

Recruiting Spanish-Speaking Families

Latino families tend to receive fewer services for their children with autism than other families. There also have not been many chances for Spanish-speaking families to take part in autism research.

Surveys from around the country show that there seems to be fewer reports of autism among Latinos than among other ethnic groups, but scientists do not know why that is so. SEED might give some answers.

The Colorado and California sites are looking for Spanish-speaking families to take part in SEED. There are many Latino families in both regions. The SEED scientists see this as a chance to learn more about autism among Latino families. It is also a chance for Spanish-speaking families to take part in autism research and learn how children with autism grow and develop. Currently, services for children with autism are less available for Spanish-speaking families than English speaking families. By taking part in autism research, Spanish-speaking parents can learn more about their children with autism and about services offered in their community.

Having Spanish-speaking families in SEED means that SEED staff members have to “go the extra mile” to help these families get through the study. It means bilingual staff members need to be involved all the way through the study and all materials have to be translated.

SEED staff members have to be sensitive to many things. They have to think about how Latino parents raise their children and about the roles of men and women in the family. They also have to be aware of what Latino parents might feel about the research. SEED Latino staff members can understand parents’ concerns. They can explain why taking part in this research is important and how it can help Spanish-speaking families with children who have autism. It does take extra time to involve Spanish-speaking families, but the scientists who lead the study know what they learn can give very important answers. And, this could mean that Latino children with autism will get better care and treatment in the future. To date, SEED has enrolled 112 families for whom Spanish is the primary language used at home.

4 Study to Explore Early Development (SEED) • Issue 3 • FALL 2010



California CADDRE

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SEED

STUDY TO EXPLORE EARLY DEVELOPMENT

SEED



Center for Autism and Developmental Disabilities Research and Epidemiology

SEED Spreads Its Roots

This spring the SEED staff at Kaiser Permanente Division of Research in Oakland, CA held a Community Advisory Board meeting. Members were particularly interested in how staff recruits Spanish-speaking families for the study and what it is like for these families to participate. They also had questions about how children develop a second language, including those with autism spectrum disorder (ASD).

The Board noted that many children learn a second language. Some learn English outside the home because they are children of immigrant families. Some children who speak English as their first language learn a second language in programs set up for that purpose. The Board agreed that some children have more trouble learning second languages than others. This is because of differences in the children's abilities and in the way the second languages are taught.

Committee members asked whether children with ASD, who have communication difficulties, have even more trouble learning a second language than those who don't. Staff talked about what is known from research. One of the Board members, Jane Schoenfeld, looked into these questions and shares her perspective.

Walk down the street in the San Francisco Bay area, and you can hear as many as five different languages. And that's just a short walk. According to the 2000 census, more than 300 different languages are spoken in the United States. So why limit your children to one language? Why not help them be bilingual?

Children who do not speak English at home have a head start. They have to learn English to function in this society. English-speaking parents know that it's good to have their children learn a second language. The American Council on the Teaching of Foreign Languages has noted that learning a second language helps children learn how language works, introduces them to other cultures and might make them more flexible thinkers. When the children are older, speaking two languages might even help them get a job.

Language learning is a long and complex process. It takes time to build a vocabulary and learn how to put sentences together. It takes more time to learn how to carry on a conversation or give a formal speech. And it might take a little longer for a child to learn two languages. Some parents wonder if learning a second language will confuse or delay the normal development of language. Researchers agree that learning two languages does not cause serious language delays. A Belgian researcher, Annick De Houwer concluded from her research that many children who grow up speaking two or more languages do not have language disorders.

But it might seem strange to hear young bilingual children speak. They might say things like "dame the fork" or "give me el tenedor." Perhaps they don't know the word for "fork" in their second language and they're using their first

FALL 2010, ISSUE 3

This is a semi-annual newsletter of the CDC-funded Study to Explore Early Development. The purpose of this newsletter is to inform the public of the study's progress. California SEED is a partnership between the Kaiser Permanente Division of Research Autism Research Program and the California Department of Public Health, www.autismresearch.kaiser.org.

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California SEED Takes Root in the Latino Community: Reflections from Valesca Santos, a Community Activist

Scientists are interested in involving Latino families in national studies on autism. What are your thoughts about this?

It's very important for Latino families to participate in research studies on autism because parents often lack the correct information. The study staff is Spanish speaking, so they can give information directly to parents about autism as well as information about their children. As a mother of a child on the autism spectrum, I never had information. I may have done things differently if I'd had information.

That's why I work with the Advisory Board. It gives me the opportunity to give information that exists now to other families.

What do you think Latino families need to know in order to decide to take part in a research study?

You need to meet families in groups. It's a way to get parents to volunteer. They may have received some information but when a staff member comes to a parent group, they can inform them directly and get them involved. They might think we'll be using them as guinea pigs, but you can explain how being in a study can help with their own child. They can talk it through so they can really see how it will help them and also how it can help the community. Updating families about research is also important, at events in the community, like Congreso Familiar. (note: Dr. Lisa Croen, Director of the Autism Research Program presented a workshop at Congreso Familiar in August).



Valesca Santos, mother of two children, and member of the SEED Community Advisory Board.

What should researchers know about Latino families as they work to recruit and engage families in research?

Parents don't know that much about research in general. They need to know what will happen with their child, what you will do to the child. You need to be specific: if you are taking blood or hair, explain why and how it will help. If you don't explain, they may feel you are taking part of their child. They need to know it's not their child's hair that will be explained in the study, but that it's information from the entire group of children that are discussed.

Parents are also concerned about privacy. It's very important that we have confidentiality - that it's not out in the community. You have to reassure them that information is protected because there's real fear that personal information will get out there. It's not just about immigration. There's concern of insurance companies having private information that could be used against them.

Parents are also not aware of benefits to participating. You should talk more about the evaluation, not just the specimens. It's a way for families to understand they have the opportunity to have an evaluation and meet with a psychologist and have that information available to them. Parents just think science takes from them, some small part of them, but the family needs to know they will learn a lot.

Latino families like direct contact. It needs to be more personal. For example, parents who are already in a study and have questions may hesitate calling the staff because they are shy, or because of cultural reasons, they may not want to bother people. But study staff should encourage them to call if they have any questions, any time, even if they have almost completed the study. Some parents are even surprised to receive an evaluation summary, and are then reluctant to call with their questions.

Research is just so important and it is so good for parents to be in a study. They learn more about their children, about services and activities for their children, and with information they can start to answer some of their questions. Some moms are not having vaccines, others are delaying, or just not doing them all at once. Parents get pressure in the community, should I give my kids vitamins? What treatments are effective? Research is so important because at some point, it will tell us what treatments are effective, and Latino families should be part of figuring that out. ■

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language to fill the gap. De Houwer has said that these substitutions mean that the children are socially aware. These children know their listener will understand them.

De Houwer and two American researchers, Kendall King and Lyn

Fogle, have also said that these types of substitutions mean that the children understand the words and how they fit in the sentence. In other words, the children have a good understanding of the structure of both of the languages they speak.

Now, what happens when children have autism? These children have problems with social awareness and language. Many people assume that learning a second language is difficult for such children. However, that might not be true. In 2000, Canadian

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researchers, Johanne Paradis, Elena Nicoladis and Fred Genessee, found that children who have problems speaking don't have any more problems learning two languages than they would have learning one. A researcher in California, Tamar Kremer-Sadlick, has found the same thing. There are doctors and speech therapists who advise parents who speak a language other than English to stop speaking their native language at home because they want the children to focus on learning English. But this advice might be harmful. Kremer-Sadlick has stated that it actually might limit the children's development. Parents can do a much better job of raising their children when they speak their native language.

Family ties are stronger when everyday conversations are in the parents' native language. The children also feel more secure. For example, a Latina parent had problems when her doctor told to speak only English to her 9-year-old daughter. The daughter had autism. "My English is not very good so our frustration was huge when we couldn't understand each other. As a result we became more distant from each other." Her relationship with her daughter improved when she decided to go back to speaking Spanish. "My daughter can understand both languages. I can read her favorite stories, and we can sing, play and learn together." The stories, songs, and games that come from a parent's native language can help a child feel more a part of his or her family and culture. The mother tongue is, after all, the language of the heart.

All young children can benefit from learning a second language. Learning two languages at the same time will not cause language problems or make language problems worse. Parents who choose to raise a child with another language will also instill an appreciation of other cultures and diversity. ■

Highlights of SEED Progress

SEED progress is being made at the steady pace that we planned. We are very pleased to have reached our enrollment goal by enrolling 2,765 families to date and will continue enrolling until we reach our goal of completing data collection with 70% of all SEED families.

We know that it is hard to get all the information we need from every family. We want to get all the questionnaires, visits, and samples from every family, but we know that some families won't be able to complete everything.

We hope you will be able to complete all of your items. If you are still working on any of the questionnaires or diaries, please make time to complete them and mail them back to us. If we have called you for an interview or to schedule a visit, please call us back. It is very important that we have all of your information. ■

Enrolled Families	2,765
Caregiver Interviews Done	2,151
*Cheek Cell Samples	1,960
Questionnaire Packets	3,911
Developmental Tests Done	1,808
Physical Examinations Done	1,641
Blood Samples	1,558
Diet Diary	1,033
Stool Diary	1,034
Complete Families	1,183

** As of July 13, 2010*

We had difficulty extracting DNA from some of the cheek swabs we received. You may receive a request to send us another set of swabs. If you receive a request, please send us another sample.

Data Collections Corner: HIPAA Medical Record Release

"HIPAA" is the Health Insurance Portability and Accountability Act of 1996. The law was passed to help people get health insurance and to protect their privacy. The requirements in HIPAA make sure that a person's health information is protected when she or he participates in medical research.

In SEED, the HIPAA medical release form is used so that families can give permission to SEED staff to get copies of their medical records. The medical records show the illnesses and medications a person has had. The medical records are the only place to get most of this information. SEED looks at the mother's medical records and the child's medical records. Getting permission to look at these

records is very important for SEED to be successful.

The HIPAA medical records release forms are in the green "Forms to Return" folder in the enrollment packet for biological mothers to complete. The medical records release form needs to be completed for certain medical providers that a mother visited during the 3 years before her child was born, as well as the health care providers that her child has seen. There is a checklist in the packet to help mothers remember all of the types of medical providers that she and her child might have seen.

If participants have questions, call 1-866-470-6115 and staff will help participants to complete these forms. ■