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Ordinary Families — Extraordinary Care Giving

John P. Ronnau

Children with severe emotional problems often have multiple needs that require disparate services including child welfare, juvenile justice, health, mental health, substance abuse, and mental retardation (Stroul, 1996). However, the primary care giving responsibilities for these youngsters still remain with their families. It is the family who shelters and clothes them; provides guidance, affection, recreation, nurturing; gets them to appointments with doctors and therapists and to school day-in-and-day-out, year after year (Lourie, 1995). Despite the invaluable and irreplaceable care provided by families, they are often maligned by a system which characterizes them as having their own problems and inadequacies.

The purpose of this research is to learn more about the strengths of families who care for children with severe emotional disabilities (SED). This exploratory descriptive study made use of focus groups attended by parents who are caring for such children. In order to improve services to these families, it is important that we understand how the notion of strengths play out in their everyday lives. Observations are made about the care giving plan, which all families devise in the course of caring for their child with special needs. Implications for paid professionals who serve these families are offered by presenting a model for putting family care givers at the hub of the service provision wheel.

Needs of Youth with SED

United States' estimates of the number of children ages 4-18 who have some type of diagnosable mental disorder range from 14% to 26%, with 7% having a serious disorder (Nixon, 1997; Rog, 1995; Stroul, 1996). However, only 20% to 30% of these children actually receive services (Nixon, 1997; Rog, 1995; Stroul, 1996). Children's mental health problems cover a wide range of disorders, including depression, anxiety, conduct, and developmental disorders. Diagnosis of children's mental health problems is especially difficult, because they may have multiple disorders, being effected by interrelated physical impairments, developmental issues, and environmental factors (Rog, 1995). Most definitions of severe emotional problems in youth (under 18) include the following characteristics: exhibiting severe behavioral, emotional, or social disabilities; these disabilities disrupt normal development and have persisted for an extended period of time;

the disabilities cannot be attributed solely to intellectual, physical, or sensory deficits; and the youth frequently requires intensive treatment (Ronnau & Poertner, 1989). "These children require a range of mental health services which are age appropriate and at varying levels of intensity. However, mental health services alone are not enough. Emotionally disturbed children almost universally manifest problems in many spheres, including home, school, and community. As a result, they require the intervention of other agencies and systems to provide special education, child welfare, health, vocational, and often, juvenile justice services" (Stroul & Friedman, 1986, p. v).

Caring for a child with a severe disability places tremendous strain upon the family and exacts a high cost (Bush, 1985; Wason, 1995). Among the stressors experienced by family care givers of these children are financial costs, stigma, constant worry and anxiety, guilt, social isolation, interruptions of sleep, limitations in recreational activities, interruption of normal routines, feeling pessimistic, and increased sibling conflict (Freeman & Simmons, 1974; Goldman, 1982; Marcus, 1977; Moroney, 1981; Thompson & Doll, 1982; Willis, 1982). Providing the structure, guidance, support, and specialized treatment that these children need is a complicated and demanding challenge.

Historical Focus on What Families Do Wrong

Despite the fact that families provide the preponderance of day-to-day care that children with SED need to function in the community, many still perceive of themselves as being on the outside of the service system looking in. Too often, they are treated as outsiders, irritants, nuisances, and as the source of their children's problems (Stroul, 1996; Turnbull & Turnbull, 1986). Causation theories that finger point at these parents have caused many to feel guilt, resentment, low self-esteem, lack of trust, and defensiveness (Turnbull & Turnbull, 1986). Barriers to constructive parent-professional relationships have been erected, which prevent the service system from capitalizing upon the energies of the most invested service providers, the parents. It is the parents who often have the most knowledge about their child's history and needs, are the most committed, and who spend the most time with the child. The Stinnett and Sauer (1977) observation from two decades ago still applies today: "most of the research, as well as most of the popular writing, in the area of marriage and the family has focused upon pathology. Too little is known about the psychological and social factors that contribute to family strengths" (p. 5).

Most families who care for children with special needs are doing the best they can with what they have under extremely challenging and stressful circumstances (Lloyd & Sallee, 1994; Ronnau & Poertner, 1993; Turnbull & Turnbull, 1986; Weick & Saleebey, 1995). Most are highly committed, caring, capable, intact families. In the author's opinion, the vast majority

of these families do an admirable job, though they may occasionally benefit from timely and measured assistance. We need to improve our assessments to recognize the parents who need intensive help. Some may appear "dysfunctional" at a given point in time due to care giving demands and stress; however, only a small percentage are incapable of caring for their children.

Early and Poertner (1993) contend that a "normalization approach" should be used with children who have SED to reduce stigma and prevent unnecessary institutionalization. Similarly, one may think about freeing up the service system to make better use of family energies, skills, knowledge, and commitment in caring for their troubled child. "When families are assumed to be at fault for their children's problems, families are not considered to be a resource for their children; rather, they are something to be 'fixed' or removed from their children's lives through placing the children out of their homes" (Early & Poertner, 1993, p. 748).

The Value of Family Care Giving

"The most important asset for a child with a serious mental disability is a *close relationship with his or her family* (or surrogate family), no matter how stressed or in pain they may be at any given time" (Cole, 1995, p. 193). It is ironic that those paid to help may actually hurt the efforts of families, unwittingly and certainly unintentionally, but the effects are no less harmful. McKnight (1995) has articulated the negative impact that paid professionals can have upon families. He stated that "through the propagation of belief in authoritative expertise, professionals cut through the social fabric of community and sow clienthood where citizenship once grew" (p. 10). It seems that somewhere along the line, we have turned the conceptual pyramid on its head. Instead of families, neighborhoods, and communities being in their rightful place as the foundation of care giving, child rearing, and nurturing law abiding citizens, people paid to "care" have taken their place as what modern society values most. Human service professionals are paid large sums of the tax payers' money to try and duplicate what families have always provided (Adams & Nelson, 1995; Levenstein, 1981).

The point is not that families are perfect nor that there is no need for paid professionals. The point is that our best hope is to learn more about what families do right so that we can learn how to help them do their job. Nothing can take their place in this care-giving equation (Stroul, 1996). "The family unit then, must be the primary object of therapeutic attention and, individually or as a group, family members must become primary participants and, as soon as possible, leaders in the treatment process" (Cole, 1995, p. 193).

The family-centered movement is a significant sign of hope for those who believe, and practice accordingly, in the central role that families must play in caring for persons with special needs.

Family-centered work starts from the recognition that professionals are not at the center of helping systems, that most of the caring and controlling in which social workers, nurses, teachers, probation officers, and even the police engage is done by others—families, kin, and neighborhood networks, informal groups, churches, schools, and other formal organizations. The effectiveness of human services depends on how well they interact with the whole complex of formal and informal elements to strengthen the community's capacity to care for its members and address shared needs and concerns (Adams & Nelson, 1995, p. 6).

The basic premise of what Adams and Nelson (1995) refer to as the "decentering" of human services is to "recognize that most of the caring and controlling in the community is normally done informally within families and neighborhoods. The task of the professionals then, is to find ways to join the community and help it in carrying out *its* work of caring for its members" (p. 7). Rapp, Shera, and Kisthardt (1993) assert that use of an "empowerment paradigm" will help us make best use of family strengths. They stated:

Some of the central features of the emerging empowerment paradigm include treating clients as subjects rather than as objects; focusing on clients' strengths rather than on pathology; clients actively participating throughout the helping process; seeing resources as the total community rather than just as formal services; emphasizing the rejuvenation of informal social networks; and monitoring, evaluating, and advocating in a collaborative fashion (p. 728).

Similarly, Lawson (1996) and Briar-Lawson (1997) describe "new partnerships" for improving service systems, which must include families in integral ways. McKnight (1997) talks about the importance of valuing families and the "associational community" over formal service systems. An effective way to help families do their job is to learn about and make use of their strengths.

Methodology

This research was carried out to answer the question: what are the strengths of families who care for children with severe emotional disabilities? This exploratory descriptive study employed an interview-guided approach. This approach was the most desirable compromise between a highly structured or a completely open-ended approach (Rubin & Babbie, 1997).

A qualitative design is appropriate because the research was conducted in the natural settings of the respondents; the variables being studied did not lend themselves to being controlled, tested, or manipulated; the information (data) provided by the respondents was influenced by their life experiences and priorities; and the primary means of analysis was to assess themes which naturally emerged from the data (Tutty, Rothery, & Grinnell, 1996). As with all research endeavors of this nature, there were both advantages and limitations. The interview guide provided systematization to the data collection process. The advantages of this were two fold: (1) it allowed for consistency across the three sites where data were collected, and (2) it provided some insights and guidance for respondents in an area that was otherwise unique to them. The limitations included threats to both internal and external validity, which were not controlled for; accordingly, no overt claims of generalizability can be made (Campbell & Stanley, 1963).

Sample

The sample consisted of forty-two parents (N=42) in four sites. Three of the sites were communities in the Southwestern United States. The fourth site was a workshop included in a national conference on family strengths. Twelve (12) of the parents self-identified as Hispanic, 8 as Native American, 1 African American, and 21 Caucasian. While four couples participated in the discussions, the bulk of the respondents represented different families. More than 90% of the participants were female. Most of the families were of modest economic means, though some of the single parents reported that they struggle financially to make ends meet.

Each of the families represented in the sample was caring for at least one child with SED, for a total of 38 children. The children's ages ranged from 3 to 18, with an average of 10.5 years. Modal age is 7 (seven children). The diagnoses assigned most frequently to the children in the sample were Attention-Deficit/Hyperactivity (70%), Oppositional Defiant (30%), Childhood Depression (10%), and Conduct Disorders (10%). Percentages are approximate. Several of the children had more than one diagnosis.

Participants were included in the study by means of purposive sampling (Grinnell, 1993). The parents were identified through local chapters of Parents for Behaviorally Different Children (PBDC), a nationwide advocacy group for families caring for children with SED. They were invited to attend the session by a local PBDC representative via telephone or mail. All participants were asked to sign a consent form, and their confidentiality was assured.

Instrumentation

The 42 parent participants were asked to think about, discuss, and list their strengths in terms of seven categories. Family functions identified by Turnbull and Turnbull (1986) comprised six of the categories. The family-functions framework was developed to remind professionals about the "total context" of family care giving. These functions are the areas of responsibilities within which a family does its job (i.e., to meet the needs of its members). They also have proven useful areas in which to look for the strengths of families (Ronnau & Page, 1991). The six family functions are

- domestic (e.g., meeting basic needs such as food, clothing, shelter)
- self-identity (e.g., self-esteem, developing positive self-image)
- affection (e.g., nurturing, showing love and caring)
- socialization (e.g., setting limits, providing guidance)
- recreation (e.g., fun, relaxation)
- education/vocational (e.g., school work, skill development)

(Turnbull & Turnbull, 1986, p. 68-69)

An "other" category was included to allow for the identification of strengths which fell outside of the family-functions framework.

Data Collection

After introductions and assurances of confidentiality, the purpose of the interview was explained to the participants. The parents then were asked to meet in groups of three and appoint a recorder. They were encouraged to openly discuss and then list the strengths they have observed in their own and other families caring for children with SED. After approximately an hour of discussion, the large group was reconvened. Each group was asked to report their findings. The lists compiled in the small groups were collected at the end of the meeting. The same data collection process was followed in each of the four sites.

Analysis

A total of 489 strengths were listed by the respondents. The strengths in each category were analyzed to search for themes. A theme was identified when a cluster of comments reflected the same strength. The size of the clusters within the first six categories ranged from 45 to 6, with an average of 15. The cluster sizes in the "Other" category were 7 and 6. The threshold for identifying a cluster was different for each category because the total number

of strengths listed in each category varied. A common cut-off point across all categories would have hidden some important themes.

Findings

One of the most valuable aspects of qualitative research is that it allows the respondents' "voices" to be heard. It is unfortunate, in that regard, that space limitations do not allow listing all the responses in each of the themes; instead, only representative comments are given. The number in parentheses following the main categories is the total number of strengths which were listed. Similarly, the number of strengths listed in each theme (i.e., the cluster size) is reported.

Strengths in Meeting Domestic Needs (84)

In the category of domestic family strengths, four themes emerged: *providing basic economic support, adapting schedules to meet the child's needs, obtaining specialized care, and meeting medical needs.*

I. Basic Economic Support (45)

- My husband and I both work to provide money to pay for our house payments and utilities
- Full-time work to provide food, clothing, and pay the mortgage
- Learn which foods help or harm
- Adjust diet, learn what helps with moods
- Provide a balanced diet
- Meals, wash clothes, bath

II. Schedules (8)

- As a single parent, I work part-time. I try to be home early so that when my child gets home from school, I spend as much time with him as possible, get his snack, make it structured
- Try to make my work schedule as flexible as possible so that I can be with the kids as much as possible and change shifts with my wife's hectic schedule (both my wife and I take turns a lot taking care of the kids, clean house, cooking, clothing them)
- Rearrange my work schedule to accommodate my child, so he can get into a schedule

- Finding work that will compliment my son's schedule

III. Specialized Care (8)

- Monitor sitter and ask on a daily basis how the day was
- I have my mother and one of my boyfriend's aunts help me out with my daughter to pick her up after school
- Finding proper care for when I'm working
- Special needs sitters

IV. Medical Care (6)

- Getting doctors that know something about ADHD
- Make sure he takes his medication
- Making sure he gets all his medication
- Knowing your medicines

It is not surprising that providing economic support is a predominant theme. It is the basic challenge of all families, especially single parents. Similarly, many parents must juggle schedules to be when and where their children need them. The last two themes, however, are particularly relevant to the needs of children with SED. Finding competent baby sitters or after school care for children with severe behavior problems is a frustrating challenge. Also, many of these children are prescribed medication. Parents must be sure their children take the medicine, often involve the school in administering it, get the prescriptions refilled, and monitor for side effects.

Strengths in enhancing Self-Identity (85)

Three themes emerged from the list of 85 developed by respondents related to the development of self-identity in their children: *providing encouragement, confidence building, and enrollment in special programs.*

I. Providing Encouragement (29)

- Telling them good things about themselves
- Thinking positive
- Praise for their achievements, a lot of kind supportive words
- Always assure him he will be supported
- Praising his good report cards and good school papers

- Tell him how smart he is

II. Confidence Building (14)

- Finding things for them to do at which they can be successful
- Giving him chores that he can succeed in then immediate reward or praise
- Encouraging self-help skills
- Telling him that he can do anything he sets himself to do like bathing, dressing, basic needs that are not so easy for him to accomplish

III. Special Programs (8)

- My son, who is very emotional, and has trouble with bullies, is now in therapy and a support group
- Entered into family counseling for behavior management
- Enrolled her in school self-esteem program

Providing encouragement and building the confidence of their children are characteristic of all good parents. However, many children with SED need an incredible amount of this reassurance because of their low self-esteem. Finding and attending special programs in order to meet their child's needs, requires a disproportionate amount of these parents' time.

Strengths in providing Affection (72)

A total of 72 strengths were listed by the parents. Two themes are observed in the list: *providing verbal reassurance and physical contact.*

I. Providing Reassurance (17)

- Ask them how their day has been and what they ate
- Use affectionate names
- Asking about how they feel
- Praise good actions

II. Providing Physical Contact (14)

- Tickling and cuddling
- Backrubs, footrubs, to soothe
- Lots of hugs

- We do a lot of hugging and holding. The girls need to cry and cry sometimes while I hold them and murmur and stroke them

The strengths listed by the parents of children with SED in this category, perhaps more than any of the others, resemble what we would expect to see in a list of strengths of any "good" and nurturing parent. The difference is in the frequency and intensity of affection and other kinds of reassurance required by these children. For many of them, physical contact can be both a trigger for acting out or have an almost magical calming effect. Knowing when and how to touch their children is an art developed by many of these parents.

Strengths in providing Socialization (65)

The parents listed 65 strengths in this area. Two themes were evident in their list: *setting limits and providing opportunities for socialization*.

I. Setting Limits (25)

- Punish the kids if they go out into the street
- Give consequences for different behaviors
- We try to correct and redirect his social behaviors without making him feel bad
- Setting limits and boundaries

II. Providing Socialization Opportunities (9)

- Have her friends spend the night
- Include other children in activities on the weekend. I try to create a social environment for her in this way
- Take him places that meet his needs—the right place at the right time

Socialization is a major parenting responsibility in all families. The strengths listed by parents of children with SED suggest that limit setting is even more of a challenge in their families. Their children require continual reminders and redirection.

Strengths in providing Recreation (66)

The list of strengths in the area of recreation totaled 66. One theme was observed: *managing excessive energy*.

1. Managing Excessive Energy (10)

- Let him tantrum thru
- Massage therapy
- Sit wrapped in his favorite blanket
- Scratching his back when he goes to sleep
- Lot of outdoor things to vent feelings and energy

The list of strengths in this category appears similar to the recreational activities one would expect to see in all families, with one notable exception. The theme which emerged reinforces the observation that many children with SED need help to slow down and relax. Their parents must be vigilant and deliberate in providing them the time and safe space in which to vent their excessive energy and exuberance.

Strengths in Meeting Education/Vocational needs (77)

The parents listed 77 strengths in this category. The four themes which emerged from the list are: *advocating; encouraging school attendance; accessing special programs; and obtaining information.*

I. Advocating (20)

- Keep in close contact with teacher and counselor
- Attend IEP meetings
- Became advocate for special needs kids
- Advocating for special programs at school
- Follow-up. Making sure that his IEP goals meet his needs
- Many, many meetings at school, IEPs or 504s

II. Encourage School Attendance (19)

- Daily notes to teacher to let her know and for her to let me know how his day (or night) went
- Work with her teacher on a daily basis
- Being involved in what's happening at school
- Reinforce how important school is

III. Accessing Special Programs (8)

- Take classes on parenting
- Having to find programs to fit special needs
- We have tried hard to find proper academic settings for our children, including paying for private school

IV. Obtaining Information (6)

- I've had to become an expert on Dyslexia, ADD, and other learning differences in order to get them what they need in school
- Learned about his disability for behavior medications
- I come to school meetings to see how my daughter is doing in school

The education/vocational category of strengths is the one in which the extraordinary efforts of these parents show up most dramatically. School is a dominant theme in the lives of all youngsters and, therefore, in the lives of their parents. In addition to parent-teacher conferences, sports, and all the other "normal" activities that kids get involved in, parents of children with SED must attend many more meetings because of their child's special needs. For many of these children, any hope of having a successful school experience requires their parents to be in constant communication with teachers and other school personnel.

"Other" Strengths (40)

A total of forty "other" strengths were listed by the respondents. Three themes emerged from the list: *patience, commitment, and advocacy.*

I. Commitment (7)

- My child means everything to me and I will do anything and everything to help him!
- We don't give up. If it doesn't work we try something else
- Never, ever, ever gave up

II. Patience (6)

- Being able to be patient and keep up with him—better than most people could
- Patience, sense of humor, commitment

- Patience, honesty, dedication in providing the best for her

III. Advocacy (5)

- My wife formed a parent advocate and support group
- Being parent advocate for autism program
- Advocacy for special needs kids

The list of "other" strengths provides insight into what the parents themselves see as important for caring for their children. Commitment and patience are required in abundance from all parents but even more so for those caring for a child with SED. While all parents at times are advocates, these parents must often fight to obtain even the basic services for their children.

Practice Implications

The results of this research support the observation that caring for a child with special needs requires all the "normal" strengths seen in most "healthy" families, plus the extraordinary ones observed in this study. This extraordinary care giving is conceptualized as an Individualized Care Giving Plan (ICGP). Depicting the family's responses over time as a "plan" is meant to denote that they continually test, adapt, and revise their approach to caring for their child with special needs. While there may not be a plan in the formal sense of the term, the author suggests that families that successfully care for a child with SED over time do, in essence, develop a plan as they respond, adapt, and respond again to their child's needs. Figure 1 depicts this special plan.

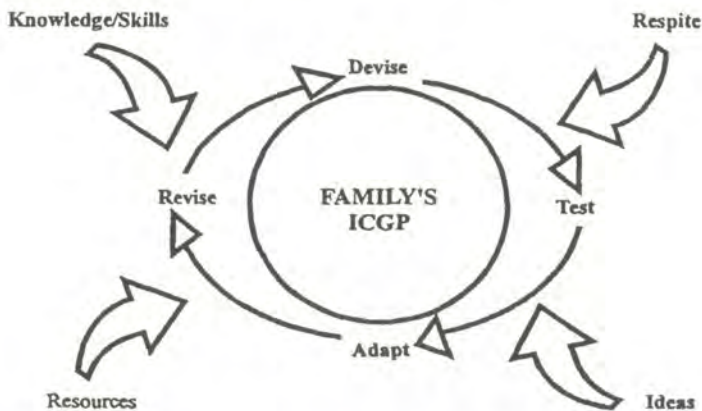


Figure 10. Family's Individual Care Giving Plan (ICGP)

The family is at the center to reflect the reality that family members provide the bulk of the intensive and sustained care required by children with special needs. If a child with SED is to grow into a healthy adult, the service plan must "wrap around" the family, instead of taking the place of, or in any way diminishing, the family's role. As Elizabeth Cole puts it "the participants in the system of care are viewed, in terms of some order of influence, as the concentric layers of the famous onion. The child's family (or surrogate family) is the first layer, most intimately involved, and directly responsible." (Cole, 1995, p. 192).

As depicted in the second circle, parents devise a plan for caring for their child. Simply put, they must continually come up with ideas and solutions. Then, they test those ideas through application. They must revise those plans and test them out. No plan is perfect and children can be very unpredictable! There are so many variables that cannot be anticipated. So parents must be adaptable. McIntyre observes that "constant restructuring in small increments contributes to overall stability in organizations and living systems—maybe families can benefit from this knowledge as well" (McIntyre, 1997, p. 4). Indeed, we should expect, predict, and celebrate the many "failed experiments" families will engage in during the process of caring for their children.

The outer circle depicts the inputs provided by workers to help families. Often what families need most are concrete and practical resources. For some, it will be help in finding transportation to appointments; for others, it will be money to buy medicine, or diapers, or pay the rent, or keep the utilities on. Many of these families need respite, which will require specialized care givers. Others need information and help to learn new skills. What does a "conduct disorder" really mean? Why did the doctor prescribe Ritalin? What will it do to my son? How do I stand up for my daughter without being labeled "an over involved parent?" Emphasizing the strengths of families does not mean that they can always go it alone. What we know about the needs of children with SED is that their families will need lots of support from friends, extended family, community, and paid professionals in order to do their jobs.

This way of working with families requires a paradigm shift. Who is really at the hub of the care giving wheel? Who provides the bulk of the most intensive and long-term care? Who is likely to be there day in and day out for the child? Who are the people who "never, ever, ever gave up" on their children? That's who should be at the center of the care giving plan. The focus of paid professionals should be on supporting their efforts.

Based upon the results of this research and all that the author has learned from working with parents caring for children with SED to date, these practice guidelines are offered:

- Just because the family is not being paid does not mean the care giving has no value;
- Even though the care giving is not perfect, does not mean it is inferior (a 24 hour per day job provides lots of opportunities to commit imperfections); and
- Family care givers are the long-term committed care givers and the child's most important resource; therefore, the paid professionals' primary role should be to support, not supplant, the family's efforts.

Family members may or may not have certificates or degrees attesting to their knowledge, and they are not paid for the care they provide to their children. The irony is that while it often is not valued, the care these families provide is priceless. In most cases, the state cannot match the quality of the "holding environment" which families provide. Just because the family is not being paid does not mean the care giving has no value; in fact, family is the most valuable resource the child has.

Our perceptions and expectations of people have powerful effects. If we expect a family to be resistant and dysfunctional, they probably will be. But if we begin our work with them by listening to their story, avidly looking for their strengths as we assist them to meet their needs and resolve their problems, we may discover and free up tremendous resources. Blaming is unproductive. "Being on the outside looking in, while various professionals fasten labels and lay blame for the (mis)behavior of their child, can only render families unable or afraid to try their own solutions to problems" (McIntyre, 1997, p. 3-4).

Conclusion

Adams and Nelson assert that instead of waiting until the family collapses from fatigue or lack of resources, paid professionals "need to recognize and support, even give respite to, those who bear the main burden of care" (Adams & Nelson, 1995, p. 6). Orthner and Cole recommend development of "community-based strategies" to support families. "Whether through churches, the work place, or community centers, families need resources to supplement the support they receive from friends or relatives in times of trouble" (Orthner & Cole, 1997, p. 4). Instead of imposing our own agenda, paid professionals should first listen, observe, and ask about what the family does well. What have they tried? What have been their successes? What have they learned from their "failures"? "What supports, relationships and energy are required to build success for that family?" (McIntyre, 1997, p. 3). The care giving provided for children with SED by their families is invaluable. The priority for paid professionals should be to keep the family and its strengths at the center of the picture in order to best support their efforts.

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