

# TOWARD AN IMPROVED QUALITY OF LIFE

## QUALITY PROGRAMS FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

*A GUIDE FOR PARENTS, FAMILY MEMBERS AND ADVOCATES*

**Legal Advocacy for Persons  
with Developmental Disabilities  
222 Grain Exchange Building  
323 Fourth Avenue South  
Minneapolis, MN 55415**

**Legal Advocacy for Persons with Developmental Disabilities in Minnesota, a project of the Legal Aid Society of Minneapolis, has produced this guidebook with funds from a grant from the Office of Human Development Services of the United States Department of Health and Human Services awarded by the Administration on Developmental Disabilities. The Legal Aid Society of Minneapolis, Inc. is solely responsible for the contents.**

**As part of this grant, Legal Advocacy has also produced Individual Habilitation Plan Review Forms for both the Home Environment and the Work or Day Program Environment Those Review Forms were developed by Cathy Macdonald and Carol Rydell. Jane Wells of Creative Community Options, White Bear Lake, Minnesota, assisted in that process. She developed this guidebook on the basis of the Review Forms and provided the added comments.**

**Consumer and advocacy organizations are encouraged to reproduce this guidebook for their own use. While an effort has been made to state principles which are generally applicable, practices prevalent in and rules applicable to program planning in Minnesota are evident in portions of the guidebook. Organizations which would like to modify this guidebook to fit local practices and rules may obtain the disc at cost A 5 1/4" disc in MS-DOS WordPerfect and an MS-DOS ASCII file are available.**

**March 3, 1988**

**TABLE OF CONTENTS; TOWARD AN IMPROVED QUALITY OF LIFE**

**Page**

**PART ONE**

<b>I. CASE MANAGEMENT .....</b>	<b>1</b>
<b>II. OVERALL PROGRAM ISSUES .....</b>	<b>3</b>
<b>III. STAFF TRAINING AND SUPERVISION.....</b>	<b>9</b>

**PART TWO**

<b>IV. ENVIRONMENT .....</b>	<b>10</b>
<b>V. MEALTIME OBSERVATION.....</b>	<b>14</b>
<b>VI. HEALTH AND SAFETY .....</b>	<b>17</b>

**PART THREE**

<b>VII. EVALUATING BEHAVIORAL OBJECTIVES .....</b>	<b>20</b>
<b>HOW WILL PROGRESS BE MEASURED AND EVALUATED .....</b>	<b>25</b>

**PART FOUR**

<b>VIII. INDEPENDENT LIVING SKILLS .....</b>	<b>27</b>
<b>IX. COMMUNITY INTEGRATION.....</b>	<b>30</b>
<b>X. VOCATIONAL SKILLS.....</b>	<b>33</b>
<b>XI. LEISURE AND RECREATION SKILLS.....</b>	<b>36</b>

**PART FIVE**

<b>XII. COMMUNICATION .....</b>	<b>38</b>
<b>XIII. BEHAVIORAL SPECIAL NEEDS .....</b>	<b>41</b>
<b>XIV. PHYSICAL AND SENSORY SPECIAL NEEDS.....</b>	<b>45</b>

**PART SIX**

<b>XV. MAKING CHANGE HAPPEN. ....</b>	<b>47</b>
---------------------------------------	-----------

## **Introduction**

As a parent or family member of a person with developmental disabilities, you can be a powerful advocate. Webster's defines "advocate" as "one that pleads the cause of another." Persons with developmental disabilities need people in their lives who are willing to be advocates, just as all of us need the support of a network of family, friends and associates.

Parents want "what's best" for their sons and daughters; however, if your son or daughter has a developmental disability, deciding "what's best" can be confusing and difficult. The "best practices" of just a few years ago are being challenged daily. Both scientific research and common sense are proving wrong some commonly held assumptions about the best ways to meet the needs of people with developmental disabilities. Your interest in this project affirms your commitment to advocate for excellence in the services provided to your son or daughter.

## **What We Believe**

The "best practices" that are reflected in this guidebook are supported by research and affirmed by values. The beliefs that have directed our efforts may seem obvious, but current practices show that implementing these ideas does not always come easily:

All people, regardless of their ability, have the right to be treated with dignity and respect.

Personal preferences and individual choices should drive decisions about service arrangements, developmental programming, and daily routines.

People need a network of relationships to provide friendship and support. Segregation is a barrier to full participation in community life. People with disabilities should be living, learning, and working with people who do not have disabilities.

We must not limit our understanding of individual potential. Our teaching strategies should focus on developing each person's level of participation in useful and meaningful activities.

Attitudes are changing--but we must continue to challenge our expectations for persons with developmental disabilities by expanding our vision of what is possible.

## **About the Guidebook**

This guidebook is intended for use by parents of persons with developmental disabilities (or siblings, relatives, advocates, volunteers, or other interested persons) to evaluate the programs of their sons and daughters. The six parts of the guidebook correspond to six three-hour training sessions. The information included in the guidebook and provided at the training sessions will enable you to complete a careful and detailed review of your son's or daughter's residential and work or day program.

Portions of the guidebook include sections for both the home environment and the work or day program environment. Brief explanations are added to some of the home environment guidelines which apply to, but are not repeated in, the work or day program environment guidelines.

In order to complete a review of your son or daughter's programs and habilitation plan,

it is suggested that you spend four to six hours at each program site reviewing records, observing interactions, and talking to staff. You may wish to review some records at home rather than spending a long period of time at the program. However, you will need to observe staff interactions with your son or daughter and take a careful look at the physical environments.

### **A Few Words About Words**

We believe that it is important to take care with the language we use when talking about people, especially people with disabilities. We tried to follow several guidelines in writing this guidebook:

Terms such as "the handicapped" or "the disabled" are archaic and demeaning. Likewise, labeling an individual with a disability in phrases such as "he is retarded" or "she is autistic" can reduce a person to one characteristic of his or her life experience. The use of initials or abbreviations in describing people, such as "he is CP," is another disrespectful practice. The preferred usage is to acknowledge the person first: person with mental retardation, or individual with a developmental disability.

In an effort to encourage age-appropriate language when referring to adults with disabilities, "sons or daughters" has been used rather than references to a child or children. In many instances, the choice of a gender specific personal pronoun was made randomly in order to avoid the somewhat awkward "he or she" or "his or her."

**PART ONE**  
**CASE MANAGEMENT AND PROGRAM PLANNING**

## I. CASE MANAGEMENT

The items in this section focus on written plans that are the legal responsibility of the county case manager in Minnesota. Each county may have a different format for defining this plan; you will most likely find the information that you need in a document called the "Individual Service Plan" or ISP.

The ISP is the basic planning document used by the county case manager to arrange for services for your son or daughter. You and your son or daughter should be involved in its development. The ISP must summarize assessment information, identify the type, amount and frequency of all services needed, state how and when these services will be obtained or developed, and include long-range and annual goals for your son or daughter.

The interdisciplinary team, which includes you, your son or daughter, the case manager, and all providers, will use the ISP to develop a single individual habilitation plan (IHP) or individual program plan (IPP). This plan should include short-term objectives designed to reach the annual goals in the ISP. Both the ISP and the IHP should plan for services to be provided in the "least restrictive environment"

- \_\_\_\_\_ 1. The ISP includes a summary of assessment information and of specific service recommendations.

*Assessments are required in the following areas:*

- a. *medical status and ongoing health needs,*
- b. *physical development,*
- c. *intellectual functioning,*
- d. *social skills,*
- e. *self-care skills,*
- f. *communication skills,*
- g. *community living skills,*
- h. *vocational skills,*
- i. *physical and social environments, and*
- j. *need for guardianship or conservatorship.*

*The summary should include specific service recommendations made by the persons doing the assessments. The summary should also include how the physical and social environment of the home and work settings will affect your son or daughter's ability to function independently.*

- \_\_\_\_\_ 2. The ISP contains written long-range goals that the individual should be able to accomplish in the next three to five years and annual goals for the coming year.

*The long-range and annual goals are goals your daughter should be able to meet with appropriate services. These goals are personal goals for her, not what services will be provided*

- 3. **The ISP includes written information describing the type, amount and frequency of all the services the individual needs.**

*The service needs should be clear and specific. The ISP should describe what services your son or daughter needs, not just where services are to be provided. The skills and training needed by the persons providing those services should be described*

- 4. **The ISP specifies in writing the plan to obtain or to develop all needed services in the least restrictive environment**

*The least restrictive environment is one in which your son or daughter can function or learn to function as independently as possible. The least restrictive environment is one in which your son or daughter can make choices, can participate in activities, and has contacts in typical community settings with persons who do not have disabilities.*

- \_\_\_\_\_ 5. **The ISP is consistent with the long-range needs and has been reviewed within the past year with the individual and her parents or guardians.**

- \_\_\_\_\_ 6. **There is a clear relationship between the long-range goals for the person's future, the ISP, and the individual program plan.**

- \_\_\_\_\_ 7. **The case manager has provided a copy of the ISP to each program that provides services to the person.**

*All providers are to follow the plans for the individual in the ISP.*

- \_\_\_\_\_ 8. **There is written information indicating that the case manager has monitored the appropriateness of the person's program plan by spending time with her at the program and reviewing program records.**

*In Minnesota, the county case manager has the responsibility to monitor the implementation of your son or daughter's program plan. The case manager must spend time with your son or daughter and have a good understanding of his needs. The case manager should observe him in the various service settings as well as review program plans and other information about his progress. Monitoring should be done as frequently as needed.*

- \_\_\_\_\_ 9. **The case manager chairs annual, quarterly, and special team meetings.**

*The case manager has responsibility for coordinating the services that your son or daughter receives; she should lead meetings of the inter-disciplinary team.*

## II. OVERALL PROGRAM ISSUES

The previous section on case management discussed written materials that are required by regulation. This section focuses on a set of questions that reflect how those plans are used to address the needs of your son or daughter: "Do people understand my son or daughter's most important needs? Are efforts being made to help her be a part of the neighborhood and community? Is he learning skills that are useful to him and will help him to be less dependent on others?"

### A. HOME

- \_\_\_\_\_ 1. The team has completed an assessment process which includes:
- a) a system for obtaining Information from people who are involved in the life of the individual,
  - b) a review of written records,
  - c) an analysis of skills that are necessary to increase the person's independence,
  - d) an analysis of the person's learning style,
  - e) a review of the total environment to learn where and how the person functions best and what changes could be made to enable him to function more independently.

*These assessments will have been completed by any number of professionals or other people who have worked with your son or daughter. As a parent or relative, your input should be included.*

- \_\_\_\_\_ 2. The assessment process includes observing the person in naturally occurring situations and in community settings.

*If the assessment is looking at your son's ability to prepare a simple snack or meal (such as making a sandwich or pouring juice), he should be observed trying to complete the task in a "natural situation-such as in the kitchen at lunch time.*

- \_\_\_\_\_ 3. The summary of the assessments includes:

- a) strengths and needs related to functional skills,
- b) what motivates or interests the person as well as her specific likes, dislikes, and preferences,
- c) teaching strategies that are known to work for the person,
- d) communication, physical, and behavioral special needs that could affect programming and adaptations that should be made as a result of these special needs,
- e) the impact of differing environments on the person.

*An assessment should identify skills to teach, strategies to use, and any adaptations of a task, of equipment, or of the physical surroundings needed for the person to perform a task as independently as possible and in community settings,*

Consider these examples:

- a) *"Jim's strengths include his ability to dress himself without staff assistance and to complete all of his daily self-care routine independently. He needs to learn to prepare foods with a minimum of assistance and to do his laundry."*

*Strengths and needs should not be described as "Sharon has good fine motor skills."*

- b) *"Peter will work hard when given frequent praise from staff members. He enjoys household chores and is motivated by opportunities to help others. He dislikes activities that require him to sit for longer than a few minutes; he prefers being active and moving around."*

*It is very important to understand what "works" for your son. Since the assessment information will guide the development of the program plan, the assessment should include information that will make success more likely by recognizing and building on your son's interests.*

- c) *"Beth seems to learn best when the task is modeled by the staff person and then given frequent verbal prompts throughout the teaching session."*

*The assessment should offer strategies for teaching skills that are judged to have the best possibility for success.*

- d) *"Patty's communication skills are limited; it will be necessary to develop an alternative communication system that can be used in all of the places she spends time."*

*"Adapted silverware and dishes will need to be obtained in order for Tim to eat more independently"*

*Rather than these special needs "getting in the way" of learning useful skills, the program plan should identify how adaptations will be used to accommodate these needs.*

- e) *"Richard cannot open a door with a regular knob. A handle should be installed so he can get in and out of rooms on his own"*

*"James often becomes angry and sometimes is aggressive when others "boss" him. Staff persons will have to ask him respectfully to do things and develop a plan to minimize others 'bossing' him"*

*The best way to allow a person to be more independent or to avoid problems is often to change the physical or social environment.*

\_\_\_\_\_ 4. **In designing the program plan, there is a focus on:**

- a) **increased participation in community life,**
- b) **the development of a growing number of personal relationships with people without handicaps,**
- c) **increased choice making in daily life experiences.**

*Often the focus of a program plan is on making the person a "better" resident or eliminating undesirable behaviors. After reading through the plan, ask yourself, "if my son or daughter meets all of these objectives, will he be more involved in the community? Will he have the opportunity to meet people without disabilities and spend time with them in everyday activities? Will he have more opportunities to make choices that affect his daily routine?"*

\_\_\_\_\_ 5. **Efforts have been made to include the person in the development of the program plan by the following:**

- a) **attendance and participation at planning meetings,**
- b) **for persons who cannot fully participate, participation by a personal advocate on the program planning team,**
- c) **training individuals to be active participants in meetings,**
- d) **development of a systematic way of getting suggestions and preferences from the person before staffings are held.**

*Although programs generally make an effort to have the individual present at staffings, participation in the development of goals and objectives is less common.*

*One way that programs could increase the person's involvement would be to talk with the individual before the meeting to get her ideas about the kinds of things she would like to learn. Team meetings can be extremely intimidating to a person with developmental disabilities, as well as to parents. The person may not feel free to speak up, since she depends on the staff for so much on a daily basis.*

\_\_\_\_\_ 6. **Training for communication, social, motor, and sensory skills is integrated into all the activities of daily living in order to increase the individual's independence.**

*If your son or daughter has problems with communication, behavior, or mobility, the program plan should reflect the need to address these issues. However, any objectives that relate to these skill areas should be integrated into other functional skills.*

*For example, your son may need regular, supervised movement of his arms to build strength and maintain or increase the ability to use his arms. This type of "range of motion" objective could be accomplished by having a 15 minute period twice a day when the therapist does range of motion activities. However, it makes more sense to seek the therapist's advice for ways to build "range of motion" into completing a task which is a*

*part of daily routines, such as opening a cupboard door, taking clothes out of a laundry basket, or wiping off the top of a table after a meal*

\_\_\_\_\_ 7. **The program plan focuses on the development of positive behaviors.**

*Sometimes the program plan objectives seem to focus on teaching the person to behave, or to reduce "noncompliance." It may be useful to use the "dead man test" when making a judgement about some objectives. The "dead man test" asks "could a dead man successfully complete the task?" Although this may sound a bit ridiculous, there are a lot of objectives that would pass this test: Tom will remain in his seat for ten minutes without talking. Shari will not interrupt when other people are having a conversation. Brian will stay in his room after 10:00 p.m. and not disrupt others.*

\_\_\_\_\_ 8. **Staff members who work with the person know and can explain the goals, objectives, and training methods.**

*Staff should be able to explain to you what your son or daughter's objectives are and how they are implemented.*

## **B. WORK OR DAY PROGRAM**

- \_\_\_\_\_ 1. The team has selected and completed an assessment process which includes:

  - a) a system for obtaining information from people who are involved in the life of the individual,
  - b) a review of written records,
  - c) an analysis of skills that are necessary to increase the person's independence,
  - d) an analysis of the person's learning style,
  - e) a review of the total environment to learn where and how the person functions best and what changes could be made to enable him to function more independently.
- \_\_\_\_\_ 2. The assessment process includes observing the person in naturally occurring situations and community settings.
- \_\_\_\_\_ 3. The summary of the assessments includes:

  - a) strengths and needs related to functional skills,
  - b) what motivates or interests the person as well as her specific likes, dislikes, and preferences,
  - c) teaching strategies that are known to work for the person,
  - d) communication, physical, and behavioral special needs that could affect programming and adaptations that should be made as a result of these special needs.
  - e) the impact of differing environments on the person.
- \_\_\_\_\_ 4. In designing the program plan, there is a focus on the following as they relate to vocational programming:

  - a) increased participation in community activities, especially those activities which will generate respect for the person within the community,
  - b) the development of a growing number of personal relationships with people without handicaps,
  - c) increased choice making in daily life experiences.
- \_\_\_\_\_ 5. Efforts have been made to include the person in the development of the program plan by one or more of the following:

  - a) attendance and participation at planning meetings,
  - b) for persons who cannot fully participate, participation by a personal advocate on the program plan team,
  - c) training individuals to be active participants in meetings,
  - d) development of a systematic way of getting suggestions and preferences from the person before staffings are held.

- 6. Training for communication, social, motor, and sensory skills is integrated into functional activities in order to increase the individual's independence.**
- 7. The program plan focuses on the development of positive behaviors.**
- 8. Staff members who work with the person know and can explain the person's goals, objectives, and training methods.**

### III. STAFF TRAINING AND SUPERVISION

Written materials alone do not guarantee a quality program. The people who spend time with your son or daughter should have regular opportunities to improve their knowledge and skills through a well-defined program of orientation and training.

1. An individualized training plan is developed for each staff person based upon needs to acquire specific job competencies.

*Just as program plans for people with developmental disabilities should be individualized, the training needs of staff members should be individualized.*

- \_\_\_\_\_ 2. The individualized staff training plan includes
  - a) priority areas for training,
  - b) how training will be provided,
  - c) timelines to acquire training
- \_\_\_\_\_ 3. New staff participate in training and orientation before beginning work.
- \_\_\_\_\_ 4. Staff receive training in normalization and community integration issues.
- \_\_\_\_\_ 5. Staff are trained in first aid and medical emergencies such as choking and aspiration of food.
- \_\_\_\_\_ 6. Staff are trained in CPR.

**PART TWO**  
**ENVIRONMENT AND OBSERVATION**

We are learning more all the time about the power of the environment on a person's behavior. We know that people who were incorrectly diagnosed many years ago as having mental retardation and then committed to institutions were in a sense "made" handicapped by an environment that provided little stimulation or opportunity for growth. As people moved from institutions into homes and jobs in the community, people achieved far more than had ever been expected.

The items that follow might be summarized by these questions: "Would I live here? Would I spend my day here? What would it be like to live here? How would people treat me, in both subtle and obvious ways? Would living in this place help me to feel better about who I am?" Each is an indicator of surroundings that reinforce the belief that people with developmental disabilities are valuable and contributing members of the community.

Most of these items can be answered by taking a careful look at the physical environment and by observing the interactions of people.

#### A. HOME

- \_\_\_\_\_ 1. **The home is a place where adults without disabilities would live.**

*With very few exceptions, adults without disabilities do not live with more than a few other people. If there are a number of people living together, they are most likely family members. Residential programs in buildings that were constructed specifically for people with developmental disabilities usually do not look like typical homes.*

- \_\_\_\_\_ 2. **The home is located in a residential neighborhood.**

- \_\_\_\_\_ 3. **The home is located near a variety of community resources (eg., grocery store, bank, stores, churches).**

*If your daughter is going to learn to use community resources, they should be readily available. If the nearest grocery store is several miles away, that distance may be a barrier in her having opportunities to go shopping.*

- \_\_\_\_\_ 4. **There are no obvious ways of identifying the building as a home for people with disabilities.**

*"Labelling" a building can create a powerful barrier to community integration. Large signs that identify the building can send a loud message that "the people who live here are very different from you and I -- stay away."*

- \_\_\_\_\_ 5. **Personal information about individuals served by the program is not posted in a public place in the home.**

*Lists of residents, toileting schedules or grooming charts in the bathrooms, a master list of cooking objectives-- these types of materials can be an invasion of privacy and clearly identify the people who live there as "different"*

- \_\_\_\_\_ 6. **The grounds and building are well maintained.**

- \_\_\_\_\_ 7. **There are no unpleasant odors or noises in the home.**

- \_\_\_\_\_ 8. **The furniture is comfortable, of good quality, and in good repair.**

- \_\_\_\_\_ 9. **The person has a single bedroom.**

*Most adults do not share their bedrooms with another person unless they are married or living together. Although there are times when adults find it necessary to share personal living space with an unrelated person, it is usually not considered to be the most desirable option; in addition, the person is almost always involved in the choice.*

- \_\_\_\_\_ 10. **There are "personal touches" in the individual's room.**

*These "personal touches" might include pictures of family members, decorations, a specific piece of furniture, a quilt made by a favorite aunt, or any number of other ways that we make a space our own.*

- \_\_\_\_\_ 11. **Each person has adequate room for her clothing and places to keep other personal possessions.**

- \_\_\_\_\_ 12. **People have a place to entertain guests in private.**

- \_\_\_\_\_ 13. **There are no living areas of the home that are "off limits" to the people who live there.**

*The way in which space is used can tell you a lot about whose home it really is. There are no places in your own home that are "off limits" to you, except for the personal space of others who live there. Things to look for might be "staff only" bathrooms or the most pleasant room in the home designated as the "staff only" office or lounge.*

- \_\_\_\_\_ 14. **The items around the house match the chronological ages and interests of the people who live there.**

*For many years, people with mental retardation were considered to be "eternal children"-- people who will never grow up. This misconception has had a very negative effect on the lives of people with developmental disabilities, "Childlike" is usually associated with dependency, helplessness, and an inability to make important decisions about one's life. These ideas have been consistently reinforced by an abundance of age-inappropriate possessions, activities, and ways of speaking about*

*people. It is important that adults with mental retardation be offered a variety of choices and options that are age-appropriate.*

\_\_\_\_\_ 15. **The individual has access to the kitchen anytime and has opportunities to prepare or help prepare food between meals and at mealtimes.**

\_\_\_\_\_ 16. **People get up in the morning, go to bed at night, and eat meals at typical intervals and times.**

\_\_\_\_\_ 17. **Staff do not change the tone or volume of their voice when talking to people in the program.**

*Usually without realizing it, some staff may address adults in a tone of voice that one might use when talking to a child or "boss" them using a loud tone of voice. There are other subtle ways that people "talk down" to people with disabilities; one way to check for this is to listen for differences in tone or volume when staff talk to each other and then to people who live there.*

\_\_\_\_\_ 18. **Staff spend more time talking to the people who live there than with each other.**

*Staff are being paid to provide supervision and assistance to the people who live there. Although it is important that staffs communicate with each other, most of their time should be spent interacting with the people being served, and not with each other. This is especially important if the people who live there are not able to talk,*

\_\_\_\_\_ 19. **Staff do not talk about people while they are present unless they are included in the conversation.**

*Often without realizing it, staff may talk about people in the third person in their presence, as if the person did not exist or was not capable of understanding that he or she was being talked about. This is disrespectful and may indicate that staff are not aware of the person's feelings.*

\_\_\_\_\_ 20. **Staff show respect for privacy through actions such as requesting permission to enter bedrooms, or to assist with grooming and hygiene.**

*Even if the person is not able to communicate by talking, common courtesy requires that staff respect the privacy of individuals.*

\_\_\_\_\_ 21. **Family, friends, and other guests are invited over occasionally to share a meal or spend time.**

\_\_\_\_\_ 22. **Residents of the home answer the door when visitors arrive and also answer the phone in a typical manner.**

**B. WORK OR DAY PROGRAM**

- \_\_\_\_\_ 1. **The building is a place where adults without disabilities would spend the day.**
- \_\_\_\_\_ 2. **The person spends most of the day in integrated environments working or learning alongside people without disabilities.**

*Although this may seem like an unattainable goal for some individuals, it is one which is possible. Segregated day programs throughout Minnesota are moving towards supported employment models and providing training in integrated community settings.*

- \_\_\_\_\_ 3. **Typical, safe places are provided for storage of personal items.**
- \_\_\_\_\_ 4. **Furnishings, equipment, and other materials in the setting are appropriate to the chronological ages of the people served.**
- \_\_\_\_\_ 5. **Personal information about individuals served by the program is not posted in a public place.**
- \_\_\_\_\_ 6. **Staff do not change the tone or volume of their voice when talking to people in the program.**
- \_\_\_\_\_ 7. **Staff do not talk about people while they are present unless they are included in the conversation.**
- \_\_\_\_\_ 8. **Staff show respect for privacy through actions such as requesting permission to assist with grooming and hygiene.**

## V. MEALTIME OBSERVATION

One good way to learn about the quality of interactions in a program is to share a meal with people. Mealtimes should be pleasant; people should have a chance to visit with each other. Meals can also provide numerous opportunities for people to use their communication skills and make choices.

### A. HOME

\_\_\_\_\_ 1. **Meals are served at typical times and are designed to take a normal amount of time (unless a physical or sensory handicap necessitates a longer meal).**

\_\_\_\_\_ 2. **The dining area looks like a typical eating area for a home.**

----- 3. **People ask for (food to be passed to them and know how to pass food to others or are receiving training to do so.**

*Although it may be more convenient for staff to put food on your son's plate, this activity is an excellent opportunity for your son to communicate to others something that is important to him.*

\_\_\_\_\_ 4. **The person has choices available about what food to eat, within the requirements of any special diets.**

*One of the many choices we make almost every day is what to eat. People with developmental disabilities who live in residential programs often have little to say about what is served at meals.*

\_\_\_\_\_ 5. **The person is not forced to eat, and food is not withheld for other than medical reasons.**

\_\_\_\_\_ 6. **Techniques and objects used at mealtimes are age-appropriate, except when necessary to further independence if the person has a physical or sensory handicap.**

*People should use, or be learning to use, knives and forks to eat meals. In almost all instances, bibs should not be use.*

\_\_\_\_\_ 7. **Positive feedback is given in a natural rather than "instructional" manner.**

*Staff should offer praise and encouragement to individuals in a conversational way that serves as a good example of adult conversation. For example, "good spearing" as a response to using a fork is a somewhat formal comment. Instead the staff member could say you are doing a good job of using your fork today"*

\_\_\_\_\_ **8. Staff provide only the level of assistance needed.**

*It may be easier to do things for people rather than helping people to do things for themselves. This is open the case during meals, when there are several people who may need assistance. However, it is important that your son only receive the amount of help he needs.*

\_\_\_\_\_ **9. Staff interactions toward the person could be described as positive and respectful.**

*The staff who work with your daughter might be the only people she will come in contact with on a regular basis. The time staff spend with your daughter is very important, and the relationships that develop are crucial to her developing self-confidence and self-esteem.*

\_\_\_\_\_ **10. Staff eat with the persons in the program, unless implementation of an eating program makes this impossible.**

\_\_\_\_\_ **11. Staff take time to interact with each individual and encourage people to interact with each other at meals.**

\_\_\_\_\_ **12. If the person is unable to speak, other ways to express choices and engage in conversation are used.**

*If your son or daughter uses an alternative communication system, it should be available and used during meals.*

## **B. WORK OR DAY PROGRAM**

\_\_\_\_\_ 1. **Meals are at a typical time of day.**

\_\_\_\_\_ 2. **The dining area is typical for a work setting.**

*Typical work settings might include vending machines to purchase coffee or soft drinks, a microwave oven to heat foods, and possibly a refrigerator to store lunches during the day.*

\_\_\_\_\_ 3. **The person is not forced to eat, and food is not withheld for other than medical reasons.**

\_\_\_\_\_ 4. **Techniques and objects used at mealtimes are age-appropriate, except when necessary to farther independence if the person has a physical or sensory handicap.**

**(Omit the following items if the person eats in an integrated setting without supervision.)**

\_\_\_\_\_ 5. **Positive feedback is given in a natural rather than "instructional" manner.**

\_\_\_\_\_ 6. **Staff provide only the level of assistance needed.**

\_\_\_\_\_ 7. **Staff encourage and display positive behavior on an ongoing basis.**

\_\_\_\_\_ 8. **Staff interactions toward the person could be described as positive and respectful.**

\_\_\_\_\_ 9. **The person eats with coworkers who do not have handicaps.**

\_\_\_\_\_ 10. **Staff take time to interact with each individual and encourage people to interact with each other at meals.**

\_\_\_\_\_ 11. **If the person is unable to speak, other ways to express choices and engage in conversation are used.**

## VI. HEALTH AND SAFETY

### A. HOME

If your son or daughter is living in a residential program, the staff have a great responsibility for monitoring his or her health and safety. Although how the staff handle emergencies is critical, it is also important that they monitor health and safety considerations on an everyday basis. Many of the items below relate to various rules and regulations; however, they are all important to insuring the health of your son or daughter.

- \_\_\_\_\_ 1. **A complete physical examination occurred within the last year, if problems were noted, a follow-up action was taken.**
- \_\_\_\_\_ 2. **A dental examination occurred within the last year; if problems were noted, a follow-up action was taken.**
- \_\_\_\_\_ 3. **For a person with a vision problem or a person unable to communicate symptoms, a vision examination occurred within the last 18 months; if problems were noted, a follow-up action was taken.**
- \_\_\_\_\_ 4. **For a person with a hearing problem or a person unable to communicate symptoms, a hearing examination occurred within the last 18 months; if problems were noted, a follow-up action was taken.**  
*"Follow-up" is just as important as identifying the health and medical concerns mentioned in the items above. If medical professionals have recommended additional tests or treatments, those recommendations should be followed and the progress noted in the individual's health records.*
- \_\_\_\_\_ 5. **The person's present weight is within an acceptable range as noted by the person's physician. The person has had a medical evaluation if his weight is not within an acceptable range and/or significant weight fluctuations have occurred within the last three years.**
- \_\_\_\_\_ 6. **For the person with chronic health problems, there is a nursing care plan identifying needs and stating procedures and actions to be taken.**
- \_\_\_\_\_ 7. **The person appeared clean and healthy.**
- \_\_\_\_\_ 8. **If injuries have occurred, they were not due to an unsafe environment, and appropriate actions were taken.**
- \_\_\_\_\_ 9. **If behavior changes have been observed since taking any medication, they have been discussed by the team and appropriate actions taken.**
- \_\_\_\_\_ 10. **If the person is taking medication(s) for seizures, the types of seizures are described in observable terms to ensure accurate charting by staff.**
- \_\_\_\_\_ 11. **Seizure records include information describing each seizure, including the length and aftereffects.**

\_\_\_\_\_ **12. Seizure records combine information from all settings where the person spends time.**

*If your son or daughter has seizures, additional records need to be kept. Although direct care staff are not medically qualified to "diagnose" the type of seizure, they should be able to describe the incident in a clear and understandable manner.*

\_\_\_\_\_ **13. Staff know specific side effects for any medication the person is taking.**

\_\_\_\_\_ **14. There is a systematic procedure for monitoring the possible side effects of all medications the person is taking.**

*Medications have a wide variety of side effects. A method should be in place which requires staff systematically to observe for side effects and not just to note "okay" or "no side effects." The problem is particularly significant with medication used for behavior modifying purposes.*

*In Minnesota institutions, regular monitoring for tardive dyskinesia is required using the DISCUS form (Dyskinesia Identification System; Condensed User Scale) and for other side effects using the MOSES form (Monitoring of Side Effects Scale). These procedures, or similar ones, should be used by trained staff whenever psychotropic medications are administered.*

\_\_\_\_\_ **15. No safety hazards were noted in the home.**

*Everyday life presents all of us with risks. Sharp kitchen knives, the stove, stairways without railings, hot water, cleaning supplies, scissors, slippery sidewalks, the bathtub—all of us are subject to a typical number of potential safety hazards. However, residential programs for people who may have additional vulnerabilities need to be aware of unnecessary and unreasonable risks in the physical environment.*

\_\_\_\_\_ **16. The environment was clean.**

## **B. WORK OR DAY PROGRAM**

Although residential programs generally have primary responsibility for ongoing medical and health care, day programs need to work in cooperation with the residential programs.

- \_\_\_\_\_ 1. **The person appeared dean and healthy.**
- \_\_\_\_\_ 2. **If injuries have occurred, they were not due to an unsafe environment and appropriate actions were taken.**
- \_\_\_\_\_ 3. **If behavior changes have been observed since taking any medication, they have been discussed by the team and appropriate actions taken.**
- \_\_\_\_\_ 4. **If the person is taking medications) for seizures, the types of seizures are defined in observable terms to ensure accurate charting by staff.**
- \_\_\_\_\_ 5. **Seizure records include information describing each seizure, including length and aftereffects,**
- \_\_\_\_\_ 6. **Seizure records combine information from all settings where the person spends time.**
- \_\_\_\_\_ 7. **The possible side effects of all medications are monitored on a regular basis wherever the person spends time.**
- \_\_\_\_\_ 8. **No hazards were noted in or around the program environment.**

**PART THREE**  
**EVALUATING PROGRAM OBJECTIVES**

## **VII. EVALUATING BEHAVIORAL OBJECTIVES**

Your son or daughter's program plan should include a number of behavioral objectives. Although there should be one program plan, each service provider may have a plan for implementing the objective in that particular setting.

In evaluating each of the objectives, you will look for a number of things. Basically, you will ask these three questions: what is the objective, how will it be implemented, and how will progress be measured and evaluated. Under each of these questions there are several points to consider.

### **WHAT IS THE OBJECTIVE?**

Each objective should be written in such a way that you can easily understand the task or skill that is being taught. Each objective should:

#### **1. State the specific behavior in a way that is both observable and measurable.**

For example, the statement "Marsha will behave in public" is not specific; it would be very difficult to measure "behave" in a meaningful way. However, "Ted will sweep the kitchen with a push broom" is a behavior that is specific, can be observed, and could be measured or counted.

#### **2. Give the conditions under which the behavior is to occur.**

You may see objectives that start with the phrase "given that . . ." This is one way to explain the situations in which your son or daughter is expected to complete the task. But beware-not all "given" statements are useful. For example, "Given staff, Beth will complete her grooming" does not tell you very much about the conditions under which Beth is expected to complete a task (nor does it tell you very much about what Beth is expected to do).

#### **3. State an objective measure of the level of performance.**

The previous example "Ted will sweep the kitchen with a push broom" gives a specific behavior, but does not tell you very much about how well Ted is expected to do. The level of performance should be stated in such a way that an observer can easily determine if Ted has completed the task in an acceptable manner.

The level of performance will differ based on the individual and the task being taught. For example, the level of performance for Ted might include how long it takes him to complete the task ("within five minutes"), a measure of accuracy ("so that no visible dirt, food particles, or pieces of paper remain on the floor"), and the number of times he is expected to complete the task over a period of time ("on five consecutive occasions within a two week period").

Don't be confused by complicated percentages. Ask yourself if the level of performance makes sense for your son or daughter in terms of the task. Crossing a busy street without a crosswalk would obviously require a greater degree of accuracy to insure safety than loading a dishwasher at home or making a sandwich.

**4. Include a deadline date for completion of the objective.**

People with developmental disabilities, especially people with mental retardation, have difficulty learning new tasks as quickly as other people. However, this does not mean that objectives should be continued indefinitely. If your son or daughter has not learned a task or behavior in a reasonable amount of time, the teaching methods should be questioned.

**5. List dates when the objective will be started and reviewed.**

Generally, objectives should be implemented as soon as possible after the team has approved the program plan. You will want to make sure that there is not an unusual amount of time between quarterly or annual team meetings and the start dates for objectives. In most situations, objectives will be reviewed every three months (quarterly).

The form of the objective is important; if it is not written in a clear and specific way, the chances of progress on it being measured effectively becomes less likely. However, a "perfectly" written objective may not be worth implementing if it does not address a number of important issues. As you review each objective, you will need to determine if it is:

**6. Functional.**

If your son or daughter learns the task stated in the objective, how will that increase her independence now and in the future? What difference will it make if she learns the task or not? This may seem like a very basic issue, but there are hundreds of objectives written that are not functional-that is, they will have little if any impact on assisting the person to be less dependent on others, or to feel more comfortable as a part of her community, or to improve the chances that he will be able to work at a job that pays decent wages.

One of the reasons that so many non-functional goals and objectives are still being written is that for a number of years we based our teaching on the "developmental model." This approach assumed that people learn things in a particular sequence; first you sit, then you crawl, then stand, then walk, run, skip, and so on. In some situations, this approach has been very useful. However, if a person with severe mental retardation must complete in sequence all of the prerequisite steps, he may never get to the real task.

A typical example involves money. You can find dozens of curriculum guides that list task analyses" for money training. Some of the prerequisites might include identifying coins, stating the value of each coin, counting to 100 by 5's, 10's and 25's, and making change up to \$10.00. In some situations, people may be working on counting by 5's to 100 before they have an opportunity to go shopping.

Another way to determine if the objective is functional is to ask, if my son or daughter does not complete this activity, will a staff person have to do it for her? For example, if Ted does not sweep the kitchen floor, someone else will in all likelihood have to do it. If Lisa does not learn to shampoo her hair, someone else will need to give her assistance. But if Brian does not sort 100 pegs into boxes by color, staff will not be asked to work overtime to finish his sorting.

**7. Future-directed.**

How does this objective relate to the future? Will learning this task or behavior enable my son or daughter to live in a setting that is less restrictive than at present? Will accomplishing this objective assist my son or daughter in learning about work and getting a job?

**8. Age-appropriate.**

Although some people with severe disabilities are able to do things that are more typical of children, we must be careful not to fall into the "mental age" trap. Adults should be learning skills that other adults without handicaps would typically be expected to do. Adaptations in teaching methods are important; however, relevant, functional objectives will focus on the development of skills that are typical for people without disabilities of the same, chronological age.

**HOW WILL THE OBJECTIVE BE IMPLEMENTED?**

In addition to the written behavioral objective, your son's program plan should include a written description of the methods that will be used to teach the skill. Several important ideas should be considered in developing this plan.

Before staff begin to teach a specific skill to your son or daughter, it is critical to determine what steps are involved to successfully complete the task, and then to determine what steps need to be taught.

This type of analysis is called a "discrepancy analysis." Although it is not routinely used in many programs, this analysis is considered to be a "best practice" procedure. A discrepancy analysis involves the following procedures:

(This example is from an article in a professional journal: The Journal of the Association for Persons with Severe Handicaps or JASH. The article appeared in the Spring 1986 issue and is titled "Adult Leisure Education for the Independent Use of a Community Recreation Center." It was written by Stuart Schleien and Angela Larson from the University of Minnesota.)

**1. A step by step analysis of the behavior to determine how the task would be completed.**

The task in this example involves using a community recreation center. The objective is as follows: "Given a recreation center, six blocks from the participant's home, the participant will walk with a peer to and from the center, stopping at each intersection, looking both ways for oncoming traffic, and crossing the inter-

section where there is no oncoming traffic, the traffic light is green, and the 'walk' light is illuminated 100% of the time."

This task is then broken down into small, specific steps:

- a. Exit front door of house and proceed to sidewalk
- b. Proceed south to the end of the block
- c. Stop and stand on corner
- d. Look in both directions for oncoming traffic
- e. Cross street when there is no oncoming traffic
- f. Proceed south one block
- g. Stop and stand on corner facing east
- h. When traffic light is green and "walk" sign is illuminated, check for traffic to stop and cross
- i. Proceed east one block
- j. Stop and stand on corner
- k. When traffic light is green and "walk" sign is illuminated, check for traffic to stop and cross
- l. Continue east three blocks, stopping at each intersection to check for on-coming traffic
- m. Enter community recreation center.

When an activity such as "walk to the recreation center" is broken down into a series of small steps in this way, it is much easier to determine what needs to be taught

Once the task analysis has been completed, the individual would attempt to complete the activity while being observed by a staff person. The "discrepancy analysis" would list:

**2. Which steps the person can and cannot currently complete.**

In our example, let's assume that the person could complete the first six steps, and the last step, but had difficulty with steps g-l.

**3. What steps will be taught, adapted, or modified.**

At this point, there are several options. We could decide to teach steps g-l, or to make some adaptations, or to modify the task.

In many situations, it will be clear that teaching the step is the most logical choice. But in some situations, an adaptation makes more sense. For example, a task analysis for brushing teeth might include the step "remove cap from tooth-paste." If the person is unable to do this because of a physical disability, an adaptation could easily be made using a toothpaste that has a "pump" container, or a device that would allow the person to remove the cap using the movements that she is capable of completing.

In other instances, we may want to modify the step. In our example involving the community recreation center, a person who cannot see will obviously not be able to check for oncoming traffic. The step would need to be modified to meet the needs of the individual. Another common example is the important independent living skill

of putting on shoes. Clearly, tying one's shoes is an important step to complete the task. However, the use of velcro straps or slip-on shoes would enable the person to be more independent if tying the laces is a skill that has not been successfully taught in the past

There is no one right answer in determining whether or not a step should be taught, adapted, or modified. When you look at your son's objectives, his individual needs and capabilities must be taken into consideration.

If the procedures outlined above in items 1-3 have been completed, a basic discrepancy analysis has been done. Now we need to look at how the steps will be taught to your son or daughter. The program plan objective should include the method that will be used to teach the skill; in many program plans there may be a place on the form called "method" or "procedure." There are three things to look for in evaluating the method:

**4. Is there a clear outline for implementing the program, including any adaptations that will be used?**

Ask yourself, if I were asked to implement this program, are the directions written in such a way that I can understand them? Is all the information that I need included?

**5. Do the teaching methods take into consideration my son's preferences? Do they show that the staff understand what motivates him? What interests him? What he likes and dislikes?**

Most methods will include the kind of positive reinforcement that will be used in teaching the task, such as verbal praise, a pat on the back, or some sort of "token." The reinforcement should be based on what we know will work.

**6. Is the training designed to take place in a variety of natural environments?**

It is possible to "teach" crossing streets by setting up a "pretend" traffic situation—drawing lines on a gym floor, moving desks around in a classroom, or even going so far as to purchase stop lights from the Department of Transportation. (It has been done, and more than once.) Simulated grocery stores are still being used, and individuals are still being taught about making purchases by using Monopoly money. This type of training simply makes no sense in light of what we know about how people with mental retardation learn.

Shopping should be taught in local stores, and in more than one store. Crossing streets should be taught outside on community streets that your son or daughter would be expected to cross. Teaching skills where they are actually used will assist your son or daughter to use that skill in other similar situations.

## HOW WILL PROGRESS BE MEASURED AND EVALUATED?

It would be possible to have well written, functional, and age-appropriate objectives that are supported by clear and specific teaching procedures based on the needs of your son or daughter and yet have no real way to measure progress. The presence of data cannot insure that meaningful learning has taken place; however, each program plan objective should include directions to insure that specific information is being gathered about how well your son or daughter is doing.

There are five things to look for in answering the question "how will progress be measured and evaluated?" The first three of these should be included in the written procedure or program plan:

**1. Specific guidelines or criteria for determining when the objective has been successfully met, and guidelines to determine if the objective will be continued or modified.**

Each objective will have a different criteria for success depending on the objective. The previous example on walking to the recreation center might have a criteria for success like this: "the person will complete all of the steps without assistance or prompting on five successive occasions during a three week period" The plan for implementing the objective might also contain these guidelines: "If he is unable to complete any one of the steps successfully on five successive attempts, the plan will be modified. The most important thing to remember is that there must be clear guidelines for determining progress and making decisions about necessary changes.

**2. A detailed explanation of data collection procedures.**

When reviewing the data collection procedure, ask yourself "would I know how to collect information about this objective? Will the data give me useful information about progress? Is the data objective rather than subjective?" It is also important to develop data collection procedures which do not unnecessarily identify the person as a "learner." Most of us do not go walking or shopping with someone with a big clipboard. Nevertheless, there must be useful data.

**3. The names of the persons responsible for writing, implementing, and monitoring results of the plan.**

You should be able to talk directly to the people who write and implement your son or daughter's programs. If the person responsible is listed as "all staff," you should find out if all of the staff are familiar with and implement the objective.

Once the data has been collected, it is also important that it be summarized in a way which makes it easy to determine progress. There are two things to look for:

**4. On at least a monthly basis, data are graphed or summarized in a way which makes sense in terms of the objective.**

This can be done with simple line graphs or more complicated charts. The important consideration is that you can look at the graph and get a good idea if progress is improving, decreasing, or staying the same. Beware of summaries or graphs which report progress on the whole task or activity. This type of information can

mask or hide both areas in which progress has been made and areas in which the training program is not working.

**5. Data are evaluated on at least a monthly basis to determine whether the objective should be continued as written, discontinued or modified.**

In situations where progress is not satisfactory, there should be a good reason for continuing the objective without changes. It is not acceptable for an objective to be continued as written if there is no progress for three months. In many instances, lack of progress over a shorter period of time should lead to revision of the program. In some circumstances, weekly review of data is necessary. A program which continues without change may trap the person to depend upon the prompts given. Then there is another problem to deal with.

**PART FOUR**  
**SKILLS FOR INCREASED INDEPENDENCE**

## DOMAINS FOR SKILL DEVELOPMENT

The following sections consider four areas or "domains" in which your son or daughter would be expected to have goals and objectives. Although still common practice, objectives in skill areas such as "gross motor" or "fine motor" should not be written. A person with developmental disabilities clearly may need to develop the ability to use his body, but the development of these skills needs to take place while learning a useful skill or activity.

### VIII. INDEPENDENT LIVING SKILLS

Independent living skills can include a wide variety of activities: getting dressed, loading a dishwasher, washing your hair, taking out the garbage, making popcorn to watch during a ball game, changing the bed linen, or putting away the groceries after a trip to the store. Too often we have limited our vision of independent living" to basic self care skills; there is much more to life than brushing your teeth after every meal.

#### A. HOME

- \_\_\_\_\_ 1. **The assessment process considers:**
  - a) **tasks the person can complete in the current living situation,**
  - b) **additional skills that could be worked on in the current living situation,**
  - c) **skills that will be important in future living situations.**

*Most residential programs are required to complete a "standardized" skill assessment. This is usually a published form that may be widely used and includes a variety of behaviors and tasks. These behavioral assessments can be useful if the staff supplements the information to include the items listed above.*
- \_\_\_\_\_ 2. **The assessment is completed using typical situations in natural environments.**
- \_\_\_\_\_ 3. **During the planning process, the team has made decisions whether to teach a specific skill, to use a form of partial participation, or to make an adaptation.**

*The principle of partial participation is defined in an article that appeared in the professional journal of The Association for Persons with Severe Handicaps (TASH) in the summer of 1982. The article is called "Principle of Partial Participation and Individualized Adaptations in Educational Programs for Severely Handicapped Students" and was written by a number of people, including Dr. Diane Baumgart from the University of Idaho and Dr. Lou Brown from the University of Wisconsin at Madison.*

*The principle of partial participation challenges some previous ideas about teaching people with severe handicaps. One of these ideas includes the belief that a person should be learning skills based on his "developmental"*

age. Another belief that is challenged is that a person must master certain "prerequisite skills" before learning more complicated tasks.

According to the article, "partial participation is essentially an affirmation that all severely handicapped students can acquire many skills that will allow them to function, at least in part, in a wide variety of least restrictive school and non-school environments and activities."

Partial participation means that, even though your son or daughter may not be able to prepare a meal independently, he or she has the capability to participate in cooking in some way. The "discrepancy analysis" discussed earlier provides the information to decide which parts of a task to train. That analysis will also identify areas where an adaptation (such as a pump dispenser for toothpaste) will allow the person to do the task himself.

\_\_\_\_\_ 4. **The interdisciplinary team has focused on skills that are critical to community acceptance (e.g., hygiene, toileting).**

*However, these skills should not be the only focus of program plans,*

\_\_\_\_\_ 5. **Programs are used as opportunities to develop social skills such as cooperation, choice making, or shared responsibility.**

*Activities such as shopping or preparing a meal can provide your daughter with a chance to team about working with other people or making decisions. Programs should be designed so that your son will not only team a particular skill, but also team about getting along with other people.*

\_\_\_\_\_ 6. **Independent living skills training occurs in natural environments at appropriate times.**

*If your daughter is learning to change the sheets on her bed, the training should take place when the sheets need to be changed on her own bed.*

\_\_\_\_\_ 7. **The person is well-groomed, wears a flattering hair style (and make-up as applies), and clothes and accessories that fit and are flattering.**

*One measure of success in teaching independent living skills is that the individual "looks good."*

**B. WORK OR DAY PROGRAM**

- \_\_\_\_\_ 1. **The assessment evaluates what skills non-handicapped workers use and what skills the person is most likely to need in current and future work situations.**
- \_\_\_\_\_ 2. **Independent living skills that are related to getting and/or keeping a job receive job support and training.**
- \_\_\_\_\_ 3. **Independent living skills that would be used frequently and are currently being "done for" the person in the work setting receive priority.**
- \_\_\_\_\_ 4. **Partial participation and adaptive devices are used as needed in independent living training tasks.**
- \_\_\_\_\_ 5. **Independent living skills training occurs in natural environments at appropriate times.**

## IX. COMMUNITY

### INTEGRATION A. HOME

- \_\_\_\_\_ 1. **The person uses a variety of community resources during non-working hours at least five times a week.**
- \_\_\_\_\_ 2. **The program promotes establishing and maintaining friendships with people without handicaps.**
- \_\_\_\_\_ 3. **Group activities (three or more people with handicaps) in the community are the exception rather than the rule.**

*There are lots of reasons that group activities are common. Staff ratios often make it difficult for one-to-one activities. It may be easier to plan one activity for a group of people rather than to arrange for separate activities based on individual interests. However, there are important reasons that group activities should be kept at an absolute minimum.*

*When people in the community see a group of people with developmental disabilities, an invisible barrier is often created. People in the community are less likely to get to know individuals when they are in groups. It can also reinforce the idea that people with mental retardation belong "with their own kind"*

*Group activities also limit the amount of individual attention that your son or daughter will receive. Programs need to make real efforts to provide individualized opportunities for people to spend time in the community.*

- \_\_\_\_\_ 4. **If available, the person uses public transportation regularly.**

*Public transportation will not be available in every community, but when it is available, your son or daughter should be given the opportunity to use it. Although it may be more convenient to rely on the facility's vehicle, segregated transportation will not provide opportunities to be a part of the neighborhood and community. If an individual is able to learn to use public transportation with whatever assistance is required, he or she will be less dependent on others.*

- \_\_\_\_\_ 5. **The person spends time in places that are typical for a person of that chronological age.**
- \_\_\_\_\_ 6. **The person regularly makes purchases in community stores.**
- \_\_\_\_\_ 7. **The person frequently participates in integrated recreation and leisure activities in the community.**

- \_\_\_\_\_ **8. If the person chooses to participate in religious activities, these activities provide contact with people without handicaps.**

*Churches and synagogues can provide excellent opportunities for people with developmental disabilities to spend time with members of the community. However, these interactions will be less likely to happen if the person attends "special Sunday School" or attends religious services with five or six other people from the group home.*

- \_\_\_\_\_ **9. The person receives services from various professionals (e.g., medical, dental, hair stylists) located in the community.**

*In addition, your son or daughter should have an opportunity to express his or her preferences for these services. For example, if you or your son or daughter would prefer to see the same family physician or dentist, the residential program should make sure that it is possible.*

- \_\_\_\_\_ **10. The person regularly spends time with people without handicaps who are not service providers.**

**B. WORK OR DAY PROGRAM**

- \_\_\_\_\_ 1. The person uses a variety of community resources on a daily basis.
- \_\_\_\_\_ 2. The program promotes establishing and maintaining friendships with non-handicapped people.
- \_\_\_\_\_ 3. Activities that include three or more people with handicaps as a group in the community are the exception rather than the rule,
- \_\_\_\_\_ 4. The person learns skills for leisure activities that are related to the job.
- \_\_\_\_\_ 5. If available, the person uses public transportation regularly.
- \_\_\_\_\_ 6. The person spends the majority of the day in places that are typical for a person of that chronological age.
- \_\_\_\_\_ 7. The person regularly spends time with people without handicaps.

## X. VOCATIONAL SKILLS

### A. HOME

**Even though a residential program is not "responsible" for what happens in other programs your son or daughter receives services from, it is important for all providers to work together to provide a coordinated program that meets each individual's needs. The items that follow are indicators that residential staff are involved in the entire life of your son or daughter, not just what happens at home.**

- \_\_\_\_\_ 1. **Residential staff actively participate in the development of the vocational plan.**

*Staff from the residential program should be included in the planning meetings for any habilitation or vocational programs. There are often issues that carry over from home to work, and all of the people who provide services to your son or daughter need to work together to develop the program plan.*

- \_\_\_\_\_ 2. **Residential staff are familiar with the vocational plan and the person's current work performance.**

- \_\_\_\_\_ 3. **Residential staff communicate to the vocational program manager relevant issues concerning the person's job.**

- \_\_\_\_\_ 4. **Residential staff provide necessary supports to enable the person to be successfully employed (e.g., address hygiene and transportation issues, accommodate work schedule).**

*Studies are beginning to indicate that people with developmental disabilities are more likely to lose their jobs due to socialization issues rather than an inability to do the job. Many of these concerns should be addressed in the person's home situation as well as the vocational program.*

## **B. WORK OR DAY PROGRAM**

The items in this section are based on the belief that day programs for people with developmental disabilities should involve work. Federal programs are providing funding across the country for traditional day programs to convert to models of "supported employment" Supported employment means that people with severe disabilities can work in real, paying jobs if the right amount of individualized, ongoing support is available.

- \_\_\_\_\_ 1. **The assessment is individualized and occurs in community work settings.**
- \_\_\_\_\_ 2. **The assessment provides information about the person's interests, strengths, and limitations.**
- \_\_\_\_\_ 3. **The assessment includes a detailed analysis of specific job skills needed for work environments.**

*To tell whether a person can do a job or to train her to do it, it is necessary to do a "task analysis" of the various steps required for that job and a "discrepancy analysis" to determine which of those steps the person can do.*

- \_\_\_\_\_ 4. **The assessment includes an analysis of job-related skills needed for potential job placements (e.g., transportation skills, judgment skills, money management).**

*Many times it is easier to leant the "job" than to leant other skills which will make the work successful such as when and how to ask for help, how to accept supervision, how to work along with a coworker, how to get to the job sue, and other related issues. Both the assessment and the program plan should consider this wide variety of job-related activities.*

- \_\_\_\_\_ 5. **The assessment provides the person with exposure to a variety of jobs if he has limited work history.**
- \_\_\_\_\_ 6. **The placement is based upon the person's needs, interests and preferences rather than only job availability.**

*If your daughter enjoys cleaning, men a job placement on a cleaning crew makes sense. If your son likes working at a desk, collating and stapling jobs would be appealing. There may be instances when the "perfect job is not available; however, since one's occupation is a very personal choice, interests and preferences need to be addressed.*

- \_\_\_\_\_ 7. **One person is responsible for coordinating all aspects of the individual's vocational program.**
- \_\_\_\_\_ 8. **The vocational program plan trains the individual in both job and job-related skills.**
- \_\_\_\_\_ 9. **The job site is a typical work environment in the community.**

- \_\_\_\_\_ 10. **The job site provides opportunities and support for social integration with non-handicapped workers.**
- \_\_\_\_\_ 11. **The present job placement is considered successful by the employer and the individual and is likely to continue.**
- \_\_\_\_\_ 12. **The team convenes to "troubleshoot" as necessary before the employer takes negative action.**

## XI. LEISURE AND RECREATION SKILLS

This section addresses both acquiring leisure and recreation skills and the use of leisure time at home. As day programs shift to a vocational emphasis, it is even more important that residential programs offer people a variety of opportunities to develop hobbies, participate in sports, enjoy entertainment in typical community settings, or pursue other free time interests. These types of opportunities should not only be made available, but your son or daughter should also be learning new skills based on his or her interests and preferences.

\_\_\_\_\_ 1. **The assessment lists the person's favorite activities and those in which the person typically engages during leisure time.**

\_\_\_\_\_ 2. **The assessment includes community activities in which the person participates.**

*Many programs complete a "leisure and recreation" checklist for each individual. These lists can be useful if they are specific-listing "sports" as an activity does not give enough information. Instead, the assessment might include details such as "league bowling during the fall and winter, enjoys attending softball games, enjoys running daily."*

\_\_\_\_\_ 3. **The assessment considers the age-appropriateness of the leisure activities that the person currently enjoys.**

*If your son or daughter shows a strong preference for leisure activities that are not typical for other people of the same age, staff will need to focus on the development of age-appropriate leisure interests.*

\_\_\_\_\_ 4. **The assessment identifies skills which the person needs to acquire to engage in a broader range of leisure activities.**

*All of us have learned and continue to learn to play as well as to work. The assessment should identify the skills a person needs to learn in order to participate in a wider range of leisure activities at home and in the community. These skills may include social skills (taking turns, playing by the rules), communication skills (responding appropriately in a leisure activity), and transportation skills (getting to an activity). Skills to be taught should be part of specific leisure activities, not skills to be learned before becoming involved in leisure activities.*

\_\_\_\_\_ 5. **The assessment identifies adaptations which can be made in leisure activities to allow full or partial participation.**

*Physical or mental limitations may prevent participation in leisure activities. An activity can be adapted to allow fuller participation for persons with physical or sensory handicaps. Complex rules of age-appropriate activities can be simplified.*

\_\_\_\_\_ 6. **The person has easy access to leisure activities.**

- \_\_\_\_\_ 7. **Leisure activities are based on the person's preferences.**
- \_\_\_\_\_ 8. **Leisure activities take into consideration the person's ability to communicate.**

*Communication is a skill that is used and should be trained as part of leisure activities. Inviting someone to play a game, making choices, and following rules are all skills that the person will need to be more independent and more involved in leisure activities.*
- \_\_\_\_\_ 9. **The program plan includes training to participate in leisure activities.**

*Choice of preferred leisure activities is limited, in part, by what a person has had a chance to learn. Ongoing leisure skills training which builds on existing strengths and preferences provides the basis for further development of preferred leisure skills.*
- \_\_\_\_\_ 10. **A major focus of leisure activities is to promote integration and interactions with people without handicaps.**

*This can be done in many ways if careful and thoughtful planning is a part of the process. Opportunities exist in even the smallest of communities--garden clubs, service organizations, church groups, bowling and softball leagues, community adult education classes, and volunteer opportunities. It is often too easy to fall back to segregated recreation programs without exploring the options for integration.*
- \_\_\_\_\_ 11. **Leisure programs use chronologically age-appropriate activities.**
- \_\_\_\_\_ 12. **Leisure activities provide opportunities for making choices.**
- \_\_\_\_\_ 13. **A balance is maintained between leisure activities adapted to allow active participation and spectator activities.**

**PART FIVE**  
**SPECIAL NEEDS CONSIDERATIONS**

## SPECIAL NEEDS AREAS

The following three sections address what are often considered "special needs": communication, behavior, and physical and sensory disabilities. Program objectives in any of these areas should emphasize ways to integrate these considerations into functional activities.

### XII. COMMUNICATION

Imagine what it would be like if you were not able to tell anyone how you felt, what you wanted, what you enjoyed, who you preferred to spend time with, what kind of foods you liked best, if the radio was too loud, or that you wanted to be left alone. It is difficult to imagine a lifetime of not being understood. Unfortunately, many people with disabilities experience that frustration every day.

\_\_\_\_\_ 1. **The communication assessment includes information about:**

- a) **her likes, dislikes, and preferences,**
- b) **receptive and expressive language abilities as observed at home and during his day program,**
- c) **motor and sensory skills that are important for communication,**
- d) **how others in the home encourage and respond to her attempts to communicate,**
- e) **how the total environment affects development of communication skills.**

*Communication skills must be assessed where a person lives, works, and plays and not just in a testing situation. It is important to learn what language a person can and cannot understand and can and cannot express in those situations. More needs to be learned, however, to develop a communication program. The behavior of other persons in each setting must be observed. Do they limit attempts to communicate by either anticipating needs or ignoring efforts to communicate? Are there opportunities for communication in daily activities which are being overlooked? Are staff persons trained to respond to the person in his language?*

\_\_\_\_\_ 2. **The possible relationship between inappropriate behavior and lack of communication skills is assessed by collecting objective data.**

*Many instances of inappropriate behavior are actually legitimate attempts to communicate. Since this is a possibility, specific data should be gathered about how and when the behavior happens. That information should be analyzed to figure out what the person might be trying to communicate. Then a plan can be made to help the person learn an appropriate alternative to the inappropriate behavior.*

- \_\_\_\_\_ 3. **If the person has difficulty communicating, communication objectives are included in the program plan.**

*It is hard to think of any instance when communication needs would not be dealt with in a program plan, for everybody should have the chance to tell others what they want or need. In some cases the communication skill trained may be very simple. Other persons, who have some communication skills, need to refine them. Too many times no communication program is developed because "she can make her wants and needs known." That skill is no reason not to train better and more effective communication, especially in a community setting.*

- \_\_\_\_\_ 4. **Objectives that involve communication skills are planned to be implemented during specific functional activities.**

*Communication is a practical skill. We communicate when we need to and where we need to. Your daughter's communication program should be part of real activities. Part of her programs to learn skills in each of the domains should be to learn how to communicate while doing that activity.*

- \_\_\_\_\_ 5. **Communication-related objectives are coordinated by both home and day programs.**

*If your son is learning how to speak or to sign or is using an alternative communication system, the teaching methods or the alternative system must be used consistently everywhere he spends time. The people who provide services to your son need to work together if programs are to be successful*

- \_\_\_\_\_ 6. **Communication training will enable the person to communicate what is most important to him, not what staff wants the person to be able to communicate.**

*When looking at a communication program, put yourself in your son's shoes and ask "is this really what he would want to learn to say or to understand?" Is it really important for him to learn to sit or stand when told to or to express his need to go to the bathroom? Frequently communication programs are really designed to train compliance, not to allow him to express what he wants to do.*

- \_\_\_\_\_ 7. **If the person cannot speak, an alternative communication system is developed in consultation with a communication specialist and other necessary therapy staff.**

- \_\_\_\_\_ 8. **The alternative communication system is based on the person's unique communication skills and needs.**

- \_\_\_\_\_ 9. **If an alternative system of communication to used, it is available for use whenever and wherever she spends time, and it provides opportunities to communicate with people without handicaps.**

*For some persons, use of sign language, communication boards or wallets, or electronic communicators will be essential. The communication specialist may have to work with a physical therapist or an occupational therapist to design a system which will work for your daughter. Some-times two systems may be necessary -- for instance, signing with persons who are around your daughter a lot and a picture system to be used in stores or restaurants.*

- \_\_\_\_\_ 10. **Frequent opportunities to communicate are a part of the daily routine.**

- \_\_\_\_\_ 11. **The person is taught to make requests independently and provided opportunities to make choices.**

*To be more independent, the person must ask for things and make decisions. You can't just wait for it to happen. Those are skills which can and must be learned,*

- \_\_\_\_\_ 12. **Staff respond immediately to communication attempts of the individual.**

*How much someone communicates often reflects how often she is given a chance to, how often she is really given a choice of things to do or have, and how readily others respond to her efforts to communicate. A "good" caregiver will sometimes anticipate too many needs and thus make communication unnecessary.*

### XIII. BEHAVIORAL SPECIAL NEEDS

Prior to developing a behavior management plan the team determined items 1-4 were true:

- \_\_\_\_\_ 1. **The person is able to make requests, to say no, and to ask for help or is receiving training in these communication areas.**

*Many "behavior problems" are actually strong messages from the individual. If your son is not able to let others know that he needs help or is frustrated, acting in a way that will get someone's attention immediately may be the best way to communicate.*

- \_\_\_\_\_ 2. **The person has frequent, daily opportunities to make choices, or is receiving training in this area.**

*People with developmental disabilities live in situations where other people have an extraordinary amount of control over their lives. Without regular opportunities to make choices, your daughter may act in ways that express her frustration.*

- \_\_\_\_\_ 3. **Tasks the person is requested to do are functional, age-appropriate, and reflect the person's interests.**

- \_\_\_\_\_ 4. **The majority of individuals the person lives with do not have behavioral special needs.**

*People learn by observing others; the idea of "when in Rome, do what the Romans do" can apply to people with behavioral special needs as well. If most of the people your son lives with also have challenging behaviors, he may learn other inappropriate behaviors. It is important that he has positive role models in addition to staff. Also, when people with similar challenges are grouped together, there may be a tendency for the "behavior problems" to overshadow other needs.*

- \_\_\_\_\_ 5. **A physician has examined the person to determine whether there are existing medical or health problems which could cause the target behavior or which must be considered in development of a behavior management plan.**

*There are instances when a problem behavior happens because of a physical condition or because the person is hurting. A doctor should be consulted to see whether this is true or whether there is a physical condition which must be considered when developing a program plan.*

- \_\_\_\_\_ 6. **A functional analysis of the target behavior(s) has been completed. The analysis identifies**

- a) **possible reasons why the behavior occurs,**
- b) **times and situations when the target behavior(s) is most and least likely to occur,**

- c) **the probable function of the behavior for the individual (e.g., social, communication, escape, boredom),**
- d) **alternative positive behavior(s) which should enable the individual to achieve the same or similar results.**

\_\_\_\_\_ 7. **The behavior management plan is based on an analysis of why the person uses the target behavior and includes plans for teaching positive alternatives.**

*It is difficult to plan what to do about a problem behavior without trying to figure out why the problem behavior is happening. Careful observation and detailed record keeping are necessary to answer this basic question. If the function the behavior serves is identified, then the program plan should focus on helping the person to satisfy that functional need appropriately, not simply to eliminate the problem behavior.*

\_\_\_\_\_ 8. **Before implementing a behavior management program, the person or his guardian gives his or her informed consent in writing.**

*Minnesota rules require informed consent before certain behavior management procedures can be used. It is preferable to require informed consent for all behavior management plans.*

*Generally, informed consent can only be given by someone legally authorized to do so after a clear explanation (orally and in writing) is given. The explanation must include, among other things, the frequency of the target behavior, a description of the procedures which will be followed, a statement of the benefits expected and risks or side effects possible, and the alternative procedures which have been attempted or considered and rejected. If the professionals on the team cannot explain why the program is needed and likely to work, odds are that they don't know. Informed consent is usually for a limited time, such as ninety days. If the person has no guardian or conservator and cannot give informed consent, a guardian or conservator should be appointed.*

\_\_\_\_\_ 9. **The behavior management plan clearly describes the procedure to follow and is implemented by trained staff at all times and in all places the person spends time; staff gather data from all the settings and review it as a team.**

*Unless a behavior management plan is clear and specific, changes will be made in the implementation of that plan by staff however well they are trained. If you would not know what to do from reading the plan, it is not clear and specific enough. The directions for collecting data must also be clear, easy to follow, and provide the kind of information necessary to determine if the plan is working.*

\_\_\_\_\_ 10. **The person is not denied participation in community integration activities due to behavior management concerns.**

*Your daughter should not be excluded from activities because of "behavior problems."*

\_\_\_\_\_ **11. The program does not include aversive or deprivation procedures.**

*"Aversive" procedures are those which plan that something painful or unpleasant will happen if the person does the targeted behavior. "Deprivation" procedures involve a plan to take something away which the person might otherwise have if the person does the targeted behavior. The best practice is not to use such procedures.*

*In Minnesota, some aversive or deprivation procedures may be used, but only when specific rules are followed.*

\_\_\_\_\_ **12. The plan specifies a termination date and includes criteria for making changes or continuing the program; programs are revised when there is insufficient progress.**

*The behavior management plan should include regular, generally weekly, dates for review of data collected. The team should decide ahead of time what results must happen to allow the program to continue unchanged.*

**(Answer these questions if behavior modifying medications are being considered or have already been prescribed. Also look at Part VI, items 13 and 14.)**

\_\_\_\_\_ **13. There is a complete medication history in her record which includes information on side effects, allergies, and past results of medication use.**

\_\_\_\_\_ **14. Less restrictive ways to modify the behavior were attempted before medication was administered.**

\_\_\_\_\_ **15. The individual, his parent, or personal advocate is involved in the team decision to administer the medication, and informed consent was obtained from the individual or guardian or conservator.**

*Informed consent for use of behavior modifying medications is similar to informed consent for behavior management programs. It is particularly important that the person giving informed consent be informed in writing of possible side effects. Some side effects of major tranquilizers (e.g., Mellaril, Thorazine, Stelazine, Haldol, Navane, Prolixin) such as tardive dyskinesia may not show up until the medication is reduced or stopped and may be irreversible in some cases.*

\_\_\_\_\_ **16. Unless blood levels determine the probable effectiveness of a behavior modifying medication, a planned effort to reach the minimal effective dose (MED) should be implemented when these medications are used.**

*For some medications, such as Lithium (also referred to as Lithobid or lithium carbonate), blood levels must be taken regularly to determine if the medication is likely to be helpful. For other behavior modifying medications, the best practice requires a planned effort, based upon data which shows if the medication is working, to reach a zero dose or the minimal effective dose.*

- 17. A behavior management program is being implemented in coordination with administration of the medication.**

#### XIV. PHYSICAL AND SENSORY SPECIAL NEEDS

If your son experiences physical or sensory disabilities, there are a number of additional considerations in reviewing his program plan. Although these issues are important, the people who work with your son should not forget that all of his needs are important, not just the needs that relate to his physical condition.

- \_\_\_\_\_ 1. **The assessment includes observation of the person's behavior in a variety of functional activities in home and community settings.**
- \_\_\_\_\_ 2. **Objectives related to physical and sensory disabilities are implemented as part of learning functional skills.**

*Your son's physical needs may require physical therapy procedures to be done by a physical therapist in a strictly therapy setting. It is possible, however, for some of these activities to be done as part of other functional tasks, either directly by the therapist or under her direction. If your daughter is blind, learning to get around should be taught in settings where that skill can be used.*

- \_\_\_\_\_ 3. **If the person has significant motor and/or sensory handicaps, objectives give him functional, age-appropriate ways to interact with his environment.**

*As we learn more about how to make use of technology, the possibilities become more exciting. Simple switches that can be activated by the smallest of movements make it possible for a person to interact with his or her environment. For example, your daughter could use a switch to turn on or off a radio or tape recorder with her favorite music.*

- \_\_\_\_\_ 4. **For a person with severe physical and/or sensory motor problems, the team has**
  - a) **incorporated the person's preferences into activities,**
  - b) **consulted with the occupational and/or physical therapist on**
  - c) **positioning and handling techniques and adaptive equipment,**
  - b) **provided many opportunities for choice making and encouraging any**
  - c) **level of participation in life activities.**

- \_\_\_\_\_ 5. **If the person has severe movement difficulty, the OT/PT staff has made recommendations including:**
  - a) **a schedule with at least two possible positions,**
  - b) **the length of time she can safely and comfortably be maintained in one position,**
  - c) **positions that will enhance her participation in activities.**

- \_\_\_\_\_ 6. **The person is in an environment where most individuals do not have similar physical or sensory special needs.**

*Because individuals with physical disabilities usually need additional*

*professional support services, such as nursing care or physical therapy, common practice has been to serve these individuals in settings with other people with similar needs. What may be more efficient or economical for people providing services is not necessarily in the best interests of the people being served.*

\_\_\_\_\_ **7. When the person is given physical assistance,**

- a) she is told when movement will take place, and**
- b) she is given opportunities to control the assistance by initiating movement or by giving staff an "OK" for assistance.**

*No matter how severe your daughter's disability may be, she should be treated with dignity and respect. Staff should not move people around without first talking to the person and giving the person a chance to respond in whatever way possible. For example, if your son has multiple disabilities and is unable to speak, he may still be able to indicate "OK" by making eye contact with the staff person.*

\_\_\_\_\_ **8. The person is given frequent opportunities to use the mobility skills he has to the fullest extent possible.**

\_\_\_\_\_ **9. Positioning is used as part of involvement in daily activities, rather than as a separate activity.**

*Staff members should consult with the therapist for suggestions on ways to incorporate positioning into the daily routine. The therapist should be responsible for training the direct care staff to implement these suggestions properly.*

\_\_\_\_\_ **10. The person eats in as normal a manner as possible (always in an upright position) with only the level of assistance needed.**

*Frequently persons who needed assistance with eating are fed too fast. Clear directions should be provided how your son is to be fed and what safety precautions are necessary.*

**PART SIX**  
**MAKING CHANGE HAPPEN**

## **MAKING CHANGE HAPPEN**

The first five parts of this guidebook provide information about evaluating the quality of programs for your sons and daughters. The obvious question is what can be done to improve the quality of the program when changes are needed.

It is much easier to identify problem areas than it is to see that needed changes are made. You may feel uneasy when you ask professionals in the field to do things differently. Sometimes it is hard to point out areas where improvement is needed to county workers or staff at the home or day program who really care about your son or daughter but are not doing what they ought to be doing. This part of the guidebook is intended to give you some suggestions about how to seek change informally and to tell you about more formal ways to make change happen when informal ways don't work.

It is possible that positive changes will be made in your son's program even if you do nothing. Most county case managers and most home or day program staff want to do a better job. Many times, however, you will have to raise your concerns with them if you want your son to get the quality program he ought to have. The squeaky wheel is the one which gets greased in everyday life. Your challenge is to be an effective squeaky wheel

### **BE INVOLVED**

Your active involvement with your daughter's program is the key to change. You should visit her home and day program regularly so that you see what happens. If you spend time with her, you will know better how she is getting along and how she likes what she is doing. Even if she can't talk very well, you will see how she reacts to what is being done.

Visiting is a good way to be involved, but visiting alone is not enough. You should also be involved with the case manager in developing your daughter's Individual Service Plan (ISP) and with the interdisciplinary team in developing her Individual Habilitation Plan (IHP). You should also attend quarterly and special team meetings. Your point of view will not be heard if you are not there to state it.

Sometimes you cannot be as involved as you would like to be because you live a long way away, because you have to work, or because you don't have transportation or can't get around easily. In that case, another family member or a friend may be able to be more involved and talk with you about her daily life and her programs.

## BE INFORMED

Being involved will help you be informed about many things which are important to your son or daughter. The more information you have about him, the more effective you can be. Knowledge gives you more power to make change happen.

Although there may be no limit to what you want to know, there are several questions which you will want to be able to answer:

### 1. What can I expect my daughter to be able to do?

Many times we won't know what a person with severe handicaps can do until she is given a real chance to try. Sometimes she will be able to do part of a task but not all of it. Enough people will have too limited expectations of her potential. Learn what you can of what she might be able to do.

### 2. What kind of services should my son receive?

This guidebook is intended to provide a starting point to answer this question.

### 3. What program services does my daughter actually receive?

You can learn some things about her program from attending meetings and from regular visits. This guidebook provides a way to organize your observations.

You should also look at program records. If you are her guardian, you have a right to review her program records. If she has no guardian, she can authorize you to look at records. If another person is her guardian, that person can authorize access to records. Look at them and ask questions about what they mean.

Ask professional staff to explain things you are not familiar with or do not understand. Remember that a professional person who cannot explain to you what he is doing and why he is doing it, probably doesn't know what he is talking about.

Write down what you observe and what you are told. That way you will be able to give examples of what concerns you in a more convincing way.

### 4. What does the county have to do for my son?

The county's basic responsibility is to provide case management services. These services are described in the case management rule, Minnesota Rules 9525.0015-9525.0165. The rule is still called Rule 185, from an old numbering system.

A copy of the rule will be provided to you at the training session. **The basic county responsibility is to obtain or develop services which meet his needs in the least restrictive environment and in a cost-effective manner.** There are basic steps in that process:

- Diagnosis - a determination whether your son is a person with mental retardation or a related condition.

- Assessment of your son's needs.
- Screening - to determine the method of payment to be used for his services.
- Development of an Individual Service Plan based upon the assessment which includes long-range and annual goals for your son, a statement of the type, amount, and frequency of all the services he needs and the competency required to provide them, and a plan to obtain or to develop the needed services.
- Authorization of services by the county to be provided by a person or organization actually able to meet your son's needs.
- Development of one Individual Habilitation Plan to be followed by all your son's providers.
- Monitoring of the services provided to see that your son's needs are met.

**5. What do the home and work or day program providers have to do for my daughter?**

The basic requirement is to provide the services required by the Individual Service Plan in a way which follows the Individual Habilitation Plan. There are also rules which govern residential services, day training and habitation services, and employment programs,

**6. What should I do with my common sense?**

Use it If something doesn't make sense to you as a parent, you probably have identified a problem. Ask questions.

**BE PREPARED**

Parents who are involved and well-informed are likely to be well-prepared to seek positive program changes. One of the key steps toward being well-prepared is to be involved and informed when your daughter's Individual Service Plan is developed by the county case manager. The ISP is important because it should state very specifically what services she needs and what goals she is supposed to achieve as a result of the services provided her.

Sometimes you may be able to change your daughter's program in ways which are very important without even mentioning her ISP. In other cases, especially if the county or the home or work or day provider does not want to make a change, it will be necessary to hold them to what the ISP says must be done. You can't hold them to something that isn't in the ISP.

You will be provided a copy of the case management rule at the training session. That rule tells how an ISP must be developed and what it must contain. You will also receive another manual which describes the case management process in detail.

## INFORMAL WAYS TO SEEK CHANGE

When you identify a problem, the first question is who best can solve the problem. For almost all issues, you can contact the county case manager. An alternative would be to talk to staff from the home or work or day program, preferably supervisory staff. If you do that, you should remember that the county case manager has overall responsibility to monitor the services provided to see that they are consistent with the Individual Service Plan and the Individual Habilitation Plan and with other requirements of the case management rule.

Whatever you choose to do, remember that change is less likely to occur if you don't talk to someone. If you choose to talk to staff persons, consider who is most likely to be able to make the decision to change.

There are some tactics which you should keep in mind:

**1. Be specific.**

The more direct you are, the more likely it is that change will be made. If your son needs communication training, say so. Then others must respond to that particular issue. You should be as specific as possible about the need for communication training, but it is not up to you to tell them how to do it.

**2. Be consistent, but be flexible.**

It is hard for someone to respond to your request for change if you ask people to do one thing one time and the opposite or a different thing the next week. But there may be times when it makes sense to change your mind because another way would work better. Keep an open mind to change what you want done if there is a good reason to do so.

**3. Be persistent**

If a change is going to be made in your daughter's program, make sure you know when that change is going to be made. Make a note of what was going to be done. Check back to see if it was.

**4. Be willing to ask for help.**

Sometimes a staff person may be the best person to help you get the change which your son needs in his program. Other times you may get help from another parent. You may want help from an advocate from the ARC or Legal Advocacy. Two people are often better than one when dealing with a team of professionals.

**5. Be helpful yourself.**

There will be times when you know something about your daughter which will help the team plan a good program. You can help by sharing that information. You may also need to help by following a communication program or a behavior management program when she is with you. If you ask for directions about how to do that, you can help by following the program.

## CONCILIATION CONFERENCES AND APPEALS

It is generally the best idea to try to work things out with the county case manager or the home or work or day program providers. This way can be easier and quicker. When people agree on what should be done, the odds that it will be done go up.

When this method to seek change does not work, or when you know that there is no real reason to believe that it will, you have other ways to proceed. The Minnesota Legislature passed a new law in 1987 which can help you. This law allows you to ask for a conciliation conference. If the conciliation conference does not give you what you want, then you can ask for a social services appeal.

The conciliation conference and the social services appeals are described in more detail in another manual which you will be given at the workshops. In this guidebook, there is only a brief outline.

You should not hesitate to ask for a conciliation conference or to take a social services appeals. The legislature passed this law to give you the right to do that.

### Conciliation Conference

#### 1. What is a conciliation conference?

It is a meeting with the case manager, a supervisor from the county, a person from the state Department of Human Services, you, and your son or daughter to try to work out an agreement about changes which will be made in what the county or the providers are doing.

#### 2. What can be brought up at a conciliation conference?

##### Many things, such as:

- Have my daughter's needs been adequately assessed?
- Is her ISP good enough?
- Are the home or work or day program providers able to meet her needs?
- Is her IHP good enough?
- Are the home or work or day program providers doing their job?
- Is the case manager checking up on what providers are doing?

#### 3. How do I ask for a conciliation conference?

You write a letter to the county social services agency asking for one. You can send this letter to the director of that agency or to your daughter's case manager.

#### 4. When will it be held?

It must be held soon after you ask for it, because the county's report on the

conference must be done in thirty days.

**5. What should I do before the conciliation conference?**

You should review your son's ISP and IHP and program records, if necessary, so that you are well informed and well prepared. It helps to make a list of the things you want to talk about and what changes you want. It is okay, and might help, to be specific in your letter to the county or to give people from the county your list of issues and the list of things you want done a few days before the conciliation conference.

**6. Where is the conciliation conference held?**

Generally at the county social services office, but it could be some other place which is more convenient to you or your son or daughter.

**7. Do I need a lawyer?**

No. You may have a lawyer or an advocate or friend along if you want.

**8. What happens at the conciliation conference?**

The person from the Department of Social Services, usually a Regional Service Specialist (RSS), will ask you what your concerns are and then ask the county to respond. The RSS will not decide who's right, but try to get you and the county to agree what should be done and when it will be done.

**9. Do I have to agree with what the county wants to do?**

No. You should agree only to what you think is right for your daughter. It helps a lot to know what the county must do under the case management rule. An experienced advocate or lawyer can help you on that.

**10. What happens after the conciliation conference?**

The county has to write a report and send it to you that summarizes what was talked about and what was agreed upon.

**11. What do I do after the conciliation conference?**

It depends. If you do not like what the county proposes, you can appeal. If you like only part of what the county says it will do, you can appeal the rest. If you like the plan agreed upon, you will have to see if the county does what it agreed to do. You can appeal at any time up to 90 days after the conciliation conference was held.

**Social Services Appeals**

Minnesota law provides for two types of social services appeals. For many years it has been possible to appeal the denial, termination, or reduction of services by a county agency or the failure of the county to act with reasonable promptness. For this type of appeal, there is no need to go through the conciliation conference process.

A new type of social services appeal is possible because of the law passed in 1987. This appeal can only be taken after requesting a conciliation conference. Two types of issues may be brought up in these new kind of appeals:

- Has the county provided case management services in the way required by the rules and laws which govern those services?
- Has the county social services agency made sure that the services a person needs according to the ISP are actually being given in the way required by law and rule?

The process followed in both types of social service appeals is the same. The major difference between the two types of appeals is that the new appeal specifically allows you to question the quality of case management services and the quality of the services given your son or daughter by the home or work or day program provides.

A lot of the questions you may have are covered in another training manual which you will be provided. Key questions about the new type of appeal are just noted here:

**1. Do I need a lawyer?**

No, but a lawyer or an experienced advocate could help. These appeals are heard by an appeals referee from the Department of Human Services, who may or may not be a lawyer. When lawyers are involved, the procedure is much more like an informal court proceeding, although everyone involved sits around a table. When lawyers are not involved, the procedure may be even less formal. The appeals referee cannot take sides, but the referee will try to see that all sides get a chance to say what they have to say, especially when the person taking the appeal does not have a lawyer or experienced advocate to help them.

Legal Advocacy cannot promise to provide an attorney or advocate to represent everyone on every appeal, but if you think that there is reason to appeal, you should not hesitate to call Legal Advocacy for help.

**2. When does an appeal have to be made?**

You can appeal at any time up to 90 days after the conciliation conference.

**3. How do I appeal?**

You write a letter saying that you want to appeal the county's actions in providing case management services to your son or daughter and send it either to the county or to the Commissioner of Human Services, 444 Lafayette Road, St Paul, MN 55155. There is no special form for this letter.

**4. What do I do before an appeal?**

If you are representing yourself, ask for the county and provider records you may need. If you are not the guardian, you will need written authorization by the guardian to do this. Think through what you want to say and write it down. If you have a lawyer or advocate, make sure that you meet before the appeal to

discuss the issues and what you want to say.

**5. What happens at an appeal?**

Each side gets to tell its story and to present evidence. If a lawyer or advocate is involved, the hearing will be like an informal trial. Strict rules of evidence are not followed.

**6. What happens then?**

The referee writes a recommended decision and gives it to the person authorized to act for the Commissioner of Human Services. The final decision must be made within 60 days of the time you appealed unless the Commissioner or her representative disagrees with the referee. If that happens, you have a chance to comment on the changes and a final order is not due until 90 days after you appealed.

**7. What can the appeal order?**

The decision can require the county to do what is necessary to follow the rules and laws involved.

**8. Is that the end of the process?**

No. Either side can appeal to the state district court. You may have to go to that court to enforce the order.