

Deafblind Focus

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Fall/Winter 2003

Fall 2003
Family Learning Weekend

Under the Magnifying Glass:
Recreation and Leisure

Families of Deaf-Blind Children Find Support Group, Friends at Weekend Retreat

(This article was written by Mark Gibson, Assistant Director, Public Affairs, Indiana State University and printed in the Terre Haute Tribune-Star. It is reprinted here by permission.)

In Delaney Buckner's five years of existence she had never known anyone like her four-year-old brother Jackson.

Not long after triplets Jackson, Nate and Josie were born into the Buckner family, parents Joe and Becky began to notice young Jack wasn't tracking objects with his eyes the way Nate and Josey were. He wasn't responding to sounds as well as his siblings, either.

Jackson, born with cerebral palsy, was diagnosed with deafblindness, a condition which affects nearly 11,000 children nationwide, according to data collected by the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind.

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Do you work 16 hour days then go home to bed only to wake up and start over again 7 days a week? Unless you are a work-a-holic, probably not. People spend time nearly every day doing something that is fun or relaxing for them as a way to re-energize. Whether it is taking a walk, playing a ball game or playing board games with friends, everybody has some type of recreation or leisure activity that they prefer.

Most of the time we participate in recreational activities without giving much, if any, thought as to what it takes for persons without disabilities to participate. However, many of the recreational and leisure activities we engage in are either not possible or require adaptations for many children with dual sensory impairments. Their unique needs limit their ability to engage in the same traditional activities as people without disabilities. However, these children still need to be able to take a break from the demands placed upon them and have fun like any kid.

Children with sensory impairments need recreational activities to help them overcome the isolation and lack of independence that comes with being deafblind. It therefore becomes necessary for families and professionals to find ways for children who are deafblind to have quality recreation and leisure activities throughout their lives. Providing appropriate recreation and leisure time is something that any family can do if they follow the simple guidelines.

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Under the Magnifying Glass: Recreation and Leisure

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The first thing to do is to find out what types of things interest a child who is deafblind. Some kids may enjoy playing team sports such as baseball while other may prefer more individualized sports such as bowling. Some children may enjoy arts and crafts activities such as painting or working with clay. Other children may have fun working on group projects such as building sandcastles or working on a puzzle. As much as possible, allow the student to choose what types of appropriate and safe activities they would like to do.

Specific Guidelines

- Choose activities that are age-appropriateness. Students who are deafblind sometimes have difficulty choosing activities that are appropriate for their age. A simple way to determine what is appropriate is to decide if a given activity is something that a student their age typically enjoys. Again, we want the child to choose what they want to do as much as possible in order to foster independence and choice making skills.
 - Identify the child's strengths and weaknesses. One should consider what the child can be reasonably expected to perform and still be a successful and active participant.
 - Maximize the vision and hearing ability the student does have at their disposal. This will help you to make the necessary adaptations needed to allow the child to participate in the recreation or leisure activity.
 - Make sure that a recreation or leisure activity is fun for the child. It would not be beneficial to anyone if the child does not enjoy what he or she is doing and may even create setbacks for the child's development.
- Consult your physician to see if there are health issues that need to be considered for activities that require more rigorous and active participation.

Types of Adaptations

As much as possible, the types of adaptations that you make should not cause the activity to differ from the original. Rule changes can be made to make an activity less complex or restrictive, which will allow for a higher level of involvement from children who are deafblind. This can include adjustments in how teams are formed, how players are positioned, and use of aides within the game.

- A sighted guide may be permitted to move around the bases with a person during a game of kickball or softball.
- Bowling can be adapted so that children can experience the sensation of knocking pins down. This can be done by pushing the students on a scooter board down an "alley" and letting their bodies knock the pins down.
- Allow children to hold a basketball instead of dribbling it.

Changes also can be made in the types of equipment used without deterring significantly from the game.

- Use a ball with a bell inside it to allow students who are visually impaired to locate it.
- Use a rail for guidance in bowling.
- Use a bell, whistle or hand-clapping as directional cues.
- Use a large sheet with "puff" painted symbols and a spinner with matching raised symbols to play a game of "Tactile Twister."

Children who are deafblind undoubtedly want to participate in normal life activities. Their disability often creates limitations for them in terms of their ability to participate in many of the recreational and leisure activities that we

take for granted every day. With a few simple modifications and adaptations, children who are deafblind can fully participate and enjoy any number of games, activities and experiences as their peers. Doing this will help develop the child's independence and help them become active members of their community.

For more information and ways to adapt activities, see Laura Lieberman and Jim Cowart's *Games for People with Sensory Impairments: Strategies for including Individuals of All Ages* and Laura Lieberman and Cathy Houston-Wilson's *Strategies for Inclusion: A Handbook for Physical Educators*.



The following list contains just a few of the recreation and leisure resources available for loan through our Resource Materials Center. To borrow these items or ask about other holdings contact us at 1-800-622-3035.

Blakely K.S., Lang, M.A., & Sosna, B.K. (1995). *Toys and Play: A guide to fun and development for children with impaired vision*. Lighthouse National Center for Vision and Child Development, Lighthouse, Inc.:New York.

Clyne, M., & Cummings, L. (1992). *A life of leisure: Leisure option for persons with dual sensory or multiple impairments*. Philip J. Rock Service Center: Glen Ellyn, IL.

Lieberman, L.J. & Cowart J.F. (1996). *Games for people with sensory impairments: Strategies for including individuals of all ages*. Human Kinetics: Champaign, IL.

Lieberman, L.J. & Houston-Wilson, C. (2002). *Strategies for Inclusion: A handbook for physical educators*. Human Kinetics: Champaign, IL.

Ray, S.J., Ray, M.T., & Green, F.P. (1997). *Community recreation and people with disabilities: Strategies for inclusion*. Paul H. Brookes: Baltimore, MD.

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Family Learning Weekend

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But as the Bucker family prepared for a weekend getaway, Becky Bucker recalled, "Delaney said 'I don't know any other kids like Jack.'" Becky assured her she would meet them that weekend.

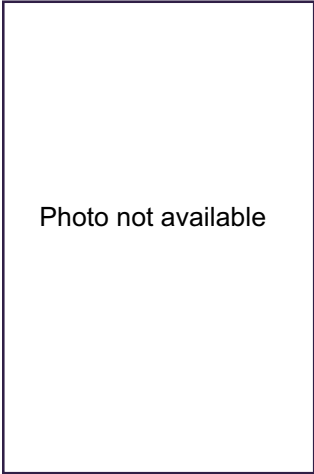
The Buckers recently took part in a Deafblind Family Learning Weekend sponsored by Indiana State University's Blumberg Center and its Indiana Deafblind Services Project. Twelve families with children who are deafblind took part in the weekend event at Bradford Woods, an outdoor retreat near Martinsville, Ind. In all, 30 children - deaf-blind and their siblings - and 24 adults participated.

Participants said the camp outing offered a support group setting by bringing together families who shared the common challenges posed in raising children with the dual impairment. Becky Bucker said not only does it help Jackson realize there are others out there like him, "It helps with my other children . . . It gives them an idea of the other kids out there. And we're doing something fun as a family. We're not going to a doctor's appointment, we're not at a clinic; we're just going to get away."

While Indiana State University special education students and school psychology students interacted with children who are deafblind and their siblings, parents participated in morning workshops with Dr. Lauren Lieberman, an expert in adaptive physical education and inclusion strategies.

Lieberman, associate professor of adaptive physical education at the State University of New York Brockport, said the biggest challenge to integrating children who are deafblind into society is attitudinal. "A person who is a teacher, no matter how sensitive they are, might not believe that a child who is deafblind can bat a ball, or ride a bike or swim in the deep end," said Lieberman, who has been working with children who are deafblind for nearly 15 years.

Communication is another major challenge. When someone has limited sight and hearing, the primary alternative for transferring information is tactile signing, a language method using hand-to-hand touch.



With fewer than 300 students who are deafblind reported in Indiana, few people are familiar with the tactile sign language. But the Family Learning Weekend brought some of them together.

“I can’t tell you how many kids followed me

around simply because I could communicate with them,” Lieberman said. “It was overwhelming to them to be in a place where so many people could ‘talk’ to them. Isolation and loneliness is pretty common to kids who are deaf-blind. Affiliation, the sense that you’re part of a group, that’s extremely difficult to feel because you don’t know who all is around you, much less feel a connection there.”

Enrico Garcia, of Terre Haute, has two adolescent boys who are deaf-blind, 18-year-old Joshua and 16-year-old Jacob, students at Terre Haute South. “The biggest challenge right now is dealing with their emotions (and) their acceptance of their disabilities, because they want to be independent,” Garcia said. “They want to be like everyone else.”

Garcia said that people at first were unsure how to behave around Joshua and Jacob as their vision and hearing deteriorated. They often responded by simply not interacting with them. But as teachers and classmates became familiar with the boys and their disabilities, some began picking up “finger spelling,” or tactile signing. “Soon, everyone wanted to know how to do it,” Garcia said. That helped break the ice. “When other students and peers find out their disability is not contagious, they’re more apt to approach them and communicate with them,” Garcia said.

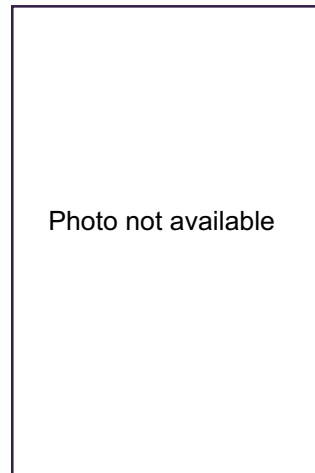
This year’s retreat was the third for the Garcias. “They were happy to be there,” Enrico Garcia said of the boys. “They look forward to going there all the time.”

The retreat workshops usually focus on a different topic each year. Past workshops have promoted discussion on behavior and communication. This year’s workshop dealt with recreation and leisure activities. “We learned a lot of things as far as activities for the boys,” Garcia said. “We also found different resources that we can access. And also the interaction between the parents with children of similar disabilities, that’s a boatful of knowledge in itself.”

Bucker added that the program provides a support group for the families. “We have made some good friends with other families,” she said. “There’s just a sense of belonging because nobody cares about the noises you make, nobody cares about the chaos in your family because we all deal with the same issues.”

During the afternoon activity session, Lieberman introduced families to games like body bowling, adaptive baseball and tactile twister to show ways families could participate as a unit in an activity. Bucker said families learned “We can still be active and have fun and get our kids involved, even if they’re in a wheelchair.”

In tactile twister, three-dimensional shapes made of puffy paint provide tangible objects, rather than colored circles, for participants to reach for. In adaptive baseball, batters hit a ball off a tee and are guided around the bases while outfielders, guided to the ball, collaborate to pass it down a human chain in an attempt to limit the number of bases the hitter reaches. In body bowling, a deaf-blind child sits on a cart and is rolled into a formation of bowling pins – they feel the movement and the contact with the pins.



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Fall 2003 Family Learning Weekend

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Lisa Poff, program coordinator for the Indiana Deafblind Services Project at ISU's Blumberg Center, said many activities for people without disabilities don't make sense to people who are deaf-blind. In bowling, for instance, "if you can't see the pins at the other end of the lane and you can't hear them fall, you don't see the point," she said. "The ball just disappears and reappears in front of you."

But in body bowling, children experience the trip of "the ball" and feel the impact of the pins when they fall over. Lieberman said those feelings are very important to people who are deaf-blind. "In our research, we've found that kids who are deaf-blind love certain things. They love to move and feel movement and feel things around them, so things like swinging or swimming or sliding down a sliding board feel good to them," she said.

And Bucker said the weekend provided great ideas for integrating her whole family into activities. "The challenge we face in a lot of social activities is finding out how we can still do things as a family without having to always focus on our special needs child, getting them to interact as siblings because he's not as functional," she said.

ISU student Chad Ryan was glad to have the opportunity to observe real-life interactions between the blinddeaf studentns and their families. "I was impressed that you can pretty much take anything that a 7, 8, 9-year-old can do and adapt it to any number of kids, as long as you can make it something that they can be successful at," said Ryan, a second-year grad student from Rutland, VT., working on a masters degree in psychology.

For ISU student volunteers like Ryan, the weekend was an eye-opening experience. "It's one thing to talk about it in a class," Poff said, "but it's another thing to see how that child functions in an environment and how the parents meet and deal with challenges that they face in real life."

For Amanda Wilson, a freshman special education and elementary education major from Fort Wayne, the weekend offered her her first glimpse at the needs of deaf-blind children. "We got to talk with the families and learn how communication differs

with families with kids that are deaf-blind to families with kids that aren't," she said. "Communication as a whole is different, anything from knocking on the table to get the child's attention to walking across the room instead of saying their name."

Other Indiana State students had volunteered for the family weekend before. Both Ryan and Beth Browning were participating for the second time.

Ryan said the program offered an excellent opportunity to spend time with populations with special needs and get a sense of their unique needs and how they adapt to their environment. "These kids really just want to experience as normal a life as possible and enjoy the things that people without disabilities enjoy," Ryan said. "Given the proper accommodations, that can be accomplished."

Browning, a senior speech language pathology major from Shelbyville, added the weekend provided an invaluable training opportunity. "It's a really good experience for me as a college student to be exposed to students with dual disabilities and find out what life is like for them so I can go out in the future and do my job better," she said.

"It's a great experience overall for the college students to be involved."

Wilson, a Blumberg scholar, said the weekend reaffirmed for her what she wants to do with her life. "I was really touched," she said. "It was amazing. I love working with children. This weekend really helped me decide, yeah, special education is exactly where I want to be and it's what I want to major in."

"Working with the children, I was blown away at how receptive the kids are. I was able to see that it's the type of occupation where I'm going to be able to have a relationship with the kids and help them grow and I'm just real excited about that."

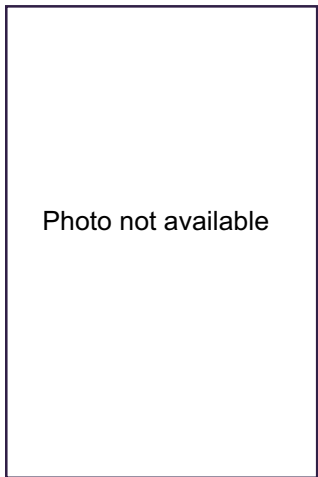
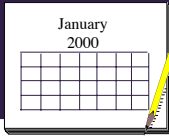


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Upcoming Events

March 11, 12, 13, 2004: *2004 Indiana Early Childhood Conference, Indiana Convention Center, Indianapolis, IN*

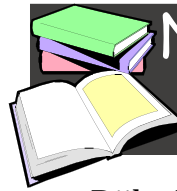
The Indiana Early Childhood Conference is the largest conference in Indiana geared toward early childhood professionals and parents of children birth through 8-years. The IAEYC state conference allows people in the early childhood field to network with other professionals, as well as gain resources they can use each day to increase the quality of care and education for young children.

The conference will include:

- *Over 190 workshops in 12 different tracks.
- *More than 50 exhibitors from across the nation to distribute information and sell educational products and services.
- *Some of the top speakers in the nation from the field of early childhood.
- *More than 3,000 attendees.
- *Activities to motivate, stimulate, and educate all those that attend.

Conference books highlighting conference workshops, keynote and highlight speakers, and registration forms are mailed out at the end of December each year. To receive a conference book call (317) 356-6884 or e-mail conference@iaeyc.org to have a book sent to you.

The 2004 online registration will open soon! Visit www.iaeyc.org for more information about registration costs and how to register on-line.



New in the Resource Materials Center

van Dijk, J., & de Kort, A. (2003). *Living with Charge: Assessment, prevention and intervention of challenging behavior.* AapNootMuis Productions: The Netherlands

This is an interactive CD-ROM on challenging behaviors that are commonly associated with Charge Syndrome. Both the stereotypical behaviors and the reactions of service providers are demonstrated with four "Chargers" of varying ages.

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