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# The Importance of Care Irrespective of Cure: The Daily Living Realities and the Service Experiences of Families with Children with Complex Mental Health Problems

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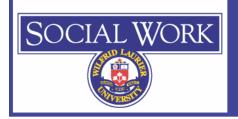# Partnerships for Children and Families Project

SOCIAL WORK
WILFRID LAURIER UNIVERSITY

**The Importance of Care Irrespective of Cure: The Daily Living Realities and the Service Experiences of Families With Children With Complex Mental Health Problems**

N. Coady

September 2004

**THE IMPORTANCE OF CARE IRRESPECTIVE
OF CURE: THE DAILY LIVING REALITIES
AND THE SERVICE EXPERIENCES OF
FAMILIES WITH CHILDREN WITH
COMPLEX MENTAL HEALTH PROBLEMS**

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1

**THE IMPORTANCE OF CARE IRRESPECTIVE OF CURE:**
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**FAMILIES WITH CHILDREN WITH COMPLEX MENTAL HEALTH PROBLEMS**

**Overview of the Study**

This study represents one part of the larger research agenda of the Partnerships for Families and Children (PFC) Project. The PFC project is supported by the Community and University Research Alliance (CURA) initiative of the Social Sciences and Humanities Research Council (SSHRC) of Canada. The PFC project is directed at understanding the lives and service experiences of families and children who are involved with child welfare and children's mental health services in Southern Ontario (the project's various research reports and review papers are posted on its website: www.wlu.ca/pcfproject).

This report summarizes the results of in-depth interviews conducted in the Summer of 2001 with parents from12 families that had children who were or had been involved with an intensive, community-based service for children with complex mental health problems. This study had a dual focus: (a) to learn about the daily living realities of families with children who have complex mental health problems, and (b) to learn about families' experiences with the mental health service. Qualitative analysis of the interviews yielded themes pertaining to each of these two areas of focus. The themes related to daily living realities paint a picture of the toll exacted on families from enduring the multiple, severe, and long-term stressors that often come with having a child with complex mental health problems. An overarching theme that emerged with regard to families' experiences with the mental health service was "the importance of care irrespective of cure".

## Overview of the Children's Mental Health Service

The children's mental health service that was the focus of this study is an intensive, individualized home and community support service. The target population is families with children (0 - 18 years) who have a history of complex mental health problems. Client families normally have a history of multiple crisis episodes and social service involvements, present with risks of family or school breakdown and/or risk of harm to self or others, and have service needs beyond the capacity of typical agency outpatient counselling.

The core services in this children's mental health program include: (a) psychological, psychiatric, and behavioural assessment; (b) service coordination and planning (including access to flexible funding for specialized or non-traditional supports); (c) intensive, in-home family support (including behavioural intervention services); and (d) family therapy/counselling (more intensive and/or longer-term than traditional mental health services).

## Methodology

A convenience sample of 12 families was gathered from the children's mental health service. Because this service was quite new at the time of the study, all families that were currently involved or that had terminated their service were approached about participating in the study. The first 12 families who agreed to participate became the sample. The sample was limited to 12 families due to the finite resources of the research project and the fact that this was one of many samples of families from different agencies (other children's mental health agencies, as well as child welfare agencies) that were part of the larger research project.

Open-ended, semi-structured interviews were conducted with parents from the 12 families over the summer of 2001. Ten mothers, one father, and one couple were interviewed. The

interviews were between one and one-half and two hours in length and were conducted by research assistants, who were students or recent graduates of master level social work or psychology programs. Although interviewers did not adhere rigidly to the preset structure, interviews generally consisted of two parts: (a) asking parents to describe the daily living realities of their families, and (b) asking parents to talk about their experiences with social service agencies (focussing primarily on the intensive children's mental health service).

Interviews were transcribed and then were analysed by research assistants and a research team member. Transcripts were read carefully in their entirety and a coding scheme was developed by classifying the content of the interviews into general topic areas within each of the two main areas of focus. For example, a general topic area within the daily living reality focus was "the impact of the children's mental health problems on the family"; a general topic area within the social service involvement focus was "quality of the relationships with the agency workers". The content of the 12 transcripts was then sorted into the various general topic areas. The information within each general topic area was reviewed in depth, and themes, with illustrative quotes, were distilled from the data. The major themes that emerged from the data analysis, and their implications, are the subject of this report.

**Results**

The results are divided into the two main areas of focus: (a) the daily living realities of the families, and (b) the families' experiences with the mental health service. The findings relevant to daily living realities are divided into three sections: profile of the families in the sample; impact of the children's mental health problems on the family; and resources, supports, and ways of coping. The findings relevant to the families experiences with the mental health service are divided into

4

four sections: service outcomes, overall client satisfaction, sources of satisfaction, and sources of dissatisfaction.

***Daily Living Realities of Families***

*Profile of the Families in the Sample*

Of the12 families in the sample, there were 6 intact two parent families; 5 separated or divorced, single-mother families; and 1 blended family. Four of the families had terminated involvement with the agency and eight families had active involvement at the time of the interviews. Sociodemographic information about the study families was not collected systematically, but it was clear that this client group was far more heterogeneous with regard to education, income, and social class than the child welfare population that was the focus of other parts of the larger research project.

The number of children in these families ranged from one to four, with a mean of two and a half. Nine of the 12 families had more than one child, and three of these families had two children who were the focus of the mental health services. With regard to the children with the identified mental health problems, there were 12 boys and 3 girls (seven families had one boy as the lone identified client, two families had one girl, two families had two boys, and one family had one boy and one girl). The mean age of these children at the time of initial involvement with the agency was seven and one-half years (range of 4-11 years), and their mean age at the time of the study interviews was nine and one-half years (range of 4-16 years).

The length of involvement with the agency for these families ranged from three months to six years, with a mean of two years involvement. These are conservative figures for length of involvement because 8 of the 12 families remained active with the agency at the time of the study.

It should be noted, however, that the intensive, community-based service that is the focus of this study was a new service at this agency and none of the study families had been involved with it for more than a year.

The norm of long-term involvement with the agency was reflective of the serious mental health issues that the children presented. Although information about the mental health diagnoses for these children was not collected systematically, it often emerged during the interviews (some parents named their child's diagnosis, whereas others described the main features). Two of the children had been diagnosed with pervasive development disorders (autism, Asperger's syndrome); at least seven children had been diagnosed with attention deficit/hyperactivity disorder (ADHD), usually of a severe nature; and many of the children had either been diagnosed with, or exhibited symptoms of, disruptive behaviour disorders (oppositional defiant or conduct disorders). Other mental health problems of the children in this sample included depression, anxiety, phobia, developmental delays, and learning difficulties. Multiple diagnoses was the norm in this sample. Most of these children presented severe, often violent behavioural problems at home and/or school, and suicidal ideation was or had been a concern for at least two of the children.

Two brief examples provide an idea of the severe nature of the children's mental health problems that were present in most of these families. One separated, single mom of an 11 year old boy described the severity of her son's behavioural problems:

> Like he'd smash the phone, he'd smash windows, he'd you know, hit me, choke
> me, try to take pills, put a knife to my throat, put a knife to his throat, you know,
> he'd yell at his sister, push his sister, just you know, and then other times he'd just
> not want to do anything, not want to get out of bed.

In another intact, two-parent family, a 10 year old boy's unexplained headaches led to emotional/behavioural difficulties that included refusal to eat, drink, or walk; which in turn led to prolonged hospitalization that included electroconvulsive therapy (ECT). At the time of the study interview, no definitive diagnosis had yet been made and although the child was back at home, he required intensive medical and therapeutic attention, and the possibility of long-term residential care was being considered. Only one of the study families had a child with a relatively simple mental health issue (a phobia that arose from deaths in the family) that responded well to short-term (three months) treatment. Although only two children in the sample had required hospitalization or residential treatment to date, this speaks more to the coping abilities of the families and the helpfulness of the services they received than to a moderate severity of presenting problems.

*Impact of the Children's Mental Health Problems on the Families*

As would be expected, the impact on these families of having one or more children with complex mental health problems was severe and multifaceted. Most of these children had exhibited problematic behaviours for a number of years prior to their families' involvements with social services, and most of the families had sought a range of other professional help before becoming involved with the intensive children's mental health service that was the focus of this study. All of these parents were extremely concerned about their children, and most of them had been worn down by years of trying to cope with and find help for their children's difficulties. The discussion of themes related to the impact of the problems on the family is organized under three headings: (a) stress on the parental relationship, (b) negative impact on family members' personal and social well-being, and (c) stress on parents' work and finances.

*Stress on the parental relationship*. The negative impact of the children's problems on the parental relationships was striking. In all but one family (the family with the child with a simple phobia), parents described severe negative effects on their intimate relationships. Six of the 12 study families had undergone parental separation or divorce, and in at least 5 of these families children's mental health difficulties were clearly a significant contributing factor. In two other families, parents noted seriously considering separation due to stress caused by their children's difficulties. Parents in three other families described the severe stress on their spousal relationship that stemmed from dealing with their children's mental health problems.

One separated, single mom with a six year old son who had severe ADHD, developmental delays, and behavioural problems described how her marital separation came about:

> Well like I said, there's not much to my life since he was born. He's my son. Everything since he was born has revolved around him. It's been very difficult, with everything wrapped around my son. Pretty much we (she and her husband) just drifted apart. There were some things going on that I just had enough of and put a stop to it. I guess it just all came to an end. Part of it could have been the fact that he was ignoring everything to do with our son.

Three other mothers spoke about the impact of the parental separation on their children. One mother said: "My son has accepted that his father can't be bothered with him; my daughter . . . it's a living nightmare. It's hell at her age . . . it's hell". Another mother with two children, whose 11 year old son had severe ADHD and suicidal and violent tendencies, spoke forcefully about the impact of her husband leaving the family:

> (The separation had) "a profound effect . . . my daughter just wants a family more than anything. She phones him and says daddy, 'I miss you, can't you come see me' and he'll say 'oh, maybe next week' (and) he doesn't call, he doesn't show up . . . it just breaks her heart. My son used to say things like 'suppose I got on the stairs and broke my legs, would dad would come see me'? And he actually would think seriously about that option.

A third single mother who was now divorced reflected back on the time when she and her husband first separated:

> I had never lived on my own . . and I was worried about being able to do all the things a single mom could do . . .this was everything hitting me all at once . . . I've got depression, I'm out of work . . .

The parents' in this study painted a vivid picture of how the stress of dealing with their children's mental health problems caused severe strain on the spousal relationship, which in turn exacerbated the difficulty of coping with their children's mental health problems. Whether or not spousal relationship difficulties lead to separation, they undermine the most important potential source of support for parents–each other. Furthermore, these relationship difficulties also impact the children and can intensify preexisting emotional and behavioural problems in the focal child and cause other children in the family to develop problems. It is not surprising that the stress of worrying about and trying to cope with the mental health problems of a child can cause spousal relationship problems: tempers become short, disagreements surface about how best to handle difficulties, guilt can arouse defensiveness, and blame can be assigned to the other. The result is often a vicious cycle that is difficult to break and spins out of control.

A more specific concern that emerges from the data about parental relationship difficulties, as illustrated in a number of the quotes above, relates to the portrait of the father who "abandons" the family when "the going gets tough". A father in the study who had stayed with his family through tough times explained what led him to consider leaving his family and how he felt about it:

> The stress level here (in the family) is extremely high . . . it's at the point where (I've considered) divorce . . I've considered it twice in the last two years, like

9

willing to lose everything I have, absolutely everything just to escape the problem.
Like that's terrible but you know what, it has come to that.

This father clearly viewed the prospect of leaving the family as a significant loss, and would have felt very guilty about doing so, but at times he felt unable to tolerate the stress in the family. Many mothers in the study expressed similar desires to "run away" from the stress; however, it is clear that this is much more difficult (emotionally and practically) for mothers to do because they are usually the primary attachment figures and caregivers. It is unlikely that the men who do leave their families under such circumstances do so because they are simply cold, uncaring, and selfish. Although this may be true for some fathers, it is likely that most have more complex reasons for their behaviour and that many struggle emotionally, particularly with regard to separating from their children. This understanding raises implications for practice. Children's mental health professionals should endeavour not only to help intact families deal with the inevitable stresses on the couple relationship, but when separation and divorce ensue, in most circumstances they should work with the father to facilitate his ongoing connection to his children.

*Negative impact on family members' personal and social well-being.* Not surprisingly, the stress in these families affected every family member's personal and social well-being. In addition to the common stress on the parental relationship, parents' emotional, physical, and/or social well-being were impacted negatively. Of course, the siblings of the focal children were not immune to the various stressors, the focal children's difficulties were exacerbated by the stress, and all intra-familial relationships were strained.

The personal toll on parents was often quite dramatic. One mother in a two-parent family was hospitalized for six weeks due to a "nervous breakdown". This seemed to stem from a

combination of factors--the stress of dealing with her son's very difficult behaviour at home, the fact of his hospitalization for severe depression, and the hospital's inordinate focus on "family problems" that might have contributed to the sudden onset of the son's problems. Although this family was financially secure and the father was able to take time off work to look after the other two children and visit the focal child in one hospital and his wife in another, the stress on him was immense. Other parents in the sample were also on the verge of "nervous breakdowns". A husband who had to work long hours to support the family recognized how difficult it was for his wife to manage the emotional and behavioural difficulties of the children: "For the most part I'm not here and (wife) is the one that gets the load . . . she's under stress and she's gotten pretty close to the edge a few times". Another mother described being "close to the edge": "There are days when you're just on the verge of tears all day long . . . it feels like my head is going to explode". One mother talked of how she had to withdraw from the family to handle stress: "I go to my room and lock myself in the room . . . I lock myself in my room and I sit there." It was not surprising that such stress also led to physical health problems for some parents. A number of mothers in the sample suffered from chronic fatigue. A single mother reported how she became physically run down:

> We were going through all the diagnosis stuff . . . I really just wanted to give up
> my job then but I needed the money. . . . I literally functioned, that's all . . . I was
> getting sick, I had to go to the doctor . . . and he realized that my iron levels were
> rock bottom.

Parents also felt stigmatised, guilty, and like bad or inadequate parents as a result of their children's mental health problems. One mother whose child was eventually diagnosed with autism said: "I thought I was stressing him . . . I felt like the meanest parent on the face of the planet . .

and there were lots of people who found it was their duty to tell me that I was". Another mother

described her conflicted feelings: "I didn't even want to look at my daughter. I saw so much hate.

I hated her . . . it's going to sound like I'm a bitch but I wish she wasn't here at times. It's too

stressful". Other parents talked of how they avoided taking their children out in public because of

their embarrassment about the inevitable behaviour problems. A mother talked of her experience

in this regard:

> I've had a lot of the general public judge me, like "you must not be a good mother
> to let your kid do what he's doing". . . . Our neighbours stopped talking to us as
> well. . . . Unless you build fences and keep him in, he's going to be out in the
> neighbourhood and people are going to know and that's going to be hard.

The stress involved in dealing with their children's difficulties also had a negative impact

on parents' sources of support and their social well-being. It has already been discussed how the

negative impact on parental relationships robbed many parents of their most important potential

source of support--their spouse. Another common problem associated with the emotional and

behavioural problems of the children was the difficulty in arranging and maintaining adequate

child care. One mother said she went through 11 different babysitters in one year. Together, the

difficulty with finding and keeping good child care, the emotional toll exacted by dealing with and

worrying about their children and the associated spousal relationship problems, the frequent

busyness of attending meetings and therapy sessions about their children, and not wanting to take

their children out in public for fear of being embarrassed or stigmatised, many of these parents did

not have the time, energy, or resources to maintain a social life and recreational pursuits. To

repeat part of a quote used earlier, one mother remarked "There's not much to my life since he

(the child with mental health problems) was born".

*Stress on parents' work and finances.* Another theme that emerged from the study's data was that having a child with complex mental health problems often places considerable stress on parents' employment and finances. In addition to the indirect negative impact of children's mental health problems on parents' finances because of separation and divorce, 7 of the 12 families noted a direct negative impact on their work and finances. Most often this involved the emotional stress from the child and family problems affecting work attendance and performance, but this also included the impact of parents needing to take time off work when child care providers quit suddenly due to their child's unmanageable behaviour, when their children had crises at school, or when they had to attend social service meetings and conferences about their child. The emotional toll and time demands of dealing with their children's problems resulted in one parent being fired from work, a second parent needing to quit her work, a third parent needing to take a stress leave from work, a fourth parent needing to take a leave from work to be with his children because his wife was hospitalized due to stress, a fifth parent needing to reduce her work hours, and two other parents delaying planned returns to work. Significant financial hardships resulted for six of these families, including one family ending up on welfare and another family needing to move in with extended family.

> A single mother who lost her job and ended on welfare talked of her experience:
>
> I had a lot of time off work due to (child) . . . and there was so much going on in my life that I don't think I was putting 100% into my job . . . I was fired . . . And I'm breaking down into tears, God knows how many times per day, each day, not finding work, suddenly realizing it's not going to be easy to find work. I had to go on welfare and that was very humiliating for me.

A married mother who quit her job explained: "I can't work right now. (Child) has threatened to kill himself . . . he's just really difficult to deal with. (Husband) ends up working lots of overtime

to help us financially . . . it's stressful." Another single mother talked of how the emotional toll of

dealing with her son's mental health issues gradually wore down her effectiveness at work and led

to her taking a leave of absence:

> They (people at work) were upset . . . I was getting phone calls at work (from
> child's school) and I wasn't always getting there . . . I was making major mistakes
> at work . . . I was just physically and mentally exhausted . . . I just broke down in
> (boss's) office and said I should stay home from work.

*Resources, Supports, and Ways of Coping*

The most common resource or support cited by families in the study was extended family.

Almost all of the parents talked about the importance of the support they received from members

of their extended family. Five of the twelve families had either lived with extended family

members or had extended family members live with them at some point as a means of coping with

emotional or instrumental (e.g., financial, child care) pressures. The most common type of

instrumental support provided by extended family was child care--and this frequently doubled as a

financial support in terms of being provided without charge. Grandparents of the children were

the most frequent extended family supports, but aunts and uncles and other extended family

frequently helped out as well. Of course, support from extended family sometimes was a double-

edged sword. One mother commented: "My parents have tried to be helpful but then they haven't

really because . . . I'd start arguing with my mother about parenting styles". Another mother

explained: "I needed this woman (her mother) . . . I had no where else to live and I didn't have

anyone else I could lean on for support . . . (but) it's a very strained relationship".

There was a range of other sources of support that parents talked about. Many of the

parents had friends and neighbours who were helpful in providing emotional support and respite

babysitting. A mother talked of how her friends even helped her in making a decision about whether to put her child on ritalin: "My friends were researching for me and sending me website addresses and cutting out articles for me and it was just amazing how 'there' they were for me". A few parents talked about how supervisors and coworkers in their place of employment were supportive both emotionally and in terms of making allowances for necessary absences. A mother commented that "I'm really lucky, I've got quite an understanding boss . . . he allows me to do makeup time". A few parents mentioned how involvement with their church was helpful. One mother stated that "everyone in church is very supportive . . . (it is) the ultimate support system . . . it's a source of strength".

The most common helpful coping strategy identified by parents was talking with supportive others (extended family, friends, neighbours, church members) about their frustrations and worries. Another common strategy was researching and reading about their children's difficulties and how to deal with them. One mother commented: "I researched everything. I researched ADHD and all sorts of stuff just because I needed to know". A number of parents talked about the helpfulness of "getting away," when possible, from pressure situations at home. Strategies ranged from getting out to socialize with friends, to going for walks, to sitting alone in a quiet place in the house. Others talked about using meditation, contact with nature, humour, and exercise as coping strategies. A father said: "I played squash to try and keep my tension levels down, cause the last thing I could do was crack up".

*Summary*

15

The impact of children's mental health problems on the daily living realities of the families in this study was profound. These families suffered severe, multiple stressors. In addition to the difficulties in coping with their children's significant emotional and behavioural difficulties and worrying about their immediate and long-term well-being, there were severe sequelae with regard to the emotional, physical, and social well-being of parents; strains on the parental relationship, frequently resulting in divorce or separation; and stress on parents' work and finances. The lives of these families were in turmoil and they were at their wits' end. Although all of these parents had or found some useful resources and sources of support, and they found ways to cope and carry on, coping was not easy and stress exacted a toll. Also, no matter how much informal support parents had, all of them felt a strong need for professional services in order to address their children's complex mental health problems.

### *Families' Experiences with Mental Health Services*

*Service Outcomes*

This study was not designed to evaluate the effectiveness or outcomes of service; however, anecdotal evidence from the interviews gave the impression that the intensive mental health service was quite helpful for most families. Although all parents noted some improvements in child and/or family functioning as a result of their service involvement, it should be emphasized that most parents had come to recognize the chronic nature of their children's mental health problems and they anticipated ongoing, long-term difficulties with their children. Of the four families in the sample who had terminated involvement with the service, only one had relatively few ongoing concerns (the family whose child had a simple phobia). Thus, the criteria for the termination of services for this agency might be more accurately construed as "ability to manage

16

ongoing problems" than as "absence of problems". A mother who found the service to be helpful commented on the long-term prospects for her child who had a pervasive development disorder: "It's kind of scary. I can only hope things will get better. I mean, that's every parent's hope, right, that things won't be like this forever. Just keep plugging away".

*Overall Client Satisfaction*

Again, this study was not designed to make generalizations about client satisfaction with the children's mental health service; however, impressionistic data specific to this sample of families emerged from the interviews. Furthermore, after a careful review of each family's transcript, researchers assigned a rating of client satisfaction with services on a scale of 1-5 (1 = very low, 5 = very high). These "ballpark," impressionistic ratings must be interpreted cautiously, but they afford some sense of parents' satisfaction with services.

The range in researcher-estimated client satisfaction on the five point scale was from 2-5, with a mean satisfaction rating of 3.6. Ratings suggested that five parents were very satisfied with services (ratings of 4-5), four were quite satisfied (ratings of 3-3.5), and only three were dissatisfied (ratings of 2-2.5). Although these ratings are impressionistic only and are based on a very small sample, overall they suggest a moderately high level of satisfaction with services, particularly given the complex nature of the focal children's mental health problems.

Although the focus in the study interviews was on parents' experiences with the intensive, community-based children's mental health centre, parents often talked about their involvement with schools, hospitals, doctors and psychiatrists, child welfare, counselling agencies, and other social services. Satisfaction often varied significantly across different services for each family; however, taking this into account, the researchers also assigned an overall rating of parental

17

satisfaction with other services on the same 5 point scale used to estimate satisfaction with the children's mental health service. It is noteworthy that the mean researcher rating of satisfaction with other services was a full point lower than the mean rating for the children's mental health service (2.6 versus 3.6, respectively). Although the results of this very rough comparison must be interpreted cautiously, the higher satisfaction with the children's mental health service makes intuitive sense because this service was designed to be more intensive out of the recognition that traditional services cannot adequately meet the needs of families with children with complex mental health problems.

*Sources of Satisfaction*

In talking about their experiences with the children's mental health service, parents had little difficulty in specifying sources of satisfaction and dissatisfaction. Sources of satisfaction were categorized under two headings: (a) a supportive relationship with an understanding worker; (b) advocacy and individualized case management, planning, and service provision.

*A supportive relationship with an understanding worker.* A good relationship with a worker, whereby the client felt understood and supported, was clearly the most important source of satisfaction for parents. Although families were often involved with more than one worker, and the types of relationships established with different workers varied in quality, all families in the sample encountered at least one worker from the agency with whom they connected well. The five families who were classified as highly satisfied with services had only positive relationships with their workers.

Descriptors such as "good" or "positive" do not do justice to the types of relationships with workers that clients found to be most helpful. These relationships had emotional connection

and depth. Workers conveyed caring and commitment beyond their professional duty. A mother who encountered a number of such workers from the agency described them in the following terms:

> . . . Very human, so human, . . . I don't know if it's just the type of people that are employed there, but you always feel that you're connecting with somebody and that they understand and I have always felt very comfortable and warm and very good. And they always took the time to ask about me and the children. I don't know how to explain it. Very good relationships. Very open and honest.

Some parents contrasted how the attitude of the worker from the intensive service was different from and more helpful than the attitudes they had encountered from other people. A mother who had been frustrated by the tendency of friends and family members to minimize her son's problems commented: "With most people, they were like, 'oh he'll grow out of it'. She (the worker) didn't do that. She knew where my concerns were coming from with it, she knew how he (her son) reacts, and it made a big difference". A father contrasted the attitude of the worker from the intensive service with the attitudes he had encountered from workers in other agencies. He described how, at the end of his first meeting with this worker, the manner in which an offer of a follow-up phone contact was made communicated an important message of caring:

> He (worker) said: 'Here's my card, call and just leave a message and tell me how you are'. And the attempt that somebody actually cared how you felt was . . . That's all I really needed. Maybe I didn't even need to call him, but the attempt was there, it felt like somebody was actually there, actually wanting to help and understand.

Both of the parents quoted above were commenting on the simple, but very important element of being taken seriously and being responded to with caring and empathy. Comments from other parents also highlighted the importance of being heard, which precluded, at least in the beginning, offering solutions. One mother talked about the initial period of engagement with her

worker: "I was floundering before then. So talking to her and having her immediately connect and not give me advice. She did not talk to me immediately and say 'well you should do this and you should do that'". Another mother commented on the importance of supportive listening: "Just for her (the worker) being here, having someone to talk to when things didn't go right, was a big help".

Parents commented on the importance of being treated respectfully and as an individual, unique family instead of as another "case". One mother said: "You felt you had their undivided attention and you were a completely unique and individual family unto itself and you weren't being compared to anyone else." Another mother reflected on the individualized attention her family received: "You almost feel like you're the only client." A third mother focussed on the importance of the worker being nonjudgmental and honest: "She (the worker) just gave the impression that she was there to help. And, she's not there to give views or to criticize or to do stuff behind our backs". Similarly, a fourth mother appreciated her worker's honest and collaborative approach: "She really does go out of her way to try and make sure that we know everything that's going on". A fifth mother's comments speak to how respect, caring, mutual liking, and helpfulness were intertwined, as well as to how this is not always the case:

> She (the worker) was a person who knew people and we related in that way. She liked (son) and she liked me and we liked her. And she just talked to us like she knew that we would understand what she was saying . . . like with respect and she was really, really helpful, which is what everybody should have been.

The commitment of workers to being helpful and to "going the extra mile" when necessary, was another issue that parents highlighted. One mother was very appreciative of her

20

worker's reliability and flexibility with regard to modifying her work hours to fit the client's

needs:

> She (the worker) always called me back.  She has called me after hours even. She
> stayed late for meetings when I was having trouble because they were giving me a
> hard time about leaving work so much. She would have meetings so that I could
> come at 5:30.

A father marvelled at the commitment his family's worker showed in staying with them despite a

number of job changes:

> (The worker) has been through three different job changes, all of which would
> have logically meant that she would not be our case manager anymore. But, she
> has stuck with it, because she wants to stick with the family, and she honestly
> believes we need that continuity. And I think that's right. And I think that's been so
> fundamental.

*Advocacy and individualized case planning, management, and service provision.* In

addition to the emotional support and understanding that workers provided through the

relationships that they developed with client families, parents identified that advocacy and

individualized case planning, management, and service provision by workers was also very

helpful. Many parents had become confused and frustrated in trying to identify, access, and

circumnavigate needed services prior to their involvement with the intensive children's mental

health service. Some parents did not know what services would be helpful and what services

existed. Many parents had difficulty accessing services because of wait-lists or not fitting the

intake criteria for agencies. Not infrequently, parents also had contentious and conflicted

relationships with professionals with whom they were involved (e.g., teachers, doctors,

psychiatrists, psychologists, and child welfare workers) and felt powerless in their dealings with

these professionals. Although workers from the intensive children's mental health service were

not always able to secure needed services in a timely manner, their help in advocating for and planning and managing individualized services was very important to parents.

The father whose wife was hospitalized due to the stress of dealing with their son's hospitalization and who had to take a leave from work to deal with the regular family responsibilities, as well as his son's various medical and social service involvements, found his worker's case management efforts to be invaluable:

> (The worker) just came forward, tremendously, and, did everything she could in terms of organizing, putting together the people, and recommending what people should be involved, and dealing with me to make that happen . . . to get those case resolution meetings going . . . to figure out what resources were available, and, ultimately, of making it happen.

A single mother whose son's severe behavioural difficulties caused constant problems at school and who had a conflicted relationship with school personnel because of this, commented on how important her worker was in helping her deal with this situation:

> She (the worker) has attended every single school meeting that I've had. They're (school meetings) scary, it doesn't matter what your background is, you're still the big bad parent and you're the bad apple and, you know, they're talking about your child. So, it's very, very uncomfortable to go to those kind of meetings. So to have somebody (the worker) there who they consider to be one of their peers and making suggestions . . . if I had suggested the same things it would have been impossible, but because she suggested them, they were ready to think about them . . .well, I think the support from the school changed as I had her.

This same mother also talked about how the worker was helpful in arranging a variety of other services for her son. The mother said that the worker contacted "every agency possible that could in any way give us help". Behavioural and psychiatric assessments led to a psychiatric diagnosis, which enabled the son to become eligible for specialized in-home services. Although there was a wait-list for these services, the mother noted how her worker had anticipated this:

"She knew that there was going to be a waiting list so she stuck his name on it as a pending thing . . . these people (the agency workers) do everything, and just as you need it".

Parents' stories highlighted the workers' efforts to create individualized case plans that matched services to families' needs. A wide variety of services were provided to these families, ranging from standard behavioural and psychiatric assessments and counselling to specialized in-home services and respite. A psychiatric diagnosis was important to many parents both because it gave an explanation for the problems their children were exhibiting and because it often made families eligible for funding and specialized services (e.g., in-home behavioural treatment). One parent noted: "The diagnosis was a relief because we got some services . . . doors opened that otherwise wouldn't have been. We have special services at home; contract workers, respite care, that sort of thing". Another parent explained, however, that a diagnosis was often a double-edged sword:

> (The diagnosis) did good and bad things.  It did good things in that, okay, I've got
> a reason. It's not that I was doing something wrong as a mother. When you've
> been told (this) for a long time you really start to doubt yourself. So, when you get
> something like that, you can say 'there', but then it was also overwhelming. It was
> like "I've got a ton of work to do. I've barely started here".

The home-based element of this intensive service, whether this involved assessment and case management meetings or the provision of treatment services, was particularly appreciated by parents for a couple of reasons. First, it seemed to facilitate relationship-building between workers and clients. It demonstrated to clients that workers were interested and cared enough to get to know them in their own environment. It also enabled families to feel better understood because workers could witness first hand what life at home was like. A parent explained: "He (the worker) saw us as a family unit. He came out to the house to witness a couple of  (family problems), just

23

to be there. He had a genuine interest". Second, home-based work usually had a very practical

focus:

> The visits would be hands-on. You know, come in and it's close to supper and
> snacks and dinner and all those arguments that people have all the time and
> observation and comments and tips. It was always ongoing learning. I found it very
> useful, hands-on, practical. Very good. I couldn't have asked for better.

Parents also appreciated respite. A single mother commented:

> They've been giving me money for respite care for the past month, so, I've got out
> once a week and let me tell you, that's been really helpful . . . a practical way to
> actually have an effect on your life and your family and your day to day living. I
> found just being nice to myself helps me more than anything else.

*Summary.* When families were most satisfied, the two general sources of satisfaction

described above were clearly intertwined. The following is a hypothesized model of how good

service delivery typically unfolded. Workers who were supportive and understanding initiated the

development of trusting relationships with families. This enabled families to be open and honest

with the worker. The deepening of the relationship with the family, which was facilitated by

meeting with and getting to know families in their home environment, enabled workers to develop

an emotional as well as a cognitive grasp of families' daily living realities. This in-depth

understanding of families' lives motivated workers to develop collaboratively with families a

detailed, practical plan for meeting their individual needs. It also motivated workers to "go the

extra mile" and to advocate strongly for families. Workers planned, coordinated, and did their

best to implement assessment and individualized, practical treatment and support services, which

in turn further strengthened the relationship. Services were generally helpful, although they did

not result in the amelioration of all problems, which tended to be chronic in nature. It should be

stressed that the worker's relationship with the family seemed to be therapeutic in and of itself,

representing the fact that "care" was important irrespective of "cure". That is, even though

children's mental health problems persisted to some degree for many families (i.e., there was no

"cure"), the support and understanding (i.e., "care") that families received from workers made

them feel better and more hopeful.

*Sources of Dissatisfaction*

Unfortunately, but not unexpectedly, things did not always unfold in the ideal fashion

outlined above and elements of dissatisfaction were not uncommon among these families. The

main sources of dissatisfaction were: workers who didn't relate well to families, worker

changes/turnover or too many workers involved, waiting periods for services, and a need for more

intensive services.

*Workers who didn't relate well.* Not surprisingly, not all families developed close, trusting

relationships with workers. Although in most instances this involved a lack of connection with

rather than a dislike of or conflict with a worker, the latter did happen occasionally. In such

instances, parents described workers who did not listen, did not seem to understand, and/or were

not supportive. Fortunately, all but one of the few families that experienced a relationship like this

with a worker also had experiences of better relationships with other agency workers. The family

that reported the most negative relationship with a worker felt that the worker was focussed

inordinately on "family problems" and seemed to blame the parents for the child's difficulties. The

mother in this family said:

> I find what they (the workers) are doing kind of wrong is knowing more about the
> family and not enough about the individual (the child) that's having the problems . .
> . What you need is a person there that can resolve the problem more so than
> tackling the adult and accusing them; that's all they're doing right now. Like that's
> no support whatsoever.

This complaint is very similar to the complaint of another study family about their experience with a counsellor from a hospital. This family felt that the hospital worker acted like a detective who was intent on discovering the family problems that caused the child's emotional/behavioural problems. The worker's attitude was accusatory and he kept "digging" to discover the "truth". Understandably, this caused the family more stress. Without hearing from the workers involved, one cannot presume to know the whole story; however, what seems clear is that even when workers have legitimate concerns about family problems, they should try to find ways to address these in an understanding and supportive versus a blaming way. One parent who felt that an agency worker had jumped to a conclusion about the "family" having a problem offered the following advice to workers: "I'd tell them to slow down and listen and take the extra time and just listen and help people problem solve and find out what's really going on".

*Worker changes/turnover or too many workers involved.* Four families talked about the difficulty of undergoing changes in workers during their involvement with the service. In all of these instances, the families had established good relationships with their original service provider. When the involvement of this original worker ended, the families mourned the loss of the relationship and found the transition to a new social worker difficult. One family lost their worker when he retired and had not yet been assigned a new caseworker at the time of the interview. The mother was critical of the agency's lack of planning around this:

> I think they should have known he was going to be leaving. I think they should
> have had us integrated into the new worker. I mean it's a nightmare here. The kids
> were going once a week and there's been nothing (since the worker left), not even
> a phone call saying you're this far up the list or your counsellor is going to start or
> who the new counsellor is.

Another family lost their worker when she left the agency for another job. The mother clearly

mourned the loss of this service provider and wondered about the problem of turnover at the

agency: "We've lost an incredibly good person . . . I don't blame her for moving on . . . (but) I'm

wondering if (the agency) is a stepping stone for some people . . . because it's not worth staying".

Two other families underwent a change in service providers because the original workers

had completed their specific duties with the family. One of these families had a good experience

with the psychologist who had completed the initial assessment of their child but since that time

had been frustrated with waiting to be assigned a new worker. The mother lamented:

> I have felt very lost in the system since our dealings with her (the psychologist) are
> finished. It kept on changing . . . At first there was one woman who was supposed
> to coordinate everything and she later got into a different department and she
> wasn't involved anymore . . . and then there was supposed to be another woman . .
> . and then they were going to assemble a team.

The other family had a very good experience with an in-home support worker, but after his

contract had finished they had difficulty engaging with subsequent workers. The mother

explained:

> We had a caseworker who was amazing. He was great and I was seeing him on a
> weekly basis if not more. Not necessarily for myself but in regards to (her son). So
> that helped, but that was pretty much it--I couldn't talk to anyone else about
> anything.

Two families, one of which had also been frustrated by changes in workers, talked about

problems associated with having too many service providers or agencies involved. Both of these

families felt a need for more coordination of planning and service delivery by a case manager. One

parent commented:

> It doesn't make a whole lot of sense to have 18 people who have their hands in the
> pot, talking to you, but not each other, or talking to each other but not you. I mean

27

they need that hub, they need one person who is going to gather everybody's information and spew it out to you.

Similarly, another mother said:

> There's so many extraneous, unneeded personnel that are coming in from all these different agencies that sit there with their notepads and write on them and do absolutely nothing and then go back to their agency. Maybe they'll go to another meeting. . . You need a couple really intimate key people working in an intense way and you don't need all these other people that aren't doing anything but just distorting the picture.

*Waiting periods for services.* Three families expressed frustration with the length of time they had to wait for services to be provided. All of these families acknowledged that the assessment process was thorough, conducted in a timely fashion, and resulted in sound recommendations; however, they were quite disappointed in the delay in implementing recommended services. One mother who was still waiting for most of the services that had been promised to her and her daughter was clearly angry about the waiting period:

> We were under the understanding initially that a lot of things were going to be done . . . that we were going to have a lot of time with different people, going through different things . . . and there really hasn't been much of anything yet. If you start off with an assessment . . . and then you have recommendations to do things . . . then do them.

A second mother, although more understanding of the systemic reasons for the waiting period for services, expressed similar frustration:

> I mean, and they know this, that they need faster access to help. They do a good job of assessing the child . . . but I kinda almost wish they had said, from day one, when you went in there, it was realistically gonna be a year before you could get any help. I kept getting told, don't worry, we're going to help with you with that . . . And it's frustrating playing the waiting game . . . And it's made worse when we had such a wonderful (assessment) presentation and report.

A third parent who had also experienced frustration in waiting for service but who also had the understanding that the agency was doing its best with limited resources, offered the following advice: "I'd tell them what they already know. They need more resources; they need more money".

*Need for more intensive services.* Although only two families talked explicitly about the need for more intensive services, it was evident that many of the families would have benefitted from and appreciated this. As explained earlier, the families that did receive more intensive in-home services (where a worker would come to the family home at least once per week to help them problem-solve difficulties) found them to be very practical and helpful. A father who was quite satisfied overall with the services from the agency reflected on how more frequent contact with his worker might have been helpful:

> I think more updating might be helpful . . . like they'll make the suggestions and then they'll tell you to put them in motion and "I'll see you in a couple weeks". Even just a phone call . . . like "how are things going, did you want to come in" . . . . just more of a checkup to find out how things are going.

A mother who had a generally good relationship with her worker talked about the need for more frequent contacts in order to make progress in managing her son's difficult behaviour and her reactions to it:

> Seeing her (the worker) for one hour every two or three weeks, to me it's not enough--at the same time, without trying to sound hypocritical, when I'm finished speaking with her (the worker) I feel hopeful because she reminds me of the things that I should be doing and saying. So I got to say like to some degree I feel a little better about me keeping control of it . . . . but when you come to the end of two or three weeks, you're back there where you forget it all because so much has happened. It's not solving any problems.

*Summary*

Although some families were dissatisfied overall with services, and most families identified some aspects of service with which they were dissatisfied, it must be remembered that a large majority of parents in this small sample (9 of 12) were quite satisfied overall with the services of the intensive children's mental health service. Also, some parents were of the opinion that some of the service shortcomings they identified (e.g., waiting periods) were beyond the agency's control. Nevertheless, parents' dissatisfactions with service need to be taken seriously and efforts to remedy these problems should become priorities.

## Implications

The results about the daily living realities and service experiences of families with children who have complex mental health problems have many implications for practice. The first and foremost general implication, as reflected in the title of the report, is the importance of "care" irrespective of "cure". Given the very difficult daily living realities of these families and the fact that parents were often worn down by worry and stress, and were demoralized, it is not surprising that a warm, supportive relationship with an understanding worker was the most important source of satisfaction with services for parents. Regardless of whether or not progress was made in ameliorating and/or effectively managing children's emotional and behavioural problems, parents appreciated and benefited from workers who listened, understood, and were supportive--workers who cared. One parent, in describing what was most important to her, summarized this: "the level of individuality of care, and real care, with a big "C".

The importance of care translates into a number of more specific implications for practice. Because most parents recognize the chronic nature of their children's mental health problems and

30

are devoid of any illusions of quick fixes or cures, it seems important that workers avoid facile advice and premature problem-solving. In the beginning, it is most important to listen respectively; attempt to develop and demonstrate an empathetic understanding of parents' worries, frustrations, and pain; and show care and support. Given that parents of children with complex mental health problems commonly feel stigmatised, guilty, and like bad or inadequate parents, it is particularly important to give them credit for caring and coping as well as they have and to carefully avoid anything that could be interpreted as blaming them. The service provider's interpersonal style also seems to be very important to developing a caring relationship with parents. Parents clearly prefer workers who are "human" (evidenced by descriptors such as warm, comfortable, genuine, and down-to-earth) as opposed to those who are professionally reserved, distant, and aloof. Relatedly, parents clearly appreciate an open, honest, collaborative partnership with workers. It was also clear that "going the extra mile," in terms of service providers doing such things as meeting with families at times that were convenient to the family or choosing to continue to work with the family despite moving to a different position within the agency, both contributed to and was a by-product of a caring relationship. In summary, all of these ways-of-being and behaving that contributed to families feeling cared for can be construed as standards of practice that workers should strive to meet and that agencies and supervisors should value and support.

There are a number of other implications for service design and delivery that could support the development of caring relationships, as well as the provision of needed services and resources. Some parents' dissatisfactions with changes in service providers and too many workers being involved underlines the importance of endeavouring to provide a long-term, primary worker

31

for families. Although the continuous involvement of a primary worker was a principle of the intensive service studied, it is not surprising that this did not always happen. There are, after all, realistic limitations to this ideal. Still, the development of creative ways to ensure the continuity of a primary worker should be a priority. In this regard, it is noteworthy that one family was extremely grateful that their service provider found a way to stay with them despite job position changes within the agency.

The fact that a number of parents' expressed a need for more frequent contacts with workers (noting that they sometimes had contact with service providers only every two to three weeks) suggests that the ideal of intensive service is also sometimes not met. There is no doubt that resource and funding limitations impact on agencies' ability to provide intensive services; however, there are also creative ways to deal with this issue. For example, as one parent suggested, more frequent phone check-ins would not be too time-consuming and would provide useful support.

Finally, the waiting period for services is clearly an issue that needs to be addressed. There is no doubt that children's mental health agencies are aware of this problem and that it is tied to inadequate government funding. Many parents also seem aware of this. Again, however, there are some things that could be done to mitigate the negative impact on clients. This could include alerting clients to and explaining the reasons for waiting periods, suggesting other resources to families on waiting lists (e.g., self-help or parent support groups, books on parenting or mental health issues), and providing support through periodic telephone check-ins.

It is hoped that the information provided by the families in this sample may prove useful to service providers. For new children's mental health workers, it might be helpful to read about the

daily living realities of the families in this sample in order to develop preparatory empathy for families they serve. The families' descriptions of sources of satisfaction and dissatisfaction with services may prove instructive to both new and experienced service providers. It is all too infrequent that workers get to hear feedback from clients. Although the importance of listening to clients and of demonstrating empathy, warmth, and genuineness toward the development of a caring and collaborative helping relationship are accepted hallmarks of effective practice, professionals can come to take this for granted. Even workers who have exceptional relational ability are prone to overlooking or downplaying its importance. Attitudes and actions that communicate acceptance, respect, trust, liking, and caring can have tremendous positive impact on people who are demoralized and who are losing hope. When this is combined with the provision of useful services and resources (e.g., psychiatric assessment, in-home support, parenting skills training, respite, advocacy), hope is instilled, and life's stresses, including children's emotional and behavioural difficulties, can be better managed.

Still, the long-term nature of many children's mental health problems, and the need for long-term support (or "care"), needs to be remembered. It seems fitting to end the report with a few quotes from parents that speak to this reality:

> I really don't look that far into the future. To be honest, I take it a day at a time. All I can say is it's come so far, it's been an enormous growth for them (her children) and for me, but I don't think that by any means it's done.

> I'm expecting less of myself. I'm trying to relax and just go along for the ride and just be happier each day. I think it's just going to get better each day but I'm learning to measure differently. And that's been the big change for me and the thing that they (the workers) really help me look at and do.

> All I can say is that overall I'm so glad they're (the agency is) there and may their funding never leave because I need them. And (son) needs them and he's going to

33

need them for a long time . . . because there are various things that are going to
come up that as a parent I can't handle by myself.

SOCIAL WORK

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