DOCUMENT RESUME

ED 282 672 RC 016 102

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TITLE Parent Perceptions of the Support System in the Rural

Area.

PUB DATE Oct 86

NOTE 13p.; Paper presented at the Annual Conference of the

National Rural and Small Schools Consortium

(Bellingham, WA, October 7-10, 1986). Reports - Research/Technical (143) --

Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.

DESCRIPTORS *Ancillary School Services; Community Attitudes;

*Community Support; Coping; Developmental

Disabilities; *Disabilities; Economic Factors; Family

Life; Family Problems; *Parent Attitudes; Parent

Role; *Participant Satisfaction; Preschool Education;

Professional Services; Quality of Life; Rural

Education; Rural Environment; *Rural Urban

Differences; Social Services; Social Support Groups;

Special Education

IDENTIFIERS Texas

ABSTRACT

PUB TYPE

The amount of support and the degree of satisfaction with available support to rural and metropolitan parents of handicapped preschoolers was studied by analyzing parents' responses to mailed questionnaires assessing family background and demographic characteristics and the mothers' perceptions of the availability and quality of support systems in their communities and school systems. Respondents were 50 urban and 30 rural Texas mothers of handicapped preschoolers. Responses about amount and quality of support fell into nine categories: amount of professional support, quality of medical support, satisfaction with professional support, number of people available for informal support, quality of informal support, satisfaction with informal support, parenting and lifestyle satisfaction, involvement in community groups, and satisfaction with community involvement. Comparison of rural and urban responses showed a slightly smaller amount of professional and informal support available to rural parents, but rural parents were more satisfied with available support than were metropolitan parents. The two areas with significant difference were quality of medical support and lifestyle/parenting satisfaction, with rural parents giving higher ratings in both areas. These results raise the possibility of overali satisfaction with rural life overriding limited outside support. (JHZ)

Parent Perceptions of the Support System in the Rural Area

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October 1986

Paper presented at the Annual Conference of the National Rural and Small Schools Consortium. (Bellingham, WA, October 7-10, 1986).

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Parent Perceptions of the Support System in the Rural Area

Abstract

The delivery of support services; i.e., screening, assessment, counseling and special education services, to the parents of handicapped children in rural areas is the focus of this research. Factors hindering and helping the parents of handicapped children in rural areas will be presented. It is proposed that the rural family has unique characteristics that the professional working with these families should be apprised of in order to best serve this population. This study utilized nine categories identified as descriptors of support services available to families with handicapped child. (Hooshyar, (A); Hooshyar, 1986 (B)). A questionnaire was sent to 75 families living in rural areas in northeast Texas. The responses returned were compared with those from families in a suburban area in the Dallas/Ft. Worth metroplex. The questionnaire elicited responses from parents about the coping strategies they use as well as the support they feel they have had access to. This is a comparison study of the parent's perception of support services available to them in rural areas versus those in suburban area. It is proposed that the problems characteristic of the rural area, i.e. isolation, distance between sparsely populated communities, etc., affect the rural family's ability to cope with their child's handicap. This is a pilot study to determine the need for future research pertaining to the match between a family's need for support and the provision of services to them. The results of this study will be presented.

The term "rural" lacks a common definition among federal agencies. Often "rural" is defined by not being "urban" where urban is defined as "an area having an incorporated city with at least 2,500 inhabitants or a city within a Standard Metropolitan Statistical Area" (National Center for Education Statistics, 1972).

The U.S. Census Bureau uses a non-rural vs rural classification system. Most often population density and occupation of residents, that is farm or non-farm, formulate guidelines. A resident of a community of less than 2,500 people is considered rural. Further, a resident is considered in the farm category if the individual lives on 10 acres or more and produces for market. All other residents of a community of 2,500 people or less are considered non-farm. The Census Bureau definition does not distinguish those residents of communities within commuting distance of metropolitan areas who leave their rural community to work and have easy access to services in the city.

Inconsistencies in definitions between the rural and nonrural population have prompted some researchers to use a metropolitan vs. nonmotropolitan approach to compare social dynamics. The nonmetropolitan definition incorporates proximity to a city of 50,000 or more residents. A Standard Metropolitan Statistical Area (SMSA) is the county in which a city of at least 50,000 residents is located. Residents outside that county are considered nonmetropolitan (Hassinger, 1978).

A reasonably accurate definition of rural, therefore, would include population density, occupation and employment status and proximity to a SMSA. For the purpose of this research, a rural resident is defined as one living and/or working in communities of smaller than 5,000 people located at least 20 miles from a metropolitan area. A nonrural resident is defined as one living and/or working within an urban or suburban portion of an area whose population is over 50,000. In support of this definition the National Rural Research Project has utilized the following definition for research purposes:

"A (school) district is considered rural when the number of inhabitants is fewer than 150 per square mile or when located in counties with 60% or pre of the population living in communities no larger than 5,000 inhabitants. Districts with more than 10,000 students and those within a Standard Metropolitan Statistical Area (SMSA), as determined by the U. S. Census Bureau, are not considered rural." (Helge, 1983, p. 8)]

The structure of the rural society includes a large dependent population. In 1970 the average age of the rural population was 28.3. However, 89.5% of this same population were persons under the age of 18 and over 65 (Hassinger, 1978). The



high incidence of dependent, and presumably nonworking persons could indicate a smaller earning population. The average family income in nonmetropolitan areas is far below that of metropolitan families (Sher, 1978). Of the 2,000 school districts where median family income is less than \$7,000 annually, 75% are rural (National Center for Educational Statistics, 1972).

Ironically, the poverty level of the rural area is usually not offset by federal support: "HEW testimony before Congress has revealed that only 5% of research dollars, 11% of library and materials funds, 13% of basic vocational aid, 13% of dropout prevention funds, and disproportionately low levels of most other federal education funds go to nonmetropolitan areas" (U.S. Congress Committee, 1975).

"Cupport" in a community has been defined in two categoriss: formal support and informal support. Formal support includes federal, state and local agencies such as counseling services, clergy, medical and other health professionals, legal advisors, parent organizations. Informal support includes the nuclear and extended family, friends, neighbors and cliques (Hassinger, 1978; Webster, 1984).

With so little federal support, the bulk of economic and social support falls to the community. However, the rural society's support is usually determined by cultural and socioeconomic factors. In the rural community the informal group; i.e. family, cliques and neighbors, forms the predominant bond for support. The informal group determines the social standards of behavior, the family's social standing and acceptance or rejection for individuals within the rural community. Personal privacy is selden available in the small community. Yet, this same tightly knit structure provides a strong source of support in time of crisis. In addition, the rural family usually goes beyond its nucleus. Extended family members lend another area of support. Again, at the price of limited privacy (Hassinger, 1978; Sundet and Mermelstein, 1984; Webster, 1984).

The family with a handicapped child lives within this framemark as any other family in the community. They have access to the same level of support as well as scruting. Their attitudes about having a handicapped child are bound to the community's attitudes. The overwhelming incidence of poverty shown in rural areas can be linked with the amount of support a family is willing to give to services for their handicapped child. With respect to educational services, it is difficult to determine cause and effect between years of schooling, educational achievement and income because numerous other factors are present. However, it is likely that education has different meanings to the poor and nonpoor: "To the middle class it stands for the road to better things for one's children and one's self. To the poor it is an obstacle course to be surmounted until the children can go to work" (National Advisory Committee, 1967, as cited by Marion, 1979, p. 10).

Attitudes of citizens of rural communities and of parents of students in special education programs have been directly . related to services provided within a rural community. has shown that attitudes such as suspicion of external and state) interference, pride in self sufficiency, resentment toward federal bureaucracy are predominant and are major inhibitors to the implementation of PL 94-142 in rural areas (NARC, 1980; Helge, 1981). The National Association for Retarded Citizens (1980) reported that "rural school districts are frequently characterized as resistant to change and suspicious of outside interference. They are proud of their traditions and sometimes perceive mandated changes, such as Public Law 94-142, as threats to their ability to control their own destiny. local school districts do not favor expenditures for handicapped feeling that these individuals will not become productive members of society" (p.6). If a community's attitude toward handicapped individuals is not accepting, there may be a negative effect on programs designed for them (Tunick, et al., 1980).

A negative attitude toward education in rural areas is also reflected in the 1969 figure of 11.2 for median years of school completed over all nonmetropolitan areas (Hassinger, 1978). Thus, repeating the cycle of limited education, poverty and resistance to change.

Cultural impact on the rural family is as diverse as the idea of culture in our society. The predominance of American Indian culture in the southwestern, and northwestern United States, including Alaska, and Chicanos and rural Blacks, including migrant workers and their families typify the rural cultural climate. Extended family ties are still strong in rural communities. These ties can form a strong support group for the parent of a handicapped child. Conversely, broken ties can be the most devastating form of isolation, when the parent is shunned from the family because of cultural superstitions and beliefs (HEW, 1977).

Of course, urban areas have culturally diverse populations as well. The difference in rural areas has been reported as rural families are more likely than their urban fellows to follow cultural traditions and, referring back to socioeconomic factors, poverty and unemployment make clinging to the support of ones culture more attractive (NARC, 1980). The special education teacher or counselor wishing to be effective in working with handicapped children and their families must be very familiar with the "cultural code" of the community. Inability to communicate with a non-english speaking parent, or disregard for family traditions and beliefs would only serve to widen the gap between parent and support services.

Confounding the issue of a community's attitude and subsequent support to the family is the availability of formal support services and adequate personnel. The same problems that



plague special education in rural areas affect the availability of outside support. Castellani, et all, (1986) reported that support was positively affected by population density and economic level or "wealth" of a community. Therefore, rural areas of high poverty levels received the least amount of support from state, county or local services. Also, within a service delivery model for rural areas, scattered population is a major topic for concern: "Vast land areas, scattered populations, and lack of services for low incidence handicapping conditions are obstacles to the development of programs requiring highly trained personnel and specialized facilities and equipment" (Helge, 1981, p. 514).

It has been reported that most rural areas do not have local chapters of parent organizations for handicapped children. Regarding school support, officials have reported limited participation of parents in individualized education planning (IEP) meetings (Helge, 1981). While PL 94-142 specifically requires parent participation, expecting conference notification letters to reach home with a student through a long busride over bumpy country roads to a parent, who in turn must make the long trip over the same roads to the school is a big request. In areas with temperate climate close to metropolitan areas, distance may not be an obstacle (Marion, 1979). However, in some areas in the northern United States scattered population is very pronounced. For example, in Alaska many school districts require a resource teacher to have a pilot license in order for him/her to adequately serve that district (Bischoff, et al, 1980).

Clearly, such tremendous obstacles would have an impact on the availability of and communication between families and other support services. While one of the hallmarks of rural society is a predisposition to self-sufficiency and deference to the informal group, it appears that the informal group for good or not is the accepted mode of support with little alternative.

The objective of this research is three fold: a) do rural parents perceive a need for a formal support system, b) are formal support systems available for rural parents of handicapped children, and c) what are rural parents' perception of the quality of support systems available to them through the community and the schools at present?

Method

Subjects

Two groups of subjects participated in this study. The first consisted of 50 mothers of handicapped (Downs syndrome and language-impaired) children residing in a metropolitan area. These families were recruited through several school districts in the Dallas/Fort Worth Metroplex, the Down Syndrome Guild, the Callier Center for Communication Disorders of The University of Texas at Dallas.



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The second group of participants consisted of 30 mothers of handicapped (Down syndrome and language-impaired) children residing in a rural area. The families were recruited through the Collin County Special Education Cooperative, The Denton County Child Development Center, and Region VIII Educational Service Center who serve early childhood units within the rural areas of northeastern Texas. Subjects were recruited using the criteria set by the metropolitan subjects in order to provide a match for an accurate comparison of data.

The mean age for the mothers of both groups was 36.0 years (SD = 6.0; Range = 20 to 45 years for mothers of Down syndrome children and SD = 4.8; Range = 26 to 45 years for mothers of language-impaired children). The educational level of the groups ranged from a minimum of high school graduate to a maximum of B.A. or B.S. degree. The mean family socioeconomic level was 51.0 (middle-class) on the Hollingshead Index of Social Status (1975).

The mean age of Down syndrome children was 61.8 months (SD = 23.6; Range = 38 to 107 months. According to Karyotype, 14 Down syndrome children whre diagnosed as Trisomy 21 and one as Translocation. The mean age of language-impaired children was 45.2 months (SD = 10.0; Range 32 to 69 months). The language-impairment of subjects was attributed primarily to middle-ear infections, cleft palate (surgically corrected), and nonspecified causes.

<u>Instruments</u>

Two questionnaires were utilized to assess: a) family background and demographic characteristics and b) mother's perception of the availability and quality of support systems in their community and school system.

For the purpose of this study, a detailed demographic background inventory was developed. The inventory consisted of items grouped into three categories: child, parents, and physical environment. Questions included areas such as age and handicapping condition of the child, educational attainment and employment and marital status of the parents, and family size. Inventories sent to rural parents asked the approximate distance of their community from a major city.

To assess parents' perception of support systems a detailed questionnaire consisting of 45 items was developed. Questions included areas such as the support system most often used by the parents and the availability and quality of support systems (in general) in their communities.

The questionnaires included questions requiring three types of responses from participants: 1) the number of people available to them in the medical and educational fields, when they had a problem with their child, when they were angry, upset



or happy; 2) a 1 - 5 mank (1 = dissatisfied, 5 = satisfied) addressing their satisfaction with this support, their parenting skills, family and social life; and 3) a 1 - 3 mank of the quality of informal support and their community involvement (3 = yes, 2 = somewhat, 1 = no/none).

The questionnaire was designed to place the responses in nine categories: 1) the number of people usually contacted for medical and educational (professional) support; 2) the quality of professional support, a 1 to 3 rating; 3) satisfaction with professional support, a 1 to 5 rating, 4) the number of people available for informal support, such as family and friends, 5) the quality of informal support, 6) satisfaction with informal support, 7) parenting and lifestyle satisfaction, a 1 to 5 rating of childcare and household chores, personal and social time; 8) community, parent group and church involvement, a 1 to 3 rating; and 9) satisfaction with community involvement.

Procedure

Parent's names, addresses and telephone numbers were obtained through the different agencies. The parents were contacted by telephone by the researchers to solicit their participation in the research. The questionnaires, with a, self-addressed, postage-paid envelope were mailed to participants. Assurance of confidentiality was given both verbally and on the cover letter for the questionnaires. Follow-up by telephone was made to confirm receipt of the data.

Results

Means were calculated for all of the responses to the 56 items on the questionnaire, rural and metropolitan responses were separated for this calculation. The 112 separate means were then grouped, rural paired with metropolitan, into nine categories.

Table 1 illustrates category means and standard deviations for the rural and metropolitan responses. A one-way analysis of variance was performed to compare the rural with metropolitan means for each category. Rural respondents reported a significantly higher degree of satisfaction with the quality of medical support (F 1, 14 = 11.17, p < .01).

To accommodate the small sample size a Student T-test was also utilized to compare the means of each category. This analysis yielded a significant difference in the means of quality of medical support category (T = 4.93, df=7, p < .01). In addition, the rural respondents rated lifestyle and parenting significantly higher than their metropolitan fellows (T=2.68, df=6, p < .01).

Table 1

Category	<u>Rural</u>		Metropolitan_		
	Mean	SD	Mean	SD	
Amount of Professional Support	4.5	1.2	5.0	.5	
Quality of Medical Support	1.79	- 19	1.51	.20	
Satisfaction with Professional Support	3. 95	. 33	3.27	.21	
Number of Informal Support	3.0	1.0	3.0	1.0	
Quality of Informal Support	1.87	. 14	1.88	. 10	
Satisfaction with Informal Support	3. 99	. 44	3.80	. 42	
Lifestyle/Parenting Satisfaction	3.25	. 54	2.98	. 47	
Community . Involvement	1.85	.05	1.92	.09	
Community Satisfaction	3.27	.16	3.33	. 15	

Discussion

The study examined the amount of support and satisfaction with support available to rural and metropolitan parents of handicapped pre-schoolers. The results reflect a slightly smaller amount of professional (formal) and informal support available to rural parents participating in the study. Yet, the degree of satisfaction rural parents have with support available is slightly higher than the metropolitan respondents. While the differences are not significant, an assumption that the amount of Justified support is related to satisfaction with support is not by this study. The two areas with significant difference, quality of medical support and lifestyle/parenting satisfaction, pose a specific question. That is, the possibility of overall satisfaction with rural life in general overriding limited outside support. Further research should address the overall satisfaction issue more specifically especially since it is somewhat contrary to some of the literature previously discussed.

Educators and others involved in providing support services should use information gleaned from this study to enhance their understanding of the parents they are in contact with. Hopefully, a better understanding of parents in rural areas would benefit



the quality of the relationship between helping professionals and parents.

Emphasis should be placed on the fact that this is a pilot study and initiated to determine flaws in research design more than to draw specific conclusions about rural support systems. The sample sizes are very small and interpretation of results must be conservative. The results are important in that they provide a basis for further research in the area of parent attitudes in the rural area.

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