1995

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Assessment Issues in Families of Individuals with Disabilities

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Mortality in mothers and infants has been reduced as medical science has advanced. The ability to extend the lives of individuals born with disabilities, or who become injured later in life, has steadily increased with advances in science. As a result, the existing population of individuals with special needs has grown, thereby increasing the numbers of families affected by a disability. In the past, individuals with severe disabilities may have been institutionalized. Now, although institutions still exist, greater numbers of individuals with disabilities are likely to be cared for in the home. What effect does this have on families and their functioning? How can families be helped to access their strengths? Accurate family assessments are a crucial component in the task of answering these and other critical questions regarding individuals with disabilities and their families.

Assessing the families of individuals with disabilities is a complex, multifaceted task. Not only must the family be assessed, a formidable task in itself, but the impact of the disability on the family, as well as on the individual with the disability, must also be factored into the assessment process. Depending on the type of disability, successful assessment may require creative approaches. Information from all family members may not be available due to the nature of the
disability. For example, people with certain disabilities may be unable to describe their perceptions of their place in the family or their sense of family cohesiveness. As each family member has his or her own view of the family system, it is important to have as many members of the family as possible complete family assessment measures (Olson, McCubbin et al., 1992). Family assessment that is unable to include the perceptions of the individual with the disability will necessarily be limited in its comprehensiveness and usefulness.

The purpose of this chapter is to provide information regarding the assessment of families of individuals with disabilities. In addition to the background information provided initially, a brief review of the literature is included. Methods of assessment and specific standardized assessment devices are then described and reviewed for their usefulness in assessing families of individuals with disabilities. Finally, critical issues to consider in assessing these special families are discussed.

LITERATURE REVIEW

The vast majority of published research has as its focus the families of children with disabilities, particularly congenital disabilities (Yura, 1987; Benson & Gross, 1989; Lobato, Faust, & Spirito, 1989; Konstantareas, 1991). A much smaller amount of information is available regarding the families of adult individuals with disabilities acquired congenitally or through accident or injury later in life (Fohs, 1991; Jackson & Haverkamp, 1991).

Research surrounding the families of children with disabilities has perhaps been spurred by the involvement of government—first in the rights of children and later in the rights of children with disabilities. Not only do laws exist that provide services for school-aged individuals with disabilities, but Public Law 99-457 extends services to birth for children with disabilities. This law also serves to underline the importance of involving the family of the individual with a disability in both assessment and provision of services (Fewell, 1991) and reflects “the assumption that family functioning and child development are inextricably intertwined” (Frey, Greenberg, & Fewell, 1989, p. 240).

Government may again provide the impetus to study individuals with disabilities and their families. The recent enactment of the Americans with Disabilities Act (ADA) has drawn attention to the rights of all individuals with disabilities, particularly adults, and may spur interest in investigating the families of these individuals.
Studies regarding families containing individuals with disabilities have often been conducted in a somewhat noncohesive fashion. Researchers have studied the individual with the disability in relationship to various individuals and systems. These include studying the individual with the disability in relationship to: the family (Newman, 1991; Seligman & Darling, 1989; Roberts, 1984); the parents (Seligman & Darling, 1989); the mother (Dunst, Trivette, & Cross, 1986; Roberts, 1986; Vadaszy & Fewell, 1986); the father (Meyer, 1986; Lamb & Meyer, 1991); the siblings (Bischoff & Tingstrom, 1991; Crnic & Leconte, 1986; Seligman & Darling, 1989; Seligman, 1991); single-parent families (Vadaszy, 1986; Wikler, Haack, & Intagliata, 1984); grandparents (Seligman & Darling, 1989; Seligman, 1991; Sonnek, 1986); and support networks and institutions (Darling, 1991; Stagg & Catron, 1986). Studies investigating cultural differences in response to family members with disabilities have also been conducted (Florian, 1989). In general, these studies show the presence of an individual with a disability has a decided impact that may be both positive and/or negative (Benson & Gross, 1989; Yura, 1987). This impact is felt in a variety of family and community areas including individual relationships, quality of life, and economics.

Type of disability is another area of focus seen in the literature. Researchers have looked at individuals with specific disabilities in relationship to the above listed individuals and systems, whereas others have studied the isolated individual effects of the disability. Disabling conditions researched include: juvenile rheumatoid arthritis (Varni, Wilcox, & Hanson, 1988); cystic fibrosis (Brinthaupt, 1991); spina bifida (Spaulding & Morgan, 1986); cerebral palsy (McCubbin, 1989); head/traumatic brain injury (Jackson & Haverkamp, 1991); Down’s syndrome (Carr, 1988; Damrosh & Perry, 1989; Ryde-Brandt, 1991); mental retardation (Donovan, 1988; Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989; Abbott & Meredith, 1986); developmental disabilities (Hampson, Beavers, & Hulgus, 1990; Thorin & Irvin, 1992; Trute & Hauch, 1988; Rimmerman & Portowicz, 1987); learning disabilities (Konstantareas, 1991; Konstantareas & Homatidis, 1989; Michaels & Lewandowski, 1990; Morrison & Zetlin, 1988, 1992); behavior disorders (Parker, Hill, & Goodnow, 1989); mental illness (Chafetz & Barnes, 1989; Medvene & Krauss, 1989); autism (Donovan, 1988; Konstantareas, 1991); visual impairments (Ammerman, VanHasselt, & Hersen, 1991; VanHasselt, Hersen, Moor, & Simon, 1986); hearing impairments (Strom, Daniels, & Jones, 1988; Warren & Hasenstab, 1986); and orthopedic impairments (Varni & Setoguchi, 1993). Comparisons of families containing children with congenital
disabilities versus families containing children with acquired disabilities are also available (Bragg, Brown, & Berninger, 1992).

Ongoing research in the area of families containing individuals with disabilities is critical, as is research regarding the impact on a family when a previously healthy adult is disabled through illness or accident. Not only the families, but the individual who has become disabled, may need assistance in coping in ways that may be very different from those of families into which a disabled member is born. Family assessment instruments designed to measure the needs, strengths, and weaknesses of families containing individuals with disabilities will be critical to increased understanding and effective service provision.

METHODS OF ASSESSMENT

A variety of family assessment methods are described in the available research. These standardized and researcher-designed methods include behavioral observations and ratings, videotaped observations, role-play tests, projective tests, questionnaires and inventories, interviews, and surveys. Many of the family assessment measures used in the research, however, have been inadequately described, making it difficult, if not impossible, to make judgments regarding the reliability, validity, or generalizability of much of the reported research. This lack of information also makes it difficult to determine the potential usefulness or adequacy of the assessment device or procedure for clinical purposes.

Infrequently cited as assessment tools in the research, but believed by Seligman (1991) to be valuable in clinical assessment and treatment planning for families containing individuals with disabilities are genograms and ECO-MAPS. The genogram (McGoldrick & Gerson, 1986) allows a multi-generational and extended view of the family. The ECO-MAP (Hartman, 1978) is a diagrammatic portrayal of the interactions of the family and the community and may be essential to the understanding of some families containing individuals with disabilities because outside supports are often critical.

By far the most frequently cited method of collecting information from the families of individuals with disabilities has been self-report. Standardized or researcher-designed protocols, instruments, or forms have been used. The use of in-home, office, and phone interviews employing both open- and close-ended questions have been used to gather information. Most of the information collected has been provided by parents, although information has also been gathered from siblings and grandparents. The effects of situational variables
and examiner variables on test outcome are well documented (Anastasi, 1988). There are dangers inherent in the use of self-report. The mood of the individual responding, his or her reaction to the interviewer, the type of interview, and the influence of seeing an interviewer face-to-face versus talking with an unknown caller or completing an anonymous form are only a few of the factors that may influence the type of response and information provided by family members.

Standardized and researcher-designed paper-and-pencil questionnaires or survey measures are frequently employed. A difficulty with many of these measures is their use of close-ended questions that may fail to uncover important variables of concern. Measures employing open-ended questions may elicit more information but may not provide enough information about constructs of particular interest. In addition, open-ended questions may tend to elicit responses which may be somewhat disjointed but reflect the immediate concerns of the individuals responding.

**STANDARDIZED ASSESSMENT INSTRUMENTS**

The most frequently mentioned standardized assessment instruments used with families of individuals with disabilities are the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS; Holroyd, 1987), the Family Adaptability and Cohesion Scales (FACES II; Olson, Portner, & Bell, 1982; FACES III; Olson, Portner & Lavee, 1985), and the Family Environment Scale (FES; Moos, 1974). The Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin, Larsen, & Olson, 1992), Parent-Adolescent Communication Form (Barnes & Olson, 1985; 1992), and Family Strengths Scale (Olson, Larsen, & McCubbin, 1992) are mentioned infrequently in the literature, but may be useful for assessing some specific areas of interest in families of individuals with disabilities. The Parenting Stress Index (PSI; Abidin, 1983, 1990) and the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) are frequently cited in the body of literature regarding families of children with disabilities; however, because they are not used in assessments of the entire family, they will not be reviewed here.

**The Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS).** The Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS; Holroyd, 1987) was constructed in order to measure stress in families caring for relatives with illness or disabilities. The questionnaire is designed for families containing individuals with
disabilities of all ages, but there is a clear lack of studies with adult populations (Holroyd, 1988). It is, however, one of the most frequently cited instruments in published studies involving the assessment of families of children with disabilities.

The QRS purports to measure the impact of the disability or illness on the respondent of the questionnaire and on other members of the family. The questionnaire consists of 285 true/false items that are self-administered, generally takes less than an hour to complete, and requires a 6th grade reading level. There is a 66-item short form intended to be used as a broad screening device. The comments presented here are based on the long form as Holroyd (1987) has reported the long form is the more reliable instrument. According to Holroyd, the QRS can provide information to clinicians regarding the problem to address first, the families who should be the first to receive care, and can be used to measure treatment effects. Because the QRS was originally designed for use in public health settings (Holroyd, 1988) in order to identify families with social assistance needs, its application is limited.

Holroyd (1987) describes the questionnaire as covering three domains: personal problems for the respondent (seven scales), family problems (three scales), and problems of the individual in the family with the disability, referred to by Holroyd as the index case (five scales). Information regarding the internal consistency of the QRS scales was provided by Holroyd (1987) using the Kuder-Richardson-20 method. Overall, internal consistency is reported as .96. No information regarding test-retest or alternate test form reliability is provided. In a recent review of the QRS, Erickson (1992) noted the validity information on the QRS is limited: Content validity is established qualitatively rather than quantitatively through the ratings of items by 12 judges; criterion validity is difficult to obtain as there are no other standard instruments in this area and construct validity is not established. Norms for the long form are based on a very limited sample of 107 families with nondisabled children.

The personal problem scales collect information regarding poor health and mood, excess time demands, negative attitude toward index case, overprotection/dependency, lack of social support, overcommitment/martyrdom, and pessimism. The family problem scales collect information regarding lack of family integration, limits on family opportunity, and financial problems. The index case scales collect information regarding physical incapacitation, lack of activities for the index case, occupational limitations for index case, social obtrusiveness, and difficult personality characteristics.
A major drawback of the QRS is that it does not provide for input from the individual with the disability. The form is to be administered to any family member other than the disabled member. Accessing the view of the individual with the disability, in addition to the remainder of the family, would be critical to a complete assessment. In addition, this exclusion from the assessment process discounts the perceptions of the individual with the disability.

Respondents to items on the QRS are given initial instructions that the questionnaire taps into their feelings regarding the family member with the disability. The nature of the majority of the questions seem to assume pathology rather than strength. The questionnaire has blanks in many of the questions and the respondent is asked to imagine his or her disabled relative’s name in the blanks, and to give their honest feelings and opinions in a true/false format. For example, Item 70 on the QRS reads “I am afraid that other members of the family will be hurt because they are related to ________” (Holroyd, 1987).

Three QRS scales are purported to deal with family problems. Scale 8 consists of 23 items reported by the author to measure lack of family integration ($r = .78$). Scale 9 consists of 9 items reported by the author to measure limits on family opportunity ($r = .69$). Scale 10 consists of 17 items reported to measure financial problems ($r = .74$). An analysis of the items in these three scales, presented below, suggest some difficulties when using them with families of individuals with disabilities.

Scale 8 measures family integration problems such as difficulty getting along with the individual with the disability or with other family members. The majority of the Scale 8 items (15 of 23 items) include references to the individual with the disability, thus continuing the more traditional medical model focus on the identified patient, rather than a focus on the entire family system. The negative wording of some of the items may present problems for individuals asked to complete this questionnaire. For instance, Item 141 reads “Because of ________ our family has never enjoyed a meal” and Item 120 reads “Taking ________ on a vacation spoils pleasure for the whole family.” Although the statement may be representative of their feelings, answering in the affirmative may be difficult for respondents, particularly parents. My clinical experience indicates that providing affirmative answers to questions such as these has the potential to produce conflicting feelings such as guilt, anger, and/or grief in some respondents. This type of item also serves to keep the focus on the individual with the disability as the source of problems. Eight of the items on
this scale are family oriented rather than patient focused. Examples of these more family focused items include Item 10 “Members of our family praise each other’s accomplishments” and Item 40 “Our family agrees on important matters.” Items of this type are far too limited to provide a solid measure of family integration.

Scale 9 measures limits on family opportunity in a variety of areas including schooling, careers, social life, and the growth and development of other family members. The majority of the Scale 9 items (6 of 9 items) include direct references to the individual with the disability. Again the focus is on an identified patient rather than the entire family system. These items tend to focus on the possible negative effects of having an individual with a disability in the home. For instance, Item 6 reads “A member of my family has had to give up education (or a job) because of ______.” and Item 32 reads “Other members of the family have to do without things because of ______.” Even those items that do not have specific blanks for the name of the individual with the disability keep the focus on the family member with the disability. For instance, the wording of Item 236 seems to imply a problem: “Members of our family get to do the same kinds of things other families do.”

Scale 10 items measure family financial problems that are a result of having an individual with a disability or chronic illness in the home. Fewer of these items (7 of 17 items) have specific references to the individual with the disability. However, these items do not measure family functioning, but are concretely geared to such things as family debt, income, amount spent on medical care, and other financial needs.

In summary, this analysis of the three QRS scales purported to measure family problems suggest these items have limited use. The items do provide information regarding how family members perceive the impact of having an individual with a disability in the home. The QRS provides a chance for family members to talk about lost opportunities and financial difficulty and can be used to provide information regarding the negative views of family members. However, the scales do not supply much information regarding family strengths that could be utilized in treatment. Nor does the questionnaire provide an opportunity for the individual with the disability to provide input. In addition, the wording of the questions assumes problems rather than solutions. The use of the word handicapped throughout the QRS is also unfortunate. Individuals with disabilities are entitled to have the focus put on their individuality and potentials before their disability.
Family Environment Scale (FES). Another instrument cited in the literature regarding families of individuals with disabilities is the Family Environment Scale (FES; Moos & Moos, 1986). The FES is composed of 10 subscales consisting of nine items each and is designed to measure family social environment. Moos (1974) believed family environments could be measured and that these environments would affect behavior. There are three forms of the FES. Form R, the Real Form, measures the perceptions of individuals regarding marital or family environments. Form I, the Ideal Form, measures individuals’ perceptions regarding the ideal family environment. Form E, the Expectations Form, measures family setting expectations. Each form consists of 90 questions to be answered in a true-false manner. Both the Ideal and Expectations Forms were created by rewording the items and instructions on the Real Form.

Three dimensions are assessed by the FES: relationship, personal growth, and system maintenance (Moos, 1974). The relationship dimension consists of three subscales: cohesion, expressiveness, and conflict. The personal growth dimension consists of five subscales: independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, and moral-religious emphasis. The system maintenance dimension consists of two subscales: organization and control.

As the FES is a paper-and-pencil measure it does require reading. The second edition of the FES manual does not report the reading grade level required. The wording of the items is fairly straightforward, however, and some reviewers (Jacob & Tennenbaum, 1988) believe a minimum age of 10 is sufficient for completion. The problems that might be associated with administering the FES orally to family members who cannot read are not addressed in the manual.

The original normative sample for the FES was large for construction of Form R, the Real Form. A group of 1,125 normal families and a group of 500 distressed families were used (Moos & Moos, 1986). The distressed families consisted of families being seen at a psychiatric clinic and a probation and parole department; families containing an alcoholic member; families of general psychiatric patients; and families with a child in crisis, a runaway, or a delinquent. In a review of the FES, Busch-Rossnagel (1985) noted the FES norms provided limit the instrument’s usefulness. Information regarding sample subgroups is not provided nor are significant differences between means of different family groups presented. Although families having individuals with psychiatric or emotional difficulties were part of the distressed family group used in the norming sample, families
containing members with other types of disabilities were not included. This obviously limits the research and clinical usefulness of the FES with families containing one or more members with a disability. Another difficulty noted (Lambert, 1985) is the lack of profiles for the model family as criteria for correlation of the perceptions of family members regarding their own family.

The FES can be administered to all family members, including the individual with the disability. According to Moos and Moos (1983), the FES can be used not only to compare and describe the social environments of families, but also to contrast the perceptions of parents and children, and to look at actual as well as preferred family environments. Billings and Moos (1982) have maintained the instrument may be used to identify interventions but the FES manual does not give information regarding how this might be accomplished. Although the FES may be useful in identifying treatment issues for families of individuals with disabilities, it has its greatest usefulness in providing the perceptions of families regarding specific areas of family life. One of the drawbacks of the FES is its lack of sensitivity to the special needs that may be present in families of individuals with disabilities; it fails to address the strengths and weaknesses such families have as a result of living with an individual with a disability.

In a recent review of the FES, L’Abate and Bagarozzi (1993) reported inadequacies in the methodology employed in the development of the scale. They noted a lack of evidence for reliability and validity, pointing out that many of the 10 subscales are not statistically independent. Another criticism concerned the lack of grounding in a conceptual framework of family development, process, functioning, or family therapy theory. These methodological weaknesses put the value of the FES in question as anything other than a measure of the perceptions of others.

The Family Adaptability and Cohesion Scales (FACES). The Family Adaptability and Cohesion Scales (FACES II; Olson, Portner, & Bell, 1982; FACES III; Olson, Portner, & Lavee, 1985) are also cited in the literature regarding families of individuals with disabilities. See Halverson (Chapter 1 in this volume) for additional discussion of the FACES. FACES IV has been developed but the manual and completed assessment device are not yet available. Olson, McCubbin et al. (1992) have reported research regarding the reliability and validity of FACES IV is currently in progress. Although FACES III is the most recent FACES version available, Olson, McCubbin et al. recommend using FACES II for the following reasons: FACES II has higher alpha reliability at .90; FACES II adaptability, social desirability, and cohe-
sion correlation are less problematic than for FACES III; and FACES II has higher concurrent validity. There are two forms of FACES II: a family version and a couples version. A Clinical Rating Scale (CRS) to be completed by clinicians observing the family has also been developed (Olson, 1989) to provide family ratings in the areas of cohesion, adaptability, and communication. Information presented here is concerned with the family version of FACES II unless otherwise indicated.

The theoretical basis of the FACES is the Circumplex Model of Marital and Family Systems originally proposed by Olson, Sprenkle, and Russell (1979). This model proposed that cohesion and adaptability were important dimensions of behavior in families. A third dimension, communication, was proposed as important in that it facilitates movement on the cohesion and adaptability dimensions. Olson, McCubbin et al. (1992) have provided information regarding the concepts upon which the FACES is built. Family cohesion is defined as the emotional bonding of individuals within the family. It appraises how members of the family are connected to or separated from the family. Family adaptability is concerned with the family’s ability to change in a variety of areas including relationship rules and roles as well as power structures.

FACES II is a paper-and-pencil self-report measure that provides individual family members’ perceptions of family functioning. According to Olson, McCubbin et al. (1992), the instrument requires about a seventh grade reading level. This eliminates children younger than about age 12 and individuals who are unable to read due to disability from completing the form. Information regarding the effects on validity and reliability due to administering the FACES II orally to accommodate a disability is not provided in the manual. Respondents are directed to read statements as they apply to their family and to rate the frequency of the behavior described on a scale ranging from 1 (almost never) to 5 (almost always). Olson, McCubbin et al. recommend that as many family members as possible take the instrument in order to capture as much of the family complexity as possible.

FACES II consists of two scales: cohesion (16 items) and adaptability (14 items). The initial FACES II consisted of 50 items and was administered to 2,412 adults in a national survey (Olson, McCubbin et al., 1992). The scale was reduced to 30 items based on reliability and factor analyses. The cohesion scale consists of 2 items in each of the following eight areas: emotional bonding, family boundaries, coalitions, time, space, friends, decision-making, and interests and recreation. The family adaptability scale consists of two or three items in
each of the following six areas: assertiveness, leadership (control),
discipline, negotiation, roles, and rules.

A major drawback to using this instrument with families of
individuals with disabilities is that they were not included in the
standardization population. This may not be significant for families
of individuals with a mild or even moderate disability; however, if
FACES II is to be used in families in which a family member has a
severe disability, the family dynamics purportedly being assessed by
the scales may look more pathological than they actually are. The
more severe the disability the more necessary it may be for all family
members to devote a considerable amount of time to caretaking tasks
such as dressing, toileting, and feeding and to tasks aimed at keeping
the family member safe. There is no vehicle in FACES II for measuring
the healthiness of what may appear to be either an enmeshed or
disconnected interaction, but may actually be highly functional be­
havior in a family coping with the demands of another family member’s
disability.

An analysis of FACES items suggests some problematic areas for
use with families of individuals with disabilities including Item 4,
“Each family member has input in major family decisions”; Item 9, “In
our family, everyone goes his/her own way”; Item 29, “Family
members pair up rather than do things as a total family”; Item 30,
“Family members share interests and hobbies with each other”; and
Item 22, “In our family, everyone shares responsibilities.” Some
difficulties with the above items are readily apparent. Major family
decisions may be driven by medical concerns and perforce must be
made primarily by parents. Individuals in families may go their own
way or team up in pairs because one family member may be required
as a caretaker and/or the individual with the disability may be
incapable of joining many activities. Sharing interests, hobbies, and
responsibilities may not be feasible for the same reason.

An advantage of FACES II is that it does take into account the
view of the individual with the disability, provided they are capable
of reading and understanding the questionnaire. Many items on
FACES II are appropriate for families of individuals with disabilities.
In addition, respondents are given the opportunity to rate items on a
continuum from (1) almost never to (5) almost always. The opportu­
nity to choose responses from a 5-point Likert scale is more likely to
capture some of the differences present due to having an individual
with a disability in the home than a true-false response format.
However, an attempt to arrive at and interpret a final score from
FACES II would not be useful in many cases. FACES II does provide
both mean and discrepancy scores. These scores can be useful in discovering differences as well as in locating the family on major dimensions. Perhaps FACES II has its greatest usefulness in evaluating individual responses to items within the context of the disability and using items to plan treatment around specific areas that appear to be problematic.

_Parent-Adolescent Communication Form._ Another paper-and-pencil measure cited in the literature is the Parent-Adolescent Communication Form (Barnes & Olson, 1985, 1992) developed as an adjunct to the Family Adaptability and Cohesion Scales (FACES). Its theoretical base, the Circumplex Model of Family and Marital Systems (Olson et al., 1979) includes communication as an important component of family behavior. The Parent-Adolescent Communication Form is a 20-item self-report questionnaire with response choices on a 5-point Likert scale ranging from (1) strongly disagree to (5) strongly agree. There are three forms: the parent form, the adolescent and mother form, and the adolescent and father form. Differences in the forms are only in targeting the mother, father, or adolescent in each question. For example, Item 7 of the parent form reads “I am very satisfied with how my child and I talk together.” On the adolescent and mother form, this item reads “I am very satisfied with how my mother and I talk together.”

The instrument consists of two subscales, open family communication and problems in family communication, that are designed to measure content as well as process issues (Barnes & Olson, 1992). Cronbach’s alpha was used to compute internal consistency of each scale (open family communication = .87; problems in family communication = .78; total scale = .88). Each subscale contains 10 items. The open family communication scale focuses on the positive dimensions of communication. It measures factual and emotional information exchanges, as well as the satisfaction and understanding experienced by participants in communication. The problems in the family communication scale look at the more problematic aspects of interactions. It measures negative interaction styles as well as caution and selectivity by the participants regarding what they communicate.

The norming sample for the Parent-Adolescent Communication Form consisted of adolescents who fell mainly in the age range 16–20 (Barnes & Olson, 1985; 1992). This raises the question of usefulness for the form with younger adolescents and developmentally delayed adolescents. No information regarding the use of families containing individuals with disabilities in the construction or refinement of the instrument is provided. This may limit the usefulness of the measure;
it certainly indicates caution must be exercised in using the norms provided to make decisions regarding the type of family communication evidenced by the instrument.

This form appears to have the potential for clinical usefulness in recognizing strengths and weaknesses in parent-adolescent communication patterns and in formulating treatment plans. Many of the items on this form appear to be both appropriate and useful for evaluating problem areas in communication between parents and adolescents in families coping with a disabling condition. However, it may not be appropriate for use with some families depending on the type of disability. For instance, a family with an individual with certain types of communication impairments may exhibit communication patterns that incorrectly appear to be dysfunctional. The items "I find it easy to discuss problems with my child" and "I am very satisfied with how my child and I talk together" on the Parent Form might be difficult for a parent to answer in the affirmative if their child was unable to express himself or herself due to a disabling condition. Therefore, the clinician might have difficulty evaluating the family communication patterns revealed by the assessment instrument.

Family Crisis Oriented Personal Evaluation Scales (F-COPES). The Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin et al., 1992) may prove to be particularly useful in treatment planning with families of individuals with disabilities. However, the clinical usefulness of F-COPES remains to be established (L’Abate & Bagarozzi, 1993). This paper-and-pencil questionnaire is based on the Double ABCX Model of Family Stress (McCubbin & Patterson, 1981) an outgrowth of Hill’s (1949, 1958) ABCX model of family stress. The measure focuses on individual to family interaction and family to environment interactions, the hypothesis being that families with greater coping skills at both levels will be more successful in their adaptation to stress (McCubbin et al., 1992). Certainly families of individuals with disabilities often operate in a chronically stressful situation and it would be useful to determine where their strengths and weaknesses in coping skills lie.

F-COPES is a paper-and-pencil self-report questionnaire that can be administered to individuals above age 12 (Jacob & Tennenbaum, 1988). Two large samples ($N = 2,582$) consisting of husbands, wives, and adolescents were used in the construction of F-COPES. No information is provided regarding the use of families of individuals with disabilities in the construction of F-COPES. Nor is there information regarding oral administration and how this might affect results. Just as in the previous measures reviewed, these factors may
limit the usefulness of F-COPES for assessing families containing individuals with disabilities.

F-COPES consists of 29 self-report items distributed over five scales: acquiring social support (9 items), reframing (8 items), seeking spiritual support (4 items), mobilizing the family to acquire and accept help (5 items), and passive appraisal (4 items). Reliability (Cronbach’s alpha) for the five factors ranged from .63 to .83, with total scale alpha reliability of .86. Four-week test-retest reliability for the total scale is .81; test-retest for the five factors range from .61 to .95. (McCubbin et al., 1992).

Instructions for F-COPES ask respondents to decide how well the statements describe their attitudes and behavior when responding to difficulties or a problem in response to a stem. Responses are made on a 5-point Likert scale ranging from (1) strongly disagree to (5) strongly agree. Items are in response to the stem: “When we face problems or difficulties in our family, we respond by:” (McCubbin et al., 1992).

Many F-COPES items are geared to the family’s response to new problems. Thus, the family’s response to long-term disability is not really being tapped. However, the focus on new problems may be particularly useful for assessing families containing individuals with disabilities as they reach new developmental milestones or as the course of the disability changes. Information from family members in the area of acquiring social support may be particularly useful for families coping with disability or long-term illness. Much of the information could be used as an aid to planning treatment and distribution of community resources.

**Family Strengths.** The instruments discussed in the preceding sections do not adequately address family strength. Olson, Larsen, et al. (1992) developed a brief 12-item, paper-and-pencil, self-report questionnaire titled Family Strengths. The instrument consists of only two subscales, pride and accord. The authors limited the concept of family strengths to these two scales because they found “the expansive definition of family strengths makes them nearly impossible to measure” (Olson, Larsen et al., 1992, p. 60). Reliability using Cronbach’s alpha was .83 for the total scale (pride = .88; accord = .72). Four week test-retest reliabilities were .58 for the total scale.

Respondents to the Family Strengths Scale are asked to rate items as they apply to their own family on a 5-point Likert scale ranging from (1) strongly disagree to (5) strongly agree. The pride scale consists of seven items designed to measure trust, respect, loyalty, and pride. The accord subscale consists of five items designed to measure the family’s sense of competency.
This measure of family strengths may be useful as a research tool or as a screening measure in assessing global family strengths in families of individuals with disabilities. However, the need to access specific, as well as global strengths, is critical, especially if the information is to be used to improve understanding of, and clinical services for, families coping with a disability.

CRITICAL ISSUES IN THE ASSESSMENT OF FAMILIES OF INDIVIDUALS WITH DISABILITIES

Elman (1991) has outlined some critical areas to be assessed in families of individuals with disabilities. These include an assessment of individual family resources such as personality, ego strength, and health; as well as pragmatic family resources such as financial resources and support from extended family and community. If the individual with the disability is a child, age and sibling position should be considered as this may precipitate different family responses at different developmental milestones. Assessment should also include individual and family perceptions of events and responses.

Other critical areas of exploration have been noted by Seligman and Darling (1989). These include asking: To what extent does the family feel socially stigmatized? If the family feels socially stigmatized, it may be critically disabling to the system. What are the positive effects of having an individual with a disability in the family? How does the family’s cultural background and socioeconomic class interact with other questions regarding the family containing an individual with a disability?

It is also important to assess the specific aspects of the disabling condition as the family assessment must always be done within the context of the particulars of the disability. Kazak (1986) has noted one of the most serious deficits in research regarding families of individuals with disabilities is the overgeneralization of results to other disabling conditions. Some important questions regarding the specifics of the disability are suggested by Elman (1991). Are there physical limitations? Do mental limitations accompany the physical difficulties? Is there a primary mental illness or mental retardation? What is the onset of the disability (i.e., birth or later)? Is the problem life threatening? How dependent will the individual with the disability be throughout the life cycle?

Fewell (1986a) reported the importance of determining the degree of severity of the disability when assessing the family. Is the disability mild, moderate, or severe? How will the type and severity of disability affect the family at critical periods of adjustment? What is
the impact on parent-child interactions, siblings, family roles, family
time, family finances, family relations with society?

The effects of having an individual with a disability in the family
on grandparenting roles and on other extended family members has
been discussed by Sonnek (1986). What are the effects on extended
family members? What is the effect of extended family members on
the family of the individual with the disability? What are the special
considerations in assessing single-parent families (Wikler, Haack,
& Intagliata, 1984; Vadasy, 1986)?

It is also critical to assess community supports in relationship to the
family. If the individual with the disability is a child, what are the school
supports and how do school interactions impact the family (Espinosa
& Shearer, 1986)? What is the interaction of the religious community in the
family system and how does that impact the family (Fewell, 1986b)?
What is the impact of the therapeutic community on the family? The
quality of the professional helping relationship with the family is known
to be critical (Darling, 1991; Moeller, 1986). Are parent-professional
relationships strained so that family members feel they are part of the
problem, rather than the solution team (Upshur, 1991)? Does the family
feel what Mallory (1986) termed “guilt by association” (p. 319); a situa­
tion where family members think helping professionals believe they are
intellectually or emotionally deficient because they have a child with an
intellectual or emotional disability in the family?

Family members with and without disabling conditions influence
each other and the family system (Lyon & Lyon, 1991; Vadasy, 1986).
How does each individual contribute to the family? This line of
thinking leads to a number of questions regarding strengths. What
are the family’s strengths? What strengths have emerged as a result
of having a family member with a disability in the home and how can
they be capitalized upon? What benefits does the family member with
the disability bring to the family? What has worked well for the
family in the past and how can that be used in the present and future?
These are all questions critical for planning effective family treatment.

CONCLUSION

There are obvious difficulties with the paper-and-pencil instru­
m ents reviewed in this chapter. Although the standardized assess­
ments described access information regarding some areas of family
functioning, they are far from complete. The difficulty in assessing
family functioning, strengths, needs, and other variables of interest is
compounded with the addition of a family member with a disability.
If a major purpose of family assessment is to improve quality of life
and service to families containing individuals with disabilities, it is crucially important for treatment professionals to look carefully at the multitude of issues discussed above. Perhaps Seligman and Darling (1989) were correct when they noted that only through long-term observation and discussion with family members regarding their strengths and needs, will true understanding of the family occur.

REFERENCES


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