Augmentative Communication News

INSIDE THIS ISSUE . . .

UPFRONT

This issue focuses on families and AAC. Someday someone will write a book. For now, that endeavor would be premature. Surprisingly, beyond a shared belief that families underlie the success of AAC users and of our practices in AAC, we don't really have much information. What do families of AAC users expect from AAC professionals? What is the impact on a family when someone has a severe communication impairment? What do families do that results in individuals establishing friendships, developing literacy skills, living independently and feeling good about themselves? What are effective ways to support AAC users and their families across the life span? How do the roles of family members (including individuals who use AAC) shift over time? What impact does technology have on communication dynamics within a family?

In addition to raising questions, this issue is designed to share some thoughts and to encourage AAC researchers, manufacturers, policy makers and service providers to address family matters more rigorously. **For Consumers** considers *what is* and *who is* a family. It also introduces the concept of *family* as a system. **Clinical News**

For Consumers
What is and who is a family?

Cultural, ethnic and religious groups define "family" differently. While it is true that family life is always enacted against a cultural backdrop, it is the family, not the cultural group, that is primary in people's lives. This, of course, is true for individuals who use AAC and those who support them. Why then aren't we studying families? Let's begin by considering two questions—what is and who is a family?

What is a family?
This definition captures the essence of the family.[2]

> Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. A family is a culture unto itself, with different values and unique ways of realizing its dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states, and nations.

There is an inherent vulnerability in the strength of families.[3]

> [They] are much like a house of cards. Each is supported by and depends on the other. When stress affects one card, the entire house may lean. And, sometimes the house falls.

Families are systems. A system is a "set or arrangement of things so related as to form a whole."[4] Many factors influence a family system: the ethnic and cultural background, the stage in the family life cycle, environmental events, external factors, individual relationships and
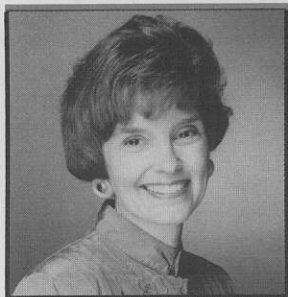
(UPFRONT cont. from page 1) gives practical suggestions for collaborating with families, and **Equipment** focuses specifically on the impact of assistive technology on the family. **Governmental** takes a look at the trend toward family-centered delivery systems. **University/ Research** summarizes discussions at ISAAC's 1994 Research Symposium. The **Resources** and **References** sections list people who helped me think about *families* and articles I read.

<u>ASHA CEUs</u>. If you signed up for 1994 ASHA Continuing Education credits, you should receive the CEU Test with this issue. Please complete and return it, together with the Participant Form and Cover Sheet, no later than January 31, 1995.

<u>ALLIANCE 95.</u> (*Outcomes in AAC*) Monterey, California, February 19-22. We're full; however, we are maintaining a waiting list. If you are interested in attending, you must let us know immediately. Participants from the U.S., Canada, England, Portugal, and Sweden will join speakers and facilitators (Susan Blockberger, Carol Cohen, Frank DeRuyter, Carol Frattali, Lewis Golinker, Mats Granlund, Penny Parnes, Michael Williams, David Yoder) in formulating a consensus about important outcomes to measure in AAC and ways to approach measurement. A publication on the *outcomes* of **Alliance 95** will be available to subscribers at a discounted price. One more thing. The first 1995 issues of both *ACN* and *Alternatively Speaking* will address *Outcomes*. If you have information that is interesting and important to share, <u>please</u> contact us very soon.

<u>HAPPY HOLIDAYS EVERYONE!</u> Already you may be feeling lighter, singing louder, laughing harder and eating more. There's the added stress, of course, and that dreaded shopping—which I was <u>not</u> born to do. All in all, however, I like the season and tradition of welcoming in a new year and bidding adieu to the one just past. For me 1994 was a year of growth, expansion, new experiences and magic. Now is a time to connect with friends, family and colleagues to share stories, thoughts and songs. So grab a cup of hot chocolate, a glass of wine or a mug of granny's grog and listen up. What follows are three of this year's favorite tidbits.[1]

- **#1** A business man needing to attend a conference in a faraway city decided to travel on country roads rather than the freeways so he could enjoy a relaxing journey. After some hours of traveling he realized he was hopelessly lost. Seeing a farmer tending his field on the side of the road, he stopped to ask for directions. "Can you tell me how far it is to Chicago?" he asked the farmer. "Well, I don't rightly know," the farmer replied. "Well, can you tell me how far it is to New York? the businessman questioned again. "Well, I don't rightly know," the farmer again replied. "Can you at least tell me the quickest way to the main road?" the exasperated businessman asked. "No, I don't rightly know," the farmer again answered. "You really don't know very much at all, do you?" blurted the impatient businessman. The farmer calmly replied, "No, but I ain't lost"

- **#2** To live fully, to love well, to find a wise and timeless understanding— all grow out of our capacity to experience and be present. A sign in a casino in Las Vegas puts it this way: **You Must Be Present to Win.**

- **#3** There are only two lasting bequests we can hope to give our children. One of these is roots, the other, wings.[1]

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For Consumers *(cont. from page 1)*

the personal and collective experiences of family members. Individuals in a family develop roles, rules to live by, communication patterns, ways to negotiate and solve problems and methods for completing tasks of daily living.[5] Families provide social support and sustenance. They share commitments and responsibilities. Beyond that, they are contexts for learning and growth and have a particularly decisive influence on the social and emotional development of young people.[6]

Who is a family?

A family is far more than a collection of individuals who share physical and psychological space.[3] Individuals traditionally enter a family system through birth, adoption or marriage. Entrance also occurs by invitation and agreement. The nature of each individual's involvement with the other and with the family collective exists along a continuum—somewhere between enmeshed with and disengaged from one another.[7]

Most roles we assume are family roles (infant, toddler, child, adolescent, sibling, adult living with parents, wife, husband, in-law, significant other, mother, father, uncle, aunt, grandparent, elder, and the infamous "black sheep.") Even roles external to the family (student, professional, boss, friend, lover, advocate, teacher, gang member) require characteristics and commitments similar to family roles.

Family systems

Family systems are dynamic. They are influenced by both external and internal factors. For example, world events affect the *what* and *who* of family systems. Consider the impact of technology. It has revolutionized communication, travel and access to

information. It is extending the life span of individuals. Technology is broadening our sense of the world community and expanding our concepts of what and who a family can be.

Dealing with stress

Virtually no family escapes stress. Stress is negatively associated with the well-being and integrity of families and the physical and mental health of individual family members. Stress may be defined as:[7]

> a particular relationship between individuals and their environment that is appraised by the person as taxing or exceeding his/her resources and endangering his/her well being.

Stressful events include birth, death, financial problems, moving, divorce, illness and dealing with a disability. Stress also can occur when external roles take precedence over family roles.

Despite our lack of systematic attention in AAC to family issues, other disciplines and areas of practice are carefully studying family dynamics, family systems, family stressors, dysfunctional family responses, positive coping behaviors and more. Within general conceptual frameworks of stress and coping, researchers are examining the adaptation of persons who have family members with disabilities.

Psychosocial theories of family systems, stress and stress reactions can provide the field of AAC with a partial framework within which to contemplate the needs of AAC families.[8-10] Professionals have been shown to be more effective collaborators when they understand family grieving, life-cycle issues and episodic loss reactions.[7] One model applied to disability issues is Kubler-Ross's five-stages of grieving.[11] She observed the process of coming to terms with death as a linear progression moving through denial, anger, bargaining, depression and finally acceptance. Family members of persons with disabilities report they experience similar stages, but out of order, several at a time, all at once or not at all.[3] Adjustment to a disability—particularly across the life span—is not a linear experience. Rather, it is episodic.

AAC families

When individuals have a severe communication impairment, everyone is affected. Frankly, it's hard to imagine a disability that is more likely to affect a family's dynamics, because communication and socialization underlie the development of meaningful relationships and the establishment of social networks.

We must learn more from families before we go too much further. First, we must learn to listen. Tables I and II highlight examples of real life issues. Both are snapshots. Both capture communication issues important to individual family members and the family system. Both make it clear why family dynamics can underlie (or undermine) the success of AAC approaches.

Table I. Snapshot A[12] (excerpted from an Exceptional Parent article, 1987).		
Mother	**Father**	**13 year old with C.P.**
"This magic device brought Kevin into the family. He became an active member and a participant in the things we were all doing." "He started junior high school in the fall and since then, things seem to have gone downhill for all of us. He and I have been involved in a strange fight. He either pounds out, 'It is none of your business or he won't answer at all.'" "My husband and I have not been able to talk about this. Right, now, I feel alone."	"I don't know what's happening to our family. Up until this fall, I thought we were a great family. My wife and son Kevin have received a lot of publicity and attention about a truly remarkable venture. "There's no question that my wife has had the major responsibility at home, but I have earned the money to make some of this possible." "Kevin has been telling me I've been expecting too much of him . . . he can't do it. I was taken aback." "My wife said if I had problems, I should start talking to the kids myself, instead of asking her to always be a spokesman for me.	"I am sorry I am such a burden to my mother and father right now. But, I have got to figure out what I can do on my own. The more I want to do things, the more my mother gets after me. . .How do you tell somebody you love to bug off?" "Everybody is looking at girls. In the school I came from, everybody knew me and they understood my voice synthesizer. Now I feel like a freak." "My father admires athletic kids. I'll never will be able to do those things. I'm stuck."

Table II. Snapshot B[13]

(prepared by Carole Krezman, 1994)

When Michael and I first got together, we assumed that love would make our relationship effortless. We very quickly found out that communication would not flow without some work. I would have a hard time understanding Michael, and my attention would begin to wander; or he would get frustrated or sense my frustration and give up communicating mid-thought. Later, I could tell when he was thinking about giving up; and my attention would wander knowing that he would probably give up soon. And so he would.

As we became more familiar with each other, the communication became worse. So we agreed on a rule: I would listen until he was done talking and I understood what he was saying. He would always finish what he had to say, making sure I understood his words. This rule served us well until I discovered I had married a night owl. We put an eleven P.M. curfew on our agreement. This worked well until we had children. Poop diapers take precedence over finishing just about any adult communication. We have learned to communicate (sometimes phrase by phrase) during lulls in the mayhem of childrearing.

Now we are working on teaching our children to follow this agreement. No saying "Ok," pretending to understand. No "Mom, what did he say?" Contrary to our expectations there was no understanding-dysarthric-speech or understanding-synthetic-speech gene passed on to our children. In our family communication doesn't come naturally, but we all know we will be heard; and we all agree we must talk until we are understood.

Clinical News
Collaboration & continuity

Families and professionals strive to develop partnerships and reach consensus on goals and objectives, but this does not always occur.[14] For example, studies have demonstrated that parents of children with disabilities often feel excluded from intervention decisions. Other studies comparing parent and professional values and priorities found significant differences in what each group regarded as valued services and outcomes. Three major frustrations parents expressed were: too many professionals, segmentation of a child based on disability labels, and fragmented service coordination.

> Without collaboration, *intervention* is at risk for being exactly as the dictionary defines it— *"interference of one person in the affairs of another."*[4] Clearly this is not the intent of the field of AAC

AAC is an area of practice that strives to enable individuals to access language and communicate in ways that allow them to participate in their families, schools, workplaces and communities. There is a widespread belief in the field of AAC that collaborative relationships yield better results. Without collaboration, *intervention* is at risk for being exactly as the dictionary defines it—"interference of one person in the affairs of another."[4] Clearly this is not the intent of the field of AAC

Note: David Yoder[15] is challenging our use of the term "intervention." Its Latin root ("inter" "venire") means "coming between." The dictionary's definition is even worse. Successful communication services don't come between or interfere.

If the term *intervention* is an inaccurate description of what we do, then what is a better term?

Checklist for practitioners

The following *Checklist for Practitioners* was compiled from the literature, presentations and interviews.[16-20] While far from comprehensive, it provides some basic strategies for improving collaboration, observations and interviews. If you answer "yes" to every question, you're doing better than I.

Note: Why is there always so much more to learn?

THE BASICS

1. Do you recognize your personal biases about ethnic groups, sexual orientations, family values and so on? Are you aware that your attitudes can be barriers that affect interactions with families?

2. Do you always keep in mind that the AAC user's needs are interdependent with those of other family members?

3. Do you treat each family as unique?

4. Do you always respect parents' desire to be trusted as authorities on their children?

5. Do you always listen carefully to the interpretations, priorities, expectations and preferences of parents, spouses and other family members?

6. Do you recognize and respect that sometimes issues of survival take precedence over educational/clinical concerns?

7. Do you appreciate a family's need for stability and continuity in AAC services? Do you provide this?

8. Do you appreciate that a family is deciding whether (or not) to trust you?

9. Every family has a schedule. Do you work around that schedule?

10. When you go into a home, do you take the clinic with you? Or, do you leave it behind and use materials and situations that occur naturally? [Note: communication isn't a tutorial. It's a part of living.]

11. Do you always include family members in discussions about changes that will have an impact on the family?

12. Are you always honest with the family? When you don't know, do you admit it?

DO YOU OBSERVE?

1. What roles family members play? Information provider, active participant, advocate, communication partner and planner.

2. In the home. Who greets you? Who participates? Who lives there? Who are the primary and secondary caregivers? Where are you asked to sit? Where does everyone else sit? Are AAC users expected to participate and communicate? Do they?

3. In the clinic. Who comes to the sessions? Where do family members sit? Who sits next to the AAC user? Who answers your questions?

4. What questions do family members ask?

DO YOU ASK?

1. Where the family prefers to meet with you?

2. How far in the future they wish to plan?

3. What the family's long and short term expectations are?

4. Who the main family members are? What role does each play? Are all influential family members participating?

5. Who the AAC user wants to include?

6. How each participant would describe the family member who uses AAC 5 years from now?

7. How each family member would describe his/her role with the AAC user 5 years from now?

USING LANGUAGE

1. Are you aware of differences in communication styles? Do you have ways of determining if a family prefers a more formal or informal approach?

2. Do you avoid using technical jargon?

3. Do you hire competent bilingual and bicultural interpreters when they are needed?

4. Do you always sample the language use of siblings and peers?

5. Do you ask families to help you select symbols to represent vocabulary on displays/devices?

6. Do you include families in vocabulary inventories and in the selection of AAC devices?

Our challenge

In 1985 Cohen[21] described the need in AAC for a lifelong management approach. While professionals come and go, only the AAC user and his/her supporters (often the family) are in-volved for the duration. Thus, while professionals have an important role to play in assisting families, it may be their ability to strengthen informal social networks that is most important.[5,20]
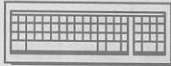
Equipment

AAC devices: Impact on families

Perhaps more than any other type of assistive technology, AAC devices necessitate the active participation of family members—starting with assessment and continuing through the prescription, training and day-to-day use of the device. After all, it often is the family that has to charge the battery, set up the device, program it and deal with breakdowns. In addition, families must manage the plethora of professionals who are intensely involved at one moment and then all but disappear the next.

"The wrong kind of technology service may not only fail to enhance a family's functioning, but can actually be a drain on family energy."[22] Investigators have documented that when assistive technology is involved, some families choose against it in favor of what they perceive as a reasonable quality of life for their family. In some cases AAC devices may be disruptive to family functioning, which can have an adverse affect on the individual using the device. Stressors include: 1) adding to a family's routines, 2) restricting family activities, 3) money issues, 4) interpersonal clashes and 5) other life style changes.

A recent survey conducted in the U.S. explores the degree of family participation in AAC assessment and prescriptive prac-tices with children from birth to 3 years of age. Researchers sent surveys to 50 states funded under P.L. 100-407 (the Tech Act). Results, based on a response rate of 80% (40 surveys), include the following observations:[22]

- Most states now provide a range of AAC services—purchasing or leasing AAC devices (67%), customizing and adapting devices (78%), training for children (81%), for families (81%), and for others (68%) and coordinating services (80%). Only 48% repaired devices.
- Although many states consider family issues (which are mandated for this age group), they do so to a lesser extent than they consider more traditional factors such as the child, technology and service system characteristics.
- All (98%) consider family preferences in the assessment process.
- Many (67%) said families play a central role in the evaluation process. Some (26%) said they did not know if families participated prior to developing Individualized Family Service Plans (IFSP).
- Family involvement varied markedly across facilities.
- Sixty-eight percent (68%) said devices changed the family routine.
- Family issues less often considered were: additional child care responsibilities, restrictions in family activities, modifications in the home, ability of the family to cope with stress, the extent to which family needs were balanced with existing resources, financial resources, and availability of personnel and community resources for training and maintenance.
- Only 58% said they were able to measure a family's satisfaction with devices and services.

- Family members are frequently overwhelmed by technology.

The authors concluded that AAC devices impact families in 3 primary ways: 1) They increase a family's time commitments and stress, 2) they change family routines and 3) they alter family interactions patterns.

Another recently published study addresses continuity in the development of AAC systems (devices, symbols, accessing techniques) with school-aged children. Although family issues were not directly mentioned in the study, the family's role in delivering continuous services can not be overlooked. Smith-Lewis[23] found professionals in AAC do not always make continuous decisions regarding changing from one device or symbol set/system to another. A discontinuous evolution in the development of AAC systems may be linked to staff changes. To maintain continuity, family involvement may be key. Smith-Lewis also recommended matching students with knowledgeable staff who remain consistently involved over time and inservice training for those working with students who use AAC systems.

Surely we need to consider family factors very carefully before prescribing AAC devices. We need ways of evaluating their impact on family systems and individual family members following the introduction of technology, and at regular periods thereafter.

Governmental
Being family-centered in AAC

"Caregiving families provide a precious national resource. As such, they require nurturing and protecting for purposes of conservation."[24]

Historically, and particularly since the advent of deinstitutionalization, families have been a primary source of caregiving for most individuals with severe disabilities. Yet, efforts to support families are relatively new in most areas of the world and often represent only a small proportion of the public resources spent on individuals with severe disabilities. Family-centered approaches emphasize[20,25]:

- a focus on the capacity, not the dysfunction, of a family.
- a culturally sensitive and respectful way of understanding the world view of the individual with a disability and his/her supporters.
- services that are provided within the context of the values and priorities of the family.

Although the autonomy of AAC users must be respected, the characteristics of a family-centered approach are well-suited to AAC delivery systems. Such practices are encouraged with young children and con-sidered desirable for people who are aging or ill (particularly those nearing death). However, they are not prevalent in educational or medical systems, which are oriented to the individual—children, after all, need to progress in school, and patients need to get better.

Everyone agrees that positive family involvement is desirable, indeed necessary, in the area of AAC. Even so, few resources are available to support family involvement. Professionals in AAC receive minimal, if any, training in family systems theory, conflict resolution, role definition, family-centered planning and team process techniques. Even fewer parents and other family members are offered such training. This remains true despite research findings that:[14, 20]

- role preparation is significantly correlated with outcome.
- training improves parents' participation in decision making and
- a statistical relationship exists between providers' perceptions of clear goals and the degree of goal attainment with mentally handicapped children.

Programs receiving government funding should find ways to broaden the use of family-centered approaches in the delivery of AAC services across settings.

University & Research
The missing research agenda

When I discovered the *Journal of Augmentative and Alternative Communication (AAC)* contained no articles with the key words "siblings" or "parents" and only one article with the key word "family" since 1985, I was shocked. When a similar review of research articles related to family, parents and siblings in ASHA and TASH publications over the past few years revealed none specifically dealing with family issues in AAC, I was dismayed.

The importance of families in AAC is widely acknowledged. Books, newsletters, and articles written by AAC users, family members and professionals document it. AAC mission statements and our day-to-day experiences give testimony to it. Interaction, language and literacy development research in AAC often includes in-formation about parents (typically mothers) but really does not focus on family issues. For example:

- In a longitudinal study of children with motor disabilities, Bjork found some parents had difficulty giving their children communicative space, *i.e.*, pausing. She concluded that it is important to train care providers to wait for responses.[25]
- In a survey of home literacy experiences of preschoolers, Light & McNaughton discovered that physically disabled children with AAC systems enter school programs with literacy backgrounds quantitatively and qualitatively different from those of their nondisabled peers. Differences were in their language experiences and cultural contexts.[26]

Families have a critical impact on the success of AAC practices:[27]

- Family members are primary communication partners.
- Families have social, cultural and economic realities that are likely to have an impact on everything we do.
- Having a family member with a severe communication impairment places stress on other family members.

- Successful AAC users always have strong, committed people—often their mothers—supporting them.

Why then, haven't we had a research agenda that addresses family issues in AAC?

At the 1994 ISAAC Research Symposium in The Netherlands, we focused on "Family involvement in the AAC intervention process." Carmen Basil, from Spain and Michael Williams and I were asked to present papers. Margriet Heim of the Netherlands led the discussions of approximately 20 participants from more than 10 countries. Major research areas discussed were:[28]

- What actually occurs in the families of AAC users?
- How do these characteristics relate to existing socio-interactive theories?
- How can we assess family life?
- How can we create language supportive environments?
- How can we assess the results of intervention in family environments?

University/Research *(cont. from page 6)*

Participants discussed several issues researchers should keep in mind: 1) To date, the focus has remained on children, particularly those with congenital disabilities. Our information base needs to be extended to include families of adults with disabilities and those with acquired conditions. 2) Information is available outside the field that should be reviewed carefully so as to avoid reinventing the wheel (particularly a broken one). 3) Both quantitative and qualitative approaches to measurement should be employed. 4) Research questions tend to represent only one perspective, the professionals'. Research questions should be developed that, when answered, will be of interest and value to families and AAC users. Some examples of questions that might be of interest to each group are delineated below:[27]

■ **Professionals:** Is there a theoretical framework to help us think about family systems in AAC? Do family-centered service delivery models operate effectively in AAC? How do they vary across settings? cultures? ages? types of disability? What do families perceive as helpful/not helpful about the AAC intervention process. Do professionals address the real needs of family members or things the professionals perceive as important?

■ **Families:** What barriers do families experience? What questions should families ask AAC professionals? AAC users? How do families prefer to receive information? What are the financial ramifications of AAC services over time? How do families know when AAC services are not working? What are the best ways to prioritize what needs to be done— self esteem, education, device training, friendships, employment?

■ **AAC users:** How do AAC user's assert their communication styles at home? How do AAC users and the services they get affect siblings? parents? spouses? What can the AAC user do to fit external caregivers into the family dynamics? What can AAC users do to enhance their participation in family life?

Table III. summarizes the symposium group's efforts toward developing a research agenda. The chart attempts to capture the research questions generated by participants during their discussions. Clearly, we need to know more, much more, about the role of the family in the lives of AAC users and in the establishment of "best practices" in our field.

Before leaving, participants at the session agreed to petition ISAAC's 4th Research Symposium committee to reconvene our discussions in the summer of 1996 in Vancouver, Canada.

Table III. Impact of AAC on family systems across the life span: An ISAAC research agenda			
Research topic areas	**User perspectives** (congenital/acquired) (all age groups)	**Family perspectives** congenital/acquired (all age groups)	**Professional perspectives** congenital/acquired (all age groups)
Socio-interactive theory	What do adults/children with acquired/developmental disabilities do? How do they do it? How do users perceive themselves, professionals and families? Is there a consensus among groups in their perceptions?	What do families do for and with AAC users? with AAC devices? How do they do it? How do families perceive themselves, users and professionals? Is there a consensus among groups in their perceptions?	What do professionals do? How do they do it? How do professionals perceive themselves, users and families? Is there a consensus among groups in their perceptions?
Assessment of family life	How do users perceive family life? What suggestions do users have for families?	What are adaptation strategies used before, during and after AAC intervention? How do families adapt to situation? to communication? What are families willing to do? How do they adapt to professionals?	How do professionals assess family life? What questions do they ask?
Language supportive environments	Can users do things to improve their literacy skills? What are the effects of keeping a diary?	What are major issues families face across the life span?	What are families doing to establish/maintain friendships? What do professionals think is necessary? Are families able to do this?
Outcomes of AAC services and approaches	How do users' perceptions of professionals affect outcome? What is the contribution of different factors to outcome? What are the relationships between different kinds of outcomes?	How do families' perceptions of professionals affect outcome? What is the contribution of different factors to outcomes? What are the relationships between different kinds of outcomes?	How do professionals' perceptions of themselves affect outcome? What is the contribution of different factors to outcome? What are the relationships between different kinds of outcomes?
Potential measurement techniques	Perceived self advocacy Focus groups Needs surveys.	Perceived support How parents solve problems Observation, questionnaires, rating scales, interviews.	Needs survey Language development data Longitudinal data, observations of interactions.

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