ASSESSING NEEDS OF FAMILIES WITH HANDICAPPED INFANTS

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A 35-item parent survey was developed to assess the functional needs of parents with young handicapped children. A rationale for scale development and content is presented. Data from 34 two-parent families with handicapped infants suggest that the instrument is a useful source of intervention goals. Several items emerged as high priority needs for mothers and fathers. Addition of an open-ended response format provided a considerable amount of useful information. A readministration of the measure 6 months later with a subset of 20 families yielded high correlations. Implications of these findings for clinicians working with families of young handicapped children are discussed.

The assessment of family needs traditionally has been the responsibility of psychologists, family therapists, and social workers. Public Law 99-457, however, makes the assessment of families with handicapped infants and toddlers a multidisciplinary responsibility, potentially involving educators, therapists, nurses, and other allied health professionals. The law requires early interventionists working with handicapped infants and toddlers to write an Individualized Family Service Plan (IFSP) that is to include a statement of family strengths and needs as well as a description of goals and services for both infants and families.

The formal requirement for family goals and services reflects a trend toward an increased family focus in early intervention (Bailey et al., 1986; Dunst, 1985), building on the premise that the family constitutes the ecological context in which the infant functions (Bronfenbrenner, 1977). Implementing a family focus, however, will be complicated by the fact that most professionals in early intervention programs have little training in assessing family needs or providing family services; this raises important issues regarding professional boundaries and responsibilities. Ultimately the problem will need to be solved by a combination of enhanced training and the inclusion of family specialists on early intervention teams to address complex child and family needs. Also needed are functional assessment tools that assess family needs in a straightforward and acceptable fashion, that can be used by multiple disciplines, and that lead to the effective identification of family goals and services.

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According to Bentovim (1986), family assessment can help clinicians (a) understand the needs of the child, (b) understand the needs of the family (c) understand the family context of such needs, (d) determine interventions required to meet child and family needs, and (e) motivate the family to engage in the intervention. Although these aims provide a framework within which any family can be assessed, several problems with existing assessment models and instruments create difficulties for infant interventionists. First, what are the essential domains or dimensions of family assessment? Potential areas for focus include psychological characteristics (e.g., attitudes, values, beliefs, traits, and personal styles of adaptation); family relationships (e.g., parent-child interactions, sibling interactions, and spouse relationships); family climate and ecology (e.g., the social and psychological context in which a particular family functions); family needs; family resources and support; and family stress. Interventionists will need to balance their professional responsibility for conducting a comprehensive assessment of family needs with a sensitivity to family privacy and a recognition that many families may view attempts to assess many of these domains as intrusive.

Second, interventionists must choose from a range of methodological options available for gathering data in each domain. Procedural options include interviews, direct observation, and ratings completed by either family members or clinicians. Not only do these options vary according to the source of information, but they also are likely to vary significantly in psychometric properties, time demands, context of observations, and who provides the information. Third, given that many infant interventionists will not have extensive training in family assessment and intervention, measures will need to be identified that are not likely to result in erroneous interpretations or that encourage interventionists to engage in therapeutic activities for which they are not adequately trained.

Ultimately, procedures must be evaluated according to their prescriptive utility: To what extent do assessment results provide practical implications for intervention? Many instruments either yield a conceptual picture of a family that is not readily translatable into intervention plans or provide isolated facts that are difficult to place into meaningful contexts. A parsimonious approach that identifies specific family needs and elicits parent priorities for service is likely to be more acceptable to families and result in more functional conclusions.

This article describes an instrument, the Family Needs Survey (FNS), for the direct assessment of family needs as one component of a comprehensive approach to family assessment in early intervention. A rationale for the content and format of the instrument is presented and data are provided to address five questions: (1) To what extent was the scale used as a source for family goals? (2) What needs were most frequently identified by mothers and fathers of handicapped infants? (3) How do mothers' and fathers' ratings of needs differ? (4) Does the addition of an open-ended question provide useful information not assessed by the measure? (5) What is the stability of ratings over a 6-month period?

METHODS AND PROCEDURES

Instrument Development

Item selection was based on a comprehensive review of the literature, extensive discussions with early interventionists, data collected in previous surveys conducted in North Carolina, and our own clinical experiences in working with families. An initial draft of the scale was reviewed by an advisory group consisting of 15 early interventionists working in home-based programs across North Carolina. Based on their comments, several items were deleted, added, or modified for clarification. The result was a 35-item scale, with items grouped into six categories as described below.

Needs for Information. Seven items assess family needs for information, based on the assumption that parents of a handicapped infant may need information beyond that required for rearing a nonhandicapped infant (Turnbull & Turnbull, 1986). High priority needs may include information about their child (Cirillo & Sorrentino, 1986), how to teach or interact with their child (Rosenberg, Robinson, & Beckman, 1984), or services available for the present or future (Ayer, 1984).

Needs for Support. Support as a mediator of family stress and coping has both a theoretical (e.g., Hill, 1949) and an empirical (e.g., Dunst, Trivette, & Cross, 1986) basis. Eight items assess parents' perceived needs for support from both formal and informal sources, based on the assumption that while support is a complex construct involving interrelated networks (Kazak, 1986), specific aspects of needs for support must be assessed systematically. High priority needs may include additional support from early intervention professionals, opportunities to meet and interact with other families with handicapped infants (Holland & Hattersly, 1980); informal support from spouses, friends, relatives, or neighbors (Cooke & Lawton, 1984); and support from ministers and religious organizations (Cluff & Cluff, 1983; Heifetz, 1987).

Explaining to Others. Anecdotal reports from families indicate that a pervasive and ongoing issue is having to explain their child's condition to others and helping others understand what it is like to be the parent of a child with special needs. Five items assess parents' needs for help in regard to explaining their child's condition to siblings (Simeonsson & Bailey, 1986); grandparents (Gabel & Kotsch, 1981); spouse (Parke, 1986); and other children, friends, neighbors, and strangers.

Community Services. Not only may parents need information about available community services (Ayer, 1984), but they also may need assistance in accessing those services (MacEachron, Pensky, & Hawes, 1986). Five items address those needs by focusing on access to medical or dental care and assistance in securing child care, including babysitters, respite services, day care, or care during religious services.

Financial Needs. Six items address financial needs, ranging from basic needs for food, clothing, housing, or transportation to needs for job counseling and special financial needs related to their infant's handicapping condition.

Family Functioning. Finally, four items assess the extent to which the parent perceives a need for assistance related to whole family functioning. Included in this domain are needs related to family problem solving, internal support systems, role allocation, and recreational activities.

Format

Other scales have utilized formats that are either confusing to families or require inferential reasoning on the part of the interventionist. For example, a scale might present a statement such as "Thinking about my child's future makes me sad," to which the parent must respond on a 1 (Strongly Disagree) to 5 (Strongly Agree) scale. What does it mean for intervention purposes when a parent of an infant with cerebral palsy responds with a 4? The interventionist could (a) provide information about future services, (b) provide information about typical development and prognoses of children with cerebral palsy, (c) form a parent support group, or (d) recommend psychotherapy. The item format does not provide information about the services that might best meet an individual family's needs, what those needs are or the priority of family needs. Some families may respond to such an item with a 5, yet not want or need services related to it.

Each of the 35 items on the Family Needs Survey begins with a phrase such as "I need more . . . . " For example, one item reads, "I need to have more opportunities to meet and talk with other parents of handicapped children." Thus the scale is need oriented rather than problem oriented. Statements reflect the parents' perspective on specific needs for services, rather than statements about nebulous problems for which many solutions are possible. The rating is from 1 to 3; rating of 1 is accompanied by the statement, "I definitely do not need help with this"; a rating of 2 is accompanied by the statement "Not sure"; and a rating of 3 is accompanied by the statement "I definitely need help with this." This format was chosen on the assumption that it would be easier for parents to respond to than the Agree-Disagree format or a 5-point rating scale, and would allow parents to make clear statements about aspects of family functioning for which they would like professional assistance. Since the items focus on the needs of individuals, the instrument is completed separately by mothers and fathers. It can also be used with extended family members (e.g., grandparents, relatives) if appropriate.

Subjects and Setting

The subjects included in the present analysis were 34 two-parent families participating in home-based infant intervention programs. The infants displayed a variety of handicapping conditions, with a mean cognitive developmental quotient of 66 and a mean motor developmental quotient of 57. The average age was 14 months. Approximately 85% of the children were white, 15% minority, 48% male, and 52% female. Nearly half (47%) of the families were in the lower two SES strata as measured by Hollingshead's four-factor index.

Procedures

The Family Needs Survey was used as part of a battery of assessment tools in a study of inservice training on family assessment and goal writing. A complete description of the study, population, and procedures is reported in Bailey et al. (in press). For the purposes of this paper, three measures are relevant. First, families completed the Family Needs Survey. Second, families were presented an open-ended question: "Please list your five greatest needs as a family." They received both the FNS and the open-ended question at the same time. Finally, interventionists for half of the families were asked to provide a list of family and child goals included in each individual program plan. Beside each goal, interventionists indicated the assessment source(s) for the goal. Interventionists distributed all measures to families. Fathers and mothers were asked to complete each form separately. Families returned their forms to the interventionists, who in turn sent them to research project staff.

RESULTS

FNA as a Source of Family Goals

For the initial goals written by interventionists, 53 citations of assessment tools indicated sources from which goals were derived. Of those 53 citations, 36 (68%) referred to the Family Needs Survey, suggesting that the instrument is a useful source of information in planning goals and services for families.

Most and Least Frequently Cited Needs

In order to determine the most frequently cited needs, we analyzed surveys separately for mothers and fathers. Percentages of mothers or fathers indicating a definite need for help (as indicated by a response of 3) are displayed in Table 1. Eight needs were identified by at least 50% of the mothers, while only four were identified by at least half of the fathers. Both mothers and fathers definitely wanted information about how to teach their child, currently available services, and services available in the future, as well as reading material about parents who have a child similar to theirs. In addition, mothers definitely wanted more information about their child's disability, opportunities to meet other parents with handicapped children, more time for themselves, and help in paying for basic expenses.

Four items on the survey were rated by less than 10% of mothers as definite needs. Those items addressed time just to talk with their child's teacher or therapist, locating a physician, securing child care during religious services, and job counseling. Five items were rated as definite needs by less than 10% of the fathers. Those items were meeting with a counselor, locating a dentist, child care during religious services, job counseling, and fulfilling household responsibilities.

Correspondence in Ratings of Mothers and Fathers

The total score correlation between mothers' and fathers' ratings was .52 ($p < .01$). As displayed in Table 1, there were fewer items for which at least half the

TABLE 1
PERCENTAGE OF MOTHERS AND FATHERS INDICATING A DEFINITE NEED FOR HELP

Item	% of Mothers	% of Fathers
Needs for Information		
1. I need more information about my child's condition or disability	53	47
2. I need more information about how to handle my child's behavior	41	27
3. I need more information about how to teach my child	65	56
4. I need more information on how to play with or talk to my child	32	24
5. I need more information on the services that are presently available for my child	56	59
6. I need more information about the services that my child might receive in the future	77	68
7. I need more information about how children grow and develop	41	35
Needs for Support		
8. I need to have someone in my family that I can talk to more about problems	29	18
9. I need to have more friends that I can talk to	32	21
10. I need to have more opportunities to meet and talk with other parents of handicapped children	62	27
11. I need to have more time just to talk with my child's teacher or therapist	6	24
12. I would like to meet more regularly with a counselor (psychologist, social worker, psychiatrist) to talk about problems	15	6
13. I need to talk more to a minister who could help me deal with problems	12	12
14. I need reading material about other parents who have a child similar to mine	74	50
15. I need to have more time for myself	59	18
Explaining to Others		
16. I need more help in how to explain my child's condition to his or her siblings	27	24
17. I need more help in explaining my child's condition to either my spouse or my spouse's parents	12	12
18. My spouse needs help in understanding and accepting our child's condition	21	12
19. I need help in knowing how to respond when friends, neighbors, or strangers ask questions about my child's condition	44	18
20. I need help in explaining my child's condition to other children	47	24
Community Services		
21. I need help locating a doctor who understands me and my child's needs	6	12
22. I need help locating a dentist who will see my child	12	6
23. I need help locating babysitters or respite care providers who are willing and able to care for my child	40	27

Item	% of Mothers	% of Fathers
24. I need help locating a day care center or preschool for my child	27	27
25. I need help in getting appropriate care for my child in our church or synagogue nursery during church services	6	6
Financial Needs		
26. I need more help in paying for expenses such as food, housing, medical care, clothing, or transportation	50	41
27. I need more help in getting special equipment for my child's needs	21	24
28. I need more help in paying for therapy, day care, or other services my child needs	21	21
29. I or my spouse need more counseling or help in getting a job	9	9
30. I need more help paying for babysitting or respite care	18	15
31. I need more help paying for toys that my child needs	18	18
Family Functioning		
32. Our family needs help in discussing problems and reaching solutions	35	12
33. Our family needs help in learning how to support each other during difficult times	44	15
34. Our family needs help in deciding who will do household chores, child care, and other family tasks	18	9
35. Our family needs help deciding on and doing recreational activities	38	15

fathers indicated a need; however, the four needs identified by the majority of fathers were included in the eight identified by the majority of mothers. The average number of items rated 3 (definitely need help) was 11.6 for mothers and 8.3 for fathers, a difference that approached statistical significance ($t = -1.84$, $p < .07$).

Eight items resulted in a discrepancy of 20 or more percentage points between mothers and fathers; in each case, mothers indicated greater needs than fathers. Mothers wanted (a) more opportunities to meet and talk with other parents of handicapped children, (b) reading material about other parents who have a child similar to theirs; (c) more time to themselves; (d) help in knowing how to respond when friends, neighbors, or strangers ask questions about their child; and (e) help in explaining their child's condition to other children. Also, they were more likely to indicate that their family needed help in discussing problems and reaching solutions, supporting each other during difficult times, and selecting and doing recreational activities.

Comparison with an Open-Ended Question

As a part of the overall assessment battery, each family was given a sheet of paper with the following request at the top: "Please list your five greatest needs as a family." Of interest was the extent to which this open-ended format compared with data provided by the Family Needs Survey. Each statement was coded in one of three ways: It was the same as a need listed on the Family Needs Survey, it clarified a FNS need, or it was a new need not listed on the FNS. Thirty-three of the 34 families responded to the open-ended format, listing a total of 218 needs. Of those, 131 (60%) either clarified or repeated information provided on the FNS. A total of 87 (40%) of the identified needs were not listed on the FNS. A qualitative analysis of newly identified needs was conducted to determine high incidence answers and to investigate the possibility that new items should be added to the FNS. The 87 new problems reflected a total of 39 different needs. Examples included needs for time alone with spouse; concerns about upcoming surgery; fatigue; feeling guilty when working; religious doubts; and stress associated with in-laws and other extended family members. The most common general concern was captured in a variety of comments related to concerns about the future, particularly the future development and skill status of their handicapped child.

Stability of Ratings

Twenty families completed the instrument again 6 months later. Correlations between the first and second administration of the instrument were calculated separately for mothers and fathers to determine stability of responses. Test-retest correlations for total scores were .67 for mothers ($p < .001$) and.81 for fathers $p < .001$). The most stable subscales for mothers were needs for support ($r = .71$), explaining to others ($r = .53$), financial ($r = .65$), and family functioning ($r = .62$). The most stable subscales for fathers were needs for support ($r = .79$), community services ($r = .54$), and financial ($r = .78$).

DISCUSSION

This article describes the development and initial field-testing of an instrument to assess the needs of families with handicapped infants for the purpose of planning and providing early intervention services. The impetus for developing the instrument was a need for interventionists to augment subjective clinical judgment without using complex measures of family functioning requiring specialized training. A sample of 34 two-parent families was used to examine its utility. Several conclusions may be drawn about the measure thus far, and additional questions requiring further research can be asked.

The clinical utility of the instrument is evidenced by the fact that it elicited numerous needs from both mothers and fathers. Thus it would appear that the measure was acceptable to families and responsive to very real needs they have experienced. The survey was reported as the source of a significant proportion of goals written on family service plans, further supporting its clinical usefulness.

The addition of an open-ended question allowed families the opportunity to clarify responses to standard items and to provide information about needs in addition to those listed in the survey. In analyzing the data obtained from the open-ended question, we determined that it did not warrant the addition of new items to the survey itself, since a diversity of responses was obtained. It appears, however, that the open-ended question is an economical but important means of gathering additional information pertinent to each individual family's unique situation.

Test-retest stability of total ratings over a 6-month period was moderate for mothers (r = .67) and high for fathers (r = .81), with greater stability observed on some subscales than others. This finding suggests that families who expressed a significant number of needs relative to other families at one point in time were also likely to do so at a later point in time.

Future research should focus on several issues. First, it is important to recognize that the direct assessment of family needs is but one component of a comprehensive system of family assessment (Bailey & Simeonsson, 1988). Other measures of child and family functioning should be gathered when appropriate, and a follow-up interview with parents in order to clarify expressed needs, discuss discrepancies between mothers and fathers, and prioritize needs and services is essential (Bailey et al., in press; Winton & Bailey, in press). Second, although the items are grouped into logical clusters, a confirmatory factor analysis would be useful to determine the statistical integrity of the subscales. Third, the usability of the instrument across different populations and programs should be investigated. The current study was conducted in a home-based context and addressed families whose infants had clearly documented handicaps. Other contexts (e.g., a center-based program) or other populations (e.g., adolescent mothers of premature infants) may warrant the addition, deletion, or rewording of certain items. We are aware of several programs that have modified the instrument to more appropriately meet the needs of the families they are serving.

One critical limitation of direct assessment of family needs is that such needs may be restricted to those that the family is able or willing to identify. Although such needs are likely to serve as appropriate intervention goals in most instances, they may at times be perceived by interventionists as low priority or inappropriate relative to family needs or problems. Needs or problems pertaining to family dynamics, for example, may not be apparent to families or reported by them. These problems may, however, not be within the realm of clinical competence of most early interventionists. By focusing on those needs that are of direct concern to families, interventionists can develop a trusting and collaborative relationship with families, assist families in achieving functional goals, and ultimately may facilitate the inclusion of the handicapped infant as an integrated family member (Bailey, 1987).

In conclusion, the diversity of family needs and the complex nature of family functioning pose special challenges to professionals responsible for working with handicapped infants and their families. It is clear that a coordinated and comprehensive assessment of child and family needs requires a multidisciplinary and multivariate approach to assessment and program planning. Cadman, Goldsmith, and Bashim (1984) have argued that clinicians need to be aware of the differences between their own values and those of parents and that "in order to validly understand and appreciate these values and preferences in decision making, they should be measured in a feasible, reliable, valid, and quantified manner" (p. 63). The direct and explicit assessment of family needs through the use of a needs survey as described in this paper constitutes one element of a comprehensive approach of practical utility for clinicians in early intervention.

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