

## **The Parents with Disabilities and Their Teens Project**

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### **Summary of Results**

The overarching goal of this project was to further knowledge about the lives of families in which one or both parents have a disability or deafness raising teens between the ages of 11 and 17. A national survey was developed for parents with disabilities, their teens, and a comparison survey was developed for parents without disabilities and their teens. These surveys were distributed to approximately 500 parents and teens. The following is a summary of the results from this survey:

#### **(A) Demographic Information About Participants**

Parents with and without disabilities who participated in this project were predominantly female (82% and 85%), Caucasian (86% and 79%), married or partnered (76% and 79%). Their ages were similar (mean = 46.4 and 45.8 years) as were the ages of their teens (mean = 15.9 and 16.2 years). About three quarters of the respondents had a physical or systemic disability (including MS). The Median age at onset was 14 years old, with a distribution of 16 years. Just under one third felt the disability was progressive, and 41% said it was stable. The daily impact was significant (mean of 3.7 on scale of 1-5), and most experienced pain at least on a weekly basis. Fully three quarters of the respondents used some type of assistive technology, but over half reported further assistive technology needs. In response to the question: "Was there any physical abuse involved in the onset or worsening of your disability?" 6% replied yes and a further 5% were not sure.

#### **(B) Comparison between parents with disabilities, grouping three disability groups together (physical, MS, visual impairment), to parents without disabilities**

Two aspects of the data are noteworthy. First, household income of parents with disabilities was on average \$15,000 per year less than that of parents without disabilities. Since parents with disabilities gave the survey to friends, we assume respondents from both groups lived in similar neighborhoods and were of similar socioeconomic status. Thus the difference in income is striking. Median annual household income was \$40,000 for parents with disabilities and \$55,000 for parents without disabilities. This is explained in part by the rates of full- and part-time employment in the different groups. Consistent with the literature citing an 80% unemployment rate for people with MS, our data show that parents with MS were least likely to be employed (only 34% were working). Parents with physical and visual impairments also were much less likely to be employed than were parents without disabilities.

The second noteworthy aspect of the data was how few differences there were between parents with and without disabilities. With just a few expected exceptions (e.g., worry about teen being rejected, worry about not being able to participate in activities with teen, access to accessible transportation, and self-report of overall health, the two sets of families were notably similar. They agreed on how many friends their teens had, weekday and weekend bedtimes, and how active their teens were after school. They attended church/temple about the same amount (weekly), ate dinner together most nights of the week, monitored their teens' music and homework, were equally likely to experience a significant stressor in the past year (e.g., hospitalization of family member), and described their families similarly. Given the higher income levels of our sample compared to national averages, particularly for the parents with disabilities, it is possible that many findings in other studies of families with disabilities reflect the effects of poverty more than disability per se.

**(C) Comparison Among Parents with One of Three Types of Disability (e.g., physical, MS, visual impairment)**

Again we found more similarities among parents with physical disabilities, MS, and visual impairments than differences, and often differences were to be expected. The MS group is notable for several findings. They were oldest at time of disability onset (33 yrs old), they reported the most fatigue (57% reported daily fatigue), they were the most likely to experience job loss (34%), and least likely to be married to a person with a disability (14%). Parents with visual impairments were the most educated (33% had graduate degrees), reported better overall health (63% reported good-excellent health), reported the least fatigue (66% reported no fatigue), and were the group that was most likely to indicate a desire for more adaptive equipment (75%; they may have been more aware than those in the other disability groups of what adaptive equipment exists). Those with physical or systemic disabilities reported the most pain (47% reported daily pain) and greater impact of disability on their daily lives (41% reported significant impact).

**(D) Comparison of Deaf Parents to Parents With Other Types of Disabilities and to Parents Without Disabilities**

For several reasons we expected the data on deaf parents to show differences between this group and the other disability groups, and between deaf parents and non-disabled parents. The data do indeed show differences. Demographic differences include that both the parents (43 yrs old) and the teens (14.9 yrs old) were younger in this group than in the other disability or the non-disabled group. This suggests that our recruitment methods, which were different for deaf families than for the other groups, garnered families at a slightly earlier stage in their family development. They also were youngest at the time of disability onset (at birth or in the first few years). Consistent with national data, 91% of deaf parents were married to a deaf person. This was less true for parents with visual impairments (35% were married to a person with a disability), physical disabilities (20%) and MS (14%). Deaf parents were also most likely to be working (75%) compared to the other disability groups and equal to the rate in the non-disabled group. Further, they were the least likely to have experienced a job loss in the past year (10%). We surmise that persons who are deaf are well matched to their jobs, and thus less likely to lose them.

Not surprisingly, they reported the greatest difficulty of all groups in communication with their children's schools (22% reported communication was very hard) and friends (25% reported communication was very hard), and they attended church/temple less often (45% attend yearly or never). It seems that communication outside the family was hampered in a variety of arenas, and thus this was the group that was most likely to report restricting activities to the family only (39%). Nonetheless, deaf parents reported a higher level of happiness on a scale of overall family happiness, but the difference, although statistically significant, is slight, and it is hard to know if it is clinically meaningful (3.9 on a 0-6 scale, compared to 3.06-3.56 for the three disability groups). Furthermore, deaf parents were most likely to report that their families had stories and traditions about deafness/disability, compared to the other disability groups (71%). This may reflect the way Deaf culture incorporates stories. However, this finding may reflect the difference in methodology. Deaf parents were responding to an interview question and answering in a face-to-face interview, whereas parents with other types of disabilities were responding to a written or phone version of the survey, and this question does not lend itself to being adequately addressed one or two survey questions.

**(E) Comparison between teens of parents with disabilities (physical, visual, MS) or deafness to teens of parents without disabilities**

Teens' responses were similar across all groups, with just a few differences. They agreed they did an average of 16 chores per week. The teens of parents with visual impairments reported more than the teens in the other groups that their parents came to their school to educate the class about disability (57%), and that they were less active with friends after school (29% reported never playing with friends after school; perhaps reflecting transportation issues for parents with visual impairments). As with the parents, teens of deaf parents were the most different from the other teens. They reported more than the other teens that they were likely to talk with friends about deafness/disability (93%). They felt their families were more supportive, but also more restrictive and less open, compared to other teens. These teens reported they were more likely to get to do things because of their parents' deafness/disability than did teens in the other groups (98%). And, as with their parents, they were more likely to report that their families had stories and traditions about deafness/disability, compared to teens in the other disability groups (69%).

**(F) Comparison of parents/teen dyads across all groups (physical, visual, MS, deaf, non-disabled)**

There was considerable agreement between parents and their teens on most questions. However, in all groups, parents said their teens did an average of 12 chores per week, and teens reported doing 16 chores. Parents were more likely than their teens to ascribe positive benefits of the parents' disabilities (e.g., teen's comfort around people with disabilities, teen's awareness of what is fair and just) but this was also the case for parents without disabilities. Parents with disabilities reported their families were more affectionate than did their teens.

Although there were a great number of similarities in responses from parents with a variety of disabilities, there also were some critical differences. This suggests that any clinical intervention would be most effective by addressing both pan-disability and disability-specific issues. And all parents with disabilities and their families would be aided by greater accessibility and acceptance in their communities.