



Impact of a Handicapped Child on the Family

Curriculum Unit 82.06.08
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Objective

The objective of this paper is to help students identify some of their own feelings toward disabled people and become aware of the effect a handicapped child may have on his family.

Introduction

The birth of a baby is usually anticipated with great excitement and expectations of a future filled with happiness and success. This exuberance may become muted with the birth of a disabled infant. It does not matter if the handicap is blindness, retardation or a physical abnormality. The family into which this child is born will change in some ways.

This paper will focus on the effect a handicapped child may have on his family. (Masculine pronouns will be used throughout the paper for continuity and because a slight majority of handicapped children are male.) A particular disability will not be addressed because parental reaction to almost any disability appears to follow certain stages. Research seems to indicate that the severity of the handicap and the degree of dependency by the child on his family is the most important factor in his acceptance, than whether he has cerebral palsy or spina bifida.

Having a handicapped child born into a family and grow into adulthood is one of the most stressful experiences a family can endure. Parental reactions to the realization that their child is exceptional usually include shock, depression, guilt, anger, sadness, and anxiety. Individuals handle each of these feelings differently and may stay in certain stages longer than others. Some parents perceive the handicapped infant as an extension of themselves and may feel shame, social rejection, ridicule or embarrassment. Parental reactions may be affected by economic status, personality traits and marital stability. In short, an initial parental response may be a form of emotional disintegration. This may evolve into a period of adjustment and later into reorganization of the family's daily life. Some parents cannot cope beyond the emotional disintegration. They must then decide whether to give the child up for adoption or to place him in an institution. This decision is not easy and is stressful to the family. However, the concern here is with the family that chooses to raise their special youngster at home.

A number of practical problems may make living with a handicapped child especially demanding. For example, there may be financial strain to provide necessary medical expenses, special equipment, possibly special

schools and care takers in the parent's absence. The family may find it difficult to entertain friends at home or to visit others. Transportation may become difficult if special equipment must be transported with the child.

From our student's perspective, the effect of a handicapped child on his siblings may be most relevant. Research will be presented for the teacher in this area. However, some evidence suggests that many children can adapt themselves to the presence of a disabled sibling but that they tend to adopt the attitudes of their parents towards the family situation.

My reasons for recommending this teaching unit in the Year of Disabled Persons (1982) are varied. Handicapping conditions occur in all ethnic groups and cross all economic strata. Most students know someone in a "special" class or of a disabled person in their neighborhood, if not in their immediate family. With handicapped students being mainstreamed into regular classes and with more barrier free environments, the disabled are becoming more visible. Perhaps a unit of this nature will sensitize students to the many problems that arise in the daily lives of some of these people and their families.

Background and Strategies

It seems advisable to present a unit on different kinds of handicapping conditions before presenting this unit. A bibliography for background information is offered to provide a foundation for discussion. The Mew Haven Public School System provides classes for Educable Mentally Retarded, Learning Disabled, Emotionally Disturbed, Hearing Impaired and Physically Handicapped students within regular school buildings. Students see and may know some of these youngsters. This recognition could be a basis for opening discussions. The physically handicapped classes have students with cerebral palsy, spina bifida, prader-willi syndrome, muscular dystrophy, epilepsy, and so on. The causes, characteristics and nature of these disorders could easily be incorporated into science, biology, health, or social studies classes.

In presenting this unit to a class it might be divided into two parts. Part one would encompass the affects of a disabled child on his parents; part two would emphasize the disabled child's effects on his brothers and sisters.

Some of the effects a handicapped child might have on his parents were mentioned briefly in the introduction. A common initial reaction of parents is disappointment and grief—grief over the death of a dream. Usually this grieving time helps the parents face their problem and begin to regroup themselves for a change. Many parents ask, "Why me?" "How did this happen?" Some parents search for a specific cause, most find out it wasn't their fault, and they could not have prevented it. Other parents may find out that a genetic basis is the cause and receive counseling regarding future children. In either case, some parents will seek whatever information they can find about their child's disability and go in search of a cure. These parents may see dozens of professionals, try new diets, drugs and therapies, all in the hope their child will become "normal". Eventually, most parents learn to accept their child, develop tolerance for his disabilities, appreciation for his uniqueness, and come to have pride in his assets.

The acceptance of a handicapped child into a family may be eased if parents have an opportunity to meet with other parents of children like their own. Within these parent groups, parents learn that their problems are not unique. They have a chance to share experiences, learn how others have coped, and work with others to find solutions to common problems. This can greatly reduce the guilt and stress many parents feel. Additionally, some of these parent organizations have become active lobbyists on behalf of their children. They have secured legislation to provide educational, recreational, and vocational services. Their task has been difficult and certainly they face many challenges in our current economic crisis. However, united they

have power and hope. Much has been said about the adverse effects of a handicapped child on the relations of the normal family members, but there is little substantial research in this area.

Faber (1963) studied the effect of retarded children on their normal brothers and sisters. He found that the variable which seemed of greatest importance to the siblings was the degree of dependence of the retarded child, that is how much he was able to do for himself. The more dependent the child, the more adverse was his effect on his siblings. In other words, the more responsibility required by the normal siblings (particularly girls), the less likely the handicapped child would be welcomed into the fold by his brothers and sisters. Jealousy and resentment may also develop if the handicapped child requires most of his parents attention, leaving short tempers and impatience for the others.

Robinson and Robinson (1965) suggest that most children can adapt themselves to the presence of a retarded brother or sister and that they tend to adopt the attitudes of their parents. Only when they are pushed aside or expected to assume maturity and responsibility beyond their years are they likely to suffer serious consequences. Parents might be advised to acknowledge and be sensitive to their other children's feelings regarding their handicapped sibling. It is important to not make the disabled child a burden to his brothers and sisters. Additionally in most case the handicapped child would probably be happier in activities in which he is not only welcome but an active participant.

While a handicapped child may provide additional stress on a family, Mahoney (1958) documented some positive effects. He found that the disabled child can have an integrative effect by focusing the family's energy in a concerned, loving manner, thereby minimizing some of the other day to day problems. Some parents expressed a new appreciation for life and ordinary things they used to take for granted.

Parental Involvement in the Educational System

The focus of this paper has been on the reactions of families to their handicapped child. As teachers it is important to be aware of parental rights within the school system. With passage of Public Law 94-142 in 1975 all handicapped children between the ages of 2.8 years through 21 years are entitled to a free appropriate public education within the least restrictive environment. The least restrictive environment clause means that a student may spend all or any part of his day in a regular classroom. Therefore, teachers with little or no special education training may be responsible for the education of some of these children. However this need not be a threatening situation. Public Law 94-142 is a comprehensive law that is constantly being amended. Teachers can read about it in more detail in the Federal Register available through the Office of Education in the Department of Health, Education and Welfare. The sections specifically dealing with parental involvement are important for teachers to know about. All school age handicapped children must have an individualized education program (I.E.P.) prepared before they begin school. A meeting including the parents, teacher(s), administrator psychologist, social worker and any needed ancillary personnel such as speech therapist, physical therapist, occupational therapist, nurse and so on, must be held. At that time the educational goals and objectives are mutually decided upon for one year. At the end of every year a new meeting must be held and the annual goals reviewed and updated. It is at this very important meeting that teachers can provide input regarding the child's present level of educational performance, his learning style and specific services that are needed to help this child learn to his maximum potential. Any problems encountered by the child in the regular classroom should be addressed at this time. Parents must be invited to this meeting and they must agree to all decisions made regarding their child. If not, they can appeal for a due process hearing. Usually however this is an important opportunity for parents and teachers to work together in a very precise and concrete manner. Parents and teachers can share their successes and frustrations and work together to reach their goals.

Conclusion

Why should I teach a unit about a handicapped child's effect on a family? Handicapped children, especially in New Haven, are being integrated into regular classes in greater numbers. Some of these children have visible handicaps others do not. All however have special problems that need to be acknowledged. By introducing this unit to "normal" students it gives them an opportunity to personalize the experience of a disability to their own life. Students are provided with lessons that start them thinking about their own families and about families they may someday have. They then must address the issue of unexpected change—a handicapped child. Lessons also encourage students to discuss the problems and responsibilities having a handicapped brother or sister might entail. These lessons are an attempt to get students to empathize with families experiencing this situation.

As handicapped students are mainstreamed, perhaps students who have completed this unit will be more tolerant and understanding towards them. Maybe there will be less name calling in neighborhoods and more accepting neighbors.

Lesson Plan

Objective Students will name the difficulties encountered by people who are blind, learning disabled, deaf, or wheelchair bound.

Materials Blindfold, mirror, wheelchair, ear plugs. (Wheelchair and assorted splints and braces may be borrowed from the physically handicapped classroom if your school has one, or from the Easter Seals Rehabilitation Center.)

Procedure To simulate blindness students could wear a blindfold and try to negotiate an obstacle course. To simulate learning disabilities a student should try to copy a passage from a book by writing with their non-dominant hand and looking at the passage through a mirror's reversed reflection. To simulate deafness have students wear ear plugs and try to watch T.V. To understand problems encountered by those confined to wheelchairs, have students try to get to the lav or around their school in a wheelchair. Ask them to think about how they could shop in a supermarket or go to church if they couldn't walk. Brainstorm problems faced by the disabled with the group and have students discuss how people might have to compensate for each disability.

Lesson Plan II

Objective Students will identify feelings and responsibilities normal siblings might have toward a disabled brother or sister.

Materials Blackboard and chalk

Procedure Role play the following situations. At the end list on the board some of the feelings that were expressed and some of the additional responsibilities the non-handicapped sibling had.

Situation A

Jeff is a non-disabled 15 year old. He just made his school's football team and has practice everyday after school. Jeff's 13 year old brother has cerebral palsy and is confined to a wheelchair. Because his mother and father both work, his parents expect Jeff to be home right after school to be with his brother. Role play Jeff's possible response to his parents request. Suggest possible alternatives.

Situation B

Mary is a high school junior and has a 10 year old brother who is autistic. Her brother is always banging things, rocking himself, hitting his head and making funny sounds. She wants to have friends come to the house but she's afraid her brother will scare people away. Role play a discussion Mary might have with her mother. Also play out a discussion of his problem between Mary and her best friend. Emphasize feelings, responsibilities and solutions.

Lesson Plan III

Objective Students will identify their own expectations for the future of their children, and what they believe their parents expect from them.

Materials Paper and pencils.

Procedure The teacher should lead a hypothetical discussion about what their students will expect from the children they may someday have. Have them set goals regarding school, occupation, life style etc. Ask them if these are what they believe their parents expect from them. How are their goals and expectations different from their parents. Then ask them to set goals for a child who may be mentally retarded. Ask how they might plan for their child's future. After the discussion have students put their thoughts into a essay. You might also have students choose different handicapping conditions and then research each disability, especially noting the maximum potential a person with that disability might have.

Lesson Plan IV

Objective Students will observe a program for disabled children and identify their reactions to the experience.

Materials Transportation, if required. Notebooks.

Procedure Students will tour a facility for disabled children. Each student should have a notebook and keep a log of everything they see and their feelings about it. Upon returning to their

classroom their logs could be shared as a group. They could then write a report about how they feel if their brother or sister attended the program they visited. They could also write a creative story pretending to be one of the children they saw and describing their life as they imagine it to be.

Places to visit: New Haven Regional Center

455 Wintergreen Ave.

New Haven, Conn.

Contact: Ms. Barbara Killany

Mr. Michael Grappone

The Celentano School

Canner St.

New Haven, Conn.

Contact: Miss Mary O'Toole

Easter Seals Rehabilitation Center

Brookside Avenue

New Haven, Conn.

Contact: Volunteer services

Student Bibliography

Feeling Free —write to: Addison Wesley, General Books Division, Reading, Massachusetts 01867

This book introduces children and adults to their disabled peers with short stories, facts, photographs, games, drawings and activities. *Feeling Free* presents a realistic approach to dealing with individual differences.

People . . . Just Like You: An Activity Guide —write to: President's Committee on Employment of the Handicapped, Washington, D.C. 20210

This guide suggests activities, such as projects, films, discussions, essays, and books which can be used to introduce basic concepts to children on various levels about common problems facing disabled people: attitudinal barriers, architectural obstacles, adaptations to the work place. Activities are coded according to grade level.

What Everyone Should Know About . . . Series —write to: Channing L. Bete Co., Inc., 45 Federal St., Greenfield, Mass. 01301. (Discounts for quantity purchases.)

A series of 18 easy to read fact booklets dealing with all varieties of disabling conditions.

Annotated Teacher Bibliography

Adams, Bert N. *The American Family* . Chicago: Markham Publishing Co., 1971.

Presents a sociological interpretation of the contemporary American family. There is a chapter on challenges and stress facing the family.

Bigge, J. L. and O'Donnell, P. A. *Teaching Individuals with Physical and Multiple Disabilities* . Columbus, Ohio: Charles E. Merrill, 1976.

Discusses teaching strategies and family involvement with children who have multiple disabilities. Emphasis on severely physically disabled.

Bricker, D. and Casuso, V. "Family Involvement: A Critical Component of Early Intervention." *Exceptional Children* , 1979, 46, 108-115.

Emphasizes the necessity of habilitation of the disabled infant from birth.

Cain, L. F. "Parent Groups: Their Role In a Better Life for the Handicapped." *Exceptional Children* , 1976, 42, 432-437.

Describes the need for parent advocacy in legislation.

Farber, B., and Jenné, W. C. "Family Organization and Parent-Child Communication: Parents and Siblings of a Retarded Child. *Monograph Soc. Res. Child Develpm* ., 1963, 28, Whole No. 91.

Discusses relationships between family members having a retarded child at home.

Finnie, Nancie R. *Handling the Young Cerebral Palsied Child at Home* . New York: E. P. Dutton, 1975.

Detailed book describing family life with a cerebral palsied child. Emphasis on the physical needs of the child feeding, positioning, etc.

Grebler, A. M. "Parental Attitudes Toward Mentally Retarded Children." *American J. on Mental Deficiency* ; 1952, 56, 475-483.

Discusses parental feelings toward their mentally retarded children.

Greer, Bobby G. "On Being the Parent of a Handicapped Child." *Exceptional Children* , 1975, 41, 519.

Mr. Greer discusses his personal feelings regarding being the parent of a handicapped child.

Heisler, V. *A Handicapped Child in the Family*. New York: Grune and Stratton, 1972.

Describes the effects of a handicapped child on the family.

Karnes, M. B. and Zehrbach, R. "Parental Attitudes and Education in the Culture of Poverty." *J. of Res. and Develop. in Education* , 1975, 8, 44-53.

Describes the attitudes of low socioeconomic parents towards education and their children.

Lichter, Paul. "Communicating with Parents: It Begins with Listening." *Teaching Exceptional Children* , 1976, 8, 66-71.

Details how parents and teachers can communicate more effectively, especially when discussing needs of exceptional children.

Mahoney, S. C. "Observations Concerning Counseling with Parents of Mentally Retarded Children." *Amer. J. of Mental Deficiency* , 1958, 63, 81-86.

This article describes parental reactions and feeling towards their mentally retarded child.

Robinson, H. and Robinson, N. M. *The Mentally Retarded Child* . New York: McGraw Hill, 1965.

Comprehensive textbook detailing all aspects of a mentally retarded individual's life and needs.

Strom, R. and Johnson, A. "The Parent as a Teacher." *Education* , 1974, 95, 40-43.

Tells how parents can help their child learn at home.

Teacher bibliography About Handicaps

Resources providing teacher's with information regarding specific disabilities.

General

Bleck, E., and Nagel, D. A.(Eds.). *Physically Handicapped Children : A Medical Atlas for teachers*. New York: Grune & Stratton, 1975.

Peterson, R. M., and Cleveland, J. O. *Medical Problems in the Classroom: An Educator's Guide* . Springfield, Ill.: Charles C. Thomas, 1976.

Cerebral Palsy

Scherzer, A. L. "Early Diagnosis, Management, and Treatment of Cerebral Palsy." *Rehabilitation Literature* , 1974, 35, 194-199.

Hemophilia

Pilling, D. *Child with a Chronic Medical Problem* . New York: Humanities, 1973.

Muscular Dystrophy

Moosa, A. "Muscular Dystrophy in Childhood." *Developmental Medicine/and Child Neurology* , 1974, 16, 97-111.

Scoliosis

Roaf, R. *Scoliosis* . New York: Longman, 1967.

Spina Bifida

Pilling, D. *Child with Spina Bifida: Social Emotional, and Educational Adjustment* . New York: Humanities, 1973.

Mental Retardation

Haring, N. G. and Schiefelbusch, R. L. *Teaching Special Children* . New York: McGraw-Hill Co., 1976.

Stephens, B. (Ed.) *Training the Developmentally Young* . New York: John Day, 1971.

Learning Disabilities

Lerner, J. W. *Children With Learning Disabilities: Theories Diagnosis and Teaching Strategies* . Boston: Houghton-Mifflin 1976.

Wallace, G., and McLaughlin, J. A. *Learning Disabilities Concepts and Characteristics* . Columbus, Ohio: Charles E. Merrill, 1975.

Adult Education Association of U.S.A.

810 18th Street, N.W.

Washington, D. C. 20006

Alexander Graham Bell Association for the Deaf, Inc.

3417 Volta Place, N.W.

Washington, D.C. 20007

American Association for Health, Physical Education, Recreation and Dance for the Handicapped

1201 16th Street, N.W.

Washington, D.C. 20005

American Association of Workers for the Blind

1511 K Street, N.W.

Washington, D.C. 20005

American Cancer Society

219 East 42nd Street

New York, New York 10017

American Coalition of Citizens with Disabilities

1200 I5th Street, N.W. Suite 201

Washington, D.C. 20005

American Foundation for the Blind, Inc.

15 West 16th Street

New York, New York 10011

American Occupational Therapy Foundation, Inc.

6000 Executive Boulevard

Rockville, Maryland 20852

American Personnel and Guidance Association

1607 New Hampshire Avenue, N.W.

Washington, D.C. 20007

American Printing House for the Blind

1839 Frankfort Avenue

Louisville, Kentucky 40206

American Speech and Hearing Association

9030 Old Georgetown Road

Washington, D.C. 20014

Association for Children with Learning Disabilities

5225 Grace Street

Pittsburgh, Pennsylvania 15236

Boy Scouts of America

Jack Richmond, Scouting for the Handicapped

Boy Scouts of America

Box 61030

Dallas/Ft. Worth Airport,

Texas 75261

CEC Information Center on Exceptional Children

The Council for Exceptional Children

1920 Association Drive

Reston, Virginia 22091

Center for Studies in Vocational Technical Education

Ohio State University

1960 Kenny Road

Columbus, Ohio 43210

Closer Look

1201 16th Street, N.W.

Washington, D.C. 20036

Department of Health, Education and Welfare

Social and Rehabilitation Service Rehabilitation Services Administration

Washington, D.C. 20201

National Association for Retarded Citizens

2709 Avenue E, East Box 6109

Arlington, Texas 76011

National Center on Educational Media and Materials for the Handicapped

Ohio State University

220 West 12th Avenue

Columbus, Ohio 43210

National Council for Homemaker-Home Health Aid Services, Inc.

67 Irving Place

6th Floor

New York, New York 10003

National Easter Society for Crippled Children and Adults

2023 West Ogden Avenue

Chicago, Illinois 60612

National Education Association

1201 16th Street, N.W.

Washington, D.C. 20006

National Information Center for the Handicapped

P.O. Box 1492

Washington, D.C. 20013

National Rehabilitation Association

1522 K Street, N.W.

Washington, D.C. 20005

President's Committee on Employment of the Handicapped

Washington, D.C. 20210

United Cerebral Palsy Association

66 East 34th Street

New York, New York 10016

U.S. Department of Labor Employment and Training Administration

Room 10225

601 D Street, N.W.

Washington, D.C. 20213

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