Parents' Perceptions of Wraparound Services in Lancaster County, Nebraska

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ABSTRACT—The role of parents in wraparound mental health systems of care for youth with emotional and behavioral disorders is evolving. The purpose of the present study was to identify variables that impact parents' perceptions of systems of care. Parents in a countywide system of care (N = 213) were surveyed to determine their perceptions of barriers to effective services and service priorities. Parents identified the ability to pay for services, long waiting lists and periods, and lack of information about community services and resources as their top barriers. Respondents indicated services coordination, mental health outreach, and mentoring programs were their greatest priorities. Time involved in the system of care and the number of agencies with which families were involved were variables that were related to parents' perceptions of barriers to services. Neither variable was found to impact parents' perceptions of service priorities, however.

Key Words: emotional and behavioral disorders, mental health, parents' perceptions, wraparound

Introduction

Until recently, treatment for children and adolescents with serious mental health challenges has generally been offered by some combination of mental health, child welfare, and juvenile justice agencies (Knitzer 1982).

However, with the increasing realization that such services have been both inadequate and fragmented (US Department of Health and Human Services 1999), there have been concerted efforts to provide more systematic and coordinated care for this population of youth and their families. This "systems of care" approach has been designed to provide coordinated, culturally competent, family driven, individualized services within the community rather than in institutional settings (Stroul and Friedman 1986).

While parents have always been involved in systems of care efforts for children and adolescents with serious mental health challenges, in recent years they have taken on more responsibilities (Osher et al. 2001). Today, families are involved in program planning, policy development, and systems governance issues (Center for Mental Health Services 1997). With the advent of statewide family advocacy networks, parents not only provide support and information to each other, they help shape the way systems of care operate through outreach and education activities (Briggs 1996). Moreover, families have become involved in the evaluation of systems (Osher et al. 2001). Even greater family involvement is desired, however, particularly with respect to parental contributions at the policy level (Huff 2002). In spite of the expanding involvement of family members in mental health systems of care, there remains scant research documenting parents' perceptions of service delivery issues such as the nature, extent, and effectiveness of support for their children and families (Lehman and Irvin 1996).

We believe only two published studies to date (i.e., Lehman and Irvin 1996; Quinn et al. 1996) have directly targeted parents' perspectives on mental health service delivery issues for youth with emotional and behavioral disorders and their families. Lehman and Irvin (1996) examined the nature and extent to which families of children with emotional and behavioral disorders received support from systems of care. A random sample of 100 parents who had contact with the Oregon Family Support Network reported receiving support from one or more formal organizations (e.g., schools, family physician, counselor). Respondents indicated their families were involved with an average of 2.2 systems of care functions (e.g., assessment, service planning). A statistically significant positive relationship was reported between number of functions of services coordination received and parents' satisfaction with quality of life. In Illinois, other researchers (i.e., Quinn et al. 1996) surveyed the perceptions of system barriers and priority needs of 230 parents of youth with mental health needs. Quinn and colleagues (1996) identified cost, access to information, and differing agency mandates as the greatest barriers to effective services. Educational support, child therapy, and career preparation were touted as major priorities.

The fact that only a few studies exist detailing parents' perceptions of systems of care issues underscores the need for more research in this area, particularly as the role of parents and caregivers in systems of care is evolving (Osher et al. 2001). Similar to Quinn et al. (1996), the overall purpose of the present study was to identify parental perceptions of the barriers and priorities in a community wraparound system of care in Lancaster County, NE. The present study was designed to both replicate and extend the current literature base. First, because there is a paucity of research describing parents' perceptions of wraparound services, the following study was designed to add to the number of parents whose collective opinions have been documented in the literature. Second, because the literature base has only described parents as a whole, we believed that it made sense to explore variables that might contribute to differences in opinions among parent groups. Specifically, we examined two variables related to parent perceptions: (1) the number of agencies in which the families were involved, and (2) family time involved in a system of care. We hypothesized that those parents whose children had been involved in more agencies or for a greater length of time would have different perceptions than those parents whose children had been involved with fewer agencies or for shorter periods of time. The present study addressed the following questions:

1. What barriers to effective services do parents see as most significant?
2. What service priorities do parents identify as most important?
3. Do the perceptions of parents relatively new to the community mental health system (i.e., involved in the system two years or less) differ with respect to barriers and priorities from those parents who have been involved in the system for a longer period of time (i.e., more than two years)?
4. Do the perceptions of parents who are involved with one mental health agency differ from those parents who are involved with multiple agencies?

Methods

Participants

A total of 693 parents who were legal guardians of youth in the mental health or juvenile justice system in Lancaster County received surveys. Parents of children involved in four county mental health and juvenile

justice agencies were targeted to complete the survey. The survey and a letter describing the study's purpose were sent directly to the home. Responses were received from 213 of the 693 individuals surveyed (31% response rate). Detailed descriptive information on youth and families was not included as part of this survey at the request of the four agencies.

Instrument

The Parent Survey was a modified version of the Service Provider Survey used by Quinn et al. (1994). The purpose of the Parent Survey was to measure parents' perceptions of the major barriers to and needs for services in the system of care in which they and their children were involved. The survey focused on four areas: (1) demographic information (e.g., agencies involved with; time in the system); (2) barriers to effective community-based care (e.g., services are poorly located; lack of evening and weekend hours); (3) service priorities (e.g., case management; mental health outreach); and (4) open-ended questions related to service barriers and priorities (a review of the open-ended questions was not included as part of this article).

Each question in the barriers and priorities sections of the Parent Survey is rated on a 4-point Likert scale (1 = major problem/priority); 2 = moderate problem/priority; 3 = minor problem/priority; 4 = no problem/ priority). The survey listed 19 potential barriers, 45 possible priorities, and 2 open-ended questions.

Procedure

Parents were contacted by mail. The mailing included a letter describing the purpose of the survey and its target audience, the survey, and a self-addressed, stamped return envelope. Respondents were assured that individual responses would be held in strict confidence. Each survey was numerically coded to allow identification of the respondents' agency affiliation and to ensure confidentiality. A second mailing was sent to non-responders about two weeks after the first, emphasizing the importance of the survey and encouraging a response.

Analysis

Descriptive statistics were used to answer the first two questions (i.e., What barriers do parents see as most significant? What service priorities do

parents identify?). Medians, means, and standard deviations were calculated and the individual items ranked by means. The Mann-Whitney U Test (Siegel and Castellan 1988), a nonparametric measure, was used to address the last two questions related to the length of time the family was receiving services and number of services received. The time variable was divided into two years or less versus more than two years in the system of care; the agency variable was divided between contact with one agency and more than one agency. The Mann-Whitney U Test was chosen over the t-test because the measurement scale of the dependent variable (i.e., 1, 2, 3, 4) was ordinal rather than interval or ratio, and because the Mann-Whitney U Test is more appropriate than the t-test in cases of nonnormal distributions (Siegel and Castellan 1988). Using a Bonferroni procedure (Miller 1981), an alpha level was set at 0.003, that is, 0.05 divided by the number of separate analyses (i.e., 19), for the barriers analysis, and 0.0011, that is, 0.05 divided by 45, for the priorities analysis.

Results

Rankings of Barriers to Service and Priority Needs

Barriers. Overall, parents did not see any of the listed barriers as major problems. Respondents rated the ability to pay for mental health services (mean = 2.53) as the greatest barrier. Five other barriers, that is, long waiting lists and periods (2.71), lack of information about community services and resources (2.73), lack of evening and weekend hours (2.75), agency will provide only certain types of services (2.87), and services do not meet family needs (2.99), were rated in the range of minor to moderate problems. Overall, respondents rated over two-thirds of the barriers as minor problems. Cultural issues pertaining to staff (i.e., lack of knowledge and inability to speak other languages) were generally not considered as problematic.

Service Priorities. Respondents rated a coordinator of services (1.92) as the greatest priority. The top five listings, that is, services coordination, mental health outreach (1.95), mental health mentoring programs (1.96), job placement (2.0), and job training (2.0), were rated as moderate or major priorities. All of the listings, however, were given importance (i.e., rated higher than minor priorities). Respondents generally ranked items dealing with mental health services or employment issues as among the highest of priorities.

Years of Involvement

Barriers. Statistically significant differences (p < 0.003) were noted in 14 of the 19 barriers (see Table 1). Parents whose families had been involved in the system more than two years rated all 19 barriers as greater problems than did parents whose families had been involved in the system two years of less. In fact, 16 of the 19 barriers were rated somewhere between a moderate problem and a minor problem by parents whose families had been in the system longer. That compares to 4 of 19 barriers rated in that range by parents whose families had been involved in the system two years or less.

Service Priorities. With respect to priorities, mean differences were noted across all 45 items rated. Overall, the mean scores of parents whose families had been involved in the system more than two years were lower than the averages of parents whose families had been involved two years or less in 42 of the 45 cases. However, a statistically significant difference (p < 0.0011) was noted in 1 of 45 items (i.e., medication and monitoring).

Agency Involvement

Barriers. Statistically significant differences in parents' perspectives (p < 0.003) were noted in 11 of the 19 barriers (see Table 2). As a group, parents involved with more than one agency ranked all 19 barriers as greater problems than did parents involved with just one agency.

Service Priorities. Parents whose families were involved with multiple agencies ranked 39 of the 45 items as greater priorities than did parents whose families were involved with a single agency. However, no statistically significant differences (p < 0.0011) were noted in any of the 45 items with respect to agency involvement.

Conclusions

The goals of the present study were to: (1) replicate previous findings by detailing parents' perceptions of barriers to and service priorities of the mental health system in Lancaster County, NE; and (2) extend the literature base of parents' perceptions of wraparound mental health services by determining whether or not the length of time and the number of agencies with which families were involved were related to their perceptions. Regarding

TABLE 1

PARENTS' PERCEPTIONS OF BARRIERS TO SERVICES WITH
RESPECT TO YEARS OF INVOLVEMENT: MEANS, STANDARD
DEVIATIONS, AND MANN-WHITNEY TEST SCORES

Item	Years of involvement in wraparound system of care		Mann-Whitney
	Less than two	Two or more	
Ability to pay for services	2.71 (1.18)	1.98 (1.06)	2842.5*
Long waiting lists and periods	2.89 (1.08)	2.19 (1.13)	2851.5*
Lack of information about community services and resources	2.93 (1.10)	2.17 (1.14)	2793.0*
Lack of dual diagnosis (mental health/substance abuse services	3.23 (1.04)	2.72 (1.20)	3124.5
Agency will provide only certain types of services	3.05 (1.03)	2.33 (1.12)	2707.5*
Services do not meet family needs	3.19 (0.96)	2.38 (1.05)	2395.5*
Lack of evening and weekend hours	2.95 (1.05)	2.12 (1.17)	2669.5*
Number of forms to fill out	3.22 (0.89)	2.50 (1.11)	2736.5*
Lack of planning for when a child switches placements	3.30 (1.02)	2.65 (1.25)	2858.5*
Cannot share records between agencies	3.26 (0.94)	2.83 (0.99)	3110.5*
Services for youth are not available locally	3.31 (0.97)	2.59 (1.17)	2823.0*
Terms and jargon used by agencies	3.31 (0.95)	2.89 (1.01)	3167.5*
Lack of good staff	3.26 (0.93)	2.72 (1.06)	3071.5*
Unable to get legal advice	3.14 (1.01)	2.69 (1.19)	3311.5*
Lack of transportation services	3.26 (0.97)	2.93 (1.06)	3555.5
Duplication of services	3.45 (0.84)	3.16 (0.93)	3259.5
Services are poorly located	3.31 (0.83)	2.89 (0.95)	2963.5*
Agencies will not serve youth with a juvenile record	3.51 (0.82)	3.32 (0.90)	3391.0
Staff do not know about other cultures or speak other languages	3.44 (0.88)	3.35 (1.01)	3723.5

Note: Items were rated by respondents as follows: 1 = Major problem, 2 = Moderate
problem, 3 = Minor problem, and 4 = Not a problem. Lower numbers indicate a greater
problem/priority. Means are in ascending order from major to no problem based on
overall parent responses. * $p<0.003$. Sample sizes ranged across items from 138 to 151
for parents in the system two years or less and 53 to 58 for parents in the system more
than two years.

TABLE 2

PARENTS' PERCEPTIONS OF BARRIERS TO SERVICES WITH RESPECT TO
NUMBER OF AGENCIES: MEANS, STANDARD DEVIATIONS, AND MANN-
WHITNEY TEST SCORES

Item	Number of agencies contacted in a wraparound system		Mann-Whitney
	One	One or more	
Ability to pay for services	2.86 (1.12)	2.13 (1.14)	3731.0*
Long waiting lists and periods	2.97 (1.10)	2.41 (1.13)	4162.0*
Lack of information about community services and resources	2.99 (1.12)	2.42 (1.14)	4144.0*
Lack of dual diagnosis (mental health/substance abuse) services	3.42 (0.95)	2.72 (1.16)	3357.5*
Agency will provide only certain types of services	3.13 (1.04)	2.55 (1.09)	3772.0*
Services do not meet family needs	3.27 (0.93)	2.65 (1.07)	3682.0*
Lack of evening and weekend hours	2.96 (1.05)	2.49 (1.20)	4412.5
Number of forms to fill out	3.40 (0.80)	2.63 (1.04)	3282.5*
Lack of planning for when a child switches placements	3.44 (0.93)	2.79 (1.21)	3594.5*
Cannot share records between agencies	3.30 (0.94)	2.96 (0.98)	4167.5
Services for youth are not available locally	3.49 (0.86)	2.73 (1.15)	3489.0*
Terms and jargon used by agencies	3.40 (0.88)	2.97 (1.01)	4134.0*
Lack of good staff	3.36 (0.87)	2.88 (1.05)	4167.0*
Unable to get legal advice	3.17 (1.05)	2.86 (1.10)	4534.5
Lack of transportation services	3.27 (0.98)	3.07 (1.01)	4863.0
Duplication of services	3.50 (0.82)	3.24 (0.91)	4287.0
Services are poorly located	3.26 (0.83)	3.14 (0.92)	5048.0
Agencies will not serve youth with a juvenile record	3.56 (0.82)	3.33 (0.88)	4091.0
Staff do not know about other cultures or speak other languages	3.49 (0.86)	3.32 (0.98)	4488.0

Note: Items were rated by respondents as follows: 1 = Major problem, 2 = Moderate
problem, 3 = Minor problem, and 4 = Not a problem. Lower numbers indicate a greater
problem/priority. Means are in ascending order from major to no problem based on
overall parent responses. * p<0.003. Sample sizes ranged across items from 99 to 108
for parents whose families were involved in one agency and 98 to 107 for parents whose
families were involved in more than one agency.

the first goal, the perceptions of respondents in Lancaster County were similar to respondents in a previous study (Quinn et al. 1996) in terms of barriers and were different in terms of priorities. Lancaster County respondents perceived ability to pay for services, long waiting lists and periods, lack of information about community services and resources, lack of evening and weekend hours, and the agency providing only certain types of services as their five greatest barriers. For the most part, respondents in Quinn et al. (1996) identified similar items. Differences were noted with perceived priorities. Lancaster County parents indicated services coordination, mental health outreach and mentoring programs, and job placement and training among their greatest priorities. While participants in Quinn et al. (1996) also identified job placement and training as important, they indicated that support for youth in the school setting, child therapy, respite care, and transition services were also among their greatest priorities.

Regarding the second goal, we found that length of time in the system and number of agencies involved were variables related to parents' perceptions in terms of barriers but not in terms of priorities. The present findings extend the evidence base since we believe no researchers to date have explored differences in parents' perceptions. Respondents who had been in the system for more than two years rated barriers to services as significantly more problematic in 14 of 19 cases, while respondents who had been involved with multiple agencies found 11 of the 19 barriers as significantly greater problems. It is hard to tell from where the differences come. First, it is possible that parents whose families end up involved with systems of care for longer periods of time or have contact with multiple agencies entered the system with more significant problems than did comparison families. Second, it could be that the time and agency involvement variables influenced parents' perception. Longer and more intensive involvement in the system of care, for example, may have contributed to parents gaining more information about services, thereby looking at situations differently than they had previously. Third, it could be that parents' increased involvement in issues related to program planning and evaluation (Center for Mental Health Services 1997; Osher et al. 2001) has led to changes in opinion. The many possible explanations for differences in parents' perceptions underscores the need for more research in this area.

Few differences were found with priorities. Of the 90 comparisons, only mental health medication and monitoring was rated significantly differently across parents. Parents whose families had been in the system of care more than two years rated the issue as a greater priority. The existence of

long-term emotional and behavioral problems in children and adolescents severe enough to have warranted ongoing psychopharmacological treat-ment–and its accompanying stress–possibly contributed to differences in parent ratings. Part of the reason for the failure to identify more statistically significant differences might have been due to the fact that parents across the board rated all priorities as important. In other words, there was consider-ably less variability in the priorities data than in the barriers data. The differences in findings across variables indicate that more research is needed in these areas as well.

Information collected in this survey has several limitations. First, the sample includes the perceptions of the 31% of parents in Lancaster County who responded. Results do not inform us of the 69% who did not respond to the survey. Second, because there were no operational definitions of the items available to respondents, it is possible they interpreted items differ-ently than researchers intended. Third, results came from a convenience sample in one midwestern county. It is difficult, then, to generalize them to the perceptions of parents in all other systems of care.

Future research might attempt to replicate the present findings with respect to variables that impact parents' perceptions, as well as add to the types of variables that might influence parents' perceptions and actions. Another variable, for example, could be the type of professional with whom parents have had the most contact. It might also be instructive to break down the time and agency involvement variables even further to ascertain when it is that parents' perceptions change. Moreover, it may be informative to follow selected parents and families over time to determine when and how perceptions of involvement in systems of care change. With the role of family members in mental health systems of care changing (Osher et al. 2001), it is likely that parents' perceptions of systems of care will change as well.

With systems of care developing uniquely within their own communi-ties, it is logical to believe that the system of care in Lancaster County will look different from systems in other locations. For example, the fact that a formal youth mentoring program (i.e., the TeamMates program begun in 1991 by current US Representative Tom Osborne and his wife, Nancy) was both introduced and highly visible in Lancaster County over the past 12 years may have influenced parental perceptions, indicating the greater im-portance of mentoring programs to parents in this sample than to parents in the Quinn et al. (1996) study. However, the fact that community resources may influence community members' opinion should not stop investigators

from looking for similarities across systems. The present research attempted to add depth and breadth to the literature base with respect to parental perceptions.

The study was also believed to be the first attempt at identifying variables influencing parental perceptions. Findings indicated that depending on the issue being raised, time involved in the system, and the number of agencies families are involved with may or may not be related to differences in parental perceptions of wraparound mental health services.

The present findings have several practical implications. On a local level, they inform mental health service providers and administrators about parents' perceptions of barriers and priorities in the system of care. Therefore, service providers and administrators can shape the county's system of care to incorporate these parents' voices. Lancaster County's service providers and administrators might also look to other communities to compare what service barriers and priorities that are similar to and unique from those in other communities. On a broader level, the information (1) adds to parental perception data, and (2) acts as an impetus for other service providers and administrators to adapt their service delivery models in ways that meet the needs of their families. With the help of research, systems of care can evolve in ways that even more effectively serve and utilize the strengths of families with which they are engaged.

Acknowledgments

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