

SIBLINGS OF CHILDREN WITH DISABILITIES

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Abstract

Many teachers will have special needs children integrated in their classes. At another time they will teach a brother or sister of a special needs child. A review of the literature indicates that some brothers and sisters harbour misconceptions about the nature, extent and implications of their sibling's disability. Teachers may wish to provide information and support to these brothers and sisters. One method of providing this is to develop a sibling support group.

Introduction

When a handicapped child is born, there is an emotional and sometimes financial impact on his or her family. While many parents receive help in coming to terms with the various needs of this new family member they may have little time or energy to expend giving attention to their other children, the siblings of that disabled child. As Featherstone (1980) explains, there can be an advantage to having a disability as it guarantees that special attention will be given but perhaps it is appropriate to give attention to the brothers and sisters of disabled children. They are special too. This study will examine a method of providing support and information to "special siblings".

Significance for Teachers

In the past, children with disabilities were sent to day or residential programs to be educated. Now, almost all children who have disabilities are educated in their home schools alongside their brothers and sisters. Consultation service is provided by itinerant therapists and special education teachers who go into schools to work with mainstreamed children who have disabilities. These specialists have noted in their conversations with teachers of "regular" students, that some mentioned that they teach the sibling of a disabled child. The teachers have expressed an interest in understanding how they should meet the needs of that child. Some concerns that have been raised are that the student is underachieving, or that he/she presents with aggressive behaviour. Some teachers have sensed that the child is having difficulty making friends or that the child feels the need to overachieve.

Research on the subject of siblings of children with disabilities,

particularly their social achievements in the classroom initially reveals little relevant material. If that examination goes beyond the education journals to which classroom teachers usually subscribe, to the social work, psychiatry and counselling literature, there is a wealth of information on the topic of siblings of children with disabilities available to parents, special educators, child psychiatrists, counsellors and marriage and family therapists. This material may not be so accessible to regular classroom teachers - those who in fact have the siblings in their classes. There is also little in the literature that pertains particularly to the classroom situation, and much of the literature is pathological in nature. This is to be expected: the people writing the case studies have been seeing these siblings of disabled people for counselling and therapy. They have little information on the positive aspects of growing up with a disabled sibling. It may be that when families, educators, counsellors and therapists take proactive steps to involve and include the entire family in the life of the disabled child, there can be positive outcomes.

Support groups may be one effective way to involve siblings. This study will provide the necessary information and materials to implement a workshop.

Review of Literature

Sibling Relationships

Research on sibling relationships indicates that children can have ambivalent feelings about their brother or sister (Dunn, 1985; Furman & Buhrmester, 1985). In their 1985 study, Wendon Furman and Duane Buhrmester interviewed forty-nine 11 - 13 year old boys and girls about their sibling relationships. The initial interviews were conducted in an

open ended format and they elicited answers to questions such as “Tell me as many good things as you can about your relationship with [name]”. From these interviews a list of relationship qualities was derived. They then used this list of qualities to develop a self reporting rating scale and this was administered to one hundred and ninety eight 11 - 13 year old boys and girls. This scale was used to assess their perception of the presence of each of the qualities in their relationships with their siblings. The four factors which emerged were 1) warmth/closeness, 2) relative status/power, 3) conflict and 4) rivalry.

They found that same sexed dyads more often reported feelings of warmth and closeness than did opposite sexed dyads. They also found that the highest levels of conflict were reported by siblings who were close in age, but when the siblings were separated in age by a few years then the younger sibling did not resent the relative status and power of the older sibling and in fact expected power differences because of age differences. They noted that conflict and rivalry were sometimes associated with perceived parental partiality, yet the children were reluctant to discuss this even though they were willing to discuss other negative aspects of their relationship.

Sibling relationships when there is a disability involved.

Some of the emotions described above, for example rivalry and warmth, are conflicting, and so it is to be expected that siblings of children with disabilities might also be confused by the emotions that they feel when asked to talk about their sibling. Some of the emotions and characteristics mentioned in Powell and Ogle, (1985), are; anger, guilt, acceptance of differences, fear of being teased, unselfishness, jealousy, overinvolvement, understanding, embarrassment, pride, loss,

maturity, worry and loneliness .

If siblings are to develop strong relationships with each other the developmental stages and qualities children bring to a relationship at each stage must be considered. Young children cannot negotiate, so sharing and turn taking between siblings may not be a realistic goal. Similarly, being able to interpret someone's feelings is a mature skill and should not be expected of preschoolers (Strain & Danko, 1995). When young children do not have the appropriate social and language skills to deal with conflict their interactions will be directive (Newman, 1994). Yet Stoneman and Brody (1993), noted that in in home observations, siblings were very competent in selecting appropriate toys with which to interact when playing with a disabled sibling. Newman (1994) also noted that outward conflict which is to be expected among siblings, is probably due to the amount of time they spend together. Feeling that they have been involved in helping a disabled sibling to learn may help siblings to feel good.

Siblings usually provide each other with the first peer relationship. In the case of having a handicapped sibling this amount of time spent together may increase due to caregiving expectations and because the disabled sibling is unable to go out (McHale et al, 1984, Gath, 1974, Lobato, 1983). As Dunn, (1985), describes it, tension can increase in proportion to the amount of time spent caring for a disabled child.

It is unfortunate that siblings also reported feelings of guilt, almost always unfounded, and of remembering normal healthy arguments or of being jealous and then wondering if their siblings death or disability was a "punishment" for their anger. One young man reminisced about his childhood,

"I'd feel like yelling out 'Damn you! You're the cause of my being trapped and lonely. You've made life hard for me!' But I never did - out loud" (cited in Murphy, 1981 p112).

Yet others have stated that approximately half of the siblings interviewed believed that the experience of living with a sibling with disabilities had enhanced their lives in that they were more understanding, sensitive and appreciative of their good health and abilities than their peers (Grossman, 1972). Dyson (1989), also noted that brothers of disabled children exhibited fewer aggressive behaviours than other boys.

Understanding the Disability

To understand the role that a disabled sibling may play in family dynamics it may be necessary to go back in the family's history and to examine how the family found out about their child's disability and how they coped with the diagnosis in the beginning. If a child is born blind or with a syndrome the parents may know this at birth, and they may or may not have known of the handicap prior to birth. If a child is born with mental disabilities, is deaf, has learning problems or autism, the parents will likely not know that until the child is about two or more years old. They may have suspected something but have been thwarted in earlier attempts to have their child diagnosed by (usually) well meaning family members or family physicians who believe that the child will "grow out of it". If a child has a dystrophy or a mental health problem, the diagnosis may not be until he is five or more years old.

Much of the bereavement literature (Shapiro, 1994, Powers, 1993) is applicable to families with special needs children. Parents may find out about the disability and grieve the loss of their normal child at different

times in that child's development. The patterns described in the literature on bereavement; anger, denial and bargaining, are evident as the parents come to accept the fact of their child's disability. They then begin to fear for the future. Parents of disabled children often have to meet with a variety of professionals they had not known existed. When they do so they may be given equipment, programs, schedules and appointments. It might seem that they no longer know what is best for their child, for they have delegated that authority to a stranger, "an expert". They may be using all of their internal resources just to get through each day.

The diagnosis of disability can profoundly affect a parent's emotional adjustment. The other children in the family must sense the grief and concern of their parents and they may be loath to ask any questions. It has been postulated that this is because they do not wish to cause their parents more pain or distress (Burton, 1975). In the book "Siblings Without Rivalry", Faber & Mazlish (1987) described a meeting of adults where one mother talked about her anguish over the exceptional needs of her disabled son. Another participant at the meeting asked how her daughter was coping and the mother happily assured her that she had no concerns about her daughter who was a perfect child, loving, giving and helpful.

The participants all looked relieved except for one man, the brother of a disabled sibling, who snapped,

"I'm sure she is wonderful, but she shouldn't have to worry about being wonderful. It's not fair to her. She's a kid. She should feel free to make demands. She shouldn't have to tiptoe through her childhood in order to compensate for her brother's problem".

Parents in their grief may even have taught their children that they must live a life of “overcompensating” and may brush aside the needs of these children, “How could you even think about going to the movies when your brother is so sick!”(Faber & Mazlish,1987). The sibling may feel that it is inappropriate to have “wants”. It is as though that child does not deserve to have fun; he should be content to have his hearing/sight/health, or whatever it is that his disabled sibling does not have.

Those siblings who do not have adequate information regarding the etiology of the disability and the expected prognosis, may begin to wonder if they have the same disability as their brother or sister, or if they caused it. “I used to have nightmares that he died because I punched him” (cited in Schiff 1977). They know that their parents attend therapy sessions, doctors appointments and school planning meetings. They may even accompany their parents and the sibling with a disability - as far as the waiting room. They are not privy to the information discussed and are rarely included in planning. Perhaps by not including the siblings in the planning, their fears of what caused their sibling’s disability and of what they are expected to do in terms of care giving are intensified (Crinic & Leconte, 1986).

Family Inclusion in Meeting the Needs of the Disabled Child

Parents often complain in retrospect about how long it took before their child’s disability was adequately explained to them. They may feel that they were excluded from much of the professional discussion, either physically, because they were not invited to participate, or intellectually, because the “experts” used so much jargon to discuss their child while they were present. Children who have disabilities and who understand

their own diagnosis and have discussed it with professionals are uncommon. Their names are usually omitted from the invitations to their own program planning sessions. It must be even more rare when a sibling is valued enough to participate in these meetings. Yet these are the same children we cast in the role of “vice-president” of the family the one who will inherit the responsibility (Seltzer & Krauss, 1993).

The current philosophy is indeed that programs should be family centred - with the family and the professionals working as partners (Dunst et al., 1993). There has been a gradual evolution of this model: the traditional therapy model of parents attending clinics for appointments and professionals providing treatment in an “expert” fashion, grew into a family focused approach whereby families were given some service options and allowed to choose from those options. The current family centred approach emphasises the strengths of the families and is a consumer driven model in that the family decide what they need and the professionals help them to find the appropriate resources. While the case studies reviewed discuss the importance of family centred practice (Singer et al, 1993, Dunst, 1993), “family” seems to mean the parent(s) and disabled child relationship and to ignore the other children in the family. This is a cause for concern as the “normal” children are part of the family and their input and needs must be recognised and valued.

When examining how parents adjust to the birth of a disabled child and the impact on their marital relationship, Breslau,(1983) noted that having a child with disabilities can affect the emotional adjustment of the parents, who may have more arguments and disagreements: this is a risk factor in maternal depression. Howe, (1993) explains that in the

general population, depression in mothers impacts on the social adjustment of the children. Bristol et al., (1988) found that when spouses understood how much emotional and instrumental support they could give each other, there was greater adjustment to the birth of a child with disabilities. It would be logical to expect that the same would be true of siblings. We know that the subsystems within a family will affect one another (Belsky, 1984) so the quality of these interdependent relationships will be important in the development of positive attitudes between and among siblings.

Howe (1993) noted that reciprocity, giving and receiving within a relationship is an important issue among siblings. This can be an issue if the disabled child's handicap is severe as he may need a great deal of care and so there might be an overemphasis on attending to and overprotecting the sibling in the relationship. A child who may yearn for an equal relationship with his or her sibling may find instead that he is expected to be a miniature parent. On the other hand, Crinic and Leconte (1986) suggest that to older brothers and sisters, younger siblings with disabilities may not present as being so disabled, but may be regarded as babies.

Families can Cope with Stress; There can be a Positive Outcome

To live with a person with disabilities can cause stress across the age span (Crinic & Leconte, 1986, Featherstone, 1980). It is likely that there will be a developmental component to dealing with that stress as people can access different resources to assist them in coping according to their age. These resources which can help to alleviate stress are: 1) health - energy - morale, 2) problem solving skills, 3) social-network supports, 4) utilitarian resources and 5) general and specific beliefs

(Folkman et al., 1979).

Taking care of their children's physical health and encouraging them to participate in hobbies and extra curricular activities is the reality in North American culture. This is how middle income parents promote a healthy lifestyle and good self esteem in their children. It can be a problem when there is a disabled child in the family as the amount of time needed to care for this child and the extra financial burden as a result of paying for therapies and assistive devices, may impact on a family's ability to pay for extra curricular activities such as piano lessons or swim club memberships. This may affect the family members' health - energy - morale. Problemsolving skills may indeed help children to deal with stress, but problem solving is a higher level, more abstract skill. Young children who think in concrete, egocentric terms, usually do not have the cognitive or language ability to problem solve effectively. The opportunity to observe others problem solve can be an important learning tool, but when siblings of disabled children are excluded from the decision making and planning meetings, they are denied an opportunity to develop and practice that skill. The social-network of children are their school and neighbourhood friends. There are contradictory studies which show on one hand that siblings of disabled children have decreased opportunities to develop their social network because they are expected to assist more with household chores and care giving (Farber, 1959, Gibb, 1993) while on the other hand Stoneman et al., in a 1988 study, found that siblings of disabled children had as many friendships as other children.

Utilitarian resources, that is supports in terms of therapy, respite

time, special materials and devices such as walkers and communication aids, are available across the lifespan. In Canada accessing funding to pay for assistive devices is not means tested. In the United States, on the contrary, many families, particularly those in the middle income bracket, are ineligible for free services, because their income is too high (Moore, 1982). Even in Canada, the family pays a portion (usually 25%) of the cost of an adaptive device. Paying for these resources can have a severe financial impact on a family (Gibb, 1993). Some families may have had their belief system challenged by the the news that their child has a disability and counselling may help them to cope (Singer, 1993). Accessing this resource can impact on the quality of life for the whole family.

Parent to Parent and Sibling to Sibling

In a description of a parent to parent program (Santelli, 1993) portrays the parents of a disabled child as belonging to a minority group and of their need to meet other parents of disabled children. Just as their parents find this helpful, so can siblings. If parents explain that the most important resource and support is another parent who understands, then it is to be expected that siblings can enjoy and benefit from the opportunity to participate in a sibling group where they might receive emotional support. Gold's research (1993), on depression among boys whose siblings had autism, stressed the need that these siblings have to talk to peers about living in a different kind of family. As Summers, (1991), explains, sibling support groups are "logical extensions" of parent support groups and can be an easy and appropriate way to provide information to the siblings of disabled children.

By interviewing some siblings to determine their needs, topics can

be developed for the sibling support groups. One description of a sibling workshop (Chinitz,1981) identifies the need to cover topics such as the cause of the handicapping condition, the effects of this disability, the types of prognosis that can be expected, and the special devices and resources disabled children can receive. Grossman(1983) suggests that children might visit the program that their disabled sibling attends and Lobato (1985) suggests allowing the sibling to try out some of the adaptive equipment.

In their book, written for children, Living with a Brother or Sister with Special Needs, Meyer et al (1985), explain that participation in a group allows children to talk to others (who know what the experience is like) about their feelings and fears. While the difficulties of living with a person with different needs are recognised, so too are the positive aspects of growing up in a special family. They describe other siblings who share feelings of embarrassment, guilt, pride and many other emotions. They confirm that many siblings do not understand how or why their brother or sister has a disability and explain that talking to someone from a similar background can help people feel less lonely.

A study on the efficacy of a sibling support group for preschool aged children (Lobato 1985), which was held once per week for six weeks, found that the children were more knowledgeable about disabilities and that their verbalisations were more positive than they had been previously. A similar study, but using school aged children (McLinden et al.,1991) indicated that a six week group was somewhat effective in that the children enjoyed going to the group. The children also reported that they had more social support than a control group of children who had not attended. The mothers of the children who attended reported some

improvement in the behaviour of those children towards their siblings, but by their report there was no significant effect on their children's knowledge, attitudes, problem behaviours or self concept. The authors do caution, however, that the children's pretest scores in these areas were within normal limits, and some of the unpublished scales used to measure the children's knowledge, attitudes, problem behaviours and self concept may have been technically inadequate.

Another study indicates that sibling groups have been effective in helping brothers and sisters to understand more about the nature of their sibling's disability (Lobato, 1990) and participation in such groups has been associated with improvements in ratings of mood (Sahler & Carpenter, 1989). Children generally like to socialise in groups, and they can and have influenced each other when they have been involved in groups (Terr, 1981, Steward et al., 1986).

The vast majority of siblings express interest in participating in a sibling group (Wilson 1989), but Summers (1991) cautions that participation should not be mandatory as some children who were placed in a group by their parents actually reported less acceptance of their disabled siblings.

While there is the suggestion that a support group can be viewed as an alternative or substitute system of help when there is no other (Pearson, 1983), the purpose of the support group is to provide an opportunity for children to share common stories, to learn a little about some disabilities, to practice some problem solving skills and to have fun. Sibling groups are not treatment groups.

A support group for siblings of children with disabilities,

Sibshops, is described by Meyer & Vadasy (1994). The workshops described are generally offered monthly or bimonthly and usually in a series, such as five Sibshops meeting once per month.

In a rural community, where many families are involved in ranching and farming, it may be difficult for children to attend a series of workshops. The difficulties arise for the following reasons:

- 1) transportation; some of the participants may live over a hundred kilometers from the site of the workshop,
- 2) there is generally a small window of opportunity for farming families to commit to attending meetings in town and that "window " falls between harvesting and seeding, and not during calving; which leads to
- 3) weather, which during winter in rural Alberta can mean snowstorms and hazardous road conditions.

Due to these factors, it may be more feasible for those who live in rural communities to offer a single session, stand alone workshop. The facilitator may wish to invite children of similar ages, for example a group of 9-12 year olds might be invited. This range in terms of age is recommended because Gurney (1983) has suggested that children under the age of nine are not aware enough of their peers to be affected by their support and to realise sharing experiences with others who are empathetic can be powerful.

The focus must be on a few achievable goals. as single session groups must be if they are to be effective. As described by Meyer et al, the purpose and goals of a of a Sibshop are:

1. To provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.
2. To provide brothers and sisters with opportunities to discuss common

joys and concerns with other siblings of children with special needs.

3. To provide brothers and sisters with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs, and,

4. To provide siblings with an opportunity to learn more about the implications of their brothers' and sisters' special needs.

Procedure

The children can initially be engaged by involving them in a game which is interesting, and activity oriented (LeCray, 1987). The first activity must be one that the children can do independently, as they arrive, so that the facilitator(s) is free to meet the participants, to take care of "housekeeping" issues such as where bathrooms are situated, where coats can go and to ensure that parents know when to come back. A suggestion in the Sibshops manual has been adapted;

10:00 Facetags

Materials: copies of facial silhouettes, scissors, glue, craft materials such as pipe cleaners, puff paint, sparkles and feathers.

The children choose a silhouette and decorate it as they wish. This facetag is then attached to an already prepared nametag which the children can pin on to their clothes.

(Source: Adapted from Sibshops. Workshops for Siblings of Children with Special Needs, p. 107)

10:15 Introductory Activity

Materials: Strengths and Weaknesses activity sheet, pencils, lollipops

This activity will help participants to begin to think in terms of their sibling with special needs. At the same time it acknowledges that we all

have strengths and weaknesses and it gives participants permission to say both flattering and unflattering things about their sibling with special needs.

As a group discuss, in general terms, things that are strengths, that people do well. Ask the children if people who have disabilities also have strengths and talk about weaknesses, things that we do not do so well. The facilitator should share his/her own strengths and weaknesses with the group. The children can then each be given a lollipop (for eight children have two each of four colours, for ten children have two each of five colours) and with their partner who has the same colour they should, using the attached activity sheet, interview each other on their strengths and weaknesses and the strengths and weaknesses of their brothers and sisters with special needs. The children spend approximately five minutes on this activity and when they regroup the participants introduce their partners and describe their partners' and partners' siblings strengths and weaknesses. At this time, as the children are being introduced, they should be asked if they know the name of their sibling's disability. Common experiences can also be explored, e.g "Does anyone else have a brother or sister who uses sign language?". (Source: Sibshops. Workshops for Siblings of Children with Special Needs, p.111-112)

The next three suggestions are cooperative activities. The purpose is to involve the children in a fun relaxing way.

10:40 Blob Tag

Materials: None. Will require a large gym or playground area.

One person is It. When It tags someone, they both become It. They hold hands and go after a third. The three, holding hands, go after a fourth, and so on until all players except one are It.

(Source: The New Games Book, p. 107)

10:55 Mutual Monsters

Materials: A sheet of letter size paper and pencils/crayons/markers for each person.

Directions: Distribute paper and pencils and have participants fold their papers in thirds. On the top third, everyone will draw the head of a monster, person, animal or creature. The children should extend the neck a little past the first crease in the paper. Then they should fold the paper so that the head is hidden and pass to a neighbour, who draws a torso and arms, this time making the waist go a little past the second crease. Now they should fold the paper and pass it along again to have the legs and feet added. When all the pictures are complete, they are unfolded and shared with the group.

(Source: The Incredible Indoor Games Book, p. 94)

11:10 Scrabble Scramble

Materials: 62 sheets of construction paper and a black felt tip marker.

The sheets are in two piles, each with a letter of the alphabet on it plus an extra set of vowels, 31 sheets in each pile.

Directions: The children are divided into two groups, then sent to stand

at one end of the gym. At the other end of the gym, the two piles of alphabet papers are stacked. A facilitator will call out the name of a category, e.g. food, television shows, animals. The teams then try to determine a word that will fit that category. They then run to the stack of letters, and pick up what they need, then run back and, each holding one letter, they arrange themselves in proper order. If there are more children than letters in the word, the others can help to arrange their team. The first team to spell a word is awarded a point for each letter. The team with the most points after all the rounds wins.

(Source: The Outrageous Outdoor Games Book, p. 56)

Lunch preparation will be an opportunity for the participants to chat informally. Some topics related to their siblings may arise incidentally and the facilitator should note areas which the children may want to discuss further. The following menu is suggested because it offers ample opportunity for all to be involved in the preparation.

11:30 Lunch Preparation

Giant Submarine, fruit and juice.

Ingredients

Two six foot submarine buns

Medium cheese (in blocks)

Summer sausage

Sliced chicken

Lettuce

Alfalfa sprouts

Tomatoes

Cucumbers

Green peppers

Carrots

Hard boiled eggs

Mayonnaise

Mustard

Apples

Oranges

Grapes

Juice boxes

Equipment

Cheese graters

Bowls for chopped ingredients

Cutting boards

Blunt knives

plates

Napkins

Clean up equipment

In the kitchen all the children will gather around the large table and be offered a chore, e.g shelling eggs, grating cheese, chopping tomatoes, quartering oranges. Then the prepared food can be put in bowls and each child can go around the table building his or her own submarine sandwich. During the preparation of lunch, photographs could be taken of the whole group and developed at a One Hour Photo Developing Lab. so that at the end of the day each child could then have a group photo signed by all the participants, to take home.

Following lunch, everyone should clean up together.

12:20 Disability Awareness Session

At this time, information about a specific disability should be discussed. It may be appropriate to focus on one particular disability, or alternatively, hearing aids, wheelchairs, walkers and/or supported seating might be borrowed so that the children can try using them. Books which describe disabilities can be shared. Following are some titles which are particularly recommended:

Leo, The Late Bloomer. R. Krause. New York: Dutton, 1973.

Lisa and Her Soundless World. E. Levine. New York: Human Science Press, 1974.

Princess Pooh. K.M. Muldoon. Toronto: General Publishing Limited, 1989.

My Brother Matthew. M. Thompson. Rockville: Woodbine House. 1992.

1:00 Dear Aunt Blabby

Materials: Letters to Aunt Blabby in individual envelopes, addressed to Dear Aunt Blabby . Examples follow.

Directions: Ask the group if they know what an advice columnist is, and if they think that advice columnists know everything. Ask if they know what an advice columnist would do if she did not know the answer to a question. What do the children in this group think that they are experts about? When it has been established that the participants are experts on being the sibling of a person with special needs, the letters are held out and the children are invited to choose one and read it to the group.

When the participant has read the letter, the group are asked for advice on what "Perplexed" should do, and the responses of the participants are challenged in a positive manner, e.g. "What might happen if Sleepless did that?". After each letter has been discussed, the helpful answers should be restated.

(Source: Sibshops. Workshops for Siblings of Children with Special Needs, p.124.)

Dear Aunt Blabby,

I don't know what to do. My little brother Mark has lots of problems learning. In September, Mark started going to my school. Some kids at my school make fun of the special education kids. I even heard them call my brother names and laugh at the things he does. Aunt Blabby, what should I do?

(signed)

Perplexed

Dear Aunt Blabby,

My little sister is deaf. Our whole family is learning sign language. It is fun to be able to talk a secret language! But I feel funny about using signs when I'm with my family in the mall or something. Sometimes kids make fun of us. They will flap their hands or make weird noises. Even adults stare at us sometimes and use words that are wrong like "deaf and dumb." Mom tells me I have to be polite to adults. How can I tell them to use the right words without sounding rude?

(signed)

Kid Teacher

Dear Aunt Blabby,

My brother always wants to play with my friends and me. He can't hit the ball. He can't catch the ball. He doesn't understand the rules. My friends get mad. This is more than I can take!

(signed)

Caught Between

Dear Aunt Blabby,

My sister who has Down syndrome never gets punished like me. My mom is unfair and gives in to her moods and stubbornness too much. What can I do?

(signed)

Miss Treated

Dear Aunt Blabby,

My sister doesn't get asked to friends houses or birthday parties like I do. She gets mad at me or Mom when I get to do something she can't. What should I do?

(signed)

Need a Life of My Own

Dear Aunt Blabby,

When my sister does not understand something in school, the teachers come to me to get some help. I feel sorry that my sister is having such a hard time, but can't they deal with it? How can I get the teachers to stop coming to me?

(signed)

Not My Job!

Dear Aunt Blabby,

My sister is driving me nuts. Melissa is four years old and has Down syndrome and everybody thinks she is so cute. Wherever we go, it's Melissa this and Melissa that. It's like I'm not even there! What can I do?

(signed)

Look at Me Too!

Dear Aunt Blabby,

Is it O.K. to tease your sister? I mean, I tease my other brothers and sisters, but when I tease my "special" sister, my grandma yells at me. I'm not doing it to be mean or anything - it's just teasing. Is it O.K. or not?

(signed)

To Tease or Not to Tease

Following the above quieter, more reflective activities, the children may need to participate in a game which involves a lot of noise and movement!

1:30 Pushpin Soccer

Materials: Inflated balloons (about two per player), two pushpins, masking tape which has marked off a goalie box.

Directions: Unlike regular soccer, the goalies do not come out to defend the goals, they score points for their team by staying in the goal box and bursting with a pushpin any balloons that come over the line. The children are divided into two teams, then each team chooses their goalie. The goalie can change throughout the game. A balloon is thrown into the middle of the court and the teams try to swat it with their hands towards their own goalie. No one is allowed to reach into the box and the goalie may not reach out.

(Source: More New Games, p. 69)

1:45 Time Capsules

Materials: Slips of paper with various "times" written on them, e.g. a time when I was really proud of my brother or sister, a time when I really was embarrassed by my brother or sister, a time when I helped my brother or sister in a special way, a time when my brother or sister made me mad, a time when my brother or sister made me laugh, a shoe box that is decorated to look like a time capsule, some film canisters to hold each slip of paper.

Directions: The children select some of the capsules, open them and

(Source: Sibshops. Workshops for Siblings of Children with Special Needs p. 122-123.)

1:55 Closure

Ask the children what they will tell their friends they did today. Ask what activities, speakers and food they might like to have at another meeting. Give each child a group photo pasted on construction paper so that they can have each other sign it and exchange phone numbers if they wish.

Summary

When a child with a disability is part of a family, there can be additional stress on the interrelationships of the parents and siblings. Some families find that their lives are stressed, some find that their lives are enhanced. The review of the literature indicates that participation in a support group might assist siblings in dealing with negative feelings while promoting their self esteem and sense of belonging. Information regarding how to organise such a group is provided.

Future research should investigate the effectiveness of sibling support groups. Through the collection of narrative data, the role of sibling support groups in 1) providing information to siblings of disabled children about different disabilities could be assessed and 2) the effect of increasing the social network of these siblings by introducing them to other siblings could be determined.

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Appendix

Information to present to groups such as parents, teachers, counsellors, and child and youth care workers.

WORKSHOP: SIBLINGS OF CHILDREN WITH DISABILITIES

Prior to the workshop make a coloured name tag for each person. Put a sticker on each name tag that depicts a sport, e.g. a soccer ball, a baseball bat. Around the room there should be flipchart paper taped to the wall and above each piece of flipchart paper, have a circle of coloured construction paper, one of each colour used for the nametags.

When the topic of siblings is discussed, many people have personal experience and can share stories about their own siblings. To introduce the topic of siblings, the group should divide into smaller groups according to the colour on the name tag.

Each person in the small group should record the answers to these three questions.

- 1) What would your sibling do if he/she won \$25,000 on the lottery
- 2) What would your parent(s) say he/she would do
- 3) Describe your relationship with your sibling.

As the participants are talking and writing, the facilitator should go around the room, giving each group a lottery ticket. The group may scratch the ticket when they have finished recording their comments. When everyone has returned to their seats, the person who scratched the lottery ticket in each group is invited to share the information that group recorded. A few people will have commented that their parents

perceptions and their own are different.

The words in bold type should be on a flipchart or overhead.

OUTLINE

1. **Sibling relationships** when there is a disability involved. (This will include insights from siblings themselves).
2. **Family** focused/ family directed **intervention**. (Who is presently included in the Individual Program Planning meetings and in delivering the various therapies, i.e. current practices and some information about the knowledge and skills that siblings have).
3. **The logical extension** - (how to provide information, problem solving skills and support to siblings. Why this program might be valuable and how to do it).

Helen Featherstone wrote a wonderful book, A Difference in the Family, (1980), which she hoped would build bridges and link families to each other. She felt that as a mother of a disabled child her family was different from other families only in degree.

She described how brothers and sisters, in her experience, were more uncertain than their parents about the nature, the extent and the implications of the disability. She found that her other children had some misunderstandings such as thinking that they might "catch" the disability. They had concerns about their future - about their own responsibilities for their sibling, and about having to find a partner who would be willing to share that responsibility. They also had concerns about becoming parents - would their children have disabilities?

When she talked to her children and to other siblings, Featherstone found that some children were angry because the handicap was a complicating factor in any natural annoyance, e.g. the deafness might excuse some mischief, "She didn't understand....".

There was also the additional trial to all children, and that is that outside their families, among their peers - they want to fit in - to be just exactly like everyone else. They want their parents to have "normal" jobs. They want to live in a "regular" house. They do not want their family to look or act differently from other families - and that special sibling may cause their family to appear different. Children are conformists, outside the home. Inside the home, however, that is different. Within their family, children want to hold a unique place - they want to be special. That is where having a disability can confer a certain advantage - Helen Featherstone (1980) calls it a passport to special attention, recognition and privileges. Inside the home, a disabled child may hold, or be perceived to hold, that unique place.

If a search of the literature is undertaken, little can be found in the educational journals about this topic. If the search is expanded to include counselling magazines, social work journals and psychiatry periodicals there is a wealth of information.

When those articles are read the indication is that it is a tremendous burden to grow up in a family when one or more of the children has a disability. There is great stress on the siblings and they are all very resentful. Even the titles of the case histories are depressing; I Get Upset When I See the Kids Playing with Jimmy, When I Grow Up I'm Never Coming Back!, Jerry Got Lost in the Shuffle and I'm Not Going

to Be John's Babysitter Forever, (page 122 Klein and Schleifer, 1993).

Yet others have stated that the experience of living with a sibling with disabilities has enhanced their lives in that they are more understanding, sensitive and appreciative of good health than their peers (Grossman, 1972). It is evident that in those journals the case studies must have been written about clients, people who were seeing the psychiatrists, social workers and counsellors for therapy. There is a video, made by The Autism Society of British Columbia, (produced by Jeffrey Groberman) which invites some siblings to describe their relationships.

The video clip shows a young man describing how he cannot imagine life without his brother, then a little girl explains how she sometimes gets jealous, then the young man is seen again, describing how living with his autistic brother has made him wise, caring and open minded.

Research on regular sibling relationships indicates that children can have ambivalent feelings about their brother or sister (Dunn,1985; Furman & Buhrmester,1985). Looking at the charts of the feelings the participants described might corroborate that. In their 1985 study, Wendon Furman and Duane Buhrmester interviewed forty-nine 11 - 13 year old boys and girls about their sibling relationships. These children were not brothers and sisters of children with disabilities. The initial interview was in an open ended format and they elicited answers to questions such as "Tell me as many good things as you can about your relationship with [name]". From these interviews they derived a list of relationship qualities. They then used this list of qualities to develop a self reporting rating scale and this was administered to one hundred and

ninety eight 11 - 13 year old boys and girls. They wanted to assess the children's perceptions of their relationship with their siblings.

The four factors which emerged were:

(This should be on an overhead or flipchart)

- 1) warmth/closeness,**
- 2) relative status/power,**
- 3) conflict and**
- 4) rivalry.**

They found that same sexed dyads, that is two sisters or two brothers, more often reported feelings of warmth and closeness than did opposite sexed dyads. They also found that the highest levels of conflict were reported by siblings who were close in age, but when the siblings were separated in age by a few years then the younger sibling did not resent the relative status and power of the older sibling and in fact expected power differences because of age differences. They noted that conflict and rivalry were sometimes associated with perceived parental partiality, yet the children were reluctant to discuss this even though they were willing to discuss other negative aspects of their relationship. That is reminiscent of those TV show comedians, The Smothers Brothers, one of whom used to say, "Mother always liked you better!" Many people will share that when they were growing up, they entertained the thought that they were adopted. Perhaps that was because they perceived parental partiality.

Earlier it was noted that Featherston described, the difference in the family as one of degree. If that is the case then brothers and sisters of disabled children should also perceive feelings of warmth/closeness,

relative status and power, conflict and rivalry, but perhaps at a more intense level.

Most parents would deny that they treat their children differently, but an anecdote to share is the story of Melody. Melody and her older sister, Hannah, attend the same daycare, but they are housed in different buildings. Melody has been diagnosed with Pervasive Developmental Disorder (PDD). One day when the daycare teachers were all outside together with the children, Hannah's teacher commented that it must be very difficult for Melody's mother to cope with her extreme hyperactivity as she seemed to be a very stressed Mom. Hannah's teacher went on to explain that the staff always had Hannah dressed and ready to leave before her Mom came so as to avoid any conflict between them. Melody's teacher was astonished. When Mom came to pick up Melody she was endlessly patient and calm, in fact to the point that she imposed no structure on the child. Both teachers went so far as to check that they were talking about the same Mom. From their discussion it seemed that Mom's expectations of Melody were so minimal, that she excused all inappropriate behaviours. On the other hand, she needed Hannah to be a model child, so that she could cope with Melody.

Are siblings of disabled children treated differently by their parents? Are the expectation different than they would be in a family without that "difference"? That daycare scenario is similar to one recounted in the book "Siblings Without Rivalry", (Faber & Mazlish 1987). A meeting of adults is described where one mother talked about her anguish over the exceptional needs of her disabled son. Another participant at the meeting asked how her daughter was coping

and the mother happily assured her that she had no concerns about her daughter who was a perfect child, loving, giving and helpful.

The participants at this meeting all looked relieved except for one man, the brother of a disabled sibling, who snapped,

“I’m sure she is wonderful, but she shouldn’t have to worry about being wonderful. It’s not fair to her. She’s a kid. She should feel free to make demands. She shouldn’t have to tiptoe through her childhood in order to compensate for her brother’s problem”.

There are other examples of children describing feelings of warmth, anger, caring, embarrassment, pressure and pride. A tape of brothers and sisters talking at the Autism International Conference in Regina in 1995 records some of those feelings. The children describe being embarrassed when friends visit, and coping with guilt when they feel they are not doing enough to help their parents with the disabled child. Video excerpts of brothers and sisters talking also explain some of the feelings of pride and of the opportunity to become a more understanding and mature person..

When the participants shared stories earlier regarding their feelings towards their siblings, some of the stories were similar to those from the tapes. Sisters do describe their brothers as nerds. Brothers complain that their sisters annoy them. Many refuse to walk to school together in case someone thinks that they are related, or worse, friends. Teenagers often complain when they are asked to babysit younger siblings. These comments are rarely considered to be cause for concern. Most parents know that other children say the same things. Most

siblings have heard their friends say the same things. When a brother has a disabled sister, however, is that child free to complain, tease and irritate his sister? Would his parents condone it or would they expect him to be more tolerant because of his siblings handicap?

Family focused or family centred intervention

At this point, the participants should regroup according to the sport sticker on their nametag, so the soccer balls should go together, the baseball bats should go together etc.

Small group activity: go to the chart paper that shows your sport and brainstorm together the answer to the following question: What is the **current practice** - who are involved in your Individual Program Planning meetings and in your intervention with a disabled child?

When the participants have finished listing all the people who are normally included, read aloud the names they have written , e.g. speech and language pathologist, parents, physiotherapist. Comment if any have included brothers and sisters in their lists.

Play the audiotape, from the Autism International Conference in Regina, which describes two siblings sitting in the waiting room while their parents discussed the brothers program. The siblings felt that they knew more about what their brother could do than their parents did.

Siblings can be a wonderful resource, they may be the ones who can best encourage change in a disabled child. They are very capable of finding appropriate activities, and will likely have more experience than anyone else of playing with their disabled brother or sister, as theirs has probably been the first peer relationship for that child. Sometimes, unfortunately, their information is not believed.

A video tape called "What About Me?" (produced by Barbara Turk), shows two children describing that their respective siblings can do things that they choose not to do when a parent is present. A mother then explains that her children tend to think that their disabled sibling is more capable than she is.

Have the participants choose a surprise ziploc bag from a large container. Inside each ziploc bag is a child's party favour, such as a windmill, a whistle, a toy watch. There should be sufficient of each favour so that the participants can be in equal groups.

As a concerned adult we may want to help these brothers and sisters to understand that they are not alone. As a parent or a teacher, it is possible to provide support just by being present for the siblings, and by letting them know that their feelings are normal. Another method of doing this might be to bring the children together with other siblings of special needs children. Many parents have shared that the single best thing that happened to them was meeting another parent - so the logical extension of this might be to arrange an occasion that could bring the siblings together.

If activities for a group of children were to be arranged, for example, for a party, some running around, some food, some quiet activities and perhaps some craft activities would be organised.

Participants should go into groups, based on the party favours they have selected.

Each group should design four activities for a sibling workshop they would like to organize. The activities will include:

- 1. an icebreaker/introduction type of activity**
- 2. a game**
- 3. a cooperative food activity, and**
- 4. an activity to get children talking to each other.**

Following this the groups are asked to share their workshop.

Summary

A review of the literature indicates that sibling groups have been effective in helping brothers and sisters to understand more about the nature of their sibling's disability (Lobato, 1990) and participation in such groups has been associated with improvements in ratings of mood (Sahler & Carpenter, 1989). Children generally like to socialise in groups, and they can and have influenced each other when they have been involved in groups (Terr, 1981, Steward et al, 1986). The intention in offering a sibling support group is that as they socialise, these children will develop a network of peers with whom they can problem solve, and that they will be involved in activities together where they can learn about disabilities.

A study on the efficacy of a sibling support group for preschool aged children (Lobato 1985), which was held once per week for six weeks, found that the children were more knowledgeable about disabilities and that their verbalisations were more positive than they had been previously. A similar study, but using school aged children (McLinden, Miller, Deprey 1991) indicated that a six week group was somewhat effective in that the children enjoyed going to the group. They also reported that they had more social support than a control group of children who had not attended. The mothers of those children who attended also reported some improvement in the behaviour of those children towards their siblings.

As teachers/parents/counsellors, perhaps we will find that these siblings can be a valuable resource to us, and maybe we can try to reach out to some of those children who have had the unusual opportunity of growing up in an exceptional family.

(Overhead projector)

Siblings of Children with Disabilities

Outline

1. Sibling Relationships
2. Family Intervention - Current Practices
3. Information and Problem Solving
4. The Logical Extension

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