Parents Speak Out: Facial Plastic Surgery for Children with Down Syndrome

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Abstract: Facial plastic surgery has been advocated as a way to improve the physical functioning, appearance and social acceptance of children with Down syndrome. However, there are also those opposed to this surgery due to concerns about its effectiveness, and potential physical and psychological risks. This qualitative study examined comments of 250 parents of children with Down syndrome and categorized their responses into positive and negative themes.

In our society, individuals with appearances that are seen as atypical or unattractive are often rejected (Gath, 1985; Kravetz, Weller, Tennenbaum, Tzuriel, & Mintzker, ; Pueschel, Monteiro, & Erickson, 1986). Today, many individuals with Down syndrome are able to read, write, and function at near normal levels due to educational and medical advances such as early intervention and cardiac surgery (Pine, 1982). A persistent obstacle to full acceptance of individuals with Down syndrome in both school and society may be their characteristic appearance (Goeke, Kassow, May, & Kundert, in press). Facial plastic surgery is an intervention that has been proposed to improve the physical functioning, appearance, and social acceptance of individuals with Down syndrome.

Facial reconstructive surgery for children with Down syndrome has involved multiple procedures to correct one or all of the distinct facial features of Down syndrome. These procedures may include tongue reduction, implants in the bridge of the nose, chin, cheeks, and jawbone, and Z-plasty on the eyelids to erase the characteristic epicanthal fold (May, 1988; Olbrisch, 1982; Ross, 1980; Shapiro, 1982; Wexler, Peled, Rand, Mintzker, & Feuerstein, 1986). Other procedures may be done on soft tissue areas of the face, such as removal of part of the lower lip to prevent drooping, removal of fatty tissue under the chin, and correction of the position and size of the ears (Lemperle & Radu, 1980; Olbrisch, 1982).

Review of relevant literature on this topic uncovered few recent publications on facial plastic surgery for individuals with Down syndrome, and no specific data on how often these surgeries are done. However, in a recent study, 89% of families of children with Down syndrome were familiar with the surgery (Goeke et al., in press) and a recent television documentary (Dismore, 1998) detailed the experience of one family who chose the surgery for their child.

During the 1980s, controversy existed between those who claimed that the surgery could improve the physical functioning, appearance, and social acceptance of individuals with Down syndrome (Olbrisch, 1982; Wexler et al., 1986) and those who doubted its effectiveness (Dodd & Leahy, 1984) and even opposed its use due to the potentially damaging psychological effects (Belfer, 1980). A limited number of studies have been performed to assess the effectiveness of facial plastic surgery for children with Down syndrome (Katz & Kravetz, 1989). Results of investigations into the benefits of surgery on appearance, physical functioning, and social acceptance are similar. As noted by Goeke et al. (in press), studies using impressionistic data based on the responses of parents and doctors who were directly involved showed evidence for the surgery’s positive outcomes (Lemperle & Radu, 1980; Wexler et al.). Studies utilizing more
critical and controlled research designs (e.g., using indirect questions, control groups, and less involved subjects) showed less positive results (Novoselsky, Katz, & Kravetz, 1988; Alkawitz, 1987; Arndt, Lefebvre, Travis, & Munro, 1986). In some cases, these results suggested that the operation failed to produce the desired effects. Some advocates for individuals with Down syndrome have argued that by choosing such an intervention, parents and professionals place the burden of change on the stigmatized individual, rather than on the stigmatizing society (Katz & Kravetz; May, 1988).

The process by which parents decide to opt for surgery has not been thoroughly explored. A small amount of literature has attempted to uncover parents’ opinions of the procedure. Pueschel et al. (1986) found that parental opposition to facial plastic surgery was consistent across all ages and genders of children. Parents surveyed for this study felt that their child was well accepted by neighbors, peers, relatives, and society, and few felt that surgery would increase this acceptance. The majority of these parents opposed surgery despite feeling that their child’s facial characteristics impaired their mental and social development. Katz, Kravetz, and Marks (1997) questioned whether parents select surgery in an effort to satisfy their own needs, or the needs of their child. The question remains as to whether parental interests can be separated in this decision-making process (May & Turnbull, 1992). More recently, Lewis (2000) investigated parental opinions of the procedure through an Internet survey. The purpose of this study was to describe parents’ feelings about facial plastic surgery for children with Down syndrome.

Participants

The sample for this study consisted of 466 parents or guardians of individuals with Down syndrome. They were members of an advocacy organization in the Northeast for parents and family members of individuals with Down syndrome.

Instrumentation

A survey was developed to collect demographic information such as marital status, age of parents, age of child with Down syndrome, number of children, level of education, and ethnicity. Multiple Likert-scale items asked about parents’ knowledge of and opinions about facial plastic surgery for children with Down syndrome; these data are reported in Goeke et al. (in press). The survey also asked for qualitative responses regarding respondents’ experiences as parents or guardians of a child/children with Down syndrome. Space was provided for respondents to write open-ended comments regarding the procedure.

Surveys were sent by first class mail to the 466 members of the Down syndrome advocacy group. A cover letter was sent with the survey that explained the purpose of the study and indicated that responses would remain confidential. If respondents wished to receive a copy of survey results, they filled out an enclosed postcard, which was immediately separated from their survey when envelopes were
opened. A self-addressed stamped envelope was provided to facilitate survey return. As surveys were returned, the code on each was recorded from the envelope. Based on a review of these recorded codes, a second mailing was distributed after eight weeks to all nonrespondents. 

Data Analysis

Data analysis for this component of the study involved immersion in the data and repeated sorting, coding, and comparison. Analysis began with open coding. Open coding describes the process by which data is reviewed for the purpose of generating initial categories as well as fitting all data into these categories (Creswell, 2000). Once all data had been collected, the written responses were read and preliminary themes and patterns that existed throughout the data were identified. Initial codes were established, such as parental needs, child abuse, sets up unrealistic expectations, sends negative message to child, children with Down syndrome are beautiful, child is who he/she was meant to be, depends on level of disability, and to improve medical condition only. Responses were sorted by code using word processing software. Several codes were then combined to form axial codes. For example, sets up unrealistic expectations, sends negative message to child, and risk of additional pain were combined into a broader code called negative consequences for child. Memos were written to document and enhance the analytic process, which consisted of questions and speculations about the data that emerged as codes were sorted and compared. Large posters with movable tags were used to facilitate the arranging and rearranging of codes within categories. Codes and categories were sorted and compared until analysis produced no new codes or categories and when all of the data were included in the core categories.

Reliability

To check for coding reliability, a colleague independently coded written data into key categories that emerged from the data analysis. Codes were not changed as a result of these reliability checks. However, when sorting choices for a particular response did not agree, data were reread and discussed until agreement was reached. As a result, several responses were recoded. The final overall agreement between his codes and the author’s was 92%.

Results

Two hundred forty-two surveys were returned after the first mailing and an additional 57 were returned after the second mailing. These 299 surveys represented a 61% return rate. Of those returned, 49 surveys were not useable since they were from individuals who were not parents or guardians (e.g., siblings). Thus, the analyses reported were based on 250 cases. Mean age of respondents was 46.88 years old ($SD = 11.73$) with a range of 23 to 82 years old. Mean age of their child or children with Down syndrome was 14.37 years old ($SD = 9.81$), with a range of 1 to 46 years old. Two hundred twenty-six (93%) respondents were Caucasian, 3 (1.6%) were Hispanic/Latino, 2 (.08%) were African American, 4 (1.6%) were Native American, and 10 (4%) were from other ethnic backgrounds. Sixty-five respondents had completed graduate education; 72 respondents had completed a four-year college education, and 63 respondents completed high school or other educational training (e.g., technical school, 2-year college).

Negative Opinions of Plastic Surgery for Children with Down Syndrome

The majority (88%) of respondents to this study reported that they did not support facial plastic surgery for children with Down syndrome. Their reasons for not supporting surgery fell into four broad and common themes: 1) certain core philosophical beliefs about children with Down syndrome; 2) the view that surgery constitutes a misplacement of energies; 3) the belief that choosing surgery reflects parental issues, not those of the child; and 4) the fear of specific negative consequences of surgery for their child. Examples of comments that represent each of these themes are presented in the following sections.

Theme one: Philosophical beliefs about children with Down syndrome. The majority of respondents reported that they would not consider facial plastic surgery for their child with Down
syndrome based on their acceptance of their child as is. Several parents enclosed photographs of their children with comments attached such as, “Why tamper with perfection?” or “Would you change that face?” Overall, respondents to this survey expressed the belief that their children, and individuals with Down syndrome in general, are quite attractive, even beautiful people, as indicated by the following statements:

As long as their physical appearance doesn’t interfere with breathing, or seeing, eating, etc., then they are who they are. Beautiful people.

Children and adults with Down syndrome are beautiful! I am lucky to be the parent of such a beautiful child.

In addition to acceptance of their child and appreciation of their facial features, many respondents indicated that they believed their child with Down syndrome was who he or she was meant to be.

I know that my daughter was meant to be born with Down syndrome. She is unique in our family, in the gifts she brings to us. I am very proud that she has Down syndrome and is my daughter. She has a pure ability to love that I will not reach before I die. She is a great teacher concerning things that are truly important in life. Her sense of humor brings much laughter into our home. She has changed and touched many other lives in 6 short years. She needs to change me, I don’t need to change her!

A mother who chose her child with Down syndrome through adoption stated:

I admit that at first I did not want to complete this survey. It seemed pointless because I believe my daughter is the person she was meant to be, and because I adopted her it places me in a unique position as her Down syndrome was not “forced” on me. I could have said no. Her birth parents knew they could not handle it so they made a very hard decision. I chose her and she has brought me more joy than I ever imagined. She has taught me the true meaning of unconditional and unending love and acceptance.

Many respondents indicated that the experience of having a child with Down syndrome had been a positive one, leading to increased personal and family growth. Several parents indicated that the process of accepting a child with Down syndrome had facilitated their own greater self-acceptance. As one mother stated:

My overall experience as a parent of a child with Down syndrome has been a positive one. In accepting him for who he is, I have accepted myself as well. Raising him has been a privilege and a mostly happy experience. His joy for life and the simple things is contagious. I can but admire his humanity. I love him just the way he is.

Theme two: Misplaced energies. Many respondents indicated that facial plastic surgery placed emphasis and energy in the wrong place. For these parents, surgery represented a diversion from the very important, and more valid, work of changing societal attitudes toward individuals with Down syndrome, and furthering their educational and social development.

Several parents expressed frustration that their children were accomplished, well adjusted, outgoing people, but that the unfamiliar public continues to respond to them in negative ways. According to some parents’ view, such negative reactions reflect the public’s ongoing desire for individuals with Down syndrome to be more shielded and dependent, and less visible. One mother likened facial surgery to “a step back into forced sterilization and the coldness of institutions,” stating, in essence, that although people with Down syndrome move more freely in society, we are still searching for ways to “hide” them. Another mother wrote:

Emily is 22 and has Down syndrome. Her quality of life is very good based on her good, outgoing, optimistic attitude and her many supportive friends who do not seem to be affected by her appearance. The unfamiliar public and neighbors have shown disgust and feel that Emily should be more “protected” and not so public or independent. I have twice been approached by children’s protective services because neighbors and a teacher’s aide felt that Emily’s independence was jeopardizing her safety. Both cases were dismissed.

In the face of such frustrations, many re-
spondents expressed the wish to change societal attitudes, not the appearance of their children.

It’s up to society to change its attitudes and not individuals with visible differences to change their appearance merely to conform.

I do not believe in facial surgery for Down syndrome people so that they will look more “normal.” They are still the same inside. They are still retarded. I think that society is what has to change. Acceptance of all people should not be based on looks.

Many respondents expressed the belief that society does not have the right to decide what is “normal” or “beautiful” and, by extension, to determine who is a candidate for physical alteration. These parents acknowledged that presenting to the world as a person with Down syndrome is difficult because, in our society, judgments are often made on the basis of appearance. However, they also stated that this is not a problem unique to Down syndrome, as many “normal” looking people will attest.

Would I consider plastic surgery for my older son, who doesn’t have a disability, because I want to change the way he looks? Absolutely not.

I understand why some may feel the need for plastic surgery to help enhance their lives, while a part of me believes God has a special design (almost angelic in nature). I have seen it in my daughter’s eyes that there is a uniqueness to her being here. I know our society continues to lean toward perfection, but do we really know and understand what that is?

Some parents felt that surgery was an unnecessary intervention because the stigma placed on their child is the result of characteristic behaviors associated with mental retardation, not the facial features associated with Down syndrome.

Depending on the child’s needs, I would have no problem with facial surgery in principle, although I can’t imagine it making much difference as the issues with social acceptance are as much or more in reaction to social “performance” than the appearance of Down syndrome features.

My daughter started out in a self-contained special ed classroom and at 7 (kindergarten) we started to include her in our neighborhood school. She is now in 6th grade and although she has friends at school, they do not call her and ask her to go places with them. This is not because of how she looks. We still have social issues we are working on. She has trouble holding a conversation and asking questions. She gets along much better with the boys because they are not as verbal - more physical. You can change your child’s appearance but they will still have Down syndrome and need help with their social skills.

Many respondents indicated that they would rather invest in furthering their child’s educational opportunities, and in building their confidence and self-esteem. For these respondents, raising a child with Down syndrome presents similar challenges to those encountered by parents of “normal” children: How to raise a confident, well-adjusted person in a society that places a great deal of emphasis on external appearance.

Plastic surgery is not the answer to educating ignorant people, nor is it a good way to provide your child with self-esteem. He needs to know he is wonderful and special the way he is. He does not need to look different to be a worthwhile person.

My child is who he is and nothing can change that. I would rather invest my time and money in educating him. More importantly, in loving him.

Interestingly, parents of daughters with Down syndrome expressed particular concern with the issue of confidence and self-esteem building. Their comments appear to reflect the more extreme societal pressure on girls - with disabilities or without - to be physically attractive. One mother of a daughter wrote:

It’s not Down syndrome, but how my daughter feels about herself. Having daughters is a challenge in a society that values men more. Building their self-esteem and maximizing their personal potential is something we try to do for our daughters. If others would let them try and support them.
during the times they fail, maybe all our children would feel better about themselves.

**Theme three: Belief that choosing surgery reflects parental issues.** Some respondents felt that the decision to have facial plastic surgery performed on a child with Down syndrome is indicative of the parents’ failure to accept their child’s disability. The decision to have surgery performed on a child is, therefore, motivated by the parents’ desire to remove the stigma placed on themselves, and to facilitate their own social acceptance, not that of their child.

I feel that the parents who have their child undergo this surgery cannot accept that their child is different, and the child doesn’t fit into their expectations. I know my son will first be judged by his appearance. But it is my hope that he will be accepted as an individual. People with Down syndrome are being included in school and all parts of society, and are losing that old stigma placed on them.

Surgery will not take away my son’s extra chromosome. He’s a real cute kid and I expect, will be an attractive adult. After plastic surgery he would still have Down syndrome. That won’t change. I believe people who have surgery on the kids are dealing with their own issues of acceptance, not society’s.

Several respondents indicated that the desire to reconstruct a child’s differences through painful surgery sends a strong message to both the child and the larger community that the parents do not accept their child’s disability and that they find their child physically unattractive.

What kind of message are you giving your child if you give them this operation? Aren’t you saying we don’t love/accept you as you are?

Several parents felt that this message would be especially damaging in families with more than one child. The child with Down syndrome would feel this negative message much more acutely due to the fact that their “normal” siblings were not candidates for physical alteration. In addition, siblings would be taught intolerance and lack of acceptance by their parents’ choice of facial plastic surgery for the child with Down syndrome. Some respondents also felt that parents serve as models for the community about how to treat their child with Down syndrome. Both familiar and unfamiliar people react to their child based on how family members present them and treat them in public. Thus, if they present their child as one whose appearance they have opted to change, they are communicating that they agree with members of society who find the appearance of individuals with Down syndrome unattractive or offensive.

**Theme four: Negative consequences for child.** The majority of respondents opposed facial plastic surgery for their child with Down syndrome due to the potential negative psychological and physical consequences. Several respondents felt that surgery would also place children with Down syndrome in danger of suffering from unrealistic expectations. These parents viewed the outward physical signs of Down syndrome as a cue to their child’s limited capabilities. If such signs were altered or removed, society, and even some children’s own parents, may expect them to behave and achieve like children who do not have Down syndrome. These respondents believed that parents who chose surgery for their child would only be disappointed, as surgery cannot remove their child’s Down syndrome; they would still be the same person under a more “normal” face.

I would strongly question parents on their feelings towards their child, because Down syndrome is a disability that is much more than appearance and their expectations could exceed reality.

Our main reason for not actively pursuing surgery was fearing the pain to our son and our total acceptance of his quite nice face - and if people are not drawn to him as he looks, his disability apparent, they would only turn away after approaching a new face and then discovering his limited capabilities.

The person who I am most familiar with who had this surgery ended up (in my opinion) not looking like a person with Down syndrome or like a person without Down syndrome.
Kids relate to other kids regarding things they have in common (personality, compatibility, etc.) not how their face looks. Facial surgery would not make her problems communicating go away. I think it would cause more teasing because kids and others would not realize she has Down syndrome and may be less tolerant and patient.

In addition to these potentially damaging psychological consequences, many respondents viewed plastic surgery as additional physical punishment inflicted on an already traumatized person. Many children with Down syndrome undergo major surgeries for cardiac conditions and hearing problems, in addition to the discomfort associated with many therapies. A large number of respondents, therefore, stated that subjecting their child to additional pain and suffering was out of the question. Many respondents equated the decision to expose one’s child to unnecessary surgery with child abuse. Several parents described it as “revolting” and “barbaric.”

This area of response produced the most emotionally intense parental comments, as illustrated by one father’s response:

Our child is the result of the love of my wife and myself. What greater gift is there, and how can he be anything but perfect to us? We feel that any parent who subjects a child to this surgery is guilty of child abuse. After heart surgery, hernia, etc., WHY would we want to subject this child (who is perfect) to additional pain? Jake is accepted and loved by family, friends, and our small community.

No child should be subjected to any surgery that is purely cosmetic. Our child has had necessary surgery three times. Putting a child through that pain and discomfort for purely cosmetic reasons is morally wrong, bordering on child abuse.

Qualified Support for Facial Plastic Surgery for Children with Down Syndrome

While the majority of respondents to this study did not support facial plastic surgery for children with Down syndrome, some respondents indicated support for the procedure under certain conditions. Two themes emerged from these respondents: 1) decisions about parenting a child with Down syndrome are a matter of personal choice; 2) the decision to have surgery performed might depend on the child’s level of disability. Examples of these themes are presented in the following sections. Twenty-one respondents reported having considered or actively investigated surgery at some point, while a single respondent indicated that her child had, in fact, undergone facial plastic surgery.

Personal choice. Qualified support was given by a small number of respondents who reported that they would only endorse plastic surgery for medical reasons (e.g., correction of speech, breathing, eating, etc.), not to conform to societal expectations for physical attractiveness. Several parents indicated that the decision to have surgery performed on their child is a personal one that each parent must make in the context of their own family and circumstances, free of outside judgment. The largest concentration of support was for the possibility of an adolescent or adult with Down syndrome choosing surgery for him or herself:

I believe that unless a person with Down syndrome is an adult and is requesting cosmetic surgery, parents should not impose these painful procedures on children.

I don’t believe it is right to perform plastic surgery on an individual with Down syndrome for purely cosmetic reasons without that individual’s informed and enthusiastic consent.

I asked my daughter if she would ever decide to get cosmetic surgery to change her facial appearance. She thought for a second, made a face as if I asked an absurd question, and replied, “No, this is who I am.” I asked her if she’s okay with how she looks. She said, “Sure, but maybe I could do plastic surgery on my clothes.”

Depends on the level of disability. Some respondents indicated that the choice to have facial plastic surgery performed might be dependent on the child’s level of disability. Interestingly, parents reasoned that surgery might be more warranted both in cases of more severe and less severe impairment. For example, parents of higher functioning children may be more justified in opting for the surgery because their child’s chances of reaching a very high level of accomplishment are more realistic:
I would never alter my daughter’s face. She is beautiful to me and our whole family. She has very mild features also. Maybe if she had strong facial features and was very bright I might consider it, but only if she wanted it done.

Conversely, some parents believed surgery may be more beneficial for more severely impaired children:

Joe is a high functioning child with Down syndrome. He is performing well in an inclusive classroom with support from an aide. His speech is age appropriate, with some articulation concerns. He has mastered printing and is beginning to read. Altogether, he is performing at kindergarten level, has made friends at school, and is well adjusted. To what extent we would consider surgery if Joe’s disability were more severe is difficult to say.

Our son’s facial appearance only displays subtle characteristics of Down syndrome. I find his appearance pleasing. I would support facial surgery in persons with extreme characteristics to move their appearance into a more subtle range, but not necessarily to remove all characteristics of Down syndrome.

A small number of participants indicated that they had looked into surgery either because they, or their child with Down syndrome, wanted it. Most of these respondents reported that they did not follow through with surgery because after a period of grief and adjustment, they began to appreciate their child’s appearance and became averse to subjecting their child to needless pain and physical risk. One respondent indicated that the barrier to investigating surgery further was that it would not be covered by health insurance. A single respondent reported that her child underwent surgery at age 4, commenting:

I believe this has made my child’s life easier. She was young so I do not know what her speech would have been like without the surgery. We did it to take away some of the stigma and to make her life easier. People are judged on appearance. We wanted to give her a chance in life.

Discussion

The purpose of this study was to describe the opinions of parents regarding facial plastic surgery for individuals with Down syndrome. One theme that emerged from this research was the belief that people with Down syndrome are beautiful, meant to be who they are, and therefore not in need of change. Negative representations of disability are prevalent in our society. Independence on the part of people with disabilities violates strongly held beliefs about what disability represents to the larger culture. The dominant medical model of disability implies that disability is a biological defect requiring persistent medical intervention (Robertson, 1994), and that the challenges faced by individuals with disabilities are solely attributable to the disability, and not to any societal, physical, or attitudinal barriers. This view is reinforced and perpetuated by images of people with disabilities that evoke pity (Robertson). Therefore, even when people with Down syndrome are functioning in the larger society, they may be subject to oppressive attitudes.

People with disabilities have increasingly viewed themselves as members of a distinct minority group, possessing a unique and valuable culture (Cristoph, 1985; Shapiro, 1993; Wade, 1992). Disability culture promotes a positive identity in people with disabilities (Johnson, 1987), and fosters the notion that disability can be a source of pride rather than shame (Disabled and Proud, 1993). According to this view, development of a positive self-identity involves embracing all aspects of one’s self, even those that mark an individual as different from the rest of society. Rather than conceptualizing disability as a deficit, it can be viewed as part of a whole, complete self, and can even be seen as beautiful (Hahn, 1988).

The views expressed by the majority of respondents to this study are consistent with the values of this emerging culture. In this study, most parents opposed facial plastic surgery for individuals with Down syndrome due to their acceptance of their child as he/she is, despite the many challenges that accompany the disability. These findings are consistent with earlier research (e.g., Pueschel et al., 1986), which found that parents opposed plastic surgery despite the impact of Down syndrome on
their child. Membership in disability culture raises questions about development of self-identity in individuals who have had the characteristic facial features of Down syndrome altered. As one respondent to this study pointed out, a child she knew who had surgery ended up not looking like a child with Down syndrome, or a child without Down syndrome. Many parents stated that they viewed their child’s facial features as a cue to the unfamiliar public about their child’s limited capabilities. Facial alteration may mean that a child with Down syndrome cannot easily fit into disability culture or the larger “normal” culture; implications of belonging to this “gray area” are unclear.

Respondents to this study discussed the positive effects of having a child with Down syndrome, such as increased family closeness and facilitation of greater self-acceptance. In the past, children with Down syndrome have been popularly portrayed as having easy temperaments and agreeable personalities, and as being easier to raise than children with other developmental disabilities (Holroyd & McArthur, 1976; Marcovitch, Goldberg, Lojkasek, & MacGregor, 1987). More recent studies (e.g., Cahill & Glidden, 1996) have suggested that this idea should be re-examined.

Research has, however, documented positive parental adjustment to having a child with a disability. For example, studies of parental adjustment have found that parents of children with mental retardation grow closer and often are less critical of family members than families without children with disabilities (Foster & Berger, 1985). Scorgie, Wilgosh, and McDonald (1999) found that “acceptance of a child with a disability as he/she is” was one of five effective coping strategies used by parents of a child with a disability. This acceptance was defined as moving away from the need to have a “normal” child and toward the acceptance of their child with a disability, active involvement in raising their child, and the determination to cope. More recently, Scorgie and Sobsey (2000) found that most parents of children with disabilities had experienced positive personal, relational, and perspectival transformations. Such positive effects are not particular to families of children with Down syndrome; children with other disabilities have similar effects on the family. In other words, most families of children with disabilities demonstrate effective coping with this task. Additional research is needed to determine whether parents of children with Down syndrome who elect to have their child’s facial features altered have less well developed coping strategies than other parents of children with disabilities.

A second theme that emerged from this study was that the discussion of facial plastic surgery as an intervention for individuals with Down syndrome constitutes a misplacement of energies that could be put to more productive use. Many respondents to this study viewed facial plastic surgery as yet another form of individual adaptation for convenience of the larger society. Historically, rehabilitation has often consisted of inducing people with disabilities to function like people without disabilities (e.g., training people to walk with crutches rather than use a wheelchair, or teaching deaf people how to speak while suppressing the use of sign language). It has been argued (e.g., Longmore, 1993) that even when rehabilitation does not produce any actual increase in functioning, effort on the part of the person with a disability to create the appearance of normality has been expected in return for societal benevolence and token acceptance.

The majority of respondents to this study viewed improvement of negative societal attitudes toward individuals with Down syndrome as their priority. Rather than making the minority adapt to the majority through unnecessary surgical intervention, they would rather invest in furthering their children’s education and self-esteem, and in changing society’s attitudes toward their children. Their responses challenged the notion that people with Down syndrome need cosmetic surgery to have a good quality of life; many parents chronicled their children’s achievements in school, work, and independent living. Proponents of facial plastic surgery assert that it will improve the appearance, physical functioning, and social acceptance of individuals with Down syndrome. According to the respondents to this study, their children are already making considerable strides in each of these areas. For these parents, educating children and adults about the abilities of individuals with Down syndrome will go further to diminish the negative expectations associated with their disabil-
ity and have a more lasting impact than surgery on a few individuals.

A third theme that emerged from this study was that facial plastic surgery results in negative physical and psychological consequences for the child with Down syndrome. A primary value implicit in the dominant medical model of disability is that people with disabilities experience a lesser quality of life, and are unacceptable as they are. Prevalence of this view means that people with disabilities are exposed to a social reflection of themselves that is extremely negative. If a person is socialized to view disability as a shameful aspect of the self, they may internalize this stigma and as a result, try to hide or deny the disability (John-son, 1987).

Early research (e.g., Lynch, 1976; Solnit & Stark, 1961) noted the stigmatization felt by some parents of children with disabilities. Some parents, for example, were likely to view their child’s disability as yet another criticism of themselves and their inability to parent. Solnit and Stark stated that the mother of a newborn with a disability may find her ability to adjust impaired by feelings of failure, of being defective herself, and of being damaged by her child. More recent research has associated the decision to have facial plastic surgery performed on a child with Down syndrome with the parents’ failure to accept their child’s disability (Katz et al., 1997).

Caution should be taken in generalizing the findings from this mostly white, married, educated sample. It is uncertain whether this reflects membership of advocacy groups in general, or is idiosyncratic to the part of the United States where the respondents lived. Parents of children with Down syndrome who do not belong to advocacy groups may have different information and opinions about facial plastic surgery; however, since they do not belong to any easily accessible group, they would be difficult to survey.

Although the majority of respondents to this study knew about facial plastic surgery for individuals with Down syndrome, we still do not know how prevalent surgery really is in the larger population, nor do we know if parents who failed to respond had different views and experiences. Further research could identify the prevalence of these surgical procedures for individuals with Down syndrome. Respondents to this study raised concerns about whether the decision to have surgery performed leads to psychological damage to the child, or erosion of the parent-child relationship and/or the relationships between siblings. Additional research is needed to determine whether such concerns are founded. Even if these procedures were only performed on a small number of children with Down syndrome, research findings suggesting any damaging physical or psychological effects would be valuable.

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