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Authors
Freeman, SFN
Alkin, MC
Kasari, CL

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Satisfaction and Desire for Change in Educational Placement for Children with Down Syndrome

Perceptions of Parents

STEFHANNY F. N. FREEMAN, MARVIN C. ALKIN, AND CONNIE L. KASARI

ABSTRACT

This study surveyed 291 parents of children with Down syndrome about their satisfaction with their child's current educational program, as well as their desire and reasons for considering change. Perceptions were compared across age, current educational placement, ethnicity, and mother's educational level. Parents of younger children, children currently enrolled in both early intervention and general education, and mothers with an education beyond a bachelor's degree were more satisfied with their children's current programs. Parents of children in general education were least likely to want a program change. Wanting change centered on seven themes: the approach of a school transition point, the desire for greater inclusion, placement in a neighborhood school, the need for additional services and support, influences of peers, parents' financial resources, and ongoing information acquisition/decision-making issues.

As school districts struggle with service delivery options for children with disabilities, parent views of educational placement are important to consider. These views, expressed through the Individualized Education Program (IEP) process, can have direct effects on placement as parents are required to participate and approve their child's educational program. Surprisingly, only a handful of studies have directly examined parental satisfaction with current programs for their children with disabilities.

These studies do, however, highlight several themes. First, parents of children with disabilities view integrated settings as opportunities for their children to have "real-world" experiences and to benefit from typically developing peer models. (Turnbull & Winton, 1983). Second, positive social interactions are thought to be supplemented by higher academic performance, although there are few data to substantiate this claim (Casey, Jones, Kugler, & Watkins, 1988; Cole & Meyer, 1991; Jenkins, Odom, & Speltz, 1989).

Perceived limitations of integrated classrooms focus on two areas. First, parents are concerned about the potential loss of support and supplemental services for their children with diagnosed disabilities (Bailey & Winton, 1987). Second, parents focus on social concerns such as rejection, teasing, and self-esteem (McDonnell, 1987). In spite of these initial parent concerns, perceived limitations of integration diminish somewhat after the child has participated in integrated programs (Bailey & Winton, 1987).

The research on parent perceptions, however, has been relatively silent on parent satisfaction with current programs for children with disabilities and why parents may or may not want change. Moreover, the few studies that have examined some aspect of parent satisfaction with inclusion have yielded mixed results. Although Guralnick, Connor, and Hammond (1995) did not measure satisfaction directly, they nevertheless viewed the perspectives of mothers as indicators of satisfaction with their children's current placement in integrated settings. Satisfaction was greater for parents of children who
met criteria for classification of cognitive delays, communication disorders, physical disabilities, and at-risk conditions. McDonnell (1987), however, in a study of parents of children with severe disabilities in special schools and integrated programs, found no significant differences in judgments of "overall program quality," considered a measure of parent satisfaction with the program. Finally, Collins (1995), in a study consisting of 12 pre- and postintegration interviews, concluded that perceptions of satisfaction were slightly higher for parents of children with severe disabilities in the segregated school setting.

Thus, satisfaction plays an important role in parent decisions about children's placement. Indeed, the desire and persistence of parents is likely a contributing factor to the inclusion of children with disabilities (Hunt et al., 1993; Stetson, 1984). It is important to understand parent satisfaction with various types of program alternatives, as well as parents' potential reasons for considering change. In this way, more appropriate programs, resources, and alternatives can be made available.

In the current study, we examined the issue of satisfaction with educational placement from the perspective of parents of children with Down syndrome. This single etiological group of children was used in order to eliminate the possibility that type of disability could be a confounding factor in parental satisfaction or desired program change. Children with Down syndrome were chosen for two reasons. First, these children are identifiable at birth and there is little ambiguity with respect to their membership in the group (Gibson, 1978). Second, current research suggests that children with Down syndrome have a higher level of sociability than other children with mental retardation. The social abilities of children with Down syndrome may be somewhat less affected than their cognitive abilities (Kasari, Mundy, Yirmiya, & Sigman, 1990; Legersten & Bowman, 1989). Indeed, children with Down syndrome may actually compensate for cognitive difficulties with social abilities (Kasari & Hodapp, 1996; Pitcairn & Wishart, 1994). As a result, the likelihood of successful inclusion may be enhanced for children with Down syndrome.

Thus, the recognized sociability of these children may convince parents that their children could especially benefit from consistent interactions with typically developing peers. However, even within the Down syndrome population, parents may differ on their preferences depending on the age of the child, the current placement of the child, and the educational and cultural background of the family. With increasing age and/or children's developmental change, parents' satisfaction with the current program and desire for change are also likely to become modified. In particular, the program satisfaction or dissatisfaction of parents of older children may be enhanced by such things as concern for safety and provision of vocational services (Hanline & Halvorsen, 1989; McDonnell, Wilcox, Boles, & Bellamy, 1985). In addition, a family's cultural beliefs and practices can affect parental views of educational placement (Correa, 1987). For example, Sontag and Schacht (1994) found that parents of Hispanic background felt less included in educational decisions for their children than did parents of Euro-American and American Indian children, suggesting that cultural background may be related to parental views.

This study was designed to examine the perceptions of parental satisfaction, desire for change, and reasons related to parents' considering program change for their children with Down syndrome. In addition to quantitative data, qualitative data were collected in order to provide well-grounded, rich descriptions and explanations of the individual needs of these parents of children with Down syndrome (Miles & Huberman, 1984).

**Method**

**Participants**

This study surveyed 291 parents of children with Down syndrome. Participants were drawn from the mailing lists of two Los Angeles-based associations of parents of children with Down syndrome, one serving English-speaking and one serving Spanish-speaking parents and professionals. We received responses from 53% (291/550) of all mailed questionnaires. However, some parents were in both groups and some recipients were professionals in the field of special education without children with Down syndrome. Thus, an exact response rate is difficult to calculate but is undoubtedly much higher. Consultation with both parent groups' executive administrators indicated that respondents were representative of the larger membership in each association in terms of child's age and ethnicity and mother's educational level. Each of the two associations' administrators were asked to provide percentages of their memberships within each of these three categories. These percentages were not significantly different from the percentages of the returned questionnaires. In addition, each association aggressively contacts parents of children with Down syndrome at birth and maintains a high level of membership relative to the area's total Down syndrome population.

The 210 English and 81 Spanish questionnaires were examined separately on all demographic variables except ethnicity. It was expected that the parents of the Spanish-speaking sample would be of a different ethnic background than the English-speaking parents. On the other demographic variables (respondent, current program, age group), no significant differences were found, except on mother's education level, $\chi^2(3, N = 291) = 73.99, p < .001$. Parents in the English-speaking sample categorized themselves as having a higher education than the parents of the Spanish-speaking sample.

As a result of these differences in mother's education level, correlations between mother's education level and satisfaction and change were examined separately within the Spanish and English samples. Similar relations were found between mother's education level and the outcome variables in each group. In addition, no group differences were found between the Spanish- and English-speaking samples on any
of the outcome variables. Therefore, the following analyses were conducted using the full set of 291 questionnaires.

Procedure

Questionnaires were mailed to the parent population in English or Spanish under the auspices of the two associations. The Spanish questionnaire was translated separately by two bilingual speakers (a PhD faculty member and a doctoral student). The translators subsequently agreed on a final version. The questionnaire was then read and approved by the director of the Spanish-speaking parent association. No qualitative differences were noted by any of the translators in the final Spanish version of the questionnaire.

Both questionnaires included demographic information (age of child, child’s ethnicity, mother’s education level), description of the current educational program in which the child with Down syndrome was participating, satisfaction with that program, and desire for change. The survey included both forced-choice (quantifiable) categories as well as opportunities to specify, elaborate, and explain responses in a qualitative fashion. In addition, parents were given the opportunity to identify themselves by name, address, and phone number so that they could be informed about the results of the study. A series of separate chi-square analyses were conducted using parents who identified themselves and parents who did not on age group, current program, mother’s education level, ethnicity, and desire for change; no significant differences were found. In addition, an independent sample t test was conducted to examine any differences between the two parent groups (parents who identified themselves vs. parents who did not) on level of satisfaction; the results were insignificant.

This article focuses on a portion of the data set: satisfaction with current program and the desire for change. Satisfaction was measured on a 5-point Likert scale (1 = very dissatisfied, 3 = neither satisfied nor dissatisfied, and 5 = very satisfied). Parents were then asked, “Have you considered changing your child’s program?” They could respond with “yes,” “no,” or “uncertain.” If their response was “yes” or “uncertain,” they were asked to please explain the reason for their response. All names given by parents have been changed to protect anonymity.

Using the qualitative data, we sought to understand the situation as it was perceived by these participants. Additionally, our aim was to relate satisfaction and desire for change to dimensions of parents’ own personal situations (e.g., age of child, child’s current educational program).

An important concern in such studies is the need to consider both the validity and generalizability of the qualitative interpretations. Strauss (1991) noted that in naturalistic research, there are no convenient quantitative indicators of “validity” or “generalizability.” However, to systematically determine and validate the themes from this questionnaire, one undergraduate research assistant and one graduate research assistant individually read all of the comments from the question, “Have you considered changing your child’s program?” They independently grouped the comments together according to themes that they believed were expressed by the parent. The undergraduate coder identified 10 themes, while the graduate coder identified 7 themes. Any grouping of less than five comments was not included, and some themes were combined (e.g., inclusion and mainstreaming were combined to form “desire for greater inclusion”; therapy, speech and language, and need for an aide were combined to form “additional services”). Thus, seven themes arose: school transition points, desire for greater inclusion, placement in a neighborhood school, additional services and support, influence of peers, parents’ financial resources, and ongoing information acquisition/decision making. Comments such as “Don’t know” and “Nothing available” were considered not categorizable.

To establish agreement on the themes, the two coders recoded the data for placement within these seven categories. For school transition points, the two coders agreed on 73.1% of the comments; for greater inclusion, the agreement was 80.6%; for placement in neighborhood school, the agreement was 80.0%; for additional services, the agreement was 70.3%; for influence of peers, the agreement was 83.3%; for parents’ financial resources, the agreement was 100%, and for ongoing information, the agreement was 100%. Thus, total average agreement for all comments was 83.9%. Disagreements were discussed and a category was agreed on.

In addition to the already mentioned methods of establishing validity and reliability, we sought to establish face validity for these themes by conducting a follow-up interview with 10% of the sample (30 parents). We identified 10% of the sample from each age group that were equally distributed in each of the three educational settings (early intervention, special education, and general education). First, a phone call was made to get permission to elicit their participation in this validation. All parents identified in the sampling agreed to participate. Then, the draft document depicting our “patterning” of parents’ perspectives was circulated to the respondents for comment and criticism. Personal phone interviews were then conducted approximately 2 weeks after receipt to determine the “reasonableness,” or face validity, of the patterns. Parents were asked if they felt that each theme was reasonable, and they were asked to comment generally about the draft. All 30 parents interviewed expressed agreement that each theme appeared reasonable and valid. A form of this procedure was previously used (Alkin, Daillak, & White, 1979) and cited in Yin (1989) as an exemplary method for validating naturalistic data.

Results

Satisfaction

The mean satisfaction levels by age group, current program, and mother’s education level are presented in Table 1. An Age Group x Current Program x Mother’s Education Level analysis of variance (ANOVA) on satisfaction indicated significant main effects of all three independent variables. Follow-up
TABLE 1. Levels of Satisfaction by Age Group, Current Program, and Mother’s Education Level

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>M*</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 to &lt; 3 years*</td>
<td>52</td>
<td>4.06</td>
<td>0.83</td>
</tr>
<tr>
<td>3 to &lt; 6 years</td>
<td>63</td>
<td>3.84</td>
<td>1.14</td>
</tr>
<tr>
<td>6 to &lt; 10 years</td>
<td>63</td>
<td>3.49</td>
<td>1.34</td>
</tr>
<tr>
<td>10 to &lt; 14 years</td>
<td>57</td>
<td>3.72</td>
<td>1.26</td>
</tr>
<tr>
<td>14 to &lt; 21 years</td>
<td>56</td>
<td>3.37</td>
<td>1.10</td>
</tr>
<tr>
<td>Child’s current program</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early intervention</td>
<td>51</td>
<td>4.04</td>
<td>0.89</td>
</tr>
<tr>
<td>Special education**</td>
<td>80</td>
<td>3.35</td>
<td>1.21</td>
</tr>
<tr>
<td>Special education/ mainstreaming**</td>
<td>102</td>
<td>3.54</td>
<td>1.12</td>
</tr>
<tr>
<td>General education</td>
<td>57</td>
<td>4.14</td>
<td>1.25</td>
</tr>
<tr>
<td>Mother’s education level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma or less</td>
<td>77</td>
<td>3.53</td>
<td>0.99</td>
</tr>
<tr>
<td>Community college/vocational school</td>
<td>90</td>
<td>3.63</td>
<td>1.17</td>
</tr>
<tr>
<td>Four-year college</td>
<td>60</td>
<td>3.57</td>
<td>1.17</td>
</tr>
<tr>
<td>Beyond bachelor’s degree*</td>
<td>59</td>
<td>4.14</td>
<td>1.31</td>
</tr>
</tbody>
</table>

*Five-point Likert scale (1 = very dissatisfied and 5 = very satisfied).
*p < .05. **p < .001.

one way ANOVA tests indicated that parents of children from birth to age 3 were significantly more satisfied with their child’s current program than parents of children over 14, F (4, 286) = 3.08, p < .05. Parents of children in special education were significantly less satisfied than parents of children in early intervention and general education, F(2, 228) = 10.84, p < .0005. Mothers with education beyond a bachelor’s degree were significantly more satisfied than mothers in all other categories of less education, F(3, 282) = 3.69, p < .05.

Change

Descriptive information on the demographic characteristics of parents who considered changing their child’s current program can be found in Table 2. Over the entire sample, 103 respondents (35%) indicated that they considered changing their child’s program. Thirty-three respondents (12%) indicated that they were uncertain, and the majority, 155 (53%), noted that a change was not currently being considered.

There were significant differences across current programs in whether changes were considered. Follow-up 2 x 2 chi-square analyses indicated that parents whose children were in general education were least inclined to consider changing programs, χ² (4, N = 291) = 11.15, p < .05. There were no significant differences in the extent to which mother’s education level or age of child was related to respondent’s desire for change in program.

Parents’ desire for change also varied significantly depending on level of satisfaction, χ² (8, N = 287) = 96.61, p < .001. The proportion of parents who wanted program change decreased with satisfaction level. Seventy-four percent of parents who were dissatisfied were considering change. On the other hand, of the parents indicating that they were satisfied, only 25% were considering change.

Reasons for Considering Change

Ninety-four of the 103 parents who indicated that they had considered changing their child’s program provided a written explanation. Moreover, 11 of the 33 parents who indicated that they were uncertain wrote an explanatory comment. Thus, the seven themes that follow are based on analyses of these 105 responses.

Table 3 depicts the breakdown of the percentage of responses within each of the seven themes by age group. Most of the parents with school-age children (6-10 years) desired greater inclusion and additional services, while parents of younger children (both 0-3 years and 3-6 years) were concerned about their children’s transition into new programs.

It must be noted that some parents commented on more than one theme within a single response. For example, one parent of a 26-month-old child who wanted to change her child’s current educational placement stated, “Trying to add outside speech therapy. Plan to also put her in a regular full-time preschool before the age of 3.” Thus, the total number as separated by theme may be greater than the total number of respondents.

School Transition Points. About 25% of respondents indicated that their primary reason for considering change was that a school transition point was approaching. The implication is that, in large part, children are part of an educational system, and the organizational structure of that system is the primary determinant of when change will take place. The transition points noted in parent comments were preschool, kindergarten, junior high school/middle school, and post high school.

One half of those who made age- or grade-related responses had children who were turning 3 years old. Thus, for this group, preschool decisions were imminent. The responses in most instances were fairly straightforward: “My child will be integrated into public school at the age of 3.”

Another two identified decision points were entry into kindergarten and entry into junior high/middle school. However, there were no comments related to high school entry. Finally, some parents did present thoughts related to the post-high school period. One parent indicated that her child would be graduating from high school this June and there was a need to “try to get some college program.” Another expressed concern about finding an appropriate “training program.”

Desire for Greater Inclusion. When parents indicated a desire for change based on a program type, virtually all the
### TABLE 2. Desire for Change, by Family Demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>n</th>
<th>Yes (%)</th>
<th>No (%)</th>
<th>Uncertain (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 to &lt; 3 years</td>
<td>55</td>
<td>31</td>
<td>51</td>
<td>18</td>
</tr>
<tr>
<td>3 to &lt; 6 years</td>
<td>62</td>
<td>34</td>
<td>58</td>
<td>8</td>
</tr>
<tr>
<td>6 to &lt; 10 years</td>
<td>63</td>
<td>44</td>
<td>48</td>
<td>8</td>
</tr>
<tr>
<td>10 to &lt; 14 years</td>
<td>56</td>
<td>36</td>
<td>57</td>
<td>7</td>
</tr>
<tr>
<td>14 to &lt; 21 years</td>
<td>55</td>
<td>31</td>
<td>51</td>
<td>18</td>
</tr>
<tr>
<td>Child’s current program</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early intervention</td>
<td>54</td>
<td>35</td>
<td>48</td>
<td>17</td>
</tr>
<tr>
<td>Special education</td>
<td>78</td>
<td>36</td>
<td>47</td>
<td>17</td>
</tr>
<tr>
<td>Special education/mainstreaming</td>
<td>101</td>
<td>40</td>
<td>50</td>
<td>10</td>
</tr>
<tr>
<td>General education*</td>
<td>57</td>
<td>28</td>
<td>70</td>
<td>2</td>
</tr>
<tr>
<td>Mother’s education level</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma or less</td>
<td>78</td>
<td>28</td>
<td>54</td>
<td>18</td>
</tr>
<tr>
<td>Community college/vocational school</td>
<td>91</td>
<td>36</td>
<td>52</td>
<td>12</td>
</tr>
<tr>
<td>Four-year college</td>
<td>60</td>
<td>37</td>
<td>52</td>
<td>12</td>
</tr>
<tr>
<td>Beyond bachelor’s degree</td>
<td>57</td>
<td>42</td>
<td>54</td>
<td>4</td>
</tr>
</tbody>
</table>

*p < .05.

### TABLE 3. Reasons for Wanting Program Change: Responses by Age Group

<table>
<thead>
<tr>
<th>Age Group (in years)</th>
<th>0-3 (n = 19)</th>
<th>3-6 (n = 22)</th>
<th>6-10 (n = 32)</th>
<th>10-14 (n = 14)</th>
<th>14-21 (n = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Themes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School transition</td>
<td>38% (8)</td>
<td>28% (9)</td>
<td>9% (4)</td>
<td>14% (3)</td>
<td>11% (2)</td>
</tr>
<tr>
<td>(n = 26)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Desire for inclusion</td>
<td>10% (2)</td>
<td>25% (8)</td>
<td>29% (13)</td>
<td>23% (5)</td>
<td>11% (2)</td>
</tr>
<tr>
<td>(n = 30)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighborhood school</td>
<td>0%</td>
<td>6% (2)</td>
<td>14% (6)</td>
<td>4% (1)</td>
<td>5% (1)</td>
</tr>
<tr>
<td>(n = 10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional services</td>
<td>19% (4)</td>
<td>22% (7)</td>
<td>35% (15)</td>
<td>23% (5)</td>
<td>26% (5)</td>
</tr>
<tr>
<td>(n = 36)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Influence of peers</td>
<td>19% (4)</td>
<td>6% (2)</td>
<td>4% (2)</td>
<td>4% (1)</td>
<td>16% (3)</td>
</tr>
<tr>
<td>(n = 12)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents’ finances</td>
<td>5% (1)</td>
<td>6% (2)</td>
<td>2% (1)</td>
<td>4% (1)</td>
<td>5% (1)</td>
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<tr>
<td>(n = 6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ongoing information</td>
<td>5% (1)</td>
<td>3% (1)</td>
<td>4% (2)</td>
<td>9% (2)</td>
<td>0%</td>
</tr>
<tr>
<td>(n = 6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not categorized</td>
<td>5% (1)</td>
<td>3% (1)</td>
<td>2% (1)</td>
<td>18% (4)</td>
<td>26% (5)</td>
</tr>
<tr>
<td>(n = 12)</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Note. n = Number of parents in that age group who answered "yes" or "uncertain" to the question, "Have you considered changing your child’s program?" and who wrote comments.
responses were in the direction of greater inclusion for their child. Some parents spoke more generally about "mainstreaming" as the explanation for considering a change in their child’s program. Comments were as simply stated as the following: "Change schools; I want her mainstreamed." Other responses on a similar theme were more elaborate, for example, "We are currently in negotiations with the school district to move Albert into a special day class at his home school. We want to mainstream Albert into second grade in afternoons, recess, and lunch."

**Placement in a Neighborhood School.** Very typically, the discussion of inclusion involved the desire to have one's child in the neighborhood school. As pointed out by Albert's parent in the previous quotation, negotiation not only related to mainstreaming but also to providing an educational placement in a local home school. Typically, many who mentioned inclusion as the reason for a desired change also incorporated neighborhood schools within their response, as exemplified by the parent who simply noted, "fully included at home school." Others provided more elaborate responses on the same theme: "We removed Jody from a county program for this school year and placed her in our home district in our neighborhood schools within their response, as exemplified by Albert's s

**Additional Services and Support.** A major theme cited as a reason for wanting change was the need for additional services and support. The comments focused on specific supplemental services parents felt would be helpful, perceived deficiencies of their child’s current teacher, or more general concerns about the need for a "supportive environment." Some parents noted the need for greater assistance in general terms. "I would like my daughter to be in the same class she is in now but that she have more attention from her teachers or the teacher's aide so she can develop more of her talents and mental capacities."

In contrast, another parent stated most parents’ aspirations simply and directly: "My daughter needs a classroom of general education with the resources of special education." Other calls for supplemental services referred more specifically to current school programs and noted deficiencies in support services and staff. Respondents commented on such things as "adding additional speech/language intervention" and "more classes in writing, reading, adaptive P.E."

A number of parents cited the current teacher's insufficient training or lack of support of their child. Some parents admonished their child's current teachers; one specifically noted, "I wish my child’s teacher was better trained to understand and deal with problems and special needs of children with Down syndrome."

**Influence of Peers.** Parents also mentioned school peers as an influence when they were considering changes in program. Program change decisions attributable to the influence of peers focused on different issues. Some referred to peer modeling as a positive influence; others commented on harassment by peers as a reason for change.

On the one hand, the parent of an 8-year-old child currently being mainstreamed and desiring a placement in general education noted, "I want my child to be in inclusion, to be able to socialize with the other kids." Another parent expressed the desire for a greater level of inclusion for her child "because now she is one of the oldest in the classroom and that is not helping her in her behavior and role models."

Another parent of a child in a separate special education classroom commented. "I want to change my daughter to a regular school because my daughter imitates other kids."

Some parents addressed harassment issues:

When she was in the seventh grade, two students kept teasing her. The special education teacher and regular education teacher tried to help but couldn’t always ... it worked out well but we really worried over it.

Because child was being teased and harassed. The physical education teacher, I felt was incompetent to deal with [child's] behavior.

**Parents’ Financial Resources.** Private financial resources were mentioned by a number of parents in their comments about considering change in their child's school program. In some instances, availability of personal resources helped to facilitate the program change decision; in others, the lack of financial resources was viewed as a constraint on decision making. Among those for whom available financial resources was an enabler, one parent, who indicated the desire to have her child mainstreamed, further noted, "I also have a very good 'daycare teacher' and she learns more there than at school."

Many parents recognized the benefits of providing privately funded services, but cited financial constraints: "The alternatives are relatively expensive for us. They involve private preschool which would not be funded by the regional center."

**Ongoing Information Acquisition/Decision Making.** Another major theme highlighted the process of ongoing information acquisition and decision making. Responses indicated that many parents were actively engaged in information acquisition and decision making on an ongoing basis, while others, who perhaps had examined alternatives, expressed a deep sense of frustration.

Several themes emerged among those who commented on information acquisition/decision making: the ongoing nature of the activity, the end of the year as a demarcation point, and the dependence on school district actions:

It would be nice to know what choices there are and what they mean before he is pushed into one.
We go on a year-to-year basis and choose the best program for his needs each year.

A number of respondents indicated a desire for program change, but their comments conveyed a sense of deep frustration. The following remarks present a picture of disillusionment with available alternatives:

- Nothing but a special education campus available.
- No other options available at this time.
- I have been told that this is the only program available.

These parents represent an interesting pattern. Each had a child with Down syndrome in the 14- to 19-year-old range who was in a special education class with some mainstreaming. When asked to identify an ideal program, each indicated the same program type in which the child was currently enrolled, opting not to check any additional program alternatives. Each indicated a desire to change their child’s program but appeared to be frustrated with existing alternatives.

**Discussion**

This study’s purpose was to examine parents’ satisfaction and desire for change in the programs of their children with Down syndrome. Quantitative data were collected via forced-choice questions; qualitative analysis provided additional insight into parents’ reasons for change. The study goes beyond related research in its specific focus on children with Down syndrome and in the consideration of children beyond the preschool age level.

In general, parents in all settings were reasonably satisfied with their child’s current program. Greater levels of satisfaction were found among parents of children in general education classrooms. This is an important finding. Turnbull and Winton (1983) found that “anecdotally, parents presented themselves as being satisfied with services [in both programs]” (p. 69). They did not examine overall program satisfaction. McDonnell (1987) found no significant differences in parent satisfaction level between two groups of parents of children with a variety of disabilities—those enrolled in special schools and those enrolled in integrated schools. It may be that the present specific focus on overall program satisfaction as well as the etiology-specific sample accounted for the differences we found.

There was a strong relation between parent satisfaction and desire for change across the sample. We found that mothers whose education was beyond the bachelor’s degree were more satisfied with their child’s current program. It may be that well-educated parents have a greater involvement in school program decisions and an increased likelihood of influencing their desired choices. Indeed, Goldring and Shapira (1993) noted that there was a significant relation between parents’ education and level of satisfaction with schools. They attributed this relation to the enhanced empowerment of well-educated parents. However, the greater satisfaction among these parents in our study did not lead to less desire for change relative to other parent groups.

Several themes emerged in terms of parents’ reasons for wanting change in program placement. First, parents desired more inclusive programs for their children. Of those who wanted change for programmatic reasons, all but one comment was specifically directed toward a desire for inclusion. The qualitative data yielded several patterns that support parent satisfaction with, and desire to maintain, an inclusive program for their child. Particular support was expressed in comments related to the advantages of neighborhood schools and the positive aspects of peer modeling. This influence of peers and desire for “real-world” participation has been confirmed by various researchers (e.g., Bailey & Winton, 1987; Reichart, Lynch, Anderson, & Svobodny, 1989).

However, in this study, parents also expressed concern about the possibility that their children might be teased or harassed, particularly when their children moved to middle school and high school. Guralnick et al. (1995) and Turnbull and Winton (1983) each mentioned parent concern about teasing, but subsequent research focusing only on preschool populations demonstrated that harassment was more perceived than real (Collins, 1995). The failure in the literature to identify negative peer influences across age groups beyond preschool suggests the need for further research.

Another theme related to children’s age. We found the highest desire for change in parents of children who were between 6 and 10 years of age, with decreasing percentages in each of the next two age groups. On the other hand, the qualitative data highlight a need for change at school transition periods. However, parents whose children were over the age of 14 and enrolling in high school did not specifically comment on their desire for change. Taken together, it may be that parents feel that there are more program choices available at earlier age levels, with decreasing options as the child gets older. It may be that there is a time in a child’s educational career when parents simply give up looking for alternatives because they have “fought the battle” and feel that they have done all that they can.

Parents viewed school and program decision making as a matter for continuing concern. In essence, satisfaction is transitory and the desire for change is constant. Parents cited the need to wait for school district decisions that would create program options they could choose from each year. School district decisions such as which schools will have inclusive programs and whether neighborhood schools are on that list shape the decisions parents make about changing their child’s program. School administrators, therefore, should continue to make available new and more effective program options for parents.

Further, parents commented on the availability of personal financial resources as a factor in program decisions. Typically, these resources were viewed as a means of supple-
menting deficiencies in school programs. A number of parents indicated that lack of financial resources constrained their program choices. Interestingly, half of the parents who indicated financial resources as a constraint had attended 4-year college and half had attained a bachelor’s degree or beyond. Presumably these parents should be among the more financially able of those within the study. However, it is possible that parents who were financially less well off did not cite finances as a constraint simply because they did not consider program changes at all.

There are several possible limitations to this study. First, because qualitative categories were generated from the open-ended survey response data, we did not have the opportunity to follow up with respondents and exhaust all possible answers (saturate respondent answers), as would have been possible in an interview format. However, we partially addressed this problem in two ways. First, we used a very large sample size; thus, even if only a small proportion of participants responded, we still had many responses. Second, and most importantly, follow-up interviews ensured that the responses that we did have were not atypical.

A second possible limitation of this study was the unavailability of the children’s current level of functioning (either through intelligence scores or current placement categories). However, given California’s inconsistent use of intelligence testing and the changes in classification for children with mental retardation, we felt that parents would be unable to accurately report their child’s level of functioning. As in earlier studies, however, we assumed that most children in our study were functioning in the moderate range of mental retardation (Hodapp, 1996).

Future research might focus on the relations between child’s ability level and parental perceptions in another geographic location where categories or intelligence test scores are recorded more systematically. This might provide a clearer relationship between the child’s ability level and the parent’s level of satisfaction and desire for change. We might also suggest an investigation of these responses using parents of children with other etiologies to consider the specific characteristics that might influence parents’ satisfaction and desire for change.

Practitioners may want to use the results of this study to determine parents’ satisfaction, desire for change, and perceptions of program needs. These data are important for designing programs for children with Down syndrome. Clearly, parents play an integral part of all programmatic decisions, and they are aware of the many aspects that make a satisfactory program for their child.

In conclusion, this study, focusing on parents’ level of satisfaction and desire for change, has confirmed a number of the findings in associated literature. Furthermore, several elements of this study—the focus on a specific etiology, the large sample size, the wide age range examined, the qualitative data, and the direct examination of satisfaction and change—have provided new insights into parents’ perceptions of programs for children with mental retardation.

STEPPHANNY F. N. FREEMAN, PhD, is a postdoctoral fellow in the Department of Child and Adolescent Psychiatry at the University of California, Los Angeles. Her research interests include factors associated with educational placements of children with disabilities, the friendship development of children with Down syndrome, and the social-emotional development of children with autism. MARVIN C. ALKIN, EdD, is a professor in the Social Research Methods Division of the Graduate School of Education and Information Studies at the University of California, Los Angeles. His long-term research interests have focused on the evaluation of educational and other social programs. Inclusion questions related to children with Down syndrome form a major part of his current research interests. CONNIE L. KASARI, PhD, is an associate professor in the Division of Psychological Studies in Education of the Graduate School of Education and Information Studies at the University of California, Los Angeles. Her current research interests include the social relationships of children with disabilities, and social-communication interventions with children with autism and their families. Address: Marvin C. Alkin, University of California-Los Angeles, Graduate School of Education and Information Studies, Box 951521, 405 Hilgard Avenue, Los Angeles, CA 90095-1521.

AUTHORS’ NOTES

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