

[CDC or Clinic Letterhead with Project Title and Logo]

DATE

Mr/Mrs/Miss/Dr <<FIRST>> <<LAST>>
<<ADDR1>>
<<ADDR2>>
<<CITY>>, <<ST>> <<ZIP>>

Dear Mr/Mrs/Miss/Dr <<LAST>>

We hope this letter finds you doing well. Once again, we would like to thank you for your participation in our focus group conducted in August. Your openness and willingness to share your experiences with the group helped make this project a success. Since our discussion, we have had the opportunity to study what was said and identify some common issues. We would like to share our findings with you at this time. In addition to this brief report, we hope to publish a longer report detailing the findings from the focus group. Such a publication will help draw attention to the problems that Hispanic families with DMD face in obtaining health care. We hope that this attention will lead to more studies of the issues discussed in our session. Ultimately, we hope these studies will help in developing programs to facilitate Hispanics families' access to health care services.

Enclosed please find a brief report of the focus group findings. If you have any questions or comments, please feel free to contact me by e-mail at liz7@ucla.edu. Thank you again, we wish you and your family all the best.

Sincerely,

Elizabeth Lizaola
Focus group study coordinator

Aileen Kenneson
Epidemiologist

Hispanic Families with Duchenne Muscular Dystrophy: Early Findings

Children with Duchenne muscular dystrophy (DMD) need a lot of care. They get care in many different ways and places. For examples, hospitals and clinics provide care. Care can include physical therapy, medicines, and surgery. There are many treatments for families to choose from. Hispanic families may face unique challenges in getting care and other services. To identify these problems, CDC conducted a focus group with four families with children who have DMD. All four families receive services from a local clinic. The discussion lasted 1 hour and 45 minutes. All of the families shared their experiences in caring for their child with DMD. The families talked about five different needs. They also talked about how they found help in getting their needs met, and things that have made it hard to get their needs met.

Needs:

- **Physical barriers.** Families with children with DMD face many physical challenges. The families talked about the problems they have in making their homes accessible, so that their child can move about. For example, hallways and doorways need to be wider so that wheelchairs can fit through them. Accessible vans, ramps and lifts are also needed.
- **Emotional health.** DMD is a difficult condition to deal with, for both the children and their parents. The mothers talked about times when they felt tired. They are overworked and frustrated by lack of helpful services. Knowing their children depend on them help them deal with their depression. Problems in school also cause feelings of isolation and trauma in their sons with DMD.

- **Day-to-day care.** The work involved in daily care of a child with DMD is often overwhelming. Families described the need for help with daily care (such as bathing, dressing, feeding), in-home nursing care, and respite care (so parents can have some time to themselves). As one parent said, “We don’t need money. We just need help.”
- **School.** Children with DMD need accessible schooling and appropriate care at school. Families said that transportation to and from school was inflexible and causes problems.
- **Health care.** Families described the need for the best healthcare possible for their children.

Things that help:

- **Muscular dystrophy clinics.** Families said that they trust doctors who specialize in DMD. They said that specialists are often more caring and understanding than other doctors. The doctors from the clinics have helped families deal with school and other problems.
- **Someone in the same situation.** Families said that it was very helpful to meet other families that have a son with DMD, especially those who speak Spanish. It is easier to talk to someone who knows what it is like to have a son with DMD. Families can also learn a lot from someone else’s experiences.

Problems:

- **Lack of information.** Families are frustrated with a lack of information. They need information about treatment options, causes of DMD, and what to expect in the course of the disease.

- **Difficult systems.** Families find that applying for services is too long and hard. Very personal questions are asked. Services take too long to get. Sometimes services are not good enough. For example, one mother was given a bed that was too narrow for her son to use.
- **Inequities.** Families said that different states give different services to families. School services also differ in different counties. Families also talked about inequities between racial groups. Families are frustrated with unfairness in the distribution of services. Richer families sometimes seem to get more services than poorer families. Differences are unfair and frustrating. Social injustice also causes frustration and anger. For example, they felt that the country seems to spend more money on the military than on health care for children with disabling conditions.
- **Issues related to Hispanics and/or immigrants.** Language is a problem for Spanish-speaking families. It is easier to try to get information and services speaking English. Parents who are undocumented residents have extra problems. For example, they may not be able to visit family in other countries. Service providers sometimes threaten to report them to the Immigration and Naturalization Service (INS). Parents who are undocumented may be afraid to apply for services.
- **Other illnesses.** Other illnesses happen in any family, including families with DMD. However, the added stress of a second illness in a parent or other family member is especially hard for DMD families.
- **Health care system problems.** Families said that several parts of the health care system cause problems. For some families, it took a long time to get their son's diagnosis. Different clinics may offer different treatments. It is hard to change from pediatric to

adult health care services.

- **Competing needs of family members.** Many mothers of children with DMD said that their care giving responsibilities made it hard to work outside of the home. One family said that a relative needed to change school systems to help take care of a family member with DMD. Also, family responsibilities often make it hard for caregivers to find time for support group and other activities. Parents expressed a need for help with the daily care of their sons with DMD, but their sons may have trouble trusting any physical care provided by someone else.

Potential Future Activities

- Continue to identify problems faced by Hispanic families with DMD including:
 - Problems faced by Hispanic families that do not receive care through the local muscular dystrophy clinic.
 - Problems faced by Hispanic families in different regions of the country.
 - Problems in common with English-speaking families.
 - Problems specific to Spanish-speaking families.
- Help to solve problems by building support systems for Hispanic families with DMD.
- Help provide information about DMD in Spanish.

We learned from the focus group that we need more research into problems that Hispanic families face in getting services for their children with DMD. Some of the problems described are specific to Hispanic families. Other problems are faced by all families of children with

DMD. This focus group was an important first step in understanding health care issues for Hispanic families with DMD.