CONGRESO FAMILIAR
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Testimony before the
Senate Select Committee on Autism
Hearing
Ensuring Fair and Equal Access to Regional Center Services

Congreso Familiar is a grass roots organization whose mission is to provide education to and develop leadership of Spanish speaking parents of children with disabilities. Over the past 20+ years, we have been gathering Spanish speaking families in Northern California for an Annual conference that draws close to 1,000 participants.

We would like to thank you for addressing the important issue of equal access to regional center services for all families. The families that we work with report serious and significant challenges in accessing appropriate services for their sons and daughters:

- Families find it very difficult to understand the service delivery system. It is a challenge when the information is all in English, even when you have a working knowledge of the language. When information is translated, translations tend to be literal and of poor quality.
- There are not enough bilingual providers. Specifically, if your child needs behavior intervention, it is critical for parents to understand the concepts and to be able to follow up with interventions. When the provider cannot explain the concepts to the parent in a way the parent can understand, the impact of the intervention is diminished.
- Families report waiting lists for services in Spanish. If services in English are available, frequently they are not offered until the parents discover they can request them. Meanwhile; time passes, opportunities are missed and, all too often, services do not happen.
- Families are unaware of their rights and, when they are aware of their rights, they find it very hard to assert them.
- When families request translation of reports, they may wait for a long time (a year) or they are told it is very expensive.

Families sometimes perceive that their social workers may not have the information to help their son/daughter with autism or may be withholding some information. Families have experienced social workers telling them that they should be grateful that they are getting some services and should not be requesting any more. They are told services are too costly and are seldom given a formal denial to the services they are requesting.

Families find support groups, workshops and conferences invaluable, but their experience tends to be that they find out about these opportunities through other parents or word of mouth and not always from their case managers. They feel like there is a fear that parents will become knowledgeable and demand more services and resources.

From our experience, we believe that education, information and support are critical to assist families in accessing services which their children need and have a right to, but that these are not enough. There needs to be a commitment from the top to equal access.