

# Disability Solutions

A resource for families and others interested in Down syndrome and related

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## "Self-Talk" in Adults with Down Syndrome

by Dennis McGuire, PhD., Brian A. Chicoine, MD., and Elaine Greenbaum, PhD.

**D**o you talk to yourself? We all do at different times and in various situations. In examining and evaluating over 500 patients at the Adult Down Syndrome Center of Lutheran General Hospital, we have heard repeatedly that adults with Down syndrome talk to themselves. Sometimes, the reports from parents and caregivers reflect deep concern that this behavior is "not normal" and symptomatic of severe psychological problems.

Preventing misinterpretation of self-talk as a sign of psychosis in adults with Down syndrome is a major motivation for this article. Too often, we believe, these conversations with self or imaginary companions have been equated with "hearing of voices" and treated with anti-psychotic medications (such as Haldol®, Mellaril®, or Risperdal®). Since it is extremely difficult to evaluate the thought processes of adults with cognitive impairments

and limited verbal skills, we urge a very cautious approach in interpreting and treating what seems to be a common and at times very helpful coping behavior for adults with Down syndrome.

The Adult Down Syndrome Center (the Center) was developed to address the health and psycho-social needs of adults with Down syndrome.<sup>1</sup> The Center is a unique collaboration of the National Association for Down Syndrome, a parent advocacy group, Advocate Health Care, a private health care provider, and the Institute on Disability and Human Development at the University of Illinois at Chicago. Since its inception in 1992, over 500 individuals have been evaluated at the Center.

Our records at the Center indicate that 81 percent of the adults seen engage in conversations with themselves or imaginary companions. Patients have ranged in age from 11 to 83 years of age. The median age in our data base is 34. This high prevalence

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## Did You Say Something... or Were You Just Talking to Yourself?

When I sit down to work at my computer for any length of time, it ends in a familiar scene: my feet are tapping, my hair is messed up, my eyes are crossed, and I'm having a heated discussion with the computer screen. My family has learned that this is a good time to run and hide because the computer is winning! Yet, I know I am not the only person who does this. I simply need to take a walk around the neighborhood to find people having similar discussions with trees, bicycles, car engines—the list is endless.

Does this mean we are demented or psychotic? No. Usually, talking to oneself, or "self-talk," is a sign of frustration about something we are doing. Living with Down syndrome, or any other disability, provides many frustrating moments. Research tells us that people with Down syndrome experience a significant difference between what they understand, and what they are able to communicate. Without proper support—friends who make the time to listen, and effective methods of communication—things that seem simple to you and me may create frustration and the need to "discuss" things—with themselves, friends, or even imaginary friends—for someone with Down syndrome. What can we do to help? How can we be supportive?

These concerns are the motif of this issue of Disability Solutions. First, "Self-Talk" in Adults with Down Syndrome defines the concern while providing guidelines for when self-talk may be a symptom of a greater concern. Strategies for Augmenting Communication and Why Bother? Networking An Adult Child with Disabilities highlight methods that promote a positive living situation that will, hopefully, minimize the frustration people with Down syndrome can encounter in their daily lives.

It might take a little time to understand how the articles fit together, but it is time well spent. As I read each one and reflected on my family, I realized that these are tools and suggestions that will help both of my sons build a lasting community around them that is less frustrating than it might have been.

Also, with the trend of moving individuals with disabilities out of institutions and into community settings, it is important to pay attention to understanding their challenges and providing proper support so they may best experience that community. In this instance, the supports are: understanding that self-talk may be a symptom of frustration rather than the beginnings of a disease or psychotic condition, building a supportive network of committed, unpaid friends who choose to be involved in our sons' future, and supporting our child's communication skills so that we may hear what he has to say as often as possible. I hope you will find these articles as helpful as I have.

Warm Regards,

# “Self-Talk” in Adults with Down Syndrome

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of self-talk does not seem to be widely known. For some parents and caregivers, the fact that “almost everyone with Down syndrome does it” is reassuring. But the content of these conversations, their frequency, tone, and context can be important in determining if treatment is warranted.

## *Helpful Self-Talk*

Families and caregivers should understand that self-talk is not only “normal” but also useful. Self-talk plays an essential role in the cognitive development of all children.<sup>2</sup> Self-talk helps children coordinate their actions and thoughts and seems to be an important tool for learning new skills and higher level thinking.<sup>3</sup> Three-year-old Suzy says to herself: “This red piece goes in the round hole.” Then Suzy puts the red piece into the round hole of the puzzle.

We suspect that self-talk serves the same useful purpose of directing behavior for adults with Down syndrome. Consider the case of twenty-two-year-old “Sam” (not his real name). His mother reported the following scene. She asks Sam to attend a family function on a Sunday afternoon. Sam’s regular routine is to go to the movies on Sunday afternoons. Sam tells his mother he will not go with the family. Then the mother asks Sam to think it over. Sam storms off to his room and slams the door.

His mother overhears this dialogue:

“You should go with your family, Sam.”

“But I want to go to the movies.”

“Listen to your Mom!”

“But Sunday is my movie day.”

“You can go next Sunday.”

Sam’s mother said he went to the family function, with the proviso that he could go to the movies the next Sunday. Sam may have been talking to an imaginary person or arguing with himself, but Sam clearly managed to cope with a situation not to his liking.

In children without identified learning problems, the use of self-talk is progressively internalized with age. Moreover, children with higher intellectual abilities seem to internalize their self-talk earlier. As self-talk is transformed into higher level thinking, it becomes abbreviated and the child begins to think rather than say the directions for his or her behavior. Thus, the intellectual and speech difficulties of adults with Down syndrome may contribute to the high prevalence of audible self-talk reported to us at the Center.

In general, the functions of self-talk among adults are not as well researched or understood. Common experience suggests that adults continue to talk to themselves out loud when they are alone and confronting new or difficult tasks. Though the occurrence may be much less frequent, the uses of the adult’s self-talk seem consistent with the findings about children. Adults talk to themselves to direct their behavior and learn new skills. Because adults are more sensitive to social context and may not want others to overhear these private conversations with themselves, their self-talk is observed less frequently.

Adults with Down syndrome show some sensitivity about the private nature of their self-talk. Like Sam in the example above, parents and caregivers report that self-talk often occurs behind closed doors or in settings where the adults think that they are alone. Having trouble judging what is supposed to be private and what is considered “socially appropriate” also may contribute to the high prevalence of easily observable self-talk among the patients visiting the Center.

In the general population, self-talk among older persons is frequently notable and, usually, easily accepted, just as it is with children. Among the elderly, social isolation and the increasing difficulty of most tasks of daily living may be important explanations for this greater frequency of self-talk. For adults with

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# “Self-Talk” in Adults

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Down syndrome, these explanations also make sense. Adults with Down syndrome are at greater risk for social isolation and the challenges of daily living can be daunting.

Additionally, we have found that many adults with Down syndrome rely on self-talk to vent feelings such as sadness or frustration. They think out loud in order to process daily life events. This is because their speech or cognitive impairments inhibit communication. In fact, caregivers frequently note that the amount and intensity of self-talk reflects the number and emotional intensity of the daily life events experienced by the individuals with Down syndrome.

For children, the elderly, and adults with Down syndrome, self-talk may be the only entertainment available when they are alone for long periods of time. For example, a mother reported that her daughter “Mary” spent hours in her room talking to her “fantasy friends” after they moved to a new neighborhood. Once Mary became more involved in social and work activities in her new neighborhood, she did not have the time or the need to talk to her imaginary friends as often.

Thus, that adults with Down syndrome use self-talk to cope, to vent, and to entertain themselves should not be viewed as a medical problem or mental illness. Indeed, self-talk may be one of the few tools available to adults with Down syndrome for asserting control over their lives and improving their sense of well-being.

## *When to Worry*

The distinction between helpful and worrisome self-talk is not easy to cast in stone. In some cases, even very loud and threatening self-talk can be harmless. This use for self-talk by the adult with Down syndrome may not be that different from someone who rarely swears but screams out a four-letter word when hitting her thumb with a hammer. Such outbursts may simply be an immediate, almost reflexive outlet for some of life’s frustrations.

Our best advice about when to worry is to listen carefully for changes in the frequency and context of the self-talk. When self-talk becomes dominated by remarks of self-disparagement and self-devaluation, intervention may be warranted. For example, it may be quite harmless when “Jenny” yells “I am a dummy,” once, right after her failure to bake a cake from scratch. However, if Jenny begins to tell herself over and over “I am a dummy and can’t do anything right,” it may be time to worry and to do something.

A marked increase in the frequency and a change in tone of the self-talk also may signal a developing problem. For example, a caregiver reported that “Bob” had begun to talk to himself more frequently and not just in his room at the group home. Bob seemed to lose interest in his housemates and spent more time in these conversations with himself. Bob talked to himself, sometimes loudly and in a threatening manner, at the bus stop, at the workshop, and at the group home. Bob was diagnosed as experiencing a severe form of depression. Over an extended period of time, Bob began to respond to an anti-depressant and to his participation in a counseling group.<sup>4</sup>

In another case, “Jim” (like Bob) showed a dramatic increase in self-talk. Jim refused to go to his workshop and to participate in the social activities that he once enjoyed. It turned out that Jim’s change in behavior was not due to depression. Instead, Jim’s family and staff at his workshop discovered that Jim was being intimidated and harassed by a new co-worker. With the removal of the bully from his workshop, Jim gradually regained his sense of trust in the safety of the workshop. His self-talk and interest in participating in activities returned to earlier levels.

Further study of the content, context, tone, and frequency of the self-talk of adults with Down syndrome may provide more insight into their private inner worlds. What we have observed and heard from family and caregivers suggests that self-talk is

# *with Down Syndrome*

an important coping tool and only rarely should it be considered a symptom of severe mental illness or psychosis. A dramatic change in self-talk may indicate a mental health or situational problem. Despite the odd or disturbing nature of the self-talk, our experience at the Center indicates that self-talk allows adults with Down syndrome to problem-solve, to vent their feelings, to entertain themselves, and to process the events of their daily lives.



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Footnotes:

1. Chicoine, B., McGuire, D., Hebein, S., and Gilly, D., "Development of a Clinic for Adults with Down Syndrome." *Mental Retardation*, Vol. 32, No. 2, 1994, p.100-106.

2. Private speech is the term used for self-talk in literature on child development. For a wide range of references on the uses of private speech: Diaz, R., Berk, L. *Private Speech: From Social Interaction to Self-Regulation*. Lawrence Erlbaum Associates, 1991. ISBN: 0805808868.

3. L.S. Vygotsky is the Russian psychologist credited with explaining how higher thought and our inner silent dialogues emerge from childhood's private speech: Vygotsky, L., in Diaz, R., Berk, L. *Private Speech: From Social Interaction to Self-Regulation*. Lawrence Erlbaum Associates, 1991. ISBN: 0805808868.

4. McGuire, D., Chicoine, B., "Depressive Disorders in Adults with Down Syndrome." *The Habilitative Mental Healthcare Newsletter*, Vol. 15, No. 1, 1996, p.1-7.

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## Strategies for Augmenting Communication

by Kimberly Voss

**D**ecisions, decisions: what to fix for dinner; what to wear to that special event; what detergent to buy; what route to take to avoid rush hour congestion, and on and on. Sometimes it seems our days are so overrun with choices that we just might consider allowing someone else to make our decisions for us. "Tell me what I should do!," one might scream to their spouse or friend for the answer to a simple problem or something more complex. Do we really want someone to tell us what to do, or to do it for us? Think again.

Choices are what define who we are: what we choose to eat; how we choose to dress; what we choose as a profession; how we choose to spend our time; what we choose to do first and last when we

establish the priorities of our day; who we choose as our friends; what tone of voice we choose to use to communicate that special thought. We exert choice and control over our lives through communication. We beg, plead, whine, debate, negotiate, yell, coax, cajole, pray, and phone anyone who will listen.

What if someone could not understand what you were communicating? What if you couldn't talk? What if you were trying to communicate and no one was listening? Like the old proverbial tree falling in an uninhabited forest, is there sound if no one is there to hear it? Is it communication if no one is listening? I can't answer the question of the tree falling in the forest but I can tell you that, yes,

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# Strategies for

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it is communication. The problem is often with the person receiving the message, not with the one sending it.

Not long ago, a friend told me about her father who recently experienced a severe stroke affecting the use of the left side of his body and robbing him of his ability to speak. Now in a long term care facility after a long and successful career as a psychiatrist, she says he talks on and on, speaking with animation and intent that is unintelligible to those listening. It is clear to her that he knows what he is saying. She said others describe him as "agitated." He could spend the entire day "working at the buckles to remove the physical restraints" so that he could execute the very basic function of choosing when to walk to the bathroom. "What can we do for him?"

Individuals with disabilities with limited or no verbal communication live daily with similar "restraints." They are frequently provided little to no choice or control over their lives. Someone else chooses what they wear, what they eat, where they eat, what t.v. shows they watch, what movies they attend and, for some individuals who also have physical disabilities, when they go to the bathroom.

In a household of typical children, it would not be unheard of for a child to say, "Can't we eat when my t.v. show is finished?" A child without verbal

communication might instead "throw a temper tantrum" as she is dragged to the dinner table. A typical child riding in a stroller through the mall while Mom shops might scream, "No stop, Mommy!" each time the stroller comes to a halt. A child without verbal communication with similar feelings might bang her head on the stroller in desperation to communicate the same message. A typical child might say, "But you know I don't like peas!" when the little green things appear on the dinner plate, while a child without more appropriate communication strategies might spit out the peas when they are spooned into her mouth.

In these examples, the "temper tantrum," head banging, and spitting are communication. What we want to find are ways to replace them with more acceptable and efficient ways of communicating.

## *Ways to Improve Communication*

Augmentative and Alternative Communication (AAC) refers to all types of strategies which increase and enhance communication through speech and handwriting. Providing this support improves communication, independence, and quality of life. Augmentative communication ranges from "no tech" strategies (such as gesture, manual sign language, and communication boards) to "high tech" devices. "High tech" devices include speech output devices which are computers programmed to deliver a message using synthesized (generated by a computer) or digitized (recorded) speech. High tech alternatives range anywhere from a few hundred dollars to thousands of dollars. This article will explore using different "no tech" and "low tech" strategies.

### *Provide Choices to Enhance Communication*

There are many ways to augment communication including the use of communication boards. A communication board is a collection of images, including icons and photographs. When an image



Using photographs to choose activities.

# Augmenting Communication

is pointed to or chosen, it sends a message to someone an individual is trying to communicate with. In turn, that choice evokes a response. For example, an icon of a stop sign can be used to represent the command, "Stop." When pointed to, the "offender" knows to stop to honor the command.

When planning a communication strategy, it is important to start simply. Here are some everyday examples of ways to use a communication board or picture system to provide the opportunities to make choices.

## Creating a Snack or Meal Time Menu

- ◆ Cut out labels from food packaging typically found in the refrigerator or pantry.
- ◆ Glue the labels on unlined index cards or poster board. Laminate the cards for extended use.
- ◆ Single hole punch them and place them on a metal ring, which can be purchased from a hobby or office supply store.
- ◆ Place the ring on the refrigerator or pantry door handle for easy access.
- ◆ Encourage the individual to thumb through the cards and select choices for drinks, snacks, etc.
- ◆ Consider grouping food groups together by using different colored poster board. For instance, put drinks on blue poster board, fruits on yellow, vegetables on green, desserts on red, and so on.

## Selecting A Restaurant

- ◆ Save napkins, cups, or other objects bearing the icon of such restaurants as Taco Bell™, McDonald's™, and Burger King™.
- ◆ Cut out the icons and place them on a piece of poster board (figure 1).
- ◆ Allow the individual to choose the restaurant they would like to go to by touching the icon. Follow up with: "You want to go to Taco Bell™?" The child might then answer "yes" or "no," even by nodding

appropriately. This provides an opportunity to begin working on a consistent and reliable response to "yes" and "no" questions which can go a long way in augmenting communication.

## Using A Computer Independently

- ◆ For independent selection and launching of computer programs, "screen capture" images of meaningful characters in your child's favorite software. This is done by taking a picture of the computer's screen. For Macintosh users, hold down the Open Apple-Shift keys simultaneously while selecting the 3 key. For Win '95 users, send an image to the computer's "clipboard" by holding down the CTRL key and the C key at the same time. Though nothing seems to happen, it is ready to "paste" into a paint program. For Win 3.1 users, it is easiest to push the "print screen" key

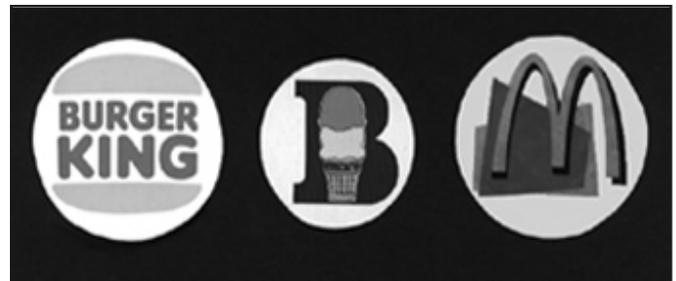


Figure 1. Restaurant choices made with logos from cups.

and send the screen image directly to the printer. There are also shareware and commercial screen capture programs for Windows users available.

- ◆ Print out the images and glue them onto a piece of poster board.
- ◆ Present the card of the software's images and ask, "Which one would you like to play?"
- ◆ Or, consider Edmark's KidDesk™. Computer programs are signified by an icon depicting a recognizable feature or character from the program. The icons appear on one of a number of jazzy desks. When the icon is selected by the click of the

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# Strategies for

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mouse, the program can be set to automatically launch the selected software.

## Choosing Something to Wear

- ◆ Label clothes with matching handmade labels, using stickers or artwork glued to index cards or poster board.
- ◆ Single hole punch the cards and place one of the matching cards on the hanger with the shirt and the other card on the hanger with the corresponding pant or skirt (figure 2).
- ◆ Instruct the individual how to choose her own clothes by matching the customized labels (“Find the other pink elephant tag on the pants which matches the pink elephant tag on this shirt.”).

## Using Text and Icons

When creating communication boards or choice card systems, consider using text with icons as a way to enhance reading. By pairing an icon, picture, or symbol with text, the word “e-a-t” becomes associated with an icon of an individual placing food in her mouth. The icon may be faded out over time. To do this, reduce the size of the icons while increasing the size of the text until the need for using the icon becomes unnecessary (figure 3). That is the point at which the text can be read. For “readers,” consider using text only for some or all selections.

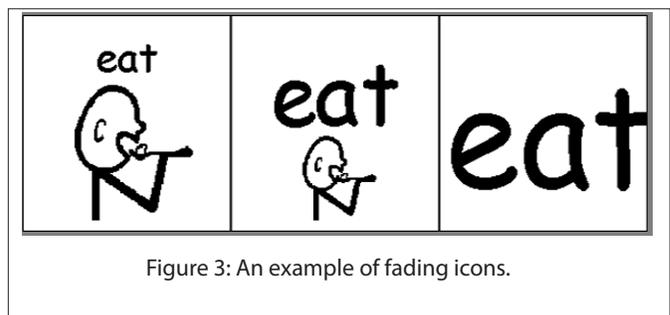
It is my belief that individual handwriting styles for designing reading materials are an unnecessary and avoidable variable. Even the same “style” of handwriting looks different depending on the writing utensil, paper, and mood of the person doing the writing. Designing by computer provides consistency and continuity in text size, design, and style, and makes it easier to read.

Rather than hand writing the words to go with the icons, consider using a good “kid” computer font at a larger point size (48 pts. or larger). Print out the

necessary text to make the communication board and glue onto the cards or poster board. Or, purchase “peel and stick” or rub on letters from hobby or office supply stores to incorporate into materials requiring text.

## Computer Generated Communication Boards

After a while, it can become tiring to make communication boards by cutting with scissors, copying, and pasting pieces of paper. A solution is to consider using Mayer-Johnson’s Boardmaker™ software.



Available for both Mac and Windows, Boardmaker™ is “a graphics database containing over 3,000 Picture Communication Symbols in bitmapped clip art form.” Boardmaker™ is designed for finding, copying and pasting icons quickly to design communication board (figure 4). Icons are provided for many



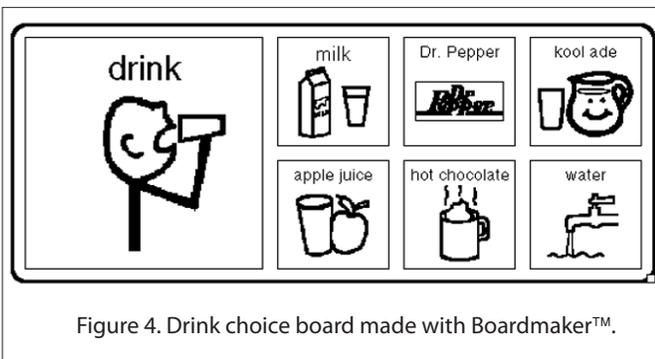
Figure 2

# Augmenting Communication

trademark symbols for such things as Coca-Cola™ and McDonald's™, as well as numerous icons for various daily activities. Icons can be resized by the computer and placed in pre-made grids, or placed in customized ones. Communication boards can be printed in either color or black and white. And additional "libraries" can be created for personally drawn images, as well as digital or scanned photos. This provides easy accessibility, as well as the opportunity to use the images over and over again.

## Simple "No Tech" Strategies

Having the tools to enhance communication is only a part of the process. The person using the communication system must be taught how to use it, and we must re-learn how to listen when they do. Here are some simple strategies that may require



slightly changing your style of communication:

- ◆ Learn to stop and "listen." Try to determine the intent of the communication or "behavior." How do you know some "behavior" is communication? You don't. But through trial and error it is often possible to find out. Look at patterns of behavior or if something seems to consistently precede or follow a "behavior."
- ◆ Think out loud. Put into words what you think the "behavior" or unintelligible speech is trying

to communicate. "Are you mad because you want to finish watching your t.v. show?" "I know you don't want the stroller to stop but Mom needs to finish shopping."

- ◆ Ask questions that provide a choice. Provide two acceptable choices; then let them choose. "Touch which one you want: the popsicle or the ice cream sandwich." "Do you want to wear the red outfit or the blue outfit?"

## Planning Ahead

As the person learns to use communication boards to augment communication, broaden the purpose and use of the communication board. Begin to anticipate and design communication alternatives prior to events, such as airplane rides, doctors' visits, first days of school, and birthday parties, to name a few.

Counting down the days to our daughter Ashley's second open heart surgery, I am beginning to think of how I can prepare to facilitate her hospital stay and recuperation. As a result of complications and stroke following her first surgery, Ashley lost her ability to verbally communicate extensively and is now an augmentative communication user. Her systems can be programmed in advance to anticipate things she may want to say. Although some may be painful for us to hear, she has the right to have access to such phrases as: "I want to go home," "I am scared," "I hurt," "I miss Megan and Wendy" (her sisters), "I miss Abby" (her dog), or "I feel sad." We can come up with communication strategies to reduce anxiety, express pain, provide her the ability to introduce herself and her family to new people, and to let people know who Ashley is beyond a hospital identification bracelet. These can help alleviate the feeling of helplessness for all of us.

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Ashley Voss celebrates her birthday with her classmates.

## *Augmenting Communication*

Just think of the possibilities. Allow the expression of their greatest fears to their wildest dreams. Provide augmentation for not only making choices but for making friendships, sharing feelings, and expressing humor. As with typically speaking individuals, the opportunities are endless. Strategies such as these can go a long way toward reducing your frustration and, more importantly, the frustration of your child, student, friend, or client.

Start simply, but start. Here's to happy and meaningful communicating!

Kimberly Voss is a software developer and owner of Ashley's Mom, Inc. Kim is the mother of three girls, one of whom has Down syndrome and additional disabilities. She resides with her family in Tulsa, Oklahoma.

### Resources

Boardmaker™ for Macintosh and Windows. \$399.00 Mayer-Johnson Co., P.O. Box 1579, Solana Beach, CA 92075-1579. 619/550-0084. <http://www.mayerjohnson.com>

Mayer-Johnson has other "low-tech" options including Picture Communication Symbols often used by professionals for reproducing to make communication boards.

Edmark, P.O. Box 97021, Redmond, WA 98073-9721. 800/362-2890. <http://www.edmark.com>

Edmark has a variety of educational software, including Kid-Desk™. They also carry adaptive hardware such as the TouchWindow™, which provides access by touching the screen rather than using a mouse.

Communicating with Signs, Sounds, and Symbols. Claire Donovan, S-LP(C). Published by: Claire Donovan, 7626 Mays Road, RR #4 Duncan, B.C. V9L 3W8, CANADA. \$20.00.

An easy-to-understand book that describes methods and strategies for augmenting communication. (Reviewed in Disability Solutions:

# Why Bother? Networking An Adult Child with Disabilities

by Linda Stengle, M.H.S.

**D**uring a program planning meeting near Philadelphia, a woman in her eighties listened carefully to the ideas the staff had for improving her son's performance at the workshop. When they had finished, they asked if she had anything she wanted to add. She said, "Can anyone help me with what's going to happen to Richie when I die? Is he going to have to go live in a state institution?"

The group was quiet, and it was clear that no one knew how to answer her question.

Finally, the case manager said that there was no money for group home placements and that people whose parents had died would probably have to be placed in a state program.

The woman left with tears in her eyes.

Parents often have strong fears about the future of their child with disabilities. Dealing with the idea of someone else taking care of your child is never easy. Though most children grow up and leave home, this process is always complicated and emotionally charged. As parents, you may be afraid that your child will not be adequately prepared for the world. In addition, planning for a child's long-term plan and support brings you face-to-face with your own mortality, which is difficult for many people.

Combined with all that, there is a feeling that no one will ever love, care for, and support your child the way you do. We've all seen what happens to people who no one cares about. How can you ensure that someone will truly care about your child?

There has been a lot written on the subject of future planning, but unfortunately most of it involves

the management of inheritances through wills and trusts. Many parents fall into the trap of thinking that if their child has money, he'll be okay. Obviously, if you have the financial resources, money can help make your child's life more secure after you die. However, it is all too easy to have those funds drained by the government to reimburse the cost of maintaining your child's placement in a group home.

Some organizations advocate that you write a detailed plan outlining what is to happen in each aspect of your child's life after your death. While it's a good idea to make your wishes clear, what if circumstances change? Who knows what services will look like in the next few years, let alone the next few decades? How will parents ensure that their children with disabilities take advantage of some of the changes and don't get lost in the shuffle?

Too many parents assume that people with cognitive disabilities are better off with their "own kind." Nothing could be further from the truth. People who are socially isolated are often unhappy and prime candidates for abuse. In addition, most people with cognitive disabilities learn best by modeling other people. When one considers that many people with cognitive disabilities need to improve their social skills, does it make sense to put them into a large group of people who all have varying social skills? Absolutely not.

So the question is: How can you, as parents, see that your child with disabilities is happy, secure, and living in a situation that meets her needs for

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## Why Bother?

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the rest of her life? How can you make sure that the environment changes with her as she ages? It doesn't seem possible to write a plan that takes all these factors into account. Is it even plausible to write some kind of prescription for a child that is supposed to dictate how she will live for twenty or sixty years beyond our deaths? Furthermore, if you write a plan that describes the type of program you want her to live in and the activities you want her to participate in, is that going to be enough to keep her safe and happy?

It seems that it would be much better to have her supported by people who know and love her, people who have some sense of her history, people who are committed to her for the long haul. It seems better to have her supported by someone with whom she feels comfortable, someone with whom she can talk when she has a problem. People with cognitive disabilities need consistency in their relationships. You don't get that kind of long term commitment from paid staff. People with cognitive disabilities need advocates who won't be swayed by budget crunches or lured away by better jobs. People with disabilities, just like everyone else, need to be loved just because of who they are. Being loved by someone who is being paid to love and support you is not the same thing. No matter what their capabilities, paid staff just don't measure up.

I am convinced the best answer to the problem of long term support is friends. What your child needs is a supportive, caring group of non-human service worker advocates who can look out for and be a support to your child after you're gone. While people are not 100% reliable, it's the only resource I know that is capable of making sure someone is happy and secure, is responsive to changing trends and laws, and can fight for changes when needed. People who give their time freely to your child, those other than paid professionals, dramatically improve your child's chances of being well cared for, properly supported, and happy.

Consider the following scenarios:

Donald used to live in an institution. His mother became dissatisfied with the care he was receiving and organized a group of supporters to look into alternative residences. She found eight people who agreed to help her with the project including her neighbor, her minister, and Donald's sister. The group decided that Donald was able to live in a group home, despite his autism and his periodic "outbursts." They put a lot of pressure on the county government and the institution and, after two years of fighting, Donald moved into a group home. His outbursts decreased, his health improved, and he began to smile a lot more. Members of his support group continued to visit Donald after he moved. Occasionally, everyone would get together to discuss his future. Then, Donald's mother died. Her neighbor took over the group making sure everybody got together regularly and recruited new members as Donald's needs dictated. Suddenly, Donald began to have outbursts again. The group found out that someone new had moved into the house and that Donald and the new guy didn't get along. The group tried to get the group home staff to move the new guy out, but the staff refused. Finally, the group decided that Donald should live in a smaller group home with only one other person and some support staff. They lobbied hard for this, eventually winning. Donald now lives with someone he likes and has 24 hour staff support. He hasn't had an outburst for five years. The neighbor still gets the group together; now they are working on getting Donald a job that he would like.

♦ ♦ ♦

Bill's son, Richard, is labeled "moderately handicapped." Bill decided that he could not rely on the human service system to set up an appropriate living situation for Richard so he took matters into his

# Networking An Adult Child with Disabilities

own hands. Bill's biggest concern has been Richard's inability to balance his checkbook. He recruited a friend who is an accountant and agreed to meet with Richard monthly to help him with his checkbook and to annually file his taxes.

Next, Bill took out a long-term lease on an apartment in a high rise building in the city near public transportation. Using his business contacts, he found Richard a job bagging groceries in a nearby grocery store. Richard moved in to the apartment about six months ago. Bill stayed with him for a week teaching him how to use public transportation.

A few weeks ago, the doorman to Richard's building stopped Bill as he was leaving. The doorman told Bill that he noticed some unsavory characters following Richard as he walked from the bus stop one night. The doorman scared the men off and now makes sure to watch out for Richard every night as he gets off the bus. Bill thanked the doorman profusely and said that he felt bad that Richard was creating extra work for him. The doorman denied that it was extra work and said that he enjoyed Richard. Bill feels that when he dies, Richard will be in good shape. Richard doesn't need much more in the way of support; he makes friends easily and will continually broaden his network. By the time Bill dies, Richard will be accustomed to his new lifestyle, and his friends, like the doorman and the accountant, will be able to help him over any rough spots.

• • •

Donald and Richard are living happy and secure lives. They are in settings that allow for growth, changing needs and individuality. They are surrounded by friends who look out for them and who are willing to help them solve problems as they come up. All in all, life is good.

Happy results like these aren't due to luck, they're due to a lot of energy and planning on the part of

their families. While the situations are different, there are some common denominators that are useful to identify:

- √ Each individual's desires and needs were strongly considered in setting up the living arrangement.
- √ Each person was involved in selecting where and how they lived.
- √ Each person has a supportive group of friends who are not paid to be involved with them.
- √ These friends maintain regular contact with the person and have a good sense of who that person is and what they need or want.
- √ The friends are willing to step in and resolve problems as they arise.
- √ There is more than one friend involved, providing back up and mutual support.
- √ Nobody assumed that the human service system was the absolute answer to their problem. In fact, the families recognized the problems inherent in the human service system and set up safeguards to avoid them.

It's tempting to let things continue as they always have been, to keep your child comfortably isolated, and to try not to think too much about the future. Maybe you'll outlive him.

Probably not.

You have probably heard some awful story about a person with a disability left alone in the world. The person who was taken away from his home and thrown in an institution somewhere out in no man's land. The person living on the street. The person who falls prey to con artists or rapists or muggers. The person who's just so unhappy that whenever someone comes to see him, he begs, "please get me out of here." The person in a residential facility who is dressed shabbily with a dead, vacant expression on his face.

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Unfortunately, you can't rely on residential programs and staff to make sure your child is happy and secure. What you may be able to count on is the involvement of other people. If staff and service providers see that your child is loved and supported, they will be much more likely to provide good service. Staff are busy people. Who are they likely to spend time on? Someone who has a visitor coming today or the person no one ever sees? This isn't an indictment of staff, it's just plain common sense.

It's time now to see that people with disabilities enjoy full participation in our communities. Parents have to help others abandon their odd notions about people with disabilities and begin to see them the way we do: as warm, giving individuals.

The only way that will happen is if people come together, one-by-one, face-to-face.

I hope that you will have the courage to begin building people into your child's life. The stakes are too high not to. As you already realize, it's not what you know that helps you make it in life, it's who you know. Don't waste time regretting what you may or may not have done in the past. Start networking your child today.

❖ ❖ ❖

Linda Stengle, M.H.S. is an advocate, consultant, freelance writer, and author of *Laying Community Foundations for Your Child with a Disability*. She and her family reside in Boyertown, Pennsylvania.

## Resources

Allen, Shea, & Associates: a technical assistance workgroup.  
1040 Main Street, Suite 200B,  
Napa, CA 94559. 707/ 258-1326.  
FAX 258-8354.

<http://www.napanet.net/business/personal/ASA/ASA/.html>

The work of this group is best highlighted by a visit to their website where you will find a cornucopia of selections for future planning, person centered planning, friendships, developing personal living arrangements, and more.

Friendships and Community Connections between People with and without Developmental Disabilities.

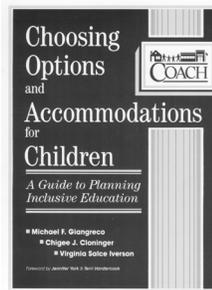
Angela Novak Amado. Published by Paul H. Brookes Publishing Co., 1993. ISBN: 1-55766-121-9. \$30.00. 800/638-8539.

A guide to building relationships and community connections

Laying Community Foundations for Your Child with a Disability. Linda J. Stengle, M.H.S. Published by Woodbine House, 1996. ISBN: 0-933149-67-0. \$15.95 800/843-7323.

A practical guide for families of children with developmental disabilities that shows how to establish a network of non-paid people who can provide lasting relationships. There are many thought-provoking checklists, charts, and examples that help families determine a path for their child's future.

## Choosing Options and Accommodations for Children (COACH): A Guide to Planning Inclusive Education



Reviewed by Mary Wilt

Choosing Options and Accommodations for Children (COACH): A Guide to Planning Inclusive Education by Michael Giangreco, Chigee Cloninger, and Virginia Iverson. Published by Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore MD 21285-0624, 1993. ISBN: 1-55766-106-5. \$29.95. (800)-638-3775.

Inclusive education is a goal that many parents strive to attain for their children, but "making it happen" is difficult at best. There are numerous resources that discuss the importance of inclusion and the benefits it brings to our children and society. The COACH manual, however, is a completely developed planning tool that can be used to devise an inclusive education program.

COACH began in 1982 as a tool used to make individualized community living plans for adults with disabilities. Over the years, the focus has changed to supporting a student's education in a regular classroom setting. Regardless, the emphasis continues to be on devising plans which improve a student's quality of life.

COACH is both an assessment guide for devising goals, and a tool to write a plan for inclusion in regular classrooms and community activities. The authors recommend that professionals on the planning team rely on the family for guidance developing life-long goals or "valued life outcomes." Another goal of COACH is to assist families in becoming better consumers of education and related services and partners in the education process. These motives are what makes this book valuable to families.

COACH is an alternative to traditional, criteria-based IEPs, that focus solely on repetitions of skills or attainment of the next developmental milestone. It is intended to supplement and support, not replace, regular curriculum goals and objectives.

COACH is organized into three main content areas that contain specific examples for guidance:

- 1) The Family Prioritization Interview. This section determines family-centered learning priorities.
- 2) Defining the Educational Program Components. This section develops goals, objectives, and supports or accommodations based on the Family Prioritization Interview.
- 3) Addressing the Educational Program Components in Inclusive Settings. In this section, the nitty-gritty details for using inclusive settings to address the goals and objectives are worked out.

The last part of the manual consists of the forms used for all three sections of COACH. Permission is granted to photocopy materials, and the ring binding makes it easy to do this. Although they look somewhat intimidating on first glance, they are actually easy to use.

Unfortunately, while family empowerment is an aim, the manual is written in language that is more suitable for a professional textbook. When you read this book have a "highlighter" ready! It is full of wonderful information, but is difficult to read.

Another drawback to the COACH program is that it demands a team approach: the process will not work without a committed educator on your side, ready and willing to be the team facilitator. This educator must understand the goals of COACH, and accept the family as the cornerstone of educational planning. This is not a book you can read and then implement on your own! However, the concepts are useful in preparing for IEP meetings, whether or not you are able to use the whole program.

If you persevere, you will come to value the insight COACH gives into what an inclusive education can do for your child. The planning is appropriate for any child regardless of ability. The program is easy to use and understand, once you have completely read the manual. I would recommend this book to any family struggling to develop a good plan for inclusive education settings, regardless of the age of the student.

Mary Wilt is the mother of three, the youngest of whom has Down syndrome. She resides in Virginia Beach, VA and is active in the Tidewater Down Syndrome Association.

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# Disability Solutions

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*Editor, Joan Guthrie Medlen, R.D., L.D.*

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