

The stress of raising a handicapped child

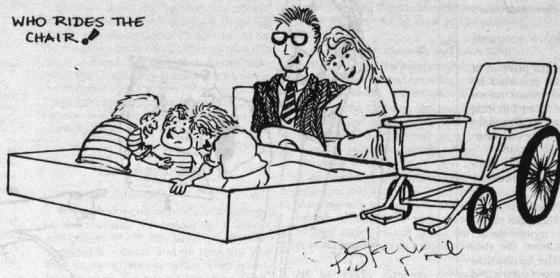
by Carolyn Routledge

Perhaps with year-end finals looming in the not-so-distant future, university students can understand what it's like to live with an abnormally high level of stress. However, not all people with stressful lives can get away from it all over the summer holidays.

According to Dr. Gerry Kysela and his colleagues including Dr. Linda McDonald in the Department of Educational Psychology, having a handicapped child as a member of the family also creates these unusual levels of stress — levels that unfortunately are not reduced by the arrival of summer.

The strains of raising a severely handicapped child are not yet precisely understood, as until recently, the facilities and services to permit a family to care for such a child within the home were unavailable, and these children tended to be institutionalized. More recently, however, programs have been designed whereby the children can

WHO RIDES THE CHAIR?



continue to live at home while the special care and support are provided to meet their particular developmental and physical needs. It is these "early childhood intervention"

programs that are the primary focus of Kysela's research.

The intervention programs are the result of a project from the 1970s, since taken over by Alberta Education in which educational programs for handicapped children from birth to six years of age were provided. This program proved to have a very positive effect on the children, and it demonstrated that these children could be helped,

and that "you could support the family in caring for the child," noted Kysela. However, the integration of these children into the family, although beneficial for the children, added new stresses and strains to cope with, affecting the delicate balance of relationships within the family.

The actual research began with a small-scale pilot project involving a survey of six families with severely

handicapped children from ages three to five. The results were surprising, says Kysela, as in some areas "they were right off the scale in terms of stress, two or three standard deviations above the mean." Subsequent research has been aimed at characterizing this stress, to determine how these families are affected, which families cope best, what support is available to them, and so on.

A more specific study has since been developed, and this is the subject of Kysela's and McDonald's most recent research work. The study involves a survey of twenty families and three different types of early intervention programs, with children three-and-a-half to five-and-a-half years of age, "usually moderately to severely delayed, at about half their chronological age developmentally." These three programs include home-based intervention, which involves a worker coming to the child's home to work with the parent and child; a center-based program where the child goes to a very structured program five half-days a week; and an integrated daycare program in which a group of 35 children might include four or five with special needs who have a worker specially assigned to spend time with them.

The survey is designed first of all to determine if measures of family stress actually help to describe how the family is functioning, and secondly whether the impact of intervention differs across the various programs, "in terms of stress and coping."

All participating families are volunteers from the three programs.

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They consent to a series of rigorous questionnaires and interviews, as well as a session on campus in which the parents' interaction with the child is videotaped. The data obtained from the interview and videotape is used to cross-tabulate the results from the questionnaires, to check the correlation and to determine the effectiveness of the written surveys.

Results thus far have shown the families to be generally within normal range for those variables affecting parent relationships, but "very stressed by the factors associated with the child." For this reason, the assessments made of the interviews and videotapes with respect to the parent-child relationships are very important. As Kysela says, "our suspicion is that these important parent-child interaction patterns will reflect stresses and strains, and will also reflect the impact of the intervention."

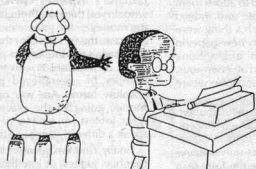
Kysela says that future plans include the development of more sensitive indices and methods of assessment, as well as "looking at a much more complex and hopefully sophisticated type of intervention," intervention designed not only to nurture the child's development, but also the development of the family.

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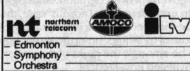
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