

Upfront



*This issue shines the spotlight on **Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners (SN)**.¹ SN is a new assessment tool designed to help practitioners to collaborate with people who have complex communication needs and their family members in setting realistic communication goals, planning specific interventions and tracking progress over time. SN can also help researchers answer specific questions about the impact of AAC interventions on people with severe communication impairments.*

SN uses a structured interview format to address a variety of factors involved in communication and can lead to interventions that enable people with severe communication impairments to communicate more effectively, in ways that matter MOST to them and to their primary communication partners.

I asked David R. Beukelman, Professor of Communication Disorders at the University of Nebraska-Lincoln, to comment on the practical relevance of the SN approach. His response follows:

A high quality of life presupposes extensive positive interactions within one's social milieu.² Social networks change across our life span. During the preschool years, networks include members of our families, family friends, caregivers, and perhaps, health care workers. During elementary, secondary, and college years, our social networks expand to include classmates, teachers,

personal friends, neighbors, and people in the community. In adulthood, people from our jobs, as well as people from our volunteer, recreational, professional, and community experiences are added to our networks. Late in life our networks again undergo extensive change as a result of retirement, the emancipation of our children, expanded volunteerism, changes in residence, death of family members and friends, health concerns, and so on.

At each stage, we attempt to remain resilient by countering the changes, threats and risks we face, using the supports and protections that emerge from a range of personal and social factors. To a considerable extent, our social networks assist us to develop and sustain these protections and supports.

Persons with chronic disabilities face unique threats and challenges; and they need robust social networks to support

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Social Networks: What is it? Why use it?

Social Networks (SN) offers a way to gather and organize important information from family members, from professionals and other paid workers, and from individuals with complex communication needs. *SN* is not a standardized test. Information is obtained during interviews that are conducted according to specific instructions provided in the *SN Manual*. *SN* can assist AAC teams in their assessment and intervention planning processes and can help measure progress over time.

SN injects several paradigms and theoretical frameworks into the intervention process. By highlighting the family's role in successful communication interventions, *SN* helps focus the attention of professionals on the distinctive needs, priorities and preferences of the people who are the "end users" of AAC strategies and their family members. Importantly, *SN* helps to clarify the distinctions between an individual's various communication partners and the particular strategies used to communicate with each. It also captures the multimodal nature of communication, enabling practitioners to collect information about the use of various modes of communication across contexts, activities

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and partners in a way that is both more systematic and more helpful than available alternatives.

By defining three clear stages of communicative competence along the road to “communicative independence,” *SN* helps clarify a person’s “intervention path” in the same way a map helps people plan a route from one place to another. By incorporating features of Light’s model of communicative competence and Beukelman and Mirenda’s participation model, *SN* can help clinicians pinpoint specific areas that require skill development, as well as identify barriers and opportunities across a person’s social

networks. *Social Networks* can also play a valuable role in illuminating distinct sociocultural contexts.

As a person-centered planning tool, *SN* links the assessment and planning processes to the outcomes sought by individuals with complex communication needs and their families. *SN* can also heighten awareness of the multidimensional challenges in AAC interventions and help practitioners better understand the similarities and differences among the populations and across the age groups of people who benefit from AAC.

Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and

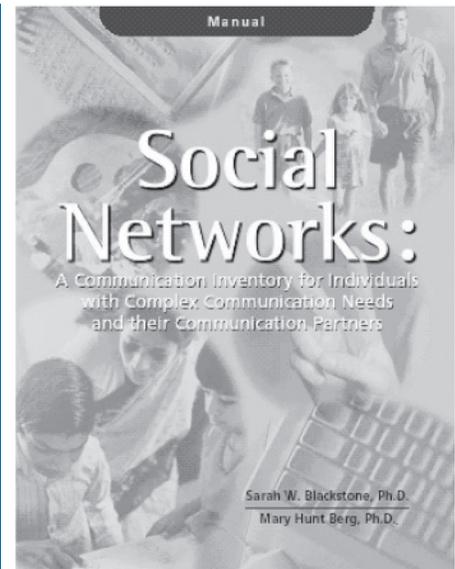


Figure 1. Cover of the *SN Manual*

their Communication Partners includes a manual and an inventory booklet.

The *SN Manual*

The *SN Manual* (Figure 1) has 51 pages, five chapters and an Appendix, as described below.

I. Concepts. The rationale for *Social Networks* and the theoretical frameworks underlying it.

II. Inventory Booklet Instructions. Detailed instructions for administering the *Social Networks Inventory*.

III. Circles of Communication Partners Orientation Forms. Forms that can be copied, laminated and used when giving the *Social Networks Inventory*.

IV. Case Examples. Seven case examples. Each illustrates the assessment process and shows how *SN* can help a team establish clinical goals, facilitate intervention planning and build team consensus.

V. Pilot Studies. A summary of results from four research studies conducted as part of the development of *SN*.

Appendices: (1) A resource list to assist with communication partner training and (2) a sample informed consent form for researchers and clinicians.

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them so they can remain resilient and experience a high quality of life. For persons with severe communication disabilities, the tasks of developing and sustaining social networks can be daunting.

Augmentative and alternative communication (AAC) strategies have been developed to support the interactions of persons with complex communication needs. Technological developments, funding support, and intervention services have evolved over the past 30 years. This progress is encouraging. However, the acquisition of appropriate AAC technology and the development of technical competence do not automatically result in fully developed social networks. Rather, careful collaboration among persons who use AAC, their communication partners, and those who assist them is required. Unfortunately, efforts to develop and maintain social networks are often informal and disorganized.

Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and Their Communication Partners provides the AAC field with tools to assess, develop, and sustain social networks. Blackstone, Hunt Berg and their colleagues have designed *Social Networks* such that it addresses the concerns of persons across the age span with a range of different communication need profiles.³

SN offers clinicians and researchers a way to collect information more systematically and more easily, using a structured interview format. Clinical News gives an overview of SN. The CCP paradigm, Modes of communication and Types of communication describe three of the major paradigms incorporated into SN. The SN Inventory gives a summary of the tool; and Case Examples illustrates its clinical uses. Finally, this issue highlights the roles people who rely on AAC play in the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC.)

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The *SN Inventory Booklet*

The *SN Inventory Booklet* has 27 pages and is used to record information during each interview. The interviewer, typically a speech-language pathologist, gives the *SN Inventory* over one or more sessions to two or three informants: (1) a family member, (2) a paid worker who is familiar with the individual's daily communication experiences and (3) whenever possible, the individual with complex communication needs. [When this occurs, it may be unnecessary to interview others.]

Interviews may be conducted as part of a collaborative process or with each individual separately. Interviewers may elect to omit a section or change the order in which sections are administered. However, such decisions are made in advance; and the rationale for omitting sections is stated and understood.

Why use *Social Networks*?

SN is already being used in clinical practice, for teaching graduate students and to conduct research with (1) children with cerebral palsy; (2) children who are deaf with concomitant problems, *e.g.*, visual impairment, autism, motor and developmental delays; (3) children who use AAC and are mainstreamed in regular schools and (4) adults with aphasia.

We asked several people to comment on their utilization of prototype versions of *SN*. Thanks to Carmen Basil from Spain, Lena Thunstrom from Sweden, Hilary Johnson from Australia, Elisa Kingsbury, Chris Toomey, Mary Hunt Berg, Liz Hanson and Gloria Soto from the U.S. for their responses, which are summarized below.

[Note: Carmen Basil, a professor from Barcelona University is translating *SN* into Catalan (the language used in all the ordinary schools in Catalonia) and Castilian Spanish.

Lena Thunstrom, a researcher from the Swedish Institute for Special Education, has translated *SN* into Swedish.]

Research questions. Researchers are using *SN* to help answer several questions. Lena Thunstrom from the Swedish Institute for Special Education is asking:

What is the daily communication situation for children who are deaf or hard-of-hearing and have additional disabilities?

What modes of expression do these children use?

How do the circles of communication partners look for these children?

What contextual factors must be in place for these children to communicate effectively?

Is *SN* a useful assessment and intervention planning tool for children who are deaf or hard-of-hearing and multiply handicapped?⁴

Carmen Basil from the University of Barcelona is using *SN* as one of her assessment tools in two research projects. The first project studies Catalan children between 5 and 18 years of age who are AAC users and mainstreamed in ordinary schools. Her questions include:

What AAC systems are being used?

What are features of the educational services being provided?

What are the communication outcomes, for social and academic purposes, of these children?

What are the possible relationships among the different variables being measured?

Her second research project focuses on adults with aphasia. She is using *SN* as a pre/post intervention assessment measure, and as a means for establishing intervention goals for each participant.⁵

Mary Hunt Berg, who directs The Bridge School's research program, is conducting longitudinal studies with a range of students with severe speech and physical impairments.⁶

A retrospective study is measuring former Bridge School students' long-term outcomes. A prospective study is tracking current student progress over time. Elisa Kingsbury⁷ and Chris Toomey⁸ at the Bridge School are administering *SN* to students (current and former) and their family members.

Clinical applications. Hilary Johnson from the Spastic Society of Victoria in Australia is doing person-centered planning with a number of people with complex communication needs who are just entering the community from residential environments. She thinks *SN* may assist staff who support these individuals to find better ways to meet each person's needs. *SN* may also help reveal how staff perceive each person's use of communication strategies, and how their perceptions might influence the use of these strategies.⁹

Liz Hanson from the University of Nebraska reports that *SN* can provide clinicians with a systematic approach to documenting and describing the communication modes and strategies people with complex communication needs use across all environments. She writes, "*SN* offers a way to study the efficacy of an intervention and provide ecological validation." Liz believes that *SN* may be especially helpful to clinicians without much experience and can also provide a valuable framework that seasoned clinicians can use to organize their evaluations:

The "circle" procedure, which allows the clinician to identify and document the range of communication partners in a person's life, is important and helpful. It's been an eye-opening experience for many of our team members and may lead to a more balanced approach to service provision (*e.g.*, focusing on providing opportunities for contact with people in empty circles.)¹⁰

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Bridge School staff are using *SN* for student assessment and specific intervention planning. Elisa Kingsbury recounts:

During the current school year, *SN* was administered to all current students in order to systematically document skill levels, communication modes, topics, partners and strategies that support interaction with multiple partners. Perspectives from both home and school are being documented.⁷

Personnel preparation programs. Professor Gloria Soto of San Francisco State University reports that she uses *SN* to help graduate students gain practical insights into a number of critical AAC issues, including:

Observing the multi-modal nature of AAC and how the AAC user may choose to use one mode over another, depending on the situational context and the intimacy shared with the interlocutor.

Gaining appreciation for the value of low-tech and unaided AAC options as equally valid tools and making a commitment to provide clients with a wide range of communication options.

Deepening the students' understanding of the social isolation many people experience as a result of their communication challenges.

Deepening the students' understanding of the relationship between social closeness and quality of life.

Giving students a clearer picture of differences in social participation depending on the user's age, educational/vocational placement, etiology, onset of disability, and cultural background.

Reinforcing the importance of including the family and significant others as critical members of the intervention team.¹¹

Benefits of using *SN*

Based on their experiences, these professionals provided an overview of some of the benefits of *SN* for family members, paid workers and individuals with

complex communication needs themselves. [See Table I.]

In addition, they made comments about the interview process with each group of informants.

Family members (1st circle). Elisa Kingsbury, Chris Toomey and Mary Hunt Berg are using *SN* to interview parents of both current and former students. Elisa is interviewing parents of students, ages 3 to 12, with a diagnosis of cerebral palsy. She noted:

One mom said, "*SN* gave a good baseline of my child's abilities. I like the idea of using *SN* to compare situations over time."

Another mother felt *SN* was "useful" and compared it to standardized tests, which were "not very useful or valid."

A grandmother felt the interview process was a great way of "building a partnership between professionals and caregivers."

One mother said she liked the modes and strategies sections because they got at the "subtleties of my child's communication." However, she did not like being asked about her child's skills and abilities, because she felt it focused on her child's deficits.

Another mom called *SN* a "legacy." She said it captured so much information that she wanted it for her child's bio-book. "Traditional baby books don't reflect what children with cerebral palsy learn to do."

While one parent liked the topics section because it pointed out her child's "real needs for intervention," another felt it "showed I don't know what my child wants to talk about because he can't speak."

Elisa also reported that family members seemed to enjoy the interview process.⁷

Chris Toomey, who is interviewing family members of former Bridge School students (now 12 to 25 years old) as part of a retrospective research study, reported:

Parents of older children/young adults thought identifying people in the circles was an interesting learning experience and enjoyed the process.

Many had difficulty identifying who best understood a certain mode of expression. It became clear, however, that the intelligibility and effectiveness of a mode was often dependent upon the familiarity of the partner.

One parent commented that questions about strategies supporting interaction were particularly helpful, and she hoped to use the information to train new attendants and team members.

Several said identifying topics a family member would like to talk about was challenging. One mother said, "It gave me a bigger picture of how many of my daughter's topics are centered around family issues. She really doesn't have many topics she can talk about with people in other circles."⁸

In her research, Lena Thunstam, who is interviewing parents of children who are deaf or hard-of-hearing, as well as autistic, visually impaired and/or motor impaired, reported:

Several (parents) believed the interviews might lead to improving the communication situations of their children.

Parents had difficulty answering some of the questions, but didn't find the interview process threatening.⁴

Paid workers (4th circle). Kingsbury and Toomey said people in this circle were interested in *SN* and were looking forward to using it themselves.^{7,8} Thunstam reported paid workers had reactions quite similar to the parents she interviewed.

An assistant thought the interview was exciting and that it was "good to sit and discuss what I do."

A preschool teacher said *SN* gave her a way to look at things more holistically and from the view of both the preschool situation and the family.

The keeper at the boarding house said *SN* information must be summarized so as to be easily understood and not too theoretical.⁴

Individuals who rely on AAC. During the development of *SN* we sought input from several individuals who rely on AAC. In addition, we

Table I. Perceived benefits of Social Networks as reported by family members, paid workers and persons with complex communication needs

	FAMILY MEMBERS	PAID WORKERS	PEOPLE with COMPLEX COMMUNICATION NEEDS
Lena Thunstam Sweden	<ul style="list-style-type: none"> * Broadens knowledge about the communication situation for their child when he/she is not at home. * Promotes understanding of the "thinking" and methods of professionals. 	<ul style="list-style-type: none"> * Helps professionals ask questions in a neutral way, so person being interviewed doesn't feel "interrogated." * Reminds people about aspects of intervention they might otherwise forget. 	<ul style="list-style-type: none"> * Helps focus on what is important. * Helps lead to a joint understanding about problems, goals, methods and interventions through consensus. * May change attitudes about communication.
Carmen Basil Spain	<ul style="list-style-type: none"> * Enables families to communicate better with professionals and make their true needs and wishes known. * Ensures active participation of family members in the assessment process. * Encourages establishment of cooperative goals. 	<ul style="list-style-type: none"> * Helps professionals distinguish between clinical results (often our most common focus) and the effects (social impact) of the intervention. * Moves the focus of our interventions toward their social impact. 	<ul style="list-style-type: none"> * Helps person to make his/her wishes clear. * Enables person to participate fully in the planning and goal setting processes. * Increases likelihood clinical goals will have social validity.
Hilary Johnson Australia	<ul style="list-style-type: none"> * Includes the person, family members and significant others in the assessment and intervention process. 	<ul style="list-style-type: none"> * Provides way of looking at change over time. 	<ul style="list-style-type: none"> * Assists people to consider communication partners in their life. * Helps people understand AAC intervention is not just about getting a new communication system, but about finding and communicating with others.
Liz Hanson USA	<ul style="list-style-type: none"> * Reminds families their loved one has many potential communication partners; and it is important to provide a balance. * Enables family members to see individuals may need more than the family and paid staff for rich social interaction. 	<ul style="list-style-type: none"> * Provides a useful framework for identifying and describing a person's communication modes/strategies. * Helps identify goals that focus on expanding communication partners. * Removes didactic burden from professional. Role is not to "tell" person/family what to do. 	<ul style="list-style-type: none"> * Yields a complete picture of person's communication strengths as well as areas within which to foster interaction and expand communication partners. * Allows communication strengths to be "discovered" that might otherwise not be identified, so they can be incorporated into treatment plans.
Elisa Kingsbury and Chris Toomey USA	<ul style="list-style-type: none"> * Allows families to share lots of information and ask questions in a comfortable (no one got upset) format. * Helps families see that all communication modes are important. * Validates the ways in which families interact with their loved ones. * May help focus intervention on developing modes that work and are valued, along with the use of technology for specific purposes. * Gives family ways to look at whom a child communicates with and how. * Helps family better understand all the strategies they use. * Illustrates the need to use different tools/strategies in different situations. 	<ul style="list-style-type: none"> * Allows professional to build a relationship with parent. * Enables professional to conduct meaningful, comprehensive interviews. * Raises awareness about importance of all communication modes. * Identifies how partners support expression/comprehension. * Helps SLPs focus on partner training issues across circles. * Gathers baseline information that can assist in educational planning. * Expedites process of getting to know person and how he/she interact with others. 	<ul style="list-style-type: none"> * May result in more complete intervention across the lifespan. * Validates focus on all modes, rather than speech/articulation or an AAC device. * Helps ensure intervention will add value to individual's 'real life.' * May lead to more integrative strategies across environments, rather than having one approach at home and another at school. * Enables individuals to better understand rationale for using certain tools and techniques in different situations, with different partners. * Helps to identify primary partners and reasons for those choices. * Encourages person to assume specific responsibility for partner training.

learned that children and adults who can spell or have access to large vocabularies can easily participate in interviews and complete sections of the *SN Inventory*. Some individuals with more limited communication skills also can participate actively. For example, Elisa Kingsbury described a young boy who indicated whether each of his assistive technologies were "helpful" or "not helpful." He also filled out his own Circles of Communication Partners (CCP) by pointing to

pictures/names of people and then to the appropriate circle.

Summary

Each person's social networks reflect who they are and create the contexts within which they live among their fellow human beings.¹² Communication skills are essential to establishing and maintaining social networks, and, needless to say, social networks play a defining role in one's quality of life.

Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners is an assessment and intervention planning instrument that can help guide people with complex communication needs, across age spans and disability groups, to access the communication approaches they need to interact effectively with people in their social networks. 

The CCP Paradigm



Circles of Communication Partners (CCP)

In 1991, Blackstone proposed adapting Circles of Friends¹³ (developed by Forest, Snow and others) to the area of AAC to help bring into focus the role communication partners play in the AAC intervention process. The resulting paradigm, Circles of Communication Partners (CCP), singles out important interactants, identifies stronger and weaker circles of communication, shows partners who could benefit from training, facilitates a person-centered planning approach and more.^{1,14,15}

[Note: Circles of Friends consists of four concentric circles: Circle #1 represents family members; Circle #2, friends; Circle #3, acquaintances; and Circle #4, paid professionals. It is extensively used to promote inclusion in classrooms.¹³]

The Circles of Communication Partners (CCP) paradigm consists of five concentric circles, with the person with complex communication needs at the center, as shown in Figure 2.

FIRST CIRCLE: The person's life-long communication partners. The first circle includes family members and others with whom an individual resides or is related. For children, these are typically parents/guardians and siblings. For older individuals, "family" may mean a parent, spouse and/or children, as well as a domestic partner or the residents in a group home.

SECOND CIRCLE: Close friends/relatives. The second circle represents individuals with whom someone spends leisure time, shares mutual interests, plays and confides. Children's second circles often include friends from their neighborhood, schoolmates and relatives who live nearby. Adults' second circles incorporate relatives, people they enjoy spending time with, as well as friends from their past with

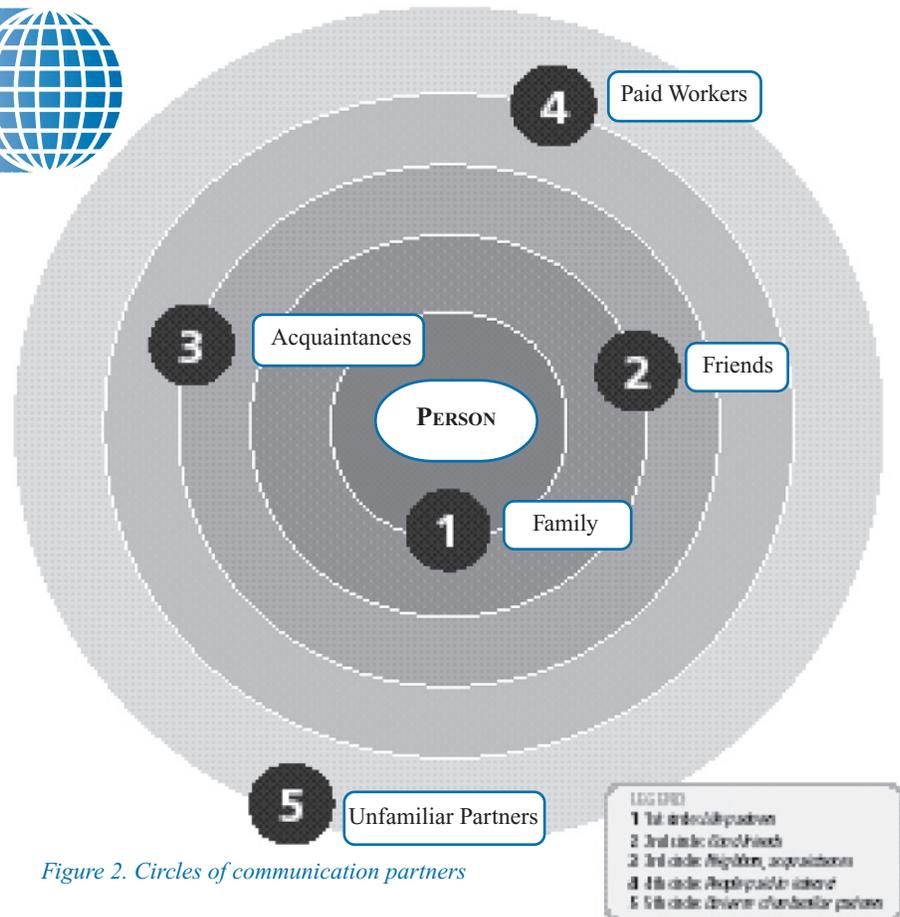


Figure 2. Circles of communication partners

whom they keep in touch. There is a degree of closeness and familiarity to these relationships.

THIRD CIRCLE: Acquaintances. This circle includes people with whom an individual is acquainted but does not socialize on a regular basis. Examples are schoolmates, colleagues, bus drivers, storekeepers, co-workers and community helpers.

FOURTH CIRCLE: Paid workers. These are people who are generally being paid during the times they are interacting with the person. They may include therapists, physicians, teachers, instructional assistants, personal assistants, babysitters, job coaches and so on. Even though some paid workers may become friends, as long as they are being paid they are listed in this circle. [Foster parents are an exception because their role places them in the first circle.]

FIFTH CIRCLE: Unfamiliar partners. The fifth circle represents "everyone else." When filling out this circle, informants do not identify specific individuals. Rather, they are instructed to think of categories of individuals

who are potential interactants.

Examples include storekeepers, waiters, public transportation workers, people in a local coffee shop, listserv participants, community helpers and so on.

The CCP paradigm is a dynamic construct. Over time and across a person's life span, each individual's CCP changes. New partners come into one's circles and other partners move out. Such is the nature of human relationships. Also, communication partners may change circles. Unfamiliar partners may well become friends; a relationship with a friend may evolve into marriage, and so a friend becomes family. As people's social networks evolve over time, so do their communication needs and the communication technologies, techniques and strategies they may require.

Using the CCP paradigm to chart communication partners is a critical step in the *Social Networks*

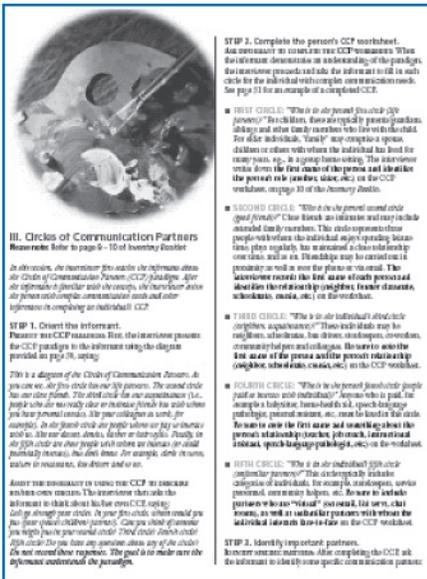


Figure 3. Page from SN Manual

Inventory. Figure 3 shows a page from the *SN Manual*, which provides instructions for collecting this information. Figure 4 is the corresponding page from the *Inventory Booklet*, where data are recorded.

Summary

Completed CCP charts identify the partners in each circle, as well as the person's primary partners (e.g., favorite, most willing to learn, spends most time with). These data are useful in developing goals that can increase successful interactions with diverse partners.

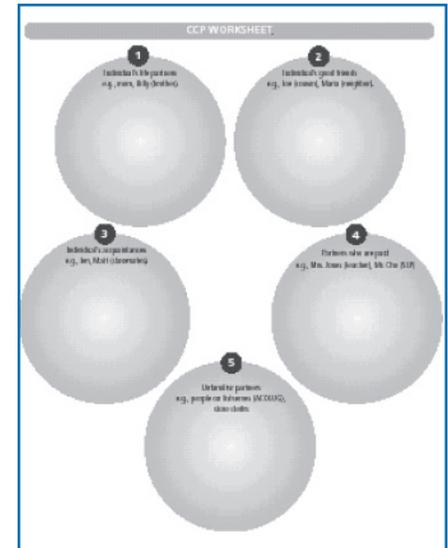


Figure 4. Page from Inventory Booklet

Modes of Communication



Everything Counts

Social Networks (SN) enables professionals to systematically collect and organize information about the use of various communication modes. It also allows practitioners to account for the modes an individual prefers across contexts, activities and partners prior to making decisions about AAC technologies and training approaches. The interviewer first collects information about all the modes an individual uses. See Figure 5. Then, the informant is asked to identify the person's primary mode in each circle and the frequency, effectiveness, efficiency and intelligibility of each mode used.

In pilot studies conducted between 1998 and 2002 (which are summarized in the *SN Manual*), the researchers found a strong correlation between circles and communication modes.¹ For example, all individuals (including those who were competent users of AAC

devices) tended to rely on their impaired speech, body language and gestures as primary modes for communicating with family members (Circle 1). Also, everyone used vocalizations and gestures across all circles. With friends and acquaintances, people used a greater variety of AAC techniques. Low-tech aids and AAC devices were the mode of choice with paid workers.

Participants in these studies used a range of AAC technologies to communicate with unfamiliar partners (5th circle) and acquaintances (3rd circle). However, those who did not have access to AAC devices, or were not able to use devices effectively, could not interact with these partners without direct support from skilled partners. We also learned that, although AAC devices were

seen as essential for individuals to develop relationships with people outside their family and to communicate effectively with strangers, they were rarely used with familiar partners. Also, e-mail and the Internet played an important role in the lives of individuals who were literate and had AAC systems that enabled them to go "online." Access to these tools was highly valued.

Pilot studies revealed that each individual's use of communication modes seemed to reflect cultural patterns, as well as his/her communication competence and language skills. Most importantly, a person's effectiveness often depended on his/her ability to use a variety of communication modes and to know the situations in which each mode would be most successful.

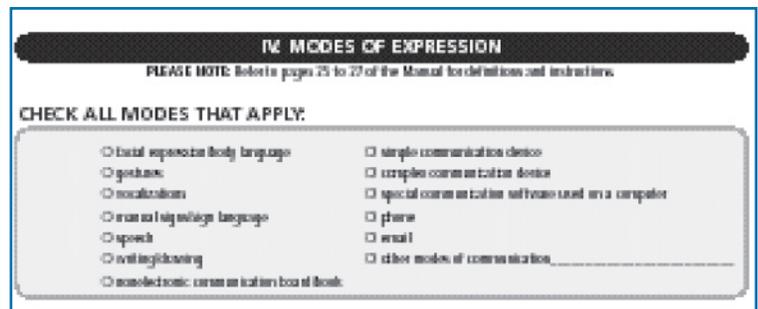


Figure 5. Page from Inventory Booklet

Types of Communication



A communication continuum

In an effort to describe the range of individuals who benefit from AAC interventions, Dowden^{16,17} has differentiated three communication groups. The groups are based on observable expressive communication behaviors, not on perceived receptive language abilities, cognitive abilities or communication needs, whether presumed or known. The groups are not discrete; rather, they comprise a continuum. The continuum ranges from (1) those who do not yet have any means of symbolic expression, to (2) those who can, without assistance, communicate some messages, in some contexts, to some partners, to (3) those who have an ability to communicate any message, to any partner, in any context. The continuum is based on a form of “communicative independence” described by Fox and Fried-Oken, where effectiveness is determined by the ability to communicate anything to anyone.¹⁸ In *Social Networks (SN)* individuals are described according to how independently they are communicating.¹

Both clinical experience and pilot data collected during the development of *SN* show that individuals do not abandon simple communication strategies. Instead, individuals add more and more sophisticated communication methods to an already existing repertoire. It is also clear that most individuals choose to use a simpler method of communication to meet certain needs with familiar partners, just as speaking

individuals choose to use gestures and facial expressions in addition to speech. Finally, the continuum can reflect

both developmental and degenerative processes. For example, a young child with severe speech and physical disabilities begins life using emerging communication. As language develops, however, the child will become a context-dependent communicator and, ultimately, an independent communicator, provided he or she receives AAC interventions along the way. On the other hand, someone with a degenerative condition begins as an independent communicator. As the disease progresses, the person may gradually lose the ability to speak and write. First, he becomes context-dependent and, ultimately, an emerging communicator unless he receives ongoing AAC interventions.

Dowden’s three groups are described below. As part of the interview process, *SN* informants are asked to select the group that best describes the individual.

Emerging communication group.

Individuals who have no reliable method of symbolic expression use emerging communication strategies. People in this group may rely on facial expressions, body language, eye gaze, gestures, vocalizations or other non-symbolic methods of communication. They have no reliable use of intelligible speech, signs or symbols. Although they may learn to use a few rote signs or utterances and a simple communication device, they often use these inappropriately.

The term “emerging communication” is not intended to describe an individual’s potential. In some cases, individuals may be capable of considerable symbolic expression but not have access to a system that meets their motor, auditory, visual or symbolic requirements. In other cases, individuals do not yet function at a symbolic level. However, they may use body language to communicate a range of communicative functions.

AAC interventions for this group typically focus on (1) establishing the first method of reliable symbolic expression, (2) increasing opportunities for interaction with diverse partners and (3) expanding communication beyond “here and now” topics. Treatment can help provide an individual with both the means and the opportunities to communicate more effectively with an increasing number of communication partners and to use symbolic communication strategies more consistently and reliably.

Context-dependent communication group.

A large percentage of individuals who receive AAC services are in the context-dependent communication group. Their skills and abilities may vary widely.

Some individuals are able to communicate in only a few contexts with a small number of highly familiar partners. Other people are able to communicate effectively in multiple contexts with different partners. However, to be understood, or to access appropriate vocabulary, all context-dependent communicators rely on familiar partners for support.

Individuals who have reliable symbolic communication skills may be limited to specific contexts or partners because they: (1) rely on severely unintelligible speech or customized communication strategies, which require partner familiarity, (2) do not have access to sufficient and/or appropriate vocabulary, (3) lack the literacy/language skills necessary to generate novel utterances, (4) depend on others to select and pre-program vocabulary for them and/or (5) do not have access to appropriate technology.

Intervention goals for people whose communication is context-dependent often focus on (1) increasing access to vocabulary, (2) increasing the skills with which AAC strategies are used, (3) developing language and literacy skills to maximize communicative independence, (4) providing AAC technologies and instruction in their use and (5) training communication partners. In addition, goals may focus on (6) increasing participation across circles and/or the number of partners within specific circles, (7) expanding the range of topics an individual can communicate about and (8) improving the person’s ability to assume responsibility for communication breakdowns and for training partners.

Context-dependent communicators benefit from learning to integrate available modes of communication, symbolic and non-symbolic, and to expand their strategic, operational, linguistic and social competencies.

As long as someone is context-dependent, he or she will need support from skilled communication partners, at least in some situations. Some people gain communicative independence over time. Others do not, for various reasons. Many will not have sufficient language and literacy skills to generate language independently. However, some will choose not to use technology and thus to remain dependent on others.

Independent communication group.

Individuals in this group can interact with both familiar and unfamiliar partners about any topic, in any context. These individuals are typically literate and have the ability to communicate novel messages independently.

Intervention goals may focus on (1) using AAC techniques to improve the individual's operational, linguistic and strategic competencies, (2) providing rate enhancement strategies, (3) expanding communication options (e.g., e-mail, Internet access, etc.), (4) refining social interaction and pragmatic skills, (5) increasing access to people in specific circles and (6) fostering participation in activities related to employment, education and community living.

Summary

Dowden's classification system is not intended, nor should it be used, to describe an individual's potential to communicate or to benefit from intervention. The system is, however, very useful in intervention planning and can help teams set goals and establish a baseline against which to measure progress. 

The SN Inventory



relies on AAC. The interviewer (typically a professional with expertise in disorders of speech, language and communication) must be

(1) thoroughly familiar with the theoretical frameworks underlying *SN*, (2) adept at using *SN* to interview family members, professionals and individuals who rely on AAC and (3) able to interpret the information collected in ways that can contribute to a collaborative, person-centered assessment process.

Interviews can be conducted with one informant at a time, or as a more collaborative process. The interviewer seeks to engage the individual with complex communication needs as an *active participant* in the *SN* process, if at all possible. The interviewer also ensures that the individual, or his/her parent/legal guardian, has been informed and has agreed to the use of *SN* as a component of the assessment and intervention processes.

Who participates?

Interviews are conducted with:

1. Someone in the person's first circle (i.e., a family member who spends the most time with the individual, e.g., parent, spouse).

Step-by-step

Social Networks (SN) is not a standardized test. It is an assessment and planning tool that enables trained professionals to collect and interpret information that can influence the nature of AAC interventions and outcomes.

Considerable thought and pilot testing contributed to decisions about what to include in *SN* and how to administer it. Data are collected in the *SN Inventory Booklet* (see Figure 6); and the instructions are delineated in the *SN Manual*. *Social Networks* may be administered in its entirety or in part, in one or more sessions, as part of a comprehensive communication assessment. A clinician or researcher may wish to change the order in which items (or sections) are administered, or even omit a section, when that clearly makes sense.

The administration of the entire tool can take about an hour for each person interviewed. It takes longer when administered to someone who

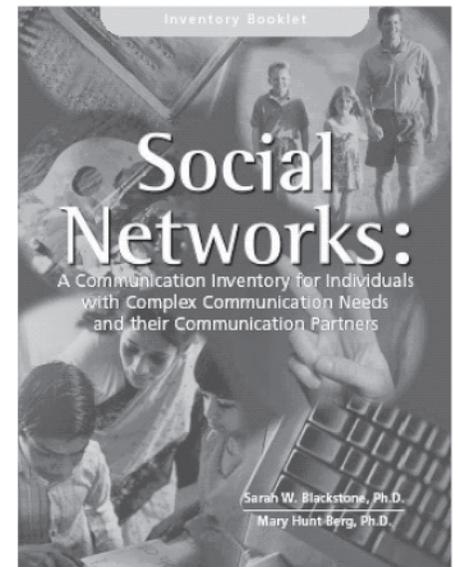


Figure 6. *Inventory Booklet* (cover)

2. Someone in the person's fourth circle (e.g., a paid worker, preferably someone who can respond to questions about the individual's language skills, such as a speech-language pathologist or teacher).

3. The individual who uses AAC, whenever possible. This greatly enhances the validity of the results and, in some cases, can eliminate the need to interview other informants. It is particularly important to find ways to ask the person about his/her Circles of Communication Partners (CCP), modes of expression, and topics of conversation, even if other sections are omitted.

Continued on page 10

VI. STRATEGIES THAT SUPPORT INTERACTION
PLEASE MARK HOW TO PAGE 27 OF THE MANUAL FOR QUESTIONS AND EXAMPLES.

STRATEGIES THAT CURRENTLY SUPPORT EXPRESSION

IDENTIFY STRATEGIES FOR EACH CIRCLE

	EFFECTIVENESS
1	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never
2	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never
3	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never
4	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never
5	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never

STRATEGIES THAT CURRENTLY SUPPORT COMPREHENSION

IDENTIFY STRATEGIES FOR EACH CIRCLE

	EFFECTIVENESS
1	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never
2	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never
3	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never
4	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never
5	<input type="checkbox"/> most of the time <input type="checkbox"/> some of the time <input type="checkbox"/> rarely <input type="checkbox"/> never

Figure 9. Strategies that support interaction

IX. Types of Communication. In the last section, the interviewer asks whether the informant would describe the person as someone who is using emergent communication, context-dependent communication or independent communication.

X. Summarizing SN information. Following each interview, information may be compiled to make it more meaningful and useful. Summary sheets enable the interviewer/team to:

1. Display all communication partners and identify key partners on one page.
2. Identify all modes being used and their effectiveness. Clarify which modes are primary for each circle.
3. Summarize information that relates to the person's skills and abilities and use of representational strategies, selection techniques, interaction strategies and topic preferences on one page.
4. Develop functional communication goals that address the individual's needs and priorities within each circle of communication partners.

Case Examples



names of communication partners in C.A.'s 1st and 4th circles; however, they struggled to contribute names for

Three examples

#1 Emerging Communication.

C.A. is 12 years old and is fully included in grade seven at his neighborhood middle school. His diagnoses include developmental delay, motor and visual impairments. Speech, language and cognitive skills are severely impaired. C.A. wears glasses. He is ambulatory, although he often requires physical assistance to maintain his balance. C.A. has no symbolic communication system and uses emerging communication methods. His family speaks Vietnamese at home; people at school speak English. *Social Networks* was administered as part of C. A.'s annual review.

C.A.'s speech-language pathologist interviewed his mother (1st circle) and his instructional assistant (IA) (4th circle). His IA accompanies him to all his classes, is most knowledgeable about his communication partners at school, and communicates regularly with C.A.'s family via a written communication notebook and telephone calls. Figure 10 shows the number of communication partners reported by his mother and IA for each of C.A.'s circles. Both informants readily provided

		Instructional Assistant
1st	4+	2
2nd	0	0
3rd	3	0
4th	13	15
5th	0	0

Figure 10. C.A.'s partners as reported by informants

his other circles. The IA listed two additional names in the 4th circle, and his mother added two names in his 1st circle, noting that other relatives come to live with them from time to time.

The team noted that C.A.'s circles were neither full nor balanced. Most partners were in his 1st and 4th circles, and there were an overwhelming number of paid professionals in his life. During the interview, C.A.'s mother said, "I didn't realize how isolated my son is."

The SN Inventory revealed that C.A. relies on non-symbolic forms of communication to express himself. His gestures, body language and vocalizations are effective in some circles and situations, but not in others. He recently began to use a simple AAC device with five prerecorded messages at school.

At home, C.A.'s family speaks to him mostly in Vietnamese. He reportedly uses gestures, eye gaze and vocalizations very effectively with his family. At school, people speak only English and C.A.'s idiosyncratic use of gestures is often not effective with staff or his peers. His IA often acts as interpreter. All agreed he uses emerging communication.

The discussion of these findings made it clear that educational staff were not attending to, or encouraging his use of gestures. Also, although the IA could interpret some of C.A.'s gestures, he had not been asked to help others learn to understand them.

C.A.'s mother was identified as his primary and most skilled partner. During her interview, she described

Continued on page 12

Case Examples. Continued from page 11

several gestures he used in meaningful ways at home. For example, she reported he wiggled his fingers in a certain way when he wanted to play music. This gesture came from a time when C.A. was very young and they often played with a toy piano together. “Now,” she said, “it means other types of music as well.” His mother also described other mouth, body and hand gestures that he uses consistently and in meaningful ways. C.A.’s mother had not realized that others might learn to interpret these gestures.

School staff decided to carefully observe C.A.’s use of specific natural gestures in order to enhance interactions at school and expand his ability to communicate in a wider range of contexts and about multiple referents, thus leading him toward symbolic communication.

His mother was not aware that C.A. was using a simple digitized speech device when communicating with some teachers and therapists. She wondered if C.A. understood the meaning of the English words that were programmed into the device, so his speech-language pathologist described his emerging use of these prerecorded spoken messages, which were short and simple. The team agreed C.A.’s use of the device was enabling him to greet people and, thus, establish social relationships.

Based on the analysis of information from the *Social Networks Inventory*, the team felt that C.A.’s daily experiences would be enhanced if he could interact with people more effectively. Familiar partners needed to understand the key role they played in facilitating these interactions, both in setting up opportunities and in training other less familiar partners to recognize

meaningful gestures. The team also realized that C.A. had second-language issues they had not fully understood, appreciated or addressed. Finally, the team developed three functional communication goals:

1. Use a "talking" switch to interact more directly and often with peers at school and with people in his apartment building.
2. Increase C.A.’s effective use of symbolic gestures by (a) having staff and family model the use of five targeted gestures as augmented input at least ten times per day and (b) encouraging C.A.’s meaningful use of the targeted gestures at school and home.
3. Increase the number of people in his 2nd, 3rd and 5th circles from baseline to at least two additional people in each circle over the next six months.

To implement these goals, his mother listed and described his natural gestures so staff could develop a gesture dictionary. Then, the team trained specific peers and staff to interpret C.A.’s natural gestures and vocalizations and to respond to his communication efforts in meaningful ways. Finally, staff and his mother programmed “greeting” messages into a talking switch for use at school and over the weekends.

#2 Context-dependent communication. J.B. was a 50-year-old accountant and mother of two when she suffered a severe stroke (CVA) in 1994. She was initially diagnosed with “global aphasia.” Today, she has a severe expressive aphasia, severe verbal apraxia and a moderate-to-severe receptive aphasia.

Over the years, J.B. has retained good motor control and has used a variety of communication strategies with many communication partners, across multiple contexts. She relies on speech, writing, gestures, drawing and communication notebooks as shown in Figure 11. J.B. aptly demonstrated most of these strategies during the *SN* interview, although her use of some was more effective than others. Her speech

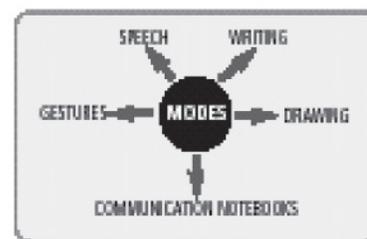


Figure 11. J.B.’s expressive modes

remains extremely limited, both by verbal apraxia and by a severe word-finding impairment. Her word-finding deficits and spelling difficulties also affect her writing, so she can’t rely on writing to resolve communication breakdowns. She prefers using non-symbolic methods, e.g., gestures, body language and facial expressions; however, in most situations, her communication notebooks and drawings are her most effective modes of communication.

J.B. is frustrated by her word-finding difficulties and her reliance on the communication notebooks. Even so, she is very persistent and resourceful in communicating under any circumstances, as long as her listeners are patient.

Although J.B. did not return to work as an accountant, she feels she leads a fairly satisfying life. She runs her household independently, doing her own shopping, cooking and cleaning, and she is, once again, pursuing old interests such as reading, traveling and gardening. Recently she became interested in computers and now spends time connecting with her family through e-mail. To do so, she uses her communication notebook to help her find and spell words.

J.B. placed three people in her immediate family (circle #1) and her two closest friends, with whom she goes to garden stores and shows, in her 2nd circle. She listed 12 people in her 3rd circle, including the group she and her husband travel with and

the extended family she contacts *via* e-mail. Her 4th circle has her dentist, two doctors, receptionists, store clerks and travel guides. J.B.'s 5th circle was relatively small because she relies heavily on others to help her negotiate situations with strangers. Notable exceptions are bus drivers and clerks in stores where she regularly shops. J.B. and her husband selected four goals:

1. Expand the number of topics in her communication notebook.
2. Develop a section of the notebook to help her compose e-mail.
3. Enhance her ability to move smoothly between modalities to repair communication breakdowns.
4. Decrease her reliance on familiar partners during interactions with unfamiliar people.

#3 Independent communication.

A.G. is 26 years old, with a diagnosis of cerebral palsy. She can communicate independently in most environments and with most people when she has access to appropriate tools and chooses to use them. She is bilingual, with Spanish as her first language. She attends a community-based adult program and has several part-time jobs. She also volunteers at a local school district, making communication boards for Spanish-speaking children who use AAC. Recently she began taking a class at a community college across town.

The *Social Networks Inventory* was administered to assess and prioritize A.G.'s communication needs and help her identify goals. The speech-language pathologist who interviewed her was surprised to learn the extent and richness of A.G.'s social networks and realized that heretofore she had little knowledge of the communication partners in A.G.'s 1st, 2nd and 3rd circles.

As shown in Figure 12, A.G.'s circles of communication partners are full and balanced. She described her ongoing contact with many members of her extended family

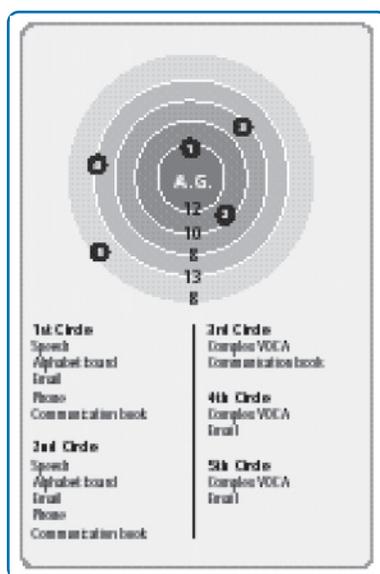


Figure 12. A.G.'s modalities and number of partners for each circle

who live nearby. In addition, she has lived in the same neighborhood since she was in elementary school and regularly sees childhood friends and new friends from work. She also indicated she is meeting more people in the community college setting. In contrast to her family and friends, however, most people at the college are still unfamiliar with her speech, gestures and aided communication strategies.

A.G. uses a variety of communication modes. She has been a competent user of AAC devices and assistive technologies for some time. Even so, she reports that she rarely uses her AAC device with familiar partners, but instead relies on speech, an alphabet board, e-mail, phone and a communication book. She made the communication book herself as a way to clarify messages for partners.

In the past, A.G. used a laptop with voice output communication software. However, she found that communicating novel messages by spelling was slow and cumbersome and that the laptop frequently broke down. She is currently going through a clinical trial process to

purchase a new AAC device to better serve her communication needs.

A.G. chooses to be a dependent communicator in some situations. This occurs when she uses speech, gestures and aided communication strategies with unfamiliar partners. To be more independent and expand her circles, she needs access to a reliable AAC device with features that allow her to communicate more efficiently with acquaintances and strangers. She also needs access to a computer at home, in school and at work, to utilize the Internet, write, make communication displays, *etc.* A.G. and her SLP developed the following goals:

1. Complete clinical trial and acquire an AAC device with synthesized speech that supports her spelling and provides rate enhancement features to assist her in communicating more efficiently and effectively with partners in her 3rd and 5th circles.
2. Use the new AAC device to (a) increase interaction with peers and strangers at her community college, (b) increase ongoing contact with partners using e-mail and (c) participate in chat rooms and listservs.
3. Learn and use strategies to train her own communication partners. For example, she will learn to use an introductory strategy that explains her communication methods.

Summary

The *Social Networks Manual* contains seven case examples. Each illustrates how the *SN* assessment process can lead to the establishment of functional communication goals. As shown here, the goals are meant to reflect the needs and priorities of individuals with complex communication needs and their primary communication partners and to enable individuals to demonstrate greater independence and success in communicating with familiar and unfamiliar partners and to expand their social networks. 



**Nothing
about us
without
us**

Five years ago, the partners of the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC)* made a pact to live up to the mantra popularized by people with disabilities, “Nothing about us without us.” This article gives examples of how people who rely on AAC have been involved in the AAC-RERC’s research, development, training and dissemination activities. These examples do not represent all activities underway that involve “end-users” of AAC technologies as participants, consultants, co-workers and collaborators; rather they illustrate the range of involvement.

* AAC-RERC partners are: Augmentative Communication, Inc., Duke University, Penn State University, Temple University, University at Buffalo, University of Nebraska and the University of North Carolina-Chapel Hill.

Research and development activities

◆ At Temple University, researchers use a participatory action research (PAR) methodology. Adults with cerebral palsy who rely on AAC technologies have had input into the design and implementation of ASSETS, a research project that provided training and support to a group of participant AAC users seeking employment. Diane Bryen reports, “These individuals were our most powerful generators of research ideas and questions. They led us to strategies we would never have thought of.” After the first ASSETS training, research participants came up with the idea of offering AS-

SETS on-line. They also provided substantial input into the ASSETS curriculum and ASSETS for high school students. They were paid either as research participants or consultants. One person is now a part-time employee.

- ◆ Individuals who rely on AAC play a significant role in all employment-related projects at Penn State University. David McNaughton notes that a total of 34 people who rely on AAC have been paid as research participants and two as consultants. Forty-one individuals have participated in the Penn State employment projects, including adults with cerebral palsy (24), amyotrophic lateral sclerosis (7) and autism (3). In addition, seven adults with cerebral palsy worked on TECH 2010, a consumer-led research project.
- ◆ Janice Light, at Penn State University, has conducted a series of studies related to improving AAC technologies for young children. “Families have played an integral part in the research process by identifying specific needs and sharing difficulties they face getting children interested in using AAC technologies,” she said. Researchers have documented the significant learning demands of today’s AAC technologies and are working alongside families to design systems that do not “sit outside the lives” of young children. Light pointed out that parents of children who rely on AAC are often very busy; and therefore, their participation in AAC-RERC research typically must relate directly to needs of their children.
- ◆ David Beukelman reports that researchers at the University of

Nebraska work closely with people who rely on AAC. “We had lots of advisory help from five or six couples, where one spouse had amyotrophic lateral sclerosis (ALS).” The ALS advisory group helped define the role of participants with disabilities and participated in attitude, new interface and organizational strategy studies. They helped formulate appropriate research questions, reviewed data and provided input on its significance. “In one case,” he says, “the advisory group forced a change in the research design.”

Beukelman also described the participation of people with aphasia and traumatic brain injury in studies of the efficiency of specific AAC interfaces.

In a project investigating the use of contextual scenes as an interface for people with aphasia, Beukelman recounts that a man with moderate/mild aphasia “helped us design everything. He came to all the research meetings, and was an every day, research collaborator.” Another man, who has a high level spinal cord injury, was “heavily involved in our head tracking work, making all the team meetings and trying out all prototypes.”

Beukelman described a flexible approach to reimbursement. Reportedly, many participants with acquired disabilities did not want to be paid. One said, “Dave, you don’t have enough money to solve my problems. Give it to her (pointing to a student).” Beukelman also noted that participants and consultants often elect to receive certificates rather than a pay check because “that won’t jeopardize my other finances.”

- ◆ Jeffrey Higginbotham at the University at Buffalo described the role individuals with cerebral palsy, amyotrophic lateral sclerosis and aphasia have played in their projects looking at “usability.” “These individuals have suggested changes that may lead to devices being more reliable, accessible and much easier to modify in the future.”

Training and dissemination activities. Many AAC stakeholder groups can benefit from training, including graduate students, engineering students, people who rely on AAC and their family members, practitioners, manufacturers, policy makers, the general public and so on. AAC-RERC partners teach classes to speech-language pathologists, teachers, engineers and other health-care professionals in pre-professional programs. They also present at conferences, conduct workshops, do Webcasts, write articles and, in short, play a very active role in the training and dissemination activities underway within the area of AAC.

Partners often ask individuals who rely on AAC to teach or co-teach a graduate-level class, present or co-present a paper, write or co-write an article for a newsletter or journal. According to Kevin Caves at Duke University, student engineering projects often require the active participation of people with AAC needs. Bryen said, “We rarely do training without a collaborator, because the messenger is often more important than the message.” Beukelman reports that AAC-RERC staff in Nebraska have helped several couples prepare videotaped versions of their life stories to present to school groups and service organizations.

Michael B. Williams writes a

column about the AAC-RERC in each issue of his newsletter, *Alternatively Speaking*. Finally, three of the eight papers presented at the AAC-RERC State of the Science Conference in August 2001 were co-authored by individuals who use AAC technologies.*

Next steps

People who rely on AAC play a vital role in the activities of the AAC-RERC. Some have participated as volunteers or unpaid participants. However, most have worked as paid participants, paid consultants or paid part-time staff.

AAC-RERC partners feel they have done well, but want to do better. Some ideas for the future are to:

1. Work collaboratively on specific projects from beginning to end. Incorporate people in planning and execution of research as research associates, in addition to their role as subjects or consultants in planning process/focus group.
2. Move people from the role of consultant with an honorarium to the roles of part-time/full-time staff.
3. Use telework/Internet as a way to involve people who rely on AAC more systematically and to circumvent transportation and on-the-job barriers.
4. Hire a team of concerned individuals to look at specific issues in AAC. Discuss problems and possible solutions and create design specs for prototypes.
5. Consider a leadership development program for one or two AAC users in training, dissemination, research and development areas of the AAC-RERC.

* Papers now available in *Assistive Technology*, The Official Journal of RESNA. vol. 14#1.

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