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ABSTRACT

The Early Referral and Follow-up Project of the University of Nebraska Medical Center was designed to facilitate developmental assessment and intervention with long-term or repeatedly hospitalized children from birth to 3 years of age. Developmentally delayed children, handicapped children, and children at risk for delays were eligible for services. A major project activity involved assisting in the referral and transition of children from the hospital into appropriate services in their local school districts, accomplished through consultation with hospital and school district staff and through follow-up services. Evaluation services available to clients included developmental, speech, physical therapy, and occupational therapy assessments. Detailed procedures are outlined for implementing referrals from the hospital setting to schools, accompanied by planning forms for assessment of family needs. Appendixes, which constitute the bulk of the document, include: (1) a list of organizational resources that offer assistance and information to disabled children and their families in the areas of alternative care options, child care, counseling, social services, funding, housing, income tax, recreation, speech and hearing, and transportation; (2) lists of Nebraska pediatric occupational and physical therapists, Headstart programs, and dentists willing to treat handicapped patients; (3) funding resource materials; (4) reading materials on such subjects as hospital discharge planning, psychological testing of disabled children and alternatives for community living; (5) toll-free telephone numbers for specific service organizations; and (6) related pamphlets. (JDD)

GUIDE FOR REFERRAL AND CASE COORDINATION FOR YOUNG CHILDREN IN HOSPITAL SETTINGS

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INTRODUCTION TO EARLY REFERRAL AND FOLLOW-UP PROJECT

DESCRIPTION OF EARLY REFERRAL SERVICES:

The Early Referral and Follow-up Project, a three year demonstration project, was awarded to UNMC by the U.S. Office of Special Education Programs. The primary purpose of this project has been to facilitate the developmental assessment and intervention with long-term or repeatedly hospitalized children birth to three years of age. Children who were suspected to be delayed or handicapped or who would be considered to be at risk for developmental delays because of chronic health problems or unfavorable environmental conditions are eligible for services from this project. A major project activity was to assist in the referral and transition of children into appropriate services in their local school districts. This was accomplished through (1) consultation to and collaboration with hospital staff including primary care nurses, and social work and child life staff; (2) consultation to local school district staff regarding the developmental assessment findings; and (3) follow-up services by project staff during the transition phase and at 6 and 12 months.

POPULATION SERVED:

The Early Referral Project has served approximately 165 infants and toddlers (birth to 3 years) from February 1984 through September 1985. These are children who experience long term or frequent hospitalizations and are identified as having handicaps (mental, motor, sensory) or are at significant risk for developmental problems.

Evaluation services available to clients may include developmental, speech, physical therapy or occupational therapy assessments. In 88% of the cases developmental assessments, including psychological, educational, or speech evaluations were completed; 62% received physical therapy screenings; and 58% received occupational therapy screenings.

REFERRED: Of the 165 children referred, 65% of the University referrals and 48% of the St. Joseph Hospital referrals had been referred to their school district of residence. The referrals were made to a total of 34 different school districts in Nebraska. The largest number of referrals from any one single school district was made to the Omaha Public Schools.

NON-REFERRED: Of these 165 children, 35% of the University referrals and 52% of the St. Joseph Hospital referrals were not referred to their school district of residence. Reasons for non-referral included: failure of children to meet eligibility criteria for school services, children whose illnesses were so critical that parents elected not to refer and in several cases death of the child. It is felt that the high percentage of children not eligible for referral at St. Joseph Hospital reflects the socio-economic at-risk status of the population that that hospital serves. Children in this group continue to receive follow-up evaluation through the Early Referral Project to monitor their developmental status.

DISSEMINATION:

During the third year of this demonstration project, staff efforts have expanded to include demonstration and dissemination efforts. One major dissemination activity has been the development of this Case Coordination Resource File. It was felt that this type of resource material would facilitate hospital staffs in their referral of children to educational and community resources. Other dissemination efforts include providing workshops to health care and educational professionals who are interested in learning more about school referral procedures, care needs of the child with developmental disabilities, and the needs of the child's family.

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DESCRIPTION OF MATERIALS IN CASE COORDINATION RESOURCE FILE

- Guide for Referral and Case Coordination for Young Children in Hospital Settings - This guide was designed to be used by Case Coordinators as a resource for understanding the school referral process for children handicapped in Nebraska as well as identifying other service needs in planning for those needs. This guide provides factual information regarding school referral process and comprehensive case coordination. It also includes resource information in the form of descriptions, reading materials, and pamphlets for parents.

- Speaking for Children: Directory of Resources for Nebraska Children - This is a directory of resources for children, developed by the Junior League of Nebraska. It was intended as a guide to finding services for children in Nebraska. The listings that are provided in this guide were not intended as endorsements or recommendations of agencies, groups, or services. This directory is located in the Resources File. Additional copies may be purchased for $10.00.

- Nebraska Educational Directory - This is a directory published by the Nebraska Department of Education. It provides a listing of all state education offices, educational service units, and school district personnel in Nebraska. This directory is located in the Resource File. ADditional copies may be purchased for $2.50 at the State Department of Education.

- Parent's Handbook - This handbook is designed to provide families with an organizational method for filing and maintaining records and correspondence regarding their child. It provides parents a means of collecting information and maintaining a booklet of information on their child regarding family and birth history, medical history, developmental and educational history, a listing of professionals they have contact with, and a parent log. This handbook is located in the Resource File. Additional copies may be purchased at Meyer Children's Rehabilitation Institute for $5.00.

- Resource Guide for Parent to Parent and Advocacy Organizations - This is a Nebraska Directory of parent to parent support groups for parents whose children are ill, injured, disabled or whose child has died. It also includes organizations and associations for specific disabilities or illnesses, Pilot Parent groups, and a listing of state agencies serving people who have disabilities. This directory is located in the Resource File.

- Directory of Nebraska Home Health Agencies - This resource summarizes individual agency responses to a statewide survey of Home Health Care Agencies concerning services available to chronically ill children and their families. It includes the range of services offered by each agency, as well as information about the child that the agency wishes to be forwarded by the discharge hospital. The directory is intended to be shared with parents prior to the day of discharge to help facilitate pre-discharge planning with the agency that best meets their needs. This directory is located in the Resource File.

- Parent and Teacher Fact Sheets: Conditions, Procedures, and Medications Regarding Developmentally Disabled Children - The fact sheets are concise introductory level explanations of entities/conditions, medications, and treatment procedures frequently associated with children who have developmental disabilities. While they are geared to parents, they are also suitable for use by teachers and therapists. Many of the fact sheets were compiled under the Early Referral Project funding; however, publications of several other service groups are included. Where possible, conditions, procedures and medications are cross-referenced. This directory is located in the Resource File.

SCHOOL REFERRAL PROCESS

Eligibility Criteria

1. Are there educational services for infant and preschool children with handicaps in Nebraska?

   PL 94-142 of the Education of All Handicapped Children Act of 1975 and Nebraska LB889 ensures that all handicapped children have available to them free, appropriate public education which includes special education and related services. In Nebraska local school districts must upon parent request provide educational services for resident, handicapped children from the date of diagnosis through age 21.

2. Which infant and preschool children with handicaps specifically benefit from this law?

   Eligibility for free public school services for children 0-5 years is based upon meeting criteria as disabled in one or more of the following categories: medical, behavior, speech and hearing, retardation and vision.

Service Options

3. What services will the schools provide?

   Services will be based on the child's individual needs as determined by specific assessments. In addition to an educational program, related services such as physical, occupational and speech therapies can be provided, if they are recommended as educationally relevant.

4. What educational services are available for infants and toddlers?

   Services for children birth to three typically occur in a home-based setting. Parents are provided with instruction regarding appropriate developmental activities for their child. Frequency of visits by the teacher or therapists varies depending on the child's individual needs, and may range from twice weekly to monthly.

5. What educational services are available for preschool children?

   Typically children ages 3 through 5 participate in a center-based preschool program. Occasionally where preschool services are not available in the community of residence, a home-based model is continued. The school is required to provide for or reimburse parents for transportation to and from educational programs.

6. What related therapeutic services are available?

   Speech therapy - The speech pathologist evaluates very young children who may not be old enough to talk or who may have some condition which limits their ability to make sounds. Assessment consists of the observation of ways in which the child communicates with others in his world. Also, parents are interviewed to obtain additional information about how the child makes his wants and needs known. Children who need therapy are referred to their local school districts or other community agencies for help.

Physical therapy - Provides diagnostic and therapeutic services for children with physical disabilities, abnormal motor development or delays in gross motor development (sitting, crawling, walking). Therapeutic services are generally designed to prevent orthopedic deformities, facilitate gross motor development and maximize the child's ability to act upon his/her environment.

Occupational therapy - Based on the belief that purposeful activity, or occupation, may be used to generate adaptive skills of children with developmental dysfunction. Developmental activities such as feeding, movement, play, and interaction with others are the primary occupation of infants and young children. By using intrinsic motivation and purposeful activities, occupational therapy personnel encourage the child to acquire an increasing repertoire of developmental skills and coping behavior patterns. Intervention promotes sensorimotor, psychosocial, and cognitive functions and may prevent disability or decrease dysfunction in order for the child to meet personal needs and adapt to the demands of the environment. Occupational therapy facilitates the performance of parents in coping effectively with the challenges of caregiving and family life.

7. Who provides these services for infant and preschool children with handicaps in Nebraska?

   The local schools are responsible for providing appropriate services for handicapped children who reside in their school district. If a school district does not elect to provide its services directly they may contract with a qualified facility to provide those services. Such providers could include another school district, Educational Service Unit, or other service agencies or private practitioners in the state.

Referral Process

8. What do schools do when a child is referred?

   A school must first determine if a child is eligible for services as defined by state law in Rule 54. Schools have the options of reviewing existing evaluation reports on children that are provided by other agencies or conducting their own independent evaluations. The results of these evaluations will determine a child's eligibility for services. Recommendations regarding placement are based on the results of these evaluations and the concerns of the school's placement team. By rule parents must be included as members of this team.

9. Are there places to obtain evaluations other than through the local school district?

In addition to the schools there are other agencies or individuals in private practice approved to provide diagnostic services for determining school eligibility. See Appendix C for a listing of private, licensed physical, occupational and speech therapists in Nebraska. Some agency options are Educational Service Units, Boys Town National Institute, Cozad Diagnostic Center, Barkley Center at UNL, and Meyer Children's Rehabilitation Institute at UNMC. Evaluations can occur in these sites on request of the schools or parents. If an agency or private practitioner is used at parent request, parents are responsible for payment unless prior approval from the school district was obtained.

10. How does one refer a child for services?

Parents, health care professionals, social workers, educators, therapists, and other professionals may refer a child for educational services to their local school district. In most cases a contact person would be the Director of Special Education or the Superintendent of Schools. The president of the local school board will need to be contacted for smaller school districts who do not have a Superintendent of Schools. Refer to the Nebraska Educational Directory, located in the Resource File, for a listing of all school districts and their personnel. Referrals should not be made without written parental consent.

11. Why is follow-up important after discharge?

Once the child has been referred for services it is important to make follow-up contact with either the parent or the school system to ensure that services were initiated. Follow-up information could be obtained via letter, phone call, or from parents in follow-up clinics.

12. Is special education for infants and preschoolers compulsory?

Although schools are obligated to provide services for eligible handicapped infants and preschoolers, parents are not obligated to request these services.

13. Are there any cases where services are mandated for infant and preschool children?

In some instances such as cases of child abuse or neglect, services may be mandated through court order.

At-Risk Population

14. What options are available for a child who is not eligible for services but is at risk for developmental delays?

Continued monitoring of children who are initially found ineligible for school services is highly recommended. Persons having ongoing contact th the child such as health care, social services, and other essionals will be able to monitor the child's development. If there change in their developmental status, children may be re-referred to school district at any time. Typically schools will not recontact parents regarding follow-up evaluations for children who they previously found to be ineligible.

15. Are there any educational intervention services available for the at-risk child?

There are very few service options in Nebraska for "at-risk" children who do not meet eligibility criteria for educational services. The primary statewide mechanism would be the Head Start Program which typically offers a preschool program (See Appendix C). In addition, Omaha Head Start provides a parent/infant program. Speech, physical and occupational therapy services can be obtained on a private basis.

Parental/Children's Rights

16. Once a child is receiving school services, what control do parents have over the content of their child's school records?

While prior request is necessary, parents have a right to personally review and request copies (possibly for a fee) of the contents of all of their child's school records. If upon inspection, parents find information which they feel is inaccurate, biased or misleading, they may request that it be corrected or removed. If the request is refused, a hearing may be initiated. At the hearing if a decision is made in favor of the school, the parents may add their own statement to their child's file.

17. Who else has access to a student's school record?

While school district professionals who are involved with the child's educational program have a legitimate reason to review educationally related records, those persons without legitimate interests have no legal right to access student information without expressed written authorization of the parents or legal guardian. Schools usually keep a record of the signatures of those persons who have in fact reviewed individual students' records.

While reports and records may remain in the child's cumulative folder in the school district offices, year to year records in the school setting usually contain only those data that are pertinent to the current educational needs of the child. A prior educational "label" need not be conveyed to subsequent educators unless parents so desire.

18. What can parents do who are dissatisfied with their child's educational program?

Parents should first discuss concerns with the educational staff and then their local school district administration. Parents may wish to have an independent evaluator assess their child. They may then bring those results back to the local school district. Such an evaluation will, however, be at their expense. If parents are not able to reach a satisfactory resolution with their district, they then have the option of appealing their district's decision to the Nebraska Department of Education. See <u>Education for Handicapped Children</u> in Appendix F.

Parent Organizations/Resources

19. Are there any cf types programs specifically for parents of handicapped children?

A parent to parent organization is beneficial where parents can support each other and share information on having a handicapped child. One such group is Pilot Parents. In the Resource File there is The Resource Guide for Parent to Parent and Advocacy Organizations and a directory of parent support groups, advocacy groups and disability organizations in the state of Nebraska.

In Appendix F there are copies of several resources for parents. You may wish to obtain a supply of these resources to have on hand in your setting. These pamphlets are the following:

- Guide to Your Child's Developmental Assessment
  This pamphlet explains an interdisciplinary evaluation process and what to expect from each discipline. Simply written, this can be helpful if given prior to the evaluations.

- Handicapped Children: Their Right to an Education; Information for Parents
  In this pamphlet parents are informed of the laws in special education and their child's right to an education.

- Nebraska ChildFind: Benefiting the Handicapped Children of Nebraska
  This brochure explains the purpose of Nebraska ChildFind to assist parents in finding a special education program and related programs for their child.

- Education for Handicapped Children
  This pamphlet provides information regarding the role of the parent in their child's educational program, i.e., the IEP process and the child's records and due process.

- Parent's Handbook - A handbook that provides families with a system for maintaining records and correspondence regarding their child.

GUIDELINES FOR IMPLEMENTING REFERRAL FROM THE HOSPITAL SETTING

1. When should a child be referred to determine eligibility for school services?

The following are eligibility criteria for educational services as outlined in the Rule 54: Regulations for Early Childhood Special Education Programs Title 92. Nebraska Administrative Code. Chapter 54, NDE (1981), pages 10-11.

Program Eligibility

Children shall be eligible when the diagnostic procedures have been carried out in accordance with this Rule and when it has been determined that the child meets one or more of the following criteria:

Visual Impairment

The loss of vision meets the definition of legal blindness or the resulting deprivation in expected development qualifies the child under the designation of developmentally delayed.

Hearing Impairment

A bilateral hearing loss is verified at or exceeding a level of 40 dB as indicated through a pure-tone average of the speech frequencies, and a delay relative to social, communication, or behavior skills is documented by appropriate staff. Children may be eligible for consultative services if the condition is such that amplification is recommended in order to ensure appropriate social/communication growth; if a chronic ear pathology has been verified by a physician or other certified personnel and a subsequent delay in oral communication is observed and verified, or if a bilateral or unilateral sensory-neural hearing loss is verified at or exceeding a level of 40 dB as indicated through a pure-tone average of the speech frequencies.

Developmental Delay

The developmental delay resulting from mental retardation, speech and communication disorders, and specific learning disabilities as assessed on a standardized wide range developmental instrument administered to the child are two or more standard deviations below the norm or if any handicapping conditions can be expected to produce such delay in later childhood (e.g., Down Syndrome).

Physical Handicaps

In the opinion of the diagnostic team the physical handicaps result in an inability to develop the skills necessary to function in the standard school program.

Disturbed Behavior

In the opinion of the multi-disciplinary team the disturbed behaviors exhibited by the child represent a significant impediment to the acquisition of skills necessary to function in the standard school program. The child may exhibit behaviors described as hyperkinetic, autistic, withdrawn, or aggressive.

2. Who should be made aware of any consideration of referral?

Children were typically identified in the Early Referral Project by Child Life or Nursing staff. Concerns with the child's development should always be discussed with the attending physician who is in charge of the child's care during hospitalization. If the attending physician is not the primary care physician, he or she will want to confer with the child's local primary physician. If a referral is recommended based on any developmental concerns, this proposed referral should then be discussed with the parents before any action is taken.

3. What are the criteria for referral of children for consideration of school eligibility?

The initial point of contact for children referred on the Early Referral Project has been either a Parent Infant Educator or a Maternal Child Health Nurse specialist. Once parental permission was obtained, an initial step in the evaluation was an assessment of the child's functioning in regard to sensorimotor development. Such an assessment was seen as a necessary first step for each child as a means of making further decisions regarding other disciplines which were appropriate for the child.

4. Where should evaluations take place?

Developmental assessments can be completed either during hospitalization or through the local school districts once the referral has been made. Factors to consider when determining whether the evaluations should be completed in the hospital or community are the following:

- availability of qualified staff
- cost of the evaluations, and availability of funds to pay for evaluations during hospitalization
- facilitation of services if evaluations are completed prior to the child's discharge from the hospital
- need for evaluations for completion of hospital diagnostic work-up.

5. Can services be initiated while a child is in the hospital?

Yes, if it is appropriate to do so. In cases of a long hospitalization, schools may elect to provide services in the hospital.

6. When should a child be referred to a specific discipline for evaluations?

The team will decide what disciplines should be contacted to provide evaluations. Suggested criteria developed by psychologist/educator, speech, physical and occupational therapists are presented in Table I.

7. Who should receive medical and evaluation records?

To help coordinate services for the child in the community, medical records should be sent to those agencies that will have primary contact with this child and family, such as local school districts, home health care agencies, local physicians, and social services. To facilitate getting records to other agencies, releases could be obtained during the child's hospitalization. Remember to remind parents to request and to keep medical and evaluation records of their child. The parent resource, Parent's Handbook, contains a suggested format for keeping this information. (A copy of the Parent's Handbook is located in Resource File.)

8. What information should parents keep for their child's record?

It is important for parents to keep a current file on their child's medical and health history and educational development. Information for parents to collect includes:

- names, addresses and phone numbers of professionals whom parents have contacted or to whom they have been referred;
- birth, medical and developmental history;
- medical records, including dates, locations, and physicians' names;
- all diagnostic and follow-up evaluation reports;
- Individual Education Plans, and other communications with the school.

TABLE 1
EVALUATION CRITERIA

Criteria for Psychological/Educational Evaluation

Assessment of infants with a broad based standardized developmental assessment such as the Bayley Scale is generally recommended with the following cautions.

Neonates to four months of age:

1. Formal standardized assessment is not generally recommended during this period; however, if assessment is needed for certification for services it is best to wait until the child is 3 months of age. In cases of significant prematurity, evaluation should be deferred until the child is at least 3 months corrected age.
2. Informal observations/developmental screening in collaboration with other disciplines is recommended for several categories of children who are at-risk for or who are demonstrating developmental delays.

Infants four months of age or older:

1. The Bayley Scales of Infant Development (Mental and Motor Scales) are recommended at this age, unless the child has significant motor or sensory impairments. In such cases it may be useful to administer the Bayley Scales but they should not be considered to be reliable for prediction of future status. This testing is done in order to evaluate the child's overall developmental age.
2. Educational assessment is also recommended at this age for the purposes of determining cognitive abilities, as well as serving as a basis for Developmental Suggestions.
3. These developmental assessments should be completed if possible when the child is medically stable. This will typically be close to the child's discharge from the hospital. Prior to this point systematic observations based upon developmental guidelines may be made.

Criteria for Speech/Language Evaluation

Neonates to infants six months of age should be seen by a communication specialist.

1. As early as possible if the child presents one of the following syndromes or physical disabilities putting him at risk for communication development:
    a. Cardiovascular accident
    b. Tracheostomy (longer than 3 weeks)
    c. Cleft palate/lip
    d. Hearing disorder
    e. Syndromes with oral motor involvement such as a physical sign, e.g., whistling face, cri-du-chat, Noonan's, etc.

TABLE 1 (continued)

2. Children six months or older should be seen by a communication specialist when social/affective/vocal/nonvocal behaviors seem out of synchrony. Such asynchrony has been observed in the following syndromes: Fragile X Syndrome, Down Syndrome, motor disorders, failure-to-thrive, Fetal Alcohol Syndrome, sensory deficits, prematurity (low birth weight), and long term NICU care (8 months or longer).

Criteria for Occupational Therapy Evaluation

Neonates to infants six months of age should be seen by OT if the following conditions are presented:

1. Cerebral vascular accident or babies demonstrating significant asymmetry in their position and movements.
2. Babies being given supplemental feedings because of weak and inefficient oral-motor skills.
3. Babies going home on tube feedings due to problems that may not be related to specific oral-motor problems such as aspiration, cardiac problems, short bowel problems, etc.
4. Children with identifiable neuromotor problems related to disorders such as myelodysplasia, hydrocephalus, or severe anoxia.
5. Babies with syndromes causing significant joint deformity of the upper extremities such as arthrogryposis, congenital amputation of multiple digits, or more extensive upper extremity involvement.

Children six to eight months or older should be seen by OT when the following conditions are presented:

1. Previously mentioned problems if no previous OT involvement.
2. A significant delay in fine motor skills associated with neuromotor problems; significant weakness; increased tone; obvious tremoring (Down Syndrome, cerebral palsy, myelodysplasia)
3. Failure to thrive babies.
4. Infants with significant oral-motor problems associated with feeding, gagging, choking, or refusal to advance in types of foods taken.

Criteria for Physical Therapy Evaluation

Neonates and infants up to four months should be seen by a physical therapist.

1. As early as possible if the child presents one of the following syndromes or disabilities making him at risk for motor development or postural deformities:
   a. Cerebral vascular accident or significant asymmetry in position and movements
   b. Myelomeningocele
   c. Arthrogryposis
   d. Osteogenesis imperfecta
   e. Amputation or limb anomalies
   f. Syndromes involving muscle tone, strength, or joint limitations

TABLE 1 (continued)

2. Children four months or older should be seen by a physical therapist when there is delayed motor development or poor quality of movement with a history such as:
    a. Prematurity (low birth weight)
    b. Intra-ventricular hemorrhage
    c. Hydrocephalus
    d. Bronchopulmonary dysplasia
    e. Failure to thrive
    f. Asphyxia (especially with low Apgar scores and seizures)

COMPREHENSIVE CASE COORDINATION PROCESS

Case Coordination Role

Case coordination or case management for developmentally disabled persons is a necessary service that insures that a client's needs are addressed and services are provided. The case coordinator is responsible for ensuring the coordination of planning, service delivery, monitoring and following up on recommendations.

The case coordination process begins when a person first enters a service system and should continue throughout the period of time the child is receiving services from that agency. The family will be an integral part of this coordination process. The case coordinator's duties will depend on the agency's definition of case coordination and the needs of the individual child and that agency's relationship to other agencies which may be involved in providing services to a family. Tasks typically include collecting the initial information on the child; coordinating assessments; conducting case conferences; ensuring that necessary documentation is in the file; and making arrangements for follow-up.

In settings where multiple disciplines are involved, the needs of the child may determine who should be the case coordinator. For the child who has many medical problems, a nurse might be an appropriate case coordinator. If the major concern is in the area of speech and language development, a speech pathologist might be the appropriate person to assume the coordinator role. In some settings a social worker or child life specialist may assume the role of case coordinator. The case coordinator may change depending on the child's needs. When such changes occur it is important that all team members be notified of the change.

If your hospital or agency does not have a system of case coordination, they may want to consider instituting one.

Record Forms for Case Coordinators:

- The Worksheet for Case Management Plan from Getting Children Home: Hospital to Community (found in Appendix C) and Family Needs Checklist Planning Forms (on pages 15 - 17) are both designed to be used by case coordinators in identifying needs and planning for those needs.

Reading Resources for Case Coordinators

- Early Intervention - A Team Approach, edited by K.E. Allen, V.P.A. Holm, and R.L. Schiefelbusch, Baltimore: University Park Press, 1978.

- Case Management in Human Service Practice, edited by M. Weil, J.M. Karls, San Francisco: Jossey-Bass Publishers, 1985.

- Coordinating Services to Handicapped Children: A Handbook for Interagency Collaboration, edited by J. Elder & P. Magrab, Baltimore, London: Paul H. Brookes Publishers, 1980.

FAMILY NEEDS CHECKLIST PLANNING FORMS

The Family Needs Checklist Planning Forms are designed to be used by case coordinators as an aid to identify service needs and planning for those needs. Available resources in this state have been identified by following this form. Description of those resources are located in the noted appendices.

There are a number of statewide resources that are available and can provide information on services in local communities. They are:

NEBRASKA CHILDFIND
Toll Free 800-742-7594
Nebraska ChildFind will assist parents of handicapped children find proper special education or related programs to benefit their children.

HOTLINE FOR THE HANDICAPPED
Toll Free 800-742-7594

An information and referral program which provides information on service agencies, associations and other resources in the State of Nebraska that provide services to handicapped persons.

DIRECTORY OF RESOURCES FOR NEBRASKA CHILDREN: SPEAKING FOR CHILDREN
One copy can be found in Resource File.

This is a directory from the Junior League of Omaha and the Child Saving Institute: a guide to find services for children and their families in Nebraska. It can be obtained for a fee at the following address:

Child Saving Institute
115 South 46th Street
Omaha, Ne. 68132

FAMILY NEEDS CHECKLIST/HEALTH CARE THERAPY AND SUPPORTIVE RESOURCES CONTACT LIST

	NAME AND ADDRESS	NOTES
1. PRIMARY CARE PHYSICIAN		
2. NEUROLOGIST		
3. ORTHOPEDICS		
4. SPECIALTY CLINICS		
5. PHYSICAL THERAPIST		
6. OCCUPATIONAL THERAPIST		
7. SPEECH/HEARING THERAPIST		
8. COUNSELING		
9. VISION TESTING		
10. HEARING TESTING		
11. GENETIC COUNSELING		
12. DENTAL HEALTH		
13. ADVOCACY GROUPS		
14. FIRST AID TRAINING		
15. PUBLIC HEALTH SERVICES/VNA		

Adapted by Early Referral and Follow-up Project; University of Nebraska Medical Center, Omaha, Nebraska, 1985 from Family Involvement with At-Risk and Handicapped Infants An HCEEP Model Demonstration Project, University of Idaho, Moscow, Idaho 1985

FAMILY NEEDS CHECKLIST/PARENTAL/EDUCATIONAL INFORMATION PLANNING LIST

*Priority= 3 high, 2 moderate
1 low, 0 do not want

	Priority*	Plan & Record
1. How to be your child's case manager.		
2. Laws related to Special Education.		
3. How to interpret reports regarding your child.		
4. Handicapping Conditions.		
5. Normal Development: a. motor/physical development.		
b. language/communication.		
c. cognitive/learning abilities.		
d. self-help skills.		
e. social skills.		
6. Testing: a. reasons for testing.		
b. results of tests.		
c. how tests affect my child.		
7. How to interact with professionals who serve your child.		
8. Record keeping,		
9. Skills for obtaining/asking for information or service.		
10. Stress management.		
11 Time management.		

Adapted by Early Referral and Follow-up Project; University of Nebraska Medical Center, Omaha, Nebraska, 1985 from Family Involvement with At-Risk and Handicapped Infants, An HCEEP Model Demonstration Project; University of Idaho, Moscow, Idaho/1985

FAMILY NEEDS CHECKLIST/PARENT SUPPORT SERVICES
PLANNING SHEET

	YES	NO	COMMENTS/CONTACT ET.
1. RESPITE CARE			
2. TRANSPORTATION			
3. SUPPLEMENT SECURITY INCOME			
4. RECREATION			
5. AID TO DEPENDENT CHILDREN			
6. DAY CARE			
7. BABYSITTING			
8. FOOD STAMPS			
9. HOUSING			
10. LEGAL AID			
11. HEALTH INSURANCE			
12. INCOME TAX INFORMATION			
13. SUPPORT GROUPS			
14. FEDERAL AND STATE FUNDED EDUCATIONAL PROGRAMS			

Adapted by Early Referral and Follow-up Project; University of Nebraska Medical Center, Omaha, Nebraska, 1985 from Family Involvement with At-Risk and Handicapped Infants An HCEEP Model Demonstration Project; University of Idaho, Moscow, Idaho/1985

FAMILY NEEDS CHECKLIST/CHILD/SIBLING NEEDS

CHILDREN IN FAM[illegible]

NAME [illegible] SEX
1.
2.
3.
4.
5.
6.

	YES	NO	COMMENTS
1. RECREATIONAL			
2. FAMILY RESPONSIBILITIES (CHORES)			
3. DISCIPLINE			
4. EMOTIONAL SUPPORT			
5. PLAY GROUP FOR HANDICAPPED CHILD			
6. CAREGIVING FOR HANDICAPPED SIBLINGS			
7. SIBLING SUPPORT GROUP			
8. SIBLING EDUCATION: a. regarding handicapping condition b. other			
9. SIBLINGS CONCERNS ABOUT THE FUTURE			
10. SIBLING CONCERNS ABOUT MEDICAL PROBLEMS			

Adapted by Early Referral and Follow-up Project; University of Nebraska Medical Center, Omaha, Nebraska, 1985 from Family Involvement with At-Risk and Handicapped Infants
An HCEEP Model Demonstration University of Idaho; Moscow, Idaho/1985

HEALTH CARE AND THERAPY CONTACT LIST

	ROLE DESCRIPTION
1. Primary Care Physician	Pediatrician/general practitioner whom parents designate as their child's primary medical coordinator and health care provider.
2. Neurologist	Physician who specializes in brain and nervous system disorders, including prescribing and monitoring of medications for seizures.
3. Orthopedist	Physician who specializes in conditions directly or indirectly involving the musculoskeletal system (i.e., cerebral palsy, spina bifida).
4. Specialty Clinics	Clinics, often multidisciplinary in nature, organized to serve a single group of handicapping conditions such as myelodysplasia or a single body systems such as endocrine, cardiac, etc. These clinics do not take the place of a primary care physician.
5. Genetic Counseling	Genetic counseling may include tracing family and reproductive histories, physical examination, and/or chromosomal analysis. Probability estimates and current treatment approaches are offered to assist clients in decision making regarding childbearing. Such counseling should be provided by persons with specialty training in this area. HBM Center for Human Genetics accepts self referral.
6. Dental Health	A dentist with specialty training in pediatrics should be involved in the care of a child with disability by the time of first tooth eruption. (Not all Nebraska dentists will serve this population. See Appendix B for a listing of dentists in Nebraska who have indicated a willingness to accept handicapped patients.)
7. Vision Testing	An ophthalmalogist trained in pediatric conditions often is necessary for children with developmental disabilities. Some special educators have specific training in determining how a child uses their vision functionally.

8.	Hearing Testing	It can include assessment of sensory neural (brainstem evoked response - BER) and/or conductive hearing losses (impedence testing).
9.	Community Health Nursing Services	Registered nursing services range from brief home visits to full 24 hour in-home care. Respite homemaker services may also be available. See Directory of Nebraska Home Health Agencies in this Resource File for specific agency offerings.
10.	Counseling	Includes behavior management, family or individual psycho therapy. Services are most appropriately delivered by persons who hold at least a Master's in Social Work, a Ph.D. in Psychology with clinical certification, or a Master's Degree in Mental Health Nursing. See Appendix A for further resource information.
11.	Occupational Therapist	Assists/intervenes to facilitate oral motor and/or fine motor functioning. Developmental activities such as feeding, movement, play and interactions with others are the primary focus of intervention with infants and young children.
12.	Speech/Language Therapist	Assesses/intervenes with children who have or are at risk for language and communication disorders. Prelinguistic communication in birth to three age group is included in this specialty.
13.	Physical Therapist	Conducts neuromotor assessments, designs/implements plans to include positioning and handling, bracing and adaptive equipment necessary for gross motor functioning and body alignment.

SUPPORT SERVICES PLANNING SHEET

Resource information is located in Resource File. See the Following:

1. Advocacy Groups Resource Guide for Parent and Advocacy Organizations
2. Alternative Care Options Appendix A, Appendix D
3. Child Care Appendix A
4. Department of Social Services (check applicable services) Appendix A
    - -Adoption services
    - -Aid to dependent children
    - -Burial assistance
    - -Day care assistance
    - -Emergency assistance
    - -Emergency shelter care
    - -Food Stamp Program
    - -Foster care
    - -Homemaker services
    - -Job Support Program
    - -Medicaid
    - -Medically Handicapped Children's Program
5. Equipment vendors Directory of Nebraska Home Health Agencies
6. Funding agencies Appendix A, Appendix C
7. Health insurance Appendix C - Paying for the Medical Help You Need
8. Housing Appendix A
9. Income Tax Information Appendix A

10. Legal Aid Appendix A

11. Recreation Appendix A

12. Respite care Appendix A, Appendix D - News Digest

13. Transportation Appendix A

14. Developmental Disabilities Council Appendix A

15. Regional Community Based Mental Retardation Program Appendix A

16. WIC (Women, Infants and Children's Program) Appendix A

17. Other

University
of Nebraska
Medical Center

C. Louis Meyer
Children's Rehabilitation Institute
444 South 44th Street
Omaha, Nebraska 68131-3795

42nd and Dewey Avenue
Omaha, NE 68105-1065

SCHOOL REFERRAL LETTER

Dear :

I would like to refer Ashley B. for evaluations through the Coleridge Public Schools. Ashley has been recently hospitalized (September 3 - 10, 1985) at University Hospital in Omaha for a medical diagnostic workup. She has a medical history that includes perinatal asphyxia with subarachnoid hemorrhage, and seizures, with a subsequent diagnosis of cerebral palsy. She has visual problems including an alternating strabismus. She is being followed medically by Dr. Torkelson, neurologist, and Dr. Hurmann, orthopedist.

Observations during this current hospitalization presented current concerns regarding delayed development. Mr. and Mrs. John B. have been made aware of this referral and will be contacting you. Their address is 1101 East 7th, Coleridge, Ne. and phone number is 402-782-1460.

Sincerely,

Case Coordinator
University Hospital

cc: To Parents

ss

APPENDIX A

RESOURCES

Appendix A is a listing of resources for children with disabilities and their families. The general resource headings are organized alphabetically. They are the following:

Alternative Care Option
Child Care
Counseling
Department of Social Services
Developmental Disabilities Council
Funding
Housing
Income Tax
Recreation
Regional Community Based Retardation Program
Speech and Hearing Therapists
Transportation

ALTERNATIVE CARE OPTIONS

The following are options for residential out of home placement for handicapped children in Nebraska. For further information contact the Department of Public Institutions or the Department of Social Services.

Residential Centers

State residential centers (Beatrice State Developmental Center and units at Hastings Regional and Lincoln Regional Center) are designated for providing services to persons with mental retardation. Admission to these centers is contingent on the lack of resources in the community based mental retardation programs and the centers' capacity level. If community based services are available, residential placement will be there instead of the residential center.

Community Based Programs

Community Based Programs through the State Office of Regional Community Based Mental Retardation Programs assist families in finding local residential care programs for their children with mental retardation. During infancy, children are placed in foster care homes which are privately contracted with the family. Payment is determined on an individual basis, but most caretakers assume the child's Supplemental Social Security Income payments. Other residential options are available for older clients, including residential group homes.

Other Alternatives

For children who are not mentally retarded private foster care placement is also available. Contact the Social Services Department. Families may also go to Juvenile Court, indicating that they cannot take care of their child at no fault of the parent. If the court rules in their favor, the parent continue to have some legal rights to their child but foster care placement will be found. The Department of Social Services has more information regarding this possibility.

Adoption

Families who no longer feel that they can care for their handicapped child may seek voluntary relinquishment of their parental rights. Once again the Department of Social Services can be contacted. The child may then be placed for adoption and this can be done through the Department of Social Services or other private adoption agencies in the state.

CHILD CARE

Child Care

Some private day care centers do accept handicapped children. They must be contacted on an individual basis. The following resources can help identify day care options:

Speaking for Children: Directory of Resources for Nebraska Children is a directory of services that include day care services throughout the State of Nebraska. This is a project of the Junior League of Omaha and can be obtained at Child Saving Institute, 115 South 46th Street, Omaha, Ne. 68132.

In Omaha two referral agencies for day care services are available for a fee ranging from $35 - $55. These include:

- Answers for Child Care at the Child Saving Institute - 553-6000
- Omaha Child Care Referral - 551-2379

A listing of registered Day Care homes is available through the Nebraska Department of Social Services - 444-6134.

Respite

Respite care is temporary care for a child with handicapping conditions that can be provided periodically or on a regular basis. Services can be provided in the family's home or out-of-home care. Child care services may include specially trained babysitters, day care services, and/or respite care services. There are several community programs (e.g., Red Cross) that train groups of people so that they can safely babysit children with special needs.

The following resources can help identify respite care options:

Regional Community Based Mental Retardation Programs

Respite services are available through Regional Community Based Mental Retardation Programs in Regions V and VI. In some areas, respite care is provided through the local Associations of Retarded Citizens or other individuals. The State of Nebraska is divided into six regions (See Appendix for a description and listing of the regional offices in Nebraska). A good resource for knowing the local respite service is your local Office of Mental Retardation. (See "A-10" for listing of regional offices).

Greater Omaha Association for Retarded Citizens

The Greater Omaha Association for Retarded Citizens sponsors a sitter/companion program. Trained sitters are available for a fee to provide short term relief to parents or guardians of persons with a developmental disability.

Address: 3610 Dodge Street, Omaha, Ne. 68131
Phone: 346-5220

Child Saving Institute

The Child Saving Institute has a Crisis Center which provides emergency residential care for children under 12 years of age depending on the level of need.

Address: 115 South 46th St., Omaha, Ne. 68132
Phone: 553-1007

COUNSELING

Counseling services for members of families who have a handicapped child may be needed for a number of reasons. Counseling may be provided to individual family members or to the entire family. Individual counseling for parents is generally designed to help a parent gain greater self understanding and acceptance. Often individual counseling is used to help solve specific personal problems such as learning to cope with stressful situations or understand depression. Counseling which involves both parents is often provided where problems exist between parents or for counseling on the management of their children's behavior. Family counseling is most often provided to help solve problems that involve all or several members of the family. Family sessions are designed to help solve family problems by changing the way members interact with one another.

Group counseling is also available to help people learn to solve a variety of personal and child related problems. Usually groups focus on specific types of problems such as child guidance or self-awareness. Groups may be time limited, running a specific number of sessions, or they may be continuing, so that there is no set point at which everyone leaves the group.

Counseling services are available from a variety of sources. Agencies, both public and private, are common sources of counseling services. In addition many professional counselors, usually psychiatrists, psychologists, and social workers maintain private practices through which counseling is provided. In Nebraska psychologists and psychiatrists must be licensed. They should have had specialized training that allows psychiatrists to be boarded and psychologists to be certified. Social workers at a minimum should have received ACSW certification.

DEPARTMENT OF SOCIAL SERVICES

1. The following services are available under the Nebraska Department of Social Services. (See pamphlet in this book for further descriptions of these programs.)

    Aid to Dependent Children (ADC) is a state program for financial aid to dependent children including the not yet born. See Appendix D for additional information.

    Food Stamp Program provides food stamps to those families meeting a certain income and resource limits.

    Job Support Program is a mandatory component of the ADC Program for recipients whose youngest child is over 3. The focus of the Job Support Program is the development of an employability plan which can include training, development of job search skills, and support services to enable ADC recipients to seek full time employment.

    Day Care Assistance Program provides payment for provision of day care for low income families who are eligible.

    Medically Handicapped Children's Program may pay for medical expenses of handicapped children.

Adoption Services find permanent homes for children who are free for adoption and whose present environments lack the stability of adoptive family settings.

Emergency Shelter Care provides immediate, temporary homes for children up to 12 years of age in crisis situations. It is available when a family has no one else on whom to rely. In Douglas County call 553-6000. Contact local Social Service Office for information in other counties.

Homemakers' Services provide services in the homes of aged, physically or mentally disabled adults and families who are unable to adequately manage the family or household due to lack of knowledge, skills, or abilities.

Transportation services are provided to aged and physically or mentally disabled persons to and from local community facilities when no other transportation is available.

Foster care provides temporary family care for a child when the child's own family is unable to meet basic needs for care.

Emergency Assistance is provided to needy families with minor children in situations where other resources are not available, e.g., imminent evictions, loss of utility services or exhaustion of food.

County burial assistance is available through selected funeral directors if the estate of the decedent and/or the income and resources of responsible relatives are insufficient to meet burial expenses as defined by the Department of Social Services. Contact must be made prior to any arrangements in order for funding to be considered. This procedure is specific to Douglas County. If in other location, contact local office for services specific to that county.

Children's Medical Program (Ribicoff) assists persons 20 years old or under in obtaining medical services when they do not qualify for other medical assistance.

In Douglas County, there is a general assistance number of 444-6215. Specific numbers can be located in Speaking for Children: Directory of Resources for Nebraska Children - Junior League of Lincoln.

FUNDING

One of the major state resources for funding handicapped children is in the Nebraska Department of Social Services. This and other funding resources are the following:

The Medically Handicapped Children's Program

Diagnostic and treatment services are covered when they are within the scope of medical coverage when there is prior authorization by the Medically Handicapped Children's Program, e.g., hospitalization, diagnosis, general care. Children are eligible based on diagnosis, medical treatment plan, and the family's ability to pay for the cost of medical care. Referral to this agency may be by a physician, parents, local social services office, social agencies, or others (See Appendix C).

Disabled Persons and Family Support Program

This program may authorize payment for such things as home architectural modifications; attendant care; non-medical costs incurred during treatment; counseling or training; home health; housekeeping; special equipment; respite care; and transportation. Other types of support may also be considered based upon individual needs and circumstances. Families with a disabled family member who need some sort of support to prevent out-of-home placement are eligible for services. Financial eligibility is also considered dependent upon the gross monthly income of the family and adjusted to the family size. (See pamphlet in this booklet for further description of this program.)

Supplemental Social Security Income

Supplemental Social Security Income (SSI) Program provides monthly cash benefits to blind and disabled children and adults. Handicapped children are eligible for SSI if they meet the SSI blindness or disability guidelines and are financially eligible. The general standard in determining whether a child is eligible is whether the child's impairment has had or will have a severe impact on physical, intellectual, emotional, and/or social development.

A person may apply to the Social Security Administration Office by mail or in person by completing the application form. (See pamphlet in this booklet and information in Appendix D for further description of this program.)

WIC (Women, Infants and Children) Program

The WIC (Women, Infants and Children) Program through the Department of Health is offered through 14 agencies statewide. The federally funded program provides nutritional services including redeemable vouchers for selected high quality foods to those pregnant women and/or children up through their 4th birthday (some provide services to age 5) who are determined to be at medical nutritional risk. (Call MCH Nutrition Division at Nebraska State Department of Health, phone 402-471-2781.

Hotline for the Handicapped

Call Hotline for further funding resources - 800-742-7594.

Reading Resources

Paying for the Medical Help You Need (This article is located in Appendix C.)

DEVELOPMENTAL DISABILITIES COUNCILS

The Developmental Disabilities Councils are organized on a regional basis that parallel the six Office of Mental Retardation regions. Each regional council has a coordinating committee (see following for contacts) that is composed of professionals and parents of that community. Each council has a designated amount of state funds that they can spend according to the needs of their community, e.g., support summer camp programs, sponsor workshops, materials for agencies, etc. No funds are available for direct services or equipment for individual children.

Evelyn Pinneker
Chair, Region I
Route 2, Box 103
Minatare, NE 69359

Ann McGee
Chair, Region II
1707 Polk
Lexington, NE 69950

Marlys Pearson
Chair, Region III
Holdrege Public Schools
315 East Avenue
Holdrege, NE 68949

Kay Cattle
Chair, Region IV
920 Walnut Street
Wayne, NE 68787

Jerry Oestmann
Chair, Region V
Child Guidance Center
312 Lincoln Center Building
Lincoln, NE 68508

Mike Monfils
Chair, Region VI
Nebraska Psychiatric Institute/UNMC
602 South 45th Street
Omaha, NE 68106

State Office - Developmental Disabilities Council - 471-2337

HOUSING

Facilities are available in Omaha for families of children using medical facilities in the Omaha area.

Ronald McDonald House

The Ronald McDonald House of Omaha is located at the Boys Town National Institute and is funded by local McDonald restaurants, Boys Town National Institute, public contributions and donations from families staying at the house. Family donations range from $5.00 to $15.00 per night depending on the number of guests and the family's ability to pay.

University House

Families receiving medical care at the University of Nebraska Medical Center may stay at the residence. The rooms are private at a fee of $22 per night. To make reservations, call 559-5597.

INCOME TAX

The following materials are available in the IRS Office:

1. Tax Information for Handicapped and Disabled Individuals - Publication 907.

   This publication covers the federal income tax rules of particular interest to handicapped and disabled people and to taxpayers with disabled dependents.

2. Medical and Dental Expense - Publication 502.

This publication explains how to claim a deduction for medical and dental expenses.

3. Child and Dependent Care Credit & Employment Taxes for Household Employees - Publication 503.

   This publication explains tax credits if you pay someone who is taking care of a dependent who is under 15, a disabled dependent or a disabled spouse so that one can work or look for work.

REGIONAL COMMUNITY BASED MENTAL RETARDATION PROGRAMS

Through efforts of parents and others, the Nebraska Legislature mandated that services for those with mental retardation be established within local communities. The state was divided into six regions with each region responsible for clients in their counties. The State Office of Mental Retardation is under the Department of Institutions.

The Regional Community Based Mental Retardation Program offers a range of services for children and adults including residential care, vocational training, and social services. (See page A10 for regional offices listings.)

RECREATION

Children can participate in recreational programs that include summer camps, after-school programs, and clubs. Information regarding recreational programs in Nebraska can be obtained through the following resources:

Hotline for the Handicapped, Toll Free Number - 1-800-742-7594
Nebraska ChildFind, Toll Free Number - 1-800-742-7594
Speaking for Children: Directory of Resources for Nebraska Children - Junior League of Lincoln.
Directory of Recreation Programs for People with Developmental Disabilities for Douglas County - Developmental Disabilities Council/Greater Omaha Association for Retarded Citizens (See Appendix G for a pamphlet)
Pipal Park in Omaha at 78th and Center Street was especially planned for children with disabilities.

SPEECH AND HEARING THERAPISTS

Local school districts are the primary resource for speech therapy services in the state. Individual language therapy may not always be a part of the individual child's program. For those children not eligible for speech and language services private practitioners would be available in most cities. For information on a listing of licensed speech therapists contact the Department of Health - Bureau of Examining Boards - 402-471-2115.

The following is a list of some agencies that can provide private speech/language services:

Boys Town National Institute for Communication Disorders in Children

Address: 555 North 30th Street, Omaha
Phone: 402-449-6540

Immanuel Medical Center
Address: 6901 North 72nd, Omaha
Phone: 402-572-2277

Laboratory of Speech and Language Disorders
Address: 4256 Douglas St., Omaha
Phone: 402-551-7338

Speech Rehabilitation Services
Address: 12793 Q St., Omaha
Phone: 402-894-0387

University of Nebraska Speech and Hearing Clinic
Address: 202 Barkley Center, Lincoln
Phone: 402-472-2071

TRANSPORTATION

School districts are responsible for providing or reimbursing parents for transportation for educational programs or educationally related evaluations.

Transportation services to and from local community facilities are provided by Department of Social Services for financially eligible persons who are also aged, physically or mentally disabled persons. Other options for transportation must be utilized before this funding is available.

REGIONAL OFFICES

Region I Office of Mental Retardation
1721 Broadway
Box 1327
Scottsbluff, NE 69361
(308) 635-3444

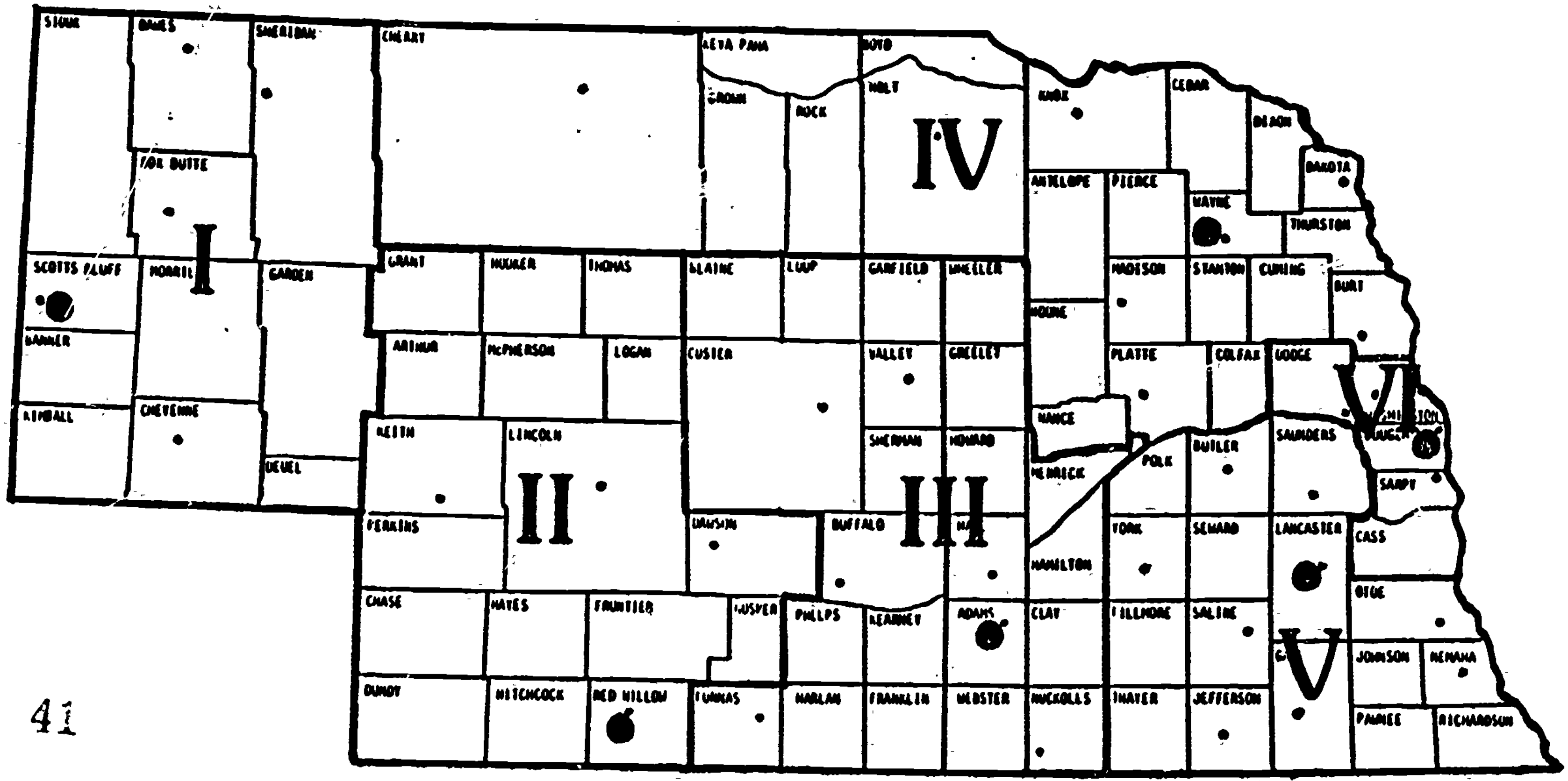
Region II Services for the Handicapped
301½ Norris Avenue
Box 683
McCook, NE 69001
(308) 345-2495

Region III Mid-Nebraska Mental Retardation Services
522 East Side Boulevard
Box 1146
Hastings, NE 68901
(402) 462-5107

Region IV Office of Developmental Disabilities
114 West Third Street
Box 352
Wayne, NE 68787
(402) 375-2880

Region V Mental Retardation Services
2311 North Cotner
Lincoln, NE 68507
(402) 464-8361

Region VI Eastern Nebraska Community Office of Retardation (ENCOR)
885 South 72nd Street
Omaha, NE 68114
(402) 444-6500



APPENDIX B

PEDIATRIC OCCUPATIONAL THERAPISTS

PEDIATRIC PHYSICAL THERAPISTS

HEADSTART PROGRAMS

DENTAL LISTINGS

PEDIATRIC PHYSICAL THERAPISTS
IN NEBRASKA

ARAPAHOE

Christine Urborm
Arapahoe Medical Clinic
Arapahoe, NE 68922
(308) 962-5464

BEATRICE

Gary Anders
Beatrice State Developmental
Center
Box 808
Beatrice, NE 68310-0808
(402) 223-2302

COLUMBUS

Ken Johnson
North Park Clinic
2360 Pershing Road
Columbus, NE 68601
(402) 564-5456

FAIRBURY

John Cervantes

FREMONT

Gail Johnson
(Fremont Public Schools)
RR#1, Box 71
Mead, Nebraska 68041
(402) 624-6225

GRAND ISLAND

Jolyne Harrington

Jane Gangwish
Grand Island Public Schools
(308) 381-5931

GOTHENBURG

Karla Bryant
2306 G, Rt. 2
P.O. Box 437
Gothenburg, NE 69138
(308) 537-2970

HASTINGS

Susan Harms, Teri Nguyen,
Anna Showalter
ESU#9
1002 E. South St.
P.O. Box 2047
Hastings, NE 68901
(402) 463-5611

KEARNEY	Jan Wiles Kearney Clinic 211 West 33rd Street Kearney, NE 68847 (308) 237-2141
LEXINGTON	Linda Hawkins Lexington Developmental Center Lexington Public Schools Lexington, NE 68850 (308) 324-6414
LINCOLN/WAVERLY	Nancy McProud Joyce Glaesemann Lincoln Public Schools 473-0229
	Laurie Haszard Lincoln General Hospital 2300 S. 16th Street Lincoln, NE 68502 (402) 473-5100
	Burdetta Thrapp Madonna Professional Care Center 2200 S. 52nd Street Lincoln, NE 68506 (402) 489-7102
	Jane Snyder Tabitha, Inc. 4720 Randolph Lincoln, NE 68512 (402) 483-7671
	Marilyn Altenhofen Waverly School District 489-7102 Extension 285
	Denise Extrom Laurie Casper
LOUP CITY	Dorothy Schott Sacred Heart Hospital 626 North Street Loup City, NE 68853
NELIGH	William Reynolds Antelope Hospital 102 W. 9th Street Neligh, NE 68756 (402) 887-4151

NORFOLK

Doris Buschkoetter
Lutheran Community Hospital
2700 West Norfolk Avenue
Norfolk, NE 68701
(402) 371-4880

Ricky Peterson
Our Lady of Lourdes Hospital
1500 Koenigstein
Norfolk, NE 68701
(402) 371-3402

NORTH PLATTE

Lisa Black
Great Plains Medical Center
601 West Leota Street
North Platte, NE 69101
(308) 532-5626

OGALLALA

Robyn Stewart

O'NEILL

Loren Mulhair
North Central P.T., Inc.
Box 902
O'Neill, NE 68763
(402) 336-3109

SEWARD

Michelle Karpenko
208 Shannon Road
Seward, NE 68434
(402) 643-3110

SIDNEY

Daryl Conger
Memorial Hospital & Home
Seventh & Osage
Sidney, NE 69162
(308) 254-5825

SCOTTSBLUFF

Nancy Forney
Scottsbluff PT Associates
211 West 38th
Scottsbluff, NE 69361
(308) 632-2733

Also PT Dept.
West Nebraska General Hospital
4021 Avenue B
Scottbluff, NE
(308) 632-0355

YORK

Vic Kennel
York P.T. Clinic
609 Grant Avenue, Box365
York, NE 68467
(402) 362-6361

WAYNE

Carol Sheldon
Region IV, ESU#1
Office of DD
P.O. Box 463
114 West Third Street
Wayne, NE 68787
(402) 287-2061

Doris Bourek
Providence Medical Center
1200 Providence Road
Wayne, NE 68787
(402) 375-3800

WEST POINT

Judy LeTrud
St. Francis Memorial Hospital
430 No. Monitor
Box 192
West Point, NE 68788
(402) 372-5143

OMAHA

Jim Miedaner
Wayne Stuberg
Penni White
Pam Dehne
Bob Fuchs
UNMC
Meyer Children's Rehabilitation Institute
444 South 44th Street
Omaha, NE 68134
(402) 559-6415

Kyle Meyer
Wendy Bruce
Methodist Hospital
8203 Dodge Street
Omaha, NE 68114
(402) 397-3000

Mary Miedaner
Cathy White
Sue Penner
Prairie Lane School
11444 Hascall Street
Omaha, Nebraska 68144

PEDIATRIC OCCUPATIONAL THERAPY LISTING

Broken Bow, Nebraska
James R. Christen
1243 South D Street
Broken Bow, Ne. 68822

Council Bluffs, Iowa
Judy Lynn Carroll
1621 Pueblo Road
Council Bluffs, Ia. 51501

Eustis, Nebraska
Judith Johnson Heins
Route 15, Box 73
Eustis, Ne. 69028

Fremont, Nebraska
Sarah Lynne Gale
2519 East 22nd
Fremont, Ne. 68025

Grand Island, Nebraska
Bonnie Jo Rott
1411 West John
Grand Island, Ne. 68801

Hastings
Joyce Anne Donovan
507 N. Kerr
Hastings, Ne. 68901

Kearney
Patsy Ann Fischer
106 East 30th
Kearney, Ne. 68847

Lincoln
Katherine M. Bangsund
400 Lyncrest Drive
Lincoln, Ne. 68510

Pamela Smith Linke
905 Sycamore Drive
Lincoln, Ne. 68505

Marjohn Petri Love
2601 South 58th St., #18
Lincoln, Ne. 68506

Lincoln (cont.)

Diane Gesiriech Ramel
2710 Sewell St.
Lincoln, Ne. 68502

Karla Marie Wahl
1701 Ridgehaven Court #7
Lincoln, Ne. 68505

Lodgepole, Nebraska

Cynthia Krueger Epling
P.O. Box 13
Lodgepole, Ne. 69149

Norfolk, Nebraska

Mary Rumbolz Surber
1202 Norfolk Avenue
Norfolk, Ne. 68701

Omaha, Nebraska

Dennis Dean Bickley
5208 Larimore Avenue
Omaha, Ne. 68112

Nancy Michelle Daly
10606 Ellison Plaza #2
Omaha, Ne. 68134

Karen Lee Eustice
2601 South 32nd Avenue
Omaha, Ne. 68105

Janice Harman Flegle
6723 South 145th St.
Omaha, Ne. 68137

Linda Lee Gabriel
5119 Decatur
Omaha, Ne. 68104

Lori Ann Hahn
12106 Poppleton Plaza #128
Omaha, Ne. 68144

Jan Gail Hardcopf-Bickley
9622 North 29th St.
Omaha, Ne. 68112

Mary Lou Henderson
5503 Harney St.
Omaha, Ne. 68132

Omaha (cont.)
Kathleen M. Keller
4824 William St.
Omaha, Ne. 68106

Patricia Lux Kipperman
4605 South 154th Avenue Circle
Omaha, Ne. 68137

Kari Trygg Miller
14811 "L" Street
Omaha, Ne. 68137

Diane Rae Neff
330 South 37th Street #10
Omaha, Ne. 68131

Lisa Wallace Scheet
7780 Greenleaf Drive
Omaha, Ne. 68128

Beth Staenberg
1907 North 102nd St.
Omaha, Ne. 68114

Sioux City, Iowa
Andrea Scott Abbott
3122 Pierce St.
Sioux City, Iowa 51104

NEBRASKA HEAD START PROGRAMS

Northwest Nebraska Community
Action Council
300 West 2nd Street
Chadron, Nebraska 69337
(308) 432-3393

Chadron State College
Box 90
Chadron, Nebraska 69337
(308) 432-5018

Blue Valley Community Action, Inc.
Box 273
Fairbury, Nebraska 68352
(402) 729-2278

Midland Lutheran College
P.O. Box 244

Fremont, Nebraska 68025
(402) 721-5480

Hall County Human Resources
Department
County Court House
Grand Island, Nebraska 68801
(308) 384-7710

Good Samaritan Village
P.O. Box 347
Hastings, Nebraska 68901
(402) 463-3181

Southeast Nebraska Community
Action Council
Box 646
Humboldt, Nebraska 68376
(402) 862-2411

Mid-Nebraska Community Services, Inc.
1920 College Drive
Kearney, Nebraska 68847
(308) 234-3916

Lincoln Action Program, Inc.
2202 South 11th Street
Lincoln, Nebraska 68502
(402) 471-4515

Lincoln Public Schools
225 South 25th Street
Lincoln, Nebraska 68510
(402) 475-8329

Central Nebraska Community
Services, Inc.
P.O. Box 509
Loup City, Nebraska 68853
(308) 745-0780

Omaha Child Development
Corporation

3025 Parker Street
Omaha, Nebraska 68111
(402) 444-5577

Chicano Awareness
4825 South 24th Street
Omaha, Nebraska 68107
(402) 444-5577

Plattsmouth Community Schools
2101 South 15th Street
Plattsmouth, Nebraska 68048
(402) 296-5250

Panhandle Community
Action Agency
P.O. Box 1469
Scottsbluff, Nebraska 69361
(308) 635-3087

Goldenrod Hills Commounity
Action Agency
P.O. Box 10
Walthill, Nebraska 68067
(402) 846-5493

NEBRASKA DENTISTS WILLING TO TREAT HANDICAPPED PATIENTS

OMAHA, NEBRASKA

Bennett, Walter
5202 Levenworth Street
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Drahota, R.J.
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Omaha, NE 68114

Fenster, Donald
2413 M. Street
Omaha, NE 68105

Free, J.D.
5440 South Street
#450
Omaha, NE 68506

Gerstner, Roger
3015 N. 90th Street
Omaha, NE 68134

Gilinsky, Rick
2413 M. Street
Omaha, NE 68105

Grove, Raymond
119 North 51st Street
Omaha, NE 68132

Henduchson, R.R.
P.O. Box 2063
Omaha, NE

Huerter, James
2410 South 73rd Street
Omaha, NE 68124

Hungerford, R.W.
601 N. 30th Street
Omaha, NE

Kathrein, William
Indian Hills Professional Bldg.
220 N. 89th Street, Suite 103
Omaha, NE 68104

Kelsey, M.N.

119 North 51st Street

Knutzen, Jeffrey
2808 N. 75th Street
Omaha, NE 68134

Butler, Benton
Suite 321 Doctors Bldg
Omaha, NE 68131

McLey, L.
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Suite 321
Omaha, NE 68124

Manhart, Mark
727 Medical Arts Bldg.
Omaha, NE 68102

Monnig, Dennis
8630 Cass
Suite 216
Omaha, NE 68114

Odorsid,Frank
10815 Elm
Omaha, NE 68105

Pietro, James
10813 Elm
Omaha, NE 68105

Shyken, Paul
7887 L. Street
Ralston, NE 68127

Tutelman, Melvin
2020 No. 72nd Street
Omaha, NE 68134

Troia, J.A.
505 W. 23rd Street
Bellevue, NE 68005

Vogelsberg, Gary
220 North 89th Street
Omaha, NE 68114

Westerman, Gary
1106 South 91st Avenue
Omaha, NE 68124

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Gemar, Gerald
Oak Hills Plaza
12745 "Q" Street
Omaha, NE 68137

Sheldon, Norman
10060 Regency Circle
Omaha, NE 68114

Fangman, Terrance
8761 West Center Rd.
Omaha, NE 68124

LINCOLN, NEBRASKA

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5440 South Street
Lincoln, NE 68506

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Lincoln, NE 68501

Gormen, T.W.
Crown Place Prof. Bldg
6930 L. Street
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Jorgensen, Donald
1413 South 13th Street
Lincoln, NE 68502

Johnston, Glenn
3315 South 31st
Lincoln, NE 68503

Maude, Harold
5640 South Street
Lincoln, NE 68506

Iteinacher, Ray
College of Dentistry
40th & Holdrege
Lincoln, NE 68583

Jurgens, Roger
Meadow Lane Shopping Center
902 No. 70th Street
Lincoln, NE 68505

King, Dennis
1676 Van Dorn
Lincoln, NE 68502

Kull, Stan
5019 Huntington #6
Lincoln, NE 68504

Martin, Max
3445 "O" Street
Lincoln, NE 68510

Parker, Richard
3100 "O" Street
Lincoln, NE 68510

Rauscher, Bruce
4009 Randolph Street
Lincoln, NE 68501

Sedlak, John
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Lincoln, NE 68506

Sonderegger, Kurt
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Elwood, Nebraska 68937

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1267½ 26th Avenue
Columbus, Nebraska 68601

Jensen, Terry
Box 206
Neligh, Nebraska 68756

Rider, Frank
Wauneta, Nebraska

Rikli, T.
Ord, Nebraska

Dubs, Houfek and Brown
508 Willard
Genoa, Nebraska

Ghangler, Lauren
315 West Eagle
Arlington, Nebraska 68002

Heimbuch, F.E.
515 Niobrara Avenue
Alliance, Nebraska 69301

Hinrichs, James
1635 Chatham Avenue
Ardzn Hills, MN 55112

Egerman, Lyle
Bancroft, Nebraska 68004

Tietsort, Mark
111 E. 9th Street
Cozad, Nebraska 69130

OTHER OUTSTATE NEBRASKA AREAS

Wesch, Jack
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Fairbury, Nebraska 68352

James, C.R.
2107 Stone Street
Falls City, NE 68355

Hendriksen, Richard
1735 East Military
Fremont, NE 68025

May, G.W.
2350 N. Clarleson
Fremont, NE 68025

Walla, William
1835 East Military
Fremont, NE 68025

Coke, Richard L
2350 N. Clarkson
Fremont, NE 68025

Kennel, L.W.
Box 242
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Janda, David
704 W. 1st Street
Grand Island, NE 68801

Janda, Mike
908 N. Howard #10
Grand Island, NE 68801

Lofgreen, David
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Staddol, David
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McPherson, Robert
12th and Laird Avenue
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Diedrichsen, Fred
130 West 14th Avenue
Holdrege, NE 68949

Sawyer, Jay
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Holdrege, NE 68949

Bryson, Michael
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Kearney, NE 68847

Bunbridge, Authur
1709 W. 38th #9A
Kearney, NE 68847

Pentz, Roger
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903 North Grant
Lexington, NE 68850

Case, C.C.
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McCormach, M.P.
106 S. 12th Street
Nebraska City, NE 68410

Strassler, G.
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Neligh, NE 68756

Doyle, James
109 N. 15th #10
Norfolk, NE 68710

Karmazin, Daniel
600½ Benjamin Avenue
Norfolk, NE 68701

Krivohlavek, Bradley
General Dentistry
405 South 17th Street
Norfolk, NE 68701

Murphy, James
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OTHER OUTSTATE NEBRASKA AREAS

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Brockman, Jerry
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O'Neill, NE 68763

Croft, Authur
Box 379
O'Neill, NE 68763

Peterson, Wm. J.
1626 L. Street
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Ord, NE 68862

Pestal, Dennis
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Osceola, NE 68651

Leppenbach, R.J.
104 N. Brown
Pierce, NE 68767

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Plattsmouth, NE 68048

Kruse, Steven
111 No. 3rd
Seward, NE 68434

Hoban, Gloria
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Schottsbluff, NE 69361

Zahradnicek, H.C.
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Scottsbluff, NE 69361

Jones, D.B.
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Osmond, NE

Jeffers, D.J.
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Valentine, NE 69201

Jeffers, Robert
331 North Cherry
Valentine, NE 69201

Higgins, D.J.
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Valentine, NE 69201

Rakov, J.
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Verdigre, NE 68783

Wessel, Wayne
115 W. 3rd Street
Wayne, NE 68787

APPENDIX C

PAYING FOR THE MEDICAL HELP YOU NEED

CHECKLIST OF INFORMATION HELPFUL WHEN APPLYING FOR SOCIAL SECURITY INCOME BENEFITS

MEDICALLY HANDICAPPED CHILDREN"S PROGRAM

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Paying for the Medical Help You Need

Your child should have all his or her medical needs taken care of, including all the *functionally* best medical equipment. So, for example, no child needs a gold-plated wheelchair, but he or she may have an electric outdoor and indoor wheelchair, especially modified to meet his or her needs. To pay for your child's medical expenses you will probably need the financial assistance of public and private agencies. You may need help not just for tens or hundreds but for thousands of dollars year after year. And if your child's medical expenses rise, the search for funds has to expand. Although you will surely be grateful for the generosity of others, the efforts to find funds can become so difficult that you may begin to feel that you are scrounging for money. But if you need financial assistance, you have to find out how to get it. Think of your search as a treasure hunt. This attitude will help you keep your perspective on the matter.

YOUR FINANCIAL NEEDS AND RESOURCES

First you must consider not only your child's medical needs but also how your family spends its money. If you are frugal and try to save, yet still need more money for medical expenses than you have available, you have to consider outside sources of help, which in our society are of three basic kinds: tax-supported government programs at the local, state, and national levels; insurance; and voluntary health agencies.

Various individuals can help you search for funds. Doctors can often direct you to sources of financial assistance in your community. Social workers working for hospitals, government agencies, and sometimes voluntary health agencies can also help. These are people to work *with* you, not for you, meaning that you must do your part, indicating your needs and providing any necessary information. Parents of other special children can also be helpful regarding support and information, especially if they have been successful in obtaining money.

When you look for help in finding financial assistance, remember that you are most familiar with your financial needs and medical problems and that you can be your child's best advocate. You must be able to provide all pertinent information to anyone helping you in your search for assistance.

THE REQUEST FOR ASSISTANCE

Regardless of which agency you contact for assistance, the appropriate approach is important.

Telephone Inquiries

Telephone inquiries are the first step in your search for financial assistance. There is a technique to making an effective phone call:

- *Consider what points you want to cover before placing your call.* It may be helpful to write these down.

- *Introduce yourself in a friendly voice:* "Hello, this is Judith Smith" or "Judith Smith, the mother of Belinda Elizabeth Smith," if such identification is appropriate. People like to know who is calling, and a friendly tone gets things off to a good start.
- *State with whom you wish to speak and why.*
- *Write down the name of the person with whom you speak.* If someone gives you information, you may want to call him or her back for more later. Furthermore, if someone gives you a commitment of some kind, you need to remember who that person was.
- *Be well organized and concise.* Refer to any notes you have made before calling if this will help.
- *Take notes during the phone call.* Do not assume you will remember everything you are told.
- *Be friendly and polite.* Since people have good and bad days, don't take a grouchy or curt response personally. Even if you get no for an answer, watch your manners. You may be able to get the party to change his or her mind or at least to help you or someone else in the future.

Interviews

If an agency is interested in more information about your request, its representative may wish to see you in person and an interview should be arranged. Make an appointment for a time when you know you will be punctual and calm and when you will have the attention and interest of the agency (which excludes appointments on Friday at 4:45 P.M.). Your general appearance is important. If you come bedecked with diamonds, people may wonder if you are really a needy case. But if you arrive looking bedraggled and worn you won't create a positive impression either.

Again, be organized and write down notes in advance, for you must be able to convince people that yours is, indeed, a worthy cause. Since many professional people are very busy, don't take up more of their time than necessary.

You can sometimes arrange interviews at home. Not only may this be more convenient for you, but it will enable the social worker or other agency official actually to see your child in the home environment and thus better appraise your child's needs. Also, someone who has been to your home is more likely to remember you when you contact him or her again.

Written Requests

You will probably need to put your request for assistance in writing. Written requests may take time to formulate, but they ensure that an agency has all the relevant information. A written request makes the best impression if it is neatly typed on standard 8½ × 11" white paper. You can give a person your written request at the time of an interview or mail it following a phone call. A written reply to your letter will then give you verification of the agency's general policy or a specific response to your request.

Refusals

Do not take any refusal personally. People are not saying they don't like you or your child. They are saying that, as they perceive the situation, they can't help you.

Be sure you know why a request is refused. In some cases, a refusal is due to an inflexible policy. But in other cases policy is open to interpretation. Check with the agency to make sure you have given all the information they need.

Don't be afraid to ask again. Assistance programs exist to assist people. If you think you have a reasonable request, keep making it. People must perceive your need before they can help you. Also, some programs change. While you may not be eligible for something now, you may well be later.

GOVERNMENT PROGRAMS

Although government programs and regulations are constantly changing, there are various major sources of government assistance for your child: the federal Medicaid program (and its equivalent on the state level), the federal program assisting the disabled (Supplemental Security Income), state programs for disabled children (often called the Crippled Children's Services or simply Children's Services), and state programs aiding the developmentally disabled. Other pro-

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Loose Jones, Monica, Home Care for the Chronically Ill and Disabled Child, NY: Harper Row, 1985.

grams provide assistance to specific groups of individuals, such as children of veterans or of Social Security recipients. Aid from these programs varies from state to state; some parents facing huge and ongoing medical expenses have actually moved to another state in order to get more comprehensive government assistance. But some aid is available in all states. Unless you can easily pay for your child's expenses, you should find out what assistance is available.

Medicaid

Medicaid is the federal program assisting the medically needy. Some states have supplemental programs providing additional benefits. But wherever you live, there are certain factors to consider.

Apply immediately for these programs at your county or city welfare or Social Security office. While sometimes payments are retroactive and may be made as long as three months after an expense has been incurred, often you have to apply *before* expenses are incurred. So, for example, if you think your child may be disabled, apply before any testing is done. If you think your child needs hospitalization, apply. If an emergency such as an accident or sudden severe illness arises, apply. You can get preliminary information by phone. Often a friend or relative can do initial legwork for you.

Eligibility requirements not only vary from state to state but are constantly being updated. If you are considering applying for assistance, call your local welfare office to find out what the general requirements are. Although you may not qualify to go on welfare, you may well qualify for a program for the "medically needy only." Such a program may provide free medical assistance or a "share of cost" (see pages 230–231).

Residency is usually a requirement for eligibility. You are usually eligible only for a program within the state in which you reside. Therefore you are not eligible when traveling in another state or abroad. Likewise, foreigners are not eligible for U.S. programs unless they are here not as visitors but as resident aliens.

Property is usually the primary determinant of eligibility. Call your local welfare office for the exact information. Do this *before* you see an agency worker, so you will know what information to bring to your first meeting. A phone call can not only save you a trip if you are ineligible but may also inform you how you could become eligible. Medicaid determines eligibility on the basis of cash and savings, but it does not take into account your outstanding bills, loans, mortgages, etc. As an example, assume the Medicaid limit of cash on hand is $1,500. If you have $3,000, you might consider paying off bills, loans, or part of your mortgage to qualify. If it is also legal in your state to purchase a "paid in full" life insurance policy of $1,500, you might consider that.

This is by no means a suggestion that you be dishonest. Rather it is a realistic picture of how you will have to work within the system and will have to understand the rules and requirements of that system. There are requirements you will not be able to work around, however. For example, a requirement may be that you not own more than one home. If you own two and sell one, the money is then part of your financial worth, probably making you too rich to qualify. You may not give property away to become eligible.

Income may or may not determine eligibility. Free medical assistance will be given if necessary. However, assistance is often granted only on a cost-sharing basis. Based upon your income and the government's cost-of-living calculations, the government determines an amount that you must pay every month for medical expenses. The government pays the rest. The amount you pay refers to your out-of-pocket expenses; if you have insurance, you pay that amount *after* the insurance has paid its portion. If you are eligible, your eligibility is from the first of the month in which you apply, and your expenses are reviewed on a monthly basis. If in any one month your expenses are high enough, you will receive assistance. So, for example, if your share of cost is $400 and your out-of-pocket expenses are $650, the government will pay $250. Since the government's calculations of monthly living expenses are very low, you may find your share of cost is very high. Your income may be high enough that you will qualify only when your child has especially high expenses, as during hospitalization. In that case you may have to reserve this program for what the medical world calls "catastrophic illnesses" and use medical insurance and private agencies to help you with regular expenses.

You are legally liable if you lie about your finances. There are occasional audits of state and county records, as well as of individual files.

The referral service provided by the welfare department's social services division can be invaluable, for that department has much information that can help you find assistance with either another government agency or a private one. This referral service is provided even if you don't qualify for Medicaid.

Crippled Children's Services

All states have programs assisting children with disabling conditions (including birth defects, accidental disabilities, and chronic diseases). Whereas the title of the program may vary from state to state, it is often called either Crippled Children's Services or simply Children's Services. Since the funding is provided by both state and local governments, the benefits can vary not only from state to state but also from county to county. The programs are usually run by the department of health or welfare.

Assistance usually provided without proof of financial eligibility includes physical and occupational therapy, which are often administered through the schools free of charge. Diagnostic testing is usually paid for only if a doctor's authorization is received *before* testing is done. This is why you should apply for assistance as soon as you think there may be a problem and not wait until one is diagnosed. Often in an emergency, coverage can begin from the time phone authorization is given by your doctor, with the understanding that you will complete any necessary paperwork as soon as possible.

Assistance based upon eligibility is often available to middle-income families who do not qualify for Medicaid. Depending upon your financial status, either your child qualifies for free services or you must assume a share of cost. Often many of the treatments prescribed by a physician are covered, including doctors' visits, testing, hospitalization, and orthopedic equipment.

Some states provide this assistance only on a loan basis, which means that you will have to repay the money over time.

Programs for the Developmentally Disabled

Most states provide assistance for the developmentally disabled, aiding children with neurological problems (mental and motor) caused by birth defects, illness, or accidents. Although these programs can be run by the departments of health, welfare, or social services, there also are private, nonprofit agencies contracting with the state for funds to provide such services. Your county health or welfare department should be able to tell you if any such agencies exist in your state. Such an agency will often first help you determine if your child is eligible for other public funding. If not, it may help you purchase services such as diagnostic testing, appropriate schooling, day care, and sometimes even homemaker services (such as cleaning and cooking). Such assistance is provided particularly if it will help maintain the child at home or in the community rather than in an institutional setting.

Since an individual agency may have some freedom in deciding how to allocate its funds, it may be up to you to indicate your need and to convince people that your child indeed represents a worthy cause. Such pleading cannot be based just upon feelings but must be substantiated by facts. For example, if you can find out how much it would cost the state to institutionalize a child in a state facility for one year and then estimate how much you would need to get enough help to allow your child to remain at home, you could show that it would be far cheaper for the state (and ultimately the taxpayer) to assist with home care than to institutionalize your child.

Supplemental Security Income

Disabled individuals with little or no income of their own may qualify for Supplemental Security Income. However, unless your child is over 18 or

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does not live at home, your whole family income is considered. So whereas this program may well aid your child when he or she gets older, it may not do so now. But check on present eligibility requirements, because these are constantly changing.

Social Security

When a parent on Social Security dies or retires, his or her severely disabled child will receive Social Security payments until the age of 18. The amount is determined by how much the parent(s) paid in. After age 18 the monthly payments continue if the child's condition prevents "substantial gainful work."

Benefits to Children of Veterans

There are programs aiding children of veterans who are at least 50 percent disabled or who have died as a result of military service. Call your nearest Veterans Administration office for details.

Title 19 Federal Deeming Waiver (Model Waiver for Disabled Children) enables a disabled child to receive assistance from Medicaid and Supplemental Security Income even though he or she would not qualify under the regular federal regulations. The first child to receive such a waiver was Katie Becket, a ventilator-dependent child who was hospitalized since birth. Her parents, appealing first to elected state officials and later to President Reagan, were finally granted a waiver of regulations so that their child would get the necessary financial assistance for home care from Medicaid and Supplemental Security Income. Do check to see if your state government has passed legislation permitting Title 19 Federal Deeming Waivers. If it has not, encourage your elected state representative to do so, for even if you don't need such assistance, some other family might.

MEDICAL INSURANCE

If you cannot find enough government assistance to pay for medical care, middle-income families in particular should next consider medical insurance.

This is another complicated matter for the lay person, for a variety of plans are available from many different insurance companies. Basically, medical insurance operates on the principle of "spread the risk," meaning that if everyone pays in a small amount to a central fund, the few who need a large amount of assistance can be aided.

Benefits vary greatly. Generally the more you pay in, the greater the coverage. Most plans cover two major areas.

The basic plan covers the smaller medical expenses, such as diagnostic testing, X rays, lab work, and medication. However, there is usually an upper limit per illness or per year.

Major-medical covers most costs not covered by a basic plan. Major-medical often requires you to pay a "deductible," like the first $100 of medical expenses per individual per calendar year, after which the insurance company usually pays 80 percent of the expenses. Sometimes there is a "stop-loss clause": after a large amount, let us say $2,000 of expenses incurred in a calendar year, the company will pay 100 percent of all subsequent claims in that year. Usually there is a lifetime maximum of benefits to be paid to one individual of about $250,000. If your child is about to reach his or her lifetime maximum, there may be other ways to get financing (see pages 239–241).

Exclusions are those items that the plan will not cover, such as preventive medicine, annual physicals, outpatient care, rehabilitation, maternity benefits, hearing aids, glasses, and sometimes preexisting conditions, which are medical conditions existing before the policyholder took out the insurance. So be sure you read the small print of every plan and go over it with the person enrolling you in the insurance program. If your child has a medical problem, *be sure that the plan includes preexisting conditions for all family members* from the day the policy is taken out, for otherwise the child will not be covered. All additional children should be covered from the moment of birth with no 30-day waiting period. (A newborn infant needing surgery or

other expensive medical care in the first month can run up a very high bill.) Although the exclusions provide general guidelines, you may try to get the medical review board of the company to consider special needs once you are insured.

Group Insurance

Group insurance is almost always a better buy than private insurance because lower premiums can be offered to a group of individuals, such as the employees of a firm or a college or members of a professional association.

Some employers offer a choice of programs. If you have a choice, the person enrolling employees for insurance should be knowledgeable and able to advise you as to the comparative virtues of the plans. If your child has problems, you are almost always better off taking the highest amount of coverage possible. The two most common options are a basic plan with major-medical and a health maintenance organization (HMO).

The basic plan and major-medical have just been discussed. If you have a choice of insurance companies, check the benefits to see which plan will give the best coverage for the types of expenses your child usually incurs.

A health maintenance organization is made up of a group of doctors, usually in one clinic, who emphasize preventive care and early detection and treatment of problems for the employees of one company. You are limited to the doctors at the clinic unless you have to be referred to an outside specialist.

Since the emphasis is on preventive medicine, coverage is available for items often not covered by regular insurance plans such as well-baby care, immunizations, periodic checkups, and sight and hearing examinations. While some expenses are covered 100 percent with no deductible, you often have copayment (a portion you must pay) on various things such as office visits, prescriptions, elective procedures (such as family planning), or treatment of mental or nervous conditions.

Most HMOs request that you pay the copayment before receiving services, which simplifies your paperwork. Such a plan may cost 20–30 percent more than a regular policy, but if your child has high medical expenses the additional coverage will probably offset this cost.

The main disadvantage of a health maintenance organization is that you are limited to the doctors in the program. If you have a choice of health maintenance organizations, check which doctors are involved in which program. If your child is already being seen by a nonaffiliated doctor with whom you have a good working relationship, you may have to consider whether improved coverage is worth changing doctors.

Preexisting conditions are often covered in group insurance. If your child has a preexisting condition so you cannot insure him or her privately, or only at very high premiums, you might consider changing employers to find a group plan that would give you the insurance coverage you need. This may sound extreme, but if your child has extensive needs you may find that where you live, where you work, and what hours you work will all be influenced by your child.

If your insurance covers preexisting conditions, never take a leave of absence or quit that job until you have another policy that will cover your child.

If your employer offers a variety of programs, preexisting conditions will usually be covered only if you take out the insurance at the time of your initial enrollment or if you change policies during the annual "open enrollment period," which is usually one month of the year. If you change plans at any other time, the company can demand a physical and thus exclude persons with preexisting conditions. The only time you can add a person with preexisting conditions to your policy during the rest of the year is if that person loses coverage from another company. For example, if parents get divorced and the employer of the parent with custody offers a group insurance policy that covers preexisting conditions at the time of enrollment, that parent can enroll the child at any time and get the benefits.

Private Insurance

The cost of private insurance is high. If you are specifically trying to insure a child with preexisting conditions, it is often astronomically high. If you cannot get group coverage and think you need insurance, make sure you have all the relevant information before taking out a policy.

Find a reputable, experienced agent who sells medical insurance and has access to a variety of plans. Again, recommendations from friends or other persons knowledgeable about the field are helpful. If you are forced to turn to the yellow pages, try to find a firm that advertises that it has been active locally for many years. Then call and ask to speak to the owner, the manager, or the head salesperson for medical insurance. Do not settle for less. You want an experienced agent so when you describe your situation he or she will be able to ask you additional questions to determine your needs. It helps if you ask the agent specific questions about whether the insurance plan covers medical expenses you think your child might incur. (The preceding pages on medical insurance should give you ideas about questions to raise.) If the agent seems unable to answer your questions readily with detailed knowledge of the actual coverage of the plan, he or she may sell you an inappropriate policy. If in doubt, call another agent to discuss your situation. If your child has unusual needs and no agent can satisfactorily answer your questions, call (collect) the national offices of a few insurance companies and discuss your problem with people well versed in medical insurance. Make sure you receive any policy explanations in writing.

Mail order firms with whom you have no personal contact have limitations precisely because it is difficult for you to know what you need without talking to an informed agent. Also, your local agent is your advocate in case there is a claim problem. The exception here may be plans with limited coverage, such as those offering, say, a limited amount for every week you are hospitalized. If you know that your child will be hospitalized for several weeks every year, you might want to take out such a policy in addition to your regular one for extra protection.

Consider the cost. If your medical expenses are going to be very high, if the cost of private insurance is also going to be very high, and your income is only moderate, you have three choices. Consider carefully the financial virtues of each.

1. Buy the insurance.
2. Change jobs so you can get a policy that will cover the preexisting conditions of your dependents.
3. Don't buy insurance and simply rely on government programs, such as Medicaid and your state's Children's Services, augmented by the help you can get from private agencies.

Getting the Most out of Your Insurance Policy

Simply being insured is not enough. You have to learn how to use the policy. Since you may have many and frequent claims, sometimes for extraordinary items, consider the following.

Withhold payment of the medical bill until you receive insurance payment if you are on a tight budget. If you explain your financial situation to your doctor, he or she may let you withhold all or part of your payment until you are reimbursed by the insurance company. The monthly statements from the physician's office will remind you to file your claims regularly and will draw your attention to any slow processing of your claims. Legally, you have to make only a small payment every month (as little as $1) to keep the bill collector at bay.

Work directly with one particular claims examiner. If you have many claims, you should deal with a person who knows your child's problems and who has the authority to help you. If your claims are not processed locally, you can try to find the appropriate person by mail, but it is usually faster and easier to call the supervisor of claims for your area and discuss your situation. (Place a collect call to the insurance company, stating that you are a customer. Your call will either be accepted or you will be asked for your number for a return call on their line. If this fails, dial direct, since that is cheapest.)

When you reach a knowledgeable person, explain your problem and ask if in the future you may send your claims directly to him or her. If so, the examiner will get to know the special problems of your child and be able to write instructions on your child's chart and enter the relevant information into the computer, thus greatly facilitating the processing of your claims.

If the company is slow in paying or rejects a claim, you can then call this individual and ask for help. Be sure to keep notes on telephone conversations about your child's claims, including the date, agents, and decisions reached.

Submit claim forms methodically. It saves time and effort if you ask all vendors of medical services to submit bills directly to the insurance company for you. However, many will ask you to pay and then submit your claim form to the insurance company for reimbursement. Have a separate "Claims Submitted" folder for each member of the family.

Fill out claim forms carefully. It is better to spend a few extra minutes to do so than to have the insurance company withhold payment because it needs additional information.

- Make sure you fill in every blank in the form.
- Make sure the form is submitted in the claimant's full name. For example, if your child's name is Belinda Elizabeth, she may be known in your community as Betsy, but the insurance company's computer will probably recognize claims only for Belinda Elizabeth Smith.
- Do not abbreviate anything. You may, for example, be tempted to write MS for muscular dystrophy or CP for cerebral palsy. If the same claims examiner does not always process your claims, the form may be returned to you for further information.

Make a copy of every claim form and bill you submit. If your forms are numbered and you are using carbon paper on an extra form for your own copy, be sure to write in the number of the original claim on your copy. However, some computers now assign a new number to a claim form when it is processed, rendering that original number useless to you and them. Your copy is important protection against loss of the original in the mail or by the insurance company; you will need it for your own reference when you receive claim payments.

Mark the upper corner of your copy with the initial of the given family member, numbering that person's claims consecutively. Your daughter Belinda Elizabeth's eleventh claim for the year would be numbered B-11. In this way you can easily keep track of any bills that are being held up. When your folders fill, these numbers are easier to refer to than the dates of the bills' submission. If, for example, you note that B-3 has not been paid but all others through B-10 have been, call your insurance supervisor collect and inquire about B-3. Sometimes claims get lost, in which case you will have to resubmit. Since you have a copy of the claim and the bills, this will not be difficult. Remember, you must always retain a copy so you can refer to or resubmit the information if necessary.

Keep a list of prescription numbers with names of the drugs in your folder. Often your receipts will list only the number of the prescription; however, the insurance company wants the drug's name. If you buy at only one pharmacy and have a charge account there, your complete monthly statement should include all prescriptions filled. If the statement lists only the prescription number, phone the pharmacist and add any new drugs with their numbers to your master list. This record will greatly assist your record keeping.

Don't claim too many different kinds of items on one form. If one item is rejected, usually the processing of the whole form is delayed. Even though the form is divided into two parts, such as health care services and prescriptions, fill in only one part. Although you will end up with more pieces of paper this way, by limiting how much you submit on each form you will ultimately simplify and expedite the processing of your claims.

Recording Claims Payments

Submitting a claim is only part of the task. Keeping track of the payments is equally important.

Start a "Claims Paid" folder for each family member. When you receive a payment, you will also receive information on how the claim was handled, often called the "Report to the Subscriber."

Be sure the claim number corresponds to the number on your original claim. If it does not, the computer may be assigning its own numbers, so check vendor, date, and cost.

Mark the report form with your code, say, B-11 and staple the report form to your copy of the original claim.

Indicate on the report form exactly what you did and when. For example, if you sent the insurance check directly to the physician, laboratory, or other vendor, note this, including the amount of the check, the vendor, and the date on which you sent it. If your insurance covers, say, 80 percent of the cost and a voluntary health agency has agreed to pay the outstanding 20 percent, send the agency a copy of the "Report to the Subscriber" with a letter reiterating the payment agreement previously reached and thanking them in advance for their assistance. This letter should then be placed in a special file for that specific agency.

Place the original claim, bill, and "Report to Subscriber," all stapled together, in your "Claims Paid" folder.

If you get a check that does not correspond to the total of any single submitted claim, the insurance company may have lumped items of different claims together. So try to add some items from another unpaid claim to the one indicated by the payment number. You may need to add up several different items to unravel the mystery. Also, some items will be paid 100 percent, while others will be covered only 80 percent, so you may have to try to figure out which items are fully covered and which only partially (and maybe even which were refused). If you are still baffled and can't solve the mystery, call your claims examiner.

Questionable and Rejected Claims

Learn what to do with rejected claims. The principle is never to take no for an answer if you think your claim is valid. Even if your child needs some unusual items, you should try to get the insurance company to pay for them. If you know when you originally submit the claim that an item may not be covered, attach a letter from your physician indicating why the item is vital for your child's medical care. If you neglect to send this cover letter and payment for the item is rejected, ask your doctor to write a support letter and send it to the supervisor, requesting that your claim be forwarded with this letter to the company's medical review board, which considers unusual claims. Since it is always difficult to get people to change their minds once they have said no, it is best to supply all convincing information when any extraordinary claim is first submitted.

Letters must be as forceful as possible. Since doctors are busy people, they do not always write long, informative letters. Therefore you may be able to work out an arrangement with your doctor whereby you provide a list of salient points, or you may even draft a letter that your doctor can then edit and have retyped on his or her letterhead. This is not being devious. Rather you are saving your doctor time and ensuring that the request has the best possible chance of being honored the first time you make it.

A questionable item is something not commonly used for medical purposes, such as a whirlpool bath, or something not purchased from a regular medical vendor, such as cleaning solution for medical equipment. If you can prove that you need the item for medical purposes, or that you can get it cheaper from a nonmedical source, the insurance company may pay for it.

VOLUNTARY HEALTH AGENCIES

After you have discovered which expenses can be defrayed by government agencies and medical insurance, if you still have more medical expenses than you can pay yourself, consider voluntary health agencies. These are established to help individuals with special needs; they vary greatly in what they can and what they are willing to provide. Since their help can be invaluable, we should indeed be grateful to them. But in case you have the impression that they simply give away money, you should be aware of how they function.

Although people working for voluntary health agencies usually genuinely desire to help, they may not understand your economic straits. Also, since these agencies work very hard to raise their money, they are usually very cautious about how it is spent. Persons in charge of fund allocation are held accountable for how they spend that money. They have budgets and bookkeeping procedures to follow that do not allow for maximum flexibility. Also, sometimes an agency will want to show the public that it is indeed helping needy individuals, so it will stress public-service projects, such as supplying a taxi van for the disabled, because this generates much more publicity and community support than providing orthopedic shoes. This is not to say that one item is more important than another but to indicate that it is sometimes difficult to get help for direct services (assistance given directly to specific persons for their individual medical needs).

Some agencies are a joy to work with; others can be extremely difficult. However, an agency is established to aid needy individuals, and you can provide it with the opportunity to assist.

Discovering which agencies can help you is not always easy. Begin by contacting all agencies that might be even remotely interested in your child's problem. All agencies provide a variety of information services, including advice about other groups that may be able to help you. While some agencies provide direct financial assistance, it is usually only for certain items or services. Therefore you may come to rely on a number of organizations for different services and funding.

Contacting the agency is the first step toward receiving assistance. Sometimes a doctor or social worker will refer you to an agency. Ordinarily you have to make contact yourself. Usually it is best to telephone the agency first to see if it can indeed help with your child's needs. At some point, personal contact must be established. Sometimes its social worker will make a home visit, in which case it is much easier for you to show him or her your living situation, your child, and your child's medical needs. If no one from an agency wants to come to you, try to take your child to the agency at least once so the personnel will know you both and have a better understanding of why you are making your request.

Financial need is usually the criterion for assistance. While a few agencies will pay for any "standard" item for someone with the designated disability or illness, regardless of your financial need (for example, the Muscular Dystrophy Association of America will buy wheelchairs), most agencies will want to assess your financial situation. If you think you have a legitimate need, it is your responsibility to prove it. Often you will have to fill out a standard form that may not clearly depict your financial situation. So feel free to add any information you think is relevant.

The actual request is your opportunity to convince an agency that your need is reasonable. Since agencies must respond to written correspondence, even if you discuss the matter by phone, make every request in writing (typed if possible), clearly and concisely stating your child's medical need and backing up your request with a written prescription or a letter from your doctor. Again, since not every doctor has the time or interest to write as complete a letter as you might desire, you will be doing both yourself and the doctor a favor by writing down all the relevant details and conveying them to your doctor in person or by mail, or at least dictating the information to his or her secretary over the phone. As mentioned before, your doctor may not mind if you draft a letter for editing. Remember, a good letter may convince the agency to help you.

Unusual requests will arise if your child has extraordinary needs. Examples of such requests, which must be convincingly made if payment is to follow, fall into three main categories:

1. *Items routinely or frequently rejected by insurance companies,* such as hearing aids or orthopedic shoes, are readily paid for if you can find an agency addressing itself to persons with that particular disability and need. However, there are other items, such as a whirlpool bath, which are requested infrequently and for which the medical

need could be considered questionable. In this case, if you can convince the insurance company to pay 80 percent (see page 236), a local agency may agree to pay the remaining 20 percent.

2. *Items no one ever paid for before* can be submitted. If your child needs unique items, perhaps made especially for you by a nonmedical person, you may be able to convince a local agency to pay for these.
3. *Costs of maintenance and repair of equipment* may be covered by whoever paid for it originally. So if the insurance company paid 80 percent of the purchase price of a piece of equipment and an agency paid 20 percent, you can try to get the same split for maintenance and repair. You can probably convince the insurance company and the local agency that the maintenance and repair of equipment your child uses regularly are ongoing costs and it is cheaper to help with this than to replace the equipment.

Retroactive requests are disliked by most agencies because they cannot carefully analyze whether the request is justified. In addition, an agency may feel pressured to provide financial assistance for an item a family has already purchased and doesn't feel it can pay for itself. An agency greatly prefers that you have prior medical authorization for all expenditures and that the requests proceed (often at a snail's pace) through the appropriate channels. Unfortunately, you are not always able to perceive needs in advance. For example, in an emergency, you need additional equipment immediately, not three weeks later after the appropriate committee has met and the board has given approval. Sometimes equipment can be rented, with the first month's rent deducted from the purchase price. This gives you 30 days to find the money. In other cases you may have to buy the item and then start the laborious process of finding someone to pay for it.

Special funds may be established by an agency if you are constantly coming up with unusual requests, often of a retroactive nature. With strong support from your physician, you may be able to work out an agreement with an agency to set up a special fund allowing a certain amount of money per year for your child's care. This way you will not have to send in a physician's support letter for every request. Such a fund could cover any amount not covered by your insurance (while it is, of course, understood that only a certain sum is available). Payment will probably be made the charity directly to the vendor upon receipt of the bill from you, without your needing to establish the legitimacy of each item. This arrangement saves time and effort for your doctor, the agency, and you.

Refusals are not uncommon. Despite all your carefully planned efforts, you may find that getting an agency to part with its money is very, very difficult.

If you get annoyed about the refusals you are sure to encounter, it is hard on you and your family and this won't help establish a good working relationship with the agencies whose assistance you really need. Keep smiling, and remain determined and persuasive. Polite insistence can work wonders.

Keeping records is vital when you are successful in getting assistance from agencies. Begin by starting a folder for each agency and keeping in it a carbon or photocopy of any correspondence or bills submitted to that agency, using a numbering system as with insurance, where B-1-CP would indicate the first claim to the United Cerebral Palsy Association for your daughter Belinda Elizabeth for that year. Also add to your folder any notes of telephone conversations. Keep careful track of bills submitted and bills paid, especially if the agency pays a vendor directly for services for which you have been billed. Computers often get very confused when an agency, rather than the individual, sends money and doesn't clearly indicate whose account should be credited.

Give thanks for any help received from an agency. It's a good idea to write thank-you letters (keeping copies in the agency's folder), since correspondence is often read at board meetings. A carefully drafted letter will help board members better understand the needs of individuals such as your child. Even if you have had extreme difficulty in getting help from a particular agency, you should still be polite to have the strongest effect. Factual information such as the date of the request and the final date of assistance received will indicate an excessively slow pace without your pointing this out specifically.

Official complaints are sometimes necessary. If you think that an agency is running a particularly abysmal show and that the needs of other children are not being met either, complain. If only your requests are being turned down, try to figure out why.

Complaints can be lodged with whoever is next up the line in the agency from the person with whom you are experiencing difficulty. If a committee reviewing your request moves very slowly, contact the director. If the director is incompetent, contact the chairman of the board. However, since incompetence is a serious accusation, be sure that it is not just a personality conflict but that the director's brusque and rude manner, tardiness in returning phone calls, etc., make it difficult for many members of the community to work with this individual and that the agency's image is being tarnished. Since you are trying to help people understand and empathize with the needy, have factual information to support any complaint, and proceed with tact. If you think insufficient monies are being spent on direct services, substantiate your claims with a review of the actual expenditures of other nonprofit organizations, which must be open to the public.

You can follow up a series of telephone complaints with a carefully drafted letter if you really feel the agency is not serving the needs of the community. If you proceed tactfully, your action should not adversely affect your future requests for assistance. Any responsible board will want to know of any serious, unwarranted difficulties a client encounters.

Becoming a board member has pros and cons. Through board or committee membership you can express gratitude, help others, and learn how such organizations function. But active participation takes time and energy—sometimes nervous energy if the agency is poorly run. You will have to decide if you can learn enough and be effective enough to make being a board member worthwhile at this time, particularly if caring for your child is very demanding.

Interagency meetings can be arranged if your child has high medical expenses and receives support from different agencies. Your social worker may coordinate work among agencies, but you know your child's needs best and are therefore often his or her best advocate. If you think a meeting including you, your physician, and representatives of the agencies that are (or that you would like to have) involved in your child's care may be helpful, discuss it with your doctor. If he or she thinks it is appropriate, let your doctor choose the meeting date and then arrange the meeting yourself, unless you have a competent social worker to do it for you. You might try to have such meetings at your house so the people can meet your child and see how he or she lives and what he or she needs. Since the main purpose of such a meeting is to establish one's financial need, and a parent can often do this best, always prepare a comprehensive financial statement (with copies for everyone) so each participant can see how much financial assistance you need and who is contributing in which areas. A sample statement is shown in figure 17-1.

Creative Financing Through Friendly yet Forceful Persuasion

Sometimes, in spite of your best efforts, you may see your child's medical bills mounting, with no way to pay them. At that point, you may need help from someone in your community or at the state level who has learned how to develop and present a comprehensive plan of an individual's financial needs to insurance and/or governmental agencies in such a way that the package is irresistible. For example, say a ventilator-dependent child who is hospitalized for $40,000 a month could be cared for at home for about $2,000 a month. And if it placed these funds into an interest-earning account, within three years the interest would pay for any continuing home care for the child. Who could resist that? And if there is no way to show irresistible savings, then one can still appeal to the finer humanitarian qualities in people. If, for example, your child has almost reached his or her lifetime insurance limit, the directors of the insurance

MEDICAL EXPENSES FOR BELINDA ELIZABETH SMITH, 1985*

	EASTER SEAL	MUSCULAR DYSTROPHY	REGIONAL CENTER	VISITING NURSES	SMITH FAMILY
Physicians					
Pediatrician					
Chiropractor					
Orthopedist					
Radiologist					
Respiratory diseases specialist					
Rehabilitation medicine specialist					
Pediatric dentist					
Laboratory work					
Prescriptions					
Food supplements					
Vitamins, protein powder, etc.					
Equipment					
IPPB machine					
Emergency bed alarm					
Wheelchair repair					
Orthopedic equipment					
Leg splints					
Body jacket					
Registered nurses					
Paramedical assistance					
TOTAL					

*[illegible] Projected Expenses, 1985

†Items not covered by insurance. All other amounts listed are the 20% not covered by insurance

Figure 17-1 Sample financial statement

company certainly wouldn't want you child to go without the health care he or she needs, would they? If carefully presented proposals fall on deaf ears, it is always possible to appeal to the public by getting the media to present your case to the people after you have told officials involved in providing financing for your child's care that unless some progress can be made by a certain date you do think the individuals in your community should be made aware of the problem. After all, the media are always looking for human interest stories and are happy to help individuals get the services that they truly need.

Some creative doctors and directors of state children's services have always managed to get their children the services they need; you can too.

PLANNING FOR THE FUTURE

Life Insurance

Unless you have a large extended family or group of friends who can financially help you in case of need, consider life insurance, if the premiums are not too high.

You may want to buy life insurance for both parents, for if your child requires a great deal of nursing care and one parent dies, the other parent will either have to stay home or hire someone to do so while he or she goes out to work.

There are both private and group life insurance plans. Group plans are cheaper and less likely to have preexisting-conditions clauses that exclude anyone with a known medical problem of a serious nature. Sometimes there are modified preexisting conditions clauses indicating that the policy will pay after a person has been enrolled for a certain length of time, such as two years. Preexisting-conditions clauses are meant to prevent terminally ill persons from taking out large policies right before their deaths.

Carefully consider if you want to insure the father, mother, or both and whether you can insure dependents. Since many family plans do not have preexisting conditions clauses for children, such insurance could be valuable. If your child has a progressive illness and you buy life insurance for him or her, you may pay premiums for years. But if your child does die, any life-insurance payments could help offset medical expenses you incurred.

Wills and Trusts

Every parent should have a will. This is especially true for parents of an ill or disabled child. Two important factors in your will will be who will be your child(ren)'s legal guardian and what will happen to your estate.

Any will should be drafted by a competent attorney who has experience in this specific type of estate planning.

A legal guardian is necessary for any minor. If your son or daughter is now unable to care for himself or herself and will probably continue to be unable to care do so as an adult, it is vital to make provision for your child's care should both parents die. To ensure that your child remains in a family and is not institutionalized, see if a close friend will agree to be designated as legal guardian of your children and estate. (Usually both of these responsibilities are delegated to one party unless you have a very large estate.) If you don't ask your friends if they would be willing to be legal guardians, your child could become a ward of the state after your death.

If your child is living at home, you might want to make an agreement with another family, recorded in the wills of both, that if the parents in one family die the other family will become the legal guardians of any surviving children and take them into its home. If your child is not living at home, he or she will still need a legal guardian until he or she comes of age.

The inheritance of your assets is the other factor to consider. If you do not have a will, any family assets will be divided equally among the surviving children. However, if your disabled child, either intentionally through your will or unintentionally through your failure to make a will, inherits assets having a value in excess of an amount specified by the government (presently $1,500) he or she will no longer be eligible for Supplemental Security Income. This can be very important if your child is very ill or severely disabled. In the absence of SSI qualification, it is often extremely difficult to qualify for any of the other state and federal benefit programs. The money provided in your bequest or gift to your disabled child may be totally insufficient to meet his or her needs, but those funds will have to be exhausted to the dollar limit before eligibility can be reobtained. This means that if you leave your child assets, either through a poorly planned will or through lack of planning, your child may be denied services for which he or she would otherwise be eligible if only the disability were considered. Therefore carefully draft your will so some portion of your estate can supplement the government benefits without disqualifying your child for those benefits. The key to financial eligibility for government benefits is the "availability" of the funds to your child. If the assets are put in a properly worded trust for your child, he or she is not considered to *own* them; rather, the assets in the trust are used to supplement other assets owned by the beneficiary or in which the beneficiary may have some interest. In other words, it should be clear that the trust is not intended to provide primary support for the ill or disabled person. The trustee (the person who manages the assets) should have complete discretion to determine when and if the beneficiary needs any supplemental services or programs. Payments that are made from the trust go directly to the persons who supply goods or services to the beneficiary. A "spendthrift" program should be included in the trust, indicating that the beneficiary has no ownership interest whatsoever in the assets placed in the trust. You can also name someone to receive the funds when your disabled child no longer needs them. A provision can even be included that would require a distribution of the remaining assets in the trust to a nondisabled family member in the event that the state brought litigation against the trust or refused to provide benefits to the disabled beneficiary because of the existence of the trust. You might contact your local association for mentally retarded persons to get the names of reputable lawyers who are well versed in the pertinent state and federal laws and who have experience in setting up such trusts and wills.

Even if your child is not so disabled as to require careful estate planning to ensure any needed government services, remember that if you do not set up a trust your child will receive his or her total inheritance upon coming of age. A trust may be appropriate if you want to give guidance for the allocation and use of funds after your child comes of age.

CHECKLIST OF INFORMATION HELPFUL WHEN APPLYING FOR SSI BENEFITS

1. Birth certificate of child
2. Bank Statements of parents (and statement of child, if he/she has a bank account)--Bring the most recent two
3. Statement of savings account of parents (and child, if applicable)--Bring most recent one
4. Description, including value, of any stocks or bonds
5. Description, including face value, of insurance policies
6. Record of any wages earned by either parent (the latest pay stub)
7. Evidence of ownership for a home or other building or dwelling
8. Evidence of ownership of a motor vehicle
9. Any medical reports, school testing reports (with IQ scores) or any other reports from doctors, psychologists, hospitals, etc.

NOTE: A statement from a physician which says "This person is disabled" is NOT enough.

Medical Information
Needed for SSI Interview

1. Any special testing done to assess your condition, where done and when done.

   A. "Special testing" can include: EKG (electrocardiogram), Chest x-ray, x-rays of any other body part, breathing tests, blood tests, EEG (brain wave), intelligence or personality tests or others).

2. The name, address and phone number of the doctor(s) who has treated you since your illness began <u>and</u> those who have your most recent medical records.

3. The name and address of any hospital or clinic where you have been treated and <u>when</u> you were treated there.

4. The place(s) where you've worked, the approximate dates you worked at the place and a general description of the work you did.

   NOTE: This applies only to people old enough to have been eligible to work.

5. A list of other agencies which may be helping you (County or State Welfare, Vocational Rehabilitation, etc.)

6. A description of the way the impairment or illness limits activity (does it confine the person to a wheelchair, bed, limit activities in any way).

Checklist of Information Helpful When Applying for Aid to Dependant Children (ADC) or Aid to the Aged, Blind & Disabled (AABD)

1. Birth certificates for all family members. If you are pregnant, you will need a doctor's statement verifying the pregnancy and indicating an approximate due date.
2. Identification, other than birth certificates, for all family members (i.e. drivers license, clinic cards, immunization records, report cards, library cards, etc.)
3. Social Security cards for all family members (If you do not have these, they will help you apply for them when you have your initial interview.)
4. All pay stubs for the last three months.
5. Verification of any other resources: Social Security, Veteran's Benefits, Workman's Compensation, Unemployment Compensation, Railroad Retirement, Indian Lease Land, Alimony, Child Support, Savings Bonds, Stocks, Property Tax Statements, Motor Vehicle Registration etc. (Either the letter, or document, or a copy of the check received.)
6. Most recent checking and/or savings account statements.
7. Bring in all health and life insurance policies (description and face value) for all family members.
8. Rent or mortage payment verification.
9. Current utility bills or receipts.
10. Marriage and/or divorce verification. (License or decree.)
11. Information on all absent or deceased parents of children (i.e. Social Security numbers, address, employer etc.) For ADC you must prove the father is not in the home, by statement from landlord, neighbors, etc.

All information given will be held in strict confidence.

MEDICALLY HANDICAPPED CHILDREN'S PROGRAM (MHCP)
NEBRASKA DEPARTMENT OF SOCIAL SERVICES
Title V Program

INFORMATION SHEET

Diagnostic and treatment services within the scope of medical coverage are provided when they are prior authorized by Medically Handicapped Children's Program (MHCP). Services must be provided by a current Medically Handicapped Children's Program contract vendor. Hospitalization is provided at hospitals where the Medically Handicapped Children's Program primary physician directly supervises the treatment. Some secondary care may be provided at other hospitals when it is part of the treatment plan recommended by the primary physician and approved by the Medically Handicapped Children's Program.

Custodial and acute care are not covered.

Clinics are operated by the Medically Handicapped Children's Program and appointments are made through the offices in Lincoln, Omaha, Grand Island, and Scottsbluff.

The preferred method of referring a child is through a physician, since this method usually provides more accurate and detailed medical information. Referrals may also be made by the parents, the local Social Service Office, or other persons or social agencies. Physicians may obtain Referral Forms (CC-110) from their Social Service Office or may refer by a letter including their findings, diagnosis, and recommendations.

Determination for individual care is based on a child's diagnosis, medical treatment plan, and the family's ability to pay for the cost of the medical care. Program coverage is as follows:

1. Orthopedic Program: General Orthopedic Care

   Coverage is provided for general orthopedic problems, congenital or acquired, excluding recent, non-complicated fractures.

   Services for hemophilia (caused by deficiency of antihemophilic globulin: Factor VIII) are provided by a hematologist.

   Services may include diagnostic evaluations, consultations, active treatment, x-rays, pathology, hospitalizations, braces and appliances and their maintenance, crutches, walkers, shoes with corrections, and limited physical therapy.

   Wheelchairs, stand-up tables, and sick room equipment are not provided.

Care is provided through contracted Orthopedists' offices located in Scottsbluff, North Platte, Kearney, Grand Island, Hastings, Lincoln, Norfolk, and Yankton, South Dakota, and orthopedic clinics held in Lincoln, Omaha, and Ainsworth.

2. Specialized Orthopedic Programs

Clinic Service

Scoliosis Clinics: Lincoln and Omaha

Rheumatoid Arthritis Clinic: Lincoln

3. Cerebral Palsy Program

All services provided are supervised by a multi-disciplinary consultation team.

Services may include general orthopedic care, and neurological care, including hospitalization, psychological evaluations, general anesthetic dental services for severely involved children, limited physical therapy, and occupational therapy.

4. Heart Program

Diagnostic and follow-up services are provided only through Clinics at the University of Nebraska Medical Center, Omaha, and outstate consultation Clinics held in Scottsbluff, North Platte, Cozad, Grand Island, Lincoln, and Norfolk. Surgery is provided only at the University of Nebraska Medical Center. Limited hospital and outpatient care is provided by private pediatric cardiologists in Omaha and Scottsbluff.

Services may include prophylactic drugs, x-rays, and pathology.

On occasion, certain complicated cardiac surgery is provided at a partially Federally funded regional center, at the Mayo Clinic in Rochester, Minnesota. This must be recommended by a contracted pediatric cardiologist and approved by the Medical Director. The application is made by the Medically Handicapped Children's Program.

5. Cystic Fibrosis Program

Diagnostic and treatment services are provided at the University of Nebraska Medical Center and at two Clinics held in North Platte each year. A consultation clinic team supervises care provided.

Services may include drugs, nebulizer machines and pathology.

6. Mid-Line Neurological Program

Diagnostic and treatment services are provided for congenital or acquired mid-line neurological conditions, principally hydrocephalus, myelomeningocele, and tumors. A multi-disciplinary consultation Clinic team supervises all care provided.

Services may include diagnostic evaluations, consultations, active treatment (pediatric, neurologic, urological, and orthopedic), x-rays, pathology, hospitalizations, braces and appliances and their maintenance, limited physical therapy, and limited drugs.

7. Oral Plastic Program

A Medically Handicapped Children's Program consultation Clinic team supervises all care for children with oral plastic conditions, including cleft lip and/or cleft palate and maxillofacial defects. Orthodontic treatment, and routine dental care which is not associated with the above conditions, is not covered.

Clinics are held in Lincoln, Omaha, and North Platte. A consultation Clinic team is composed of the following specialists: plastic surgeon, pediatrician, speech pathologist, otologist, psychologist, pedodontist, orthodontist, prosthodonist, and dental hygienist.

Surgery is provided in Lincoln and Omaha.

Eligible dental and orthodontic care is provided by local dentists and orthodontists.

Other services may include speech therapy, care for hearing loss including hearing aids, x-rays, and pathology.

8. Eye Program

Coverage is restricted to eye conditions amenable to surgery, such as esotropia, exotropia, strabismus, ptosis, and congenital cataracts.

Diagnostic and follow-up evaluations are provided through offices of contracted ophthalmologists in Lincoln, Omaha, Hastings, Grand Island, Columbus, Kearney, Scottsbluff, and through Clinics in Lincoln and Omaha.

9. Hearing Loss Program

Diagnosis and treatment, including hospitalization, are provided for children who have a hearing loss or a condition which may result in a permanent hearing loss.

Services may include hearing aids and maintenance, audiological services.

Physicians' office services are provided by contracted otologists, in Scottsbluff, Kearney, Hastings, Lincoln and Omaha. Consultation Clinic services are provided in Lincoln, Omaha and at outstate Clinics.

10. Neoplasm Program

Coverage is provided for neoplasms, including leukemia and lymphomas. Neoplastic growths may or may not be malignant, but must be crippling or potentially crippling.

Services may include physicians' services (hematologist, pediatrician, surgeon) for both diagnosis and treatment, hospitalizations, x-rays, pathology, and treatment drugs.

Primary care is provided by the Medically Handicapped Children's Program contracted hematologists in Lincoln and Omaha, as well as through the Oncology Departments at the University of Nebraska Medical Center, the University of Creighton Medical Center, and the Children's Hospital in Denver, Colorado.

11. Asthma Program

Coverage for severe, chronic asthma is provided by contracted pediatric allergists in Lincoln, Omaha, and Scottsbluff, as well as local care provided by the family physician under the supervision of the pediatric allergist.

Services may include pathology, x-rays, limited drugs, cardiopulmonary studies, hospitalizations, and desensitization injections.

12. Major Medical Program

Coverage is provided for medical diagnoses determined as chronic, prolonged, and crippling or potentially crippling in need of active treatment.

Primary care is arranged by the Medically Handicapped Children's Program with contracted physicians who are boarded or board eligible in the specialty directly related to the diagnosis.

Subclassifications are as follows:

a. Prematurity

Determining factors are birth weight, gestational age, and the need for active treatment. Hospitalization only for acute care or weight gain is ineligible.

Hospitalization is only covered at Medically Handicapped Children's designated Intensive Care Units, which currently are: St. Joseph Hospital, University Hospital, Children's Memorial Hospital, and Archbishop Bergan Mercy Hospital, Omaha; St. Elizabeth Community Health Center, Lincoln; St. Francis Hospital, Grand Island; Mary Lanning Hospital, Hastings; Good Samaritan Hospital, Kearney; Great Plans Medical Center, North Platte; West Nebraska General Hospital, South, Scottsbluff; Sacred Heart Hospital, Yankton, South Dakota; and the Children's Hospital, Denver, Colorado.

b. Burns

Determining factors are the degree of the burn and the percentage of the body surface burned.

Hospitalization is covered at St. Elizabeth Community Health Center, Lincoln, and at Children's Memorial Hospital, Omaha.

c. Neurological

Diagnoses may include seizures, subdural hematoma, encephalocele, and Guillain-Barre syndrome.

Primary physicians must be pediatric neurologists. Coverage includes pathology, limited drugs, and hospitalizations.

d. Genital-Urological

Diagnoses may include bilateral ureteral reflux, extensive hypospadius, and ambiguous genitalia.

e. Gastro-Intestinal

Diagnoses may include cystic hygroma, esophageal atresia, Hirschsprung's disease, imperforate anus, massive ischemia bowel, omphalocele, and tracheo-esophageal fistula.

f. Hematologic

Diagnoses may include systemic lupus erythymatosus and sickle cell anemia.

g. Respiratory-pulmonary

Diagnoses may include broncho pulmonary dysplasia, pulmonary fibrosis, and subglottic tracheal stenosis.

h. Metabolic

Diabetes is a covered diagnosis for which hospitalization is provided. Other metabolic disorders may be covered upon review of the Medical Director. These conditions may include conditions of the thyroid, pituitary, thymus and adrenal glands.

i. Other anomalies

Other diagnoses requiring major, chronic care will be considered for medical eligibility.

13. Screening Program

Screening evaluations are provided at Norfolk, Ainsworth, and Chadron area clinics, only. Children may be referred for conditions related to program coverage. Any child may be evaluated once without charge to determine medical need and eligibility. All other screening referrals are handled by appointment through local pediatricians.

The Medically Handicapped Children's Program will refer children from the Screening Clinic or pediatrician's office to other Medically Handicapped Children's Program specialized Clinics, as appropriate.

14. Genetically Handicapped Program

L.B. 989 of 1980 allows the Medically Handicapped Children's Program to administer Medical Services to individuals over 21 years of age with a diagnosis of Cystic F[illegible], Hemophilia, and Sickle Cell Anemia. Specific coverage [illegible]mined by available funding based on priorities found in State [illegible]ation. Persons referred to the Medically Handicapped Children's Program must meet the same eligibility requirements as for all other Medically Handicapped Children's Programs.

Cystic Fibrosis

Diagnostic and treatment services are provided at the University of Nebraska Medical Center, as well as through contracted physicians specializing in pulmonology.

Services may include drugs, nebulizer machines, pathology, and hospitalization.

Hemophilia

Services for hemophilia (caused by deficiency of antihemophilic globuline: Factor VIII) are provided by a hematologist.

Services may include diagnostic evaluations, consultations, active treatment, x-rays, pathology, and hospitalizations.

Sickle Cell Anemia

Services are provided by a hematologist and coverage may include hospitalization, pathology, and outpatient evaluations.

15. Educationally Related Therapy Services

This is a coordinated program developed by the Nebraska Department of Education, Special Education Branch; and the Medically Handicapped Children's Program; to provide educationally related physical and occupational therapy services to handicapped students in Nebraska.

Any child who may need physical therapy and occupational therapy services must be referred to that child's local school district. Children are referred to the Medically Handicapped Children's Program for entry into this program by the local school system only.

Services consist of assessments provided by the Medically Handicapped Children's Program through a network of clinics throughout the State; Physical Therapy, and Occupational Therapy.

16. Home Parenteral Hyperalimentation

This program is coordinated through the University of Nebraska Medical Center, Department of Pediatric Gastroenterology, to provide for the treatment of infants whose digestive system cannot absorb sufficient nutrition for survival.

Diagnoses eligible for this program include short bowel, intractable diarrhea and Crohn's disease.

Services are provided for those children receiving treatment in their own, or substitute home and may include: infusion pumps, catheters, intravenous infusion systems, laboratory studies, monitoring medical care and parenteral nutrition fluids. Inpatient hospital care is not covered under this Program.

Financial Eligibility

If a child is determined medically eligible for any of the above programs, a family's ability to pay for the cost of specialized medical treatment must be determined prior to commitment for payment by the Medically Handicapped Children's Program.

Civil Rights

The Medically Handicapped Children's Program is administered so that no person is excluded from participation, is denied the benefits of, or is otherwise subjected to discrimination because of race, color, national origin or on the basis of handicap. Each individual has the right to apply, and be considered for the same aid, care, services, and other benefits which are provided by the Social Service agency or by other agencies, organizations, institutions or individuals with whom arrangements have been made for services, regardless of race, color, national origin or handicap.

An individual may file a complaint with the local or State Social Service Office or the Federal Department of Health and Human Services whenever discriminatory conditions or practices are felt to exist, and will obtain prompt and just consideration and action on the complaint.

Grievance and Appeal

An adult applicant, a parent or guardian of a child, or the representative of an adult who is dissatisfied with any action with regard to the furnishing or denial of services may file a formal grievance within 90 days of that action. The resulting grievance decision may be appealed (not to include decisions specifically related to a medical eligibility or treatment plan decision) within 90 days with a request for a fair hearing within the guidelines of the Nebraska Department of Social Services fair hearing regulations.

APPENDIX D

GETTING CHILDREN HOME: HOSPITAL TO COMMUNITY

NEWS DIGEST ISSUES FROM NATIONAL INFORMATION CENTER
FOR HANDICAPPED CHILDREN AND YOUTH

CHILDREN WITH HANDICAPS, PARENT AND FAMILY ISSUES: A GUIDE TO READINGS

PSYCHOLOGICAL TESTING OF CHILDREN WITH DISABILITIES

ALTERNATIVES FOR COMMUNITY LIVING

WORKBOOK SERIES FOR PROVIDING SERVICES TO CHILDREN WITH HANDICAPS AND THEIR FAMILIES

GETTING CHILDREN HOME: HOSPITAL TO COMMUNITY

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Prepared by Georgetown University Child Development Center for the Division of Maternal and Child Health under Grant #MCJ-113368-01-1, Project Director, Phyllis R. Magrab, Ph.D.

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TO THE PARENTS AND CARE MANAGERS

Fortunately, times and attitudes change in health care. For decades the pediatric community believed that severely disabled children could be cared for only in an acute-care hospital or in an institution. Now we have realized that the least restrictive environment, usually the child's own home, is the best locale for the child. This workbook, intended for parents, care managers, and all those dedicated to health care is about Getting Children Home: Hospital to Community.

Until recently many severely medically involved "high tech" children were "institutional cases" because of their highly specialized medical needs. The 1980s have made the health-care professionals increasingly aware of the plight of severely handicapped youngsters and their families. The term "least restrictive environment," once thought to be the concern only of educators of handicapped children, is the concern of the pediatric community as well. The conceptual model presented in this workbook is an effort to provide a map for the journey from primary diagnosis to in-home care. The pilot for this journey is a professional care manager who has learned the critical components of service planning and community involvement. The manager can assist the parents to participate in planning for the child.

The journey from the primary diagnosis to home can be long and tedious--yet distinguished by landmarks only the child and his family can truly appreciate. This workoook is a roadmap and a time schedule for the journey. The first section outlines the three phases from initial planning to the placement in the home. The next section outlines the roles of various guides and pilots of the journey. The third section details the actual map, or discharge plan and home care plan. The final section centers upon using the community resources--the gas stations and repair shops--which help during the trip and especially after the journey is complete and the child is at home. Throughout, the workbook incorporates checklists, charts, diagrams. and sample documents to aid you--the parents/care managers.

THE THREE PHASES IN PLANNING FOR HOME/COMMUNITY DISCHARGE

There are three consecutive and distinct phases in the journey; each takes the child and family closer to a successful return home. Each phase can be understood in terms of:

- Its goal
  - The key players and their roles
    - The major activities needed for successful completion of that phase

Phase I

The first phase consists of appropriate identification of the candidate for in-home care. The assessment of the child and his/her total environment should ordinarily include the child's Parents, the primary medical specialist or attending Physician, the Interdisciplinary Team, and the Care Manager.

GOAL: Evaluation of the candidate for home care

Phase II

After the child has been identified as a candidate for discharge from the medical (institutional) facility for in-home care, the task is to identify specific objectives, service providers, funding sources, etc., necessary to realize the child's in-home placement. This phase requires careful analysis by the Care Manager and the child's Parents, and all plans must be double-checked to assure that all objectives are met before the child's discharge. During this phase, the Discharge Plan is developed and implemented and the Home Care Plan is designed.

GOAL: Drawing up Discharge and Home Care Plans

This phase is crucial in planning for the discharge and home care. The major conceptualization, scheduling, and analysis must take place in this phase BEFORE the child comes home.

Phase III

The final phase begins as soon as the child is discharged from the medical facility to a family home. Then the Home Care Plan is fully implemented, services to the child and his/her family are in place, and maintenance at home begins.

GOAL: Discharge from the institution and implementing the Home Care Plan

SECTION II

THE KEY ROLES

The journey from hospital to home requires the interaction of many people. While "the crew" varies with each child, several key positions will always need to be filled--and their tasks assigned--to make the trip home a pleasant voyage. The major participants are the child's Parents (or legal guardian), the primary Physician, the Care Manager, the Interdisciplinary Team, and the Community Support Services personnel.

The Parents

The definition of Parent includes mother and/or father, or the child's court-appointed legal guardian--the person who has legal responsibility for the child's care, support, and protection. In most cases, the child's Parents will be actively involved in the Care Plan, but many severely disabled children are under the guardianship of public and private welfare agencies because of the inability or unwillingness of the child's parents to assume the responsibility for the child's care and support. In such cases the child will probably have a social worker representing the guardianship agency. This agency must be involved in approving and coordinating the child's discharge.

During Phase I, the Parents are both participants and subjects in the assessment process. Professionals will evaluate the Parents' interest and overall ability to care full-time for their child at home. The limit of the focus of attention in this phase should not be the stability of the child's condition or the feasibility of maintaining the child outside a specialized facility. The child's family must participate in determining their ability to cope with the many adjustments of full-time caring for the child at home.

Along with the Care Manager, the Parents must be actively involved during Phase II. They will help to identify the needed services and supports necessary to achieve in-home care. The parents must be involved not only in the development of the Home Care Plan, but in its implementation. When the child enters the home, Phase III, the Parents begin to assume more and more responsibility for the care of the child.

GUIDELINES FOR PARENTS*

1. Get as much information as you can about the child's disability. Talk to professionals; search for the most recent books, brochures, and articles. In the interest of your child, you are on your way to becoming an expert.
2. Ask questions about where your child's condition is NOW. Avoid being discouraged. Remember that there are changes and advances in research, services, and legislation.
3. Keep a written record of all conversations and information given to you by experts.
4. Think of how you will budget your time to meet the needs of your child, your spouse, your other children, your extended family, your friends, and YOURSELF.
5. Persuade gently. You are your child's primary advocate. Remain polite, but firm. Insist on your right to be included in all decisions.
6. Listen to your child. His/her point of view is paramount, and he/she is the real expert in this area.
7. Talk to other parents who have shared similar experiences.

The Physician

The Physician has both primary medical responsibility for the child and is key in the discharge planning process. Usually the child's doctor will first recognize the possibility of moving the child from hospital to community. Thus the Physician is actively involved during Phase I in determining a candidate for home care.

During Phase II, the Physician remains responsible for the child's overall medical care during development of the Discharge Plan. The Physician will usually have the most active role in identifying equipment and related medical needs to be included in the Discharge and Home Care Plans. The Physician must give medical approval to the plan prior to discharge. During Phase III, the Physician continues to assume responsibility for monitoring medical care.

The primary care Physician in the hospital will not necessarily be the doctor who eventually takes care of the child in the community. For example, the neonatologist--in conjunction with another hospital pediatrician--may be involved in the decision to send an infant home. In most instances, more than one physician will be involved. Hospital-based physicians or sub-specialists may have primary responsibility for in-hospital care in Phase I, while in Phase III a community-based physician may be responsible for the child's ongoing medical care. It is important that all of the physicians work together effectively in order to insure the effective Discharge and Home Care Plans.

The Care Manager

The Care Manager is a trained professional (usually a social worker) responsible for writing, coordinating, and implementing the Home Care Plan after the child's discharge. The coordination is all important to avoid duplication of efforts and service gaps in the Discharge or Home Care Plans. In Phase I (the determination of a candidate for home care), the Care Manager may be an inactive participant, but his/her knowledge of existing and potential community support systems and services may be essential in the determination of home care.

Once the child is a candidate for community-based care, the Care Manager's role increases during Phase II as he/she assumes the major responsibility for devising, coordinating, and implementing the Home Care Plan. The Care Manager may also assist in developing the Discharge Plan. With the child's Parents (or guardian), the Care Manager will insure that community support services are available and accessible.

During Phase III, the Care Manager's role diminishes after the child is at home. At this point, the chief task of the professional is to provide back-up support to the family or to be a temporary coordinator in cases of significant changes in the home setting.

GUIDELINES FOR CARE MANAGERS

1. See that the parents are involved in every aspect of the decision-making process.
2. Make schedules of family life, before and after the placement of the child at home.
3. Help suggest actual daily living plans for the child after you have as much information as possible about the family and the child.
4. Remain "on top of" all community services.
5. Give copies of all written reports to parents. Explain the "jargon" contained in the reports.
6. Help the parent to know the child's strengths and abilities.
7. Become involved with the whole family to develop a general picture of needs.
8. Explain how to coordinate needs and services.
9. Listen!

*Some of the points mentioned in the guidelines were suggested by or adapted from *Looking Forward: A Guide for Parents of Children with Disabilities*, published by the Maryland State Planning Council on Developmental Disabilities, Copyright January 1980.

The Interdisciplinary Team

The Interdisciplinary Team includes all professionals from the various disciplines (medical, social services, nursing, speech and hearing, etc.) involved in the development and implementation of the Home Care Plan. This team may also include parents of other severely disabled children successfully moved to family care; these parents have developed applicable knowledge and skills. In fact, they are often the real "experts."

The various disciplines represented by the Interdisciplinary Team are necessary to the overall viability of the plan. One part of the Interdisciplinary Team, the nursing component, can give the most accurate information concerning required care, feeding, the activity level, or other vital information about the child. During Phase I, the team should participate in determining whether the child is a candidate for discharge to a less restrictive setting.

During Phase II, the Interdisciplinary Team members actively participate in the development of the Discharge and Home Care Plans and in the identification of community resources. The team should also be active in educating the parents or other care providers for the child's move home. During this phase, all arrangements must be made, all environmental changes to the home completed, funding sources confirmed, and the plan double-checked.

During Phase III, the Interdisciplinary Team provides as-needed support and assistance to the Parents as the latter assume the major responsibility for the care of the child.

Community Support Services

Community Support Services include all resources, vendors, and agencies with a role in supporting the family and insuring the child's adjustment within the family. Although these service providers are not actively involved during Phase I, the discharge team must take into account what resources are offered, available, accessible, or potentially developable within the community.

During Phase II, the Care Manager, the Parents, and the Interdisciplinary Team must: a) specify the needs of the child and the family; b) identify and arrange commitment of the Community Support Services for in-home care.

PROVISIONS FOR COMMUNITY SUPPORT SERVICES AND FOR IDENTIFYING POTENTIAL PROBLEMS MUST BE MADE BEFORE THE CHILD GOES HOME

In Phase III, these Community Support Services become active participants in the actual delivery of services and continue as long as necessary. The degree of the child's disability and the impact the child will have upon the other members of the family should be fully discussed before the child comes home. Potential problems should be identified, and the family should be given every possible support in their adjustment to their new role. Too often, these important considerations are left to Phase III; sometimes it is then too late to avoid serious family disruption. A medical Discharge Plan and a Home Care Plan should be clearly in place before the child comes home. The Parents should clearly understand their role and expected functions before the child is home.

CHART OF PHASES, ROLES, AND ACTIVITIES

PARTICIPANT	ACTIVITY Acute Care to Stabilization Phase 1	Planning the Discharge and Home Care Phase 2	Implementing the Home Care Plan Phase 3
Parent Mother and/or father; legal guardian.	1. helps determine if child can come home; 2. evaluates and is evaluated on ability to give home care.	1. helps develop Home Care Plan; 2. requests training needed for Home Care Plan; 3. helps identify needed services and supports; 4. plans any necessary home modification. 5. charts time required for ordinary domestic activities before child comes home.	1. assumes major responsibility for care of child; 2. evaluates and requests additional needed services; 3. charts family activity after child comes home.
Physician Primary attending medical specialist--provides medical care in all phases.	1. recognizes possibility of moving child from hospital to community.	1. develops Discharge Plan; 2. identifies medicine, medical needs, and equipment necessary for home care; 3. develops Home Care Plan in conjunction with parent(s), care manager, and interdisciplinary team.	1. continues (in most cases) to provide medical care; 2. serves as consultant to parents, care manager, interdisciplinary team, and support services.
Care Manager Trained professional (usually a social worker) who devises, coordinates, and helps implement the Home Care Plan.	1. serves as consultant to parent(s) and physician about community support systems.	1. assumes overall responsibility for development of Home Care Plan; 2. can participate with physician in developing Discharge Plan. 3. works closely with parents and insures availability of community support services.	1. provides backup support to parents as they assume responsibility for care management; 2. is available for periodic trouble-shooting.
Interdisciplinary Team Professionals from all disciplines (medical, nursing, social services, speech and hearing, educational, and often other parents) whose expertise comes from experience.	1. serve as consultants about possibility of discharge to community. The hospital's nursing team provides information about levels of care, feeding, nutrition, and activity of the child.	1. participate in development of Discharge Plan and Home Care Plan; 2. help identify community resources; 3. educate parents to prepare for child's placement at home-- a. environmental changes b. confirmation of funding c. training.	1. serve as consultants as needed and provide ongoing support.
Community Support Services All resources, parent support groups, voluntary organizations, national organizations, vendors, and agencies insuring the child's adjustment to the home.		1. contacted by care manager, parents, or interdisciplinary team to check availability and provision of resources; 2. consulted in Discharge Plan and Home Care Plan.	1. deliver services.

SECTION III

PLANNING FOR DISCHARGE AND HOME

The Discharge Plan

The phases of progression from hospital to home have been defined; the roles of the pilots and planners have been delineated; now the plans must be formulated.

The child (in most cases) has been the resident of an acute-care facility for an extended period. When his/her condition becomes stabilized, the physician determines that home care is feasible. After the child has been moved from intensive care to a regular pediatric unit, the recognition of home care as the most effective and psychologically appropriate care leads to the development of a plan for future care.

The Physician and Interdisciplinary Team will develop an overall medical Discharge Plan during Phase II. This plan should detail all equipment needs, all prescribed medicine, and all needed supplies. It should clearly define the medical protocol to be followed at home. Additionally, the plan should include any alternative arrangements that might be necessary, such as with a local hospital to care for the child in a medical emergency, or with the discharging hospital for emergency return.

For some children, the plan will be brief; for others, it will be extensive. The details of the plan are the responsibility of the discharging hospital and require the approval of the physician in charge. The plan will indicate needed hours of nursing and training, both for nurses and parents, prior to the child's discharge.

State agencies such as specialized Maternal and Child Health programs and Crippled Children's programs may be developing and directing specialized state programs for these populations and would participate with the discharge team in the last phases of the plan in order to assure its feasibility. Assuring the availability of nursing service, specific training, home service and maintenance--all are examples of the participation of state agencies.

The Home Care Plan

As the Physician draws up the Discharge Plan in Phase II, the Care Manager--designated in this phase--is simultaneously drawing up the Home Care Plan. The Discharge Plan includes the medical aspects of needed services; the Home Care Plan includes the "nitty-gritty" to implement these services. The Home Care Plan is really a series of plans which includes the following elements:

a) Care Management Services:

The designated Care Manager should coordinate the services of other providers. These services and their providers should be described in the plan. The Care Manager will:

- help the family avoid duplication of services;
- assure that the child's needs can be met in the home;
- provide the family with information regarding alternatives in care choices, available services, and their rights as parents;
- initiate referrals cconsistent with the plan and acceptable to the needs of the family;
- act as an advocate for the family in negotiations to obtain necessary services as detailed in the plan. (see pages 12 and 13)

b) Respite Care Services:

Attention should be given to providing for temporary residential, respite, and supportive services to assure that the child can remain in the community if the family requires temporary relief from care-giving responsibilities.

c) Home Modification:

For some children, changes in the home (such as additional electrical wiring, insulation, weatherproofing of the windows, construction of wheelchair ramps, etc.) may be necessary. Such environmental modifications should be detailed in the plan and SHOULD BE COMPLETED LONG BEFORE THE CHILD'S DISCHARGE. (see pages 14-15)

d) Nursing Services:

A detailed plan for nursing services should include hiring, training, and planning for reimbursement for nurses. This plan should be consistent with the Nursing Act for the state in which the child lives. The nursing staff should be familiar both with the overall medical Discharge Plan and the Home Care Plan.

e) Supplies and Equipment Plan:

Based upon the Discharge Plan, a section of the Home Care Plan should include methods of getting supplies and equipment and of replenishing them when needed. This part of the Home Care Plan should identify the vendor(s) and should be kept near the bed so that the person in charge can obtain additional equipment easily. (see page 17)

f) The Family Support Plan

Each family should have someone, either the Care Manager or a social worker, to share their concerns about the impact of the placement of their child in the home. The Care Manager should draw up a schedule of family activities both before and after the child comes home. Once these activities are charted and the differences are seen, some of the possible friction can be avoided by rescheduling activities and by taking into account the needs of all--child, parents, siblings, and the entire family unit. (see page 18)

g) The Family Finance Plan:

The Home Care Plan should give a detailed suggested financing plan for the family; the plan might recommend application to one or more of the following:

- Insurance companies;
- Community funds;
- Crippled Children's funds;
- Title XIX Medicaid and/or Title XIX Medicaid Waiver.

The Care Manager (or in some cases a member of the Interdisciplinary Team) should work out these funding suggestions to avoid any possibility of the family's loss of funds which enable the child to remain at home. Again, this aspect of the plan should be worked out WELL IN ADVANCE OF THE CHILD'S DISCHARGE.

In devising the financial plan, the Care Manager and the Parents should investigate the following resources:

1. Social Security (a part of the S.S. program is set aside for families with a disabled member).
2. Supplemental Security Income (S.S.I.) for Aged, Blind, and Disabled (S.S. program). Application can be made by a parent, guardian, or other responsible person for a disabled child or adult. The S.S. office makes the determination of eligibility for the program.

Family Finance Plan (continued)

3. Veteran's Administration. Financial aid for medical care is provided to a spouse or a child of a veteran (living or deceased) who has a permanent, total disability resulting from an injury during military service. Consult the V.A. for further details.
4. Medicaid programs. Consult the Department of Social Services in your local health department to determine elegibility.
5. Medicare programs. Primarily for families who receive S.S. benefits. Consult the Department of Social Services in your local health department to determine elegibility.
6. Other programs: Aid to Families with Dependent Children; Food Stamps; Nutrition Program for Women, Infants, and Children (WIC); Emergency Assistance Grants; Private Voluntary Agencies.

h) The Community Support Plan:

In most cases, many community agencies may play vital roles in making the entire plan successful. For example, if 24-hour nursing is needed, the highway department's cooperation may be necessary to insure that roads to the house are passable in bad weather. If electric power is needed for life-sustaining equipment, the power company should be aware of the family's vital need. These same principles apply to other emergency measures from local services and utilities (telephone, ambulance, etc.). Your key to success is stating politely and clearly your request before an emergency occurs. Included below are sample letters to the various companies as a guide to how information can be relayed to the companies. (see pages 19 and 20)

CONCLUSION

These plans give not only a profile of services needed, but of the family itself. Thus, the plan is actually a series of plans, each divided into a category. The Care Plan must take into account both the operating model of the family and the intellectual and emotional capacity for family and child adjustment to the home environment.

The Care Manager must make the Home Care Plan fit the family, not the family fit the plan.

If the Care Manager tries to force the family into a plan, the plan could lead to disaster. Therefore, the more schematically the Care Manager can visualize the family operation, the more the likelihood of the plan's success. The family profile of behaviors, needs, and timing can help the Care Manager to suggest a plan which in constructive, not obstructive. The Care Manager works by suggestion and observation, rather than by command.

Office ____________
Telephone ____________
Other ____________

Coordinator ____________
Date ____________

INITIAL CONTACT SUMMARY

Patient's Name ____________ SSI# ____________ DSCC# ____________

Address ____________ IDPA# ____________ REC# ____________

County ____________ B.D. ____________ Tel# ____________

Guardian's Name ____________ Address ____________

Verify SSI ____________ Verify IDPA ____________ Verify Insurance ____________

FAMILY

MEDICAL HISTORY
(According to Parents)

INVOLVED SERVICE PROVIDERS

SERVICES NEEDED
(Parents' perspective:
goals and expectations)

PLAN

SSI-DCP#9.3

NAME____________________________

SSI#_______________DSCC#__________

City_______________County__________

PROBLEM	REMEDIAL ACTIVITY	OBJECTIVES	PROVIDER/ PAYEE & DATE
			SSI-DCP#11

PHYSICAL FACILITY CHECKLIST FOR THE HOME

HOSPTIAL________________ CITY________________ DATE________________
PATIENT'S NAME________________ HOSPITAL I.D.#________________
PREPARED BY________________ TITLE________________ TELEPHONE________________

PHYSICAL FACILITY STANDARDS FOR THE HOME	SATISFACTORY	UNSATISFACTORY
I. Accessibility A. Physical facility must accomodate the child's specific disability (to include equipment necessary for facilitating mobility and/or transport) to provide access with single caretaker assistance.		
B. Where applicable, physical facility must not restrict delivery of large or heavy medical equipment		
II. Space Requirements A. Child's room must have minimum square footage area of 9 ft. X 9 ft. Note: Any living area in the house may be designated as the "child's room" (e.g., bedroom, dining room, recreation room).		
B. Storage 1. Immediate access, e.g., night stand--used to store equipment/supplies with utilization frequency of 8 hrs. or less, e.g., suction catheters, suction machine, gloves, dropper bottle. 2. Proximal access, e.g., closet--used to store equipment/supplies with utilization frequency of 24 hrs. or less, e.g., infant scale, water bottles, specimen cups, and immediate access items in larger quantities. Can include small volumes of oxygen replacement. The proximal access storage area must be in close proximity to the child's room. 3. Bulk storage, e.g., basement or garage--must be large enough to accommodate 1 month's equipment/supplies and at least 1 week's oxygen supply. Storage areas must be free from excessive dampness. The temperature must not permit water to freeze. Storage areas must not contain toxic chemicals, e.g. cleaning solutions, fertilizer.		

PHYSICAL FACILITY CHECKLIST FOR THE HOME (continued)

PHYSICAL FACILITY STANDARDS FOR THE HOME	SATISFACTORY	UNSATISFACTORY
III. Electricity Requirements		
A. A qualified electrician is required to evaluate the physical facility for ability to accommodate the child's electrical supply needs.		
B. The physical facility must be supplied by a minimum of 100 amp. electrical service.		
C. A minimum of two separate 15 amp. branch circuits must supply the child's room.		
D. If the main distribution panel utilizes fuses, four spare fuses of appropriate capacity are required to be stored near the fuse box.		
E. A minimum of four duplex electrical outlets on each of the two 15 amp. branch circuits is required for a total of eight duplex outlets in the child's room. Note: This is in addition to the usual and customary installation. Therefore, this requirement is not to be interpreted as the total number of outlets required for the child's room.		
IV. Special Equipment		
A. A telephone should be at the child's bedside.		
B. A mechanical whistle should be at the child's bedside.		
C. A battery-powered flourescent flood light should be at the child's bedside.		
D. Power failure alarm/light should be plugged into the same house electrical circuit as the ventilator.		
E. One smoke alarm and one five pound CO_2 fire extinguisher should be located on each level of the home (including the basement).		

PHYSICAL FACILITY CHECKLIST FOR THE HOME (continued)

PHYSICAL FACILITY STANDARDS FOR THE HOME	SATISFACTORY	UNSATISFACTORY
V. Ventilation A. Ventilation must be adequate to permit safe recharging of wet cell marine type batteries.		
B. Oxygen storage areas must have adequate ventilation.		
I. General The house must meet local safety, sanitation, and building requirements.		
II. Other Considerations		

III. Summary of equipment/home modifications necessary for safe discharge home:

(This checklist was drawn up by the Children's Home Health Network of Illinois.)

DETERMINATION OF SERVICE/EQUIPMENT NEEDS FOR CARE MANAGERS AND PARENTS

Statement of Need	Reason for Need	Resource Required	How to Secure Resources		
			Who	When	Cost
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					

CHECKLIST OF RESOURCES TO ANSWER NEEDS

Resources of family: (ex.: mother is a teacher)	1. 2. 3.	
Resources of extended family: (ex.: aunt is a nurse)	1. 2. 3. 4. 5.	
Resources presently used: (ex.: assistance from church group for transportation)	1. 2. 3. 4. 5.	
		Methods of Identifyin and Contact
Resources (above) to be expanded: (ex.: other churches in same denomination could supply transportation, respite care, etc.)	1. 2. 3. 4. 5.	1. 2. 3. 4. 5.
Other potential resources (ex.: parents of children with similar handicaps)	1. 2. 3. 4. 5. 6.	1. 2. 3. 4. 5. 6.

SAMPLE LETTERS

Manager-Midwestern Power Company
132 Main Street
Indianapolis, Indiana 60321

October 26, 19__

Dear Sir:

My son has a rare and very serious disease called adrenoleukodystrophy. After his stay in the hospital for the last few months, the doctor has decided that he can come home. We are looking forward to bringing him home next Saturday.

I am writing this letter to let you know that John also has other complications requiring the regular use of life-support equipment which uses electricity. The social worker at the hospital suggested that I write to you and let you know of our acute need for electrical power. She said that you might be able to repair power lines and other equipment in our area more quickly if you were aware of such a medical need. We will have a battery back-up power source, but we will feel more comfortable knowing that your company is aware of the need for power in this home. Please feel free to call me, or perhaps I can stop by your office and discuss the situation in more detail. Our physician is Dr. Tom Smith; his phone number is (312) 345-7632. Dr. Smith said that he would be very willing to discuss John's case in more detail if you feel it is necessary.

Thank you for your consideration of this matter which is very important to my family.

Very truly yours,

Susan Alexander

County Highway Department
132 West Jackson
Springfield, Illinois 60432

October 26, 19__

Dear Sir:

Local medical providers and Children's Hospital have arranged for the discharge of a severely disabled child whose life is being supported by a ventilator. Jim McBee will be moved from Children's Hospital to his own home on November 3, 19__. His care plan includes around-the-clock nursing service.

This letter is to request your cooperation in establishing a priority for keeping the roads open to 1223 West Washington Street. As you know, this house is approximately a mile from the edge of the city and in inclement weather has access problems. We would like to make every effort possible to assure that nurses can get to this home every eight hours.

We sincerely hope that the highway department will take this medical situation into consideration when establishing snow-removal priorities. Please feel free to contact either me or the family.

Thank you for your cooperation.

Very truly yours,

Paula Epstein
Medical Social Worker
Children's Hospital

SAMPLE LETTERS

Ace Ambulance Company
1472 West Jefferson Street
Springfield, USA 12345

October 26, 19__

Dear Sir:

John Sarvis, an 8-year-old severely disabled child, is being discharged to his home on November 22, 19__. John's condition has stabilized in the last few months, and the medical team at Children's Hospital feels comfortable about discharging him to home care. There may, however, be a need for him to be taken to the local hospital in an emergency situation. We would like to notify your company of the location of the home (14 Maple Street at the corner of Oak Avenue) and the quickest way to get there in an emergency (Main Street north to Maple Street, turn left and proceed two blocks). Even though we do not anticipate such an emergency, please call me at (301) 123-8765 to discuss the situation in detail and to make all necessary arrangements.

Thank you for your cooperation.

Very truly yours,

Harriet Gage
Social Worker

Commissioner Harry Jones
Uptown Fire Department
19 Main Street
Grovers Corners, USA 10229

October 22, 19__

Dear Sir:

I am writing to inform you that Don Miller is being is being discharged from Beth Israel Hospital on November 20, 19__. Donald, who has a series of physical ailments, including bronchopulmonary dysplasia, will be residing at his parents' home at 24 Monroe Street here in Grovers Corners. He is dependent upon life-support equipment like a ventilator and suction machines. He is also scheduled to receive 24-hour daily nursing care. Episodic flare-ups may require emergency attention, even though the doctors at Beth Israel have determined that his conditon is quite stable. We are, therefore, making sure to give notice to your department in the event that Don may someday need emergency care best provided by the Rescue Emergency Squad of the Fire Department. Also, in case of fire, it would be difficult to move Donald. Therefore, we are requesting your advice, and would welcome further conversations about this matter. If someone from the Fire Department feels that a visit to the home would be helpful, please call me at (415) 337-3842.

Thank you for your cooperation.

Sincerely,

Susan Green
Social Worker

SECTION IV

ORGANIZATIONAL SYSTEM OF COMMUNITY RESOURCES

Incredible stories abound about families trying to meet their child's needs through involvement with a large number of health and social service agencies and having many needs go unmet. These tales include competing agencies, duplication of services, and a lack of knowledge on the part of many agencies about the functions and roles of other agencies.

A well-developed program for organizing support services for handicapped children and their family should include an educational and supportive component. The family could then become their own advocates.

In a number of states, state Maternal and Child Health programs, Crippled Children Services programs, special education programs, or others are actively attempting to organize community resources for these children. Ask the Care Manager assigned to your child to help you to familiarize yourself with the programs in your own state. Each state has a different system of agencies and regulations, and the Care Manager will assist you in your exploration and discovery of community resources.

The task of this workbook is to suggest methods for constructing a system for parents and designated Care Managers to enhance their ability to optimize the environment in which the child and family live.

The Systems Approach

Define the Need

The medical needs of the child should be prescribed by the child's primary care physician and listed in both the Discharge and Home Care Plans. The other needs of the child and family should be established by the Care Manager and included in the child's Home Care Plan. The family and Care Manager should list the child's unmet needs and then develop a plan with the broader Interdisciplinary Team to meet those needs. Otherwise, the family might waste time requesting inappropriate items or services, or might request duplicate services.

Identify the Appropriate Resource

1. Ask the social worker at your local hospital or your pediatrician for referrals to a national organization dedicated to the disability of your child; ask also for their local office; inquire about the scope of their services.
2. Ask your clergyman for resource referral.
3. Ask another parent of a similarly disabled child about local organizations for parents; attend their meetings; request their literature.
4. Make an appointment in the school system with your local special education director, teacher, or other allied personnel concerning your child's needs.
5. Call the local coordinating council for handicapped or disabled children if one exists in your area.
6. Consult your telephone book for statewide Crippled Children and other specialized programs to which your child may apply. Call your local Social Security office and inquire about your child's eligibility for SSI.

Identify the Appropriate Resource (continued)

Your participation in the evaluation process should be the participation of a peer with other professionals. If, in your opinion, a professional discounts your input or excludes you from the overall process because you are "only a parent," request another professional. Remember that you are an equal, but you must speak up if your opinions and words are to be recorded and your advice is to be acted upon.

Based upon changes in the child's development, treatment plans need to be continually reassessed. Successful, reputable agencies and special education programs will conduct frequent staff meetings to reexamine the original goals and make changes in the child's plan as necessary. Remember also that public schools are required, under the provisions of Public Law 94-142, to review your child's Individualized Educational Program at least once a year. You should feel free at all times to request a reevaluation.

The wealth of information and possiblities can have its drawbacks. Families of disabled individuals are often overwhelmed by the number and complexity of individuals, agencies, and service organizations. Recently in the Midwest, over 25 agencies and 47 individuals were involved in the delivery of services to a moderately disabled child and his family. Too much assistance can be detrimental. Unrecognized and unmet needs might result from the abundance and the total situation might become close to chaotic. The task is best accomplished if one person with an appropriate supportive team defines the needs of the child and the family, and then develops a plan for meeting those needs. Contacts with the family, community resources, agencies, and other individuals should be the responsibility of one individual, and not all of the involved people. One member of the family will eventually become the Care Manager, and he/she--as did the original Care Manager--will be responsible for insuring all needed services without duplication.

A well-developed program for organizing support services for handicapped children and their family should include an educational and supportive component. This program would ultimately allow the family to become their own advocates. By mobilizing their resources to call for improvements in resources, the family can more effectively meet the needs of the child.

Readers of this workbook should also consult Power-Brokering in the Community, one of the companion books in this series.

Understanding the Approach

Many community voluntary health chapters have prescribed available areas of service. Often, you must seek them; these groups will not necessarily come to you and your disabled child.

Parent support groups are beginning to spring up all over the nation. These groups are very valuable to parents and others involved with planning and care management for disabled and handicapped children. Such groups are often able to provide more than support by actually imparting information to new parents, speaking before groups, representing the cause before legislators, explaining the burdens to state and other public officials, and in effect, forming an advocacy group for children. Such groups are usually staffed by parents and are extremely valuable in helping other parents work through their emotional and functional difficulties.

National foundations and health chapters have proved themselves as valuable resources in meeting unusual and well-defined needs. For the best response from a foundation, make sure your case is adequately presented to them. A very useful source of identifying these agencies is A National List of Voluntary Organizations in Medical Genetics and Maternal and Child Health, available from the National Center for Education in Maternal and Child Health, 3520 Prospect Street, Washington, DC 20057. Many states have homemaker and nursing services provided for by either that state's child welfare or public welfare agencies. The social worker at your local hospital or a clergyman should be able to tell you if such resources exist in your community.

A "court of last resort" for concerned parents is to explain their situation and their needs to their state representative or congressman. Groups are more usually more successful than individuals in bringing a legitimate need to a legislator and will usually receive an understanding hearing. This hearing will often result in a service or activity to alleviate the problem area.

The discovery of additional resources will probably proliferate from the resources known to the individuals of the Interdisciplinary Team. The wise Care Manager will bring all unusual and unmet needs to this group.

The Future

Only a few years ago, many of the severely medically involved and disabled children would not have survived. Many of these children are still relatively young and our collective experience with them as teenagers, young adults, and adults, is extremely limited. The limits of their potential remain unknown.

As we begin to look at this group, we must recognize that not all such children have parents with the parenting ability, stamina, interest, coping power, capacity, or support systems necessary to provide an in-home setting for their children. It is, of course, critical during Phase I when the medical team is considering if a child is a candidate for in-home care, to assess carefully the child's parent as a potential resource. In cases when the parent is not available, what is the future of the child? Is the child to be committed to long-term care in a medical facility, or do we have a responsibility to search for a substitute home environment within the child's extended family, or through the development of a highly specialized medical foster home? With commitment of the medical community to in-home care comes the alternative need for highly specialized medical foster-family homes. To move in this direction, specific standards for these homes must be developed, either nationally or individually by state. In most states, existing standards for foster family care can be used to develop the required specialized standards. Additionally, intensive training and preparation of the non-parent caretaker will be an essential aspect of providing for the severely disabled child.

Foster-family or relative homes may be augmented by community development of specialized medical group home settings to serve some severely medically involved children. To preserve the family atmosphere of such group homes, the number of disabled children in any one home must be limited. Cost-effectiveness factors are a consideration in communities large enough to support this kind of resource. Perhaps, for example, one nurse could provide care to two or more children at one time; less emergency equipment may be necessary; less inventory of parts for equipment repair may be needed.

Public awareness and education are other challenges as more and more severely handicapped children leave hospital settings for family/community care. We must look to the future to the kinds of care and the needs of these individuals as adults. Some may be able to live fairly independently; some may require a type of sheltered/supportive living arrangement; others may require more intensive care in family or group home settings.

Parent support groups are a viable, necessary link in the community support system. Probably no one can better help the parents of a child just diagnosed as having a severely disabling medical condition than another parent who has already gone through the experience. Parent support groups can provide a number of services: assisting individual families; serving as members of the Discharge Team; providing public education and awareness campaigns; working with social agencies and others to recruit, train, and prepare foster families; serving as community advocates for the educational, recreational, and social needs; lobbying for funds to make in-home care possible.

Finally, it is the responsibility of all of those committed to piloting the children on the journey from hospital to community to identify the road-blocks--financial, social, communal, attitudinal--and to seek effective ways to remove these barriers. We are just at the beginning. As we move ahead, we find unanticipated barriers and blocks which must not stand in the way of any child who is a candidate for community-based care.

The trip might be perilous, but we will rise with the road to meet its challenges. Each journey begins with but a single step, and this journey is a necessary one. It is only the first step which is difficult.

SPECIAL NOTE: To the Parents of Children Between the Ages of 0-3

While some states may lack active programs for children between birth and three years, many are now developing early intervention programs specifically created for early identification of developmental problems in children. If you feel your child has a noticeable problem or handicap, or seems to be falling behind other children in specific developmental tasks such as walking, talking, hearing, or controlling intensity of activity, you may want to call your public health nurse or your local special education program about information on early intervention programs. One of the advantages of participating in these programs will be the contact with other parents experiencing similar thoughts, anxieties, and questions.

Depending upon your state and the size of your community, there are various establishments (including health agencies, hospitals, university child development centers, private and public schools) with specialized early intervention programs to meet the needs of your child. Your aggressive and persistent efforts--coupled with those of your Care Manager--will pay off for your child. In almost every American community is a network of people dedicated to serving those with special needs. Your participation will give you the opportunity to bring to them needed information while you receive from them encouragement and support.

NOTES

News Digest

Information from the
National Information Center for
Handicapped Children and Youth

OCTOBER 1985

Psychological Testing of Children with Disabilities

Children with handicaps who are in need of special education services must be identified through an assessment process. The letters received by the National Information Center for Handicapped Children and Youth indicate that psychological testing, an important part of the assessment process, is a topic about which parents want more information. The purpose of this edition of *News Digest* is to provide parents and others concerned about the needs of children with handicaps with an introduction to testing and an overview of literature that will allow them to do further research on the subject.

There are certain things that parents should bear in mind from the beginning of the testing process. The purpose of testing is to understand the nature of the child and to provide guidance for decisions about the kind of educational programming the child will receive. Stanley D. Klein in *Psychological Testing of Children: A Consumer's Guide* compares psychological testing to the kind of sampling a cook does when cooking stew. The cook tastes the stew to make a generalization about how well the dish is turning out. In the same way, samples of behavior gotten through psychological tests allow psychologists to make generalizations about a child's behavior. No test or group of tests can provide a complete picture of a child's development. Klein cautions against basing decisions about a child's education on the results of a single test. Children undergoing assessment should be given a group (sometimes called a battery) of tests.

Legally, the assessment process must consist of information from a variety of sources. The child must not only be given tests but must also be observed working and playing in natural settings. People who know the child must be asked to provide information about him or her. The views of parents are especially important. Only through a variety of sources can an adequate picture be obtained of the child's strengths and weaknesses. Together, this information can be used to determine whether the child needs special help, and, if so, to design an appropriate program.

The way tests are administered is also important. If the results of the test are to be useful, the child's performance on the test should be representative of his/her behavior. The person giving the test should make sure the child is comfortable in the testing situation. If necessary, adaptations must be made to ensure that a child's physical or sensory disabilities do not interfere with the testing of a child's aptitudes. Public Law 94-142 requires that tests be conducted in a way that prevents physical or sensory impairments from interfering with the measurement of a child's aptitudes. The law also requires that diagnostic tests be given in the language and mode of communication a child understands. It is also important in administering tests that the psychologist observe the way in which the child responds to questions. Klein points out that how a child approaches problems can be as revealing as the answers that the child gives to specific questions.

Parents have an important role to play in the testing process. As an active participant in the planning of their child's educational program, they should feel free to ask questions about the techniques being used to assess their child. The person giving the test should be able to tell the parent what information the assessment is trying to uncover. "The Role of Parents in the Assessment Process" (1983) makes several suggestions on how parents can become more involved in the assessment process. It is important that parents meet with the person conducting the test before the testing takes place. This gives the parents an opportunity to ask any questions they may have. Such a meeting also allows the person giving the test an opportunity to ask about the parents' views on the child's development. Parents also should prepare the child for the assessment process. Testing may make some children anxious. This is particularly so if the child has been identified for testing because of poor school performance. Such anxiety can interfere with a child's performance on the test. Professionals should take extra care in explaining the results of tests to parents.

Key Concepts in Psychological Testing

Both Klein in the work previously cited and David L. Wodrich in *Children's Psychological Testing: A Guide for Nonpsychologists* provide an introduction to the concepts of psychological testing. The following is a brief survey of important ideas that parents and others need to understand in order to determine the usefulness of psychological testing.

One goal of psychological tests is to find out how the child performs compared to other children of the same age. In order for this comparison to be meaningful a valid norm group must be defined. A norm group is a large number of children who are representative of all of the children in that age group. Such a group can be obtained by selecting a group of children that have the characteristics of children across the United States, that is, a certain percentage must be from each gender; from various ethnic backgrounds (e.g., white, black, American Indian, Asian, Spanish-speaking); from each geographic area (e.g., Southeast, Midwest and so forth); from an urban, rural, or suburban area; and from each socioeconomic class (usually determined by the father's occupation). Not all tests use large, representative norm groups. Before making assumptions about a child's abilities based on test results, it is necessary to know something about the group to which the child is being compared.

It is also necessary to know whether the tests are reliable and valid. A test is valid if it measures what it claims to measure. For instance, if the test is supposed to measure intelligence, there should be a definition of intelligence. It is reliable if a person who takes it more than once obtains nearly the same score each time. Wodrich describes the scientific methods used to determine whether or not a test is valid and reliable. For example, if a test claims to measure anxiety, a person's scores should be higher under a stressful situation than under a nonstressful situation.

Another consideration is the experience and skill of the person giving the test. As mentioned earlier, the examiner needs to be able to make the child feel comfortable with the testing situation so he or she can concentrate on the task at hand. At the same time the examiner must use uniform procedures, presenting each item in the same way to each child. Without uniform procedures, it would be impossible to know whether differences found among children were due to differences in their development or to the different procedures used.

An understanding of how standardized tests are scored is necessary to making sense of the results. The first score is the raw score. Raw scores are usually the number of "correct" answers. The raw score is then changed to a derived score, which shows how the child's raw score compares with the raw scores of the norm group. This comparison can be provided in several ways: (1) An age or grade equivalent means that the child scored the same as other children of a particular age or grade level. For example, a score of 5.3 means that on a particular test the child scored the same as other children in the third month of the fifth grade. (2) Percentile ranks indicate what percentage of the norm group was exceeded by the child. For example, a derived score of 35% means that the child scored better than did 35% (or 35 out of 100 students) in the norm group. (3) A standard score shows how far below or above the average score of the norm group the child's score is. A standard score provides information about where the child stands in relation to the norm group.

Many psychological tests include a series of subtests. Analysis of these subtests can provide more information than is available from the overall derived score. The child's scores on the subtest show whether the child can perform equally well in all areas tested (e.g., reading, arithmetic) or is stronger in one area than in another. Even more detailed information can be gained by examining the pattern of answers on each subtest.

A child's response to items can provide information about his/her learning style. For example, some children understand information better if it is read out loud to them; others, if they can read for themselves. These differences will affect their test scores and should be noted by the person administering the test. Such information can later be used in designing an educational program most suitable to a child's learning style.

Before a test is given, the reason for giving it must be known. There are many tests available and choosing the right ones depends upon the nature of the problem. Thus the more detail that can be provided about the child's behavior and the possible reasons for it, the better a psychologist is able to choose the appropriate tests to administer.

In summary, Klein and Wodrich both provide information to help parents and others to better understand psychological testing. To determine the usefulness of test information, it is necessary to know the following: (1) How do test results compare with other information gained from observation of the child in natural settings? (2) Who is the child being compared to? (Did the test makers use an adequate norm group?) (3) Does the test measure what it claims to measure? (Is it valid?) (4) Would the results be the same if the test were taken more than once? (Is it reliable?) (5) Is the person giving the test well trained and responsive to the child being tested? (6) Has the test been given according to standard procedures? (7) How is the test scored, and have the results been interpreted carefully? (8) Has the right test been given?

Test Types

The literature reviewed for this paper focused on four types of tests commonly used in assessments of children with handicapping conditions: infant development scales, intelligence tests, special abilities tests, and personality tests.

Infant Development Scales

Because early intervention can help handicapped children reach their fullest potential, it is important that handicapping conditions be identified as soon as possible. Several tests have been constructed to compare an infant's developmental level with the expected level for his or her age group. These tests have not been very successful in predicting how well the child will function in the future, but they do identify children who are "at risk." Infants so identified can be monitored so that any future delays in development can be identified quickly and an intervention program can be designed, if needed. In Chapter 3 of his book, Wodrich reviews some of the more commonly used infant scales. These include:

- *The Brazelton Neonatal Behavioral Assessment Scale*, which tests an infant's (1) neurological intactness, (2) interactive behavior (including motoric control such as putting the thumb in the mouth and remaining calm and alert in response to stimuli such as a bell, a light, and pinprick), and (3) responsiveness to the examiner and need for stimulation.
- *The Bayley Scales of Infant Development*, which test mental abilities including memory, learning, and problem-solving behavior; motor skills; and social behaviors such as social orientation, fearfulness, and cooperation.
- *The Gesell Developmental Schedules*, which test for fine and gross motor behavior; language behavior; adaptive behavior including eye-hand coordination, imitation, and object recovery; and personal-social behavior including reaction to persons, initiative, independence, and play response.
- *The Denver Developmental Screening Test*, which is used to suggest problems which should be more carefully evaluated later. It measures four areas: personal/social, fine motor/adaptive, language, and gross motor skills.

In addition to these tests which are discussed in detail by Wodrich, Klein mentions the *Cattell Infant Intelligence Scale*, the *Kuhlmann-Binet*, and the *Griffiths Mental Development Scale*. Sources for tests designed to be used with infants with specific handicapping conditions will be provided in a later section.

Preschool and School-Age Intelligence Tests

Most children who are tested for a handicapping condition will be given an intelligence test (IQ test) as part of the assessment process. Klein states that in general IQ tests define intelligence as having two attributes, the "ability (1) to learn from experience, and (2) to solve problems" (p. 22). IQ test scores reflect an interaction between a child's natural abilities and his or her life experiences. A child's score may change over time, especially if the test is given at a young age. One reason is that the nature of intelligence changes as a child matures, with older children being expected to use abstract reasoning not expected of younger children. Another reason is that such stressful life experiences as parents getting a divorce can temporarily make a child less motivated to learn and thus may temporarily lower his or her IQ scores; on the other hand, such positive life experiences as being placed in an appropriately challenging educational program can increase a child's scores. However, by age 8 most children's IQ scores will be close to those they will have as adults.

Both Klein (1977) and Wodrich (1984) review the two most commonly used IQ tests—the *Stanford-Binet* and the *Wechsler*. Wodrich describes the tests in detail and gives examples of test items. Klein provides an easy-to-understand explanation of how the tests are scored. For both tests, a score of 90 to 109 is normal or average, meaning that half the people taking the test will score in that range. A lower score is below average and a higher one is above average.

The *Stanford-Binet* can be used with both preschool and school-age children and is usually administered to children between the ages of 2 and 8. Examples of what is required include remembering where an object was hidden, building a four-block tower to match an existing tower, explaining the uses of common objects, and identifying by name pictured objects. One disadvantage of the *Stanford-Binet* is that it gives only an overall score, assessing general thinking and problem-solving ability and does not provide subtest scores about particular strengths and weaknesses. Some items are culture-specific so the test is best suited for middle-class English-speaking children. It may not provide a fair assessment of bilingual or bicultural children. Depending upon the child's age, the test requires vision, eye-hand coordination, hearing and speech.

The *Wechsler* has separate forms for preschool and school-age children. The preschool form is called the *Wechsler Preschool and Primary Scale of Intelligence* (WPPSI), and the school-age form is called the *Wechsler Intelligence Scale for Children—Revised* (WISC-R). The *WISC-R* is the test most likely to be used to assess the cognitive functioning of school-age children. It has six verbal and six performance subtests. In each case, five tests are always administered and the sixth is optional.

Some examples of items similar to but not exactly the same as *WISC-R* items are provided by Wodrich. For the verbal scales these include the following: "During what month is Christmas?" "How are a river and a lake alike?" "If four doughnuts cost 60 cents, how much would six doughnuts cost?" "What is a cow?" "What are some reasons why we should not steal?" For the performance scales, the child is asked to identify a missing element in a picture of a common object (the picture might show a baby carriage with a wheel missing), to arrange a series of scrambled pictures into a logical story, to reproduce the design of several blocks, to rearrange pieces of an object to make a picture, and to copy symbols associated with specific marks or numbers. The verbal scales are read orally to the child, who answers orally. The performance scales require the child to physically manipulate objects.

Wodrich also describes the *McCarthy Scales of Children's Abilities*, an intelligence test designed for children 2½ to 8 years old. It has a cognitive index made up of three subtests: verbal, perceptual/performance (nonverbal thinking and problem solving), and quantitative (number knowledge and reasoning). It also contains a memory and a motor index. The perceptual/performance subtest can be used with preschool children who are bilingual, bicultural, or have specific language or visual problems. The test is preferred to the *Stanford-Binet* if a child within the specific age group is thought to be learning disabled. It should not be used with children who are severely retarded. Other preschool-age tests mentioned by Klein are the *Merrill-Palmer Scale* and the *Minnesota Preschool Scale*.

Problems with IQ Tests

Both handicapped and minority children with normal intelligence may receive below normal scores on intelligence tests. One reason is that norm groups often consist entirely of white middle-class, nonhandicapped students. Even when minorities and handicapped students are included in the norm group, because they are included in comparatively small numbers, the children are still primarily being compared to nonhandicapped and nonminority children. Another reason is that many test items require familiarity with middle-class values and experiences. Children who do not have such experiences may obtain a lower score for reasons other than their intelligence. Even items that appear on the surface to be nonbiased are not necessarily so. For example, a child who plays every day with blocks similar to those used in the *Stanford-Binet* block-building task is likely to do better on the task than a child who has never played with blocks. Similarily, a child with normal intelligence who has eye-hand coordination problems will have trouble with the block-building task, but for physical rather than intellectual reasons.

A review of the issues involved in nondiscriminatory testing is provided by Chinn and Kamp (1982). They also describe the *System of Multicultural Pluralistic Assessment* (SOMPA), a test based on the *WISC-R*, which was designed to take into account a child's handicapping condition and sociocultural background and thus to be nondiscriminatory. Duffey, Salvia, Tucker, and Ysseldyke (1981) review the various approaches such as the *SOMPA* that have been used to make intelligence testing less biased and discuss the problems associated with each. They believe that the solution lies in abandoning the use of labels such as mentally retarded, emotionally disturbed, and learning disabled and instead assessing levels of skill development. The results of a test would then provide information directly applicable to designing an appropriate educational program for the child. To date, however, attempts to ensure fairness of testing have consisted of adapting existing measures and changing procedures to ensure that accurate and relevant information is obtained. For example, the Education for All Handicapped Children Act, the federal law protecting the educational rights of handicapped children, requires that more than one procedure be used to determine the child's educational program, that the evaluation be made by a multidisciplinary team including a person knowledgeable in the area of the suspected disability, and that the child be assessed in all areas related to the suspected disability. The full requirements of the federal law can be obtained by writing the National Information Center for Handicapped Children and Youth (NICHCY), P.O. Box 1492, Washington, DC 20013.

Special Abilities Tests

In addition to IQ tests, there are special abilities tests. Such tests can provide valuable information prior to a full-scale evaluation or can add to information obtained from an IQ test. Special ability tests should be chosen carefully and should never be used alone as a measure of intelligence. Many are available, not all are useful. Wodrich describes three such tests in detail and provides a summary of several others in an appendix.

- *The Bender Visual Motor Gestalt Test* is used to assess visual perceptual skills and eye-hand coordination. The child is given nine geometric figures, one at a time, and asked to copy them.
- *The Peabody Picture Vocabulary Test* assesses familiarity with vocabulary words without requiring the child to speak. The child is shown four pictures at a time and must point to (or otherwise indicate) the one that corresponds to the word the examiner says. Part of the reason the test was originally designed was to be used with children who are nonverbal, mentally retarded and/or have cerebral palsy.
- *The Detroit Test of Learning Aptitude* measures auditory and visual memory and concentration.

Klein (1977) briefly describes the *Draw-a-Person* or *Draw-a-Man* test, the *Leiter International Performance Scale*, the *Columbia Mental Maturity Scale*, and the *Ravens Progressive Matrices* as special abilities tests that require fewer communications skills, and for the most part, less motor coordination than do the *Stanford-Binet* or the *Wechsler*. These tests do not, however, provide a complete picture of the child's abilities because they concentrate on specific skills.

Personality Tests

Both Klein (1977) and Wodrich (1984) review the personality tests that can be used to help determine a child's emotional state. Klein provides an overview of the reasons that personality tests are included in the battery of tests taken by children with disabilities undergoing assessment. Personality tests provide an additional dimension to the picture that emerges from a psychological assessment. Tests of this kind provide the child with hypothetical situations based on real life. The response of the child to these situations allows the psychologist to gather information about the unique features of the child's personality. The results of personality tests should be considered in conjunction with the observations of those familiar with the child (particularly parents) and the results of other psychological tests. Generally there are two types of tests: objective and projective.

Objective Tests

Objective tests are pencil-and-paper tests containing several hundred items designed to determine the child's predominant personality traits or behaviors. Example items provided by Wodrich are: "I am often nervous," "Most days I feel discouraged," and "I often hit or destroy things when I am angry." The child or the child's parent indicates whether or not the statement is true. The test is scored by grouping together all of the items measuring a certain trait such as aggression or depression and comparing the child's score on these groups of items with the scores of a norm group.

The most well known objective test is the *Minnesota Multiphasic Personality Inventory* (MMPI), which was originally designed for use with adults but can also be used with adolescents. Separate adolescent norms are available and must be used in order for results to be meaningful. *The Personality Inventory for Children* (PIC) is one of the few objective tests for younger children.

Projective Tests

Projective tests provide the child with a stimulus such as inkblots, a set of pictures, or incomplete sentences, with the idea that the child's responses will reveal his or her unique view of the world, including issues of concern and emotional needs. Another type of projective test provides instructions for the child to draw a picture, again with the idea that the drawing will reveal information about the child's inner self.

The inkblot test is a series of nebulous shapes. The child's response to these shapes has been found to be related to his or her larger response to the world. For example, children who see only the small details in the inkblot instead of the whole shape may be overly concerned with small details in their daily lives. *The Rorschach Test* was the first inkblot test and the one still most commonly used. *The Holtzman Inkblot Technique* is another projective test that may substitute for the *Rorschach*.

Picture story tests consist of a series of pictures of people or animals in a variety of human situations. The child is asked to tell a story about each picture. In interpreting the results, the psychologist looks for themes in the child's response. For example, a child who is concerned about the illness of a sibling is likely to respond to many of the pictures with a story about illness. The most common picture story tests are the *Thematic Apperception Test* (TAT) and the *Children's Apperception Test* (CAT). Other picture story tests are the *Michigan Picture Test*, the *Tasks of Emotional Development Test*, the *Blacky Pictures*, and the *Make-a-Picture-Story Test*.

Completion tests consist of a series of incomplete sentences or stories, which the child is asked to complete. Examples of incomplete sentences are: "It makes me sad to—," "There are times when—," and "My mother should—." One example of a story completion test is the *Rosenzweig Picture Frustration Study*, which presents a frustrating situation in cartoon form. The statements of one character are left blank for the child to fill in.

Drawing tests require the child to draw pictures. In one such test the child is asked to draw a person and then to draw a person of the opposite sex. In another, the child draws a whole family; and in still another, a house, a tree, and a person.

Each of these tests can provide useful information about a child's needs and concerns. Each test, however, relies heavily upon the interpretations of a psychologist, and thus requires that he or she be well trained, experienced, and competent in using the particular technique. The tests must be interpreted cautiously and used only in conjunction with other sources of information about the child.

Testing and Specific Handicapping Conditions

A number of authors discuss issues involved in testing children with specific handicapping conditions. Haring (1982) provides a section on assessment for each of the handicapping conditions discussed in his book. Other sources of information are provided in the following discussion.

Mental Retardation

An IQ score below 69 indicates that a child may be mentally retarded. However, a low IQ score in itself is not sufficient for a diagnosis. A child's adaptive behavior must also be measured. Adaptive behavior refers to a child's ability to carry out everyday living skills such as dressing, eating, washing, playing, functioning independently, and cooperating with others. Several instruments have been developed to measure age-appropriate behavior in such skills. These include the *Vineland Social Maturity Scale*, the *American Association on Mental Deficiency's* (AAMD), *Adaptive Behavior Scales*, and the *Adaptive Behavior Inventory for Children*. The first two are described by Wodrich (1984, pp. 67-72). Two further sources of information about adaptive behavior are Mulliken and Buckley (1983, pp. 53-89) and Sternberg and Adams (1984, pp. 53-89). Mulliken and Buckley provide a brief summary of 30 adaptive behavior instruments. Sternberg and Adams provide a more extensive review of 14 instruments.

Huberty, Koller, and Ten Brink (1980) review state definitions of mental retardation. They discuss the importance of measuring adaptive behavior and the need for uniform standards across states. The issue of adaptive behavior and nondiscriminatory testing is discussed in an article by Slate (1983). She reports the results of a research study that compared the use of the *Vineland*, the *Adaptive Behavior Inventory for Children*, and the *Behavior Rating Profile* with white and black children from four socioeconomic levels. *The Adaptive Behavior Inventory for Children* was shown to be the least discriminatory of the three instruments.

A low overall IQ score and a low overall score on adaptive behavior are still not enough evidence to label a child as mentally retarded. In addition, the child should show "significantly delayed development across all measured psychometric areas" (Wodrich, 1984, pp. 73). If the child is functioning well in one or two areas, his or her low scores in the other areas may be because of poor motivation, a specific learning disability, or another disability besides mental retardation. School-age children also need to be given an individually administered achievement test. A child who shows an ability to achieve well academically is not mentally retarded even if his or her other test scores are low.

Learning Disabilities

Wodrich (1984) discusses assessment as it relates to learning disabled preschool (pp. 78-81) and school-age (pp. 110-119) children. Learning disabled children have disabilities in specific areas such as reading, writing, or arithmetic and because of these disabilities have lower achievement records than would be expected from their overall IQ score. At the preschool level the children are apt to have problems in either language or visual perceptual-motor functioning. The *WPPSI* and the *McCarthy* are better IQ tests than the *Stanford-Binet* for learning disabled preschool children because they provide information about the particular areas in which the child is having difficulty. School-age children should be given an intelligence measure such as the *WISC-R*, which measures overall ability and at the same time provides information about specific disabilities. They also must be given an individual academic achievement test to measure whether their achievement level is lower than expected based on their IQ score. Further sources of information about diagnosing learning disabilities are available in NICHCY's publication *News Digest (June, 1985)*. For a free copy, write NICHCY, P.O. Box 1492, Washington, DC 20013.

Emotional Disturbance

Mulliken and Buckley (1983, pp. 197-201) and Garwood (1983, pp. 377-385) discuss some of the issues involved in testing emotionally disturbed children. Both authors point out that there is a close relationship between emotional and cognitive development and that children with emotional problems often also obtain lower than average IQ scores. Mulliken and Buckley state that the examiner must go to extra lengths to ensure a calm testing environment, that several short sessions rather than one long session may help the child perform to the best of his or her ability, and that providing variety in the situation, for example by sometimes talking softly and sometimes talking in a louder voice, may help the child stay on task.

Hearing Impairment

By the nature of their disability, children with hearing impairments have limited, if any, exposure to verbal language. Thus, because verbal linguistic skills are such a large part of intelligence tests, these children may be improperly diagnosed as mentally retarded, unless special care is taken when they are tested. Lowenbraun and Thompson (1982) discuss the issues involved in testing hearing impaired children. They suggest that the *Bayley Scales of Infant Development*, the *Uzgiris-Hunt Ordinal Scales of Psychological Development*, and the *Smith-Johnson Nonverbal Performance Scale* can be used with preschool hearing impaired children. The *WISC-R*, in conjunction with the *Hiskey-Nebraska Test of Learning Aptitude* can be used with school-age children. Other tests discussed by the authors are *Ravens Progressive Matrices*, the *Leiter International Performance Scale*, and the *Nonverbal Test of Cognitive Skills*.

Zieziula (1982) provides a comprehensive summary of commonly used tests, with information about their appropriateness for use with hearing impaired people. His summaries include information on reliability, validity, and norms. He also provides sources for obtaining further information about the tests. In Appendix A, Garwood (1983), provides a brief description of tests that can be used with preschool hearing impaired children.

Visual Impairment

DeMott (1982) discusses assessment of visually impaired children. Two considerations in testing these children are (1) the materials must be presented in a form the child can use (large print, braille, or orally) and (2) items that require visual knowledge (such as "describe the evening sky") must be eliminated or modified. Modifications are sometimes made to tests such as the *WISC-R*. In addition, tests specifically developed for visually impaired children are available. One such test is the *Perkins-Binet Tests of Intelligence for Blind Children*. Tests for use with preschool visually impaired children are briefly described in Garwood's (1983) Appendix A.

Severe Handicaps, Multiple Handicaps, and Deaf-Blindness

Severely handicapped, multiply handicapped, and deaf-blind children present special testing problems. Few tests have been developed to meet their special needs. Standardized tests can be adapted for use with these children but then comparisons with the norm group cannot be made. Mulliken and Buckley (1983) discuss a procedure called "testing the limits" where the child is first tested using standard procedures and then retested this time with adaptations being made to help a particular child respond to the best of his or her abilities.

One caution provided by a number of authors writing on the topic of testing severely handicapped children is that they must not be given tests designed for nonhandicapped infants.

Mulliken and Buckley (1983) include a chapter on assessing multiply handicapped and developmentally disabled children in each of the following areas: cognitive skills, psychomotor skills, social development, emotional disorders, communication, and educational achievement. At the end of each chapter is a list of assessment measures with a brief description of each. Sternberg and Adams (1982) include a chapter on assessment of severely and profoundly handicapped children including a comprehensive summary of 14 adaptive behavior instruments (see the section on mentally retarded students for a brief description of adaptive behavior measures). Bennett, Hughes, and Hughes (1979) discuss the use of three tests with deaf-blind children: the *Deaf-Blind Program and Ability Screening Test*, the *Peabody Intellectual Performance Scale*, and the *Callier-Azusa Scale*.

Further information about assessment techniques is provided in an article by Hupp and Donofrio (1983). They provide a model of assessment which is tailored to the student's instructional programming needs and emphasizes the importance of carefully planning the assessment based on prior observations of the child and discussions with the parents and teachers. The problem of adequate training for school psychologists is discussed in an article by Irons, Irons, and Maddux (1984). They suggest that instructional personnel should be more directly involved in the assessment process of severely handicapped children.

Communication Disorders

Russell (1984) discusses problems of assessing children with communication disorders. These vary depending upon the cause and the severity of the disorder. However, tests may need to be selected that require only a yes-no response, which can be signaled by the child in a variety of ways. As mentioned previously, standardized tests can be adapted to the needs of a particular child but such adaptations make comparisons with the norm group impossible. Mulliken and Buckley (1983) provide a chapter on communication disorders, including a brief discussion of assessment. Langdon (1983) discusses assessment of bilingual language disordered students.

Interpreting Test Results

Psychological testing can add to the information obtained about a child's ability to function in a variety of situations. Such information is valuable only if it is used as a basis for helping the child function better in those areas where problems are found. Wodrich (1984) provides the following advice for evaluating the usefulness of test results. The test findings should address the referral question. For example, if the referral question concerned the child's readiness for kindergarten, the report describing the findings should answer the question directly, discussing the child's abilities to function in kindergarten based on the findings. The findings should be interpreted into a meaningful statement about the child rather than simply describe the child's test scores. They should be written clearly so that people not familiar with the jargon of psychological testing can understand them. The report should make suggestions about what actions should be taken to help the child make any needed changes. For example, if a child is found to have a short attention span, the report might suggest particular games or exercises for increasing concentration. Finally, Wodrich reminds the reader that standard acceptable procedures must be used in administering psychological tests and that the limitations of such testing must be acknowledged. Such tests can be a useful tool if used as a part of a total, comprehensive assessment process.

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News Digest

Information from the
National Information Center for
Handicapped Children and Youth

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Children with Handicaps, Parent and Family Issues: A Guide to Readings

The birth of a child with a handicap or the discovery that a child has a disability can have profound effects on a family. On a regular basis, the National Information Center for Handicapped Children and Youth responds to letters from parents asking for advice on dealing with the pressures involved in raising a child with a handicap. The purpose of this issue of the *News Digest* is to give parents and the professionals who work with them a guide to literature that will be helpful in understanding the problems and developing solutions.

When parents find out that their child is handicapped, they begin a process of adjustment. For each family the experience is both unique and shared. How they react depends upon their own unique makeup; the attitudes and behaviors of family members, friends, and the larger society; and the child himself. However, certain feelings and reactions have been found to be shared by most parents as they learn to accept their handicapped child. These have been written about by both parents themselves and by researchers.

Initial reactions are similar to the reactions a person has with other traumatic events. The parents' reaction to having a child with a handicap is in part the product of earlier experiences. Several articles state that during pregnancy parents imagine their ideal child and when they learn that their child is handicapped, they must grieve over the loss of the imagined child before they can become attached to the real child. Bristor (1984) is one source of information about this idea.

Many authors have described the progression of feelings experienced by parents upon learning that their child is handicapped. Parents' initial reactions are often shock, disbelief, disorganization, and confusion, which may be accompanied by physical symptoms such as numbness, nausea, headaches, and fainting. This acute state of anxiety and stress is usually brief and is followed by a period of denial, where parents may not hear what is being said to them or may distort what they hear. During this period they may alternate between hope and despair or may avoid feelings altogether. A common reaction is to believe that the problem will simply disappear or that a magical cure will take place.

As parents begin to accept the reality of the situation, they often feel intense anger which may be directed toward self, spouse, medical personnel, God, and others; a need to find someone to blame; guilt about having such angry feelings and guilt about past actions that may have harmed the child. Other feelings include a sense of helplessness, self-pity, self-doubt, sadness, loneliness, a loss of interpersonal warmth, and fatigue.

These feelings were written about by Smith (1984) from the perspective of a parent who has experienced them herself and who has talked with many other parents who have described their own feelings. Dougan, Isbell, and Vyas (1979) also write as parents about their own experiences and feelings. They write short vignettes about a variety of topics, including the shock and grief they felt when they first found out that their child was handicapped.

Articles for family therapists describing from a research point of view many of the same feelings described in the articles by parents were covered by Fortier and Wanlass (19[illegible] and Bristor (1984). They discuss the stages that families go through in adjusting to having a handicapped child. Fortier and Wanlass describe five stages from impact to closure; Bristor describes six stages from initial awareness to transcending the loss.

Several articles discuss chronic sorrow and periodic reoccurrences of intense feelings of loss. Shafer (1983) describes initial feelings of grief and says that these feelings tend to reoccur when the child reaches developmental milestones, such as the time for walking, entry into a special school, and the 21st birthday. This view also is expressed by Hamilton (1977), the mother of a retarded child who writes about feelings of anger, guilt, and shame.

These feelings can be intense and overwhelming and it is important for parents to know that they are normal and acceptable. They need to be able to express their feelings to someone who understands what they are going through. This can be accomplished by talking to another parent of a handicapped child, by joining a group of parents who have had similar experiences or by talking with a

Parents of handicapped children not only need emotional support but they also need information. They need to know about their child's handicapping condition, about what services are available, and about what they can do to help their child develop to the fullest extent of his or her capabilities.

professional counselor who understands the nature of the loss the parents are experiencing. For information about parent groups in local areas, write the National Information Center for Handicapped Children and Youth (NICHCY), PO Box 1492, Washington, DC 20013.

Some guidelines for therapists working to help parents during the grieving process are provided by Fortier and Wanlass (1984) and Bristor (1984). Smith describes 20 constructive actions parents can take to help themselves during the adjustment process. In addition to joining a parent group, these include talking with mates and other significant persons, taking one day at a time, seeking information, keeping daily routines as normal as possible, and loving and enjoying their child.

Finding Information and Services

Parents of handicapped children not only need emotional support but they also need information. They need to know about their child's handicapping condition, about what services are available, and about what they can do to help their child develop to the fullest extent of his or her capabilities. This information is sometimes difficult to obtain.

Some parents have difficulty in obtaining a diagnosis. McGlynn (n.d.) describes her six-year struggle to find an accurate diagnosis of her son's rare condition, which caused him to scream in terror every night. Based on her experiences, she makes suggestions to help other parents faced with similar problems. She suggests that parents keep accurate records that may provide a clue to the problem, use the library to research the problem, and find a specialist who takes them seriously and will work with them until a solution is found. She also suggests that the parents talk to everybody—not only to doctors, nurses, pharmacists, and teachers, but also to other parents, friends, neighbors, and people at work. Somebody may know somebody who can help. Parents should also evaluate information based on their own knowledge of the child. And finally, they should not give up until they have the information they need.

Additional information about the difficulties parents may encounter in their interactions with medical professionals is provided by Duffy, McGlynn, Mariska, and Murphy (n.d.). These authors, who are themselves parents of handicapped children, write about their good experiences as well as their bad ones.

Information on parents' legal rights and on some steps they can take to ensure that their children receive appropriate educational services are found in Dougan et al. (1979). Duffy et al. (n.d.) also discuss steps parents can take to obtain new services or to improve existing services. These include getting to know those in power and understanding their point of view, finding out what has been done in the past, obtaining the support of other community organizations, consolidating positive support, using a reasoned approach, undertaking a public information campaign with the help of local media, and continuing efforts even after success has been achieved.

Stress and Family Adjustment

Adjusting to the birth of a handicapped child can create stress within the family. As previously discussed, the parents must deal with the grief they feel over the loss of the imagined child. Parents' individual feelings of loss can interfere with their ability to provide support to each other, creating stress within the marriage. Coping with uncertainty about the child's development is another source of stress. Even when the diagnosis is clear, there are still many unknowns such as how the child will respond to treatment, how friends and relatives will react, and what types of programs will be available immediately and in the future. Financial worries, the reality of caring for the child, and difficulties in finding appropriate services can also create stress.

The research literature on stress reactions in families with handicapped children has been reviewed by Crnic, Friedrich, and Greenberg (1983) and Sherman and Cocozza (1984), who find contradictory results. For example, some studies have found that family relationships deteriorate and others have found that they are strengthened by having a handicapped member. Both sets of authors conclude that the different findings are partly because of problems in research methodology and partly because of differences in family situations. Both provide evidence that social and community supports can reduce the stress experienced by families. Such supports include family members and friends who like the child and assume some of the caretaking responsibilities; positive community attitudes about handicapped persons; the availability of services such as parent support groups, respite care, and appropriate educational programs; and referral services that help match parents with needed services immediately following the diagnosis.

Family coping resources also influence how families react to stress according to Crnic et al. Such resources include energy/health/morale, problem-solving skills, supportive relationships, financial resources, religious beliefs, and feelings of self-efficacy.

Personal examples of how the support of family, friends, service providers, and community can help families make a positive adjustment to living with their handicapped child and establish a normalized routine can be found in Dougan et al. (1979) and Duffy et al. (n.d.).

Examples of how a family therapist can provide support during times of stress are given in the Family Life section of *Exceptional Parent*. A therapy session is described in the February 1982 issue in which the parents and maternal grandparents of Jill, an infant with cerebral palsy, discuss the problems they have had in communicating with each other since Jill's birth. The grandparents want to help find a program for Jill but their efforts are seen as interference by the parents, who are feeling isolated from each other and overwhelmed by the responsibilities of caring for a handicapped child.

In another session described in the August 1982 issue, the parents of two boys—John, a 20-year-old who has cerebral palsy and Jerry, a tenth-grade student who is not handicapped, talk with a therapist about their problems in helping Jerry choose the right school program. In a separate session Jerry discusses his problems with his parents, with having a handicapped older brother, and with school.

In the April 1984 issue, a divorced mother talks about how difficult it is for her to raise Billy, her learning disabled son and how she would like more support from Billy's father. In a separate session, Billy's father discusses his own problems in being a part-time parent.

In all three of these cases, the family therapist was able to help the family members understand and accept their own confusing feelings, to communicate better with each other, and to take some concrete actions to reduce family stress.

> A growing awareness that the adjustment to the special needs of a handicapped child influences all family members has resulted in literature and programs being developed especially for fathers, siblings, and grandparents.

The impact of having a handicapped child on the family system is discussed by Perske (1981). He says that although some families grow closer as a result of their handicapped child, others do not. Some families blame their handicapped member for all the problems they have and play games such as "he-broke-us-up," "he's-our-master," and "it's-all-his-fault." The author also discusses some of the good and bad aspects of being the sibling of a handicapped child.

A growing awareness that the adjustment to the special needs of a handicapped child influences all family members has resulted in literature and programs being developed especially for fathers, siblings, and grandparents. In a study of fathers' involvement in early childhood education programs, Markowitz (1984) conducted telephone interviews with the directors of 15 early education programs. She found that fathers participate in program activities when special efforts are made to include them. These include scheduling meetings to accommodate their work schedules, contacting them personally, including topics of particular interest to them, and having male staff members. She also found that the fathers' involvement in program activities resulted in positive changes within the family.

One program for fathers described by Markowitz is also described in greater detail by Vadasy (1982). This program consists of two-hour Saturday sessions for fathers and their young handicapped children. The fathers have an opportunity to discuss common parenting issues, to hear guest speakers, and to learn games and activities that they can carry out with their children. The curriculum was developed by the University of Washington's Supporting Extended Family Members (SEFAM) program and is available to other groups that are starting a program for fathers. SEFAM is also developing programs for siblings and grandparents.

Extensive information about how parents and professionals can help the siblings of handicapped children is provided by Powell and Ogle (1985). They review the research literature on the sibling relationship; describe some of the special needs and concerns of siblings; describe strategies parents can use to provide information and emotional support to siblings; discuss the use of counseling; provide strategies for encouraging social interaction; and discuss siblings as teachers, at school, and as adults. They also include a list of books that can help children and young adults adjust to having a handicapped brother or sister. A second list gives the names, addresses, and telephone numbers of organizations that provide support to parents and siblings of handicapped children.

One such organization is the Sibling Information Network, which publishes a newsletter and serves as a "clearinghouse of information, ideas, projects, literature, and research regarding siblings and other issues related to the needs of families with handicapped members." In addition to disseminating information, the network provides a way for members with similar interests to contact each other. Another such organization is Siblings for Significant Change. It is a sibling membership organization that disseminates infor-

Part of the adjustment process in having a handicapped child is preparing for the future. Depending upon the nature of the child's handicap, special training may be needed so that he or she will be able to function as independently as possible as an adult.

mation, conducts conferences and workshops, and promotes greater public awareness of the needs of handicapped persons and their families.

Help for grandparents is available in the form of a newsletter published by the King County (Seattle, Washington) Association for Retarded Citizens. The newsletter, called *Especially Grandparents* contains articles on topics of concern to grandparents and is designed to help them cope with the special challenges they face.

Preparing for the Future

Part of the adjustment process in having a handicapped child is preparing for the future. Depending upon the nature of the child's handicap, special training may be needed so that he or she will be able to function as independently as possible as an adult. Moon and Beale (1984) outline some steps parents can take at the elementary, middle, and high school levels to ensure that their children learn the skills they will need to obtain employment after they have completed school. These include teaching the child to meet his or her own personal care needs and to perform household chores; providing him or her the opportunity to interact with a wide range of people in all kinds of settings to encourage the development of appropriate social skills; creating opportunities for the young child to learn about workers and what they do; and helping the older child find work after school, on weekends, and in the summer. In addition, Moon and Beale discuss the parents' role in working with the schools and the local rehabilitation agency to ensure that their child's educational program includes appropriate job training and to plan for his or her future employment.

Several publications discuss future employment opportunities for handicapped children. Smith-Davis (1983) provides an overview of the employment situation for handicapped youth. She discusses employment trends, the need for interagency collaboration, the role of business and industry in expanding opportunities for handicapped workers, the implications of the Job Partnership Training Act passed by Congress in 1982, adaptations colleges are making to accommodate handicapped students, and career paths in the arts.

Some approaches that have been developed to provide employment opportunities for severely handicapped persons are reviewed in the National Information Center for Handicapped Children and Youth's (NICHCY) January 1984 newsletter and in HEATH Resource Center's March 1985 fact sheet.

NICHCY's newsletter describes suitable methods for training severely handicapped persons to function successfully at work and reproduces a checklist of work skills developed by Egan, Fredericks, Hendrickson, Peterson, and Moore (1983). The list can be used to help determine the skills a handicapped person already has and those he or she still must develop in order to enter and remain in the competitive work force. The newsletter also describes several programs across the country designed to train and provide support to severely handicapped workers and to encourage businesses to hire such workers.

Other models of supported employment programs are described in the HEATH Resources Center's fact sheet. The fact sheet also provides information about postsecondary education, recreational, and residential programs for severely handicapped persons over the age of 21. The names and addresses of organizations that either provide programs themselves or disseminate information about available opportunities are included.

Although employment opportunities are increasing for handicapped persons, many will need some type of continued support throughout their lives. They may need both financial support and a legal guardian to protect their interests. Parents need to plan how this support will be provided after they die. Two sources of information on such planning are Hermanson (1984) and Appolloni and Cooke (1984). Hermanson provides a brief review of the steps parents should take in planning their estate. These include finding a lawyer who is experienced and knowledgeable in planning for the future needs of handicapped children, evaluating the child's needs and deciding what kind of care should be provided, determining what funds will be needed, and planning how the funds will be transferred to the child. Appolloni and Cooke provide a comprehensive discussion of guardianship and estate planning. Among the topics discussed in their book are:

- A trend for the government to cut back on human services programs, resulting in the need for improved strategies on the part of parents and advocates to provide for the future needs of handicapped persons.
- Legal considerations in appointing a guardian.
- Options for living arrangements such as shared living arrangements or institutional placement, group homes, foster families, and options for persons to serve as guardians such as siblings, friends, legal ad-

visors, bankers, and public or private agencies.

- Methods for writing wills that will provide for the care of the handicapped person and safeguard his or her entitlement to government benefits.
- Considerations in determining whether or not a particular handicapped person needs a guardian and, if so, whether a full or limited guardian is needed. This discussion includes a list of the types of decisions a person needs to be able to make in daily life and methods for determining whether or not help is needed in each of the areas.
- Recent developments in guardianship models, including an explanation of public and corporate guardianship and a description of several existing programs. The programs described include public programs developed in California and in Alberta, Canada, and several private programs—The Foundation for the Handicapped in the state of Washington; the Guardianship, Advocacy, and Protective Services program in Oregon; the Oakdale Guardianship Program in Michigan; and Crossroad Services Program in Iowa. Each program is different but each helps parents plan for the future care of their handicapped child and acts as a replacement parent after they have died. Some services include assisting the handicapped person in such areas as obtaining government benefits, maintaining suitable living arrangements, making purchases, entering into contracts, and obtaining appropriate educational services; managing trusts; monitoring programs; and advocating for the rights of the handicapped person.

> As parents plan for the practical aspects of caring for their handicapped child in the future, they should also consider the emotional aspects.

As parents plan for the practical aspects of caring for their handicapped child in the future, they should also consider the emotional aspects. Dougan et al. describe their feelings as they watch their handicapped children become adults, obtain jobs, and move away from home. Konanc and Warren (1984) discuss the problems families may have at the time their handicapped child graduates from high school. They describe therapy sessions for three families and provide guidelines for family therapists working with families during this transitional period.

In this issue of the *News Digest*, we have reviewed recent literature to present current thinking in three problem areas for parents of children with handicaps. We have cited tips for parents as they seek information and services, have explored patterns of stress families often face, and have looked at options for parents as they plan for their child's future. While we realize that each family's situation is different, we hope both parents and professionals will use this issue as a data source from which they can draw current information which can be applied to a family's own special needs in caring for their child with a handicap.

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INFORMATION RESOURCES

For further information on sibling networks contact:

The Sibling Information Network
249 Glenbrook Road, Box U-64
Department of Educational Psychology
The University of Connecticut
Storrs, CT 06268

Siblings for Significant Change
105 East 22nd Street
New York, NY 10017
(212) 420-0430

For information on how you can obtain a free subscription to *Especially Grandparents* write or call (206) 622-9292.

Especially Grandparents
King County ARC
2230 Eighth Avenue
Seattle, WA 98121

For further information on the SEFAM Project write:

Don Meyer
SEFAM
Experimental Education Unit
WJ-10
Child Development and Mental Retardation Center
University of Washington
Seattle, WA 98195
(206) 543-4011

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Handicapped Children and Youth
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APPENDIX E

TOLL FREE NUMBERS

SOURCES OF HELP AND INFORMATION

LIST OF AVAILABLE INFORMATION

TOLL FREE NUMBERS CONTINUED. . .

Abuse/Neglect Hotline	(800) 652-1999
American Cancer Society	(800) 642-8116
American Heart Association	(800) 642-8400
Arthritis Foundation	(800) 642-5292
Contact Inc.	(800) 228-3225
Diabetes - American Association State Chapter	(800) 642-1267
Epilepsy Information Line	(800) 542-7054
Feld Prescription Service	(800) 642-1455
Hearing Helpline	(800) 424-8576
HEATH Resource Center	(800) 54-HEATH
Hotline for the Handicapped	(800) 742-7594
Insurance Hotline	(800) 423-8000
International Shriners Headquarters	(800) 237-5055
Job Accommodation Network	(800) 526-7234
Job Opportunities for the Blind	(800) 638-7518
Lawyer Referral Program	(800) 742-3005
Legal Aid Society - Norfolk	(800) 672-8319
Legal Aid Society - Omaha	(800) 642-8223
Legal Service Office - Beatrice	(800) 742-7389
Legal Service Office - Scot[illegible]bluff	(800) 682-5113
Legal Service Office - North Platte	(800) 662-2907
Legal Service Office - Grand Island	(800) 742-7456
Legal Service Office - Lincoln	(800) 742-7555
Library for the Blind & Physically Handicapped - North Platte	(800) 742-7691
Library for the Blind & Physically Handicapped - Lincoln	(800) 742-7691

TOLL FREE NUMBERS CONTINUED . . .

National Center for Stuttering	(800) 221-2483
National Crisis for the Deaf	(800) 446-9876
National Down's Syndrome	(800) 221-4602
National Easter Seal Society	(800) 221-6827
National Kidney Foundation	(800) 642-1255
Nebraska ChildFind	(800) 742-7594
Nebraska Diagnostic Resource Center	(800) 652-0033
Nebraska Special Olympics	(800) 247-0105
Parent Assistance Line	(800) 642-9909
Social Security Hotline	(800) 642-8310
Spina Bifida Hotline	(800) 621-3141
Spinal Hotline	(800) 526-3456
Sudden Infant Death Syndrome	(800) 742-7844
Task Force on Education for the Handicapped	(800) 332-4433

National Information Center for Handicapped Children and Youth

P O BOX 1492
WASHINGTON. D.C. 20013

SOURCES OF HELP AND INFORMATION

There are a number of sources for more information on handicaps and related issues. This section describes some of the things you can have sent to you.

DISABLED USA

President's Committee on Employment
of the Handicapped
Washington, D.C. 20210.
(Published Monthly)

Reports progress in opportunities for people with disabilities and developments in rehabilitation and employment.

THE INDEPENDENT

Center for Independent Living,
2539 Telegraph Avenue
Berkeley, CA 94704
(Published quarterly)

Articles about disabilities and up-to-date information on independent living.

REPORT

The National Center for a Barrier
Free Environment
1015 15th Street, N.W. Suite 700
Washington, DC 20005
(Published bi-monthly)

News about legislation related to accessibility, news briefs and summaries of articles and books mainly concerned with barriers.

SIBLING INFORMATION NETWORK NEWSLETTER

Department of Educational Psychology
Box U-64
University of Connecticut
Storrs, CT 06268

Research and literature reviews, meetings, family relationship information of interest to siblings of youth with handicaps.

THE EXCEPTIONAL PARENT

The Exceptional Parent
295 Boylston Street
3rd Floor
Boston, MA 02116
(Published eight times yearly)

Emphasis on education, diagnosis, attitudes, care; covering all handicaps, it is directed toward parents.

THE GREEN SOURCE BOOK -- NATIONAL DIRECTORY OF PRODUCTS AND SERVICES FOR THE DISABLED (Formerly entitled GREEN PAGES)

Source Book Publications
P.O. Box 1586
Winter Park, FL 32789
(Published annually)

Annual Directory of products and services. Subscription includes an occasional newsletter, "Green Papers," with legislative information and stories about people with handicaps.

UPFRONT

Mafex Associates, Inc.
90 Cherry Street, Box 519
Johnstown, PA 15907
(Published 11 times a year)

A newspaper for and about physically and mentally disabled people.

INFORMATION ABOUT HANDICAPPING CONDITIONS

Write to these agencies for information about all handicapping conditions. Specify exactly what you are interested in. Organizations dealing with specific handicapping conditions are listed on individual fact sheets.

American Civil Liberties Union
132 West 43rd Street
New York, NY 10036

American Genetics Association
818 18th Street, NW
Washington, DC 20036

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Developmental Disabilitites Office
U.S. Department of Health and Human
Services
200 Independence Avenue, SW
Room 338E
Washington, DC 20201

Human Resources Center
I.U. Willets Road
Albertson, NY 11507

Library of Congress
Division for Blind and Physically
Handicapped
1291 Taylor Street, NW
Washington, DC 20542

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

National Rehabilitation Association
633 South Washington Street
Alexandria, VA 22314

Office for Handicapped Individuals
U.S. Department of Health and Human
Services
200 Independence Avenue, SW
Washington, DC 20201

Office of Rehabilitation Services
U.S. Department of Education
Switzer Building
330 "C" Street, SW
Washington, DC 20202

President's Committee on Employment
of the Handicapped
Washington, DC 20010

President's Committee on Mental
Retardation
Washington, DC 20201

Special Education Programs
U. S. Department of Education
Switzer Building
330 "C" Street, SW
Washington, DC 20202

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National Information Center for Handicapped Children and Youth

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LIST OF AVAILABLE INFORMATION

STATE SHEETS

Available for each state and territory and the District of Columbia, the State Sheets provide names and addresses of public agengies and other groups who are concerned with handicapped children and youth. Each State Sheet is also accompanied by a Public Agencies sheet that describes the purposes and activities of each agency or organization. Updated yearly.

GENERAL INFORMATION

Sources of help and information that provide general information about handicapping conditions and related issues, this list includes organizations and publications of special interest.

FACT SHEETS ON HANDICAPS

Each sheet contains a description of the handicapping condition, statistics on prevalence, educational implications and references and resources for further information. Currently the following topics are available:

Autism
Cerebral Palsy
Deafness and Hearing Impairments
Down's Syndrome
Emotional Disturbances
Epilepsy
Learning Disabilities
Legal Definitions of Handicapping Conditions
Mental Retardation
Physical Disabilities and Special Health Problems
Severe Handicaps
Speech and Language Impairments
Spina Bifida
Visual Impairments

LEGAL INFORMATION

An information package that contains fact sheets on the rights of children with handicaps, primarily related to education. Basic information includes the topics of assessment, due process, individualized educational programs, the special concerns of minority children with handicaps, resources for legal advice and support, and a listing of regional offices of the Office of Civil Rights.

PARENT INFORMATION

An information packet that contains information on direct services for children, advocacy and parent support groups, and accepting a child's handicap.

TEACHER/PARENT INFORMATION

An information packet that includes topics of implications for teaching children with specific handicaps, attitudes and expectations, team teaching, the teacher/parent relationship, classroom management, and sources of teaching materials and further information.

STUDENT INFORMATION

An information packet that includes brief descriptions of careers serving children and youth with handicaps through special education and related services, locations of personnel preparation programs, and sources of financial aid.

APPENDIX F

PAMPHLETS RELATED TO SCHOOL REFERRAL PROCESS

HANDICAPPED CHILDREN: THEIR RIGHT TO AN EDUCATION

EDUCATION FOR HANDICAPPED CHILDREN

GUIDE TO YOUR CHILD'S DEVELOPMENTAL ASSESSMENT

PAMPHLETS RELATED TO COMPREHENSIVE CASE COORDINATION

NEBRASKA DEPARTMENT OF SOCIAL SERVICES
General Information
Emergency Assistance
Aid to Dependent Children
Disabled Persons and Family Support

WE ARE LOOKING FOR SPECIAL CHILDREN - NEBRASKA CHILDFIND

DIRECTORY OF RECREATION PROGRAMS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

NATIONAL INFORMATION CENTER FOR HANDCIAPPED CHILDREN AND YOUTH

EDUCATION FOR HANDICAPPED CHILDREN

EDUCATION FOR CHILDREN

THEIR RIGHTS

Table of Contents Page

Some of the most common questions asked by parents and guardians of handicapped students are included at the end of each section of the pamphlet.

GLOSSARY

Special education programs shall include, but not be restricted to, the development of self-realization, social awareness, economic usefulness, and civic responsibility.

Special education shall mean educational experiences and services through the use of special facilities and special adaptive classrooms, or either of the same to provide special instruction or the supportive services necessary to diagnose, place and maintain handicapped children in appropriate programs.

Special facilities and special adaptive classrooms shall mean those rooms within school buildings which meet the learning needs of handicapped children.

Supportive services shall mean all resources available to the individual to help meet appropriate educational goals and objectives, and shall include auxiliary and resource personnel and materiel and facility resources.

Related services shall mean only services required to assist a handicapped child to benefit from special education.

Auxiliary and resource personnel shall mean those persons who have full or part-time employment as licensed or certificated resource teachers; speech/language pathologists; hearing clinicians or audiologists; professional diagnostic personnel; supervisory and administrative personnel; special reader personnel; braillists, and orientation and mobility specialists for the visually handicapped; physical and occupational therapists; vocational adjustment and work-study coordinators; specialized consultants; and home and hospital instructional personnel. Aides and paraprofessionals under the supervision of licensed or certificated personnel may be included.

Materiel resources shall mean special instructional equipment, supplies, and publications which are necessary for teaching children with specific handicapping conditions Such equipment and material shall be restricted to those items which are identified for instructional purposes and practices for the specific handicapping conditions.

ELIGIBILITY

Eligibility for Special Education

The local school districts in Nebraska by law must provide educational services for resident handicapped children from the date of diagnosis to age 21. Service may be provided by the school district or within a combination of school districts, Educational Service Units, Office of Mental Retardation programs or other state approved programs. Each special program must be approved by the State Department of Education. The school district pays for the special education program and may be eligible for reimbursement of allowable excess cost by the State Department of Education.

Children who Benefit from Special Education

Children who benefit from special education may have one or more of the following verified handicapping conditions. visual, speech, acoustical hearing, orthopedic, behaviorally impaired, specific learning disability, mental retardation, educable mentally handicapped or multiply handicapped severe-profound. These children may be able to participate in the regular classroom with special support services, or they may be served in special facilities or adaptive classrooms.

How Children Qualify for Special Education

A parent, teacher, principal or specialist may suspect that a child needs special education. These concerns should be communicated to appropriate school officials. Written permission must be obtained from the parents in order for the child to receive a diagnostic evaluation. It is the school's responsibility to obtain this written permission. The child's needs are determined by school personnel with analysis and possible verification of the handicapping conditions made by a qualified professional multidisciplinary team.

The multidisciplinary team or group of persons shall include at least one of the student's classroom teachers or other specialist with knowledge in the area of the suspected handicap. The evaluations shall be administered in the child's native or primary language or mode of communication (i.e , sign language, finger spelling, gestures, etc.) and shall be used to assess the specific areas of educational need of that child and not be merely general intelligence quotient tests.

The multidisciplinary team shall prepare a written report summarizing the results of the evaluation. The report shall include a statement of whether or not the child qualifies as handicapped with reference to specific categories, the basis for the decision to qualify the student and a listing of the team members as defined by state regulation.

The team members may certify in writing that the report reflects their conclusion. If it doesn't, individual team members may submit a separate statement presenting his or her conclusion. The statement shall be furnished to the school district and the parent.

Independent Evaluation

If the parent disagrees with an evaluation obtained by the school district, a parent/guardian has a right to request an independent educational evaluation at public expense. Parents/guardians should direct inquiries to school officials to determine if the school district will arrange for further evaluation at public expense. If school district officials feel the original evaluation was appropriate and the parents disagree, a due process hearing may be initiated. If it is determined that the original evaluation was appropriate, the parents still have the right to an independent educational evaluation at their own expense. Information on independent evaluators will be available through the Nebraska Department of Education or your local school district.

Each child receiving special education services shall be assessed every three years, or more frequently if the conditions warrant. Verification of permanent conditions need not be repeated. Written prior notice of a re-evaluation must be provided to the parent, but parental consent is not required for a re-evaluation.

ELIGIBILITY

How are handicapped children identified?

Each school district shall identify all children who would benefit from special education services.

How are children referred for testing?

A review (screening) of the child's progress must occur prior to referral and shall include identification of the learning problems of the child and consideration of alternative services available.

Must all referrals for diagnosis be made by school district personnel?

No. Parents or guardians may make a request to the ool district for diagnosis.

Can a child be identified as handicapped based on a single test?

No. A single procedure cannot be used as a sole criterion for determining an appropriate educational program for a child.

Who is included on the multidisciplinary team?

The team should include at least one of the student's classroom teachers or other specialist with knowledge in the area of the suspected handicap.

Is it possible for me to review the kinds of tests my child is taking?

Yes. You have the right to information concerning the evaluation procedure and tests used for placement. You also have the right to have someone available to explain the evaluation procedure and the tests or evaluation procedure used for placement.

INDIVIDUAL EDUCATION PROGRAM

Individualized Education Program (IEP)

The Individualized Education Program (IEP) is a written statement for a handicapped child that specifies the special education and related services necessary to assure that child a free appropriate public education. The IEP shall include a statement of the child's present level of educational performance, annual goals and instructional objectives, timelines for services, regular program involvement, program evaluation and a list of persons responsible for implementing the IEP. The resident school district is responsible for initiating and conducting an IEP conference. The IEP must be in effect before special education and related services are provided to a child.

Temporary Placement

A school district may make a temporary placement with the written approval of a parent or guardian in a special education program not to exceed thirty (30) calendar days. With parental permission, an "interim" IEP, not to exceed 30 days, may be developed which establishes the specific conditions and timelines for any trial placement as part of the evaluation process prior to finalization. At the end of the trial period, a meeting must be conducted to construct the final IEP. The IEP shall be implemented as soon as possible following the IEP conference, and must be reviewed at least annually.

Timelines for IEP's

Within thirty (30) days after a child is diagnosed, a meeting(s) must be held to develop an IEP, with the consent and participation of the parent/guardian and the local school district. Parents/guardians shall be afforded an opportunity to participate in the planning conference at a mutually agreed time and place and shall be afforded alternative opportunities should they be unable to attend. If the conference must occur without the parents being present, the school district shall document attempts to include them and such documentation shall be made part of the IEP record.

IEP Conference

Parents/guardians shall be notified of the persons who will be in attendance. The IEP conference shall include at least the following:

1. A representative of the school district;
2. The child's teacher;
3. One or both parents/guardians;
4. The child (when appropriate);
5. One member of the multidisciplinary evaluation team when the child has been evaluated for the first time; and
6. Other individuals, at the discretion of the parent/guardian or school district.

INDIVIDUAL EDUCATION PROGRAM

May I have a written copy of the IEP?

Yes. The school district will provide you with a copy either after the meeting or through the mail.

Do I have to sign the IEP?

No. It is not necessary if you are dissatisifed with the IEP meeting and wish to meet again for more discussion.

Yes. If you are satisfied that the IEP meets the needs of your child it is a good idea to have a signed document in effect.

May I invite another person to attend the meeting?

Yes. It is possible to bring another person but it is usually a good idea to inform the school before the scheduled meeting.

What services are available for children below age five?

Services vary according to the needs of the child. Some of the services may include speech therapy, physical and occupational therapy, and developmental skill training through in-home services or center-based programs.

Can services for more than one handicapping condition be written into the IEP?

Yes. Any combination of services can be written into the IEP if the team determines they are necessary for the education of the child.

PLACEMENT

Least Restrictive Environment Requirements

The child's placement in a special education program is dependent on the programmatic needs as outlined in the Individualized Education Program and must be determined at least annually. The school district must re that handicapped children are educated with children who are not handicapped, to the maximum extent possible. Children are entitled to have supplementary aids and services to help them in a regular educational setting. Handicapped children may be placed in special classes, separate schools or other situations outside the regular educational environment when the nature of the child's needs require specialized educational techniques which are not available in the current settings.

Notification of Parents/Confidentiality

Written notice shall be given to the parents/guardians a reasonable time before a school district:

1. Proposes to initiate or change the diagnosis of a child; or
2. Proposes to initiate, change or terminate the educational placement of a child.

This written notice shall include a full explanation of safeguards under state and federal law, a description of the action proposed or refused by the school district, a description of the evaluation procedure and a description of any other factors which have a bearing on the situation.

The notice must be written or translated orally to the parent/guardian in his or her native language.

Parental Consent

Parental consent must be obtained by the school district before conducting a pre-placement evaluation and initial placement in a special education program.

Parent Refusal to Consent

If parents/guardians refuse the evaluation or placement, the school district may initiate a hearing. If an independent hearing officer or any court decides in favor of the school district, the school may evaluate and/or place the student without parental consent and may refuse to provide or pay for any further inappropriate educational program.

Placement Requirements

School districts may place children in special education programs provided:

1. Written permission is obtained from the parent or
2. An order is obtained from a Hearing Officer or Court of Jurisdiction.

Temporary Placements

A school district may make a temporary placement in a program not to exceed thirty (30) calendar days with written approval of parents or guardians. An interim IEP for the 30 day period shall be prepared prior to the student's temporary placement.

Independent Placements

If the school district of residence has made available an appropriate special education program to a handicapped child and the child's parents or guardians choose to place the child in an alternative service agency, the district is not required to pay for the student's education in the alternative setting. Disagreements between parents or guardians and a school district regarding whether or not the school district has such a program available, or regarding the question of responsibility, are subject to due process procedures.

Residential Placements

Whenever a child must temporarily reside in a residential facility, boarding home, or foster home in order to receive an appropriate special education program, the State of Nebraska shall provide for the ordinary and reasonable cost of the residential care for the duration of this placement.

No school district shall make a placement in a special education program requiring residential care without advance consultation with the Nebraska Department of Education. Applications for approval of special education placements requiring residential care shall be signed by the parent/guardian, submitted through the school district and acted upon by the Nebraska Department of Education within thirty (30) days of its receipt.

If the application is denied, the parent/guardian shall be provided written notification by the Nebraska Department of Education of the right to appeal this decision.

Surrogates

Each local school district shall insure that the rights of a child are protected by the appointment of a surrogate when: (1) a parent cannot be identified; (2) the local school district, after reasonable efforts, cannot locate the parents; or (3) the child is a Ward of the State or any Court.

The surrogate may represent the child in all matters relating to: (1) the identification, evaluation, and educational placement of a child; and (2) the provision of a free appropriate public education to the child.

PLACEMENT

How is my child placed in a special education program?

The IEP must be in effect before special education and related services are provided to a child.

Would my child ever have a temporary special education placement?

A school district may make a temporary placement only for the purpose of observation or evaluation. The parent or guardian must give permission for the placement and it may not exceed thirty (30) calendar days.

How can services for handicapped students be provided?

The school district must provide educational services for resident, handicapped children from the date of diagnosis to age 21. Special education programs may be provided by the school district, by contracting with another school district, or service agency, or by some combination of educational service units, the local or regional office of mental retardation, or any program operated by the State of Nebraska provided that only nonsectarian services shall be purchased.

How do school districts initially place children in special education programs?

1. The parents give written permission to place the child in the proposed program; or
2. An order to place the child in a proposed program is obtained from a Hearing Officer or Court of competent jurisdiction.

Can a school make a change in placement for a handicapped child without written parental approval or order of a hearing officer or a court?

Yes, provided that the following requirements are met:

1. Written prior notice is sent to parents or guardians;
2. Requirements for diagnosis and eligibility have been met; and
3. The change in placement is based on child's current IEP and any other information relating to the child and his/her current educational performance.

When can a school district end a special education program?

A school district cannot terminate an education program for a handicapped student prior to age 21 unless:

1. The school district has a written policy concerning completion prior to age 21;
2. A plan for program completion has been communicated to the handicapped student and parents or guardians; and
3. Parents or guardians have been informed of the due process and complaint procedures.

Where can I find out about special education services that are available in the state?

Childfind and Hotline for the Handicapped office provides assistance and a directory of all services available for handicapped children in the state. The toll free number for Childfind and Hotline are 800-742-7594 and 402-471-3644 and includes TTY service.

RECORDS

Confidentiality of Records

Types of Records (personal)

The school district maintains personal records which include the student's name, address, phone number, grades, attendance records, classes attended, grade level completed and year completed. Other information that may be a part of a cumulative record includes health files, standardized test results, teacher's notes, diagnostic and evaluation results and recommendations, the IEP and statements pertaining to the educational placement of the child. The parents/guardians have the right to inspect and review educational records of their child without charge, and the school shall comply with the request without unnecessary delay and in no case more than 45 days after the request has been made. The school may charge if the parent/guardian request copies of the child's educational records. Additionally, the parents/guardians may request the school to provide explanations and interpretations of their child's educational records. If there is information in the child's records with which the parents disagree and the school refuses to change or modify the information, a hearing can be initiated. If the parents lose the hearing, they may file their own statement which will be added to the child's records.

Types of Records (permanent)

Basic information, such as name, birthdate, address, and phone number may be maintained without time limitations. All other information (i.e. IEP, diagnostic information, etc.) that is part of the confidential file must be destroyed within five (5) years, after the child leaves school. Parents/guardians and students shall be notified before these records are destroyed and may request a copy of the data.

The parents/guardians and their representative or the child who has reached the age of majority shall have access to any information maintained in the agency pertaining to placement of the child.

Do I have to contact the school district before viewing the records?

Yes. The agency or institution shall comply with a request within a reasonable period of time, but in no case more than forty-five (45) days after the request has been made.

Do I have a right to a copy of the school records?

The right to inspect and review educational records includes the right to obtain copies of the records where failure of the educational agency to provide copies would effectively prevent a parent/guardian/student from exercising the right to inspect and review.

Who pays for the copies of the school record?

A school district may charge a fee for copies made for parents/guardians and students provided the fee does not effectively prevent parents/guardians/ students from exercising their right to inspect and review.

How do I challenge the contents of my child's record?

The parent/guardian/student who believes the information contained in the student file is inaccurate or misleading or violates the privacy or other right of the pupil may request that the records be amended. The school district decides whether to change the records in accordance with the request. If the school district refuses to change the records, school personnel shall inform the parent/guardian/student of their decision and advise the parent/guardian/student of their right to a hearing.

Who has access to the records within the school building?

A listing of the types and locations of educational records maintained by the school district and the titles and addresses of the officials responsible for those records are contained in the school district policy. A school district may disclose a student's files to school officials within the district who have been determined to have legitimate educational interests. School district policy must specify the criteria for determining which parties are "school officials" and what the school district considers a "legitimate educational interest".

COMPLAINTS AND DUE PROCESS

The Complaint Process

The Education for the Handicapped Act, Public Law 94-142, requires that the Nebraska Department of Education and the local school district establish safeguards to ensure that handicapped children receive a free appropriate public education.

The complaint process affords parents an opportunity to present complaints relating to the identification, evaluation, or educational placement of their child, or the provision of a free appropriate public education.

Any complaint(s) should be submitted, in writing, to the Compliance Director, Special Education Office, Nebraska Department of Education, P.O. Box 94987, Lincoln, Nebraska 68509. This written, signed complaint must give a detailed explanation of the specific facts. If it is determined that the complaint is related to violations of special education rules, the following steps will be taken:

1. Within sixty (60) calendar days of receipt of a signed written complaint, the Special Education Office Compliance Director will provide written notification of findings and the basis for such findings to all parties involved.
2. If, as a result of extenuating circumstances the Nebraska Department of Education, Special Education Office is not able to complete the investigation within the sixty (60) calendar days, an extension period of forty-five (45) calendar days will be implemented. The Nebraska Department of Education, Special Education Office will notify each complainant, the school district, and if appropriate, the service agency of the 45 day extension.

Due Process

Due Process gives the parent/guardian the right to request a hearing as relates to the identification, evaluation or educational placement of their child, or the provision of a free appropriate public education. Parents may also request a due process hearing when any initiation, change or termination in their child's educational program is proposed. No change in the student's educational placement may be made while a due process procedure is pending, unless both parties agree or for health and safety reasons.

A written request for a hearing, called the petition, must be filed with the Nebraska Department of Education, Special Education Office, 301 Centennial Mall South, Box 94987, Lincoln, Nebraska 68509.

This written petition must contain the following information:

1. The name, address and telephone number of both the person filing the petition (petitioner) and the educational agency against whom the complaint is made (respondent);
2. The name, birthdate, handicap and current educational placement of the student;
3. A short description of the dispute;
4. A statement that efforts have been made to settle the dispute, how this was tried, and a final statement that settlement does not seem likely;
5. Statement of what outcome the petitioner is requesting; and
6. Signature of the petitioner or a representative.

A parent or guardian shall not be entitled to reimbursement for any expenses incurred more than sixty (60) days prior to the filing of the petition.

Upon receipt of the petition, the Department of Education will make a determination whether the petition meets all requirements. If the petition meets all requirements, the Department shall assign the petition to a hearing officer and notify the petitioner of the assignment. Hearing officers shall have exclusive, original jurisdiction over special education cases.

The hearing officer will request an answer from the respondent, who must file the written answer, within ten (10) calendar days of the receipt of the request. The answer must be filed with the hearing officer and contain the following:

1. Name, address and telephone number of the respondent,
2. General and concise statements regarding the facts stated in the petition; and
3. The signature of the respondent.

Upon receiving the answer, the hearing officer will arrange a convenient time and place for the hearing. At least five (5) days before the hearing, both the petitioner and the respondent must submit to each other and the hearing officer a summary of the evidence they intend to introduce at the hearing, a list of witnesses to be called and copies of complicated exhibits. At least three (3) days before the hearing, any party may deliver to the hearing officer a written request asking that the hearing be bound by the rules of evidence applicable in a Nebraska district court and by mailing copies of the request at the same time to the other parties and the Nebraska Department of Education. Any party may also request the hearing officer to issue a subpoena requiring the attendance of a witness, and any witness, who is summoned and who responds, is entitled to the same fees paid by the requesting party that apply in the Nebraska district courts.

The hearing officer insures that a record is made of the testimony of each witness. Each party, either in person or by counsel, may present an oral or written opening and closing statement, witnesses and exhibits.

After the hearing, the hearing officer sends a written summary of the evidence, report, final decision and order to each of the parties. The final decision and order takes effect thirty (30) calendar days after the parties receive it, if no appeal is made by any of the parties. Any parent or school district who is not satsified with the order may appeal to the District Court.

Under Nebraska Statute, a copy of the procedures specified in the rules and regulations of the Department of Education for complaints and hearings shall be provided by local school districts to all parents and guardians of handicapped children.

COMPLAINTS AND DUE PROCESS

How do I file a petition?

You may request a petition form from the Nebraska Department of Education, Special Education Office, 301 Centennial Mall South, Box 94987, Lincoln, Nebraska 68509. When completed, the forms are to be returned to the Department (same address).

How are the hearing officers assigned?

Independent hearing officers are assigned on a regional basis by the Department of Education. Hearing officers cannot be employed by the state or by local school districts.

Will I be able to call the hearing officer?

Yes, if you have questions regarding the due process hearing such as location, time and dates.

No, if you want to discuss the case, or ask for legal advice.

How long is the due process procedure?

The hearing officer shall hold the hearing and issue the Report and the Final Decision and Order within forty-five (45) calendar days of receipt of a petition by the Department of Education. This 45 calendar day limit may be extended by the hearing officer at the request of either party for good cause shown.

What does the hearing officer's final decision and order do? Is the order binding?

The order describes the action to be taken based on the findings of fact and conclusions of law in the decision. The order shall take effect thirty (30) calendar days after receipt by both parties unless there is an appeal.

Can I bring a lawyer to the due process hearing to present my case?

Yes. You may be accompanied by the counsel of your choice.

Do I have to file a complaint before due process?

No. It is not necessary to file a complaint to the Department's Compliance Director before submitting a petition requesting a due process hearing.

Often, a complaint to the Compliance Director will be filed and resolved so that due process is not necessary. A complaint to the Compliance Director, however, does not preserve your right to reimbursement of costs you have incurred for evaluation, educational programming or related services for your handicapped child.

What if I believe that the due process hearing was not conducted fairly or if I believe it was decided incorrectly?

You may file an appeal either in the district court of the county or in the federal district court to obtain judicial review of the hearing officer's Final Decision and Order. Such an appeal must be filed within thirty (30) days after receipt of the hearing officer's Final Decision and Order.

Where would I find services available for free or low cost legal assistance?

If you are unable to afford legal counsel, contact the Department of Education, Special Education Office for information on available free or low-cost legal services. Names, addresses and telephone numbers are available to persons needing these services.

REFERENCES

Education of the Handicapped Act
    Title 20, United States Code, Sections 1401 to 1460
Family Educational Rights and Privacy Act
    Title 20, United States Code, Section 1232g
Education of the Handicapped Act Regulations
    Volume 34, Code of Federal Regulations, Part 300
Family Educational Rights and Privacy Act Regulations
    Volume 34, Code of Federal Regulations, Part 99
Care and Education of Handicapped Children
    43 Nebraska Revised Statutes, Sections 601-680
Nebraska Department of Education Regulations
    Title 92, Nebraska Administrative Code Chapters 51, 53 and 55

Special Education
Nebraska Department of Education
301 Centennial Mall South
Box 94987
Lincoln, Nebraska 68509

Guide to—

Your Child's Developmental Assessment

Developed by the Meyer Children's Rehabilitation Institute, University of Nebraska Medical Center

Welcome

Welcome to the Early Referral and Follow-up Project. In this program, we will evaluate your baby's development. This booklet will acquaint you with what you can do to prepare for the evaluations and how you can help during the process.

Evaluation Process

You may wonder if your baby is too young or too ill for evaluations. The Early Referral Project Team frequently sees children who are very young and/or sick. We take these factors into consideration when we perform the evaluations and interpret the results. In special situations, we may perform limited evaluations.

The information we learn from these evaluations is important for several reasons. First, it helps us determine what services your child may need. Also, it helps you understand your baby's needs so you can help him or her grow and develop.

We will rely on you to tell us about your baby, such as the best time of day to schedule appointments. You know your baby better than anyone else, so any information you can give us about him or her is important during the evaluations. It is important for you to attend these evaluations in case your baby needs to be changed, fed or comforted during the procedures.

things to Bring

When you and your baby come for the evaluations, you should bring a bottle, snack, pacifier, diapers, a favorite toy or anything else that will make your baby more comfortable during the evaluations.

Early Referral *Project Team*

Evaluations are conducted by Early Referral Project Team members, including an infant specialist, a parent-infant teacher, a physical therapist, an occupational therapist, a speech pathologist and a clinical nurse specialist. Your baby's needs will determine the team members.

If you have questions or concerns about your child's development, this will be a good opportunity for you to discuss these with us. Feel free to ask questions during the evaluations.

Parent-Infant Teacher and Infant Assessment Specialist

Both the teacher and infant assessment specialist test your baby to observe how he or she interacts with objects and people. For example, does your baby follow objects with his eyes, reach for toys, bring things to his mouth to examine them, and look for toys which have been moved out of sight?

During this evaluation, the specialist will give you suggestions about activities and appropriate toys you should use when playing with your baby. They may also recommend that your baby be tested again in a few months to observe his improvement and to give you new suggestions.

Speech Pathologist

In many cases, the children we see are not old enough to talk or may have some condition that limits their ability to make sounds. However, all babies communicate in a variety of ways. The speech pathologist is interested in the ways your child interacts with you, how well he or she gets a message across, and what your child understands about his environment.

Occupational Therapist

The occupational therapist (OT) is concerned about how your baby performs everyday activities such as eating, touching and exploring with his hands. The OT is especially interested in how your baby is eating and any problems that he or she may have in this area. The therapist will ask you what kinds of foods your baby is eating and if he or she is having any difficulties sucking, biting, chewing or swallowing food.

The OT is also interested in how your child is using his or her hands in activities such as reaching, holding and letting go of objects. These activities are referred to as fine motor skills. The therapist evaluates fine motor skills by observing how your child plays with toys.

Physical Therapist

The physical therapist (PT) considers how your child moves, looks at the quality of movement and the development of gross motor skills.

Gross motor skills begin with how your child holds his head and trunk steady, and progress to skills such as rolling over, sitting, crawling and walking.

The therapist will check to see if your child is strong, stiff, floppy or jittery. Does your child prefer using one hand more than the other? Does he or she kick both legs equally? These are questions the PT will consider when evaluating your baby's quality of movement.

The therapist may also help you adapt equipment to assist your baby in maintaining certain positions, such as sitting, standing or lying down.

Clinical Nurse Specialist

The nurse will help you become comfortable with the basic care routines you use with your child. The nurse can answer questions you have about such things as medications or special monitoring and can discuss your concerns about your child in regard to feeding/meal planning, skin care, elimination and sleep disturbances. The nurse is also available to discuss health questions in regard to other members of your family as well.

Summary

Suggestions

1.

2.

3.

My case manager is

If I need to call, the phone number is:

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Nebraska
Department of
Social Services

Information

Day Care provides care and supervision of children for part of a day. This service may be provided in a variety of settings which may include the child's own home, the provider's home or a center.

Day Care Providers Should Possess:

- A warm, caring personality
- The patience and understanding to work with children
- The ability to respond to emergency situations
- A willingness to abide by state and local child-care laws
- No previous record of inappropriate behaviors concerning children

Responsibilities of Day Care Providers May Include:

- Providing a clean and safe environment
- Preparing and serving nutritious meals and snacks
- Providing a variety of appropriate activities
- Keeping records concerning emergency phone numbers, immunizations, medications and attendance

DAY CARE PROVIDERS CARE FOR AND ABOUT CHILDREN!

For More Information

If you interested in becoming a Day Care Provider, or would like more information on Day Care Services, please contact your local office of the Nebraska Department of Social Services.

Adult Family Homes provide family settings within the community for aged and physically or mentally disabled adults who, because of limitations, are in need of some supervision.

Residents of Adult Family Homes are not in need of institutional or nursing care but are unable to live alone in the community and have no relative who can provide appropriate care. Instead, their needs are most appropriately met in a home-like living environment where a sponsor can provide personal support. Individuals or families who act as sponsors may be reimbursed for their services given.

Adult Family Home Sponsors Should Possess:

- The willingness to open one's home to an aged or disabled adult
- The ability to display patience and understanding, and a positive outlook on life
- The willingness to work cooperatively with the Department of Social Services or other community agencies

Adult Family Home Sponsors Have Responsibility To:

- Provide a safe, clean living environment and assistance with personal care
- Include the resident in family activities and communication
- Maintain a record of important information about each resident including the name and telephone number of resident's doctor and hospital and pharmacy preference
- Arrange for special access to the home, when necessary, for a disabled resident

ADULT FAMILY HOME SPONSORS HELP SPECIAL ADULTS BECOME PART OF A FAMILY!

For More Information

If you are interested in becoming an Adult Family Home Sponsor, or would like more information on the Adult Family Home Program, please contact your local office of Nebraska Department of Social Services.

Personal Care Services provide medically related services based on an individual's physical, emotional, environmental, and personal care needs. Personal Care Providers are not substitutes for nurses and physicians, but support the medical plan of care.

These services are offered to low income individuals who, due to illness or disability, need personal care assistance to remain in their home environments. Personal Care Providers may be financially compensated for their services.

Personal Care Providers Are:

- Individuals, age 18 or older, who are not related to the person receiving care
- Concerned about the physical well being of an individual with special medical needs
- Able to properly perform the needed services derived from an individual's illness or disability
- Dependable, being available at agreed-upon times
- Willing to work cooperatively with the Department of Social Services, the individual, and the individual's physician

Responsibilities Of Personal Care Providers May Include:

- Helping the individual to follow medical recommendations i.e. helping to follow doctor's orders, watching their diet
- Preparing and serving special food
- Assisting with eating, dressing, bathing, getting in and out of bed, etc.
- Accompanying the individual to a clinic or physician's office

PERSONAL CARE PROVIDERS CAN MAKE THE DIFFERENCE IN AN INDIVIDUAL'S PHYSICAL WELL-BEING!

For More Information

If you are interested in becoming a Personal Care Provider, or would like more information on Personal Care Services, please contact your local office of the Nebraska Department of Social Services.

Personal Care Services

Homemakers provide services in the homes of aged, physically or mentally disabled adults, and families who are unable to adequately manage the family or household due to lack of knowledge, skills, or ability. The Homemaker client may be a low income individual or family, or have a special need regardless of income.

Homemakers provide assistance and instruction to maintain and strengthen families and alleviate stresses in the home. The Department of Social Services may financially compensate those individuals who give their time and support through Homemaker Services.

Some Characteristics Homemakers Should Possess Are:

* The ability to exhibit emotional maturity in assuming responsibility and adapting to new environments and household situations
* The ability to share knowledge and homemaker experience with family members
* The desire to establish open communication and caring relationships with individuals through a supportive atmosphere
* The willingness to work cooperatively with the Department of Social Services

Responsibilities Of Homemakers May Include:

* Organizing of household activities and time and budget instruction
* Providing knowledge on personal hygiene and health care
* Instructing on cleaning and maintaining appliances, furniture, household supplies, and clothing
* Training in the care of children or disabled family members, through enrichment of parenting skills

HOMEMAKERS ARE A STRENGTHENING FORCE TO INDIVIDUALS AND FAMILIES!

For More Information

If you are interested in becoming a Homemaker, or would like more information on Homemaker Services, please contact your local office of the Nebraska Department of Social Services.

Transportation Services

Transportation Services provide aged and physically or mentally disabled adults with transportation to and from local community facilities when no other transportation is available. Transportation Services for families provide a means of travel to and from other services such as family planning, day care services, health related care, child protective services and foster care.

Adults or families needing transportation do not have access to a vehicle or other transportation. Individuals who devote their time and energy to Transportation Services may be financially compensated for their special help.

Some Of The Abilities Transportation Providers Should Possess Are:

- Knowledge of state and local traffic rules and dependability when providing transportation
- The willingness to and capability of assisting handicapped adults and children
- Patience and understanding when assisting individuals
- The willingness to work cooperatively with the Department of Social Services

Responsibilities Of Transportation Providers May Include:

- Ensuring that the transporting vehicle is licensed, properly insured, and equipped with safety devices and adequate ventilation
- Providing transportation to assist individuals in applying for education or employment
- Providing transportation for individuals with health, housing, legal, or nutritional needs
- Supplying transportation to individuals returning from or entering a hospital or nursing home

PROVIDE A MEANS FOR INDEPENDENCE AS A TRANSPORTATION PROVIDER!

For More Information

If you are interested in becoming a Transportation Provider, or would like more information on Transportation Services, please contact your local office of the Nebraska Department of Social Services.

Transportation Services

Emergency Shelter Care provides immediate, temporary homes for children in crisis situations. The shelter may be a foster home or other facility which provides 24-hour physical care and supervision to children whose families face immediate problems such as the critical illness or sudden disability of a parent, or to children who are victims of abuse or neglect.

Emergency Shelter Care provides for a child's immediate need for care in a supportive setting, which can help reduce the child's fear, anxiety and shock. Placement is from one day to a maximum of 15 days, to allow time for a more permanent arrangement for the child to be made. Individuals and families who open their homes to children in crisis situations may be financially reimbursed for their services.

Emergency Care Providers Should Possess:

* The ability to be flexible, accepting care of a child with little advance notice
* The ability to remain calm in spite of any crisis
* The ability to warmly support the child in dealing with the crisis situation and other problems
* The ability to maintain an atmosphere of optimism and enjoyment in the home
* The willingness to work cooperatively with the Department of Social Services

Individuals Who Provide Emergency Shelter Care Have The Responsibility To:

* Provide day-to-day care of the child for the necessary period of time
* Respect the worth of the child regardless of age, race, sex, religion, or disability
* Provide a safe, positive home environment and good communication
* Notify the Department of Social Services of a change of address or any problems that may arise in the home

EMERGENCIES CAN BE PLANNED FOR WITH THE HELP OF EMERGENCY CARE PROVIDERS!

For More Information

If you are interested in becoming an Emergency Care Provider, or would like more information on Emergency Shelter Care, please contact your local office of the Nebraska Department of Social Services.

Chore Services are provided in the homes of aged and physically or mentally disabled adults who are unable to perform basic tasks themselves.

These services include housekeeping, personal care, bill paying, laundry, cooking, simple home repairs, essential shopping errands, escort service, snow removal, and yard maintenance.

Chore Service Providers are people who are willing to offer time and support to individuals in their home environments. Chore Service Providers may be paid for their efforts.

Chore Service Providers Should Possess:

* The willingness to provide a helping hand to aged and disabled adults, while encouraging them to be self-reliant
* The knowledge of and ability to perform a vital chore service
* The ability to adapt to varying household and personal situations
* The willingness to practice reasonable caution and care in the use and storage of equipment, appliances, and tools

Chore Service Providers Perform A Variety Of Tasks Including:

* Cleaning and care of household equipment, appliances, or furnishings
* Assisting with personal care such as bathing, dressing, shaving, and shampooing
* Preparing meals necessary to maintain independence
* Assisting individuals in bill paying
* Shopping for groceries and/or clothing
* Providing minor repairs and yard maintenance such as mowing or snow removal
* Accompanying individuals who are unable to travel by themselves in order to obtain health care, employment, housing, legal, or other services

THE HELPING HAND OF A CHORE SERVICE PROVIDER IS VITAL!

For More Information

If you are interested in becoming a Chore Service Provider, or would like more information on Chore Services, please contact your local office of the Nebraska Department of Social Services.

Respite Care provides temporary care for children or adults when the usual caregivers are in need of relief from the daily stresses of raising children or maintaining a family.

Respite Care may consist of care for a few hours, a day, an evening, or a weekend. It is available when a break from routine is needed, an emergency occurs, or even when a situation arises where it's impossible to be in two places at once. Individuals who provide Respite Care may be reimbursed depending on the individual situation and the time entailed.

Characteristics Of Respite Care Providers May Include:

- The ability to be flexible, accepting care of children or adults openly and sometimes with little advance notice
- The ability to enjoy the company of children and the responsibility of substitute parenting, or the capacity to provide friendly supervision to adults
- The ability to warmly support a child or adult in dealing with a temporary break from routine, whether within the home setting or in a substitute environment, i.e. that of the provider
- The willingness to work cooperatively with the Department of Social Services

The Responsibilities Of Respite Care Providers Include:

- Providing supervision for children or adults when the usual caregiver is in need of assistance
- Accepting children or adults as members of the family during a stay, if necessary and including them in conversations and activities
- Respecting the worth of a child or adult regardless of age, race, sex, religion, or disability
- Providing basic care for the necessary period of time
- Following the recommendations and expectations of the client
- Notifying the Department of Social Services of a change of address or any problems that may arise in the home

WHEN INDIVIDUALS NEED A BREAK FROM ROUTINE, RESPITE CARE PROVIDERS ARE THERE!

For More Information

If you are interested in becoming a Respite Care Provider, or would like more information on Respite Care, please contact your local office of the Nebraska Department of Social Services.

Respite Care

Foster Care provides temporary family care for a child when the child's own family is unable to meet basic needs for care, protection, and love. It is a cooperative effort among natural parents, foster parents, and the Department of Social Services.

Foster Care is needed when a child's own family cannot care for the child properly, and when a child is waiting to be placed for adoption. For most children, life in a family foster home can come closer to normal family living than any other type of setting.

Foster Parents don't have to have special homes. Almost any home will do. Both single and married adults can be Foster Parents. Reimbursement is provided on a monthly basis from the Department of Social Services to those who help.

Some Of The Characteristics Foster Parents Should Possess Are:

* The ability to enjoy the company of children and the responsibility of parenthood
* The capacity to give without expecting too much from the child in the way of gratitude, affection, or behavioral changes
* The ability to accept the child's relationships with his or her natural parents
* The willingness to work cooperatively with the Department of Social Services

The Responsibilities Of Foster Parents Include:

* Providing a warm, nurturing home environment for the child
* Assisting with the day-to-day care and training of the child, including involvement with the school, transportation to medical and counseling appointments, and daily activities in the life of the child
* Accepting the child as a member of the family, while working to help the child's return to the natural family
* Establishing good communication with the child's natural family
* Advising a service worker of any problems in the home that may affect the child, such as marital difficulties, health problems, or financial problems

FOSTER PARENTS PROVIDE THE ENVIRONMENT EVERY CHILD NEEDS–A FAMILY ENVIRONMENT!

For More Information

If you are interested in becoming a Foster Parent, or would like more information on Foster Care, please contact your local office of the Nebraska Department of Social Services.

Adoption Services

Adoption Services find permanent homes for children who are free for adoption and whose present environments lack the stability of adoptive family settings.

The Department of Social Services places all ages and types of children. The majority of children are older, siblings needing placement together, of a minority race, or have some type of behavioral, emotional, or physical handicap. There is no fee for Adoption Services.

Subsidized Adoption provides financial compensation to adoptive parents after the adoption is final, in the event that adoption would not be possible without financial aid.

Married Couples Or Single Individuals May Become Adoptive Parents If They Possess:

- A healthy desire to care for children and to take on the responsibilities of parenthood
- The ability to present an appropriate child care plan which considers the needs of children
- Values and ethical standards conducive to the well-being of children
- The ability to extend nurturing to another child when children already exist in the family
- The willingness to work cooperatively with the Department of Social Services and other community agencies

The Responsibilities Of Adoptive Parents Include:

- Providing a living environment that promotes the health, safety, and well-being of children
- Accepting the fact that the child may come to the family with already-learned patterns and behaviors
- Teaching the child acceptable ways to behave and standards of good conduct, and holding reasonable expectations of the child
- Encouraging the child in personal and social relationships and activities in the same manner as other family members
- Assisting the child with personal care to promote functioning as a future adult
- Establishing a parental bond with the child which promotes open communication, mutual trust, stability, and family ties

CHILDREN NEED THE LASTING ENVIRONMENT THAT ADOPTIVE PARENTS CAN GIVE!

For More Information

If you are interested in becoming an Adoptive Parent, or would like more information on Adoption Services, please contact your local office of the Nebraska Department of Social Services.

Adoption Services

Volunteers add new dimensions to the services provided by the Department of Social Services and symbolize community concern. Volunteers are individuals from all age groups and all walks of life who give their time and effort to help people who need a little assistance in their daily lives: transportation to necessary places, home chores, preparation of meals, or someone just to talk to.

Volunteers Should Possess:

- * A sincere desire to provide assistance to people or to agencies serving people, and a willingness to learn
- * Sufficient knowledge and skill in the assigned task
- * Willingness to comply with agency requirements, principles, regulations, and procedures
- * Warmth, courtesy, and a belief in the dignity of all people
- * Dependability in being available at agreed-upon times

Types Of Volunteer Activities Include:

- * Helping with general office work
- * Typing, filing and/or answering the telephone
- * Being a 'friend' to a client
- * Teaching homemaker skills to clients
- * Visiting lonely or immobile individuals
- * Making daily telephone calls to isolated clients
- * Providing transportation
- * Running errands or shopping for clients
- * Doing yardwork or home repair
- * Helping to distribute surplus food

Some Benefits Of Being A Volunteer Are:

- * A sense of personal satisfaction
- * Valuable work experience for employment or education
- * Experiences for learning new skills or enhancement of current skills
- * New relationships and contacts
- * Better understanding of Social Services programs
- * Opportunity to make a meaningful contribution to the community

VOLUNTEERS CARE BY SHARING TIME AND TALENT WITH PEOPLE WHO NEED HELP. SHARE YOUR CARE!

For More Information

If you are interested in becoming a Volunteer, or would like more information on the Volunteer Services Program, please contact your local office of the Nebraska Department of Social Services.

The Nebraska Department of Social Services does not discriminate against anyone because of race, color, creed, national origin, sex, age, marital status, religious or political affiliation, or physical or mental disability.

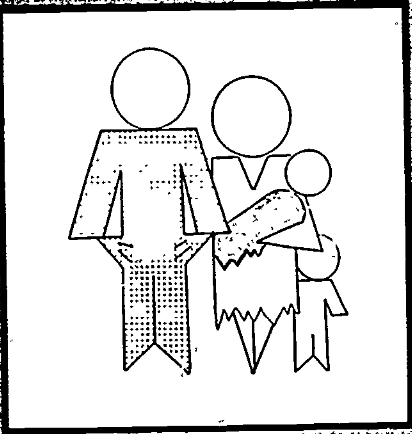
Information which identifies individuals who apply for or receive assistance, benefits, or services from the Nebraska Department of Social Services is confidential.

Nebraska Department of Social Services

For more information, contact your local office of the Nebraska Department of Social Services, the Central Office, Box 95026, Lincoln, Nebraska 68509-5026, Phone (402) 471-3121.

DSS-PAM-120-5/85 (99011)

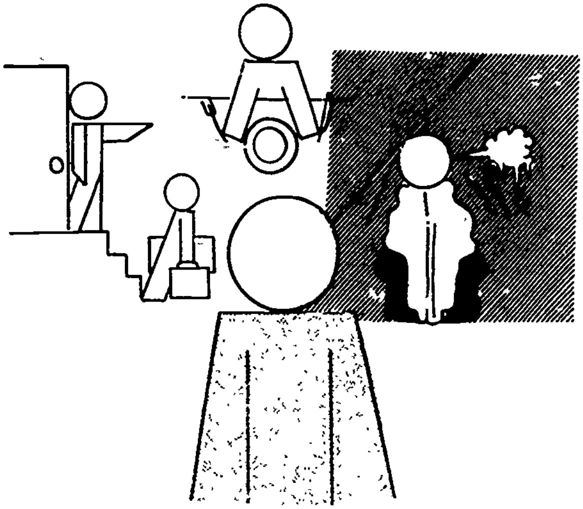
EMERGENCY ASSISTANCE



Emergency Assistance is provided to needy families with minor children in situations where other resources are not available.

NEBRASKA
DEPARTMENT
OF
SOCIAL
SERVICES

Emergency Assistance is provided to needy families with minor children in situations where other resources are not available. Examples of situations for which assistance is available are imminent evictions, loss of utility service, or exhaustion of food.



Eligibility Requirements:

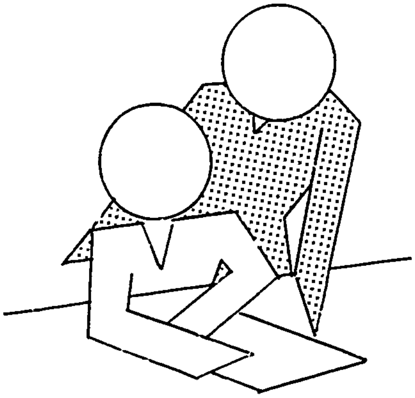
Emergency Assistance is provided to needy families —

1. With a child who is age 18 or under. (A family whose only child is unborn is not eligible.)
2. With a child who is currently living with any close relatives. This includes a child who has lived with close relatives within six months of their request for assistance.
3. Who is without income and resources immediately accessible to meet its needs.
4. Whose need did not occur because the child (if age 16 or older and not in school) or the relative responsible for support and care refused without good cause to accept employment or training for employment.

Responsibilities:

The applicant has the responsibility to —

1. Cooperate with the worker in exploring all other sources of aid available.
2. Accept any aid available to help in a crisis situation.
3. Develop with the worker a plan to help solve the problem and to prevent the crisis from occurring again.



Appeal Process:

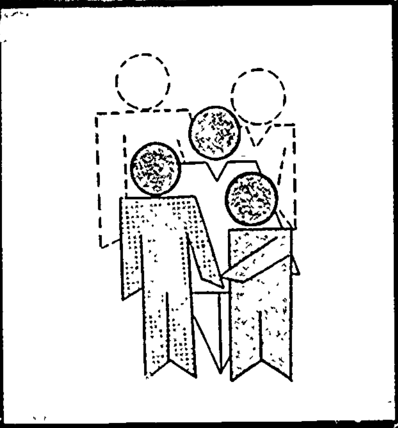
Every applicant for or recipient of Emergency Assistance has a right to appeal to the Director of the Nebraska Department of Social Services for a hearing on any action or inaction of any Department employee or official in regard to the program. The appeal must be filed in writing within 90 days of the action.

If you have any questions regarding the Emergency Assistance Program please contact your local office, Department of Social Services.

Nebraska Department of Social Services

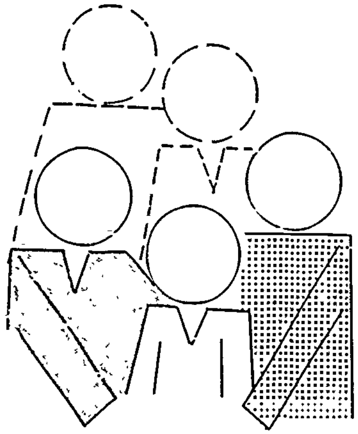
DSS-PAM-131 8/85 (99037)

AID TO DEPENDENT CHILDREN



What is Aid to Dependent Children?

Aid to Dependent Children provides money payments to children age 17 or younger who are deprived of support of one or both parents, because of death, continual absence from the home, physical or mental incapacity, or unemployment.



In addition to being deprived of support, children who are 18 years of age are eligible only if they are in high school, or in a program in a vocational or technical school that is equivalent to a high school and that will prepare for employment, children must be expected to complete their schooling before reaching the age of 19.

Where may I apply for Aid to Dependent Children?

At the Local Office, Department of Social Services in the county where you live.

How long must the children live in Nebraska to be eligible?

It must be established at the time of the application that the home of the child(ren) is in the State of Nebraska. No period of residence is required.

How must you cooperate with the Child Support Enforcement Office?

To be eligible for an assistance payment, your rights child support and medical support payments be assigned to the State of Nebraska.

Applicants who are receiving Aid to Dependent Children payments must cooperate in locating the absent parent and in obtaining financial and medical support, unless good cause for refusing to do so can be established.

You must also cooperate in determining the father of a child born out-of-wedlock.

May a minor parent receive assistance?

Yes. If the minor parent is living with his/her parent(s) or legal guardian, income of the parents/legal guardian may be considered in determining the amount of payment for the minor and his/her child(ren).

May a family have income and be eligible for Aid to Dependent Children?

Yes. If income such as wages, business transactions, contributions, payments from Social Security, Railroad Retirement, military benefits, does not exceed the monthly need standard

How much property may a family own and still be eligible for assistance?

- The home in which they live.
- Reasonable furnishings for their home.
- Reasonable wearing apparel and personal effects used in daily living.
- Other resources of which the net value does not exceed $1,000.

If children are eligible for Aid to Dependent Children, what amount is paid?

The amount of payment depends on the family need and how much of it can be met from the income of the family.

The Aid to Dependent Children maximum monthly payment is determined by Nebraska law.

To whom are payments made?

Payments can be made to the following people if they are providing care for the child: parent, or another specified relative who is taking care of the child.

Will Aid to Dependent Children payments always be in the same amount?

No. The needs of the child(ren) change from time to time, and the amount available to the child may change.

Will payments be made for medical care?

Yes. If there is approved medical care, payment will be made directly to the provider of health services.

Must a stepparent support his/her stepchildren?

Yes. A stepparent has the responsibility for care and support of minor children to the same extent as a natural or adoptive parent.

Am I expected to find employment?

You may be asked to search for work or participate in training, unless you are exempted from these activities.

Do I have any responsibilities while I am receiving assistance?

Yes. The client is responsible for telling the Local Office if there are any changes, such as a change in address, a change in income or household size.

Do I have other rights?

Yes. Title VI of the Civil Rights Act enacted by Congress in 1964 provides that the Aid to Dependent Children program must be administered so that no person is excluded from participation in, is denied the benefits of, or is otherwise subject to discrimination by the program because of race, color, national origin, age, sex, handicap, political beliefs, or religion.

May a Local Office give out information about clients of Aid to Dependent Children to other persons?

No, in most cases. The law requires that the case record be kept confidential unless the client authorizes that the information may be released. Some information regarding a fugitive felon may be given to a local or state law enforcement officer.

What may a client do if a decision made by the Department is unsatisfactory?

Nebraska law provides for a procedure of appeal in which the client may request a review of his/her case by the Director of Social Services.

The appeal may be filed with the Local Office of the Nebraska Department of Social Services or with the Director of Social Services.

If an application is not approved, can you apply again?

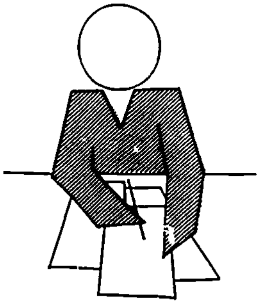
Yes. You may re-apply at anytime.

What happens if an individual receives assistance and is not entitled to it?

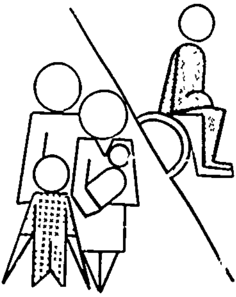
If an individual knowingly receives money payments or medical care and is not entitled, the individual is subject to prosecution for fraud.

You can get an application form at the local office or have the Department of Social Services send it to you.

When you get the form, fill it out as soon as possible, because the earliest date for which you may be eligible for financial assistance is the date your form is received in the local office.



Social Services
Nebraska Department of



The Disabled Persons and Family Support Program coordinates and purchases services and items to assist employed disabled adults or to help families keep disabled family members in their homes.

NEBRASKA DEPARTMENT OF SOCIAL SERVICES

DISABLED PERSONS AND FAMILY SUPPORT

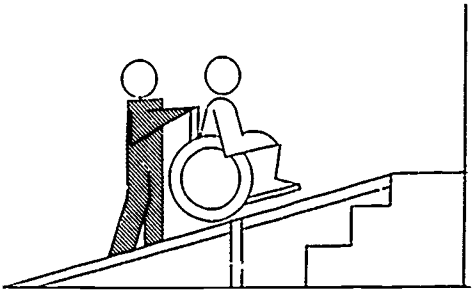
The Disabled Persons and Family Support (DPF) Program is based on a state law passed by the Nebraska Legislature in 1981. It supports the following beliefs:

1. The family is important to the development of each person and families want to provide for disabled family members at home; and

2. Disabled adults who are able to work may be financially prevented from doing so because of loss of benefits and disability-related expenses.

What items and services are available through the Disabled Persons and Family Support Program?

The program may authorize payment for disability-related expenses such as architectural home modification to remove barriers; attendant care; non-medical costs incurred during treatment; counseling or training; home health care; housekeeping; special equipment; respite care; and transportation. Other types of support may also be considered, based upon individual need and circumstances.



Example A: A family caring for a disabled family member may need a ramp to provide access to the home and may need respite care to allow time away from ongoing responsibilities.

Example B: An employed disabled person might need help paying for disability-related supplies and for an attendant to help with personal care.

The maximum payment for services available to any disabled person or family is $300 per month averaged over the number of months in the eligibility period.

Who is eligible for Disabled Persons and Family Support?

The program serves two populations:

1. Families with a disabled family member (either adult or child) living with them who need some form of support to prevent out-of-home placement; or

2. Persons who are disabled and employed (or could be employed), earning at least $300 per month, who need some form of support to maintain employment.

The Disabled Persons and Family Support program cannot pay for items or services available from other sources. Persons who apply must explore all other possible resources to show need.

Persons may be financially eligible if their gross monthly income, adjusted for family size does not exceed the following:

Family Size	Gross Monthly Income
1	$ 1076
2	1407
3	1738
4	2069
5	2400
6	2731
7	2793
8	2856
9 or more	2918

In addition to financial and need eligibility, Disabled Persons and Family Support requires medical information to determine severe chronic disability.

How are payments made?

The program may either reimburse the disabled person or caretaker for authorized expenses or provide direct payment to the provider of the service.

How can I apply for Disabled Persons and Family Support?

To request an application for yourself or on behalf of someone else, or for additional information, contact —

Disabled Persons and Family Support
Nebraska Department of Social Services
Box 95026
Lincoln, Nebraska 68509-5026

Attention: Lenore Spencer or Pattie Flury

In Lincoln: 471-3121

Toll free: (800) 358-8802

Nebraska Department of Social Services

DSS-PAM-134 8/85 (99040)

WE ARE LOOKING FOR SPECIAL CHILDREN

NEBRASKA CHILDFIND

...Benefiting The
Handicapped Children
of Nebraska

NEBRASKA CHILDFIND
. . . because we care

NEBRASKA CHILDFIND is an intensive ongoing statewide search for all unserved handicapped children, ages birth to 21. Nebraska ChildFind will assist parents of unserved handicapped children to find proper special education or related programs to benefit their children.

NEBRASKA CHILDFIND maintains a computerized directory of services for handicapped children. Callers will be provided information on available resources in their geographic area that provide services for the age level and handicapping disorder of the child for whom they are requesting help.

NEBRASKA CHILDFIND
. . . because the need exists

While many different types of services are available to Nebraska's handicapped population, some of this state's handicapped youth **DO** remain unserved.

These children are not participating in special education programs, school environments or special activities. This is not because of a lack of resources in many cases, but rather because many parents of handicapped children do not know of such programs or because they do not recognize the handicapping conditions of their children.

Many younger children suffer from handicapping conditions which can go undetected. These conditions may exist and remain unnoticed, and as a result, many handicapped children in Nebraska exist unserved simply because they exist unknown.

These are the concerns of
NEBRASKA
CHILDFIND.........
and we need your help.

FINDING A PROGRAM....

Nebraska law guarantees a free appropriate public education to all children. Special programs are available through the public schools for all children with special education needs in areas of:

... speech and language disorders

... hearing impairments

... visual impairments

... mental retardation

... specific learning disabilities

... emotional and behavioral disorders

... physical and neurological handicaps

... severe or multiple handicaps

School districts are required to provide special education services for resident handicapped children 5-21 according to P.L. 94-142 and L.B. 403. Existing legislation was amended by L.B. 889 to include educational programs for children under 5 with moderate to severe handicapping conditions. Parents are encouraged to call their local school district for more information regarding these free special education services.

NEBRASKA CHILDFIND.....

BENEFITING THE HANDICAPPED CHILDREN IN NEBRASKA

WHO ARE THE SPECIAL CHILDREN?

A Special Child

may be mentally retarded, physically handicapped, learning disabled or have severe behavior problems

The child may have difficulty sitting, walking, talking, seeing or hearing

But a special child can learn and your public school wants to help meet your child's educational needs

Help the Special Child receive services. Call your local school district.

HOW CAN I HELP?

IF YOU ARE A PARENT of an unserved handicapped child, if you suspect your child may be handicapped, or if you know of a handicapped child in your neighborhood or community who is not receiving services, we urge you to

Contact Your Local
School District

or call
NEBRASKA CHILDFIND
Toll-Free 800-742-7594

In Lincoln 471-3656
(TTY - Please Signal)

Nebraska Department of Education
301 Centennial Mall South,
Sixth Floor
Lincoln, Nebraska 68509

DIRECTORY OF RECREATION PROGRAMS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Published by the Region VI
Developmental Disabilities Council
and the
Greater Omaha Association for Retarded Citizens (GOARC)

Groups, Programs and Clubs

• **Red Cross**, 3838 Dewey Street, 341-2723, Safety Services Office. They offer adapted swimming, conoeing and sailing at various locations and times. Classes are offered at no charge or for very little cost.

• **West Branch Y.M.C.A.**, 75th and Maple Streets, 393-3700. The "Y" offers a class called "Fun and Fitness" for children of school age with developmental disabilities. This class includes swimming, gym, social and arts and crafts skills development.

• **Council Bluffs Y.M.C.A.**, #7 Fourth Street, Council Bluffs, Iowa. This "Y" offers a special time on Saturday afternoons for persons with handicaps and their assistants to swim for no charge.

• **Omaha Public Libraries** All nine Omaha Libraries offer various programs for children during the summer. These include pre-school, arts and crafts, various presentations, dramatic clubs, reading clubs, read-to-me clubs and a variety of other activities. Call the library nearest you.

Special Olympics of NE, Margaret Morford, 345-5414. Bellevue Club, 733-6325.

• **Omaha Children's Museum**, 342-6164. They are equipped to mainstream at any time as activities are individual and they also have a small wheelchair available for use. Activities are participation oriented.

• **Emmy Gifford Children's Theater**, 3504 Center Street, 345-4849. The theater offers classes in theater, ballet, art and others. They are willing to mainstream any classes where appropriate to do so.

Henry Doorly Zoo, 733-8400, open from April 1-October 31. Wheelchair accessible and chairs are available for use at the zoo.

• **Nebraska Theater Caravan** Clinics and presentations are made for children on occasions throughout the year. They operate through the Omaha Community Playhouse, 553-0800.

• **Boy's Clubs of America** Contact either club in Omaha at 342-1600, Don Preiste.

• **Girl's Clubs of America** Contact either club in Omaha at 457-4318 or 457-4676.

• **Great Plains Girl Scout Council**, Jayne Lyons at 393-4200.

• **Boy Scouts of America**, Stan Haines at 341-2086.

• **Campfire Clubs**, 345-2491, Nebowa Council.

• **Four-H Clubs**, Beth Ann Pillen, 5134 South 24th Street, 444-7804. 4-H operates through neighborhood groups and children decide individually upon projects suited to them.

Fontennelle Forest Activities, hiking, nature studies and clubs, 731-3140.

Winds Marina, 138th and Fort Streets, 493-3400 or 571-1915. Rentals of various recreational equipment available: bicycles, roller skates, canoes, skis, paddle boats, sail boats and more.

Music Therapy, Carol Gerelman. Classes offered privately, group or arranged appropriately 231 Midland Drive, Council Bluffs, Iowa 51501.

Joslyn Museum, 2200 Dodge Street, 342-3300. Includes various display for children and adults from Tuesday through Sunday.

• **Nebraska Gymnastics Development**, 4401 South 134th Street. Frank or Sandy O'Connor at 333-1434 for more information concerning mainstreaming your son or daughter into an existing class. They are currently, and have been, involved in several mainstreamed situations.

• **Family Fun Center**, 70th and Dodge Streets, 553-9298. This center is very family oriented with two floors of video games and two mini-golf courses. The video area is accessible to wheelchairs.

Wheelchair Basketball and Softball, 572-6603, Robert Sanderhoff.

• **Christ Child Center**, 1248 South 10th Street. Daytime summer fun programs for grade-school aged children.

• **Benson Arts and Crafts**, 556-2998, offers classes for children and if the activity is appropriate for the child, they are happy to mainstream your son or daughter.

• **Mangelson's**, 391-6225, 3457 South 84th Street. Same as above.

•These programs and agencies are happy to mainstream your son or daughter or anyone if the activity is appropriate.

Summer Camps

Hattie B. Munroe Summer Camp, 44th and Dewey Streets. Contact Debra Pelzer at 559-6415. Day camp for developmentally disabled and physically involved persons ages 3-21.

Hattie B. Munroe "Outreach" Camp, same location base. Contact camp director Debra Pelzer at 559-6415. This involves arranging for a volunteer from the Munroe Camp to attend one of a variety of area daycamps with your son or daughter. Area day camps accept children from ages 6-16.

Omaha Adaptive Recreation Contact Cathy Andrews at 444-5935. Day camp activities for children with developmental disabilities at Montclair Center and at Elmwood Park. A mainstreamed situation can also be achieved at a number of camp sites around Omaha. The City of Omaha also offers trips for teens and a number of programs for adults with developmental disabilities.

Great Plains Girl Scout Council, Mary Kallman, Director of Camps at 393-4200. One week day camp session at camp "Maha;" south of l Ms: Michelle Moody, day camp director is a teacher at the J. P. Lord School and has extensive experience working with l ped children. She is anxious to accommodate appropriately aged girls. (See also Hattie B. Munroe "Outreach" Camp.)

Summer Camps Continued

Four-H Clubs Camp, Douglas County Extension Office at 444-7804. The camp is located near Gretna, Nebraska and last year sponsored one week of camp for children with developmental disabilities. Contact also Cathy Andrews, 444-5935.

Easter Seals Summer Camp, Easter Seals Office, Lincoln Center Building, Room 409, 215 Cenntennial Mall South, Lincoln, Nebraska 68508. Toll-free call 1-800-742-7568. This is a residential camp located 22 miles west of Lincoln, Nebraska.

Courage Center Camp Contact Cathy Andrews at 444-5935 or Camp Courage at 895-1989. This is a day camp offered at Elmwood Park July 23rd through August 3rd. The cost is $1.00 to cover the insurance!

Special Olympics Weekend Sports Camps, Margaret Morford, 406 Keeline Bldg., 345-5414. These are weekend camps offered statewide at various locations across Nebraska. They are sports and nature oriented.

Y.M.C.A. Summer Daycamp, Downtown "Y" Camp Office, 341-1600. Week long sessions of daycamp offered to children ages 5-16 with various themes of interest to your child. We have in the past mainstreamed children at this camp. (See also Hattie B. Munroe "Outreach" Camp.) (Transportation provided)

Boy Scouts of America Contact Stan Haines at 341-2086. Boy Scouts attend camp by age and by troop number. They are willing to mainstream an appropriate boy into camp and a troop.

Y.W.C.A. Summer Day Camp Contact Ginny Cook at 345-6555. The YWCA takes children to Camp Brewster in Bellevue and transportation is provided. (See also Hattie B. Munroe "Outreach" Camp.)

Salvation Army Camp for Adults This camp operates during August and is limited to adults (over 16) who are fairly self-sufficient or those who choose to bring a friend to assist them with daily activities. Call Mrs. Stillwell at 346-5155, ext. 26.

Christ Child Center Camp Call the center at 342-4566 for a brochure describing dates, etc. Transportation is provided from two locations and they are quite willing to mainstream your son or daughter. (See also Hattie B. Munroe "Outreach" Camp.)

Gene Eppley Boy's Club Ranch Contact the Boy's Club at 342-2300 for camp information. They are very willing to mainstream your son or daughter. (See also Hattie B. Munroe "Outreach" Camp.)

Other

Hotline for the Handicapped, Toll-Free 1-800-742-7594
Nebraska Child-Find, Box 94987, Lincoln, Nebraska 68508

"The Guided Tour" Newsletter advertising vacations and programs adapted for Special Population. Write "The Guided Tour", 555 Ashbourne Road, Elkins Park, Pennsylvania 19117, (215) 782-1370.

Elmwood Park, at 60th and Dodge Streets. Exercise parcourse, frisbie golf course. There are 20 stations for exercising and jogging open to the public year round. The course is paved with wood chips.

Immanuel Medical Center, 6901 North 72nd. Exercise parcourse. This is open to the public and trails are paved with gravel.

Nebraska Medical Center, 40th and Dewey Streets. Exercise parcourse. This is open to the public and the trails are paved with dirt.

K.V.N.O. Radio Station, FM dial at 90.7. One-half hour episodes of popular stories, movies and books on weeknights at different times. Call 554-2716 for monthly program brochures.

K.I.O.S. Radio Station, FM dial at 91.0. One-half hour episodes of popular stories and movies on Monday-Wednesday-Fridays. These are aired morning and evening and schedules can be obtained by calling 556-2770.

National Information Center for Handicapped Children and Youth

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WASHINGTON, D.C. 20013

SOURCES OF HELP AND INFORMATION

There are a number of sources for more information on handicaps and related issues. This section describes some of the things you can have sent to you.

DISABLED USA

President's Committee on Employment
of the Handicapped
Washington, D.C. 20210.
(Published Monthly)

Reports progress in opportunities for people with disabilities and developments in rehabilitation and employment.

THE INDEPENDENT

Center for Independent Living,
2539 Telegraph Avenue
Berkeley, CA 94704
(Published quarterly)

Articles about disabilities and up-to-date information on independent living.

REPORT

The National Center for a Barrier
Free Environment
1015 15th Street, N.W. Suite 700
Washington, DC 20005
(Published bi-monthly)

News about legislation related to accessibility, news briefs and summaries of articles and books mainly concerned with barriers.

SIBLING INFORMATION NETWORK NEWSLETTER

Department of Educational Psychology
Box U-64
University of Connecticut
Storrs, CT 06268

Research and literature reviews, meetings, family relationship information of interest to siblings of youth with handicaps.

THE EXCEPTIONAL PARENT

The Exceptional Parent
296 Boylston Street
3rd Floor
Boston, MA 02116
(Published eight times yearly)

Emphasis on education, diagnosis, attitudes, care; covering all handicaps, it is directed toward parents.

THE GREEN SOURCE BOOK -- NATIONAL DIRECTORY OF PRODUCTS AND SERVICES FOR THE DISABLED (Formerly entitled GREEN PAGES)

Source Book Publications
P.O. Box 1586
Winter Park, FL 32789
(Published annually)

Annual Directory of products and services. Subscription includes an occasional newsletter, "Green Papers," with legislative information and stories about people with handicaps.

UPFRONT

Mafex Associates, Inc.
90 Cherry Street, Box 519
Johnstown, PA 15907
(Published 11 times a year)

A newspaper for and about physically and mentally disabled people.

INFORMATION ABOUT HANDICAPPING CONDITIONS

Write to these agencies for information about all handicapping conditions. Specify exactly what you are interested in. Organizations dealing with specific handicapping conditions are listed on individual fact sheets.

American Civil Liberties Union
132 West 43rd Street
New York, NY 10036

American Genetics Association
818 18th Street, NW
Washington, DC 20036

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Developmental Disabilitites Office
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 338E
Washington, DC 20201

Human Resources Center
I.U. Willets Road
Albertson, NY 11507

Library of Congress
Division for Blind and Physically Handicapped
1291 Taylor Street, NW
Washington, DC 20542

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

National Rehabilitation Association
633 South Washington Street
Alexandria, VA 22314

Office for Handicapped Individuals
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Office of Rehabilitation Services
U.S. Department of Education
Switzer Building
330 "C" Street, SW
Washington, DC 20202

President's Committee on Employment of the Handicapped
Washington, DC 20010

President's Committee on Mental Retardation
Washington, DC 20201

Special Education Programs
U. S. Department of Education
Switzer Building
330 "C" Street, SW
Washington, DC 20202

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LIST OF AVAILABLE INFORMATION

P.O. BOX 1492
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STATE SHEETS

Available for each state and territory and the District of Columbia, the State Sheets provide names and addresses of public agengies and other groups who are concerned with handicapped children and youth. Each State Sheet is also accompanied by a Public Agencies sheet that describes the purposes and activities of each agency or organization. Updated yearly.

GENERAL INFORMATION

Sources of help and information that provide general information about handicapping conditions and related issues, this list includes organizations and publications of special interest.

FACT SHEETS ON HANDICAPS

Each sheet contains a description of the handicapping condition, statistics on prevalence, educational implications and references and resources for further information. Currently the following topics are available:

- Autism
- Cerebral Palsy
- Deafness and Hearing Impairments
- Down's Syndrome
- Emotional Disturbances
- Epilepsy
- Learning Disabilities
- Legal Definitions of Handicapping Conditions
- Mental Retardation
- Physical Disabilities and Special Health Problems
- Severe Handicaps
- Speech and Language Impairments
- Spina Bifida
- Visual Impairments

LEGAL INFORMATION

An information package that contains fact sheets on the rights of children with handicaps, primarily related to education. Basic information includes the topics of assessment, due process, individualized educational programs, the special concerns of minority children with handicaps, resources for legal advice and support, and a listing of regional offices of the Office of Civil Rights.

PARENT INFORMATION

An information packet that contains information on direct services for children, advocacy and parent support groups, and accepting a child's handicap.

TEACHER/PARENT INFORMATION

An information packet that includes topics of implications for teaching children with specific handicaps, attitudes and expectations, team teaching, the teacher/parent relationship, classroom management, and sources of teaching materials and further information.

STUDENT INFORMATION

An information packet that includes brief descriptions of careers serving children and youth with handicaps through special education and related services, locations of personnel preparation programs, and sources of financial aid.