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ABSTRACT

This participant's manual covers "Changing Times", the second module of a four-module training program for all individuals employed in programs funded by Oklahoma's Developmental Disabilities Services Division. This includes van drivers, recreation workers, residential staff, administrators, case managers, secretarial/clerical staff, vocational staff, advocates, physicians, psychologists, and others. The primary objective of the module is to have the participant understand and apply the principle of normalization to the concepts of rights and values of people with developmental disabilities. Secondary objectives focus on perceptions of individuals with developmental disabilities through various periods of history, congregate settings, legislative rights and other rights, types of abuse and neglect, values of individuals with developmental disabilities, the importance of the principle of normalization for improving public images for people with developmental disabilities as well as promoting their social integration within the community, and methods of recognizing and eliminating barriers to normalization. The module includes the primary and secondary objectives, a text and question format that allows participants to become actively involved in the learning process, information from transparencies used in training, and copies of handouts. (JDD)

MODULE TWO

Foundation Level Training

Changing Times

Participant's Manual

Department of Human Services
Developmental Disabilities
Services Division

Department of Human Services
Developmental Disabilities Services Division

P.O. Box 25352
Oklahoma City, Oklahoma 73125

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MODULE TWO

Foundation Level Training
Changing Times

Participant's Manual

Department of Human Services
Developmental Disabilities Services Division

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INTRODUCTION

Foundation Level Training

INTRODUCTION

Foundation Level Training

People with developmental disabilities are PEOPLE FIRST. Their humanity is more important than their disabilities. They have dreams, hopes, likes and dislikes. They want to be loved and give love. They want to be respected by others and by themselves. They want challenges in their lives — a chance to accomplish things, to exercise their abilities and be productive citizens. They want to make a contribution to their communities. They want to have work that means something and that pays them enough to meet their basic needs.

They want a decent place to live in a decent neighborhood. They want to be as healthy as possible. They want the freedom to come and go as they choose, to be as independent as possible. They want privacy and the freedom to choose where and with whom they live. They want to be able to make choices about their daily lives; from what to wear and eat to when to go to bed.

In other words, they want what we want.

In the past, and even sometimes today, people with developmental disabilities have been seen only as people with needs which others must meet. Although this was never a true perspective — because people with developmental disabilities have had so few opportunities to exercise their talents and to give of themselves to others — it may have appeared to indeed be the situation.

This traditional viewpoint is one of the most important attitudes we must attempt to change — first in ourselves, then in others.

Today in Oklahoma, people with developmental disabilities are working at real jobs, volunteering in community service, being good

INTRODUCTION

Foundation Level
Training

neighbors, participating in their government, attending classes, and in general, doing what all people do.

This foundation level training will give you an idea of who we serve, how we got here, where Oklahoma is today and what the future may hold. Most importantly, it will allow you to look at your own beliefs and hopefully develop an awareness that...

◆

People are... People!

FOUNDATION LEVEL

Primary Objectives

Foundation training was developed to meet the primary training needs of staff, individuals, and family working with people with developmental disabilities. The primary objectives for the Foundation Level training course are to:

PRIMARY OBJECTIVES

Foundation Level Training

1 Provide all staff with a shared vision of what Oklahoma's system of services looks like, today and in the future.

2 Provide a consistent information, knowledge, and skill base for all individuals who serve people with developmental disabilities.

3 Prepare staff to become more effective members of the teams that provide assessment, planning, and delivery of services for individuals with developmental disabilities.

4 Improve the quality of communication and social interaction skills of staff who provide services.

5 Provide a functional definition of developmental disabilities and help staff understand common types of developmental disabilities.

6 Provide an understanding of historical issues influencing individuals with developmental disabilities and how these issues influence today's attitudes.

7 Provide staff and individuals with an understanding of the principle of normalization.

8 Provide a philosophy of services that is consistent with current state and national trends in service delivery.

9 Provide staff and individuals with a better awareness of the individual with developmental disabilities rights and legal issues surrounding service delivery.

10 Provide staff and individuals with an understanding of the services available within the State of Oklahoma and specifically, through the Developmental Disabilities Services Division.

11 Provide an understanding of mistreatment/ maltreatment, reporting measures for suspected abuse and neglect, and the importance of the use of non-aversive techniques.

12 Provide an introduction to future technological trends that may influence the quality of life of individuals with developmental disabilities.

13 Provide an awareness of the role of the state and the Statement of Beliefs that influence services for individuals with developmental disabilities.

For the objectives of the course to be met, participants will need to demonstrate mastery of the subjects presented by passing a written exam at the end of each module, completing in-class activities, and demonstrating specific skills through written exercises.

Foundation Level Modules

Foundation Training is composed of four modules of instruction:

MODULE ONE - "PEOPLE ARE PEOPLE"

Introduces the use of **People First** language. Defines the term, developmental disability, and describes some of the disabilities included in that term. Emphasis is placed on the concept of looking at individuals as *people rather than products of their disability.*

MODULE TWO - "CHANGING TIMES"

Traces the historical events that influenced how services for people with developmental disabilities developed across the nation and in Oklahoma. Emphasizes an understanding of what didn't work and why it didn't work so that we don't repeat the mistakes of the past. Also introduces the principle of normalization and the importance of role models.

MODULE THREE - "SYSTEMS AND POLICIES"

A snapshot of the State of Oklahoma service delivery system today, including public and private service providers, families, advocates, etc. Reaffirms the importance of individuals who work most closely with people with developmental disabilities.

MODULE FOUR - "THE NEW FRONTIERS"

Provides a "Vision of the Future," a blueprint which logically emerges from the previous three modules. It also provides a look at future technological trends that may influence the lives of individuals with developmental disabilities.

These modules are designed to be taught in consecutive order to give participants an awareness and understanding of the history, development and future goals of Oklahoma's Developmental

Disabilities Services Division. Each module includes learning objectives that will be addressed by the instructor through illustrated lectures, videos, and other audio/visual materials. Participants will take part in a variety of activities and exercises designed to clarify and illustrate each module's objectives.

Foundation Level Format

The Participant's Manual for Foundation training consists of four separately bound modules. Each module's format is organized into three sections:

LIST OF OBJECTIVES

Comprised of each module's Primary and Secondary objectives. Secondary objectives allow participants to accomplish mastery of the goals outlined by the module's Primary objective.

GUIDED NOTES

A text and question format that allows participants to become actively involved in the learning process. Most of the information in the transparencies shown by the instructor for each module are also included in right column boxes. Test questions will be taken from the Guided Notes section of the Participant's Manual. Participants are encouraged to complete all questions in their Manual as well as take additional notes. This information will be helpful in their employment settings long after training has ended.

HANDOUTS

Copies of the handouts emphasized in the training are located in the last section of the module. Other supplementary material may also be handed out by the instructor as training progresses.

MODULE TWO

Changing Times

TABLE OF CONTENTS

MODULE TWO - CHANGING TIMES

M O D U L E T W O

Changing Times Objectives

MODULE TWO - CHANGING TIMES

OBJECTIVES

Primary Objective

Primary Objective:

Upon completion of this training and given the appropriate materials, the participant will be able to understand and apply the concepts of rights and values using the Principle of Normalization to people with developmental disabilities.

Secondary Objectives

Secondary Objectives:

- Compare and discuss periods of history in relation to the way individuals with developmental disabilities are viewed.
- Discuss the lessons we have learned from history regarding congregation and congregate settings.
- Compare and discuss the differences between legislative rights and other rights in relation to individuals with developmental disabilities.
- Identify types of abuse and neglect and discuss the term "non-aversive" treatment.
- Discuss the things all individuals value and relate these values to people with developmental disabilities.
- Describe the Principle of Normalization; how it began and why it is called an ecological concept.
- List four misconceptions concerning the Principle of Normalization.
- Discuss the importance of using the principle of normalization to improve public imagery for people with developmental disabilities as well as promote full social integration within the community.
- Discuss three methods of recognizing and eliminating barriers to normalization.

GUIDED NOTES

Changing Times

MODULE 2 - FOUNDATION TRAINING

As Santayana so succinctly put it, if we do not learn from the mistakes made by generations past, then we will repeat those mistakes. We have seen examples throughout history of conditions that degraded and jeopardized individuals. Child labor in factories, orphanages, and slave trading are all situations from which we have learned and put behind us. Our treatment of individuals with developmental disabilities is also an example.

> ***"Those who don't benefit from history are doomed to repeat it."***
>
> — Santayana

We've made a lot of mistakes in serving children and adults who have developmental disabilities:

- Although they are consumers and we work for them, we rarely gave them a say in what was done to — or for — them;
- Although many individuals with developmental disabilities learned best by imitating others, we surrounded them with people like themselves who did not have basic self-care skills, who had trouble communicating, or in other respects were not good role models;
- We expected people with developmental disabilities to live in places where we ourselves would not live — and were amazed when they rebelled.

Handouts

As Paul Williams, an advocate from England, said:

> *"We have a need for somewhere homelike to live, for fulfilling occupations, for affection and appreciation, for a chance to give of our best. We have emotions of sadness, happiness, anger, shame, joy. We believe we have the same rights as you to adequate housing, security, a fair day's pay for a fair day's work, and a right to determine the pattern of our own lives. We believe that we exercise responsibility to the same extent as you do. We do not abuse our freedoms any more than you do; we believe that our record of irresponsible, criminal or violent behavior, of divorce, drunkenness, ill-treatment of our fellow human beings, selfishness, cruelty or dishonesty, when compared with yours, reflects credit on us rather than the reverse.*
>
> *It is often said that we like being with people of our own kind, that we need the company of our peers, that we enjoy living in communities of people with similar disabilities. Some of us do, because it is what we are used to, but we often do not feel that we have anything in common with other people with disabilities, nor do we particularly want them as close friends, nor do we want to live with them. We are rarely offered any real choice as to whom we mix with, so we are very often thrown into the company of other people with developmental disabilities and we develop skills of mixing with each other and accepting each other's company — we probably have greater skills than you in accepting people with disabilities in our environment. However, given a choice of mixing with people with disabilities or with you, we will very often choose you — just as you choose you.*
>
> *We are delighted when you respect us as adults and take the trouble to listen to our verbal or non-verbal communications. One of the best ways in which you can do this is just to be with us sharing experiences with us. We generally respond very well when you are just sitting with us, talking to us, or engaging in everyday things with us like washing up or*

> *watching television or working or eating. We are very grateful to you when you teach us new things or organize special events for us, but really we would often prefer that you became our friends rather than our teachers or our leisure organizers. We want to be involved in individual relationships with ordinary people doing ordinary things. Take us to the seaside by all means, but come back and sleep in the next bed afterwards. Teach us how to button our clothes, but please come and share a meal with us also. By all means assess our abilities and interests, but sit and tell us about yours as well. Only in this way will our disabilities be reduced — and your disabilities be reduced too."*

Objective One: Discuss and compare periods of history in relation to the way individuals with developmental disabilities are viewed.

History

HISTORICAL OUTLINE

1790 – 1850____

____

____

1850 – 1890____

____

____

1890 – 1910____

____

____

1910 – 1930-40's

1940-50's – 1950's, early 60's

Mid 60's – Mid 70's

1970's – 1980's

Late 70's – early 80's

HISTORICAL ROLE PERCEPTIONS

As seen from the historical overview, throughout history society has developed certain perceptions of individuals with disabilities. Some of these are discussed in the following section.

Transparency

SUBHUMAN ORGANISM

Transparency

OBJECT OF PITY ______________________________

____

____

OBJECT OF RIDICULE ______________________________

____

____

UNSPEAKABLE OBJECTS OF DREAD ______________________________

____

____

HOLY INNOCENTS ______________________________

____

____

ETERNAL CHILD ______________________________

____

____

SICK PERSON ______________________________

____

____

MENACE TO SOCIETY ______________________________

____

____

OBJECT OF CHARITY ______________________________

____

____

OTHER MISCONCEPTIONS HISTORICALLY PERPETUATED

Certain beliefs and misconceptions about people with developmental disabilities have been, and still are, commonly found in our society. The following misconceptions have been historically perpetuated.

Transparency

A Life of Complete Dependency ____________________

____

____

Mental Retardation Equals Mental Illness ____________________

____

____

All People with Mental Retardation Act Alike ____________________

____

____

A Person Can Function to the Extent of his/her Mental Age or IQ

____

____

____

People with Developmental Disabilities should have "Special" Environments ____________________

____

____

You do a great disservice to an individual when you limit his or her potential

Don't develop preconceptions. As you begin, or perhaps continue, your work with people who have developmental disabilities, you will be working with a varied group of people. Individual strengths and weakness must be taken into consideration. Some will very seldom need more than a question answered or occasional assistance doing a new task. A few people will need continuous physical care twenty-four hours each day and will be unable to perform any task. Some people will need assistance only during certain times in their lives while others will need support throughout their lives.

SUMMARY

Each individual is a unique, one-of-a-kind person with his own likes and dislikes, temperament and personality. Most need only a small portion of help. Most are able to actively participate in their community and contribute as fully as any other member of society. While they may have disabling conditions, with the appropriate support and assistance, they need not be severely limited by those conditions.

Present History

THE PARENT MOVEMENT — 1940+

In the 1940's, parents began to seek each other out and band together, forming small self-help groups in cities and towns across the country. The stigma associated with one disability was so strong that an editor of a local New Jersey newspaper refused to publish a personal advertisement in which a mother was trying to make contact with other parents of children with disabilities.

Parents realized their children's potential. Some parents had been told that their sons and daughters would never sit up, never walk, never feed themselves, never communicate, never recognize their parents. However, with good teachers, therapists, and lots of work by their families, the children did progress and did learn to do those very things. When parents saw this happen, they knew their children's potentials were greater than they had been told. They also learned that often professionals simply were not able to accurately predict what might occur in their children's lives.

Handouts

As the years went by, the demands of providing care for their children while at the same time working as advocates began to tire parents. **Families helped each other as best they could** but the difficulties of their own situations didn't leave much energy left over to help anyone else.

THE "ASSOCIATION FOR RETARDED CITIZENS" (THE Arc)

The "Association for Retarded Citizens," which had been formed in 1950 as the Association for Retarded Children, was instrumental in leading the movement for both institutional reform and, subsequently, for deinstitutionalization and the creation of new community alternatives.

Today, this group is called The Arc. The Arc changed its name at the 1991 National Convention, dropping the term "retarded" because of the connotations associated with that term. Many parent members have sons and/or daughters with conditions that require the same services as children/adults with mental retardation — but their children are not mentally retarded. They did not want their sons or daughters to carry another label on top of the ones they already have.

The Arc has been particularly influential in the establishment of improved educational, residential, and support services for persons with developmental disabilities. For example, in the 1950's, the Arc called for restrictions on the size of institutions; in the 1960's, it assisted with establishing minimum federal and state standards for residential care facilities; in the 1970's, it passed a resolution to recommend "residential facilities consisting of small living units, each replicating a normal home environment to the closest extent possible" and "that such residential facilities take absolute precedence over further capital investments in existing or large scale institutions." In the 1980's, it supported legislation to shift Medicaid funding from institutional settings to the community.

The Arc also has been an active plaintiff in federal and state court cases involving the rights of citizens with developmental disabilities and their:

- Right to treatment:
- Right to free and appropriate public education:
- Right to the least restrictive alternative environments.

OTHER PARENT GROUPS

Other parents have been equally active in promoting education and related services for children and youth with disabilities. In addition to the Arc, parent groups like the Autism Society, United Cerebral Palsy Association, and the Association for Children and Adults with Learning Disabilities have actively pursued education and related services for people with disabilities.

HELP FROM POLICY MAKERS — 1950'S, 60'S, 70'S

Disillusionment

With increased funding, some changes did occur. People were clothed, professionals hired, direct care staff were trained. But even with these improvements, parents and others began to realize that increased funding for the institutions did not change them.

Group Discussion

Facilities improved...

Based on public attention, media exposes, and federal lawsuits filed on behalf on individuals living in institutions, sweeping changes were initiated.

Congregate public facilities are still a residential option in Oklahoma. The Northern Oklahoma Resource Center at Enid (NORCE) and the Southern Oklahoma Resource Center at Pauls Valley (SORC) are striving for full inclusion and participation in local communities for individuals who call the facilities home.

The Oklahoma Experience

The Oklahoma Parent Experience was the same as that of parents across the rest of the country — with one important exception. Community services were much later arriving here than elsewhere. By 1985, because of the lack of community services, many parents and their children were struggling to maintain family integrity.

THE OKLAHOMA DEINSTITUTIONALIZATION EXPERIENCE - HISSOM

THE HOMEWARD BOUND VS. THE HISSOM MEMORIAL CENTER LAWSUIT

In 1981, several Oklahoma parents who were frustrated by the lack of family support and the need for more community options formed an advocacy organization which they called **Homeward Bound.**

EXERCISE — AFFECT ON FAMILIES

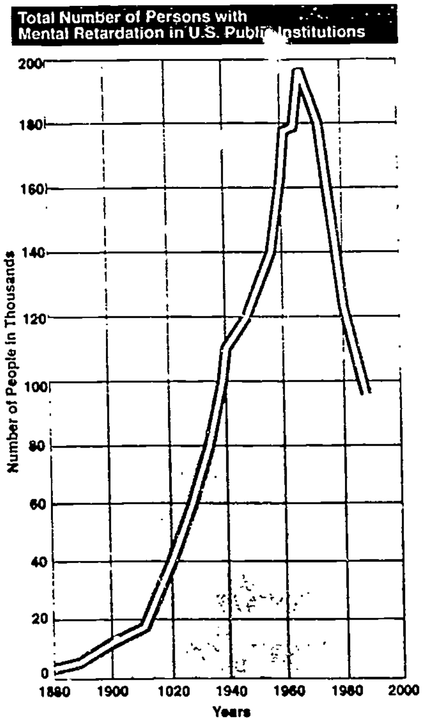
1.

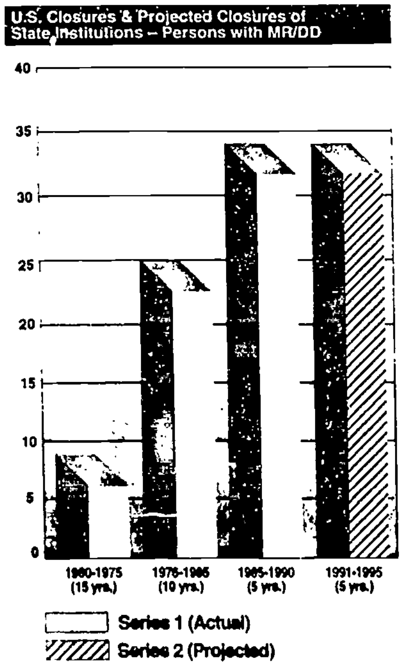
2.

3.

SUMMARY

The nation has come a long way in the way society views people with disabilities. Oklahoma has come a long way also. However, we must always be aware that if "we do not learn from the past, we will surely repeat it."


Total Number of Persons with Mental Retardation in U.S. Public Institutions


U.S. Closures & Projected Closures of State Institutions – Persons with MR/DD

Population: 220,000 Peak
65,000 Currently

Questions

1. Do you believe the old adage, "Those who do not benefit from history are doomed to repeat it? Why or why not? ____________

2. In Stage One, "The Parent Movement," the common practice of professionals was to tell parents what concerning their child's disability and its affects on that child's potential? ____________

3. Professionals often diagnosed parent's tiredness and depression as what? What was the real underlying cause? ____________

4. List three policy makers that helped the parents' cause.

5. What effect did exposes have on influencing policy making and legislation? ____________

6. What was the original name of the Arc, and why was it changed? ____________

7. What was, and is, the major role of the Arc? ____________

8. Did the parent movement in Oklahoma differ from the national movement? ____________________

____

____

9. What effect did the court decision have on families? __________

____

____

Objective Two: Discuss the lessons we have learned from history regarding congregation and congregate settings.

Congregation

Why have congregate settings for people with disabilities not worked? **It's not because of the people who work in them.** Those people are no different than community service workers. They are just human beings. They care. They work hard. But there is no system that is perfect — that is why we are constantly trying to improve and move toward the illusive goal of excellence.

ARGUMENTS ON WHY CONGREGATION HAS NOT WORKED

Transparency

If you put people into groups, you subordinate individualization for the greater good of the whole.

____

____

Imitation and role modeling are powerful learning tools.

____

____

Transparency

Absence does not make the heart grow fonder.

Skills need to be taught in the environments where they will be used.

"Special" often isn't. "Pre" means never.

Bigger isn't better or cheaper.

Lack of contact

When all is said and done, the acid test that can be applied by you as a human being to places where people with disabilities live, work, play, or learn is:

Would you sleep, eat, work, and live here?

Often, people with developmental disabilities have not been given the opportunity or the support necessary to do their best at home, at school or at work. **Sometimes the barriers to integration (presence), to inclusion (presence and participation) in our world are physical.** People who use wheelchairs cannot access a building if there are no ramps or elevators. They can't communicate with us because they haven't been provided with an electronic or manual communication device.

SEGREGATION...

Segregation is the separation of an individual from society and from other individuals within that society. Such an environment, especially one that is artificial, manufactured, isolated, or markedly different from the norm will frustrate the development of "normal" social living skills, or even encourage development of really "different" behaviors.

For instance, people in a segregated environment learn the skills necessary to live there. They learn how to stand in line, how to wait for instructions, how to be dependent, how to let others make decisions about their lives.

Lack of contact =
Lack of knowledge =
Fear of the unknown =
Justification for distancing (Us/them)

Transparency

Segregation reinforces the belief in others that those who are segregated **need** to be segregated; they benefit from it.

It reinforces fear of people with developmental needs, and the belief, that if society has seen fit to put these people away, it must be for a good reason — they must represent some type of threat. We cannot form an objective opinion of them. Lack of understanding gradually metamorphoses into a belief that they must be menacing or unsociable.

Segregation may result from the attitudes and expectations of others. Frequently, people with disabilities have been segregated from their communities and congregated together in large institutions with others who also have disabilities. This may have been done with the best of intentions but the results were, and are, disastrous.

The results of deprivation, segregation and congregation are wrong, but not just for the people removed from society. The wrongness bends back upon the community until it forms a circle. People were removed from the community because society perceived them as carrying a stigma. And the act of removal reinforced the perception of stigma, which further rationalized the removal.

And the rest of us lose the opportunity to interact with an entire segment of society.

Questions

10. Define the terms segregation and congregation and discuss the differences between the two.

11. List three reasons why congregate environments have not worked.

12. What is meant by the term "lack of contact?" How does it apply to segregation?

13. How can well-educated professionals be caught up in the previous concepts?

Objective Three: Compare and discuss the differences between legislative rights and other rights in relation to individuals with developmental disabilities.

Rights

In Oklahoma and throughout the United States, parents participated in the struggle for rights for their sons and daughters.

IT CONTINUES

The sequence of events in the parent movement was pretty much the same in every state:

1. Parents joining together to help each other with their sons and daughters in such activities as setting up volunteer-operated children's centers in church basements with equipment donated by community citizens;
2. An attempt to improve the institutions;
3. Disenchantment with institutions and a belief that they must be abandoned;
4. Attempts to make community services a matter of right, not privilege, by lobbying the executive branch (governor's office) and legislative branch (state representatives and senators) of state and federal government;
5. When all of that either failed or moved too slowly, they went to the judicial branch of government;

What are the rights of people with developmental disabilities? What laws and court decisions have been written that we need to know about that established rights for individuals with disabilities?

EXERCISE: WRITE DOWN FIVE RIGHTS YOU ENJOY.

1. ______________________________

2. ______________________________

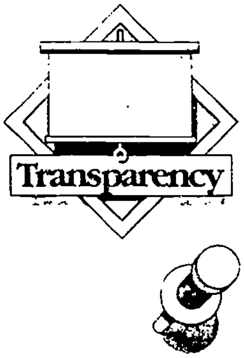
3. ______________________________

4. ______________________________

5. ______________________________

Legislation

A BRIEF OVERVIEW AND DISCUSSION OF LEGISLATION



REHABILITATION ACT (1973)

Section 504 of the Rehabilitation Act (1973)

- Guarantee of Civil Rights
- Law prohibits discrimination
- Who is protected?
- Who must comply?
- Protection provided

REHABILITATION ACT (1973)

Section 504 of the **Rehabilitation Act** (1973) was the first civil rights law which guaranteed equal opportunity for more than 35 million Americans with disabilities.

The language of the law is similar to that in other civil rights acts which prohibit discrimination.

The law mandates that:

"No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal assistance."

WHO IS PROTECTED BY SECTION 504?

Section 504 covers only people with disabilities. For purposes of this law, a person is protected if they:

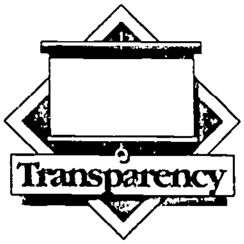
- have any physical or mental impairment which **substantially limits** one or more major life activities:
- have a past record of such impairment, but are **not presently** handicapped;
- are not handicapped and never have been but **are regarded by others** as having a handicap(s).

As seen in the first item, the definition covers much more than just mental retardation or developmental disabilities. Any physical or mental impairment is covered, as long as it **substantially** limits one or more major life activities.

THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT (PUBLIC LAW 94-142)

In 1975, this Act was amended to the:

INDIVIDUALS WITH DISABILITIES EDUCATION ACT (PUBLIC LAW 99-457)



This law guarantees the right of all children with disabilities to a free, appropriate public education. The law applies to all children (ages 3 - 21) regardless of where they live. Some of the most important features of this law are:

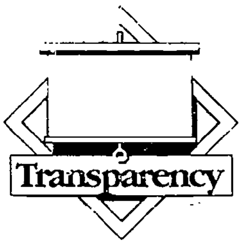
1. It places responsibility at the local school district level (where the child lives);
2. It requires that the child be educated in the least restrictive, most integrated setting;
3. It guarantees parent/advocate involvement in the planning process;

4. It requires that an individual education plan (IEP) be developed for each child:

5. It requires that a variety of services, such as occupational and physical therapy, health services, language training, etc., be made available if required by the child's IEP.

6. Established the early intervention program for children from birth to the age of three.

Appropriate implementation of IDEA will ensure that the history of exclusion and neglect shown by public schools will not be perpetuated.



DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

Developmental Disabilities Assistance and Bill of Rights Act established a federally assisted state program designed:

- To enhance the role of the family in assisting people with developmental disabilities to achieve their maximum potential;
- To provide interdisciplinary training and technical assistance to professionals, paraprofessionals, family members, and individuals with developmental disabilities;
- To advocate for public policy change and community acceptance of all people with developmental disabilities and their families so that the necessary services, supports, and other assistance and opportunities are available;
- To promote the inclusion of all people with developmental disabilities;
- To promote the interdependent activity of all people with developmental disabilities;
- To recognize the contribution of all people with developmental disabilities as they share their talents at home, school, and work, and in recreation and leisure time; and

- To ensure the protection of the legal and human rights of people with developmental disabilities. (Section 102(b))

AMERICANS WITH DISABILITIES (ADA) (1990)

The Act (ADA) of 1990 gives civil rights protection to individuals with disabilities that are similiar to those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations (hotels, restaurants, movie theaters, stores, pools,) transportation, and telecommunications.

Most of the requirements of the ADA were effective as of January 26, 1992. Some of the requirements do not become effective until 1994 or 1996, while others do not begin until 2010.

Other Rights

EXERCISE: RIGHTS

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RIGHT TO VOTE

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RIGHT TO HAVE GRIEVANCES HEARD

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OTHER RIGHTS

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Moving toward interdependence **(because none of us is truly "independent" of each other),** competence, and control of one's own life is a great adventure. One of the ways we can play an important role in that adventure is by helping the people we serve secure for themselves the full enjoyment of their rights.

Choice

Group Discussion

14. What is the difference between a choice and a right?

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As with all people, individuals with disabilities have limits on their rights. The exercise of their rights may not infringe upon the rights of others or upon their own safety or health. There are responsibilities associated with rights and choices.

Questions

15. What is an "informed choice?" ______________________

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16. Why is the right of choice a major concern to individuals with disabilities? ______________________________

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Objective Four: Identify types of abuse and neglect and discuss the term "non-aversive" treatment.

Preventing Mistreatment

All individuals have the right to live without fear of bodily harm, neglect, or exploitation. This right is one we as service providers must always strive to protect for the people we serve.

There are certain factors that are important to consider when discussing abuse and neglect. Individuals who have developmental disabilities are often very vulnerable. They must rely upon others to protect them and so may be at a high risk of being abused and neglected. We must be able to recognize the types of abuse and neglect and we must be able to be responsible for the safety of those we serve.

Mistreatment/Maltreatment

"Mistreatment/Maltreatment" means harm or threatened harm to a child's or resident's health or welfare by a person responsible for that individual's health or welfare.

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1. ____

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2. ____

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3. ____

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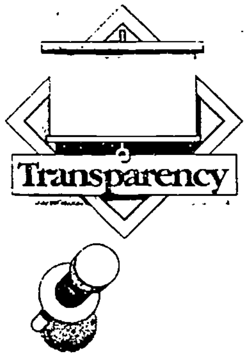

MISTREATMENT/MALTREATMENT

Mistreatment results in, or creates the risk of, injury of a child or resident including (but not limited to) the following situations:

1. Conduct which evidences a reckless disregard for the health or safety of a child or resident.
2. Acts or omissions which contribute to the delinquency of a child.
3. Excessive or unauthorized use of force.

TYPES OF MISTREATMENT

There are three major categories of mistreatment:

1. ____

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2. ____

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3. ____

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Abuse

The term "Abuse" means the intentional infliction of physical pain, injury or mental anguish, or the deprivation of food, clothing, shelter, or medical care by a caretaker or other person responsible for providing these services.

PHYSICAL ABUSE

Physical abuse is the intentional (nonaccidental) use or offer of physical force by a person responsible for an individual's health or welfare and is aimed at hurting or injuring the individual either physically or emotionally. This includes encouraging, knowingly causing or permitting any person to intentionally injure an individual. Examples of physical abuse are:

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Some signs of physical abuse are:

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SEXUAL ABUSE

Sexual abuse is a form of physical and/or emotional abuse in which sexual activity is initiated toward an individual by a person that is in a position of power over the individual. Examples of sexual abuse may be:

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Some signs of sexual abuse may be:

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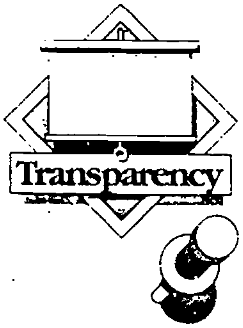


PHYSICAL ABUSE

Some examples of physical abuse are:

- Hitting, shoving, tripping, pushing, scratching, cutting, biting, etc.
- Using physical or chemical restraints

Some signs of physical abuse are:

- bruises and welts
- cuts, punctures, scratches
- broken bones and fractures
- burns
- human bite marks
- internal injuries
- suspicious scars
- unexplained fear of caregiver
- unexplained injuries or injuries that do not "add up"

SEXUAL ABUSE

Some signs of sexual abuse may be:

- behavioral changes
- recurrent nightmares, night fears
- infantile behavior
- unusual interest in or knowledge about sexual matters
- self-destructive behavior
- overheard sexual remarks concerning rape or abuse

Physical signs may include:

- torn or stained underclothing
- vaginal or rectal bleeding, pain, itching or swollen genitals, vaginal discharge
- vaginal infection or disease

Physical signs may include:

EMOTIONAL ABUSE

Emotional abuse results from subjecting an individual to an atmosphere is which that person does not feel wanted, secure, or worthy. Examples of emotional neglect and abuse may include:

Signs of emotional abuse may include:

Exploitation

The term "Exploitation" means the unjust or improper use of the personal resources of a person for the profit or advantage, pecuniary or otherwise, of another person. Exploitation includes but is not limited to prohibited business transactions such as follows:

Examples of exploitation may be:

EMOTIONAL ABUSE

Examples of emotional neglect and abuse may include:

- Constant negative atmosphere
- Extreme teasing or humiliation
- Talking down to the individual
- Threatening with physical harm
- Withholding emotional support

Signs of emotional abuse may include:

- changes in behavior
- expression of fears
- expression of suspicion
- unwillingness to talk

EXPLOITATION

The term "Exploitation" means the unjust or improper use of the personal resources of a person for the profit or advantage, pecuniary or otherwise, of another person. Exploitation includes but is not limited to prohibited business transactions such as follows:

- Buying or selling any item or items for money or items of trade to clients
- Trading articles by force from a client
- Taking any article by force or stealing from a client
- Bartering with a client for articles or money
- Borrowing money or any item of value from a client
- Accepting articles in the form of a gift from a client

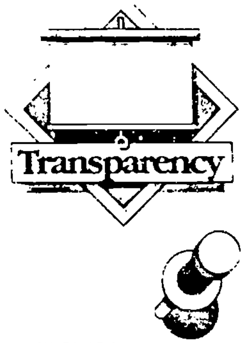
Some signs of exploitation may include:

Neglect

Neglect is characterized by willful omission — rather than commission — of an act. It is influenced by the community and cultural norms and ranges from mild to severe in form.

Examples of neglect may be:

Some signs of neglect may be:



NEGLECT

Examples of neglect may be:

- Insufficient diet
- Insufficient opportunity for personal hygiene
- Inadequate shelter
- Medical neglect
- Inadequate supervision

Some signs of neglect may be:

- provider has an alcohol or drug problem
- individual is fearful of a provider
- health problems
- dehydration
- decubiti

Reporting Mistreatment

State of Oklahoma law requires that "any person having reasonable cause to believe that a child is experiencing abuse or neglect, or an elderly person or incapacitated adult is suffering from abuse, neglect or financial exploitation is mandated to make a report to either the Department of Human Services (Child Protection Services, Adult Protection Services, or Office of Client Advocacy) or the office of the district attorney in the county in which the suspected incident occurred.

Any person who knowingly and willfully fails to promptly report any abuse, neglect, or exploitation shall, upon conviction, be guilty of a misdemeanor. Any person who willfully or recklessly makes a false report or a report without a reasonable basis shall be liable in a civil suit for any actual damages suffered by the person(s) being reported and for any punitive damages set by the court or jury."

The law also provides that any person exercising good faith and due care in making a report... "shall have immunity from any civil or criminal liability that might otherwise be incurred." In other words, no one is excused from reporting signs of mistreatment. You must make an immediate report. This includes all direct care staff, police, doctors, nurses..., everyone.

It is safe to report. You have immunity from any retaliatory action which means you cannot get into trouble with the law or at your work if you make a report and it turns out to be wrong. If you do not report something, however, that should be reported, your job may be in jeopardy and under certain circumstances, you may find yourself the subject of an allegation of neglect for failure to report.

To make a report call:

- the local DHS office;
- or the local offfice of the District Attorney;
- or the DHS Abuse Hotline,

1-800-522-3511.

You may also call the Office of Client Advocacy at

1-800-522-8014 or 1-405-521-3491

Group Discussion

Transparency

GENERAL RULES FOR PREVENTING MISTREATMENT

Wise care givers take precautions to prevent situations that may lead to mistreatment occurring. Some of these are;

- Treat all people with dignity and respect.
- Do not make verbal threats. Words can turn into actions.
- Call for help if you are in doubt about how to handle a client or situation.
- Admit when you have made a mistake. The people you serve can be right about issues, just as you can be right.
- Get enough sleep so you are alert on the job and so your patience will remain intact.
- Never drink alcohol or use tranquilizing or stimulating drugs before coming to work.
- Be careful what you wear; don't let your clothes give off sexual messages.
- Don't be so preoccupied with orderliness and good behavior that control and authority are the only means used to teach clients appropriate behavior.
- Most importantly!!! Send a clear message to those around you that you will report mistreatment.

CONTENT OF REPORTS

All reports of abuse and neglect should include the following information:

- The name and address of the individual being abused or neglected;
- The name and address of the caretaker, if any;
- A description of the situation.

General Rules for Preventing Mistreatment

Wise care givers take precautions to prevent situations that may lead to mistreatment occurring.
Some of these are:

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Most importantly!!! Send a clear message to those around you that you will report mistreatment.

"What you stand for in this world depends on what you want!"

Non-Aversive Treatment

The past has held a long history of abuse for people with disabilities. Historicallly, certain behavior modification techniques were used including the use of punishment. Untrained people were allowed to use such approaches as uncompromising holding or pushing without supervision. As a result, people had bones broken when they were pushed or grappled down to the floor. The term "aversive" is defined as causing the avoidance of a noxious or punishing stimulus. Aversive methods often involved the use of physical force to compel compliant behavior.

Earlier we talked about programs and staff that are preoccupied with control, authority, and making sure that "clients" know who is in charge. These are indicators of staff who may lack adequate skills or whose attitudes are not consistent with the Developmental Disabilities System.

We have learned that behavior that may appear dysfunctional or destructive is, for some people, their only means of communicating their needs. Self-injurious behavior is almost always communicative; it expresses the need to get away from something, to get something, etc.

The key is not to blame people for what is not under their control. We need to accept the responsibility to try and figure out what possible solutions there are to the problems they are expressing. We need to teach people less destructive methods of communication. We need to read their environment to understand their needs.

Oklahoma has committed itself to eliminating aversive methods. The use of physical punishment in any form is ground for termination and possible prosecution under the law.

Assignments

17. Define and discuss three types of abuse and neglect.

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Questions

Questions

18. What conditions may lead to incidents of abuse and neglect?

19. Discuss methods of preventing abuse and neglect.

20. What does the term "non-aversive" mean in relation to Oklahoma's philosophy of treatment of individuals with developmental disabilities?

SUMMARY: CODE OF RESPONSIBILITY

We respect the dignity and worth of all individuals. We strive for the preservation of human rights. We protect the welfare of those we serve while supporting and enhancing their self-responsibility. We apply the following universal values to our work with people with developmental disabilities. These values are:

WE AFFIRM THAT:

- We abstain from the non-medical use of any mood-altering chemicals while working.
- We do not become sexually involved with individuals we serve because this violates trust. Sexual intimacy in any form is unethical; including remarks, gestures, or anything of a sexual nature.
- We avoid conflict of interest — we do not sell goods or services to individuals we serve because they may not feel they can tell us "no." We avoid dual relationships of any kind which might impair the helping relationship.
- We respect the privacy of the individuals we serve.
- We recognize the boundaries of our training and experience.
- We use only those techniques for which we are qualified.
- We neither claim nor imply qualifications exceeding those we possess.
- We recognize that continuing education and training is a good practice. Further, we hold ourselves responsible for our own personal growth.
- We are aware of the dependency/unequal power in our relationships with the people we serve, and we maintain respect for them by avoiding activities which meet our personal needs rather than their needs. We avoid bringing our personal issues into the relationship. Our responsibility is to the individuals we serve, FIRST.
- We are aware of the negative impact of racial, sexual, and disability stereotyping and guard the dignity of the people we serve.
- We respect the right of the individuals we serve to be involved in any plans made in their interests and hold

Transparency

ourselves responsible for involving them or an unbiased advocate when individuals cannot speak for themselves.

- When an individual's condition indicates a possible danger to self or others, we have a responsibility to immediately inform responsible parties and take reasonable personal action, consulting with others as soon as possible.
- If we possess information about possible unethical conduct of a colleague, we must take action to rectify the situation immediately.

Transparency

- We act with integrity toward our colleagues, respecting their areas of competence and cooperating with them fully for the welfare of the individuals we serve. We use appropriate practices for expressing disagreement. Further, we are committed to educating our colleagues regarding effective practices.

Objective Five: Discuss the things all individuals value and relate these values to people with developmental disabilities.

The Things We Value

We value many things in our lives: our legal rights, our ability to make choices, our freedom to be protected from abuse or mistreatment. But, often people fail to remember that individuals with developmental disabilities value the same sorts of things we value.

Too often we take the things we value for granted. Think of a time you were laid up from an injury. Remember how hard it was to get around, and remember how people stared at your cast? We forget how much we value mobility and inconspicuousness until we lose it. If we're lucky, it's only a temporary thing. Some people aren't that lucky.

VALUES

- We value being recognized as individuals, separate from any class label.
- We value being accepted by friends, neighbors and sales people as OK.
- We value living with people we love. A comfortable home. Good neighbors.
- We value having the opportunity to make choices and not being limited to one job, or one outfit, or one TV show.
- We value doing things for ourselves. Being as independent as possible.
- We value making our own decisions and knowing the joy of being right, or even being wrong, if we can learn from it.
- We value being respected for doing a job well, being considered competent.
- We value having friends who enjoy our company so we have the option of being included socially. To take in a Saturday night movie with the gang is a lot of fun. So is shooting the breeze during a card game.

21. Define "values." ______________________________

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Questions

It's difficult to imagine how you could go on living without these things. And yet, many people do. When you see someone, or a group, deliberately deprived of something that everyone values, you realize that the right to lead a normal life has been violated. **All** people value normal environments in which they can live, work, and enjoy life in their community.

PRACTICAL APPLICATIONS OF VALUES

What are practical ways you can apply the abstract concepts of values to the real world?

There is a way to do this — it's called the **Principle of Normalization.** This principle gives workers in the field the realistic tools they need to make environments for people with disabilities as normal as possible. It is an **application** of the concepts we have learned. To this extent, the Principle of Normalization recognizes the power of the environment on people and addresses the basic human needs that all people value.

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Objective Six: Describe the Principle of Normalization; how it began and why it is called an ecological concept.

Normalization

Questions

22. Define "Normalization." ______________________________
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Characteristics of Normalization

- ■ Conditions of everday living
- ■ Normal rhythms
- ■ Normal activities
- ■ Culturally appropriate theaching strategies
- ■ Integrated lifestyles

Handouts

NORMALIZATION

The Normal Rhythm of the Day — *Bengt Nirje*

"Normalization means a normal rhythm of day for persons with developmental disabilities. It means getting out of bed and getting dressed, even when you are profoundly mentally retarded and physically disabled. It means eating under normal circumstances: sometimes, during the span of the day, you may eat in large groups, but mostly eating is a family situation which implies rest, harmony, and satisfaction. A normal daily rhythm also means not having to go to bed earlier than your peers because you are mentally retarded, nor earlier than your younger sisters and brothers, or not too early because of lack of personnel. Facilities must also give consideration to the individual's need for a personal rhythm, allowing him to break away occasionally from the routine of the group.

The normalization principle also implies a normal routine of life. Most people live in one place, work or attend school somewhere else, and have leisure-time activities in a variety of places. Consequently, it is wrong when a person with disabilities, for example, has his training classes, his structured therapies, and his recreation activities in the same building that serves also as his "home."

People Interact With Thier Environments

It is important to understand that the concept of normalization is an **ecological** concept, that is, our first task is **not to try to "change" the person with the disability,** but rather to create living, learning, and work **environments** which are as normal as possible. It does not mean we are trying to make people "normal" (whatever that means). We don't deny the differences of people with disabilities, but we don't let those differences obscure their essential humanity either.

We know from studies done in psychology, sociology and other sciences that all behavior is purposeful. Often, people act in certain ways because of the environments in which they live. **"Environment" as used here means all of the things which we come into contact with, which influence us.** This can be:

- the physical environment (what we see, feel, hear, smell, taste, or touch), or
- the interaction (the bonding, affection, love, communication, and understanding) with other human beings.
- Normalization recognizes the power of the environment on people.

Objective Seven: List four misconceptions concerning the Principle of Normalization.

Misconceptions About Normalization

The Principle of Normalization has in the past often been misinterpreted. Some of these misconceptions are:

Normalization means making people "normal." ____________
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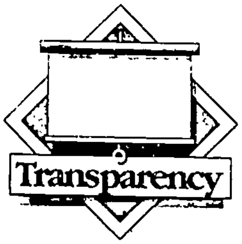

Transparency

Special services are inconsistent with the normalization principle, which supports dumping people from institutions into the community without support. ____________________

Normalization is an all or nothing concept, and applies only to people with mild disabilities. ____________________

People with developmental disabilities are best off with their own kind, protected from the rigors of society. ____________________

Normalization is a Scandinavian concept inapplicable elsewhere. ____________________

Normalization is a humanistic concept, but idealized and impractical. ____________________

Questions

23. What is a practical application of the concepts we have learned? ____________________

24. What are "stigmas?" ____________________

Questions

25. What is meant by a "normal" environment?

26. Isolation from society results in what?

27. Discuss the origin of the Principle of Normalization.

28. According to the Principle of Normalization, what is meant by the word "environment?"

Objective Eight: Discuss the importance of using the principle of normalization to improve public imagery for people with developmental disabilities as well as promote full social integration within the community.

Imagery

BETTER IMAGES

Normalization includes ensuring the best possible image — both self image and image in the eyes of the community — for individuals with developmental disabilities.

Normalization means doing everything we can to integrate people who have developmental disabilities into the everyday community life we all enjoy.

INTERPERSONAL RELATIONS

People are frequently at a loss as to how to act around individuals with disabilities. "What should I do?" "How can I know if I'm doing the right thing?" "If I look at the person, will s/he think I'm staring?" "If I don't look at the person, will s/he think I'm ignoring him or her?" are just a few of the questions they ask themselves and are typical reactions of people who have had little or no exposure to people with developmental disabilities. As people get to know individuals with developmental disabilities, their comfort levels improve and they discover mutual interests. They learn that **people are people.**

Here are some of the more common mistakes we make in our dealings with people who have disabilities:

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FULL SOCIAL INTEGRATION

NORMALIZATION means that people with developmental disabilities learn the skills necessary to function in society in the same way we do. They learn them by living and operating within the community. That means you learn to eat at a Macdonald's by **eating** at a Macdonald's, to **work** at WalMart by working at WalMart.

Here are a few hints about what we can do to foster full social integration:

- Encourage the mixing and interaction of people having developmental disabilities with ordinary people their own age in all areas of life.

- Demonstrate that integrated classes and job training are better growing and learning environments than segregated settings. Remember that "Pre" means "never":

  "Pre-Vocational"
  "Pre-Educational"
  "Pre-Living"

  These "getting-ready-to" phrases usually justify and continue segregation and dependency.

- Do your best to ensure that people with developmental disabilities dress, act, and appear in ways which don't make them appear odd.

- Be aware that when different groups with different needs are congregated together, we transfer erroneous or negative images from one group to the other.

Questions

29. What is meant by the term, "Social Integration?"

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30. Why will an environment that is artificial, manufactured, isolated, or markedly different from the norm frustrate the development of "normal" social living skills, or even encourage development of really "different" behaviors?

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31. Discuss several ways you can foster full social integration.

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Normalization teaches us that the way to treat people with disabilities is like any other people. You have your good days and your bad.

So do they.

You value your dignity and independence.

So do they.

You dislike being put down.

So do they.

Transparency

HERE ARE A FEW TIPS TO KEEP IN MIND:

- Where you live says a lot about who you are and how you are viewed by yourself or others. A home that looks "down and out" with a lawn that hasn't been mowed or paint peeling from the walls says the people who live there don't care and don't matter.
- A home should be in a residential neighborhood and should be an easy walk to shopping, recreation, and public transportation resources. It should be in the middle of things.
- Don't give a home an official name. You can't improve on the street address. Signs on the door only clang.
- Homes should fit in with their surrounding neighborhoods as much as possible.
- Living arrangements for people with developmental disabilities should be highly dispersed and not in zoning ghettos.

- A home should feel and look warm, be decorated thoughtfully and age appropriately.
- People with disabilities should be helped to dress in ways that are typical for their age. Adults should not wear childlike clothing. School-age children and teenagers should look like all other kids their own age.

People with disabilities are trying to overcome years of negative imagery. Their gains can be fragile. While most of our fellow Oklahomans are generally accepting, some are still carrying stereotypes and attitudes from the past.

Objective Nine· Discuss three methods of recognizing and eliminating barriers to normalization.

Recognizing and Eliminating Barriers to Normalization

AWARENESS OF CLANGERS

In this training on Normalization, we decided that the best way to describe things that aren't normal was to help people understand and become sensitive to environments or behaviors that perpetuate labeling or stigmatization. Since each of us plays a role in helping create the environments in which people with developmental disabilities live, work, play, and learn, it's important to keep our antennas up and tuned to signals that say "label" or "stigma" or "obstacle." We call these signals **CLANGERS. A clanger is that instant recognition of oddity. It's a realization that something doesn't fit.** It might stick out like a sore thumb. Or, it might be very subtle.

A CLANGER is that instant recognition of oddity.

Clangers can logically be divided into three types:

1. ______________________________

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2. ______________________________

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3. ______________________________

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EYE CLANGERS

Eye clangers are visual oddities.

Examples: ______________________________

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EAR CLANGERS

An ear clanger is something that sounds strange or upsetting, or something that alerts you to a mismatch.

Examples: ______________________________

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MIND CLANGERS

Mind clangers are things that jar your awareness. Something sets off a vibration in you that says there is something wrong.

Examples: ______________________________

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Remember that clangers are created by people who frequently are not aware that they are creating oddities. Even when they are aware of it, they may not be self conscious about it. People sometimes suspend their normal judgement when working with people who depend upon them. That's why we see people yelling loudly at an elderly person, assuming all people that age are hard of hearing.

APPROPRIATENESS

Inappropriate labels and symbols are clangers that focus negative attention on people with developmental disabilities.

Questions

32. How can inappropriate methods of dress, behavior, and activities focus negative attention on people with developmental disabilities? ____

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33. Discuss why a behavior might seem inappropriate for an individual with developmental disabilities but not for someone else.

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NORMALIZATION encourages us to require the full use of modern methods and technology in eliminating the physical and social obstacles that stand in the way of establishing normal environments for the people we serve. It encourages us to support men and women of compassion for leadership positions in our public and private organizations. And it encourages us to use the media in a way that is responsible — not dehumanizing or stigmatizing.

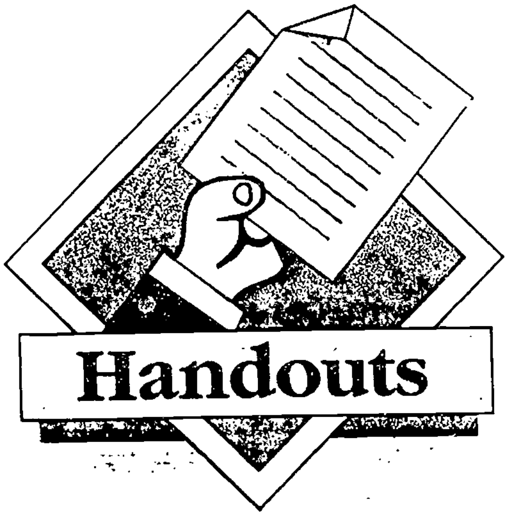
SUMMARY

We have had the opportunity to change history and we have succeeded. But, there is still a long way to go.

The image of a person with disabilities can be very fragile. Positive imagery must be promoted. People with developmental disabilities must first become comfortable with their own self-worth. Attitudes, both of the individual and his/her family as well as society must change. And although this may be a time-consuming and frustrating task at times, we will eventually reap a harvest of valuable individuals who recognize their own worth, their own talents, skills and capabilities, and whom society recognizes and cherishes as important, contributing members.

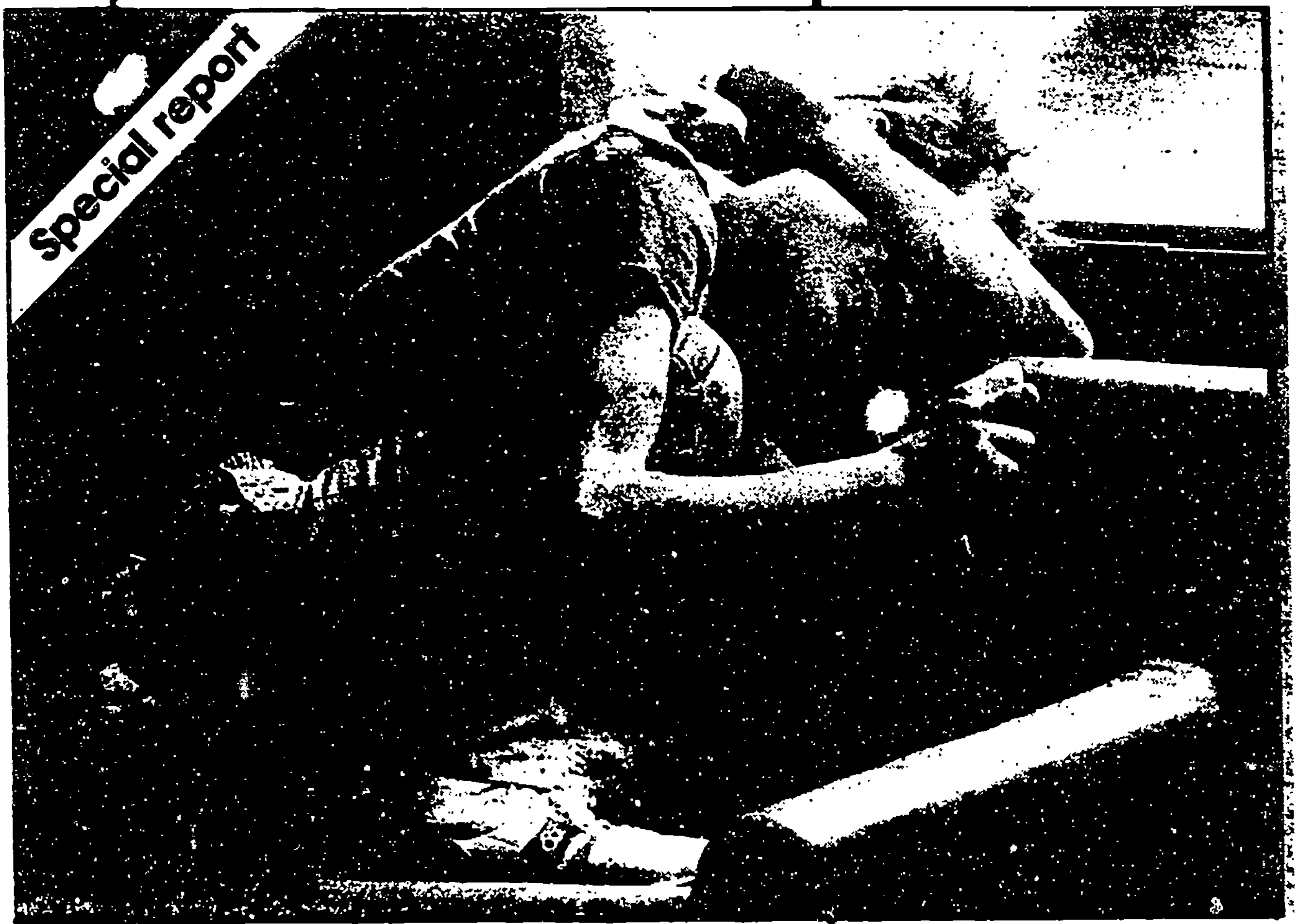
MODULE TWO

Foundation Level Training
Changing Times



The Tulsa Tribune

Wasting away in Oklahoma



Oklahoma is scrambling to overhaul its system of care for the mentally retarded for the first time in decades.

But change is slow for the 90,000 retarded Oklahomans neglected by an archaic system . . .

Reprint of a series
published Oct. 1-10, 1984

Group homes: families fearful of unknown

Dennis Gray cleans the pool at Alpha House.

BY THE TIME he was 21, Dennis Gray, a mildly retarded young Tulsan, had heard the question from his father many times.

"He would say: 'One of these days, Dennis, I'm not going to be here. What are you going to do, what are you going to do?' "

What Dennis did was move to Tulsa's Alpha House, one of a handful of group homes for the mentally retarded operated by non-profit organizations in Oklahoma.

He is one of the lucky ones.

For many other parents, the question still is a haunting refrain.

What happens to a retarded offspring when parents or other family members die?

Who will care?

Who will provide?

Who will guard?

For years the state's answers to those questions were its three institutions or nursing homes.

AS OKLAHOMA alters its methods of caring for the mentally retarded, however, parents and families of the mentally handicapped are going to be facing choices they never have had before.

And for some, the new choices are as frightening as the old questions.

Dennis' father opposed his son's move into the group home at first.

"He kept telling my mama: 'He'll never make it there,' " Gray said. "I showed him, though. I made it."

LIKE PARENTS in other states who have switched from reliance on institutional care to community care, Oklahoma parents might be split into factions over the direction the state's services should take.

In other states, some parents have lobbied hard to do away with all institutions.

Others, initially opposed to the idea of having their children in contact with other "normal" persons, changed their minds once they saw progress.

And, some still are fighting to keep their children in the institutions they feel are safer and more appropriate for their children.

"I didn't want them in a group home. You hear bad things about group homes, too," said Mary Hatt, a Lincoln, Neb., mother. "It's not that I was embarrassed by them. I just didn't want them to be shoved aside by the rest of the world."

She was hesitant but finally consen ed to allow her twin retarded daughter to leave an institution, after 10 years, live in a group home.

Now she hopes her daughters remai in the group home for the rest of the lives.

"The decision to put a child in institution, believe me that's hard. It worse than losing them to death," she said. "Then to go through it all ove again; the grieving happens all ove when you take them out."

There are parents who are infuriate by scandals in some community programs and too rapid deinstitutionalization.

"**I THINK** there should be a whol array of services to serve the retarded," said Pat Crawford, who is active in national organizations that oppose taking all mentally retarded persons out of institutions.

"It's so hard for people to understand how much a severely retarded persor needs. I think it's scary . that some people want to get rid of (institutions entirely."

DELORES BOURLAND, whose 33-year-old son has lived at Pauls Valley State School since he was 7, is an Oklahoma parent who fears the move toward community placements.

"My son has not been trained to become independent or semi-independent," she said.

"I don't know whether at 33 he can make the transition. All of us find the older we get, the harder it is to make adjustments.

"He's happy, content. He works at a sheltered workshop, and it's a good routine for him.

"**"I'm a widow. I'm 58 years old. I do have a lot of apprehension about what's going to happen to this young man when I'm not here."**

With the institution, "I've always had the feeling he will be cared for.

"In the community, I don't have that security, I don't know what the followup will be.

"I just don't see it as the answer for his life," she said.

SHARON SMITH of Enid said she had similar fears for her 16-year-old daughter, Diane.

The girl has lived at Enid State School since she was 6 except for a yearlong stay at home when she was 13.

The mother said she is pleased with the care her daughter gets at Enid.

"If I wasn't, she wouldn't be there."

But, she said, "I want her to be as much as she possibly can."

Tests show Diane works at the third-grade level. This year she is attending vocational classes, learning to cook and clean and care for herself, with the hope of someday moving to a group home.

"It has really done a lot for her self-esteem," the girl's mother said.

Slowly, she said, her fears are subsiding and she sees "group homes are what it's all about."

"I think when they are established people will get used to the idea, and I don't think so many parents will be so frightened," she said.

At first apprehensive about plans for her daughter, Smith said staff members asked her to listen for 15 minutes.

"And they set me down and they were able to convince me that this would be good for Diane.

"**And that's what it's all about: What's**

The men of Alpha House pose for a "family" portrait with houseparents Myrt and Bill [illegible]

Sand Springs
Leader
Wednesday, July 3, 1991

Removed from the 'shelter,' Hissom client feels free

The first encounter staff working in the supported employment project sponsored by the Department of Human Service had with Susie Meech was in a sheltered workshop where the perpetually happy young woman had been employed in a sheltered, non-competitive job for five years. She had also worked at a flower nursery at The Hissom Memorial Center but there had been no history of work in the community for wages.

Now, after 2½ years, this 27-year-old woman has her own apartment, job and busy social calendar. Meech is also a person with a developmental disability, Down Syndrome.

The about-face in Meech's employment career started when she was assigned a job coach through a Department of Human Services employment program. Dorsey Taylor-Zinga began working with Meech. She located a job Meech was interested in, educated the employers and co-workers about the developmentally disabled and actually worked the job personally to learn all the job entailed.

When it was established the job would be an appropriate job match, Meech went to work. The employer, McDonald's, has been a leader in hiring individuals with developmental disabilities.

Meech's work schedule was Friday, Saturday and Sunday from 5 a.m. until 12 noon, making salads and biscuits. As Zinga's alarm went off at 3 a.m. on those days, she would groan, dress and stumble out the door. But not Meech! When her alarm rang, she was ready and anxious to don her work uniform which she had washed and ironed the night before. By 4:30 a.m., she had made her bed, bathed, and styled her hair. At 4:35 a.m. she was in front of the house with purse in hand, waiting for her job coach.

Zinga had worked out a time and training schedule which allowed for some of the obstacles Meech might, and did, encounter. A task analysis was completed to break down each job task into do-able smaller parts to help the worker understand what is required to get rticular task completed. tasks were learned through verbal instructions, instructional repetition, and modeling techniques. Zinga soon learned Meech's main problem was the rate (speed) at which certain tasks were being done.

Susie Meech goes to work with briefcase.

After trying several methods to speed up Meech's production, Zinga finally found the answer in music and rythm. Using a 'rap' form of training, she found rhythm and consistent beat trigered an internal cue for Meech to work by

After five months of intensive training, Meech was able to work completely on her own. Meech held her job for two years before deciding she would like to have a job where she could talk to others who had developmental disabilities.

In May of this year, Transitional Living, Inc., Tulsa, hired Meech as client communication coordinator/client social director and part time office hostess. Her job duties include coordinating special events, setting up meetings and meeting rooms and communicating all of the social and recreational events that are available in the area to the clients.

Zinga said she was flooded with emotions at Meech's employment success. "I am so proud of her but I also know our relationship will never be the same again ... Susie no long needs me."

Cheryl Piwenitzky sorts pills into boxes.

> *"The biggest problem mentally handicapped people face is that other people try to put limits on them."*
>
> — Nancy Ward

Nancy Ward is pursuing her dream of becoming a nurse.

Label deters struggle by handicapped

LINCOLN, Neb. — Over dinner at a downtown restaurant, Nancy Ward was taking an attorney and a lobbyist to task for using discriminatory language against the mentally handicapped.

"The biggest problem mentally handicapped people face is that other people try to put limits on them," she was saying.

Ward is an articulate, animated spokesman for her cause.

It is a fight she knows well — she is mentally retarded.

"I don't like being called retarded," she said as she cut up a steak for her wheelchair-bound friend, Cheryl Piwenitzky.

"I guess it is because of when I was in school," Ward continued. "I remember being called retarded then."

Mental retardation is defined by physicians as below-average intelligence and functioning caused by a birth defect or an injury in the developing years.

It is difficult, though, for a medical definition to reveal the frustration of the words "mentally retarded."

Or to measure how far determination can stretch the limits of the handicap.

PIWENITZKY, a cerebral palsy victim, is confined to a wheelchair and has limited use of only one hand.

She must have help to eat and dress. In addition to her severe physical handicaps, she is mildly retarded.

Intense speech therapy helped her to communicate, although it is sometimes difficult to understand everything she says.

Those who know her have discovered her intelligence and a wry sense of humor, said Lynn Rucker, director of the Lincoln area's services for the mentally retarded.

IQ means little to Nebraska social workers who deal with the mentally retarded, Rucker said.

"It's artificial," Rucker said. "It can't measure how well a person adjusts or how well a person carries on in society."

Today, Piwenitsky lives in her own apartment with a hired attendant. A motorized wheelchair allows her to go to work each day at a sheltered workshop, sorting non-prescription drugs into boxes and doing other hand work.

She, like Ward, is active in People First, a self-advocacy group for the mentally handicapped.

They are fighting discrimination, such as the Nebraska state law Piwenitzky and friends broke at her 30th birthday party.

It is against the law to serve liquor to the "feebleminded," so her friends had to order a strawberry daiquiri for her.

WARD WORKS at a motel laundry and lives in an apartment by herself. As president of Lincoln's People First chapter, she spends her spare time teaching other mentally handicapped people about assertiveness, handling discrimination and how to lobby politicians for what they need.

She was placed in special education classes in sixth grade and spent years in speech therapy.

Today, she speaks like a pro.

"She ought to be in a courtroom," said the attorney whose terminology she had challenged.

At 34, Ward, has battled discrimination much of her life.

Her dream of becoming a nurse has been thwarted so far, she said, because she was not allowed to take science, algebra or geometry in her high school special education classes.

All these subjects are necessary to be accepted into an LPN nursing program at the local community college.

She has spent the past five years slowly and painfully taking one college or adult education course at a time t get the background she needs for th nursing program.

"Sometimes the classes are too har for me. It's really hard for me to remember things," she said.

Her friends spend hours reading text books to her, making material easie for her to understand.

She has failed the entrance exam t the nursing program twice, the las time by one point. She can take it on once more, and she plans to try agai next year.

Her parents and some friends wan her to quit. They are afraid, she sai she won't be able to handle the frustration if she fails the third time.

She said she isn't sure how she woul handle it, but she isn't going to quit.

But Ward has had her triumphs.

She just finished a college algebr class that one of her high school specia education teachers warned she woul never be able to handle.

She not only made an "A," she had th highest marks in her class.

The first thing she did was take th report card to the special educatio teacher.

"She was flabbergasted. She didn say anything," she recalled. ■

Mentally handicapped definitions

The American Academy of Mental Deficiency defines mental retardation as below average intelligence and functioning caused by birth defects or injury during a child's developing years, typically before age 16.

It is not mental illness, and it can't be cured.

It generally is measured as being the 3 percent of the population with an IQ of 70 or below, says Susan Farrell, a physician with Tulsa's Developmental Pediatrics Center.

In addition, the mentally handicapped are divided into categories: borderline, mild, moderate, severe and profound.

Generally, Farrell said, those classified borderline are ones with IQs of 75 to 85 who do not fall into the technical category of retardation but who have trouble adjusting to society.

Most retarded persons fall into the range of mildly retarded with 59 to 69 IQ and typically can function with about two-thirds of the ability of an average person.

The moderately retarded are considered to be those with about half-normal functioning, an IQ of 40 to 55.

Severe is considered an IQ of 25 to 39, profound below 25.

But, Farrell cautions, IQ is only a number measured by tests.

Mentally retarded people often have physical handicaps that can make taking tests difficult.

"It's pretty hard to take a test when you're blind and can't see the test or are deaf and can't hear it," she said. ■

Consent Decree Signed in Hissom Case; Review Panel Established

On December 4, U.S.District Judge James Ellison of the Northern District court of Oklahoma approved a consent decree that will substitute for a 1987 "court plan and order of deinstitutionalization" in the case of "Homeward bound v. the Hissom Memorial Center. The consent decree establishes a framework for a community service system that will serve as an alternative to institutional care for current residents of Hissom (As well as some former residents).

Background. The suit was initially filed on may, 1985 on behalf of the Hissom class, to obtain relief from alleged unlawful treatment by the Oklahoma Department of Human Services. The class consists of the "focus class," which is made up of all people who currently reside a t Hissom, or who resided there prior to May 2, 1985 and the "balance class," including all other former residents. After several interim orders related to services provided at Hissom, the "court plan and order of deinstitutionalization" beam effective on October 21, 1987. The court appointed a monitor in May, 1988 to facilitate the implementation of the decree. In addition, an appeal filed by the State DHS is still pending in the U.S. Court of Appeals for the Tenth Circuit.

In May, 1989, the Department was directed by the court to "devote substantial resources" to the development of plans to afford present and former Hissom residents "quality habilitative care in community settings." This directive emerged, in part, from the fact that both parties in the litigation "have now had almost two years of experience under the 1987 court order, and based on that experience, they have a much better understanding of the difficulties involved int he transition from a system of care... based primarily on institutional treatment to a system based primarily on community services, of the amount of these required to effect transitions of (Hissom residents) to community settings, of the resources that are available to support a service deliver system based primarily on community service, and of the costs involved in such a system."

As a result of this experience, according to the consent decree, the plaintiffs, and the defendants now wish to terminate the litigation concerning care and treatment of the class, including the pending appeal, and move to an agreed upon structure for carrying out a service program that will provide appropriate relief for the class, in a manner that is sistent with the 1987 order. Thus, the December 4 consent decree supersedes the 1987 order and all subsequent orders.

Provisions of the Consent Decree. The consent decree consists of six sections, each divided into a series of provisions. These sections are summarized in the succeeding sections of this article.

Provisions Related to the "Focus Class." The central goal of both the court order and the consent decree is to transfer all Hissom residents (and the approximately 100 other individuals who reside in Hissom in May, 1985 and subsequently were discharged) to appropriate community settings or to provide an appropriate array of services and supports for them in accordance with their individualized habilitation plans. No new admissions will be made to Hissom, and the target date for completion of outplacements in October 1, 1993. The range of residential options will include independent living, natural homes, adult companion programs, shared living arrangements, foster homes, supported living arrangements, small group homes and small ICE?MRs.

According to the placement process outlined in the consent decree, individual habilitation plans will be developed by interdisciplinary teams, reviewed and approved by DHS, and submitted to a review panel for certification recommendation. The review panel must recommend either approval, or that a conference or hearing be held; the client and his or her representative will have an opportunity to participate in a conference or hearing. Priority for discharge will be given to class members who request placement in community settings.

All focus class members will have a case manger on or before June 30, 1990; case managers will be qualified mental retardation professionals. During the transition process, there will be one case manger for every ten clients; when class members have been in their community placements for one year, and are considered stabilized in such settings, the ratio will be one case manager to twenty clients.

Provisions Related to the "Balance Class." The decree categorizes balance class members into those residing in: (a) a private ICF/MR; (b) an institutional setting other than a private ICF/MR; or (c) community settings. For those in private ICF/MRs or institutional settings other than private ICF/MRs, IHPs will be prepared by October 1, 1990. They will be offered the opportunity to transfer to community settings. For those already in community settings, case managers will be assigned by October 1993.

Provisions Related to the Entire Class The role of parents/families is outlined in the agreement: parents/guardians will be members of the IDT for their family member and involved in all team decisions. Clients and families will have the right to select service providers from a State-approved list of providers. A system of safeguards is outlined in the decree, and DHS is directed to secure technical assistance from the outside, assist in the development and implementation of a quality assurance program, including compliance with ACDD standards. The facility will be maintained and operated as an ICF/MR, in compliance with State and federal requirements, during the entire period covered by the consent decree. DHS agreed to prepare a phase down plan for Hissom, to be submitted to the court by March 5, 1990.

Provisions Related to Oversight and Dispute Resolution. The consent decree includes detailed section on oversight and dispute resolution, outlining a process for informed resolution as a preferred option. The court establishes in the decree, the Homeward Bound Review panel, a panel of three individuals who will be assigned primary responsibility for assisting the court and the parties in the suit to carry out the decree. This panel will replace the Court Monitor whose role will be terminated.

The panel is authorized to hire up to three staff members with experience in mental retardation and two support staff members.

Financial Provisions. A series of additional provisions governing access to records, termination of the decree, definitions and legal provisions are included in the final section of the consent decree. The decree will be terminated three months after the last client is transferred out of Hissom.

(reprinted for Newsletter of the National Asso. of State Mental Retardation Program Directors, Inc.)

The Homeward Bound vs. The Hissom Memorial Center Lawsuit

In 1981, several Oklahoma parents who were frustrated by the lack of family support and the need for more community options came together and formed a new advocacy organization which they called **Homeward Bound**. Homeward Bound's original purpose was to provide services for children and adults with severe, multiple disabilities.

At that time, there were no out-of-home placements for an adult with severe, multiple disabilities except in a state institution or one of a few nursing homes. There were other places for people with mild or moderate mental retardation and some facilities would take people who also had less severe physical disabilities. However, all these excluded people with disabilities as severe as the Homeward Bound parents' children.

As there seemed to be few options for their children in Oklahoma, the group began to research the options other states provided for people with disabilities. They discovered that other states had been providing a wide array of services for people with very severe disabilities in the community for many years. Family supports (in/out-of-home respite care, cash vouchers, etc.) enabled parents to care for their children at home. Children whose families were unable to care for them, even with supports, were being cared for in specialized foster care.

For adults, there were group homes and other more normal types of living arrangements, as well as a wide range of vocational services. After hearing about what was possible, the group began to be hopeful that the services would be provided in Oklahoma.

The Homeward Bound supporters worked for several years with anyone who would listen to them concerning community services. They found other states providing services using money from Title XIX Home and Community Based Waiver. This was a federal program that allowed states to obtain federal funding which had previously been limited to the operation of institutions.

Lloyd Rader, the long-time director of the Department of Human Services, stated that Oklahoma would never have such a program. They also inquired about the possibility of their children being served by the then newly-funded state group home program. They were told that the program at that time was only for people with mild mental retardation who were employable in competitive employment. They also explored the possibility of getting money from private foundations but those foundations they contacted were unresponsive. They decided to wait for things to change.

Things did change. Rader left. The interim director, Henry Bellmon, brought in new leadership and created a new unit to serve people with developmental disabilities. Unfortunately, it was a case of too little, too late. Several more of the Homeward Bound families experienced life changes that forced them to place their children at Hissom.

As problems continued to exist in the institution, the parents again drew upon their advocacy experience and began to agitate for change. They wrote to the new state leadership and asked for help. There were unexplained injuries, lack of proper clothing, no physical or occupational therapy, school programs that only lasted an hour or two a day, and illness caused by lack of sanitation. The parents were assured that the problems would be corrected.

From what they had read and their discussions with people from other state, the parents learned that, in some states, changes in services for people with developmental disabilities had come about as a result of what were called class action lawsuits.

The parents wanted to explore this possibility in case their efforts to get change in other ways didn't work. They talked to Steve Novik of Legal Aid of Western Oklahoma about the serious difficulties their children were having at Hissom and the information they had from talking with people who worked at Hissom. Novik said that he would try to find a way to represent them if it became necessary, but he recommended waiting until new leadership at the Department of Human Services had a chance to correct the problems.

They waited. Parents continued to write letters asking for help for their children. But, nothing happened except that their children continued to have multiple needs that weren't being met in the institution or in the community. Eventually, all of the children of the Homeward Bound group ended up at Hissom.

When one Hissom child experienced such severe neglect that he nearly died, parents took action. They went to the district attorney, the Protection and Advocacy Agency, Office of Handicapped Concerns, and the Child Abuse Hot Line for help, but no one was willing or able to help. The parents were referred to the Oklahoma Commission on Children and Youth -- which did investigate. Their findings showed severe neglect. but the Department of Human Services did not respond to the report.

In the meantime, a parent who was not a member of the original Homeward Bound group filed a lawsuit charging abuse and neglect of their child at Hissom. The resulting investigation revealed that a doctor employed at Hissom had never attended medical school. It was also found that her child had been seriously injured but no one could explain how.

The Homeward Bound parents were told by officials that this had been an isolated incident and was not representative of the care residents received at Hissom. The parents replied that they knew this was not true because their own children had experienced similar problems.

Tulsa media investigating the mother's allegations checked public records and found that two of the Homeward Bound parents had filed a lawsuit against Hissom to gain access to their children's records.

The parents told the reporters about other states which did provide family support services. One Tulsa newspaper expanded their story to a series of articles titled "Wasting Away in Oklahoma" which told the story of institutions in Oklahoma. The reporters traveled to Nebraska, a state which had been at the forefront of community service development, to visit their programs and compare the Nebraska experience to that in Oklahoma.

The parents expected to hear a public outcry as a result of the articles, but were disappointed. At this point, they decided to formally reactivate the Homeward Bound organization -- this time as an organization to develop systems advocacy to obtain services for people with severe disabilities in the community. They sent a delegation of parents to Nebraska to see with their own eyes what they had read and heard about. The delegation came back convinced of the rightness of their undertaking.

They began to ask for meetings with public policy makers to try to convince them that there were dangerous problems at Hissom and that the solution would be to provide services in the community for people with severe disabilities. They met with several legislators, the head of the Department of Human Services, the head of the Developmental Disabilities Services Division, the chairman of the Oklahoma Commission for Human Services. They tried to meet with the Governor but were referred instead to a recently formed task force on mental retardation. They found that the task force apparently felt none of the urgency they felt since it was not scheduled to report for two years.

The parents contacted state and national organizations seeking help. Oklahoma organizations were unresponsive, but national organizations provided information about ways to effect change. The parents became convinced that the only way to get permanent change was to file a class action lawsuit against the state. They began to meet with law firms in Oklahoma to ask for help. They were told by everyone that a private law firm could not afford to take such a suit because of the costs involved. Legal Aid also refused to take the suit because of the costs involved.

In other states, the United States Justice Department had participated in investigations of institutions and class action law suits. The parents contacted the Justice Department but were told that under the new administration (Reagan), the department was no longer participating in such suits.

The parents were referred to the Public Interest Law Center of Philadelphia (PILCOP). This law firm had handled other deinstitutionalization lawsuits in other states (they had helped close the Pennhurst institution in Pennsylvania). PILCOP had received a federal grant which gave them the financial stability necessary to absorb the costs of a protracted court case. PILCOP contacted Louis and Pat Bullock, two Oklahoma attorneys who had been successful in other human rights cases, and asked them to join in representing the parents in Oklahoma.

In April of 1985, the parents formally asked PILCOP to file suit. The class action suit filed in Federal District Court by Homeward Bound, Inc., and six named plaintiffs on May 2, 1985, alleged that Hissom was a dangerous place to live. Among the relief requested was that the state provide services to all plaintiffs and members of the class in the least separate, most integrated community setting appropriate to their needs.

Testimony was heard in the U.S. Federal Court in Tulsa by Judge James Ellison. It lasted from June to December of 1986 and testimony was given by numerous witnesses, experts, advisors, and other parties. However, not all parents of residents in the institution agreed with the plaintiffs. About 120 parents joined as "intervenors," attempting to assure that Hissom remained open as an option to the community.

On July 24, 1987, the Court issued its Findings of Fact and Conclusions of Law and the Court Plan and Order of Deinstitutionalization. The latter defined the members of the class, set out a comprehensive plan of community services, and established a four-year timetable for placing all Hissom residents into the community. On October 21, 1987, the Court entered the judgement by the judge in favor of the plaintiffs. The state filed an appeal. A monitor was appointed to oversee the Plan of Deinstitutionalization.

Later, the state's appeal was dropped and the parties entered a Consent Decree which was adopted by the Court on February 1, 1990. The Consent Decree superseded the previous orders, included plans for provision of community services, limited case manager's case loads, provided a schedule for placing all class members in appropriate community settings by October 1, 1994, and targeted the discharge of all remaining residents form Hissom by October 1, 1993.

It also provided for the replacement of the Court Monitor by a three-member Review Panel of professionals who had experience in developing community services and closing institutions.

While the case only affected people who had lived at Hissom, it was nevertheless a significant factor in Oklahoma's shifting emphasis away from institutions and toward normal community lifestyles for people with disabilities.

All because of a handful of people.

Developed by Mary Ann Duncan

I remember growing up, whenever explaining or defending my disability to others, I'd talk about my normal intelligence. I'd say things like, "At least I'm not retarded."

The Hierarchy of Acceptance

by Carol Marfisi

When we think of discrimination and stigmatization, we think of it as being imposed from outside. But we need to put time and energy into dissolving stereotypes which exist within the disability community as well.

Whether we grew up with a disability or acquired one later in life, we know the unproclaimed hierarchy of acceptance which exists. Spinal cord injured people — paras and quads — have always been considered the creme de la creme. A little lower down the pecking order are those with muscular dystrophy, multiple sclerosis, people in wheelchairs who had polio, people with spina bifida. Still lower are those of us with cerebral palsy; even lower are those of us with related speech impediments. And of course on the bottom of the hierarchy are people with "mental deficiencies."

It is this last group to which I think we as a community have been the most insensitive. I remember growing up, whenever explaining or defending my disability to others, I'd talk about my normal intelligence. I'd say things like, "At least I'm not retarded."

This pompous attitude was reflected by my family, too. "At least she has a good mind." Implicit in that kind of thinking is the belief that to be mentally different is a fate worse than death.

If we who belong to the disability community remain trapped in the stereotypic thinking that has oppresssed all of us from time immemorial, we will not be able to truly move forwared and educate others. It is not an empty truism that oppressing any one of us oppresses all of us.

One of the best things that has evolved from all the political action around the passage of the Americans with Disabilities Act is that we not only moved forward politically but as human beings we laid down our insecurities about our disabilities and connected authentically and strongly with one another.

One of the most memorable times for me during all the actions in Washington was to see how the leaders from ADAPT became focused on listening to those of us who have severe speech problems or who communicate in an unspeaking manner. I think that act in itself is what gives ADAPT enormous credibility, credibility which it truly deserves.

Until we can look at each other and see the person — the mind, soul and heart — and not judge one another according to the degree of, or manner in which we function, we will never truly be able to accept ourselves and be proud of who we are. ■

2H

The Enlightening Principle of Normalization

Normalization means. . .*a normal rhythm of the day.*
You get out of bed in the morning, even if you are profoundly retarded and physically handicapped;
you get dressed,
and leave the house for school or work, you don't stay home;
in the morning you anticipate events,
in the evening you think back on what you have accomplished;
the day is not a monotonous 24 hours with every minute endless.
You eat at normal times of the day and in a normal fashion;
not just with a spoon, unless you are an infant;
not in bed, but at a table;
not early in the afternoon for the convenience of the staff.

Normalization means...*a normal rhythm of the week.*
You live one place,
go to work in another,
and participate in leisure activities in yet another.
You anticipate leisure activities on weekends,
and look forward to getting back to school or work on Monday.

Normalization means...*a normal rhythm of the year.*
A vacation to break the routines of the year.
Seasonal changes bring with them a variety of types of food, work, cultural events, sports, leisure activities.
Just think...we thrive on these seasonal changes.

Normalization means...*normal developmental experiences of the life cycle.*
In childhood, children, but not adults, go to summer camps.
In adolescence one is interested in grooming, hairstyles, music, boyfriends and girlfriends.
In adulthood, life is filled with work and responsibilities.
In old age, one has memories to look back on, and can enjoy the wisdom of experience.

Normalization means...*having a range of choices, wishes, and desires respected and considered.*
Adults have the freedom to decide where they would like to live,
what kind of job they would like to have, and can best perform.
Whether they would prefer to go bowling with a group,
instead of staying home to watch television.

Normalization means...*living in a world made of two sexes.*
Children and adults both develop relationships with members of the opposite sex.
Teenagers become interested in having boyfriends and girlfriends.
And adults may fall in love, and decide to marry.

Normalization means...*the right to normal economic standards.*

All of us have basic financial privileges and responsibilities,
are able to take advantage of compensatory economic security means, such as child allowances, old age pensions, and minimum wage regulations.
We should have money to decide how to spend; on personal luxuries or necessities.

Normalization means...*living in normal housing in a normal neighborhood.*
Not in a large facility with 20, 50, 100 other people because you are retarded.
And not isolated from the rest of the community.
nal locations and normal size homes will give residents better opportunities for successful integration with
communities.

A CASE FOR TEACHING FUNCTIONAL SKILLS

by Preston Lewis - from December, 1987 TASH Newsletter

My Other Brother Daryl

...is 18 years old. Has an I.Q. range of 30-40. Has been in elementary school for 12 years, never been served in any setting other than elementary school. He has had a number of years in "individual instruction." He has learned a lot of things!

Daryl can now do lots of things he couldn't do before! He can put 100 pegs in a board in less than ten minutes while in his seat with 95% accuracy. But, he can't put quarters in vending machines.

Upon command, he can touch his nose, shoulder, leg, foot, hair, and ear. He's still working on wrist, ankle, hips. But he can't blow his nose when he needs to.

He can now do a 12 piece Big Bird puzzle with 100% accuracy and color an Easter Bunny while staying in between the lines. He prefers music but was never taught how to use a radio or record player.

He can now fold primary paper in halves and even quarters. But, he can't fold his own clothes.

He can sort blocks by color, up to fifteen colors! But, he can't sort clothes: whites from colors for washing.

He can roll Play Dough and make wonderful clay snakes. But, he can't roll bread dough and cut out biscuits.

He can string beads in alternating colors and match it to a pattern on a DLM card. But, he can't lace his shoes.

He can sing his ABC's and tell me names of all the letters of the alphabet when presented on a card in upper case with 80% accuracy. But, he can't tell the men's room from the ladies room when we go out to McDonald's.

He can be told it's cloudy/rainy and take a black felt cloud and put it on the day of the week on an enlarged calendar (with assistance). But, he still goes out in the rain without a raincoat or a hat.

He can identify with 100% accuracy 100 different Peabody Picture cards by pointing! But, he can't order a hamburger by pointing to a picture or gesturing.

He can walk a balance beam frontwards, sideways, and backwards. But, he can't walk up the steps or bleachers unassisted in the gym to a basketball game.

He can count to 100 by rote memory. But, he doesn't know how many dollars it takes to pay the cashier a $2.59 coupon special.

He can put cubes in a box, under the box, beside the box, and behind the box. But, he can't find the trash bin and empty his trash in it.

He can sit in a circle with appropriate behavior and sing songs and play "Duck, Duck, Goose." But, nobody else in his neighborhood his age wants to do that.

I guess he's just not ready yet....

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