Actual Versus Desired Family-Centered Practice in Early Intervention for Children With Hearing Loss

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Early intervention programs (EIPs) for children with hearing loss (HL) are increasingly characterized by a growing family-centered orientation. This article examined mothers’ and professionals’ assessments of actual and desired parental involvement in 6 educational centers in Israel that implement an EIP for young children with HL and their parents. Hundred twenty mothers and 60 professionals participated in the study. Data were collected via FOCAS: Family Orientation of Community and Agency Services questionnaire (family and professional versions) that were initially designed in the United States for measuring the level of collaboration between professionals and parents in the course of early intervention. Descriptive statistics and t-test analyses were calculated. The findings indicated that parental involvement in the programs was perceived by mothers and professionals as satisfactorily family centered. However, these programs also need further improvements. Outcomes suggested that parents should be offered a wide range of services to respond to diverse needs, thus increasing parental motivation to become increasingly involved in EIPs.

Over the past four decades, early intervention programs (EIPs) have increasingly shifted toward a family-centered orientation, accentuating that the child’s family and community should take an active role in the habilitation process (Bronfenbrenner, 1974, 1992; Guralnick, 1997). In 2001, the U.S. Council for Exceptional Children: Division of Early Childhood published the Recommended Family-Based Practices Guidelines, which proposed that families and professionals should share responsibility and work collaboratively in family-centered EIPs (Hemmeter, Joseph, Smith, & Sandall, 2001). This policy is grounded in the belief that families should be strengthened to participate and become involved in monitoring the intervention for their children (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993).

Today, the concept of family-centered services dominates service delivery in many Western countries. Parents are invited to become involved in their child’s care and have the opportunity to share their opinions and preferences with professionals (Guralnick, 1997; Klassen et al., 2008; Klein, 1991). Dunst (2002) suggested that the label “family-centered EIP” should be reserved for practices that regard families with dignity and respect; that share information so that families can make informed decisions; that encourage family choices regarding any number of intervention options; that apply individualized, flexible, and responsive practices; that foster parent–professional collaboration and partnerships; and that provide and mobilize the resources and supports necessary for families to care for and rear their children in ways that produce optimal child, parent, and family outcomes. Fundamental elements of family-centered philosophies include treating parents as experts regarding their child and family needs and responding to such perceived needs and expectations to achieve their preferred outcomes (Ingber & Dromi, in press).

Professionals’ simultaneous uses of both relational and participatory resources define their beliefs and dictate their practices in family-centered EIPs (Dunst & Trivette, 1996). Relational components include professional skills such as active listening, compassion, empathy, respect, a nonjudgmental approach, and a set of beliefs about parenting capabilities and...
competencies. Participatory components include practices that (a) are individually tailored, flexible, and responsive to concerns and priorities of each family and (b) provide families with opportunities to be actively involved in decisions and choices, to collaborate with professionals, and to take actions targeting desired goals and outcomes (Bruder & Dunst, 2008; Epps & Jackson, 2000; Murray, Salomon, & Mathers, 2000; Sass-Lehrer, 2002).

A most important criterion in the evaluation of a program’s family centeredness is the extent to which parents participate during the planning and actual implementation of the clinical intervention (Gallagher, Rhodes, & Darling, 2004; McCracken & Baglin, 2000; R. A. McWilliam, Snyder, Harbin, Porter, & Munn, 2000). From the philosophical point of view, a family-centered program’s mission should state that parents comprise an integral component of the intervention (Mahoney et al., 1999).

In the case of young children with hearing loss (HL), family-centered EIPs are vital because of the crucial early decisions that parents should make with reference to the method of intervention (i.e., aural–oral, sign, or total—combination of spoken language and signs—communication) and the choice of hearing device (i.e., conventional hearing aid or cochlear implant). The family is required to make decisions as to whether the child will be educated using an aural–oral mode (auditory training, residual hearing, speech reading, and speech to communicate), a total mode (combination of spoken language and signs, which includes sign language, voice, fingerspelling, lipreading, amplification, writing, gesture, and visual), or a sign language mode (manual language used by the Deaf community). Such decisions should certainly involve intensive consultation between parents and professionals (DesJardin, Eisenberg, & Hodapp, 2006; Sass-Lehrer, 2002; Zaidman-Zait & Jamieson, 2007; Zaidman-Zait & Most, 2005). Furthermore, in this population the impairment of the children crucially affects the communication among all family members.

In many countries around the world, young children with HL receive intensive communication and language training in the home environment, or in educational centers as well as at the home. Hence, parents are encouraged to actively participate in therapy and also frequently asked to take part in consultation with professionals (e.g., DesJardin et al., 2006; Dromi & Ingber, 1999; Kaiser & Hancock, 2003; Moeller, 2000; Sass-Lehrer & Bodner-Johnson, 2003).

Very few studies to date have assessed the family centeredness philosophy and practice in EIPs for children with HL. In one such study, Tharpe (2000) found that 57% of the parents were dissatisfied with the way audiological evaluations were conducted and delivered to parents without accomplishing the philosophy of family centeredness. In the same study, 50% of the parents complained that their suggestions regarding the intervention contents with their children had not been considered by the professionals. Young et al. (2006) reported that parents of children with HL criticized professionals for not always making them fully aware of the available range of choices in supporting their child. Some parents stated that professionals give biased information on communication options. In other cases, parents described their relations with professionals as predominantly lacking an appropriate basis to fully support an independent decision-making process by parents.

The importance of empowering parents was seen by parents as one of the major factors in allowing children with deafness to fulfill their potential. The failure to empower parents, therefore, can be viewed as an obstacle in early interventions with deaf children (Gregory et al., 2001). However, some research evidence shows that not all parents necessarily desire such empowerment. Some parents prefer that professionals, who are experts in deafness, direct the major decisions about their child’s development (Powers et al., 1999).

Blue-Banning, Summers, Franklin, Nelson, and Beegle (2004) found that a major barrier to fruitful collaboration between professionals and parents was that parents were not perceived by professionals as equal partners who maintained control over the intervention. Similar findings were demonstrated by others (Blue-Banning, Turnbull, & Pereira, 2000; Harry, Rueda, & Kalyanpur, 1999; Jones, Garlow, Turnbull, & Barber, 1996; Turnbull & Turnbull, 2001). Eber (1996) noted that professionals often report...
discomfort when parents take on decision-making and leadership roles. Bailey, Blasco, and Simeonsson (1992) argued that professionals may be committed to working with families but may encounter difficulties in the implementation of their ideology due to a lack of the necessary skills to engage in mutual responsibility and full partnership with parents. Due to the diversity of parent and professional attitudes and behaviors surrounding early intervention, researchers have asserted that further studies on family-centered practices and the collaboration between professionals and families of young children with HL are desperately needed (Calderon & Greenberg, 1997; Guralnick, 1997).

Dinnebeil, Hale, and Rule (1996) pinpointed two main elements that are related to satisfaction from EIPs: first, philosophy—beliefs, values, and attitudes toward the family’s role in the program—and second, practice—ways in which parents and professionals work together. Dinnebeil et al. emphasized that the manner in which services are delivered and the interpersonal processes involved were the most important contributors to reported satisfaction. These findings indicate that both practice and philosophy are important for implementing a family-centered EIP, but what professionals say or believe is not always congruent with what they actually do in practice.

Although the theory that underlies family-centered EIPs is repeatedly advocated in the literature, limited scientific efforts have so far been directed at the investigation of optional gaps between philosophy and practice (Bailey, Buysse, Smith, & Elam, 1992; Bjorck-Akesson & Granlund, 1995; Crais, Poston, & Free, 2006). In other words, although family involvement in early intervention is frequently recommended, practices that are family centered are slowly emerging and in many countries are not yet fully developed and have not been directly investigated (Alliston, 2007). Therefore, despite the existence of models, principles, and recommended practices, it seems likely that one of early intervention’s greatest challenges is to integrate the statements into actions in EIPs.

It appears that the identification of key principles and recommended practices is an important step forward for the early intervention field, and in addition, there is an active research agenda considering not only how to implement those practices but also how to identify more explicitly what needs to be done for making desired principles into active practices.

Several previous studies on various populations of children with special educational needs directly assessed family centeredness via the utilization of scales specifically designed for that purpose. Such scales provide feedback to practitioners about the extent to which family service plans reflect family-centered principles, including information on family–professional collaboration. One of the most commonly used research instruments is the FOCAS: Family Orientation of Community and Agency Services (Bailey, 1990), a self-rating of family-centered practice in EIPs (P. J. McWilliam & Winton, 1991).

However, to the best of our knowledge, no research has assessed actual versus desired practices in Israeli EIPs for children with HL (Kesher) using internationally acknowledged measures of family centeredness.

Method

Current Study Objectives

This article was designed to systematically analyze family centeredness in six rehabilitation centers for children with HL in Israel. These centers have implemented a family-centered EIP since the early 1990s. Al-Yagon and Margalit (2005) reported that most of the 10 core criteria for family-centered programs, presented in Guralnick (2001), were observed in these centers. However, to the best of our knowledge, ours is the first empirical investigation of the Kesher EIP as judged by its parents and professionals, via the utilization of a direct measure of family centeredness.

Thus, the goal of this study was to explore the actual and desired family centeredness of EIPs for children with HL in the Israeli context, by investigating both parents’ and professionals’ viewpoints using the FOCAS questionnaire. The specific study goals were as follows:

1. To assess and compare mothers’ perceptions about the actual versus desired family centeredness of the Kesher EIP.
2. To assess and compare professionals’ perceptions about the actual versus desired family centeredness of Kesher EIP.
3. To examine the compatibility between parental and professional perspectives on family centeredness.

Setting: The MICHA Centers and Kesher EIPs

The same Kesher EIP is practiced in six educational centers throughout Israel: four centers for the general population (operated by the MICHA nonprofit organization for young children with HL in the age range of 0–7 years) and two very similar centers for the religious Jewish sector (for individuals with HL in the age range of 0–21 years). Altogether, these centers serve a culturally diverse population of Jewish and Arab, religious and nonreligious Israelis. The vast majority of Kesher families are Hebrew speakers because the centers’ formal standard language is Hebrew. Hearing parents comprise 88.3% of the centers’ population (compared to 90% in the United States; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003).

A very important goal in the Kesher philosophy and practice is to address the central role of the family in the child’s development. Parents are attributed with the utmost responsibility in the habilitation process and are granted respect for their expertise and role in decision making, in line with the internationally accepted family-centered approach. The parents participate in many activities such as information exchange meetings and advocacy training, and they are offered lectures on high-priority topics. Parents learn to promote their child’s conversational language and skills through play and everyday activities. They are also invited to actively participate in monitoring and developing communicative competencies with their child.

Providing emotional support for families comprises another essential component of the Kesher program. Such support helps families gain insight into their needs, strengths, and strategies for coping with crisis. Family members enroll in parents groups, which provide them the opportunity to share experiences and brainstorm possible solutions for raising their young child with an HL. Appreciation for unique family characteristics is fundamental to the Kesher program.

By offering a variety of options and collaborating with parents, the professionals can individualize the implementation of each intervention plan according to the family’s and child’s particular needs.

Participants

Participants were mothers and professionals recruited from all six educational centers throughout Israel that implement the same Kesher EIP, which espouses a family-centered philosophy and practice.

Mothers’ characteristics (N = 120). Participating parents were recruited through mailings to each center’s educational director, who directed the questionnaire to those 180 families who met the study’s recruitment criteria. Inclusion criteria required that the parent (a) had at least one child enrolled in Kesher for at least 1 year following the identification of the HL, to assure sufficient familiarity with the program’s philosophy and practices; (b) was Hebrew speakers, to ensure that he/she could complete the questionnaire; and (c) was the primary caregiver who is regularly involved in the EIP. In response to the latter criterion, only mothers qualified for participation in the sample. This coincides with previous research on fathers’ low rates of participation in EIPs (Raikes, Summers, & Roggman, 2005). Two thirds of the mothers (120 of 180) returned the completed questionnaire.

Mothers’ average age was 33.42 years (SD = 5.36) and mean educational level 13.30 years (SD = 2.28). Regarding mothers’ hearing status, most (88.3%) had normal hearing; only 11.7% (n = 14) had HL.

Their children with HL currently in the EIP had an average age of 53 months (SD = 21.29; range 12–95 months). Children’s mean age at beginning of intervention was 17.09 months (SD = 13.37; range 1–60 months). Children’s average length of time in EIP at the time of the study was 23.5 months (SD = 16.26; range 13–35 months) All the children had congenital, bilateral, sensorineural HL: 4.2% with mild HL, 29.2% with moderate HL, 27.4% with severe HL, and 39.2% with profound HL. All children in the study used personal amplification: 67% of the children used binaural hearing aids and 32.5% had...
cochlear implants. Regarding communication mode at home and in treatment, 60% of the children used aural–oral communication and 40% used total communication. One third of the families had more than one child with HL.

Professionals’ characteristics (N = 60). Professionals who worked in the EIPs were approached through mailings to each center’s educational director, who asked all 90 professionals in the six centers to complete the questionnaire. One third (30 of 90) of the completed questionnaires were excluded from the current study because those professionals did not have a therapeutic relationship with the families whose mothers participated in the study. The remaining 60 participating professionals included 20 speech and language therapists (33.3%), 23 kindergarten teachers (38.4%), 5 occupational therapists (8.4%), 8 social workers (13.3%), and 4 educational psychologists (6.6%). Their mean education level was 16.66 years (SD = 1.86) and their mean number of years experience working in their center 9.76 years (range 1–32). Most of the professionals had participated in a training program that prepared them to work with families, where they had learned how to support the family, to establish rapport with parents, to collaborate with them, and to empower them. Average length of time working in Kesher since their specialized training to support families was 1.56 years (range 1–2).

Instrument

Participants completed one of two versions of the FOCAS questionnaire: either for parents (FOCAS-PAR) or for professionals (FOCAS-PRO; Bailey, 1990; R. A. McWilliam et al., 2000). The FOCAS questionnaire was designed to explore parental and professional attitudes toward a family-centered orientation in EIPs for children with special needs and to assess respondents’ perceptions about how families are and should be included in family-oriented EIPs. The questionnaire was previously used largely in the Unites States (e.g., Crais, 1991) and in several cross-cultural studies (e.g., Bjorck-Akesson & Granlund, 1995). The FOCAS asks respondents to indicate current and desired practices on numerical scales, with behavioral anchors at each extreme and the midpoint of the scale. The FOCAS has been used in planning changes in preschool special education services, and its format has been shown to be sensitive to shifts in parents’ and professionals’ perceptions of special education practices during organizational change efforts (Bailey et al., 1992; Winton, McWilliam, Harrison, Owens, & Bailey, 1992).

Adaptation of FOCAS for application in Israel. To examine the questionnaire’s suitability to Israeli families with a child with HL, (a) we translated both versions from English to Hebrew and back to English by three different native English and Hebrew speakers, to ensure that the translation was adequate, using discussion to resolve any disagreements, and (b) we conducted a pilot study with three veteran Israeli professionals and with three Israeli mothers who were involved in their child’s EIP according to reports by professionals who worked with them in the past. In the pilot study, (a) the mothers completed the FOCAS-PAR, (b) the professionals completed the FOCAS-PRO, and (c) both groups were interviewed about the instrument’s applicability to the Kesher program, to family-centered philosophies and practices in Israel, and to the investigation of EIPs for children with HL. About 96% of both mothers and professionals stated that all the questionnaire items illustrated the family-centered orientation of Kesher. This finding convinced us that the Hebrew version of FOCAS is acceptable for application in Israel.

The 12-item questionnaire relates to typical EIP structures and practices that demonstrate a family-centered orientation: (a) program philosophy about working with families; (b) family–professional collaboration in developing the program philosophy; (c) parents’ participation in decisions about their child’s assessment; (d) parents as a part of and contributing to the child’s assessment; (e) identifying family concerns, priorities, and resources; (f) family participation in decisions about identifying family concerns and needs; (g) parents’ participation in team meetings; (h) parents’ role in decision making; (i) individualized family intervention plan services (IFPS) format; (j) family goals on the IFPS; (k) flow of services; and (l)
case management. Each item was scored on a 9-point scale ranging from a very professional-centered approach (1) to a very family-centered approach (9). The midpoint scores of the scale articulated an in-between predisposition to involve parents in the program but not to give them the role of leading the EIPs or being its core concern.

Each item was rated twice by all respondents, to compare mothers’ and professionals’ perceptions about (a) the actual family centeredness of the EIP for the child with HL (e.g., “What is happening now?”—mothers’ version) and depicting professionals’ utilization of family-centered strategies (e.g., “Where are you now?”—professionals’ version) and (b) the desired family centeredness of the EIP, or how the respondents would desire the situation to be regarding the EIP’s family centeredness (e.g., “What would you like to happen?”—mothers’ version) and regarding family-centered strategy utilization (e.g., “Where do you want to be?”—professionals’ version). The “actual” responses reflected respondents’ (parents’ and professionals’) perceptions of the current EIP, whereas the “desired” responses reflected respondents’ expectations from the program and motivation to modify and adapt a family-centered orientation in it. Each version of the questionnaire (for professionals and parents) showed an internal consistency (Cronbach alpha) of .83. R. A. McWilliam et al. (2000) previously reported the same internal consistency and also found stability of the measure over time, with no significant differences on a retest 8 months later.

Procedure

Mothers were asked to voluntarily participate in a study that aimed to help characterize and improve the design of more family-centered EIPs in Israel. Mothers were assured that all information would be collected and processed anonymously and that ethical clearance was followed according to Helsinki requirements. Only those mothers who agreed to participate in the study received the questionnaires through a graduate student who was blind to the purpose of the study and who assisted in data collection. The mothers were asked to complete the questionnaire at home within 2 weeks and to submit it in a sealed envelope to the main researcher’s office; precautionary steps were taken to ensure anonymity.

Professionals were invited to voluntarily complete the questionnaires while given the purpose of the study and promising them feedback on the results. The questionnaires were completed by the professionals in their free time and returned after 1 month.

Results

Mothers’ Perceptions About Actual Versus Desired EIP Family Centeredness

In line with the first goal of this study, mothers of children with HL reported slightly higher than the midpoint scores for all 12 “actual” items of the FOCAS-PAR ($M = 5.60, SD = 1.26$), thus indicating their perception that the actual approach employed by professionals in their intervention programs did encourage a family-centered orientation and expressing mothers’ overall satisfaction with the Israeli EIP’s actual practice. As seen in Figure 1, of all the actual practices evaluated, mothers gave the highest ratings to the program’s actual philosophy for working with families ($M = 6.93, SD = 1.61$), indicating that mothers appreciate professionals’ positive and supportive attitudes toward a central parental role in the EIP. Mothers gave the lowest ratings to professionals’ actual encouragement of the parental role and involvement in decision making ($M = 4.73, SD = 2.16$), indicating that mothers perceive professionals, on the one hand, as giving them a chance to make suggestions about what to work on and what services they need before designing the individualized plan but, on the other hand, as not sufficiently encouraging them to take charge of decision making or to carry the main influence during this process.

These mothers of children with HL reported a level higher than the midpoint scores for all 12 “desired” items of the FOCAS-PAR ($M = 6.94, SD = .96$), thus indicating their strong motivation to be involved and integrated into their children’s educational and rehabilitation process. As seen in Figure 1, of all the desired practices, mothers gave the highest scores to the program philosophy ($M = 7.69, SD = 1.29$), asserting mothers’ desire for an EIP philosophy that supports a family-centered orientation. Their lowest
scores were given to the desired parental role in decision making \( (M = 5.91, \text{SD} = 2.10) \), indicating that mothers expected the program to have a family-centered approach but did not desire more responsibility within the program’s decision-making process.

Concerning divergence between actual and desired practices in EIPs, mothers’ highest gap (2.47) emerged between their perceptions of the actual \( (M = 5.03, \text{SD} = 2.58) \) and the desired \( (M = 7.50, \text{SD} = 1.95) \) flow of services, indicating that professionals in the programs work within a multidisciplinary system but not as well as parents would like. The smallest gap (0.59) between actual \( (M = 6.22, \text{SD} = 1.59) \) and desired \( (M = 6.81, \text{SD} = 1.34) \) practices emerged for parent participation in team meetings, implying that mothers perceived professionals as encouraging parents to participate and contribute to professional meetings but had no motivation to become more involved in team meetings.

To examine the divergence between the total actual score and the total desired score, we conducted a \( t \) test for dependent variables. A significant difference emerged between mothers’ actual and desired scores, \( t = 12.16, p < .001 \), accentuating greater maternal motivation to be involved in the program and to see a family-centered approach than that perceived as occurring in actuality in the Kesher EIP.

Professionals’ Perceptions About Actual Versus Desired EIP Family Centeredness

In addressing the second goal of the study, professionals working with these families evaluated their actual practices at the FOCAS-PRO scale’s midpoint \( (M = 4.90, \text{SD} = 1.08) \) for all 12 “actual” items. As seen in Figure 2, of all the actual practices evaluated, professionals, like mothers, gave the highest ratings to the program’s actual philosophy for working with families \( (M = 6.77, \text{SD} = 1.77) \), indicating that professionals believe in and support parents’ central role in the EIP.

Professionals gave the lowest rates to parents’ actual involvement in their child’s assessment \( (M = 4.33, \text{SD} = 1.97) \), suggesting that professionals believe parents should be involved but not in charge of their child’s assessment process.

Professionals’ FOCAS-PRO responses regarding their desired approach to the parents’ part in the intervention program revealed a level higher than the midpoint scores for all 12 “desired” items \( (M = 6.95, \text{SD} = .93) \), thus indicating professionals’ strong motivation to encourage the family to take on an essential role in the EIP and to be involved and integrated into their children’s educational and rehabilitation process. As seen in Figure 2, of all the desired practices, professionals gave the highest mean

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**Figure 1** Mean scores for mothers’ evaluations of actual and desired early intervention practices using the FOCAS: Family Orientation of Community and Agency Services questionnaire. Note. IPF = individualized intervention plan format; IFPS = individual family plan services.
score \( (M = 8.13, SD = 1.27) \) to the program’s desired philosophy for working with families, asserting professionals’ motivation to offer intervention adapted to the central role of parents in the EIP. Their lowest mean score \( (M = 5.82, SD = 1.69) \) was given to the desired parental role of taking a central part in the assessment procedure, indicating that professionals expected the mothers to be involved in the process of decision making about the child’s assessment but did not wish mothers to take on central responsibility in this matter.

Concerning divergence between actual and desired practices in EIPs, professionals’ highest gap (2.06) emerged between their perceptions of the actual multidisciplinary flow of services \( (M = 6.04, SD = 1.81) \) and their desired flow of services \( (M = 8.10, SD = 1.20) \), indicating that professionals in the programs understood the parental need for incorporated services but could not accomplish it as much as they would have liked. The smallest gap (1.02) between actual \( (M = 6.46, SD = 2.20) \) and desired \( (M = 7.48, SD = 1.57) \) practices emerged for identifying family needs and strengths, implying that professionals perceived themselves as already gathering information not only on the child’s needs but also on the whole family’s needs and strengths, and they had no motivation to enhance this process.

To examine the divergence between professionals’ total actual performance score and their desired practices score, we calculated Pearson correlation coefficients. The high correlation \( (r = .57, p < .001) \) indicated the reciprocal connection between professionals’ actual and desired attitudes toward family-centered EIPs, indicating that there was no significant divergence between professionals’ actual versus desired scores.

Mothers’ Versus Professionals’ Perceptions About Actual/Desired EIP Family Centeredness

To examine the study’s third goal, a unidirectional multivariate analysis of variance with repeated measures was conducted for the mothers’ and professionals’ actual and desired FOCAS scores. Post hoc comparisons revealed that only the perceptions about the actual approach toward parental involvement yielded a significant difference between the two groups, \( F(2, 57) = 9.01, p < .001 \). Mothers reported a program approach that was more family centered \( (M = 5.59, SD = 1.12) \) than the professionals judged \( (M = 4.90, SD = 1.08) \). Furthermore, in calculating Pearson coefficients, no significant correlation was found between mothers’ and professionals’ actual versus desired FOCAS scores. In other words, maternal......
actual and desired perceptions about family involvement in EIPs were not associated with professionals' attitudes toward parental involvement and their motivation to accomplish it.

Discussion

The current findings indicated that parental involvement in Kesher, an Israeli EIP for children with HL, is perceived by mothers as satisfactorily family centered yet as needing some further improvement. Our results coincide with previous studies conducted in the United States on other populations with special needs. Several authors have claimed that despite the remarkable current shift in EIPs toward a family-centered approach, considerable advances are still needed to enhance a mutual and an active partnership between parents and professionals (Calderon & Greenberg, 1997; Dunst, 2000; Guralnick, 1997; Iversen, Shimmel, Ciacera, & Prabhakar, 2003).

Mothers’ Perceptions

Interestingly, the mothers in the present sample ranked the philosophy of the program as moderately family centered. They perceived most activities that are geared toward collaborative efforts as currently practiced at slightly above midpoint levels (5.6 on a scale of nine points). The significant difference that emerged between mothers’ actual and desired scores indicated that these Israeli mothers expressed a strong desire to enhance collaborative practices even further. They wished to close the existing gap between their desire to become more actively involved in their child's program and the actual practices that they currently experienced.

Mothers in this study expressed satisfaction with professionals’ actual attitudes and practices toward family participation in the program. They described professionals as willing to collaborate with parents, as encouraging parents to participate in assessing the child, and as empowering them in the process of early intervention. Along the same lines, mothers expressed strong motivation to become even more involved in the program as well as a desire to become a larger part of the planning team and child assessment procedures. This finding substantiates the recommendation made in the United States by Sass-Lehrer in 2002 to further encourage parents’ active participation during the assessment process.

The current mothers’ wish to play a more active and central role in decision making corroborates McGregor’s (1960) and Tuckman’s (1999) research, which claimed that the role of motivation in determining the level of activities in any given plan is highly important. When addressing practical issues that reflect EIP practices, such as decision making and participation in assessment, mothers in the current cohort expressed their view that in practical matters, professionals are (in actual practice) and should be (in desired practice) the leaders of the habilitation process.

Mothers in this study expressed a desire for more interdisciplinary teamwork, greater professional guidance concerning decision making, and increased support by a team that works together and cooperates with them. These findings validate Roush’s (1994) and Young et al.’s (2006) studies that described parents’ need to obtain information and guidance from professionals and at the same time their expectation to be assisted by a large team in making their own decisions at later stages.

Notably, maternal perceptions about desired involvement in decision making revealed a high standard deviation (2.09), indicating that the level of desired involvement in EIPs is not identical for all parents. Different families choose to participate in different activities within EIPs and may choose to adopt diverse styles of involvement as well as various degrees of collaboration with professionals.

Professionals’ Perceptions

Our results show that the Israeli professionals in our sample are committed to the philosophy of encouraging parental involvement in EIPs for children with HL. Unsurprisingly, those who reported positive attitudes toward parental involvement also desired an amplification of family-centered services. Interestingly, professionals reported a highly family-centered philosophy similarly to mothers, but when relating to practical matters (participation of parents in assessment and decision making), they only revealed a moderately family-centered attitude, expressing their difficulty in
implementing services that involve the family as the primary leader of the intervention processes.

Bruder (2000) and Guralnick (1997) pinpointed a prevalent difficulty in implementing family-centered intervention when professionals maintain the attitude that they are the “experts” and that family members are the “clients” or “patients.” When professionals assume control and make all the cardinal decisions on their own, they may consider the parents only insofar as they can carry out given instructions in accordance with the program goals. These researchers highlighted the advantages of viewing parents as a resource of knowledge and as experts with reference to their children’s developmental needs. They emphasized that professionals must acquire the knowledge and skills necessary to help promote parents’ decision making, choices, and self-determination within the EIP (see also Dromi & Ingber, 1999; King et al., 2003; Trivette, Dunst, & Hamby, 1996; Turnbull, Turbiville, & Turnbull, 2000).

Professionals’ attitudes toward parents have repeatedly been shown to be the critical variable in predicting the amount and quality of parental involvement in family-centered practices (Hilton & Henderson, 1993; Minke & Scott, 1995). Research has shown that many professionals do favor collaborative interactions with parents but that very frequently a gap exists between their positive attitudes toward collaboration and their actual practice (R. A. McWilliam et al., 1998, 2000; Sanders, 1999).

In support of Dinnebeil et al.’s (1996) conclusion that what professionals say or believe does not always coincide with their actual performance in practice, the currently studied professionals revealed a gap between the actual and the desired flow of EIP services. Thus, professionals appeared to understand the parental need for incorporated services but did not attempt to carry this out as well as they would have liked. It seems that professionals still have some barriers in responding to parental needs in family-centered EIPs, underscoring the need to provide professionals with appropriate training and support to ensure that they will acquire the knowledge and ability necessary to further enhance parental involvement (Bailey & Bruder, 2005; Bailey, McWilliam, Winton, & Simeonsson, 1992).

Nevertheless, the significant correlations that emerged here between professionals’ assessments of their actual and desired approach to family-centered EIPs support the claim that professionals who had a high motivation to increase parental involvement were also more sensitive and open to actually enhancing parental involvement and collaborating more efficiently with the parents.

Mothers’ Versus Professionals’ Perceptions

The comparison of parents’ and professionals’ views of early intervention services reveals some common ground as well as some important differences between these two groups. In terms of their judgments of the family centeredness of early intervention services, both parents and professionals felt that Kesher EIPs were generally good at providing family-centered services and treating the families in a supportive and caring manner. At the same time, both groups viewed the EIP as relatively poor at empowering parents to become leaders in decision-making processes concerning their child with HL. These findings support previous results by Moore and Larkin (2006).

The difference found between mothers’ and professionals’ judgments on the level of collaboration in Kesher indicated that mothers viewed the program as more collaborative than the professionals did. Similarly, mothers’ motivation for collaboration was higher than their perceptions about professionals’ actual efforts to create family-centered EIP. As Dinnebeil et al. (1996) stated that sometimes the gap between the declared attitudes of parents and professionals rests in the differences involving perceptions about decision making, locus of control, and mutual communication. These variables need to be studied further in future research.

Interestingly, our findings revealed that mothers in the current study articulated their independent views about the level of centeredness that they wanted and actually experienced in the EIP for their children. Mothers’ judgments were not directly linked to the attitudes of the service providers in Kesher. This finding is encouraging as it shows that the participants of the current study felt sure of themselves, were not hesitant to express their views, and were also confident that they can share their judgments with us.
Taken together, the findings of this study corroborate Dunst and his colleagues’ hypothesis that in many programs that adopt the philosophy of active collaboration between professionals and parents, a gap remains between theoretical positions and actual everyday practices (Dunst, 2002; Dunst, Johanson, Trivette, & Hamby, 1991). According to Dunst’s model, the Kesher EIP indeed espouses a family-centered philosophy and highlights the family’s value while offering the family a central role in the program. However, when addressing practical issues, both families and professionals who participated in the program (at the time of data collection) noticed a gap between the rhetoric of family-centered practice and the reality of the overall services that the families received.

Overall, the literature indicates that although family-centered practice has been a preferred service philosophy in many EIPs all over the world, translating the principles into practice has proven relatively elusive. Kesher is quite a young EIP, evolving its family-centered philosophy over the past 10 years. Plausibly, with time, parents will internalize the open invitation that professionals already claim they are offering them and will better utilize available opportunities to contribute to the program more substantially. Professionals, on their part, should take into consideration the important contribution of parental involvement in decision making and implementation of EIPs. Professionals and parents must join each other in a lengthy journey toward achieving a genuine partnership. Future challenges involve the generation of beliefs about the contributions of each partner to the child’s overall development (Flett & Conderman, 2001; Park & Turnbull, 2003) and common agreement about the unique input of each partner to promote an efficient partnership (Hughes & MacNaughton, 2002; Martin & Hagan-Burke, 2002).

Ongoing evaluations of parents’ perceptions about their collaboration in EIPs, as well as the perceptions of professionals on how such collaborations might be encouraged, are essential for reaching better understanding on how family-centered programs can become even more effective (e.g., Baker, Goesling, & Letendre, 2002). For this reason, continuous assessment of family-centered EIPs should be undertaken, in an ongoing attempt to identify their underlying philosophy, defining components, current goals, and actual practices from the different partners’ perspectives. The results of the current study can serve as a guide for enhancing the implementation of, and continued investigation into, family-centered practices of EIPs for children with HL and can add key information toward the identification of evidence-based practices.

References


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