

The Least Dangerous Assumption A Challenge to Create a New Paradigm

by Cheryl Jorgensen, Ph.D.

Imagine you are about to meet for the first time a young woman who will be coming to your high school this year. Before you do, the following was shared with you about her.

Kim is a 16-year-old student who has a label of severe mental retardation.¹ The usual battery of intelligence tests and adaptive behavioral evaluations have assigned her an IQ score of 40 and a developmental age of 36 months. She has seizures and sensory impairments. Her motor movements are jerky and uncoordinated, making it difficult for her to get around in small areas, write legibly, or use a computer. She is sensitive to certain environmental stimuli such as bright lights, loud noises, and rough textures in her clothing. She has no conventional way of communicating. She uses facial expressions and random

1. Cheryl cautions readers to question traditional definitions whenever the words "mental retardation" or "intelligence" are used.

vocalizations to express emotions. When she is frustrated by a task or situation, she runs away or sometimes hits herself or others. She does not appear to be able to read.

How does this information affect her parents' and educators' decisions about Kim's educational program and adult life? Should you assume that these test results, labels, and observations are accurate representations of her current abilities and future learning potential? Do you advocate for her educational program to reflect content learning from the general education curriculum or is it based on teaching functional life skills? Should she be educated alongside students with significant disabilities only or included in a general education class?

In order to answer these questions, you first need to understand the prevailing paradigm, or belief, that governs the way that most people think about intelligence and

intelligence testing, the label of mental retardation, and the vision that we have for students with this label. In this article, I want to propose and add my voice to the work of other parents and educators who believe that only by creating a new paradigm, or shared belief, of high expectations based on the principle of the least dangerous assumption can anyone, parent or professional, make decisions about students' educational programs that will lead to a quality life in school and throughout their adult lives.

In 1984, Anne Donnellan, a respected researcher in special education, wrote that "the criterion of least dangerous assumption holds that in the absence of conclusive data, educational decisions ought to be based on assumptions which, if incorrect, will have the least dangerous effect on the likelihood that students will be able to function independently as adults." Furthermore, she concluded "we should assume

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Welcome

Letter from the Editor

A Feeling of “Settling In”

It's clear that Fall is here: I can see my breath in the air, the leaves are beginning to turn bright red and orange, and in Oregon, after months of consistently sunny days, the rainy season has begun. Fall brings more than a change in season. It brings the start of school and a feeling of settling in. We're settling in to our new home at Creating Solutions and would like to share with you what has been happening since our last publication.

Many of you have asked about the role of a fiscal sponsor. A fiscal sponsor, sometimes known as an “umbrella organization,” is a legal way to receive tax-deductible contributions and grants by putting your project under the tax-exempt umbrella of an existing nonprofit organization. It's a simpler and less expensive way to receive funds for charitable purposes than creating a separate nonprofit organization.

Our fiscal sponsor, The San Francisco Foundation Community Initiative Funds (TSFFCIF), provides much more than use of their tax-exempt status. TSFFCIF provides accounting services, and other administrative support services in keeping with IRS Code for public charities for a small fee. Our partnership with TSFFCIF has saved Creating Solutions a great deal of time and money. It has also allowed us to focus on fulfilling the mission of Creating Solutions: “To do good work for, and with, people with disabilities and their families.”

Other News

- ♦ We are pleased to welcome Terri Couwenhoven, MS to our advisory board. Terri is the owner of TC Services, Clinic Coordinator for the Down Syndrome Clinic in Wisconsin, member of the Parent Advisory Board for the National

Down Syndrome Congress, an author for *Disability Solutions* (4:5&6), and the mother of two daughters, one of whom has Down syndrome.

- ♦ We also welcome the addition of our Book Review Editor, Mary Beth Pilewski Paul, M.Ed. Mary Beth coordinates and contributes reviews for *Disability Solutions* as well as for our website. Mary Beth has worked and lived with people who have developmental disabilities, and is the mother of a teenaged son who has Down syndrome and autism. If you would like to be a part of the review team, send an email to TheEditor@disabilitysolutions.org.
- ♦ If you haven't visited our website lately, take a moment to check it out. Not only does it have a new look, but, in the spirit of both *O* and *Real Simple* magazines, we've created a “Calendar of Ideas and Inspirations” (www.disabilitysolutions.org/calendar.htm). We hope you will find tips and tricks that make life easier as well as thoughts to inspire and nourish your soul.
- ♦ Also on the website you will find our “Gifts of Celebration” (www.disabilitysolutions.org/celebrate.htm), a list of volunteer opportunities, and our newest addition, “The Editor's Blog,” a periodic editorial (www.disabilitysolutions.org/blog.htm).
- ♦ We have begun work on *The Down Syndrome and Autistic Spectrum Disorder Information Center*, an internet-based program by beginning to establish an advisory board. We are excited about working collaboratively with many different advocacy groups, medical and education professionals, and families to provide up-to-date

tangible information. Our 1999 special issue on this dual diagnosis continues to be the second-most downloaded issue of *Disability Solutions* and the most frequently requested back issue.

We received so many letters after our last publication, getting the mail each day became an “event.” What a treat to hear from so many of you. Your generosity has paid for about half of the costs for printing this issue, reaching over 10,000 readers in print along with an average of 200 people who visit our website each day and download over 25,000 issues of *Disability Solutions* in the month of September alone.

Equally important are the warm and supportive messages we received regarding our move to a separate entity, Creating Solutions. Your suggestions, words of encouragement, and donations are a great boost to all of us as we settle in to our new home. On behalf of the advisory board, I want to thank you for your dedication and support.

As we continue to create a road map for Creating Solutions, your involvement is critical to our long-term success. If you have questions or comments, we want to hear from you. Send an email, letter, or call. Our contact information is on the back cover.

I hope you all take a little time to enjoy the crisp, colorful landscape of fall.

Warmly,



Joan Guthrie Medlen is the Project Director of Creating Solutions, Editor of Disability Solutions, and author of The Down Syndrome Nutrition Handbook. She is the mother of two teenaged boys, one of whom has Down syndrome and autism.

Feature Story

Enhancing Literacy with Books on Tape

by Karin Mentz, M.L.S.

Potter-mania struck our house along with countless other homes around the world. My daughter Kate and I picked up our copy of the latest book at the Barnes and Noble midnight party and I read the book over the weekend. Kate read it next. Now it's David's turn. He and I are listening to the audio version. David is twenty-three. He has autism, intellectual disabilities, and recently began experiencing grand mal seizures. Rowling's new book, *The Half-Blood Prince*, is the sixth *Harry Potter* book and David has listened to them all. He seems to enjoy them, laughing when something is funny and listening intently when it's serious. These are not the first books David has read on tape. He has read probably 20 or 30 books with me over the last ten or twelve years as well as another 15 or 20 alone and it has been a real joy for him.

It seems to me that the value of audio books is often ignored as a valuable reading experience for children and adults with and without developmental disabilities. Think about it: everyone uses traditional book and cassette sets with young children – up through preschool. Then, children begin learning to read and the audio portion of their pre-reading experience is left behind. Parents, teachers and librarians

still read aloud to children once they are reading on their own, but with the pressure of reading and other assignments every evening, this activity loses ground. Slowly, the act of holding a book and looking at the page while listening to a reader is gone, in most cases, forever. It isn't a deliberate loss. There are only 24 hours in each day. After subtracting time spent sleeping, eating, in school, at sports practice, and everything else there is to do in a day, it is hard to find time for homework, much less for recreational reading, no matter who is doing the reading!

Often when working with people with developmental disabilities, this loss can be even greater due, in part, to the belief they don't understand, so it doesn't matter. In keeping with this belief, listening to a book on tape is often overlooked because people believe the disabled don't understand what they hear. It is seen as "just audio stimulation," and somehow not valuable. How do we know that is true? How do we know that someone, like my son, does not understand and does not benefit from listening to books on tape? What is the harm in assuming he understands and enjoys this activity?

Literacy for children and adults with developmental disabilities is often

difficult, if not impossible, to prove. For this article, "literacy" means the ability to read and understand as well as the ability to listen and enjoy. In my experience with David, assumptions made about his abilities – or lack of them – are dangerous and misleading. With this in mind, it seems to me that the audio book is a resource for David and other people with developmental disabilities of all ages that is frequently under-utilized or overlooked entirely. In a good educational program, a tremendous amount of time and effort is spent on pre-reading and reading skills. However, if a team decides a person cannot read, little or no time is spent on what I would call "auditory literacy." I define auditory literacy as the ability to listen to and enjoy literature— either by listening to someone read aloud in person or by listening to recorded books on cassettes, compact discs, or digital audio files. I believe if a person cannot read the printed word, that inability does not prevent them from being able to understand those words when they are read aloud.

In fact, audio stimulation for its own sake is often a good thing. For example, how often do you get into the car and immediately turn on the radio or a CD? That is audio stimulation. Can we honestly claim that listening to the radio or CD player while we are at work, in the car, or anywhere else is anything more profound than audio stimulation? Not usually. For many people, audio stimulation—listening to music or voice on the radio or recorded medium—helps them focus. You may have heard people say they

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Feature Story

Next Chapter Book Club

Learning Never Ends



by Tom Fish, Ph.D. and Jillian Ober, M.A., C.R.C.

Learning never ends. Unfortunately, our society does not apply this idea to people with intellectual disabilities. People with intellectual disabilities leave the formal education system around age 21 with few, if any, expectations that they are interested in, or capable of, continuing to learn. Those who do express an interest in learning are usually sent to adult basic education programs, where the staff is not prepared to work with someone who needs support. Even if someone with intellectual disabilities finds a reading program, it is generally a solitary, one-on-one activity. The last thing people with disabilities who live in the community need is another isolated activity without friends or the opportunity to make them.

In addition, adults with intellectual disabilities have historically been denied opportunities to participate in activities that are not segregated. They rarely participate in community activities, even though more and more are living and working independently in the community. Many research investigators have noted that living in the community is not the same as being a part of the community. Community inclusion extends beyond one's home and work. It involves interacting and forming relationships with other community members and belonging to clubs and organizations.

With that in mind, a small group of parents, adults with intellectual disabilities, siblings, professionals, and I set out three years ago to

create a book club for adults with intellectual disabilities. We called it The Next Chapter Book Club (NCBC). The idea is pretty simple. A group of six to eight people who have intellectual disabilities, gather with two volunteer facilitators in a local bookstore or café to read and discuss a book for one hour a week. We accept people with every level of reading ability. Any one who is interested in joining a book club is welcome. Much like members of any other book club, NCBC participants choose the book they want to read and they would like to structure their book club. It typically takes a Next Chapter Book Clubs 12 to 14 weeks to complete a book. When they are done, the club members decide to continue with another book or disband—we've never had one disband.

Three years later, our book clubs continue to defy the assumptions we made during the planning process. I vividly remember going out to buy eight tape players before starting our first book club. I thought the participants would need or want to listen to the books on tape, because they probably could not read, and then come to the book club prepared to discuss the book. I could not have been more wrong. All of the 20 book clubs we have started have chosen to read their books aloud together. The tape players have never been opened. So much for our preconceived notions about what people with intellectual disabilities want to do or are able to accomplish.

Patty is a 43-year-old member of one NCBC who lives with her sister.

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that poor performance is due to instructional inadequacy rather than to student deficits.” In other words, if a student does not do well, the quality of the instruction should be questioned before the student’s ability to learn. Thus, for Donnellan, the least-dangerous assumption when working with students with significant disabilities is to assume that they are competent and able to learn, because to do otherwise would result in harm such as fewer educational opportunities, inferior literacy instruction, a segregated education, and fewer choices as an adult.

The Prevailing Paradigm

Thomas Kuhn (1962), a scientist-philosopher, defined paradigms as shared world views. These shared views are so strong and institutionalized that only a sudden and dramatic break from these conventional perspectives can bring on a positive revolution in thinking. What is the prevailing paradigm about disability and competence? It is defined by four ideas:

1. Intelligence is something that can be reliably measured.
2. Mental retardation is defined as low levels of intelligence.
3. Students who experience mental retardation can’t learn much general education content. Therefore, the benefits of attending general education classes are limited or do not exist.
4. When we aren’t sure that students know, understand,

can learn, or have something to say, we presume that they don’t, can’t, and probably never will.

How Does the Prevailing Paradigm Impact Our Beliefs and Actions?

The influence of this paradigm is clear in both our beliefs about students’ abilities and in the decisions that we make about their educational programs.

When people do not assume that students with disabilities are competent and able to learn general education curriculum, educational programs often have the following characteristics:

- Students are not included in general education classrooms. If they are, they participate in functional portions of instructional routines, but not in the discussion of ideas or content knowledge. Usually, students are given different materials and resources than those used by the rest of the class.
- People talk with students as if they are talking with a much younger child. They use words geared to perceived developmental levels or IQ scores as measured by traditional assessments.
- Students are not supported to engage in social activities with same-age peers. Those activities are considered inappropriate or too advanced.

- Planning for students’ futures does not include the choice of a postsecondary education or their interests are not considered over their abilities. Career options are geared to lower-skilled jobs or sheltered workshops rather than to jobs in integrated workplaces that require higher-order thinking or literacy skills.

A Proposition

As Kuhn said, it is only when we question a prevailing paradigm that we can be open to changing not only our beliefs, but our actions. I propose that believing in the paradigm of mental retardation leads to low expectations for students with significant disabilities. These low expectations result in segregated educational programs, or programs that do not focus on literacy or content learning, and narrow visions for the future. Thus, changing our paradigm about intelligence and mental retardation is central to promoting students’ learning, inclusion, achievement, and quality of life now and in the future.

Flaws in the Construct of Mental Retardation

An important step in challenging the prevailing paradigm is understanding the flaws in the idea and assessment of both intelligence and mental retardation. Stephen Jay Gould (1981), an evolutionary biologist, criticized some of the earliest attempts at testing intelligence as being fraught with

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The Least Dangerous Assumption

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bad science, politics, and racism that resulted in the mistaken conclusion that people of northern European descent were more intelligent than non-Caucasians. Howard Gardner (1984), an educational researcher, has criticized intelligence testing because the kinds of intelligence measured by traditional I.Q. tests (verbal and language skills and math and problem-solving skills) represent just one part of a complicated, multi-dimensional framework. Based on this logic, let's agree that measuring intelligence is difficult, if not impossible. That means measuring the lack of intelligence is also difficult, if not impossible. If we believe these things, then we ought to view the label of mental retardation with great skepticism.

When we think about people with significant or multiple disabilities, in particular, this skepticism is justified. These are precisely the people who have difficulty communicating, whose bodies move erratically, and who have not been taught the language or skills intelligence and adaptive behavior tests measure. How would you score on an intelligence test if you could not talk, write, or type accurately? If you were not exposed to or taught receptive or expressive language skills? How well would you do taking the test if the sensory environment

of the testing situation was stressful or noisy?

Another reason for questioning the prevailing beliefs about intelligence and mental retardation is a body of emerging research that shows that with high expectations, good instruction, and the support of assistive and communication technology, a growing number of people labeled mentally retarded

“...we should assume that poor performance is due to instructional inadequacy rather than to student deficits.”

Ann Donnellan

acquire literacy skills and demonstrate intelligence beyond what would have been predicted by their test results (Biklen & Cardinal, 1997; Broderick & Casa-Hendrickson, 2001; Erickson, Koppenhaver, & Yoder, 2002; Erickson, Koppenhaver, Yoder, & Nance, 1997; Koppenhaver et al, 2001; Ryndak, Morrison, & Sommerstein, 1999).

A New Paradigm

If we are seeing more and more examples of people whose experience does not align with the prevailing paradigm—who show, when supported, they have learned more than we assumed they were able to learn, then a new paradigm must be developed that accounts for this. This paradigm would be characterized by the following ideas:

1. All people have different talents and skills.
2. Intelligence is not a one-

dimensional construct, nor can it (or its absence) be measured accurately and reliably enough to base students' educational programs and future goals on test results.

3. Children learn best when they feel valued, when people hold high expectations for them, and when they are taught and supported well.

Let's return to the story of Kim who was described at the beginning of this article. If we “walk through” two scenarios that represent very different decisions about her educational program and use Donnellan's principle of the least dangerous assumption to consider the potential impact of each decision, it might help us decide which path would be in Kim's best interests now and in the future. (See colored box on page 7).

Influence of the New Paradigm on Our Beliefs and Actions

If schools adopt the new paradigm of least-dangerous assumption and the presumption of competence, the following would be evident:

- “Person-first” language is used so that people say “students with autism,” not “autistic students.”
- Language classifying students based on their functioning or developmental level is not used; rather, descriptions of students

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Scenario One

Assumptions

We assume that Kim is not “smart” – that she does, in fact, have mental retardation, defined as significantly sub-average intelligence and ability to learn. How might she be treated?

Educational Setting

First, we might not try to teach her to read or if we did, it would be functional sight words. Second, we would speak to her in language more appropriate to a younger child. Third, Kim would probably spend her educational career being taught functional skills such as dressing, eating, shopping, cooking, and cleaning. In most states she would be educated in a separate classroom alongside other students who also have significant disabilities. If she did join the rest of the student body, it might be during lunch or perhaps a class such as music or art.

Communication Support

The communication vocabulary and supports that we would make available to her would correspond to our assessment of her sub-average intelligence and relate to the functional skills we were teaching. The messages might include “hi, bye, more, bathroom, hungry, break, I feel _____, yes, and no,” instead of age-appropriate social vocabulary and messages that would enable her to communicate about the general education curriculum.

Friendships and Dreams

We would not encourage her to participate in the typical social life of her same age classmates because we would assume that her disabilities were too significant for her to enjoy the same activities. Interactions between her and students without disabilities would be limited to their volunteering to be her peer buddy or helper. As she approached the end of her school career, the possibility of her attending college would not even be considered. Instead, we would plan for her to move into a group home, attend a day habilitation program or work in a sheltered environment, and pursue specialized leisure and recreational opportunities with other adults who have similar disabilities. We would not expect her to have opinions about world events, her future, love, or about anything else considered to be above her cognitive level.

Scenario Two

Assumptions

We are not sure about what she knows or might be able to learn in the future...we don't have conclusive data to guide our decision-making. But this time, we operate from a different set of assumptions. We treat her as if she is smart, because we distrust the validity of her test results in light of her communication and movement difficulties.

Educational Setting

First, we use a variety of methods to teach her to read. Second, we talk to her the same way we do other 16 year old students who have no disabilities. Third, we enroll her in general academic classes where we implement her reading program and support her with adapted materials and instructional supports. We take advantage of natural opportunities to teach her the functional skills that are essential for membership, full participation, and learning.

Communication Support

We talk with her about current events. We make sure her communication system includes words and concepts that are appropriate for someone who thinks about current events, love, relationships, and her future.

Friendships and Dreams

We encourage her to participate in activities that her classmates are involved in and provide communication tools and support for her to be successful. We encourage her to make friendships and assume she is capable of, and interested in, having friends. As she approaches the end of her school career, we prepare for a variety of options including postsecondary education as a graduation option. In addition, we plan for her to move into an apartment, own her own home, work at a real job, or travel.

**Which do you think is
The Least Dangerous Assumption?
Once you choose, turn the page.**

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The Least Dangerous Assumption

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It is now several years in the future. A remarkable discovery has made it possible to determine without question how smart someone is using a simple brain scan. Here are the results.

Scenario One

The brain scan results show, surprisingly, that Kim has an IQ of 100. She does not have an intellectual disability. What are the consequences of our original assumption of a low IQ—of our being wrong? Has any harm been done?

Most people say we lost an opportunity to teach her things she could have learned. We did not include her in the mainstream of general education as much as we could have and she did not develop a wide network of social connections or friendships. She missed out on the regular high school experience. It is possible we negatively influenced her self-esteem by treating her as if she were not smart. We narrowed the possibilities for her future career or post secondary education. And certainly, we wasted a lot of money pursuing the wrong educational program.

Scenario Two

The brain scan results show that Kim has an IQ of 40. She does have an intellectual disability. What are the consequences of our original assumption of her intelligence being wrong? Has any harm been done?

Most people say nothing has been lost. Even though Kim may not have learned much of the general education curriculum, her educational program offered her opportunities to develop life-long interests, to make friends with students with and without disabilities, to be part of the social life of the school, and to truly be part of the community after graduation. Because we took advantage of natural opportunities to teach her functional skills within the natural context of the day, she probably learned and generalized them better than if they had been taught as a discrete skill in an isolated or segregated setting.

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focus on their abilities and strengths.

- Annual goals on IEPs reflect content standards from the general education curriculum and the functional skills necessary for students to fully participate in the mainstream of school and community life. For example, IEPs would contain priority goals in all of the

general education subjects and meaningful functional goals such as learning to use email, asking a friend out on a date, providing guidance to a personal care assistant, and putting on make up or shaving.

- Students are seen as capable of learning; educators do not predict that certain students will never acquire certain

knowledge or skills.

- People speak directly to students rather than speaking to students through a buffer supplied by paraprofessionals or other people who are considered to be assisting the students.
- People use age-appropriate vocabulary, topics, and inflection when talking to students.

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- People do not discuss students' lack of skills or challenges in front of them unless they are a part of the conversation.
- Parents receive feedback regarding student success rather than highlighting student failures and disabilities.
- Staff members respect students' privacy by discussing the students' personal care, medical needs, and other sensitive issues out of earshot from others, and only with those people who genuinely need the information.

Five Reasons Why Our Least Dangerous Assumption Should Be to Presume Competence

There are at least five reasons why I believe our least dangerous assumption is to presume competence.

1. Human intelligence is a multi-faceted construct rather than a uni-dimensional characteristic and measuring it with a test is invalid and leads to mistaken conclusions about a person's capacity to learn.
2. Assessments of students' I.Q. are seriously flawed when they have difficulty communicating and movement challenges.
3. Research shows that a growing number of children and adults labeled retarded

show they are more capable when they have a means to communicate and are provided with high quality instruction.

4. To presume incompetence could result in harm to our students if we are wrong.
5. Even if we are wrong about students' capacities to learn general education curriculum content, the consequences to the student of that incorrect presumption are not as dangerous as the alternative.

Deciding on Your Least Dangerous Assumption

Those of us involved in the educational lives of students—parents, teachers, psychologists, speech-language pathologists, policy makers, and researchers—must decide what our least dangerous assumption will be and whether we can live with the possibility of being wrong. If we are not sure, we might ask ourselves:

- How would I want to be treated if someday I was unable to communicate or demonstrate my competence?
- How would I want others to treat my child if he or she were in the same situation?
- What do adults with disabilities tell us about their educational experiences and how they want to be treated?
- What does research tell us?
- What does history tell us?

Parents and educators of students with disabilities care about and want to do the very best for those students. Using least dangerous assumption as a guide is a powerful tool for keeping alive a vision of a valuable life and quality communities.

Cheryl M. Jorgensen, Ph.D., is an Assistant Research Professor with The Institute on Disability at the University of New Hampshire, A Center of Excellence in Disabilities; Project Director for "Beyond Access: A Model that Promotes Learning of General Education Curriculum Content for Students with Significant Disabilities;" and teaches students to become Inclusion Facilitators. Dr. Jorgensen is a co-author of Including Students with Severe Disabilities in Schools, and author of Restructuring High Schools for All Students: Taking Inclusion to the Next Level and The Inclusion Facilitator's Guide (Available Fall, 2005 from Brookes Publishing).

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Books on Tape

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work better with “background noise.” That background noise is audio stimulation. It can also be soothing and relaxing during stressful moments. Even if that is all a person gets out of listening to music or an audio book, isn’t that good enough?

My son, David, does not talk. That’s not to say that he makes no sounds or cannot communicate. He does both rather well. In addition, his attention span is different: it can be longer or shorter depending upon what is happening around him. Dave has always loved videos and books. We discovered that he has a sense of humor because he was listening to an audio book (*Go, Dog, Go!*) and laughing uproariously whenever the tape reached a funny part. This was great as long when he was young enough to enjoy children’s book cassette sets. Years later, at the Erie County Library Bookmobile, he discovered an audio edition of a *Star Trek* book that he owns in paperback. We borrowed this book and he listened to it several times before it was due back. That was the beginning of our collection of audio books. He clearly has favorites, because he plays some of them over and over and others he doesn’t finish.

I like listening to books—in the car and at lunch when I was working. This expands Dave’s literary horizons to include spy novels, adventure, fantasy and other science fiction. When I find an audio book I like, I share it with him. If I read a book I think will interest him, I find out if it is available in an audio format.

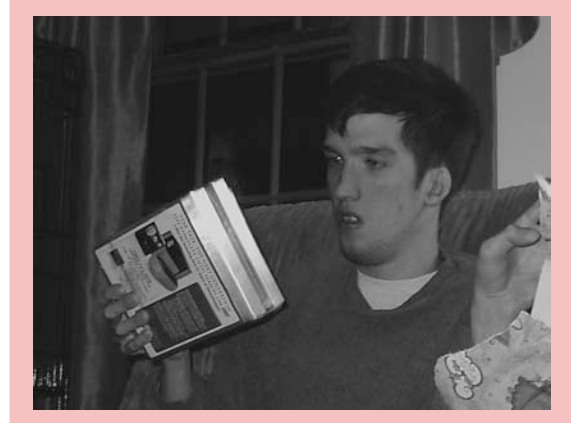
David seems to enjoy our literary adventures. He continues to laugh when it’s funny. I’ve noticed that he displays less head-rocking and tapping when we’re listening to a book.

It may take longer for us to listen to a book together as compared to reading it separately, but I believe that it is time well spent. Through audio books, David touches popular culture. He participates. He belongs. He waits for books to be published that relate to movies he has seen or wants to see. Finding them in audio format is truly exciting. Among our most recent non-audio book purchases are novelizations of *Fantastic Four* and *Batman Begins*, and we are eagerly hoping to find them in audio format.

Getting started with audio books with your child or adult is easy. Choose a title that relates to something your child is interested in. We started with books that are novelizations or adaptations of television programs or movies Dave enjoys. As I mentioned earlier, Dave saw a *Star Trek* Book in audio format that we already had in paperback and let me know he wanted to listen to it. We borrowed it from the library where he saw it. I showed him the cassettes were the same as the book. He already knew how to operate the cassette player. Once we established that this was the story, Dave was in great shape. Persuading him to use headphones was, and continues to be, an “iffy” proposition. He doesn’t like things

on his head. Most of the time, this isn’t a problem because he and I listen when we are alone together at home or in the car. Generally, if he has headphones when other people are in the car, he will use them, at least for awhile.

It’s important not to force the issue. I ask Dave if he wants to hear some of whatever we’re currently listening to, and if he nods “Yes,” he or I put it on. If he nods “No,” or pushes me away, I wait for another time. Just like anyone else, he doesn’t always want to listen to a book. It is important to allow your child or adult to listen to age-appropriate books. I’ve seen special education teachers stop trying to read to their middle and high school aged



students because they disapproved of subjects or language. (People with disabilities apparently aren’t supposed to know about sex or strong language.)

It is a great pity that publishers typically publish audio editions of bestsellers only and, often, in abridged format. Dave would be happy if all the *Star Trek* episodes – in all four incarnations – were

available in audio books as well as all the related books. He would probably say the same for programs like *SeaQuest DSV*, *The A-Team*, *Space: Above and Beyond*, *Space Rangers*, *Battlestar Galactica*, *Stargate*, *MacGyver*, and many others. All of the *Star Trek* and *Star Wars* books are not to be found in audio editions. It's a shame for him and many others. I know a few folks who would like to own and listen to them, over and over.

I enjoy this time with Dave. Together, we have listened to and enjoyed a number of books (see below). Audio books can be enjoyed anytime and almost anywhere. Dave, for instance, used to listen to cassettes while we waited for his sister at track

practice and until the beginning of track meets. Sometimes, he listens alone but, for the past few years, we have listened together. And together, we continue to look for new titles. He knows where the audio sections are located in our local Barnes and Noble and Waldenbooks. It's really frustrating for him when the displays are moved. Our local Barnes and Noble store recently moved the audio section back to its original location after trying out a different layout. Dave couldn't be happier. He never liked the "new" location.

Now that Dave has finished high school, he and I continue to enjoy audio books together, and on our own. We encourage you to try this

activity. I'm sure that Dave would tell you audio books are a great invention! Our next adventure is *The Hunt for Red October*. Our best wishes to you on yours.

Karin Mentz, MLS, is a librarian who has worked many years assisting people with disabilities, their families, and others find resources. She is the mother of two children, one of whom is David, an avid audiobook reader.

Editor's Note:

As we go to press, I received an email from Karin telling me David has discovered two Star Trek titles he has not read (recently), asked for new batteries for his tape player, and was heading happily to his room for a new adventure.

Dave's Audio Book Recommendations

An "(A)" after a title indicates it is an abridged title.

The Phantom of the Opera
Harry Potter and the Sorcerer's Stone
Harry Potter and the Chamber of Secrets
Harry Potter and the Prisoner of Azkaban
Harry Potter and the Goblet of Fire
Harry Potter and the Order of the Phoenix
The Hobbit
The Fellowship of the Ring
The Two Towers
The Return of the King
Nine Princes in Amber (A)
The Guns of Avalon (A)
Sign of the Unicorn (A)
The Hand of Oberon (A)
The Courts of Chaos (A)

The Trumps of Doom (A)
Knight of Shadow (A)
Sign of Chaos (A)
Blood of Amber (A)
Prince of Chaos (A)
The Quiller Memorandum
Quiller's Run
The Tango Briefing
Quiller Barracuda
The Pekin Target
Star Trek: The Return (A)
Star Trek Voyager: Mosaic (A)
Star Trek Voyager: Caretaker (A)
Star Trek Deep Space 9: Emissary (A)
Star Trek the Next Generation: The Valiant (A)
Star Trek the Next Generation: Kahless (A)

Star Trek: Sarek (A)
Star Trek: Spock vs. Q
Star Trek: Generations (A)
Star Trek the Next Generation: First Contact (A)
Star Trek the Next Generation: Ashes of Eden (A)
Star Trek the Next Generation: Insurrection (A)
Star Trek: Web of the Romulans (A)
Star Trek Deep Space 9: Fallen Heroes (A)
Star Wars: The Approaching Storm
Star Wars: Attack of the Clones
Star Wars: The Phantom Menace
Star Wars: A New Hope
Clive Cussler's Trojan Odyssey

Next Chapter Book Club

Continued from page 4

After about six months of bringing Patty to and from her book club, her sister said she was amazed at how much more Patty had been reading since being in the NCBC. She specifically noticed Patty was reading billboards and traffic signs as they drove to and from the book club, something she had never done before. Gene, a 60-year-old member of an NCBC shares, the impact the book club has had on his life: “This is what I’ve wanted to do all my life. Since I’ve been in the book club I’ve been learning.” Family members tell us their loved ones have “made lasting friendships” as a result of participation in their book club. A volunteer facilitator said, “We have all become real friends and, to a great extent, have positively changed each other’s lives.” It sounds like any other book club, doesn’t it?

Each Next Chapter Book Club is full of racial and ethnic diversity, a wide

range of reading abilities and literacy behaviors, and a unique personality as a result of this unintentional variety. We currently have 20 book clubs with 115 participants and 40 volunteers who range in age from 18 to 82. Our volunteer facilitators are college and high school students, retirees, homemakers, professionals, and people with disabilities. We provide training and support for our facilitators providing a variety of strategies to include all participants.

Next Chapter Book Clubs are held in inviting, community settings such as *Border’s Books and Music*, *Barnes and Noble*, *Panera Bread*, *Target Café*, and *Caribou Coffee*. The inclusive nature of the NCBC changes public awareness of people with disabilities. It also provides adults with intellectual disabilities the opportunity to experience the culture of bookstores, cafés, and

coffee houses, which have emerged as social gathering places for many people.

The books in our library are chosen based on their popularity and readability. Many groups choose to read adapted classic novels such as *The Secret Garden*, *Tom Sawyer*, and *A Wrinkle in Time*, while others choose current stories such as the *Harry Potter* series. Still others have chosen to focus their reading on sports and spend their time reading the sports page of the local newspaper.

The NCBC is designed to promote literacy, social interaction, and community inclusion. It is an opportunity to reduce the social isolation and segregation many adults with intellectual disabilities face and engage in meaningful literacy and social activities. More importantly, however, NCBC members are learning and making friends and having a lot of fun doing it.

Tom Fish is the Program Director of The Next Chapter Book Club Program. He directs the Family Support and Employment Program at the Ohio State University Nisonger Center on Excellence in Disabilities and serves on the board of the Ohio Down Syndrome Association. Jillian Ober is the Program Coordinator for NCBC and an employee of the OSU Nisonger Center.

More information about The Next Chapter Book Clubs is on page 15.



Book Review

Reviewed by

Mary Beth Pilewski Paul

Herbert Lovett, Ph.D. of Boston, was a leader, scholar, teacher, and advocate for people with disabilities and their families. He died in an automobile accident in 1998. He was 48. His untimely death brought an outpouring of grief and condolences from people around the world.

From the Paul Brookes' Publishing Co. web page.

My original interest in *Learning to Listen* came at a time in my son's life when he would scream very loudly. He hit, scratched and tried to bite people, and ripped things off walls. He couldn't use words to tell us what bothered him, and the people around him were frightened, angry, and exasperated with him all the time.

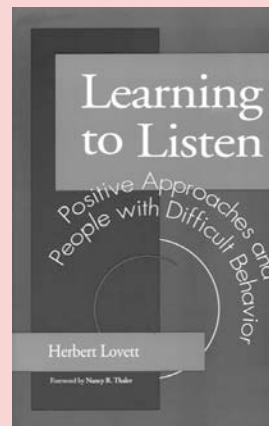
I dipped into this book and talked with people who had worked with Herb Lovett. What I was able to learn about positive supports helped us as our family, friends, and school team began to sort out what purpose my son's screaming and other behaviors served.

I hadn't read *Learning to Listen* all the way through until recently. Now I am even more aware that my son is still trying desperately to connect with us. I love Herb Lovett's challenge to dig deeper, encourage relationships, and help our son live his life.

Learning to Listen: Positive Approaches and People with Difficult Behavior

By Herbert Lovett, Ph.D.

Paul H. Brookes Publishing Co., Inc., 1996. ISBN 1-55766-164-2 . \$29.95



Lovett begins with a simple enough premise: when people in power are in charge of people who have no power, they tend to hide behind the guise of “We know what is best for you, and we will help you change.”

But then he turns this premise on its head with the application of the Golden Rule. Who in our lives decides when we eat, go to bed, have a say-so in how we fill our days? How would I feel if everyone I knew was meeting about me, devising a plan that would make me easier to manage? How would I feel if the only people who spent time with me were paid to be with me? How would I feel if no one ever put their arms around me because “adults don't hug”?

Lovett covers the premise of what is now generally referred to as “positive approaches” in this challenging book. He asks that we think not just about the surface issues concerning those with “dangerous behaviors”, but to imagine what purpose the behaviors serve. While there is no cookbook approach here, he urges us to ask: “How can I help?” “Can

you tell me what you need?” “Does your head hurt?”

He asks us to use “best guesses” when someone communicates with difficult or even dangerous behaviors. He claims to have no answers. Instead, he offers approaches, strategies, and painful struggles.

Throughout each chapter he tells stories about real people with difficult behaviors and how the staff/caregivers/teachers/agency teams responded, failed, asked for help, changed, and/or abandoned that individual.

The lengthy chapter on “The Hierarchy of Control” takes an unflinching look at some subtexts of behaviorism. Here is where I realized this is a political book, as Lovett talks about behaviorism as a system that exerts power and control over the helpless instead of being there to serve.

This book stands apart because Lovett also puts himself in the shoes of the agency staff, of the failing systems, of the direct caregivers. He believes that most people attempting

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Book Review

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to help do have good intentions; they don't want to abandon people who desperately need them but they too often feel helpless and ignored.

Another poignant aspect of this book is Lovett's own humility, and thus we see his own humanity. By putting himself in others' shoes he was willing to expose his own pain and doubts. In this context, his death was quite untimely, just two years after *Learning to Listen* was published.

"After all-and before all-some people really need help to live. The problem lies in how we

have chosen to view the people who need help and how we have acted on our subsequent good intentions. Our most pressing problem is that we have not listened carefully to those we would serve.

...By living with, working with, and respecting people who are "not in control," we can all learn an invaluable (and sometimes new) social skill-cooperation."

My paperback copy of *Learning to Listen* is now filled with underlines and exclamation points. There are

dozens of lines such as the above that we can reflect on and act on. Doing so would honor the legacy that Herb Lovett left behind, that of helping people gain some control over their own lives without being punished, hurt, or ignored.

Mary Beth Pilewski Paul, M.Ed., is the Book Review Editor for Disability Solutions. She spent many years living and working with people with disabilities. She is the mother of Pete, a teenager who has Down syndrome and autism. Mary Beth lives with her husband and son in central Ohio.

One outcome of reconsidering the least dangerous assumption is a change in how others view people with disabilities. The person-first language movement changed how we describe people with disabilities. Dr. Jorgensen challenges us to change our beliefs about the potential for people with intellectual disabilities and how we support them. One of the first signs that change is beginning to take hold is when it is seen in the content and language of books.

During the editing process for this issue I began to look at the books in the Creating Solutions library. As I did, I realized the latest release sent for review, *Believe in My Child with Special Needs! Helping Children Achieve Their Potential in School* already reflects this shift in attitude toward people with intellectual and other disabilities. My first thumb through, I thought this book was just another guide to navigating the system and crafting an I.E.P. filled

with the usual information. Once I began to read it more carefully, I changed my mind.

Falvey challenges readers to find supports to fit the student. She doesn't stop with stating the fact that students are entitled to supports for success, she challenges readers to reframe how they view supports. One small example is a table in which she educates professionals regarding ways to reframe their thinking titled, "Positive Alternatives to Weakness Statements." In addition, she describes the different methods of creating supports for success.

Most general handbooks stop short of explaining what supports may be useful. Falvey describes them: social

Believe in My Child With Special Needs!

Helping Children Achieve Their Potential in School

by Mary A. Falvey

*Paul H. Brookes Company, 2005.
ISBN: 1-55766-702-0. \$18.95*



stories, creating positive, welcoming environments, and developing friendships are a few examples.

In the end, Falvey, a professor at CSUN Los Angeles and mother of a child with disabilities, has written a guide to the educational system from birth to age 21 that embraces the change in belief system Dr. Jorgensen presents. What makes this book stand out is her clear student-centered approach the highly respectful tone and presentation. And it comes with a bumper sticker, too! —JEGM

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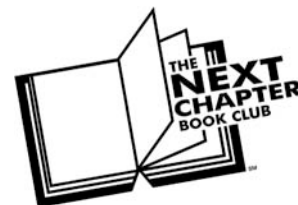
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Suite A-2
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A Resource for Families and Others Interested in Down Syndrome and Developmental Disabilities

Editor, Joan Guthrie Medlen, R.D., L.D.
Book Review Editor, Mary Beth Pilewski Paul

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14535 Westlake Drive
Suite A-2
Lake Oswego, OR 97035
www.disabilitysolutions.org
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