



Study to Explore Early Development (SEED)

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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 research.

Surveys from around the country show there is less autism among Latinos than other ethnic groups, but scientists do not know why. 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 in Latino families. It is also a chance for Spanish speaking families to be in research and learn about how children grow and develop. Services for children with autism are less available for Spanish speaking families. By taking part in research, parents can learn more about their children and about services in the community.

Having Spanish speaking families in SEED means that the staff has to "go an extra mile" to help these families

get through the study. It means bilingual staff needs 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 really help develop service options for Latino families. 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.

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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.

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INSIDE THIS ISSUE

Data Collections Corner	2
SEED Progress	2
Social Skills in Preschoolers with Autism	3
Recruiting Spanish-Speaking Families	4



SEED Spreads Its Roots

This spring the SEED staff at Kaiser Permanente Division of Research in Oakland, CA held a Community Advisory Board meeting. Board members talked about recruiting Spanish speaking families for the study and 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 three hundred different languages are spoken in the United States. So why limit your children to English? 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 teach their children a second language. The children learn how language works and may become more flexible thinkers. They also learn about other cultures. When the children are older, speaking two languages may even help them get a job.

Language learning is a long and complex process. It takes time to learn vocabulary and how to put sentences together. It takes

more time to learn how to carry on a conversation or give a formal speech. But researchers agree that learning two languages does not cause language delays. A Belgian researcher, Annick De Houwer, said that many children grow up speaking two or more languages and do not have language disorders.

But it may seem strange to hear young bilingual children speak. They 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 one to fill the gap. Researchers say these substitutions mean that the children are socially aware. These children know their listener will understand them. Researchers also say these substitutions mean that the children understand the words and how they fit in the sentence. These children have a good understanding of how language works.

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 them. But that may not be true. Researchers in Canada and the USA have found that children who have problems speaking don't have any more problems when they're learning two languages.

Many doctors and speech therapists advise parents to stop speaking their

(Continued on page 2)

SEED Spreads Its Roots (cont'd)

native language at home because they want the children to focus on learning English. However, Kremer-Sadlick, a researcher in California, says that it may 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. 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." Life improved when she decided to go back to Spanish. "My daughter can understand both languages. I can read her favorite stories, and we can sing, play and learn together." These stories, songs and games help the children feel part of their

family and their culture. The mother tongue is, after all, the language of the heart.

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. And children whose first language is not English should speak their native language at home. This will give them a better chance of succeeding in the English speaking world.

Data Collections Corner: HIPAA Medical Record Release

"HIPAA" refers to the Health Insurance Portability and Accountability Act of 1996. The law was passed to help people get health insurance and to protect their privacy. It is important for medical research.

In SEED, the HIPAA Medical Release Form allows families to give permission to SEED staff to get copies of medical records for children and their mothers. The medical records show the illnesses, medications and other

procedures a person has had. The medical records are the best place to get this information. 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. Biological mothers should complete the medical records release forms for all the medical providers she visited in the three years before her child was born.

A parent or guardian should complete forms for all of the health care providers the child has seen since birth. There is a checklist in the packet to help families remember all of the types of medical providers that the mother and child may have seen.

If you have questions, please call us, toll free, at 1-866-633-8003 and we can help you complete these forms. THANKS.

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 Swabs	1,960
Questionnaire Packets	3,911
Developmental Tests Done	1,808
Physical Exams Done	1,641
Blood Samples	1,558
Diet Diary	1,033
Stool Diary	1,034
Complete Families	1,183

* As of July 13, 2010

Social Skills in Preschoolers with Autism

One of the defining features of autism spectrum disorders (ASD) is difficulty with social interaction. As preschoolers, children with ASD often fail to develop the pretend play and conversational skills that their typically developing peers are gaining at the same time. Children with ASD are more likely to prefer to play alone and to play repetitively with toys and other objects, rather than engage in interactive make-believe play. They are also likely to have a difficult time talking to adults and other children, due to difficulty making eye contact and using language in social ways.

As part of their child's therapeutic team, parents can help their children improve their social interactions by playing with them. Pretend play gives children a more motivating opportunity to practice their language skills and helps them develop skills that will help them relate to their peers. Below are some suggestions for helping children with ASD expand their pretend play:

- o **Join your child on the floor and begin by playing next to him or her.** Take toys similar to the ones he/she is playing with and try imitating your child. If your child doesn't seem to notice, try gently interrupting his/her play. For example, if your child is rolling cars on the floor, try rolling a different car nearby. Have your car gently crash into your child's.
- o **Ask questions.** Have your child tell you what he/she is doing with the toys, and ask questions

about what is going to happen next. Try to give your child suggestions for story "ideas" to help him or her pretend. For example, if your child is lining up dinosaurs, ask if the dinosaurs are going on a trip. Are they going to the playground? To school?

- o **Model pretend play.** Show your child how to pretend. Pick a toy figure or animal and have it "talk" to your child or to the other toys. Use an animated voice and excited gestures to help draw your child in and show him/her how to create a story.
- o **Change it up.** If your child usually follows the same script in his/her play, try to gently insert new ideas. For example, if your child always has a birthday party for the teddy bear, try making it a different toy's birthday or introducing a new game at the "birthday party." If your child only plays with trains, try playing nearby with airplanes.
- o **Have fun!** Remember, ultimately the most important thing you can do for your child is to be there. So enjoy playing with your child in ways that are fun for him/her as well, while gently expanding his/her play skills. Just having fun time with you gives your child the chance to build new social skills.

Highlights of NC SEED Progress

471 of 2,765 (or 15.1%) of the total number of families enrolled in SEED have come from NC.

So far we have invited 3718 families, 471 have enrolled, and approximately 233 have finished their participation. Many families are still working through the multiple study steps and a few have needed to drop out. All study staff realize that families devote a lot of time to complete so many forms, interviews and assessments. We truly appreciate our North Carolina families who have given their time to support our research efforts.

Enrolled Families	471
Caregiver Interview done	380
Cheek Swabs (# of families)	378
Medical Records Releases (# of families)	338
Questionnaire Packet 1	318
Questionnaire Packet 2	304
Developmental Test done	315
Physical Exam done	319
Blood samples (# of families)	245
Diet/Stool Diary	224

*As of August 20, 2010

