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ABSTRACT

Two-hundred and fifty parents of children with emotional or behavioral disorders residing in Oregon were surveyed concerning the nature and extent of support they received. Parents were affiliated with the Oregon Family Support Network, a statewide, parent-run, information and family advocacy organization. One hundred usable surveys were returned. Major findings indicated: 29 percent reported receiving none of the seven identified functions of service coordination; the most commonly received function was assessment and the least commonly received function was teaching in self-advocacy skills; school personnel provided service coordination more frequently than any other discipline; families with children ages 11 to 18 received more services than families with children younger or older; there was a significant positive relationship between parent satisfaction and number of functions of service coordination received; and parents expressed needs for respite care, transition services, and services for young adults. Findings support continued efforts to provide service coordination within a child-centered and family-focused system of support. (DB)

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# An Examination of the Support Families Receive and Parent Perceptions of How Helpful These Supports are in Meeting the Needs of Their Children and Families

Authors

Introduction Method Results Discussion

## Introduction

Families with children who have emotional or behavioral disorders face complex and multiple challenges. Progress has been made to develop child-centered and family-focused systems of support to help families cope with stressful circumstances and access services from the categorical systems. However, parent input is rarely sought when planning, implementing, and evaluating these efforts.

This study examined the nature and extent of support families received from their informal social networks and from paid professionals, and how helpful these types of assistance were in meeting child and family needs. Results indicated that more support was provided by formal organizations and paid professionals than by informal organizations and unpaid individuals. Family members, however, provided the most help/support in coping with daily challenges. In addition, the greater the number of functions of service coordination received, the more successful parents were in accessing formal support and the more satisfied they were with their family's quality of life. Results indicated that receipt of service coordination may contribute to positive outcomes for families with children who have emotional or behavioral disorders. Findings imply that professionals should rely more on parent input to ensure that community support systems effectively address child and family needs.

## Method

Mail survey research methods were used to explore the nature and extent of support families received. The following areas were examined: (a) characteristics of children with emotional or behavioral disorders and their families, (b) types of informal and formal support families received, (c) relationships between child and family characteristics and support received, (d) helpfulness of support received, (e) functions of service coordination received, (f) the relationship between receipt of functions of service coordination and parent success in getting help, and (g) the relationship between receipt of functions of service coordination and child well-being and family quality of life.

### Participants

Participants were parents residing in Oregon who had a child with an emotional or behavioral disorder. A sample of 250 parents was randomly selected from the Oregon Family Support Network (OFSN) database of 1000. The OFSN is a statewide, parent-run, information and family advocacy organization to support both the children and youth with emotional, behavioral, and mental disabilities and their families.

Survey packets were mailed to all selected parents. A total of 120 surveys were returned. Of these, 100 met the requirements for inclusion in the sample to be used for data analysis. The 40% return rate of useable surveys was sufficient to answer the research questions.

### Instrument

A self-administered questionnaire was used for data collection. The instrument was pilot tested by meeting with three parent-run support groups. A total of 18 parents, representing (a) rural and urban settings, (b) a range of ages, incomes, and educational attainment, and (c) with children of different ages and disability labels, attended three separate meetings. As a result of the pilot test, minor changes were made in both the terminology and instructions for completing the survey.

### Reliability

The survey was divided into five parts. A test-retest reliability procedure was conducted by mailing each of the four parts of the questionnaire that included quantifiable responses to four subgroups of the 100 respondents approximately one month after receipt of the original questionnaire. Absolute agreement was calculated for Part I (family characteristics) and Part II (child characteristics). For Part I the agreement ratio was 89%, and for Part II the agreement ratio was 82%. For Part III (support families received), the percent of agreement was 77% and for Part IV (family service coordination and family outcomes), the percent of agreement was 87%. Pearson Correlation percent of agreement was 87%. Pearson Correlation Coefficients were calculated for items with interval data in Part III and Part IV. The highest reliability coefficient was .90 for responses related to family service coordination. The lowest was .73 for the items related to helpfulness of support received. Inter-rater reliability for Part V, the one open-ended question, was calculated for 10 of the 65 parents who responded. The average agreement between raters was 85%.

### Analysis

Descriptive statistics (frequencies, percentages, means, and standard deviations) and statistical analyses were conducted using the Statistical Program for the Social Sciences (SPSS). When testing statistical significance, a conservative alpha level of $p < .01$ was used to protect against experiment wise error for t-test results, chi-square test of association, Pearson Correlation Coefficients, and Friedman Two-Way Analysis of Variance by Ranks.

## Results

Respondents represented families residing in 22 of Oregon's 36 counties, characterizing the general population of Oregon. The children and youth with emotional or behavioral disorders reflected the racial mix of the national population, with a slightly lower percentage (87%) reported as Caucasian than in the Oregon population. A wide range of child and youth disability categories were represented. The range of disability labels per child was 1 to 9, and a mean of 2.6 per child. Of the 100 children and youth represented in this study, 82 (82%) were participating in-school programs, with the largest number (72%) attending in-school programs that were not associated with day or residential treatment.

Parents were asked to report the extent to which their families received the functions of service coordination during the past year. These functions were: (a) assess the needs and strengths of the child and family; (b) develop the family service plan; (c) link the child and family with services appropriate to child and family needs; (d) monitor the delivery of services and child and family progress toward goals; (e) advocate for the child and family; (f) provide information to parents regarding where to find resources; and (g) teach self-advocacy.

Of the 100 respondents, 29 (29%) reported receiving none of the 7 functions of service coordination. The assessment function was received most frequently ($n = 59$). The least frequently received function was self-advocacy ($n = 14$). The pattern that emerged was that as the number of functions received increased, the number of families receiving those functions decreased. School personnel provided service coordination more frequently than any other discipline ($n = 29$) and schools combined with education service districts accounted for 44% of the service education service districts accounted for 44% of the service providers identified as delivering functions of service coordination.

Families with children ages 11 to 18 received more functions of service coordination than those ages 3 - 10 and 19 - 28; the group of 11 families with young adults ages 19 to 28 with emotional or behavioral disorders received less service coordination than the other age groups.

To examine the relationship between the extent of service coordination families received and overall parent satisfaction with family quality of life, satisfaction was measured on a scale of 1 to 4, with 1 being "not at all satisfied" and 4 being "very satisfied." The mean satisfaction rating for 91 parents was 2.19 (SD = .9). The Pearson Correlation Coefficient of $r = .2675$ was statistically significant at the $p < .01$ level of significance, indicating a positive relationship between parent satisfaction with family quality of life and number of functions of service coordination received. Statistical analysis of the relationship between parent success in being able to get the support their child and family needed and the receipt of functions of service revealed a significant positive relationship between these two variables ($r = .3387$; $p < .01$). In addition, a correlation of $r = .6180$ ($p < .001$) indicated a strong positive relationship between parent success in getting help and family quality of life.

The open-ended question asked parents to provide additional information about the support their child and family received. As a result of content analysis, 11 themes emerged. Of these, three were considered the most relevant to the purpose of the study: (a) parent feelings, (b) parent needs, and (c) parent recommendations. Parents' expressions of stress and difficulty in coping were described more frequently than feelings of satisfaction and hopefulness. Parent needs were categorized in 7 primary categories. These were (a) respite care, (b) transition services, (c) services for young adults (independent living: vocational, life skills, recreational), (d) service coordination, (e) financial assistance for health services, (f) child's behavior to be more positive, and (g) support for relinquishing custody. Recommendations made by parents included increased flexibility and coordination of services across the categorical systems.

## Discussion

This study explored the nature and extent of the informal and formal support families receive and how helpful these types of assistance were in meeting the needs of both children who have emotional or behavioral disorders and their families. The socioeconomic characteristics of the families reflected the general population of Oregon. Child characteristics were consistent with the literature describing the characteristics and educational placements of children and youth with emotional or behavioral disorders. However, findings may not be generalizable to the population of children, youth, and families since the sample was purposeful.

Families received support from both formal and informal sources. However, parents relied mostly on family members (informal support) when they needed someone to talk to about the daily challenges they faced. In addition, even though support received was generally perceived as helpful, parent anecdotal comments suggested that the current service system continues to be fragmented and difficult to access.

Findings from this study support continued efforts to provide service coordination within a child-centered and family-focused system of support. Statistically significant relationships were found between parent success in getting needed help and the number of functions of service coordination received. These findings suggest that family service coordination may be an effective means to ensure that families receive timely and appropriate assistance.

Results from this study support future research that examines community service delivery programs that systematically incorporate informal social networks into community-based service delivery in order to increase the amount and availability of support, and also more closely match child and family needs with the resources most appropriate to meet those needs. This concept appears more promising as local communities look for innovative ways to transform the categorical systems at a time of dwindling resources and increased demand for government accountability.

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