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YOUTH & CARING: STATEMENT OF INTEREST

INTRODUCTION. This project will study siblings of developmentally delayed and multiply handicapped children to examine levels of caring behavior and the relationship of these behaviors to other caregiver attitudes and attributes. The study will also introduce an ethnic variable, since it is possible that sustained impulses toward caring are mediated by culture. The goal of the project is to identify how sibling caring is manifested behaviorally and attitudinally, and to assess how this caring is related to demographic variables such as age, sex, and ethnicity; as well as such variables as depression, self-esteem, community involvement, and career choice.

RATIONALE FOR PROJECT. Research in the field of developmental disabilities has identified the often unremitting needs for physical and emotional caring that fall not only on parents of disabled children, but on siblings as well. Frequently it appears that siblings pay a psychological price for such emotional investment. However, more recent evidence suggests associations of sibling caring with more positive outcomes, such as increased empathy and a professional interest in the "caring" occupations. Thus, impact of caring behavior on the sibling caregiver is unclear.

Sibling caring also appears to be related to such independent variables as gender, age, and birth order. Women have been called the "caring" sex, and there is some evidence to indicate that the cumulative effect of oldest sibling status and female gender overwhelms the coping capacity of even the most devoted child. On the other hand, the fact that boys are limited by sex-role expectations in the ways they can legitimately express caring also may have deleterious consequences. Further, in families with a disabled child, there occurs the unusual situation of chronologically younger siblings assuming caregiving functions normally reserved for the firstborn. All these variations on sibling caregiving deserve exploration.

A final factor to consider is that of ethnicity. As research becomes concerned with multiethnic samples, we are increasingly aware that culture plays an important role in how families respond to the presence of disability, including their definitions of caring. It is reasonable to expect that different ethnic samples might exhibit culturally sanctioned caring roles, and that the relation of fulfillment of these roles to caregiver adjustment might be mediated by cultural expectations.

METHODS AND MEASURES. For the purposes of this exploratory study, sibling caring will be defined both attitudinally and behaviorally. Four dimensions are currently being considered: 1) Protectiveness, ie., the extent to which the sibling displays evidence of protecting the disabled child from physical or emotional harm. This dimension is conceived as a continuum from lack of concern (distanciation) to overprotectiveness (hypervigilance). 2) Education, ie., the caregiver's tendency to participate voluntarily in the intellectual, social, emotional, and

physical development of the disabled child. 3) Physical tasks, ie., situations in which the caregiver voluntarily supports the disabled child in physical tasks which he or she is incapable of completing independently. 4) Emotional support, in which the caregiver expresses concern and acts as a support resource regarding the emotional wellbeing of the disabled child. 5) Rights, ie., the extent to which the sibling is concerned about the rights of the disabled child, including access to educational and health care systems; and, in the future, opportunities for meaningful employment and independent living.

Sibling caregiver measures will include: 1) Attitudes: a) Attitudes toward the disabled (Yuker, 1966) - a general measure of attitudes toward persons with disabilities b) Attitudes toward other disadvantaged groups 2) Self-esteem (Piers-Harris) 3) Depression (Zung) 4) Career aspirations 5) Community involvement 6) Personal characteristics of empathy and understanding. Measures used will include self, parent, and teacher report, and will be both standardized questionnaires, semi-structured interviews, and modifications of Draw-a-Person for younger subjects.

Subjects will include 2 ethnic groups, Hispanic and Caucasian; 2 age groups (6-11; 12-18); and will be balanced by sex. In addition, a control group will be identified through local neighborhoods and schools, which will be matched by age, sex, ethnicity, and approximate number of siblings. The purpose of the control group is to measure variation in caring among disabled and nondisabled populations. A total of 80 experimental and 80 control subjects will be assessed.

Subjects will be recruited through the Los Angeles Regional Center, the Orange County Center for Developmental Disabilities, the Irvine Children's Educational Center, and PROUD (Parents' Regional Outreach for Understanding Downs), all sites where the investigator has had previous contacts.

POLICY IMPLICATIONS. Identification of both negative and positive correlates of sibling caring will help target improvements in family support services. As we better understand which aspects of sibling caring are beneficial and which deleterious, parents, teachers, and other professionals such as family physicians can be better prepared to support siblings in specific, constructive ways. Further, evidence that caring behaviors enhance the lives of both givers and receivers would have implications for educational concepts such as mainstreaming and full inclusion. More complete integration of disabled persons into social systems has the potential to result in greater opportunities for the expression of caring behaviors, especially if this is given consideration in the structuring of such programs.

RELATIONSHIP TO PREVIOUS WORK. This investigator has a long history of both clinical and research activities with families of developmentally delayed children. Some of this work has included a cross-cultural component involving Hispanic families. In addition, the investigator's position in an academic department of family medicine provides incentive to explore how physicians and other professionals can promote the development of caring environments in the home.

POSSIBLE FUTURE SOURCES OF FUNDING. Likely sources of

continued funding might include the Behavioral Science Division of the March of Dimes Foundation; and the Department of Health and Human Services.