

“Let Me Just Tell You What I Do All Day . . .”

The Family Story at the Center of Intervention Research and Practice

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Professionals who ask parents about everyday life with a child with disabilities can plan and implement interventions that will better support the family's daily routine. No intervention will have an impact if it cannot find a slot in the daily routines of an organization, family, or individual. We followed 102 families with children with disabilities for 15 years, listening to their descriptions of their daily lives. A major theme running through all the stories was accommodation—changes made or intentionally not made to the family's daily routine of activities due, at least in part, to their child with disabilities. Accommodations are usually adaptations to everyday routines, not responses to stress; are responsive to how children impact parents' daily routine, not to children's test scores; are related to parents' differing goals and values; do not fit a single script or model for what is good or bad parenting; and predict family sustainability of daily routines, rather than child outcomes. Accommodations can and do change—so interventions can indeed find their places. The practitioner participates in this “conversation” between the social structural constraints and opportunities of families and communities, the beliefs and values of parents, and the valuable contributions of the intervention. **Key words:** *accommodation, daily routines, family-centered practice*

Professionals kept asking me what my “needs” were. I didn't know what to say, I finally told them, “Look, I'm not sure what you're talking about. So let me just tell you what happens from the time I get up in the morning until I go to sleep at night. Maybe that will help.” (Remark made by parent panelist at a 1989 Handicapped Children's Early Ed-

ucation Program [HCEEP] conference on Parent-Professional Partnerships, reported in Bernheimer, Gallimore, and Kaufman, 1993, p. 267)

FAMILY-CENTERED practices in early intervention have cast parents of children with disabilities in a new role. Once thought by researchers and practitioners mainly as sources of information about their child's developmental history, parents are now encouraged to identify goals for themselves as well as for their child in the Individual Family Service Plan (IFSP) process (Bernheimer & Keogh, 1995). Family centeredness is more than the solicitation of parent input, however. As characterized by Dunst (2002), it encompasses beliefs and practices that (1) treat families with dignity and respect; (2) include individualized, flexible, and responsive practices; (3) encourage family choice regarding multiple aspects of program practices and intervention options; (4) consider parent-professional partnerships and collaboration as the context for family-program relations; and (5) provide

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resources and supports necessary for families to raise their children in ways that produce optimal parent, child, and family outcomes.

The successful implementation of family-centered practices requires new skills, as well as attitudes, on the part of professionals. In the past decade, professionals have been exhorted to move from a perspective of family needs to one of family strengths and resources (Turnbull, Turbiville, & Turnbull, 2000). But professionals who merely gather information about parents' strengths and resources are unlikely to get sufficient information to implement true family-centered practices. They will get far more useful and meaningful information from parents who tell them what they do from the moment they get up in the morning to the time they go to bed. At the University of California Los Angeles (UCLA), we have been working for the past 15 years to encourage family members to "tell their story" about their child and family adaptation, and include in that story a description of their daily routines. This work, Project CHILD, has yielded findings that we believe have implications for research and for practice.

Our work is guided by an ecocultural (ecological + cultural) approach, reflecting the fact that families actively and proactively respond to the circumstances in which they live, and that they build and organize environments that give meaning and direction to their lives (Bernheimer, Gallimore, & Weisner, 1990; Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Weisner, 2002). Socialization for all children, not just those with disabilities, is the intentional design of psychologically salient and socioculturally meaningful environments for children. The daily routine consists of linked sequences of activities and the contexts that organize those activities. Imagine the child and parent as on a developmental pathway in their lives, and imagine that the stepping-stones for that path are the activities that are repeated, with variations, each day (getting up and ready, driving to school, therapy, a bus ride, dinner time, TV watching, bedtime, going to church, visiting grandparents). Ecocultural

theory zeroes in on that pathway and its stepping-stones (activities and practices) as among the most important influences in a child's and family's life (Weisner, 2002, 2005).

These pathways are visible in the everyday routine, in which families use the resources they have to adapt, exploit, counterbalance, and react to many competing forces (Gallimore et al., 1989). For the families in Project CHILD, one of the "competing forces" was their child with developmental delays of uncertain etiology. *Accommodations* are the intentional adjustments made by families to sustain a daily routine. These include actions taken (eg, try and eat dinner together as a family) as well as actions not taken (eg, the parent turns down the job because the hours conflict with the child's therapy sessions). In our work, we focus on accommodations that were due, at least in part, to the child with a disability.

The concept of family accommodation emerged from the analysis of the stories of 102 Euro-American families who had a child with developmental delays. Children were aged between 32 months and 55 months at the time of entry; the mean IQ was 72.32. (For detailed information about the sample and its recruitment, see Gallimore et al., 1989.)

All families were visited by trained fieldworkers who encouraged families to "tell their story" during a 2- to 3-hour semistructured interview with the principal caretakers (nearly all mothers). Fieldworkers were given specific topics to be covered on the basis of the ecocultural domains that are likely to be important for family socialization proposed by Weisner (1984). Interviewers were trained to use probes to ensure that equivalent information was obtained for all families (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). The families' stories and the information provided by the probes resulted in accounts of the families' shared project for development: the creation of a daily routine that was sustainable given family resources; meaningful with respect to family goals, values, and beliefs; congruent with individual needs of all family members; and reasonably

Table 1. Accommodation domains with definitions and examples^a

Domain	Definition with example
Family subsistence	Hours worked; flexibility of work schedule; adequacy of and satisfaction with financial resources; career vs job orientation. <i>Mother stayed home because child "needed" her; later went back to work to afford speech therapy.</i>
Services	Availability of and eligibility for services. Sources of transportation; amount of parent involvement required. <i>Parents each take time from work to make trips to doctor.</i>
Home/neighborhood safety and convenience	Safety of locks and accessibility of play area; alterations in home (installation of locks, fences for safety, choice of specific neighborhood). <i>Move to larger house to accommodate child's wheelchair.</i>
Domestic workload	Amount of work and persons available to do it; amount of time spent by different family members. <i>Mother puts less priority on house and housework, higher priority on working with child.</i>
Childcare tasks	Complexity of childcare tasks; extraordinary childcare demands (medical or behavioral problems); number and availability of caregivers. <i>Child's older sisters provide care; no help outside family circle.</i>
Child playgroups	Children with disabilities vs typically developing children; amount of parent supervision; role of siblings as playmates. <i>Mother started playgroup for child in neighborhood.</i>
Marital roles	Amount of shared decision making regarding child with delays; degree to which childcare and household tasks shared. <i>Parents sleep separately for 6 months due to child's sleeping problems.</i>
Social support	Availability and use of formal (church, parent groups) and informal (friend, relatives) sources of support; costs of using support. <i>Mother lives rent-free with grandparents; grandfather helps with child.</i>
Father's role	Amount of involvement with child with delays; amount of emotional support provided. <i>Father takes over on weekends as has long working hours during week.</i>
Parent information	Reliance on professional vs nonprofessional sources; amount of time and effort spent accessing information. <i>Father's former girlfriend speech therapist; she helps family access services at her clinic.</i>

^aAdapted from Gallimore et al. (1993) and Bernheimer and Keogh (1995).

predictable (Weisner, Matheson, Coots, & Bernheimer, 2005).

The 10 accommodation domains, with definitions and examples, are presented in Table 1.

After each interview, fieldworkers coded each domain for the *intensity* of the activity using a scale of 0–8. Zero to 2 indicated that there was little or no evidence of accom-

modation activity related to the child with delays; 3, 4, or 5 indicated evidence of moderate accommodation; and 6, 7, 8 indicated high accommodation, or a dominant theme of accommodation related to the child with delays. Reliability of coding was established by independent "blind" ratings of transcribed audio interview for 13 families, randomly selected. The overall average was 82% simple

rater agreement, within one adjacent scale point. The quantitative scores for intensity of accommodation allowed us to examine the relationship between accommodation and selected child and family characteristics. In addition, fieldworkers wrote cues derived from the interview material for each of the domains. Additional details about scoring the domains and the reliability of the coding may be found in the study of Gallimore et al. (1993). We visited families when their children were aged 3, 7, 11, 13, and 16. This report will focus on our findings when the children were 3.

SUMMARY OF FINDINGS

Accommodations usually occur in response to mundane circumstances of everyday life and are not necessarily responses to stress

Accommodations are not necessarily signs of underlying distress and trouble. Gallimore, Bernheimer, and Weisner (1999) reviewed the literature on families adapting to childhood disability and concluded that sustaining a daily routine is a major family function, one that is distinguishable from coping with stress. They noted, however, that the literature examining family stress often includes descriptions of accommodations made to sustain the family's daily routine. Examples included keeping a protected space clean for the ventilation system in homes with technology-dependent children (Bradley, Parette, & VanBiervliet, 1995), reliance on grandparents for help with domestic workload and childcare (Leyser, 1994), and maintaining social support networks (Sloper, Knussen, Turner, & Cunningham, 1991). Other investigators emphasizing the distinction between sustaining a daily routine and coping with stress include Scorgie, Wilgosh, and McDonald (1999), and Brannan and Heflinger (2002). Scorgie et al. (1999) differentiate coping with stress and management strategies. Management strategies, like accommodations, are used day-in and day-out to enable family life to run smoothly.

Among the Project CHILD parents, one single mother switched to a less stressful job, although it meant giving up her career. In another family, a father who worked close to home came home very day at lunchtime to give the mother some respite.

Accommodations are related to child "hassle," not to child test scores

Intensity of accommodation was not related to Gesell test scores, or to the Communication and Daily Living subscales of the Vineland (Gallimore et al., 1993). In other words, test scores are not directly driving what families "do" in response to having a child with developmental delays. More salient to families was the "hassle" level of the child, similar to the "caregiver strain" described by Brannan and Heflinger (2002). "Hassle" was a term frequently used by parents in our interviews, and was used to organize many parents' stories about their daily routine and activities and about the types and intensity of their accommodations. We capitalized on this, and fieldworkers developed a systematic rating of hassle on a scale from 0 to 9 (Gallimore et al., 1993). Hassle was not simply child problems; parents might report that a child had a problem (eg, behavior, speech, retardation) but it was not a hassle in that it did not have an impact on the family's daily routine and accommodations. Parents reported 6 different types of hassle: behavioral (eg, frequent tantrums); medical (eg, unusual care demands); communicative (eg, nonverbal); social appropriacy (eg, tiresome overtures); activity rate (eg, extremely active); responsiveness (eg, ignores, does not respond to others).

Parents who had children who were high hassle reported more accommodations. For example, one family's accommodations were related to the behavior of a child who required constant monitoring. When he was 3, his mother commented: "Our house is set up around Michael. We still have a gate in here and there's a smaller area for him and he can function better, and it isn't that he's ever been destructive, it's just that he can't control

himself" (Keogh, Bernheimer, Gallimore, & Weisner, 1998).

Several other investigators have identified a relationship between the child's impact on the daily routine and family activity. Diamond and Kontos (2004) examined the relationship between the developmental needs of toddlers with delays and families' resources and accommodations. Their findings indicated that the number and types of family accommodations were related to their child's developmental needs. In a study of childcare patterns for families of preschool children with disabilities, parents who cited special needs as a reason for keeping their children out of formal childcare had children with lower self-help skills than parents who did not indicate that special needs were an issue (Booth-LaForce & Kelly, 2004). Said differently, parents of the children with low self-help skills were using informal care (relatives, neighbors) or keeping the child at home. Just as we found for accommodations in Project CHILD, the higher and lower self-help skills groups did not differ in diagnoses, or in mental or motor development test scores. In a study examining the relationship between parents' work and children with developmental disabilities (Freedman, Litchfield, & Warfield, 1995), the authors reported accommodations similar to those reported in Project CHILD: parents quitting jobs, delaying return to work, working part-time because appropriate affordable childcare was not available, changing work schedules to accommodate the child's needs. Families who reported making more accommodations had children with severe medical or behavioral conditions requiring special monitoring and care. Similar findings were reported by Bernheimer et al. (1993).

At age 3, 75% of the families were scored as engaging in moderate- or high-intensity accommodations in child care, sources of information, and support; 30% to 40% of families were scored as moderate or high in subsistence, home/neighborhood, and domestic workload. The most frequent accommodations to high hassle were in the areas of childcare, services, and subsistence. Families ac-

commodating to child hassles were not as active in accommodations in the domains of social support or child playgroups.

Accommodations are shaped by cultural and family values and goals

Family daily routines depend, to a large extent, on cultural and family values and goals (Gallimore et al., 1989, 1993; Kellegrew, 2000; Weisner, 1999). Families of children with disabilities may find it easier to maintain a hectic schedule of driving the child to a variety of community activities if they have strong "normalization" values; parents with strong familistic values, on the other hand, will have trouble sustaining a daily routine that is driven primarily by the demands of their high-pressure careers (Gallimore, Bernheimer, et al., 1999). It is not surprising, then, that accommodations are only moderately related to SES and maternal education. Values and goals related to maternal employment (career track vs job only) had stronger associations with accommodation activities than did SES or income (Gallimore et al., 1993). Our job/career and SES variables included total family income and the Hollingshead SES as well as 2 other variables: mother's employment (full, part, unemployed, and temporarily unemployed) and mother's description of her employment (career-minded/employed; a job only/no plans to quit; only a job, and hopes to quit; and homemaker). The mother's description of her employment reflected her values and expectations regarding employment outside the home, not only what she was doing at that time about work and income. (An identical father variable was not assessed because of lack of variance: fathers virtually all worked.) As we expected, sources of information about the disability, role of father/spouse, marital roles, and accessibility to services all were accommodations that were associated with mother's employment and career trajectories, in addition to the need for the mother to work for financial reasons.

Family values and goals for the child with delays often drove accommodations in the domain of child playgroups. For example, one

family strongly valued "good behavior" for their 2½-year-old daughter. Because she was prone to tantrums they avoided certain activities, for example, birthday parties, going to the park. Another mother, who was determined that her son be placed in general education classes when he turned 5, went out of her way to expose him to typically developing peers. When he was only 18 months old, she joined a mother-toddler group with 2-year-olds so that he might be "stimulated."

Accommodations are neither positive nor negative

Is working at a job the father does not really like but which has stable medical insurance while another job does not, "good"? Is moving to another apartment and dealing with all the associated disruptions because early intervention services seem better there, "good"? Every accommodation has costs as well as benefits to each individual in the family (Gallimore, Keogh, & Bernheimer, 1999). As examples, the frequent use of older siblings for childcare might be positive for the child and parents, but have a negative impact on siblings; time spent organizing play dates with typically developing peers might be positive for the child but have a negative impact on the mother's workload (Gallimore, Keogh, et al., 1999). Parents of children with disabilities, like all parents, must balance their personal roles and responsibilities: parent, spouse, employer/employee (Scorgie et al., 1999). There was no one accommodation "menu" for success, since, among other reasons, family resources, goals, conflicts, and stability varied; what might be an accommodation that fit well for one family would not fit for another. Parents interviewed by Scorgie et al. were divided over the usefulness of connecting with other parents of children with disabilities, or of relying on extended family members or the church for support. Similarly, while gathering information was important to parents, several respondents commented that much of the information they received was of limited value. The valence of any accommodation must be determined by its correlation with other vari-

ables and its fit with parents' overall project, which is the sustainability of the family routine. The "goodness" of accommodations over time depends on their long-term outcomes for all family members, including, but not limited to, the child with delays (Gallimore, Keogh, et al., 1999). If the overall family project is more sustainable over time, this should benefit all family members, including the child with disabilities.

Accommodations are not related to child outcome

Just as accommodations are neither positive nor negative a priori, the intensity of accommodations is not related to a "better" child outcome. Keogh, Garnier, Bernheimer, and Gallimore (2000) used path-analytic techniques to compare the fit of child-driven and transactional models. Children's status in cognitive, personal-social, behavior competencies and problems, and "hassle" domains were assessed at child ages 3, 7, and 11. Results indicated that the longitudinal relationships between children's cognitive and daily living competencies and family accommodation were best explained by a child-driven model. The lower the child's competence at age 3, the more intense the family's accommodations at age 7, suggesting that families made accommodations and adaptations in response to the characteristics and limitations of their children. There is no reason to believe that one or the other type of accommodation produces a better child outcome, given that the accommodations we studied were not pathological and well within the normative range of American family practices (Gallimore et al., 1993).

A caveat: The lack of a relationship between family accommodation and child outcome should not be construed as indicating that the daily routines of these families did not contain any everyday learning opportunities. Recall that actions taken and actions not taken could both be scored on the high end of the accommodation scale. The parents who kept their child away from the park and birthday parties and the mother who joined a

toddler group for 2-year-olds when her son was 18 months old, both scored in the high range of accommodation. Our focus was on the accommodations made to create a sustainable daily routine for the family, one that was congruent with family values and goals, and not on the identification of specific learning opportunities within that routine. Knowledge of family accommodations and their impact on the daily routine allows the early interventionist to locate and capitalize upon those learning opportunities.

IMPLICATIONS FOR RESEARCH

"Even basic received wisdom from academia may be at odds with family members' way of making sense of their worlds" (Singer, 2002, p. 149). Families' stories offer a window into the way in which families make sense of their worlds. We agree with Ferguson (2002) that family research often uses research constructs and measures specifically designed to fit the categories of the model being tested, for example, research on family stress. Ferguson cites the need to collect less structured descriptions of family life but instead to explore how well the model fits when families generate the terms and categories in their own narratives. In our case, families' descriptions of different kinds of child hassles proved invaluable to our exploration of the types and intensity of accommodations families used to create their daily routines.

Gathering stories through the use of semistructured interviews did not restrict us to qualitative data alone. The accommodation domains were used to provide a framework for gathering information; each accommodation domain was then given a quantitative score on a 9-point scale. Yet researchers who only have scores to work with are faced with the nagging question, What does a "3" mean? How does a family who scores a "3" on a measure of life satisfaction actually differ from a family who scores a "5" on the same measure in their activities, daily routines, and beliefs? The gathering of family stories allowed us to

capture the meaning of each rating through the cue or reason provided for the ratings based on conversations with parents. Thus the cues from parent conversations, or reasons for making a certain rating, are as much a finding, or data to be used regarding the family or child, as the ratings themselves. Statistical analyses of ratings are then mapped back on to the qualitative data from cues and other notes (Weisner, Coots, Bernheimer, & Arzubiaga, 1997). We developed a database system, EthnoNotes, specifically for this purpose (Lieber, Weisner, & Presley, 2003).

There is only one study to date that has directly tested the efficacy of our interview focused on family routines and accommodation to assist intervention practice. Moes and Frea (2002) conducted a multiple baseline design study of the use of ecocultural family context information in the functional communication training of preschool children with autism, and found that consideration of family context improved goodness of fit of the interventions and both the stability and durability of reductions in challenging behaviors of children with autism.

Finally, intensity of accommodation as a family unit level of analysis is a valuable addition to measures of family outcomes in the evaluation of early intervention programs. What are the accommodations to the daily routine that families make because of participating in early intervention services, for example (Bailey et al., 1998)? In evaluating the family outcomes of early intervention, family accommodation may be used as a confound as well as an outcome: that is, was the outcome due to early intervention, or to accommodations made by the family in part because of the intervention, although not part of the intervention protocol (Bailey, Aytch, Odom, Symons, & Wolery, 1999)? Our own work indicates that child outcome (as an individual child measure) is not related to accommodation. However, there is a relationship between family accommodation and life satisfaction, family well-being, and sustainability of that family routine (Weisner et al., 2005). Our findings suggest the need to focus on family

impacts along with child impacts, not only one or the other.

IMPLICATIONS FOR PRACTICE

Well before the era of family-centered practices, Featherstone (1981) issued a challenge to professionals who serve parents in our clock-driven, time-scarce contemporary world:

Where is that fifteen minutes [to carry out the intervention plan] going to come from? What am I supposed to give up? Taking the kids to the park? Reading a bedtime story to my eldest? Washing the breakfast dishes? Sorting the laundry? Grading students' papers? Because there is no time that hasn't been spoken for, and for every fifteen-minute activity that is added, one has to be taken away. (p. 78, quoted in Gallimore, Bernheimer, et al., 1999)

If there is one message for practitioners from our parents and from our longitudinal studies, it is that no intervention, no matter how well designed or implemented, will have an impact if it cannot find a slot in the daily routines of an organization, family, or individual. The intervention (the information and practices that make it up) must fit into the existing beliefs and practices already in place. The accommodations that parents make in their daily routines show that family routines and practices can and do change—that interventions can indeed find their places. The practitioner participates in this “conversation” between the social structural constraints and opportunities of families and communities, the beliefs and values of parents, and the valuable contributions of the intervention.

The data on our 3-year-olds were collected in 1987–1988, well before the era of family-centered practices and service delivery in natural environments. Parents were still driving to clinics for therapies, and the majority of children in programs were in segregated early intervention settings. When they entered into the study, most were in the process of transitioning to Part B services, and families had never participated in IFSPs. Nevertheless, our findings do speak to contemporary practice.

Family stories focused on accommodations provide home visitors with multiple opportunities for identifying slots in the daily routine that contain embedded learning opportunities. Information gleaned from families' stories makes the “individual” in the IFSP a meaningful construct (Bernheimer & Keogh, 1995) and makes it more feasible to implement family-centered practices as described by Dunst (2002) and Mannan, Summers, Turnbull, and Poston (2006). It can also make a valuable contribution to the transition process, providing a more continuous experience as families and children move from Part C to Part B services (M. Ballard-Rosa, oral communication, September 9, 2005).

Other literature on developing interventions also supports consideration of the daily routine and accommodations. Dunst and colleagues (Dunst, Bruder, Trivette, Hamby, Raab, & Mclean, 2001; Dunst, Bruder, Trivette, & Hamby, 2006; Dunst, Hamby, Trivette, Raab, & Bruder, 2000) have argued that knowledge of family accommodation is critical for identifying and building upon everyday natural learning opportunities. Additional examples include Roper and Dunst (2003) regarding communication intervention; Woods and Wetherby (2003) regarding intervention for infants and toddlers at risk for autism spectrum disorders; Tisot and Thurman (2002) on using behavior setting theory to define natural settings and McWilliam's (1992, 2001) routines-based approach to family-centered intervention planning.

We recognize that the current zeitgeist, including *No Child Left Behind*, is focused on child outcomes, particularly those related to academic achievement, and that this focus extends to increasingly younger children. An exclusive focus on child outcomes, however, is not in the best interests of early interventionists, or the children and families they serve. Regarding home-based services, for example, McWilliam (2001) has observed that many home-based approaches are little more than clinical sessions dumped onto the living room floor. Both McWilliam (2001) and Edelman (2004) remind us that what happens between

home visits has a critical impact on children's learning. While the home visitor is obligated to use his or her disability-related expertise in developing interventions, without knowledge and understanding of the family's daily life, the efficacy of these interventions will be diluted.

The field of early intervention has come a long way in the past 25 years. The recognition of the importance of the daily routine in planning interventions now plays a major role in supporting child and family-sensitive practices that are likely to be sustained over time. There is nothing mysterious or diffi-

cult about obtaining this type of information. Telling their story comes much more naturally to parents, and is less intrusive, than talking about their "needs" or stress, or being asked only to circle numbers on a questionnaire or fill in blanks on a form. All that one has to do is to ask what happens from the time they get up in the morning to the time they go to bed at night, see the family world from that point of view, and integrate our growing general research knowledge about daily routines with the always-unique circumstances of each family.

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