitation engineers;
architectural recommendations for deaf-blind residences;
assistive devices;
lifts, ramps, bumpers;
transportation needs;
sheltered workshop.

Alarm systems with flashing lights and vibration are well known for this population. The potental of flashing lights to precipitate seizures must be remembered, especially at this period when anticonvulsants may have been decreased or eliminated. Environmental controls are successfully used by severely mentally and physically handicapped persons. Robots have been developed at Johns Hopkins and UCLA with the capability of feeding (Cain, 1985). Possibilities of neuroprostheses or sensory prostheses are currently being researched (Desch, 1986). The Mowak sensor (a hand-held mobility aid using a narrow beam of reflected high intensity light that produces vibration in the sensor when the sound is reflecting from an ooject) and the Sonic Guide are in limited use (Mellor, 1984). Assistive devices and electronic communication aides are exciting but require very prescriptive trials with the individual client in his specific setting to demonstrate functional usefulness. Artificial intelligence, robotics, interactive video simulations, and telecommunication systems may have practical value in the near future (Cain, 1985).

The physician compiles, in a timely manner, the formulation of the medical history, physical exam, and consultations into a concise document, and makes specific recommendations for inclusion in the adult care plan.

Adult Care Plan

The family and the designated transition team work together to develop the lifelong health care plan. Transition stresses the families. It also stresses those school, pediatric, or other developmental professionals who must alter or relinquish their helping roles. A family's wish to continue contact with a favorite provider (often the ophthalmologist) should be honored. A successful bridge to the community requires very precise descriptions of services needed and clearly stated limits of acceptability. The "child-team members" must be open to flexible, segmented, nonfamiliar, and even nontraditional patterns of service delivery. Once again, value clarification, priority establishment, and compromise are critical. Clear and honest communication is essential between the child and the adult health care teams.

The adult care plan includes provisions for wellness promotion, management of current health problems, intercurrent care and critical care. Wellness promotion includes optimal nutrition, dental care, fitness prescription (endurance, flexibility, strength), communication, safety, accident prevention, and socialization. If hearing was stable at the transition assessment, then scheduled audiological evaluation should occur every 18-24 months to ensure aids are functioning. If fluctuating hearing or loss of hearing is documented, then the interval should be every three months. A visual acuity and intra-ovular pressure measurement schedule is developed according to the individual's needs. The annual complete physical examination will necessarily include appropriate screening studies indicated by the CRS (hemoglobin A_1 and thyroid antibody screens), family history, and the patient's age.

The prescribed management of current health issues would be a direct follow-up of the transition assessment. Three examples of sample plans follow:

Dental:
fluoride supplement in water source;
limit high carbohydrate, occlusive snacks to once weekly;

self-brushing after each meal;
caretaker brushing once daily;
hygiene appointment every six months;
dental consultation yearly;
be sure that the preferred provider has accessible office and specific skills for dentistry for the disabled.

Sexuality (young woman):
personal hygiene program generalized;
behavior modification program continues regarding privacy requirement for masturbation (baseline frequency once monthly in public);
Depo-Provera 250 mg every three months to prevent pregnancy;
breast exam, pelvic exam, Pap smear, and review of Depo-Provera;
strong family history of breast cancer indicating need for baseline mammogram at age 35 years;
be sure that the preferred provider is woman gynecologist with accessible office in community.

Hearing:
if stable at transition health assessment, then audiologic evaluation to ensure aids are still functioning every 18 to 24 months;
if fluctuating or a loss is documented, then audiologic evaluation required every three months;
current equipment description, maintenance, reference and source;
be sure that the preferred provider is an otologist or audiologist with medical referral available

Intercurrent and critical medical care may be provided by various combinations of private, public, and university settings. The hierarchy of possible services ranges from a visiting public health nurse to a neighborhood practice or a regional emergency room. Historically, deinstitutionalized mentally retarded young adults have utilized primary care services more intensely than the control population (Schor, Smalky, & Neff, 1981). Means of transportation and the designated interpreter are identified. Severity of illness may require the primary practitioner to utilize a consultant, a laboratory facility or an inpatient hospital admission. High value is placed on the comfort of the patient, consistency of caretaker, and an efficient outpatient evaluation where possible. Appropriate hospital staff will receive preadmission training if admission is necessary. Environmental consistency will be sought. A family member or caretaker-advocate will be present as counselor and interpreter throughout all procedures and through anesthesia induction in the case of surgery. Issues of informed consent, patient advocacy, decision-making, funding responsibilities and discharge planning will occur in accordance with the plan and be reviewed prior to admission.

Advance planning for critical care demands identification of both an emergency transport system and preferred tertiary level emergency room and intensive care unit. A normal life span is expected. Predictable issues such as the right to treatment, resuscitation, extraordinary life supports, experimental therapy, painful procedures (bronchoscopy, cardiac catheterization), research participation, and terminal care require discussion and clarification. Even decisions regarding autopsy, organ donation, cremation, and/or interment are integral to the life planning process.

Families are confronted with an endless continuum of parental responsibility for a young adult who will always remain dependent. After years of a stable routine, changes occur along all the dimensions: new setting, new program, new staff. There will be different community adult vocational and rehabilitation programs. There will be Social Security Supplemental Income, Medicaid, guardianships, wills, trusts, legal, and ethical

decisions. As the transition process evolves, families are asked both to make very immediate decisions about today's program and to project decisions beyond their own deaths.

The summary document of the transition health assessment is shared with the family and distributed throughout the identified health care network from visiting nurse to regional transport system. It includes not only the identified present and future health needs, but an action plan to meet those needs. The front of this document is a one-page profile of critical data for this young adult. After the necessary identification information, the medical content lists diagnostic categories, functional levels, height, weight, blood pressure, visual acuity, ocular pressure, audiologic information, medication detail, allergies, and identified risk factors. The psychological content includes the responsible caretaker-advocate or family member, communication mode, interpreter's name and phone number, comfort and pain indicators. The final section includes the funding documentation and the designated community health network. Responsibility for the ongoing update of the information in this document rests with the caretaker-advocate. Modification of the lifelong health strategy plan requires a combination of the family, the primary physician, and the caretaker-advocate.

Although there are health care issues to be addressed during this transition process, we must remember that caring relationships are far more essential to the young adult's well-being than any medical service. Health care services today are indeed portable and can be delivered to his or her setting. Decisions regarding medical services are secondary to finding a home.

Family Interpretive

Genetic counseling has been routinely provided to families of children affected with genetic diseases, handicapped school leavers (Vowles, 1981) and deaf students (Warren, Gallien, & Porter, 1982). There are few models for counseling of the brothers, sisters, parents and cousins of a youth who is profoundly handicapped with deafness and blindness. The time immediately following completion of the transition health assessment is very appropriate to share medical information. Siblings and parents may still have many unanswered questions about CRS. All those family members entering childbearing years have the right to information. Our experience with the format of the adolescent interpretive interview with 11-14-year-olds with physical disabilities and chronic illness affirms the richness of interest even in the absence of traditional indications for genetic counseling. The disability is viewed in a social context. Myths and misconceptions abound (Hassler & Hostler, 1986). Preparation, attention to process and content, privacy, and adequate time allotment are critical to a successful interpretive session. The interpretive conference can serve as the safe forum for the issues of life expectancy, future caretaking responsibility, and recognition of the role for all family members.

Service Needs of the Family: Psychosocial

What are the needs of the survivor families? And they are, in fact, survivors! The families themselves are best qualified to identify their own service needs, and Mary O'Donnell in her reaction to this paper (included in this book) will provide the expert testimony for this session. Forty-eight parents with children at the stage of transition from school to adulthood identified residential placements for their children as the greatest need (Turnbull & Summers, 1985). The parents of physically disabled adolescents receiving inpatient care at the Children's Rehabilitation Center listed the "return of their dignity" as the greatest need. This is in sharp contrast with the earlier stated needs for respite and discrete services (Tarran, 1981). Stress often increases with the age of the child (Gallagher, Beckman, & Cross, 1983). One study found parents of older children were less supported and more in need of expanded services (Suelzle & Keenan, 1981).

A "Family State-of-the-Art" Conference in February, 1986, was sponsored by the Office of Special Education and the Division of Maternal and Child Health. A list of needs generated by that parent-professional group included hope, control, power, friendship, choice, self-worth, privacy, respect for one's uniqueness, freedom from guilt, respite, leisure, personal growth, the permission to exclude the special child, trust in service providers, elimination of "placement" from the language, enactment of Medicaid amendments for residential life in the community, payment of family members as health care providers and more. The full proceedings have been edited by Dr. Ann Turnbull for an April 1986 distribution. I look forward to hearing Mary O'Donnell's experience with the New Jersey Association of Deaf-Blind and the comments of other parents here to identify the needs of families.

The resilience of families is truly astonishing. Their steadiness is especially commendable in this period of continual philosophical shifts among professionals shifting from segregated regional centers to integrated mainstreaming; as well as trying out oral, manual, total, and augmentative modes of communication. In the lifetime of these young adults, the system's view of families has evolved from seeing the family as the cause of the problem to having a parenting deficit to responsibility as a parent-teacher, to taking responsibilities as lobbyists, to becoming decision-makers, and, finally, to becoming the architects of the deaf-blind group home movement. A particular difficulty has been the system's inability to keep up with the changing nature and needs of families over the life cycle.

At the time these families had young children, the literature was filled with descriptions of what is wrong with families with handicapped children (Bryne & Cunningham, 1985). Today, however, researchers such as Dr. Vincent of the University of Wisconsin report that the data-based research since 1980, while indeed describing increased stress in families with handicapped children, does not describe the increased dysfunction (Pans, Brown, & Vincent, 1986) such as the increased divorce and suicide rates reported with families of mentally retarded children (Price-Bonham & Addison, 1978). Are these families coping better than regular families? Heresy! In fact, the current model of research activity seeks to discover how these same families cope and adapt to stress (Crnic, Friedrich, & Greenberg, 1983). While professionals and policy makers have been struggling with developing a conceptual model, most families have reared their deaf-blind child—sometimes with the support of the system, and sometimes in spite of the system.

Families form a diverse group with different sizes, shapes, and beliefs. An example is the strong family pride of Mexican-American families who reject outside help and prefer home care (Adkins & Young, 1976). Very few households meet the traditional model of mom, dad and two children, all biologically related. The 1980 census, in fact, reports only nine percent of households meet these strict criteria. And families who participate in national conferences are probably not representative of all the families. Consequently, flexible options for services are needed to reflect the rich differences in families and their values. Supported home care (Cina & Caro, 1984), nursing homes or hospices may be preferred by some families to the model of community-based residence.

Change in any one member of a family affects everyone else in the family. No one member is more important than another and all strive to have their needs met. All families experience the crisis times in the "letting go" process involved in parenting an adolescent (Minuchin, 1974; Simon, 1982). Most families have many opportunities to practice letting go—the curfew, the mohawk, the driver's license—before the move away from home. The sameness of the profoundly handicapped youngster precludes many of these practicing exercises. There are fewer ceremonial markers (graduations weddings) for this kind of rite of passage. Even when the actual move to a group home is an overwhelming success, there may be tremendous feelings of loss and sadness in all family members. The transition may awaken the brother's worry about who will be caretaker after his parents' death, the sister's worry that her pregnancy may be problematic,

or the parents' grieving. Extended family members and neighbors may not appreciate the sadness and may seem insensitive and unsupportive. The family may experience what Peck calls a "little death" before it reestablishes its balance and, with time, translates the pain into growth (1978).

How can the system support all family members in this transition? First, by remembering that all families have coping strengths and resources. Families successfully use the following coping strategies to reduce feelings of stress: (a) passive appraisal ("time for a bubble bath"), (b) reframing ("grass is browner"), (c) spiritual support ("my special child"), (d) social support ("without my hubby . . . "), and (e) professional support. Practice exercises for building coping strength have been compiled in a family self-help manual (Goldfarb, Brotherson, Summers, & Turnbull, 1986).

In Brotherson's interviews with 48 parents of transition aged children, she found the most important strategy for coping with future planning was reframing. Consultation with professionals ranked equally with alcohol, cigarettes, and TV and only slightly above medications as the most important coping strategy (Turnbull & Summers, 1985). In light of those findings, perhaps the health system might offer real social supports such as opening clinics to birthday parties, reunions, weddings, and other simple social events (Haggerty, 1980). Possibly the most important service the system can provide parents is not to become an additional source of stress (Turnbull & Turnbull, 1978). As Dr. Ann Turnbull exhorted at a recent conference: "Ask first not what families can do for the service delivery system but what the service delivery system can do for families."

Needs of the Health Care System

What are the needs of the health care delivery system? The system needs organization at a community and national level for anticipation of predictable crises, information exchange, resource sharing, technical assistance, and appropriate support to meet the stated needs of the individual and his family. Individual providers need communication skills, integrated service networks, consultation, and access to the informational systems. A wish of the system might be to rewrite the history of the past 21 years in such a way that transition planning had been mandated and all activities prior to transition had focused on "survival" life training. If, for life to have value, as Freud suggested, the primary needs of all individuals are to work and to love, then survivorship programming would have included early socialization, sexuality, and prevocational training.

First, let us discuss the communication skills needed by the individual providers, specifically, the physician. Pediatricians are accustomed to caring for patients who do not talk and who need a grown-up to take care of them. That is neither the expectation, training, or experience of the adult practitioner. Parents of disabled children have even been critical of some pediatricians' inability to communicate. The concept of a health care team within the hospital is better understood. Adult physicians participate in health teams primarily in rehabilitative, psychiatric and geriatric settings.

In the special education literature (Wolraich, 1982; Gallagher et al., 1982) and the pediatric literature (Taft, Matthews, & Molnar, 1984; Martin, 1985), specific characteristics of successful physician-parent interaction have been identified. Effective physicians demonstrate the art of communication. They listen as well as they talk. They possess adequate knowledge of the disability. Or they seek out essential information. Parents of disabled children have long described their frustration at the need to become an expert on their children because service providers were not well inform' Effective practitioners also exhibit positive atttitudes toward the child with a disability (he calls her by name) (Armstrong, Jones, Race, & Ruddock, 1980). The practical interactional skills needed by all providers include allowing enough time for health care interaction, learning how to use an interpreter, and gaining patience to delay doing the procedure until it has been explained. (Are these characteristics inate?)

How do we meet the needs for improved communication skills among the practioners?

Many medical schools have introduced courses and experiences to teach interpersonal skills and the social aspects of disease and disability. Economic forces are creating a different disability. Economic forces are creating a different medical school applicant. They are choosing medicine because of the cooperative role, the increased flexibility in practice styles and maybe even idealism. Nearly half the entering classes are now women--hopefully a caring and nurturing group! At best, training produces changes in behaviors but probably not changes in values and beliefs. The latter requires sequential affirming experiences to challenge and modify beliefs.

To create the numbers of physicians necessary today to care for this population means identifying the community practitioners with compatible value systems. The increasing numbers of physically disabled, mentally handicapped, and chronically ill adolescents entering the adult world will change the internist's medical as well as social experiences. Hopefully the behavior of younger graduates will reflect their training and idealism.

The individual provider, especially the physician, needs to develop communication skills with the other community members of the integrated service network. Practitioners learn team behaviors in sports, family life, medical school, hospital training, and on-the-job experience in the community. Successful teamwork demands structured interaction as well as timely reaction in crisis. The identified link person or caretaker-advocate must have ready access to and respect of the system. Patient-related success and a broadened world view are compensations for loss of time, money, and control. Appreciation of the contribution of the ASPCA volunteer or the recreational therapist simply takes experience. Others will never learn.

All community professionals need access to specific materials for sexuality training or training videotapes for hospital personnel, and expert consultation over confusing aspects of care for those who are deaf-blind. Access to the new technology must include trial periods with the clients. A lending library of training resources and a clearinghouse of helpful devices could serve a regional area.

The wants of the service delivery system are as important as its needs. Individual providers want to be valued. Professionals expect reasonable compensation for services. Quality services are not obtained as "favors" or charity. Not only do professionals want comfort and control in their lives, they also want joy and meaning. A conscious remodeling of our community interaction framework could meet both the needs and the wants of all involved.

On a national level, a network is needed for an appropriate exchange of successful problem-solving, innovative materials, and rare services such as psychiatric services for deaf-blind individuals. I propose establishing a periodic regional national conference with a mechanism for dissemination of the rich experiences resulting from work with this population to other parents and professionals.

On a societal level, a provision is needed for developmental services from cradle to grave, the right to live and work in a community, and the right to health-sustaining and other services. We need simplification of legal procedures, guardianships, wills and trusts, and a mechanism of peer review of all providers of services. We need flexible uses of health care dollars. We need Medicaid waivers to maintain our activities in the community, and we need access to the recreational arenas (swimming pools, parks) and transportation systems.

In sum, public policy must reflect responsibility for ensuring each person's right to health. Professional leadership such as we have at this conference can influence policy, can look beyond the present to see the future, can use knowledge to create solutions, and can muster the courage to act when others think it immoral, illegal, or impossible to act.

Over two million youngsters under the age of seventeen experience some degree of limitation in their school, play or other recreational activities because of chronic conditions (Newacheck, Budetti, & Halfon, 1986). The health care system needs a stimulus to achieve excellence. Excellence in the problem-solving for this population

with profound, multiple handicaps of deafness and blindness can be translated into a whole spectrum of available services.

Conclusion

Let us review. We have discussed the specific health concerns for the young adult with profound multiple handicaps of deaf-blindness. A care plan must include provisions for wellness promotion, management of existing problems, screening for late onset sequelae, and periodic reevaluation of the plan with special attention to the usefulness of new technologies. Transition necessarily highlights issues and decisions regarding sexuality, independence, and separation.

As periods of transition are the periods of greatest stress, it is reasonable to expect family members and even systems to react. Parents, brothers, and sisters have issues. Families have different values and styles of coping, and these family differences demand flexible options. At the very least, the system should not add to family stress.

The health care system primarily needs a clearinghouse of resources and information organized at the local and national level. Participation in community health teams will require new communication skills. Model programs and practices are few but are sufficient to serve as a foundation. Services are portable and can follow the child into the community.

The well-being of the young adult is more related to caring relationships than to provision of medical services. To my fellow physicians, I offer the challenges of sharing risk-taking, the same risk-taking we ask of parents and of communities.

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In Response to Sharon Hostler

A Medical Service Delivery System for Clients in New Jersey

Mary M. O'Donnell

It is an honor to be here at this conference and in such distinguished company.

I would like first to make some comments regarding Sharon's very inspiring talk and then tell you how we are developing a medical service delivery system for our community residence clients in New Jersey.

Sharon mentioned the conference, "1980 is Now." When it was completed and the proceedings published, it was hailed throughout the deaf-blind community as innovative and forward looking. It held the promise of a rosy future for all. We looked forward to a lifelong service delivery for those who are deaf-blind being in place by 1980. The conference was 12 years ago, folks. The promises should have been realities six years ago, and here we are at the crossroad, at 21 years old, at the time of transition! Many of us are finding that our children are transitioning into nothing!

I commend Helen Keller National Center for trying to coordinate through TAC (or correct the lack of) service for young adults who are deaf-blind. Now, we need a Catalyst-Coordinator or a mechanism to bring together key people from all corners of the U. S. to a place where they will have an opportunity to study the state of the art of service delivery to those who are deaf-blind. We need to hear what did not work for their clients or in their state; we need to hear of their successes, and the good people and the good systems in their local governments that facilitate success in a service delivery system that meets the needs of the citizen who is deaf-blind. We need to be inspired, encouraged, and rejuvenated by others who have the same dreams, goals, frustrations, and ideals for our people who have such unique needs.

Sharon mentioned that only two congenital rubella syndrome (CRS) cases were reported

in 1985. That may very well be true. However, experience and a child-find program in New Jersey are constantly turning up new congenital deaf-blind cases caused by the drug culture. Also, the great strides in neonatal, postnatal care are increasing the survival rate for infants with severe problems. This must be true throughout the country. We in New Jersey are finding that preschool and school aged children who are deaf-blind are continuing to appear in surprisingly large numbers. This care, nurturing, education, and total service delivery for those who are deaf-blind of all ages is an ongoing, growing phenomenon. The need is not going to go away! Services are needed and, for the foreseeable future, will continue to be needed.

Health issues for this group will always be of primary concern. A multiplicity of problems must be treated and monitored on a continuing basis, and now history is showing us how important it is to monitor closely each of these folks, particularly those with CRS, to watch for glaucoma, diabetes, thyroid, coronary, and kidney problems which appear as they enter adulthood.

The all-inclusive wellness plan and adult care plans which Sharon has suggested offer a complete, well thought-out program. I hope we can find health providers with time and the interest in offering such programs. I hope we can find physicians who are willing to study the literature to stay current with the latest developments and treatment procedures. I hope, as new findings surface about CRS and other causes of deaf-blindness, there continues to be a forum for the exchange of information. Perhaps Helen Keller National Center will be the catalyst, perhaps some of our federal agencies should look toward acting as facilitators for a group such as those who are deaf-blind. But most of all, I hope that when we find the proper caretakers who are willing, knowledgeable, and able to care for the unique needs of the person who is deaf-blind, that we will also find the dollars to support the kind of wellness and adult health programs we need.

We will all be anxious to read Dr. Ann Turnbull's proceedings of the family conference referred to here. Although each family is different in so many ways, a common denominator is usually present in that the family wants each of its members to be safe, productive, and happy.

I commend Sharon for involving the family--particularly brothers and sisters--in the clients' lifetime plan. Families should be encouraged and offered nonthreatening opportunities for close contact with the disabled member without inconvenience or feeling of intrusion. All living arrangements should provide opportunities for family interaction.

In New Jersey, we are fortunate to have a well-developed human service delivery system. The Commission for the Blind, an offshoot of our Department of Human Services, has historically been the provider and facilitator of all service delivery to those who are deaf-blind in New Jersey. Fortunately, the Commission has developed a good working relationship with the State Department of Education and most school districts. Rehabilitation for citizens of New Jersey who are blind, including deaf-blind, is handled through the Commission for the Blind. The Department of Developmental Disabilities and Division of Youth and Family Service (also divisions of Department of Human Services) work cooperatively with the Commission to provide client services. I don't mean to suggest we live in a Utopian State! That's hardly the case. There are certainly flaws in the systems and, as always, the systems can only work as well as the people who implement them. We have some talented, dedicated, creative, and innovative people in New Jersey who have dedicated outstanding professional careers to the service of those who are deaf-blind; and we certainly have our share of "do-nothings" and "dead wood" always on hand to "mess up" a potentially good plan! But, at least we have an agency structure that can enhance service delivery when it's working well. This, unfortunately, is not the case in all states.

Over the years, we parents have had a rather loose-knit statewide parents group, sort of a support system, that sprung into action during times of crises but had no real

structure. In the early 1980s, we parents of "the transition" group were becoming alarmed about the future as were some of our "caring" administrators at the Commission for the Blind. In late 1983, a grant was awarded to our nonprofit parent group, the New Jersey Association for the Deaf-Blind, by the Commission for the Blind. It provided operating expenses to hire an Executive Director and clerical help, and establish an office to facilitate delivery of services directly to those who are deaf-blind in our state, bypassing the great burden of bureaucracy which can so often hinder progress.

We've had our growing pains, and they will continue. However, one of our successes is my subject for today. We opened our first community residence for six young adult clients, 21-22 years of age, on February 10, 1986. The house was funded with, and support will continue to come from, Department of Developmental Disabilities resources. We selected the location, found the house, supervised renovations, dealt with all the inspectors, met all the code requirements, educated the town fathers, courted the neighbors, checked community resources--vocational, recreation, medical, leisure--developed staffing patterns and training procedures, purchased a van, furnishings, and recreation supplies. We developed our client selection criteria and, with the help of knowledgeable professionals, reviewed 14 clients presented from the Commission for the Blind and Department of Developmental Disabilities client registers to select our six for this first home.

The processes involved interviewing families, staff in schools clients attended, and using the resources of our own Commission for the Blind, Vocational Rehabilitation, Department of Developmental Disabilities, Helen Keller National Center, Technical Assistance Center, The Association for Persons with Severe Handicaps, United States Department of Education, in addition to the expert advice generously shared by those of you who have had experience in the development of residences. Also, our Executive Director had a valuable range of experience in residential development, in addition to excellent training skills which have been utilized in staff orientation and management.

After our clients were selected, but before they moved into their home, a detailed profile was developed for each. Medical histories were reviewed and updated with the previous program nursing staff; medical records were reviewed; and families were interviewed. Families were given the option to continue with doctors who had cared for their children or to use the team contacted by our agency. Parents made these choices based on location and convenience, and their wishes will be honored. Each client was required to have a physical before moving into the home.

Our general medical service contact is at one of the receiving hospitals of the location of the residence. This hospital has in place a well-established clinic with a team of specialists whose practices are devoted to treating the developmentally disabled. We hope and anticipate their cooperation in keeping abreast of and contributing to the literature and body of knowledge being developed about those who are deaf-blind. It is, of course, too soon to tell if this will happen. An initial screening and evaluation on each of the clients was completed at this clinic shortly after they moved into the home.

Four of our clients wear glasses, and three wear hearing aids. We contacted a local optician and hearing aid shop and both agreed to care for the appliances. They are ready for us if we need them.

A registered nurse of the Commision for the Blind staff has done inservice training for our house staff and will continue to do so periodically. This person will be "on call" for consultation. Local Fire Department and Rescue Squad personnel were contacted. They visited the house for inspection before occupancy, and since occupancy, have met the clients and conducted safety drills.

A dentist contacted through the New Jersey Association for Dentistry for the Handicapped has agreed to provide dental care for those clients who will not continue with their previous dentist.

Members of the Rubella Project at Roosevelt Hospital in New York City recently received ongoing grant money to continue monitoring and caring for their clients beyond

21 years. They have offered their services and will act as consultants to our staff. We are located about two hours from this facility. Dr. Zearing, whom many of you knew when he was with the Rubella Project, has also very kindly agreed to act as a medical consultant for our agency, and he is currently located only about 45 minutes from us.

The housemother is responsible for maintaining all health records. Menstrual cycles are charted—BMs are charted for those with problems. Appliances are checked and must be in good working order. (Menstrual and constipation problems, as well as nonworking appliances, are primary causes of discomfort and frustration among deaf-blind adolescents and youth. Most such individuals are unable to communicate the presence of these difficulties. Thus, acting out and inappropriate behaviors result. A major concern of parents, it is of utmost importance that all staff members are not only aware of these problems but take steps, on a daily basis, to prevent them.) Regular checkup appointments will be scheduled by the housemother, taking into consideration those medical problems for which the literature and our consultants feel this population may be in an "at risk" status. All staff have been alerted to be aware of signs or changes in behavior that may indicate medical problems.

One of our clients had a minor acting-out adjustment situation in the workplace. Prompt response and technical assistance from TASH have been most helpful in resolving this incidence.

We have been very conscious of the families and are encouraging active family participation. We will, of course, carry this philosophy through in all medically related areas for our clients. We tried to anticipate and plan for needed services before the clients moved into their home, using the profiles we had developed. Our goal was to be prepared to handle an emergency before it arose, to have a reasonable plan and resource available in anticipation of need. We will continue with this philosophy as experience teaches us where more areas of need may be.

I have one more area to address and hope you will be kind enough to bear with me. I must try to express my point of view! There has been and will be much talk at this conference of normalization, age-appropriate activities, and integrated work places.

Why do our young people who are disabled—deaf and blind—need to ask your permission to be different and unique? And why won't you, of all people, give them permission?

I submit here some food for your thought. Each of you in this room is out of step with normalization whether you have a high school diploma or a Ph.D. to prove your normalcy. Why? Because you are here! In today's materialistic world where the dollar and what it can buy (self-indulgence) where the yuppie and "ME" cultures are popular, you are giving your talents, energies, and time to develop a better quality of life for those less able than yourselves. You have permission to be different and unique, to associate and work with your peers, and choose your recreation according to your likes.

At some point you left your parents' home as many of our children are doing. Did you expect necessarily to live and work within a few miles of your parents' home? Did you choose your line of work with a quota system in mind? "I'll be the white Catholic, female, Irish descent, middle-income background, B.A. degree, blue-eyed, blonde in your integrated workplace!" Was this your parent's dream for you? Is it yours for your children?

Most likely, you live close to where you work. You work at something you enjoy doing, with people who have interests and skills compatible with yours. You choose your friends because they're like you; you have common interests; you can communicate well with each other.

If you have a serious medical problem and you have a reasonable choice, you will live where care is accessible. If necessary, you will consider the quality and need for transportation when choosing your residence. Has anyone told you lately you can't sit on the backyard swing, on the park swing, or go on the amusements at the fair because these activities are not age-appropriate?

When planning for our children who often cannot make their own decisions, let's consider them each different and unique! Consider their likes, dislikes, and comfort; their environmental and communication needs; what activities they enjoy for recreation opportunities; how they wish to live, work, and recreate in the company of their peers. Our children are different and unique; please respect their differences and uniqueness, and cater to them!

In Response to Sharon L. Hostler

Principles and Practices of Community Integration for Persons with Severe and Profound Disabilities

Hank A. Bersani, Jr.

I want today to speak about the issue of social change and how we have come to have newer, better services for people with severe, profound, and multiple disabilities. I also want to give a template for today's discussion and ask people to think about social change in the past as happening in three related spheres: the sphere of ideology, the sphere of practice, and the sphere of legal initiative. First, I want to explain what each of these means.

Three Spheres of Social Change

Ideology. If we use as an example the issue of integrated education for children with severe handicaps, we see that we began with a well-defined ideology We knew that we wanted to find ways for children without handicaps and children with handicaps to go to school together. Over the years, that ideology became more and more well articulated. We said it is desirable for all children to go to school together in truly integrated settings, without regard to their labels, abilities, or disabilities.

Practice. Simultaneous to the development of that ideology, we made improvements in educational practice to the point that we were able to teach children we had previously thought could not be taught, and to teach children in integrated settings whom we previously thought required segregated settings. So we experienced an increase in sophistication in terms of the state of the art of integrated education.

Legal initiative. The third change was in the legal sphere. The passage of Public Law 94-142 gave a legal mandate for the education of all handicapped children. Thus

we had the ideology that it was desirable for all children to be educated together, the practical skills to be successful, and the legal mandate, which required integration and made some money available to encourage that all children be educated together. These three together resulted in major social change.

When we talk about social services, especially residential services, for people with severe handicaps, we are at this point still lacking a legal mandate. We don't have a residential equivalent of P.L. 94-142, but a great deal has happened in terms of ideology. I also wish to discuss the public policy issues that I think point the way for a legal mandate.

The Story of Amy and Jimmy

I want to tell you the stories of two children whom we met in the research project that I am affiliated with. We call these children Amy and Jimmy. Amy is a girl, and Jimmy is a boy; otherwise they have a lot in common. Both are eight years old. They both have hydrocephaly and a multitude of associated problems, including blindness, and seizures. Both take nutrition by g-tubes, and are susceptible to choking, infection, bed sores, and sudden drops in body temperature or hypothermia. Fortunately for Amy and Jimmy, they happen to live in states where people are committed to serving children with severe disabilities in the community. Jimmy lives with five other children in a Medicaid-certified group home just outside Gibson Landing, Michigan, and Amy lives with her foster parents, Mr. and Mrs. Parker, in Lincoln, Nebraska.

We have a several-page description of how the children's lives now go (Taylor, Racino, Knoll, & Lutfiyya, 1986). What becomes very clear is that, first of all, there was the supportive ideology. Michigan and Nebraska are states in which people are committed to serving children with severe disabilities in the community. Second, these children are receiving clinical services, the "hands-on" intervention, that make it possible for them to live in a community whereas, just a few years ago, conditions like hydrocephaly, hypothermia, blindness, seizures, and certainly the use of gastric tubes would be clear indicators of an inability to live in a community. Here we see strides in both practice and ideology, and are seeing now the development of policy statements that will lead to, I think, a legal foundation for greater services. As we have learned over the past fifteen years in developmental disabilities, there is a common link of several basic principles that are not disability-specific. I believe that these principles apply equally to deaf-blindness as well as severe and profound mental retardation, and people called "medically fragile." In short, these principles apply to all of the people we call the "most difficult to serve."

The Ideology of Integration

The two projects that I am affiliated with through the Syracuse University Center on Human Policy--one project called the Community Integration Project, and the second called the Research and Training Center on Community Integration, of which I am the Director--have jointly developed a series of policy statements about integrated community living, and I want to share those with you now. They are, for the most part, self-explanatory.

1. People with developmental disabilities, including those with the most severe disabilities, should be served in their home communities.

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2. Community living arrangements should be on a family scale and should be located in residential neighborhoods.
3. Services should support people in typical homes, jobs, and community environments.
4. Services should foster the development of practical life skills.
5. Parents, as well as those who have the disabilities, should be involved in the design, operation and monitoring of services.

These policy statements indicate a change from the old kind of model of forming group homes for eight or twelve or fifteen people for everybody who comes down the line. People don't come in cases of 24, or in half cases of 12, or even 6-packs. People come as families and as individuals as people who have friends, and as people who have their own individual needs. If we are going to begin to devise a service system for all people with all types of severe disabilities, that service system needs to focus on the concept of a home, particularly with children, but even with adults. People should be supported whenever possible in their own natural homes. If the natural family (sometimes called the biological family) cannot or is not willing to keep that person at home, even with substantial supports, then we need to move on to an adoptive environment. Only if adoption is clearly out of the picture (and we are finding more and more that adoption is reasonable for people who were previously called unadoptable), only then will we look at foster care for a child. Only after we have explored supporting the family—an adoptive family or a foster family—would we then begin to think about other settings such as group settings. In day-to-day practice, we may need to compromise, but our ideology must be clear: families first.

Several systems around the country are saying no to group-based care for children, even for children with the most severe disabilities. The Macomb-Oakland region north of Detroit serves a population base of 3 million people and, as of today, has only seventeen children in the entire population base who are living in other than family settings—five children in one group home, ten children in a transitional ICF/MR, and two additional children currently in the regional center. By Christmas 1986, they plan to have all of those children into foster homes, adoptive homes, or biological homes.

As a result of the experience in systems like Macomb-Oakland, we are rethinking the need for a so-called residential continuum. We have talked for too long about the need for a continuum of buildings such as large group homes, small group homes, specialized group homes for people with behavior problems, specialized group homes for people with medical needs. We have focused on buildings. We have had what I would like to call an "edifice complex," focusing too much on the buildings and too little on supports. We need to realize from lessons learned over the past fifteen years that buildings are not services. We do not need a continuum of buildings; we do need an array of services. If we focus too much on buildings we get into a dilemma that Seymour Sarason has written about (1972) where the building becomes a distraction or a trap. We talk more about my building and less about the service.

As we direct our attention to services, we must be aware of what I call the "self-satisfaction trap." There is great pressure in the field of severe disabilities to identify "model" programs and then, if you will, anoint them as the service we should all seek to emulate. There are at least two problems in identifying model programs. The first problem is that so-called model programs are never as good as we say they are or will be. Our old ideas pale so by comparison that we over sell the new model.

The second problem with the self-satisfaction of "models" is resistance to change. If we say that we are a "model" program, then there is no need for us to change. Then we become what I call "a failing success," and in 15 years, the "model" is still in the same place with fifteen-year-old technology, fifteen-year-old innovation, fifteen-year-old service models that are no longer innovative, and are no longer "model," and often no longer even adequate.

As I've visited a variety of school programs as well as residential programs, I have kept a list of what I called "lessons learned" over the years, things that we maybe

didn't do so well in the past, or things that have become obvious as we had more experience with integration.

Lessons Learned

Good teachers can teach anyone, and bad teachers should not teach at all. We don't need to have two groups of teachers—special education teachers and regular education teachers. The ability of a teacher to cope with differences is intrinsic to being a good teacher, and teachers who lack that ability, teachers who cannot cope with differences in the classroom, cannot be accepted as a reason for segregating children. Rather than seeking out segregated settings because teachers cannot cope with differences, we need to seek out teachers who can cope with those differences.

There is no aspect of so-called regular education that cannot benefit all students. Everyone can benefit from being in a regular classroom with a variety of students. There is not just one middle group that benefits from regular education with those who are handicapped needing one type of special education and those who have the other terrible label, "gifted and talented," needing another type. Students will learn best together.

There is no aspect of so-called "special education" that cannot be practiced by any good teacher. The principles of individualization, program planning, writing IEPs, doing a task analysis, high repetition, or whatever it is that constitutes special education are not magic. Any good teacher can master these techniques.

We have focused in the past entirely too much attention on independence as a goal. What we have learned recently is that independence is really not an appropriate goal for anyone; all people must learn to be interdependent. None of us in our own lives are truly independent; we are all interdependent. This misplaced emphasis on independence can eat up a great deal of concern and instructional time. While being independent has its place, we are dealing with people who will for the rest of their lives need to learn to be interdependent.

One's ability to function interdependently is not related directly to one's ability to function independently. That is, we can't increase someone's ability to be interdependent by giving them more personal independence skills; some people will do very well at being interdependent with fewer independence skills. As they gain skills of independence, those skills may not help their ability to be interdependent at all; in fact, they may get in the way. If we focus too much on independence, we may fail to give a person opportunities to function interdependently.

Educational settings need to be truly integrated, not just "mainstreamed." To be integrated means to become a part of, to be made whole. We no longer can justify segregated schools, or even segregated classes based on educational differences or medical differences. Educational settings can be truly integrated in ways that benefit all the students involved.

Heterogeneity is preferable to homogeneity. Again, we have in the past tried to seek more and more homogeneous settings where we would put everybody with behavior disorders in one program so that we could specialize the staff. But we found that what used to be called behavior-shaping units are now in some places called behavior-sharing units because everybody begins to share their inappropriate behaviors. The homogeneous grouping worked against us. Homogeneous grouping has clearly presented problems in programming for people labeled autistic. We take a group of children who don't make eye contact, don't relate well, don't initiate friendships, and put them in a roomful of other students who don't make eye contact, don't make friends well, and don't initiate contacts, and after a year we say, "My goodness what a surprise! This person still doesn't make eye contact, doesn't initiate contacts, and doesn't form relationships." That homogeneous grouping clearly works against them, and it will work against students grouped on the basis of their deaf-blindness as well. We need to achieve a level of heterogeneity, or what Lou Brown has called "natural proportions."

This doesn't mean mixing only people with various disabilities. Heterogeneity should include large numbers of people who have no disabilities and a small, natural proportion of those with other disabilities, so that we see the full range and spectrum of life. Homogeneity results in an unnatural or excessive congregation of people with certain types of needs. Then those needs become blown out of proportion and become overwhelming.

Social integration is more important than physical integration. Many programs these days are focusing on getting people physically integrated. Our residences are located in regular neighborhoods. Our classrooms are located in a regular school. We go out to the community on a regular basis, and that is good. That kind of physical integration is a necessary step to social integration. But the only reason physical integration is worth doing is if it some day leads to social integration, such as being involved with people, going to school with other students, making friends, not just being located in a residential neighborhood. So we need to think more about social integration beyond physical integration.

Acceptance cannot precede integration. There is a lot of talk these days saying that we'll mainstream the schools more when the school children are ready, when they are more accepting. Or we'll put a group home in the neighborhood when the neighbors are ready, when they are more accepting. Social acceptance is an outcome of integration, it is not a requirement for it. We cannot go into segregated schools full of students who are labeled normal, armed with puppets and blindfold walk experiences, and expect them to develop social acceptance. Acceptance comes from personal experience with peers with disabilities.

Friends are more important than volunteers. Too many programs today attempt mainstreaming by setting up so-called special friends and buddy systems, where nonhandicapped children are "assigned" to a handicapped peer. In some programs, members of a youth group earn points for "logging" a specific number of hours with students with special needs. The overriding human need is for long-term, freely given, personal relationships. These are not necessarily generated by volunteer projects and helper-helpee relationships. True friendships cannot be legislated, programmed, or trained. They can only be nurtured, and that takes time.

Three Decision Rules

Promoting community integration is a complex procedure. We could list about a dozen rules for promoting the physical and social integration of people with profound disabilities into society. In the context of today's discussion, I want to offer three questions that I believe will focus our attention on the essentials of integration.

Is the community involved? Seymour Sarason (1972), who writes extensively about creating community-based settings, said, "a program which purports to be community oriented is not consistent with its purpose if it accepts cases in ways which absolve the community of continuing, concrete responsibility" (p. 172). That is, if we say that we are a community-based program, we can't then assume full responsibility ourselves for everything that those people need. We have a problem in the developmental disabilities field of seeking out developmental disability specialist physicians and developmental disability specialist psychologists and dentists and home visitation nurses, to the point that we relieve the rest of the community of any need for ongoing continuous concrete involvement in our program with our people. I've been calling this a "responsibility trap." The more things that we assume responsibility for as service providers, the more responsibility we absolve the community from having. Then we are surprised that the community doesn't know about people with special needs.

I recently read a magazine article in which the author was reflecting on a mistake (from his point of view), that the gay community in California had made around the issue of AIDS. They had developed a history of going only to so-called "Gay Physicians," physicians who were not necessarily gay themselves, but who specialized in dealing with

gay men, and then as the AIDS epidemic grew, they stayed only with those physicians, so that they had in fact absolved the rest of the medical community from knowing about people who were gay in general or about AIDS in particular. I was stunned by the fact that this man realized the limits of this approach with just two or three years experience around AIDS. It is something that we have been practicing for twenty years in mental retardation and developmental disabilities, and many places still have not yet realized that if we claim to be a community-based program, we need to be careful not to absolve the community of ongoing involvement with our programs and with our people.

Does it promote quality of life? Mark Gold made a series of videotapes portraying people. In the last videotape he made before he died, Mark dealt with the issues of quality of life, and talked about the things that are important to all of us, whether handicapped or not. He talked about privacy, meaning not just modesty or being able to close the bathroom door, but also having time alone. If you live in groups of 6 or 8, with staff coming and going in three shifts, you experience very little privacy, little or no time to yourself. Modesty is also difficult to manage with men and women staff working with men and women who need help bathing, and are living in group of 6 or 8 or 12 or 15 or more. Privacy is clearly one of the ways in which we measure the quality of our own lives, and it should be a quality marker in the lives of those we serve.

The second quality indicator that Mark Gold mentioned was that of choice. Do people have choices? He points out that when you talk to service providers, particularly residential providers, they say something very interesting. They say, "Oh yes, we let them choose." Gold says that you can't "let" somebody choose. It doesn't work that way. That by saying that you "let" people do it, it is not really a matter of choice. Choice has to be something that people have, not something they are allowed. He goes on to talk about the merits of dignity, status, and respect, things that we all want for ourselves. We want to have a certain dignity, status, and to be treated with respect. These are difficult traits to afford people whom we think of as having a set of syndromes, or as being clients, or as being severely handicapped.

He also talks a bit about the importance of reciprocity of relationships. I can relate to this very well because it is something that I found in a study I did of staff in community residences for adults with mental retardation. I was struck by the contrast between the lives of the staff and the lives of the residents. I asked staff about what were the satisfactions that helped them get through the bad times in working in residences. They answered by talking about a person who was previously reluctant to share and wouldn't open up, or wouldn't engage in a personal relationship with a staff member. They would tell a story to the effect that one day the person was bothered, and said "no," they didn't want to talk about it. So the staff member said, "Well, I may not be able to help you but I would be very willing to at least discuss it with you. I wish you would open up, and at least share with me, and tell me what it is that's bothering you." And then, one day, the resident did in fact open up and share. Maybe the staff member was able to fix the problem, maybe they couldn't, but they felt good knowing that someone had trusted them enough to share and tell them what was on their mind. That was what staff said gave them satisfaction, a sense of self-worth.

We must ask ourselves how many occasions have there been in this setting in which the resident has offered to console a staff member. Does the staff member accord that same dignity to the residents? As a staff member, I was always trained to say "no, you know we are here to work on your problems, not on mine." We, in fact, systematically have denied to others that very satisfaction we find so strong for ourselves. The issue is not whether they are in any position to help us with our problems. Very often we can't help the people who share with us. The issue is that by sharing our problems with somebody else, we afford them equal status, dignity, and respect through that reciprocal relationship.

The last thing that Gold talks about in terms of quality of life is in the context of rules. Any family or household has rules, just like an program or facility or residence.

The true differences are in who makes the rules, and what are the underlying values of the rules. In a program, the rules are made by the few (the staff) for the many (the people who actually live there), as opposed to a household in which the rules are appropriately made by all the people who live there, instead of by outsiders who don't live there. The underlying values in a family or household could be that we want to make this a good place to live with opportunities for sharing, and taking into account everybody's concerns. The rules in a group home or in a facility generally don't have the same level of quality. The rules tend to focus on what will help things run efficiently, or what is good for the staff, or what is good for the program, or what is required by funding--a very different origin for those rules. When we think about what would be a quality program, we need to direct ourselves to the issues of privacy, choice, dignity, status and respect, reciprocity of relationships, and the rules and where they come from and whom they affect.

What is the potential for harm? The last question comes from Ira Glasser of the ACLU (1978). He is not an expert in services, per se, but is someone who has given a lot of thought to how to tell what is good when you see it and what is not so good. In a chapter he wrote called "Prisoners of Benevolence, Power vs. Liberty in the Welfare State," he talks about people and liberty. The words he uses are "seduced and ravaged by good intentions." We say that we are going to help people, but, in fact, we destroy their liberty and detract from their lives. He proposes what he calls a doctrine of least harm. Instead of looking at programs that are designed to help people and evaluating them on the basis of how much good they might do, he says we need to look at them for their potential to do harm, and that we should adopt those programs that seem less likely to make things worse. He maintains that if we had that point of view, we would never have had institutionalized atrocities like those at Willowbrook. The doctrine of least harm will be familiar to folks with medical backgrounds as the doctrine of "at least do no harm." We clearly established institutions in the guise of trying to help people. We have done them more harm by segregating and isolating and doing things that enhance their differences rather than enhancing their humanness and giving them more opportunities.

If there is anything to be learned from the last ten or fifteen years in terms of services to people with severe disabilities, this is it. If we could just stop doing harm we would be well on our way to doing good.

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Report of the Working Group on Health/Psychosocial Issues and Services

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Introduction

This report addresses the transitional health and psychosocial needs of the estimated 2,000-4,000 youth and young adults with both hearing and visual impairments. Legally defined as "deaf-blind," most of these youth, in particular those with congenital rubella syndrome, have additional handicaps affecting their communication, ambulation, and cognitive development, which also places them in the larger category of severely and profoundly handicapped. Recognizing the paucity of appropriate services for deaf-blind and profoundly handicapped youth and adults, it is urgent that a comprehensive physical and psychosocial health care system be developed to meet the transitional needs of this vulnerable population.

Of primary importance is the recognition of the individual and diverse needs of the individuals with profound/muliple handicaps and deafness-blindness. It is essential to understand the need for flexibility of options in health care, and imperative to acknowledge the fundamental right of access to comprehensive and appropriate care for physical and psychosocial health needs.

Service Approach

The ultimate goal of a comprehensive health care system is the utilization of the interdisciplinary health care team in providing an adult health care plan to

1. develop assessment mechanisms;
2. implement comprehensive individual care plans;
3. develop a case mangement system to access services, follow through, keep records of current health needs;
4. disseminate current information to all providers in the system as appropriate.

The main objective in the establishment of a comprehensive health care system for profoundly/multiply handicapped deaf-blind is the coordination and integration of services addressing both medical and psychosocial aspects of health.

Issues and Considerations

For ease in addressing responsibilities and issues, this report is separated into five "levels" of care provision: individuals (patients, cases, or clients); families; groups (group homes, community living situations); health care providers; and agencies. Although some themes are repetitive, the specific issues and possible actions and responses vary among the levels.

I. Individuals

A. Responsibilities. The development of a comprehensive health care system for profoundly/multiply handicapped deaf-blind youth requires better definition of the needs of this very special population, with particular emphasis on the integration of services for physical and psychosocial aspects of health.

B. Issues.

1. Individual differences in abilities and needs must be clearly recognized.
2. The necessity to address age-appropriate health care is imperative to adequate care.
3. Individual rights and privileges including privacy and safety must be addressed.
4. Access to effective case management services (ombudsman) is neces ary to ensure that quality care and rights are being honored.

II. Families

A. Responsibilities. The family unit has been defined as a multigenerational group of people who transmit values and share love and loyalty. While the usual family group may include immediate biological or adopted relatives (parents, siblings) or extended families, similar needs and issues are common to other units which are primarily responsible for the care (physical and emotional) of these multiply handicapped persons. Such relationships may include surrogate families, or group care providers who are primarily responsible for the immediate and continual care of these individuals.

B. Issues. Several issues are of primary importance to "family members" to satisfy their own needs as they relate to and care for multiply handicapped youth or young adults.

1. The diversity of opinions and individual needs within and among "families" must be recognized and addressed.
2. The needs and desires of the "family" must be considered in service development.
3. Financial issues and constraints should be recognized.
4. Values and moral systems of the "family" should be respected, especially when addressing sensitive issues such as sexuality.

5. Issues of transition that must be recognized and directly addressed include separation from family or other caregivers, and development of confidence and trust in newly responsible persons, community resources, and quality assurance.

III. Groups (Alternative Living Arrangements, Community-based Services)

A. Responsibilities. The development of homes and community-based services facilitate the very important development of normalization and integration into the community. Such units also address the problems of societal acceptance and interpersonal relationships. Although often not clearly recognized, the interdependence among peers and their caretakers and immediate community evolves from these settings. It is the responsibility of this group of caretakers to identify and understand the impact of their unit on the community in which they reside.

B. Issues. Although many similarities exist between "groups" and families, additional issues are of utmost importance in the development of an adequate group care system. The necessary qualifications and competency must be characterized, since these caretakers will be providers outside the usual health care system. The mechanisms for funding and decisions about financial responsibility must be clarified.

IV. Direct Health Care Providers

A. Responsibilities. The health care professionals who are participating in provision of care to this population are responsible for acquiring the training and expertise to understand and provide adequate and comprehensive health care to these individuals. The professionals must develop rapport with the patients and their caretakers, as well as recognize the need for referral and long-term follow-up. Expert professionals should serve as consultants to the systems and agencies in preparing guidelines, developing models, and monitoring progress.

B. Issues. Some issues are similar to those raised with caretakers, including

1. identification of basic qualifications and skills including communication as well as medical expertise,
2. understanding of the impact of issues important to the family including protection, privacy, sexuality, and the rights of individuals.

Other issues include

3. the recognition of potential biases in the health care system, and honest attempts to provide truly comprehensive long-term as well as acute health care;
4. knowledge of communication modes, appliances, and interpreter services, and acceptance and willingness to interact openly with patients and family members;
5. up-to-date information regarding medical issues, and information on a case by case basis readily shared with all service providers of the individual;
6. recognition that availability and funding of services and medical resources is not uniform;
7. recognition of the full range of health services (i.e. nutrition, physical therapy, etc.) beyond primary and referral physician care.

V. Agencies

A. Responsibilities. Local, state and federal agencies are responsible for development of policies and regulations regarding service delivery for profoundly/multiply handicapped deaf-blind persons. In addition, these agencies are also responsible for guidelines for training programs. Recognition of available resources, identification of funding sources, and provision of funding through several mechanisms are all the responsibility of governmental agencies.

B. Issues. In addition to the issues related to provision of comprehensive care to individuals and families, agencies must deal with the issues of limitations and barriers created by laws and mandated policies. Such barriers include age restrictions to service programs and mandated services (e.g., in most states restricted to under age 21) and limitations in payment for services due to definitions of handicaps and limitations of served populations.

Recommendations

This section is organized into the same categories as the issues and considerations sections: Individuals, Families, Groups, Health Care Providers, and Agencies. In addition, a summary recommendation section is included.

Individuals

1. Capitalization on the period of transition for planning and needs assessment for adult life (see Hostler).
2. Development of a health assessment that includes review of health documents, a current health profile, and review of symptoms and concerns of caretakers. A complete adult physical examination should be a part of the assessment. This assessment plan should be initiated prior to transition (e.g., age 18) to prepare adequately for adult health care.
3. Implementation of a comprehensive health care plan dictates special attention to the following areas:
   a. promotion of wellness;
   b. identification and diagnosis of late onset sequelae of deaf-blindness syndromes including
      (1) cardiovascular complications,
      (2) endocrinopathies (e.g., diabetes, thyroid),
      (3) autoimmune disorders,
      (4) neurological abnormalities,
      (5) behavior disorders;
   c. transition from pediatric to adult health care issues such as
      (1) sexual function/dysfunction,
      (2) secondary sexual development.
4. Design of a checklist format of key areas of health assessment and care that could be utilized uniformly by all health and service providers to ensure addressing all critical health issues.
5. Design of an adult care plan including management of current health problems, intercurrent care, and critical care.
6. Development of more complete applications of scientific/technological advancements as appreciation grows regarding the importance of these devices.

Family

1. Development of assessment protocols (for families) that clearly address the family's needs, desires, and stresses that relate to the care of profoundly, multiply handicapped deaf-blind persons, along with identification of strengths and weaknesses in the family unit.
2. Identification and development of support services for families by
   a. establishing peer support and education groups for parents and siblings;
   b. enhancing and coordinating professional mental health services;
   c. identifying and expanding state agency and voluntary services including
      (1) surrogate families,
      (2) intervener programs (e.g., Canadian Model),
      (3) surrogate siblings and grandparents,

(4) paid companions
(5) community trusts.

3. Identification and improvement of funding resources for family units caring for these adults.
4. Location and dissemination of new information and data regarding family studies to professionals, agencies, and families in a timely fashion.
5. Development of a case management link for individual and family services.

Groups (Alternative Living Arrangements, Community-based Services)

1. Model programs (such as Seattle and New Jersey) should be identified, and the information regarding their development made freely available through as many sources as possible (education, Maternal and Child Health, University Affiliated Facility, Helen Keller National Center, Administration for Developmental Disabilities, Office of Special Education and Rehabilitation Services, etc.).
2. Potential funding sources should be identified and working financial models made available.
3. Research into innovative partnerships with private and philanthropic agencies should be encouraged.
4. Definition and development of a "case manager" model system should be pursued in the following ways:
   a. federal funding of a conference for sharing of models,
   b. provision of funding for demonstration projects of various models
   c. sharing of current developments through a network of "case manager" professionals,
   d. definition of the case managers as coordinators of diverse physical and mental health care services,
   e. development of evaluation and monitoring of quality assurance measures for these professionals.
5. Funding should be made of studies of the advantages and disadvantages in rural versus urban settings for such facilities.
6. Creative mechanisms should be developed for coordination and transport of mobile health services to these facilities to enhance the comprehensive care of clients.
7. Mechanisms of leadership and organization of home health care teams and all medical support systems, including policies and procedures, should be developed.
8. Barrier removal and enhancement of technology should be encouraged to improve physical and psychosocial health.

Direct Health Care Providers

1. Identification of experts and encouragement of the dissemination of their new research findings to a broad audience.
2. Encouragement (and funding) of health care providers to provide adequate training to new professionals, such as through the University Affiliated Facility (UAF) network.
3. Development of continuing education programs for health care providers which focus on the problems of the population in question.
4. Consideration of medical and psychological health research projects focusing on this population as an immediate priority for funding through federal resources.
5. Development of new relationships should be developed with professionals from other disciplines (e.g. environmental and recreational engineers) to enhance the development of innovative devices for use by these clients.
6. Development of regionalized teams of health professionals representing several medical disciplines because the health care needs of this population are so complex. This model should permit more complete health care provision, while absolving individual primary health care providers from performing all aspects of total health care.

7. Identification of adult onset problems associated with syndromes causing multiple handicaps in deaf-blind persons and dissemination of this information to appropriate specialists to enhance health care.

Agency

1. At the national level and with federal support, policy should be developed which mandates the collection of badly needed information regarding the adult health care needs of the population in question.
2. With the advice of experts representing a broad range of subspecialities, guidelines for comprehensive assessment protocols should be established and published from the federal system.
3. Guidelines for staff qualifications for group home personnel and case managers should be developed and made readily accessible.
4. Special efforts at federal and state levels should be made to recognize and eliminate systemic problems in funding services such as age limitations and geographic barriers (e.g. state lines). Models which utilize MCH funds for special programs (e.g. genetics) may be utilized.
5. Networks of health care providers across the country should be established for the full and timely sharing of both effective and ineffective methods for providing comprehensive services.
6. Agencies with special funding and expertise should be utilized to their fullest capacities including UAF's, ADD, TAC, MCH, HKNC. Special projects of high priority should include
   a. provision of specialized training for providers including case managers by HKNC;
   b. support for an interdisciplinary conference by MCH to discuss available information and health issues of the adults who are multiply handicapped with deaf-blindness and dissemination of gathered information;
   c. sponsorship of a conference on development of a workable care (or case) manager system that functions in conjunction with, but outside the aegis of, funding agencies to avoid conflict of interest;
   d. continued support and expansion of HKNC as a technical assistance center for transition adult multiply handicapped deaf-blind persons; and
   e. utilization of HKNC for repository and clearing house for dissemination of state of the art information on services for this population.

A Summary of the Above Recommendations

1. To enhance the comprehensive nature of services there should be sharing of responsibilities among agencies at federal, state, and local levels for program development and fiscal responsibility.
   a. focus should be placed on an interagency collaborative model at the federal level among OSERS, MCH, and ADD to promote joint projects and gather information;
   b. new methods for collaboration between public and private sectors should be sought.
2. New models should be developed for mechanisms of total case management for individuals and their families.
3. Competency of all providers should be assessed, with emphasis on their total acceptance of those who are deaf-blind and multiply handicapped. Training should be provided and salaries offered that promote long-term employment.
4. Technology and knowledge, now shared on an ad hoc basis should be more universally applied with more forceful delivery methods and implementation of strategies:
   a. HKNC should be funded to continue and expand services including repository for information and training of providers;

b. UAFs should take active role in research and training of this population;
c. MCH, OSERS, and ADD should continue collaborative leadership role in policy and support of comprehensive services and act as a role model for state and local interagency cooperation.