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ABSTRACT

Extended quotations from informal interviews with eight families focus on the experiences of parents in adjusting to life with a handicapped child. In the first part of this paper, seven interview questions probe the following issues: positive and negative experiences with other people's reactions; most and least helpful actions by others; effects of the child's disability on the family (social, emotional, financial, professional, marital); and type and degree of support offered by the spouse. Subsequent sections present brief quotes from parents organized under the following titles: "Tips for Educators," "Kudos to Educators," "Tips for Parents," and "Attitudes and Sayings to Avoid." Among recommendations for teachers are to treat parents with respect, avoid conversational cliches, and recognize that parents are experts about their children. (JW)

THE RUBBERBAND SYNDROME:

Family Life with a Child with a Disability

Developed by Deb Brower for "The Parent-Educator Connection" Project, Iowa Department of Public Instruction and Virginia K. Wright for the Nebraska Parent Training Grant, Nebraska Department of Education.

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INTRODUCTION

This monograph was developed for the purpose of sharing very sensitive information about families who have children with disabilities. The families interviewed in this monograph are special people. They aren't special because they have children with disabilities, but because they were willing to talk about issues and emotions that have caused them pain. They shared this information in the hope that if parents and educators know each other as people first they will be able to work together more effectively for children. This information is a good start.

Deb Brower

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INTERVIEW QUESTIONS

LOOKING BACK AND THINKING ABOUT HOW PEOPLE HAVE REACTED TO YOUR DISABLED CHILD WHAT IS THE WORST EXPERIENCE YOU CAN REMEMBER, PERHAPS IT WAS SOMETHING SOMEONE SAID?

WHAT WAS THE MOST COMFORTING THING SOMEONE DID FOR OR SAID TO YOU?

WHAT WAS THE MOST HELPFUL THING SOMEONE DID FOR YOU?

WHAT WAS THE LEAST HELPFUL THING SOMEONE DID?

HOW HAS YOUR CHILD'S DISABILITY AFFECTED YOU AND YOUR FAMILY SOCIALLY, EMOTIONALLY, FINANCIALLY, AND PROFESSIONALLY?

WHAT EFFECT HAS YOUR CHILD'S DISABILITY HAD ON YOUR MARRIAGE?

WHAT DO YOU FEEL YOUR HUSBAND OR WIFE HAS DONE TO OFFER SUPPORT?

THE RUBBER BAND SYNDROME: FAMILY LIFE WITH A CHILD WITH A DISABILITY

Families of children with disabilities are faced with a unique experience, one that thrusts them into a cycle of adjustment that continues throughout their entire lives. Most families have control over some of the adjustments, but other factors are beyond their control.

A series of interviews was conducted with eight families to better understand the adjustment cycle. The interviews provide ways in which educators might assist parents at different stages of the adjustment cycle. Parents were asked to respond to questions about ways in which educators, friends, and spouses can and have assisted. Special attention was given to the spousal relationship and how each partner is affected by his/her child's disability.

The eight families who were interviewed varied in their socio-economic, educational, religious, and professional backgrounds. Children of the families range in age from 3-25 and have mild to severe disabilities. Some of the families were large, others small.

How do educators affect the adjustment cycle? How are educators affected by the parents' stages of adjustment? The belief exists that a family's ability to make adjustments can be greatly affected by their educators. The thought is, the emotional state of the family significantly affects the relationship of parents and educators and their combined ability to effectively plan for the education of the child. Parents interviewed agree with this.

Educators have expressed feelings of helplessness and frustration when they work with parents. The stress, strain, and day-to-day parenting of a child with disabilities are sometimes difficult to describe. It is hard enough to provide support when parents are able to identify the need and ask for support. Providing support becomes even more difficult when a family cannot articulate the need or find individuals to assist them. Educators need guidance on how to respond, what role they can play in a family's adjustment cycle, and to recognize their own skills and limitations as helpers.

One of the most dramatic realizations for families is how powerful words are. Most families have an experience or statement made to them about their child with disabilities that they will _never_ forget. Many of the statements negatively affected the family, even though most comments were believed to have been given to offer comfort. People seem to have difficulty knowing what to say or how to be helpful. In addition to what people said to parents, it is what they don't say or how they look at them that negatively affects them.

Parents report many positive experiences which emphasizes that most educators provide support and understanding, and did indeed say and do "the right things." While there are no 'pat' responses there are things that most parents identify as appropriate, helpful or comforting. A strong message conveyed was that it doesn't take what might be viewed as great acts or deeds to provide comfort. What it takes is sensitivity: to know that someone is hurting and to know when no words are needed.

Exhibiting respect and being receptive to what parents have to say about their children is essential. Small things make a big difference.

A common thread is educators can and have played a significant role in providing support to families. Parents look to educators for support.

A sincere thank you is extended to the individuals who agreed to share their experiences. Their responses are sensitive, frank, and insightful. The questions elicited feelings and experiences long buried for some yet, still fresh for others.

LOOKING BACK AND THINKING ABOUT HOW PEOPLE HAVE REACTED TO YOUR DISABLED CHILD WHAT IS THE WORST EXPERIENCE YOU CAN REMEMBER, PERHAPS IT WAS SOMETHING SOMEONE SAID?

> "There have been many bizarre, negative experiences with Rick for some reason, an Easter holiday right after Rick was officially diagnosed stands out in my mind. It was the first time we had been together with my husband's 'large family.' The topic turned to Rick and 'his problem.' The general consensus was that it must have been something we (my husband and I did)--not things like hurting him, but things like not lying him down on the floor on a blanket and allowing him to develop. I left in tears not to return to a family gathering for months. We never had an apology from anyone either."

> "The day the classroom teacher and learning disabilities teacher called me to a meeting and told me my child could no longer function in a regular classroom."

> "So many people said, 'I'm so sorry.' We were still excited about Stephanie's birth and people were sending condolences. We even received sympathy cards from people instead of cards of congratulations."

> "When we were told there was nothing we could do about our daughter's disability. The doctors were very evasive, vague and seemingly disinterested in what we felt as parents..."

> "One of the worst experiences was when I took Susan to McDonalds for lunch. I fed her lunch at the hospital and then pushed her to McDonalds for my lunch and ice

cream for her. At the time, she was unable to hold her head up, drooled constantly, was restrained with chest and lap restraints and was not able to make eye contact. The McDonalds was very busy and it was as if the Red Sea parted in front of us as we walked through. Everyone stared, jumped to get napkins, spoons, etc. They couldn't understand why someone like Susan was eating out."

"The worst experience would be the latest experience. What I mean to say is it is an ever evolving process. With age comes change. At birth, we found out who our true friends were. At seven or eight, people started staring because of physical differences. Now, people stare at and avoid him and us to some degree."

"The day it was decided Brad needed residential treatment (after three years) and they wouldn't provide it because my husband wouldn't agree to it."

It is often a revelation to parents that no one is exempt from having a child with disabilities. A family's socio-economic status, professional status, educational background, religious affiliation, social status and level of community involvement has no influence on a family having a disabled child.

The severity of a child's disability alone does not determine <u>how well</u> a family accepts and adjusts to the child's disability. The adjustment cycle is affected by many factors: the way in which the information was delivered, the family's financial status at the time the disability is identified, how stable the marriage is, what kind of emotional support is available from family and friends, how secure an individual feels about him/herself, how many other children there are, the state of their spirituality, and countless other factors.

WHAT WAS THE MOST COMFORTING THING SOMEONE DID FOR OR SAID TO YOU?

"We were comforted by many. When people said, 'If anyone can handle this, you can,' we took it as a compliment."

"My best friend had a child with Down syndrome. She just put her arms around me."

"A friend brought lunch to my home on a day that I learned the self-contained classroom my daughter was to be placed in had no room for her. My friend let me cry and be sad, but she was there, and I knew someone cared."

"A close friend I had would just listen. She would never say 'I know,' but just be there, plus she would watch Rick for me."

"Uncle Doc and Auntie Joy who had a profoundly involved daughter set a parental/familial example as to how to incorporate our daughter into our family. And, to not let others' views, pity or sympathy detract us from being loving and caring parents."

"The most comforting thing was people in general--not actions or words so much, but their attitudes and their calmness."

"The most comforting experience was when people shared their faith and reminded me that God gives the strength needed to deal with problems."

"Placement in residential treatment for my son after eight years."

WHAT WAS THE MOST HELPFUL THING SOMEONE DID FOR YOU?

"A psychologist that we worked with was the most helpful. He helped us with the school and gave us advice."

"There have been a lot of positive times too...listening by friends and listening and finding resources for us by our educational consultant."

"Dr. Paulette Hanna from a Rehabilitation Institute in Chicago said we must treat our child as we would any other child--that she will develop and do things 'normal' children will do only she will do them somewhat differently."

"The most helpful thing someone did happened after Susan was out of the intensive care unit. A nurse caring for her was on one side of the bed and I was on the other. It had become my habit to whisper to Susan, 'come on baby, wake-up, you can do it, you're a fighter and it's time to start fighting.' The nurse turned to me and said, 'Don't you understand, if she wasn't trying and fighting she would be dead.' I never said that again. I think the reality of our situation had become real to me."

"A person informed us of our rights under the law. We were also given directions on how to find the most appropriate program for our child."

"The most helpful thing someone did for me was listen to my feelings."

WHAT WAS THE LEAST HELPFUL THING SOMEONE DID?

"Not listening to me about my son's problem. I always thought Brad was hyperactive. No one would admit that; instead they would call his behavior everything else, but not hyperactive. No one believed me."

"The least helpful experience was refusal on the part of school and others to acknowledge his problems."

"Being ignored simply because we are parents of a child with a handicap. This non-acceptance is one of my most frustrating problems."

"Those who said things like 'well, it's probably best. If she hadn't been hurt this way, she'd probably be into drugs or worse.'"

"A few hours after Stephanie was born we saw our neurosurgeon and he could not look us in the eye. Also, everything he said was negative. ...and it really made me angry."

"The least helpful things for us were the multicategorical classrooms our daughter was in."

"The least helpful were people who tried to tell us: 1) how bad we have it and, 2) how it could be worse...

"Professionals telling us what we already knew about our daughter in reference to her physical disabilities. Also telling us as parents there was nothing we could do to change how our daughter may potentially maximize her potential."

Many parents identify their worst experiences as those times when educators didn't give them credit for what they knew about their child. Parents also express years of frustration because educators would not 'listen' to them about their child and would eventually arrive at a diagnosis that parents had suspected and tried to share for years.

Parents say it is not helpful when people made statements about "how bad they have it" or marvel at how "they handle it." Most parents of children with disabilities don't want to be singled out as 'martyrs' or as 'special.' The common response made when parents were asked "How do you do it?" was "You just <u>do</u> it and you are not more special than anyone else because of it." Families interviewed indicated that they were not comfortable being viewed as special because they are parents of a child with disabilities.

HOW HAS YOUR CHILD'S DISABILITY AFFECTED YOU AND YOUR FAMILY SOCIALLY, EMOTIONALLY, FINANCIALLY, AND PROFESSIONALLY?

"Naturally, we went through a similar kind of grieving process that other parents of handicapped children do. I am glad educators in the field are finally beginning to recognize that grieving is recurrent and occurs especially during developmental milestones in a child's life. This is something we parents have known for a long time despite the occasionally aggravating urging of 'social work types' to 'just deal with it and get on with life'."

"Financially, Brad has never caused us a problem because we were never in a position to pay for services he received. Socially, we were affected because so many times others were so upset with his behavior that we couldn't go back. Emotionally, we were very affected. There was constant turmoil between my husband and myself. We were always at each other. Brad contributed to our problems and we contributed to his. My husband blamed me for our son's behavior. He felt I was too hard on Brad, that I picked on him, and that I didn't give him a chance."

"Socially we were affected by the loss of some of our friends. We were hesitant to bring others into our home and were unable to function in some family activities due to our son's physical disabilities. Emotionally, I was affected by a loss of self confidence. Financially, our medical expenses increased and life insurance was difficult to obtain. I feel my job choices have been limited due to family demands because we have a child with disabilities."

"Emotionally, the effect is ongoing. It seems that one of us (my husband or myself) is always going in or out of the grief cycle. The family is very much affected emotionally. Financially, I don't feel our child has affected us much. Professionally, as a father, I don't feel it has affected us adversely as a family. I did leave a job for a better school or learning possibilities for our disabled child. Our child could limit my advancements, literally, because of the school system he is now enrolled in."

"Socially, we have fewer close friends. More friendships are flexible. Some of our very close friends and family too, for a time, almost dropped out of our lives. I think we have grown away from people too. . . our attitudes have changed. It makes us hard to be around. Emotionally, Susan has been a drain on all of us. It was especially hard on her younger sister. Professionally, I guess it hasn't changed our lives from what they would have been except for the statewide connections I've developed because of it. ...our attitude toward family, community, and community responsibility has changed."

"We didn't change our activities. Emotionally, Stephanie made us aware of others. We are more aware of our responsibilities as the parents of a disabled child. Our picture of parenting has been altered. Our commitment is more long term. Financially, insurance is always an issue and a constant drain for us. We have worked hard to put ourselves in a position to <u>not</u> feel bitter. This affects our entire family. We do feel it was part of God's plan and we do have a healthy acceptance of that and a good medical understanding. Professionally it has limited my (father's) job possibilities because we are very aware of school differences and we don't want to lose a good program. We could potentially lose our insurance if we move. We no longer consider an increase in pay as the significant factor for job change. There are many other factors that are important such as the flexibility I have."

"Professionally, it has stimulated a special interest in male issues and how stereotypes and sociocultural beliefs negatively affect the quality of male health from a wholistic perspective."

"Professionally, whether or not you have a Ph.D or a pilot's license, when you are the mother of a handicapped child, this appears to be the major way in which others view you. Fathers do not have the same problem."

"Socially, we have b [illegible] ffected when on rare occasions we have not gone to a [illegible] tion because it was difficult to keep track of our c [illegible] r or she would be overly excited. Emotionally, I think we have been affected the hardest. There have been a lot of lows and highs, tears, anger, and frustration. I have tended to be less patient with my children because of the constant demands of a learning disabled child. I've been less patient with friends and other people. I tend to think their concerns seem trivial and unimportant. Financially, it has not been too difficult. We have had to pay for medication and private medical fees for a psychologist. There have also been expenses for tutors and summer school tuition."

"Our daughter's disabilities have allowed me to become more appreciative of my physical abilities--to run, jump, talk. It has also given me the opportunity to express my emotions, to ask for help with my inability to be emotional and express my emotions. Socially it has limited the scope of activities in reference to my wife and me doing things close and this is no different than having a non-disabled child. The introduction of children into a family system creates chaos and a need to reorganize."

"Socially, we have been limited in how and where we go and who we choose for friends (love me love my child), how long we can be gone, the number of times we can go, how many can go, and what the weather is like. Many things my husband and I have to do together instead of just with me or just with Roger because, at present, its lots easier with two to help. Emotionally, it's hard watching other families, dealing with our own emotions let alone other relationships (husband/wife, father/son, mother/son). Certain words trigger emotion, e.g. deformed, abnormal, spas. It seems like the highs are higher, that lows are lower. Financially, we are stuck with certain medical insurance, medical equipment, medication, missed work, a van for transportation (with lower gas mileage), having to pay more for certain items like a razor because in order for Rick to use it it has to be a certain design so he can handle it and rechargeable so he won't have to plug it in--so, of course it is more expensive. We are faced with limitations in marketing for everything we use: dishes that are light enough so he can move and pick them up, silverware that he can grasp easier, tables that he can fit under... The points I guess I am trying to make are, 1) every purchase we make for the house is made with Rick in mind. We can't mindlessly buy major things and 2) Whatever it is it will be the most expensive (rule of thumb). Professionally, it has limited me in scheduling in place of work and in my own mind. I get really tired of my vacation being spent on hospitalizations or something evolving around Rick."

"Socially, all of our friends changed initially, that is, we lost friends and acquired others. Our new friends tended to be people who had more than average concern and caring about social/human needs and rights. We sought out new friends who had common experiences and avoided, in particular, judgmental and biased people. Emotionally, we both matured faster than we would have otherwise. My acceptance of other peoples' differences rose astronomically. We are also compelled, for reason of sheer survival, to seek out more effective and structured mechanisms for coping with stress. Professionally, whether or not you have a Ph.D or a pilot's license, when you are the mother of a handicapped child, this appears to be the major way in which others view you. Fathers do not have the same problem. I know mothers of handicapped children who are lawyers, chemists, teachers, doctors, technicians, artists, and they each experience similar difficulties with the identity dilemma. We think it probably comes from an underlying assumption on the part of poorly trained educators that well-educated and socially situated people simply don't have handicapped children. To bear a handicapped child is indicative of some basic ignorance/fault. John Peters well described this attitude in his book A Passion for Excellence. He refers to companies who treat their customers (parents) with TDC (thinly disguised contempt). This is perhaps the most descriptive and appropriate metaphor I have heard to describe the problem."

When a disabled child is born into a family, all aspects of family life are affected: social, emotional, financial, professional, personal, and spiritual. Social interactions change and the degree of change is often influenced by how others initially respond to a family when a disability is identified. Many families felt that because their perspective and attitudes changed, the way others responded to them socially also changed. It seems to be a reciprocal process.

Most families of disabled children are faced with some added financial responsibilities and others with overwhelming financial burdens. Families of disabled children are affected by insurance--obtaining it, keeping it, what it will cover is a constant consideration which even influences whether or not a family can move or change jobs. The probability is if a child is identified as having a disability, the family will probably have some sort of medical expense. This may be medication for the child with a learning disability or adaptive equipment for the child with physical disabilities, or psychotherapy and medications for a behaviorally impaired child.

WHAT EFFECT HAS YOUR CHILD'S DISABILITY HAD ON YOUR MARRIAGE?

"In order to 'do everything right' for the disabled child, life has a tendency to become a rigor of behavioral observances, doctor visits, conferences, etc. Our marriage is neither an institution or a psychological laboratory and we simply cannot cope with such rigors all the hours of the day--day-after-day, week-after-week and year-after-year."

The effect of disability on marriage is as varied as the people in the marriage. There are positive challenges, negative losses, nothingness, good, and bad.

"Marriage is much more difficult... There is simply less time to spend nurturing the marriage relationship when a special needs child is present. If the child's needs are put off (and they occasionally are) one must then cope with the resultant guilt. . . We figure it is better for our child to have two parents present most of the time even if it does result in more than average shifting of priorities based on stress factors. This is what professionals call 'inconsistency.'"

"There have been many good things and many bad things.

The good things have been that we have had to work together for our child, make long term plans and set goals, have more of a tolerance for problems in general, have a stronger faith, and we've had to depend on one another. The bad things have been that there are more stresses and resultant behaviors, more blocks to communication, and a greater fear of the future that governs everything we do. I've come to refer to this as the 'rubber band syndrome.' We are stretched so taunt then let go, then stretched so taunt and then let go. It is so exhausting and draining to cover that range of emotion and its like it gets rougher each time, but it can't show. I guess you see what I really worry about is that the rubber band can do that only so many times without breaking and I worry about that for us."

"Brad's disability caused problems in our marriage. I always, in my husband's opinion, agreed with everyone except him regarding Brad and his problems. My husband used Brad's problems as an excuse to drink. He even told Brad that I 'signed him away.'"

"We have needed to learn to communicate more effectively. We are continually dealing with hurt and non-acceptance. Both of us have learned to give more of ourselves. We have a greater tolerance of each other. Divorce is not an easy option with a handicapped child."

"I feel we have learned to depend on each other more. We approach our marriage and our child's disability more objectively."

"Having a disabled child has strengthened our marriage. We have both been able to grieve. Had that not been the case it could have torn us apart. We had to learn to communicate. We shared a deep faith before Stephanie was born and that faith helped us after Stephanie's birth. Divorce isn't an alternative."

"We were both so involved trying to handle and accept our feelings that we pulled away from each other. As our daughter got older it got easier."

"This is difficult to tell because my wife and I are in the process of a divorce. I know our daughter's disability has had a large impact on me emotionally. When we first found out about our daughter's disability we were not able to be a support to each other. I was attempting to reason out what we had been told. My wife was experiencing the emotional trauma of what we were told. Our daughter's disability has allowed my wife and me to come closer together as parents especially in child care and accepting all responsibilities of being parents."

WHAT DO YOU FEEL YOUR HUSBAND OR WIFE HAS DONE TO OFFER SUPPORT?

"The real question is 'What could I have done to make the situation easier for my husband?' I was bullheaded about keeping our daughter at home and that almost pulled us apart."

"My husband gets very upset by our daughter's characteristics. He has had to handle those himself and didn't give me a lot of emotional support and I guess I didn't give it to him either. He has always taken his turn at spending time with our daughter and he helps with homework, takes her with him to run errands."

"My wife was always positive and wanted to know what she could do to help. There was a time that the family responsibilities were taking over my job. My wife took the initiative to get the information we needed and brought me along. We learned together."

"My husband always provided me with emotional support. It was easy to share the sorrows and joys."

"My wife was always there to nurture or to help adjust my attitude. She is my best friend."

"My husband always supported me the most by being open, willing, and demanding good communication."

"My husband was no support. He always dwelled on things other than what was the problem."

"He's always been a quiet support. He is becoming more verbal and an active contributor through the years. We seem to have a scale we keep in balance--when he is down I am up and vice-versa. We also laugh together at inside jokes."

"To make life easier, my husband could treat the children equally and make more of an effort to be patient with them. His expectations should not be so high. Sometimes only a word or a pleasant gesture can make the difference in an entire day."

Parents express a new or increased tolerance for others' differences because they had a child with disabilities. Also, they see themselves as more patient toward their spouses because of the experiences they have had with their child with disabilities.

The need for increased communication or more effective communication was expressed by many couples. They have faced the possibility of divorce, yet feel that it is not an option because of the increased emotional and financial strain a child with a handicap would put on each of them if they were alone.

Women report that their husbands usually did not or could not ask for support. They were less likely to express their emotions regarding how the family member with disabilities affected them. In many cases, husbands put themselves in a position where they pretty much said to their wives, 'What do you want me to do (for you)?' Thus implying that they did not need any help themselves.

Women stated they often deal with the emotional aspect of having a disabled child before their husbands. In contrast, men seem to deal with rational, practical matters or the implications of having a child with disabilities. However, some men mentioned that having a child with disabilities allowed them to express their emotions.

TIPS FOR EDUCATORS

"Don't be afraid to ask questions."

"Tell me what you expect of me."

"Tell me what you expect of my child."

"Tell me what you worry about when you work with my child."

"Tell me you like my child and act like you like him."

"As often as possible, pretend you are the parent or student that you are addressing. Walk in the other's shoes, if you will."

"Avoid thinly disguised contempt."

"Avoid the standard cliches that parents can't stand like:

- He has plateaued and that's why he has not made more progress.
- What I hear you saying is . . .
- What does MOTHER think?
- We understand how you feel.
- This must be difficult for you but . . .
- Are any of your other children handicapped?
- Let's try not to get emotional.

"Meet parents on their own level and respect their thoughts."

"Educators should recognize that parents are experts about their children."

"Treat parents with respect."

"Understand that sometimes when a parent appears to be angry he or she may not be angry at the educator, but at the situation."

"Realize that we live with our child and can't go home at the end of the day."

"Be sensitive to parents and have a working knowledge of the grief cycle.

"Accept your own feelings and limitations when working with parents and children with disabilities."

"Believe parents; take them seriously."

"Say things in ways that are understandable and help us work together better as a team."

"Be aware of the limits on time of the family."

"Remember that certain reactions from parents may be a reaction totally unrelated to you (the educator) personally."

"Speak the facts and don't embellish them with emotionally charged descriptors to bolster your argument."

"Deal with the child and his or her problem then deal with the family."

"Educators shouldn't pretend they know it all."

"<u>Never</u> tell a parent that because you are the educator that you know best."

"Educators need to work and watch with the family and not push or steer them to what educators want for the child."

"Tell it like it is. Don't try to make things look or seem better (or worse) than they are."

"Don't take parental input as a personal affront to what you know."

"View parents as equals in regard to input about the child's needs."

KUDOS TO EDUCATORS

The following are experiences parents have had with educators that had a positive impact on them and left them with good feelings about themselves and about their children.

"There are a number of educators I know who always hold the needs of the child as the primary determiner in decision making. These are courageous folks. The educators I know who remember their mission without fail may have some temporary setbacks, but they usually end up in strong leadership positions. They make me feel great because they are willing to challenge and speak out for what is right and often end up leading us all."

"Said good things about my child."

"Acknowledged my opinions and feelings."

"The fact that they believe there are kids that need special help."

"It feels good when educators treat me as an expert regarding my child."

"An educator sat down with us one-to-one and discussed our child's handicap. He didn't pull any punches and gave it to us straight. He took the time to answer all of our questions and offered us hope for the future. There were no labels just three adults talking about a child's handicap and how to work with it."

"All the educators we have worked with have accepted Stephanie for what she is. They have liked her and this has built up her self esteem."

"An educator called after a particularly difficult and negative staffing and told us he admired the way we handled the situation."

"The teachers and therapists working with Susan gave many hours and much effort above and beyond the call of the job. They cared. I feel I was very lucky to know and work with them. They made me feel I was part of the team."

TIPS FOR PARENTS

"Tell educators what you need to hear or know."

"Learn to be assertive, not aggressive or passive aggressive."

"Seek a real support person when you know you are being overloaded."

"Continue your personal growth."

"Pursue emotional and physical fitness."

"Cut a portion out of your day for yourself."

"Keep a log of your contact with educators and other professionals."

"Give yourself permission to enjoy life, have fun, feel happy..."

"Accept that you are doing the best job possible at this time."

"Keep informed."

"Say thank you to educators when things go well."

"Give yourself plenty of time when you meet to discuss important issues."

"Look at yourself closely to identify habits or attitudes that interfere with effective communication or your being taken seriously."

"Look at people when you talk to them."

"Make a list before you go to a meeting of things you want to say and take it with you to the meeting."

"Describe your needs in behavioral terms; not emotional terms."

"Remember that the people you are working with care for your child too."

"Deal with the current situation and current facts."

"Be willing to work with others actively and honestly."

"Avoid interruptions when you meet with others."

"Take someone with you when you attend a meeting."

ATTITUDES AND SAYINGS TO AVOID

"I'm so sorry," followed by sympathy cards at the time of our daughter's birth.

"Why do you put your son through this?" (take him out in public)

"It would be better if these children with defects weren't born."

"You must be very special for God to have chosen you to have a 'special' child."

"How do you do it?"

"I couldn't handle what you do." (most parents expressed this had been said to them and that their response was - "Of course you could, you do what you have to do an you keep doing it".)

"I don't know how you put up with him/her."

"You're an inspiration."

"I understand because I used to have a cat that was handicapped."

"I know just how you feel."

THINGS NOT SAID, BUT PAINFUL NONE-THE-LESS

The "Can't you do something about that child's behavior?!" look.

The "You poor people" look.

The "Non-look" look.

The "How do you do it?" look.

RESOURCES

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