

Spring 2009

# THE Connection

News and Information from the National Court Appointed Special Advocate Association



*Like a flower...*

*A child can  
overcome, heal  
& grow...*

*Into Something Awesome.*

*Angel J. Harris '09*

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# volunteer voice

## Pat Stackhouse

CASA Volunteer  
Miami County CASA Program  
Peru, IN

I received a telephone call one afternoon saying, "You have been recommended as a CASA volunteer. Would you be interested?" It took me all of 10 seconds to say, "Yes." I took the CASA classes, passed the requirements and was sworn in as a volunteer. That was 18 years ago.

Eagerly I waited for a case. I was ready. Nothing came. I'm not a real patient person by nature. Finally, the phone rang. It was the CASA director. She said, "We have a case for you. Can you come to the office and pick up the file?"

Promptly and enthusiastically I went to the office. I dug into the file and became an advocate for an older teenage girl with a beautiful name. I researched the case, made my first of many visitations, wrote my report and believed I was ready for court. My first experience in court turned out to be a "baptism by fire." A tough attorney put me through the paces.

Since becoming an advocate I have served over 30 children. Four years ago, my husband John, formerly CFO of a newspaper group, joined me as a co-CASA volunteer. Together we make a strong team. We have formed a special relationship with each child—the oldest being 16 years old and the youngest just 2.

We have dealt with children who were sexually abused, neglected, emotionally hurt—children who struggled for their very self-esteem. They were all looking for love and proper concern from their caregivers.

Presently we share four cases. People say to us, "I could never do what you do." We have only one answer for them: "Sure you could."

Serving the children is the most rewarding thing I have done besides being a wife to John and a mother to our seven children. John adds, "I feel that standing up in court for what we believe to be in the best interest of the child is one of the most important parts of being a CASA."

One of the more satisfying cases we have encountered since becoming co-volunteers involves an older child who chose to maintain a relationship with us after we facilitated her move into a stable environment—a happy ending that followed placements in eight foster homes. And there are the little things, like a letter I received from a teenaged girl telling me how much I had helped her as a volunteer, that make it all worthwhile.

Do we leave the cases at the children's doorstep following visits? This is impossible for us. We certainly take the cases home. In fact, much reflection is done in the day and often into the night. Many of our discussions center around the children and how we can help them.

Do we ever get discouraged? Of course we do. But have we thought of quitting? No.

John explains, "What do you do when you get frustrated or overwhelmed? You step back, try to look at the big picture and remember why you are there."

We both remember, plain and simple, that our interest is for the child and his or her well-being. Is being a CASA volunteer stressful? Frankly, being a CASA is not for sissies. But if you want to make a difference and leave the world a better place, being a volunteer advocate could be for you. Words cannot express the way it has made us feel making a difference in the children's lives. The CASA program has given us this opportunity.

We would like to end by saying: God bless the children and all the volunteers everywhere who are advocating for them. 📣



Husband-and-wife co-CASA volunteers  
John and Pat Stackhouse



# What If?

Michael Piraino  
CEO, National CASA

I took this photograph on January 20 in front of the United States Capitol. It expresses something I love about America at its best: a sense of hope, common purpose and willingness to get to work to make things better.



My father, in a letter he wrote to our new president, referred to the US as a “nation-community.” I like that phrase. It means that all of us—Republican or Democrat, young or old—have not just the right but the responsibility to come together in times of trouble. That is definitely how it felt that cold day on the National Mall.

So I wondered: What if a nation-community came together on behalf of our children, especially those who cannot live safely at home? What if the emotions you see on the faces of the people in this photograph could be harnessed around the goal of ensuring the well-being of every child in out-of-home care?

We have, in fact, been given a tool that could help create this. The Fostering Connections to Success and Increasing Adoptions Act of 2008 could initiate a series of decisions in Washington, DC, and in the states which would focus on the well-being of children and youth in new ways. At a reception on Capitol Hill celebrating the act’s passage, a senator said, “Now is the time to solve big problems.”

One of those big problems faced by older youth is transitioning out of care and, all too often, into homelessness, poverty, unemployment and lack of health care. Here is a big

problem our nation-community should solve. We owe it to these young people because the state took over responsibility, at least

for a time, for their upbringing. What parent would drop them in such a time of need?

My proposals for older youth include:

- Eliminate the idea of being “in foster care.” What young adult really wants to be in someone else’s care? We should blur the hard distinction between being in care and not. These young people should be like my own sons: taking increasing responsibility for their own adult lives but staying connected to adults they can rely on.
- Conceptualize this period as a partnership with young adults to smooth their paths to success.
- Broaden the thinking around permanency when it comes to young adults in care beyond adoption or reunification. Both solutions work for many older youth. For others, especially when these young adults direct their own transition, it may be life-long connections to two or three family members or other significant adults that make the difference.
- Change our conception of the role of court processes from adversarial to problem-solving.

We should also, perhaps, change our conception of ourselves. I believe these young adults still need us to advocate for them. But they will be less likely to need someone to substitute their own judgment and more likely to need reliable adults to advise and encourage them.

What will really make this period a success for young adults will not be a project. It will not be a single targeted service. It *will* be a web of relationships that help them identify goals, recognize what barriers they face and commit to specific strategies to achieve success. It will be a time to move from being advocated for to self-advocacy.

There is scientific evidence that such an approach could dramatically improve outcomes. An experiment by researchers at the University of Michigan found positive impacts that increased over time and lasted at least two years (Daphna Oyserman, Deborah Bybee and Kathy Terry, “Possible Selves and Academic Outcomes: How and When Possible Selves Impel Action,” *Journal of Personality and Social Psychology*, 2006, Vol. 91, No. 1, 188–204). The African-American and Hispanic students in the study achieved more academically, demonstrated less



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# THE Connection

News and Information from the National Court Appointed Special Advocate Association



A publication of the National CASA Association, representing 1,018 program offices and 68,842 CASA volunteers serving 240,894 children nationwide.

The nationwide Court Appointed Special Advocate (CASA) movement mobilizes community volunteers to speak up for the best interests of abused and neglected children.

CASA volunteers work for the judge to review and monitor cases of children who become part of the child protection system. CASA volunteers work closely with the child and family to bring an independent assessment of the case to court, recommending to the judge what is best for the child's future.

CASA volunteers help prevent children from becoming "lost" in the child welfare system. They give children a chance to grow up in safe, permanent homes.

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Unless otherwise noted, children in *Connection* photos are not from actual abuse and neglect cases.



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## Cover Artist



Artwork for this issue's cover was created by Angel D. Adams. An alumna of foster care, Adams is currently a student at the University of Alaska Anchorage.

# Coordinating Treatment for Children in Foster Care with Physically Disabling Conditions

Moir Szilagyi, MD, PhD  
Vice-Chair  
American Academy of Pediatrics Task Force on Foster Care



All children and adolescents in foster care are classified as children with special health care needs by the American Academy of Pediatrics. This commentary, however, addresses the 5–10% of children and teens in foster care with chronic, physically disabling conditions. These youth may be cognitively normal, as are many children with spina bifida, for example, or they may have significant cognitive impairment. Additional stressors on these children include the emotional impact of childhood trauma, separation and loss as well as ongoing uncertainty, issues of identity, lack of self-efficacy and alienation related to their disability.

Children and teens with severe physical disabilities may enter foster care for reasons of abuse and neglect or because their parents were overwhelmed by their care, lacking the knowledge or resources to safely provide for them. The exact numbers of children and teens in foster care who have significant physical disabilities, their placement stability and lengths of stay are unknown because such data is not collected. Some are infants recovering from premature birth who will, with excellent care, outgrow their disabilities. Others have conditions that are permanent or that may even worsen over time.

Often the disabled child is the only child removed from the family

of origin. Maintaining a child's attachment to parents, siblings and extended family should be a priority in the absence of compelling reasons not to do so. When appropriate, foster parents can enrich the child's life by engaging birth parents to encourage visitation, phone contact and attendance at special events in the child's life. This may be more challenging if the child has communication difficulties, transportation needs or multiple medical problems that limit the frequency and duration of visits. Birth parents may experience guilt about their inability to care for their child and even decrease their visit frequency over time if they feel the child is better cared for elsewhere. Loss of family connections then becomes an added source of emotional trauma for the child or teen.

We know little about placement stability for this population, but we do know that length of stay in foster care is often longer. Children with emotional and behavioral problems, in addition to their physical disabilities, are less likely to experience stable placements or to reunify.

Foster parents caring for youth with severe physical disabilities should receive extensive training in the child's health needs prior to placement. The reality, however, is that this seldom happens. Foster parents receive limited training

by hospital staff when a child is admitted to their home from the hospital. However, there may not be any health training, medication or equipment provided when children enter foster care from other settings.

Children and teens with a physically disabling condition covered by Medicaid may not have access to all the health care they need. They should have ongoing primary care services over time in the context of a "medical home" (see definition in sidebar). Managing and coordinating all of their subspecialty, educational, medication, equipment, developmental and other services is often a Herculean task—and one for

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**A medical home** addresses how a primary health care professional works in partnership with the family/patient to assure that all of the medical and non-medical needs of the patient are met. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective.

—American Academy of Pediatrics website

which foster parents and child welfare caseworkers may be ill equipped. The primary care physician should be helpful with this. In addition, if the child has Medicaid Managed Care, the insurance agency should assign a care coordinator to assist.

CASA volunteers and caseworkers should also be aware of the following:

- Health information should be obtained from prior health providers, the birth parent/guardian, schools, childcare settings and older children with disabilities themselves.
- Children with chronic physical conditions should have a health assessment within 24 hours of each placement and a comprehensive health, mental health, dental and developmental/educational evaluation within 30 days of placement.
- Caregivers often need access to home health services. It is also helpful to assist caregivers with accessing respite services, which should be covered by Medicaid or other sources but are in very limited supply.

Everyone involved in the care of a physically disabled child or teen should remain alert to the possibility of child abuse or neglect that may occur during unsupervised moments in visitation, in the foster home, in childcare settings, at school, etc. Children with disabilities, especially those dependent on others for personal care or those with communication difficulties, are at particular risk for neglect or physical, emotional or sexual abuse.

The CASA volunteer has a special role in the life of the disabled child or teen in foster care. These children often feel that they lack a voice in their own care, and the volunteer may be best situated to listen, advocate and facilitate. CASA volunteers should be aware of and advocate for services that children with physical or other disabilities are *entitled* to under federal law. Medicaid's child health component, known as the Early and Periodic Screening, Diagnosis and Treatment

(EPSDT) program, requires that Medicaid cover a very comprehensive set of benefits and services for children. EPSDT is intended to ensure that children have access to:

- *Early* identification of health problems
- *Periodic* health assessments including physical, mental health and developmental *screening* at specific intervals
- *Diagnostic* testing for any concerns that arise during screening
- *Treatment* for any problems identified

Another federal law, the Child Abuse Prevention and Treatment Act, was amended in 2003 so that any child up to 36 months of age with an indicated child abuse or neglect referral is automatically eligible for a developmental evaluation through Early Intervention. In addition, the Individuals with Disabilities Education Act (IDEA) requires that each child with a disability have a written individualized education program (IEP). As of 2005, IDEA also provides protections for children transitioning among school districts, a common occurrence in foster care. School districts must follow an existing IEP from a prior school district until they either adopt it themselves or develop and implement a new one. The CASA volunteer can cite IDEA to advocate for optimal educational placement and services on behalf of the child.

Compelling ethical issues may arise during the child's stay in foster care. Concerns about confidential treatment and consent are common. The CASA volunteer and caseworker should ensure that all the stakeholders have the information necessary to provide appropriate care for the child while protecting and guarding the privacy of the child and family. Health providers should make ongoing determinations of a teen's capacity to consent for health issues protected under mature minor laws (reproductive health care, for example).

Adolescents, when cognitively able, should be partners in their own health care, together with their caregivers and caseworker. Occasionally, a child's health status may deteriorate to the extent that decisions about extraordinary means and end-of-life care need to be considered; such decisions should include all the child's parents and others as appropriate as well as be rooted in the best interests of the child.

Children with complex physical disabilities or chronic medical conditions will eventually transition out of foster care, either through reunification, adoption, state guardianship or emancipation. Planning for this transition involves ensuring that:

- The child's health plan is part of the permanency plan.
- The child's complete health records are transferred to new providers.
- The IEP is transferred if there is a change in schools.
- All medications and medical equipment are available to the new caregiver—or the emancipating youth—at discharge.
- The new caregivers and the youth, when possible, are well educated about the child's health needs and care.

As we have seen, managing a child's illness or disability can be extremely complex. CASA volunteers often play a critical role in supporting children in care as they navigate a variety of medical and educational systems. 📌

*Moir Szilagyi, MD, PhD, is associate professor of pediatrics at the University of Rochester and medical director of Starlight Pediatrics, a medical home dedicated to improving health outcomes of children in care. As vice-chair of the American Academy of Pediatrics Task Force on Foster Care, her interests include emotional, behavioral and developmental health of children in care, therapeutic parenting and improving health care quality.*



# CASA Volunteers and Physically Challenged Youth: Partners in Empowerment

Brandi Lyn and Alexa Curtis  
CASA of Nevada County  
Nevada City, CA



## Brandi

Hi. My name is Brandi Lyn. I am 14 years old and have lived in two foster homes. I also have epidermolysis bullosa, otherwise known as *EB*. *EB* makes it so my skin doesn't stick to my body. I wear bandages to cover my wounds to decrease the chance of infection and injury. My bandages need to be changed and my wounds cleaned several times a week. *EB* also affects the cornea of the eyes and skin of the mouth and throat (esophagus). This makes it difficult to swallow, so I have tube feedings during the night to improve my nutrition. *EB* also causes webbing in your hands, making them extremely small and very difficult to use. Walking is very painful for me because my feet are sensitive to friction and I get blisters, so I need to use a wheelchair for anything but short distances.

Some people call my condition a *disability*, but I prefer to be considered *physically challenged*. When people hear the word *disability*, they sometimes assume that I am incapable, incompetent or unable to understand. I am not incompetent; I have extra challenges, not disabilities. Growing up with these challenges was often frustrating. I had to be extra careful playing so that I didn't scrape my skin. It was frustrating to stop playing or leave a television show because it was time for a two-and-a-half-hour dressing change. I have missed a lot of school because of all my medi-

cal appointments, and I have been separated from my friends and put in special education classes. But it hasn't been all bad. Long dressing changes and travel to medical appointments have allowed me to have one-on-one time with my care providers. I also appreciate that the special education classes have offered me more physical protection and individualized instruction.

Moving from family to family has been scary, lonely and heartbreaking. Scary because you don't know what is coming at you. You don't know if the family is going to be mean or cool. You are going to people who have no idea who you are. The first time my new foster mom had to give me a bath and change my dressings was so embarrassing. I hardly knew her, and I was 13 years old! It is lonely because you have no one you know in the home and heartbreaking because you are being separated from the people you have known your whole life, like my brothers.

I met my CASA volunteer, Alexa, when I arrived in my new foster home. I had no idea what CASA was. To me it was just another one of the peoples trying to help. What has been most helpful about having a CASA is that Alexa takes the time to get to know me as a person. When she speaks for my best interests, I feel like she really knows who I am. She is also very good about staying in touch and keeping me informed. It is so frustrating not to

know what is going on! My advice to volunteers working with kids with challenges is not to assume we are incompetent or mentally retarded. I would much rather you ask me directly what is wrong with me than try to guess. I actually like it when people ask because it is fun to explain and educate people, but correcting people's assumptions is really frustrating. Also, kids with challenges in foster care need their space. When they are ready, and if they need help, they will come to you. I feel like I am even more overly protected than other foster kids because of my challenges. But—hello—I'm 14, and I need some independence here.

## Alexa

Brandi is my first CASA assignment, and it has been a wonderful experience. Of course the greatest joy in this work has been the opportunity to establish a relationship with her. She is a delight and an inspiration. Although I was originally assigned to Brandi because of my nursing background, CASA volunteers without medical experience should not be discouraged from working with challenged youth. Medically inexperienced advocates may simply need additional support in adjusting to the youth's physical limitations and in learning the medical terminology necessary to communicate effectively with care providers and the judicial system.

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### Tips for Volunteers Working with Challenged Youth

1. Honestly assess your comfort level in working with challenged youth before accepting an assignment.
2. Work closely with your CASA supervisor to establish a positive match.
3. Learn as much as you can about the youth's condition through research and consultation with the professionals involved.
4. Don't be afraid to ask youth questions; they are the experts on their conditions.
5. After learning as much as possible, look beyond the limitations and appreciate the individual.
6. Let go of your assumptions.
7. Don't be intimidated by all the *peoples*; help bridge communication.
8. Plan your outings/meetings with consideration to the youth's condition, including treatment schedules.
9. Share your authentic self and enjoy the relationship.
10. Be a model of advocacy and empowerment.

One of my initial concerns in working with Brandi was where I fit in with all her *peoples*, as she describes them. All foster youth have an array of professionals assigned to their case; with physically challenged youth, you add an additional stack of specialists and sub-specialists. I felt like I might just become another card cluttering Brandi's wallet. However, I learned that the CASA role is different. Our relationship is less formal and more intimate, bringing another perspective to the process of deciding what is in the best interest of the child. This is particularly important with a challenged youth who can feel burdened by assumptions. I also quickly learned that communication among all the *peoples* can be

cumbersome. As Brandi expressed, I think she has been most grateful for my attempts to keep her well informed.

One of my initial frustrations as a CASA volunteer was the perceived lack of power. As a nurse, I am accustomed to making and implementing decisions. As a CASA, my power is limited to voice and advocacy. But combined with persistence, these can be powerful tools. From my perspective, working with Brandi has come down to empowerment, supporting her in learning to productively advocate for her own needs. Writing this article together is a great example of how CASA volunteers and youth can become partners in empowerment. 📩

## Judges and others share insights into the work of CASA volunteers in the latest issue of *The Judges' Page*.

The most recent issue of *The Judges' Page* spotlights extraordinary achievements of CASA programs and includes reflections by judges on the work of CASA volunteers.

*The Judges' Page* is an online newsletter edited by Judge J. Dean Lewis (*retired*) that informs not only judges but also CASA volunteers, staff and representatives of other child welfare organizations. Published by National CASA three times a year, each issue includes articles by expert authors who are members of the judicial, legal and child welfare communities.

**Subscribing is free.** Go to [casaforchildren.org](http://casaforchildren.org) and click on "Judges' Page" (located in the top bar).

*The Judges' Page* is co-sponsored by the National Council of Juvenile and Family Court Judges and the National CASA Association.





# Constant, Demanding and Daily: The Challenges Faced by Foster Youth with Chronic Illnesses and Severe Disabilities

John M. Palladino, PhD

*"We found his 'amazing!'" Bridget James cried. A mother of two children with severe disabilities, James remembers the day her 8-year-old son was diagnosed with Asperger's syndrome. "All children with chronic illnesses and severe disabilities, including youth in foster care, are amazing. We knew his diagnosis meant we, his family, had to educate ourselves because we had to change. We needed to adapt to let his amazing out." Now a volunteer with CASA/Children Worth Saving, Inc. in Dodge City, KS, James makes excellent use of her expertise on disability.*

Suzanne Roberts, MD, pediatrician at Los Angeles Children's Hospital, coordinates medical care for abuse and neglect victims in what could be described as an ideal approach to treating foster care youth. The hospital houses one of Los Angeles's six medical hubs for new foster care entrants. Intervention plans are created after combined medical and mental health screenings. Foster parents continue to access the centers' services throughout the duration of a child's placement in their home, and birth parents have the option of continuing their children's intervention plans upon reunification. Addressing youth's medical needs at the onset of their foster care journey allows Dr. Roberts and her colleagues to address what she terms as the "constant, demanding and daily" needs of foster care youth with chronic illnesses and severe disabilities.

Although a minority within the foster care population and among CASA cases, youth with chronic illnesses and severe disabilities suffer daunting challenges that perplex even the most veteran CASA volunteer. Programs like that of Dr. Roberts at Los Angeles Children's Hospital are rare, and the lack of upfront medical attention results in CASA volunteers' uncertainty about how they should best intervene and advocate. The purpose of this article is 1) to share with readers the prevalence of chronic illnesses and severe disabilities among children in foster care; 2) to provide insights from volunteer advocates, foster parents and other professionals about the challenges birth parents and foster parents encounter when caring for these children; and 3) to present implications for how volunteers might promote the overall well-being of this often-overlooked population.

## Prevalence of Chronic Illnesses and Severe Disabilities

National census data about chronic illnesses and severe disabilities in foster care is nonexistent. Data that is available fails to paint a complete picture of the problem. Studies in various locales that have attempted to determine the rate suggest that at least 33% of the foster care population has a chronic illness or severe disability. The rate increases to approximately 40% for maltreated infants under the age of 3 who enter foster care due to neglect, the most common reason for removal from a primary caregiver. Furthermore, the presence of more than one chronic illness is common and proportionately higher than in the non-foster care population, with asthma as the most reported condition. (See sidebars for references to these studies.)

Jayanthi Kasiraj, PhD, clinical psychologist in the Department of Pediatrics, University of Davis Children's Hospital (Sacramento, CA), specializes in the treatment of victims of abuse and neglect. "The problem with getting a better sense of the scope is that we do not dually diagnose issues," says Kasiraj. "For example, I recently treated a young boy in foster care who was referred to me because of his extreme restlessness. In reality, we needed to revisit his asthma medication, which can have biological reactions that cause restlessness. Although the referral I received was for behavior, the issue was medical."

Sara Cohen, a volunteer with the Enotah CASA Program in Dahlonaga, GA, had served as a foster parent for more than 40 years prior to becoming an advocate. She often cared for medically fragile infants because of her nursing background.

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She considers the prevalence higher than what is reported. “When a child is removed from a caregiver’s home, we need to assume that special education and chronic illnesses will be an issue because their root causes oftentimes are neglect and deprivation,” Cohen says.

Regardless of the prevalence rates, the outcomes are clear—chronic illnesses and severe disabilities significantly reduce the likelihood of family reunification for children in out-of-home placement. CASA volunteers must often advocate for the well-being of children with chronic illnesses and severe disabilities within a three-pronged framework: 1) accessing services for this population, 2) ensuring that care providers support birth parents as they assume greater responsibility for their children’s medical care and 3) ensuring that foster parents’ potential stress and burnout are addressed.

### Service Coordination

Two federal laws target early intervention for infants and toddlers entering foster care with chronic illnesses and disabilities. First, the *Child Abuse and Prevention Treatment Act* (CAPTA) outlines the need for integrated social, legal, health, mental health and educational services. Second, the *Individuals with Disabilities Education Act* (IDEA) contains a specific section addressing early intervention services for infants and toddlers. States requesting federal funds for these programs (known as Part C of IDEA) must provide a description of their policies and procedures that require a referral for early intervention services. This applies to any child under the age of 3 who is involved in a substantiated case of child abuse or neglect, or who is identified as

affected by illegal substance abuse or who has suffered from withdrawal symptoms resulting from prenatal exposure.

Despite the mandate, coordination between the judicial system (CAPTA) and the educational system (IDEA) is fragmented. Although judges may require that families coordinate their own access of early intervention services for their children as part of a reunification plan, these are voluntary programs. Additional fissures exist between the court and education systems in regard to Part B, the section of IDEA that pertains to students with disabilities enrolled in K-12 public schools and their access to intervention services. Therefore, it is important that CASA volunteers facilitate conversations

that ultimately lead to youth’s placement in existing intervention programs.

Jeanie Zortman, a governor appointee to the Kansas Commission on Autism and a volunteer with CASA/Children Worth Saving, Inc. in Dodge City, KS, cautions against advocates’ hesitations to grapple with these laws. “CASAs need to keep up-to-date with special education laws,” says this mother of an autistic child. “Yes, bureaucracy is frustrating, but education is the *only* time to access certain intervention services. Keep in mind—we are about creating adults. Young children with chronic illnesses and disabilities need all the early intervention they can obtain for the best possible outcomes down the road.”

Volunteer Jo Ann Engquist with Harmony House CASA, Inc. in LaPorte, IN, is a former special education teacher and administrator from Michigan City. She recollects her experiences as a volunteer for a special education case, a five-year assignment that included numerous foster care placement turnovers: “The CASA can be the one constant who knows about the child’s intervention plans and access to services,” she says. “This responsibility is extremely important when foster home changes mean school placement changes too. We need to be the fountain of information who can say, ‘Here are the intervention services that were in place at the last district.’”

It is important for all birth parents and foster parents to educate themselves about a child’s illness or disability. Many hospitals, particularly children’s hospitals, have family resource centers that will research and supply families with readable information about a particular condition.

## Common Chronic Health Conditions and Special Education Needs Among Youth in Foster Care

### Chronic Health Conditions

- Anemia
- Asthma
- Cerebral palsy
- Chronic heart condition
- Diabetes
- Eczema/other skin diseases
- Fetal alcohol syndrome
- High blood pressure
- HIV/AIDS
- Birth defects (for example, cleft palate)
- Respiratory problems
- Repeated ear infections
- Severe allergies
- Sickle cell anemia
- Spina bifida

### Health Conditions Leading to Special Education Needs

- Autism
- Emotional impairment/behavior disorder
- Hearing impairment/deafness
- Cognitive impairment (mental retardation)
- Orthopedic impairment
- Specific learning disability
- Speech or language impairment
- Traumatic brain injury
- Visual impairment/blindness

*Source: National Survey of Child and Adolescent Well-Being, No. 7: Special Health Care Needs Among Children in Child Welfare, United States Department of Health and Human Services, Administration for Children and Families. Available at [acf.hhs.gov/programs/opre/abuse\\_neglect/nscaw](http://acf.hhs.gov/programs/opre/abuse_neglect/nscaw).*

their children by referring them to appropriate services. CASA volunteers should be aware that some birth parents also have disabilities that may hinder their successful use of services for themselves or their children. These occurrences will require service delivery accommodations designed to realistically engage birth parents to the maximum extent possible.

Kristen Hines, executive director of CASA/Children Worth Saving, Inc., recalls identifying the need for a volunteer to advocate for a failure-to-thrive baby and to be particularly sensitive to the needs of his birth parents, who neglected the infant due to their mental retardation: "The court had ordered parenting classes for these parents, but the content

Also see the Web-Based Resources and Components of a Comprehensive Health and Development Assessment sidebars for sites to help you as you begin your research.

### Birth Families

The complexities of chronic illnesses and severe disabilities may cause youth to linger in foster care. CASA volunteer involvement is critical to promoting permanency objectives rather than long-term foster care. As they do so, advocates have a unique opportunity to enhance birth parents' skills in providing the medical and special care of

was delivered at too fast a pace," she says. "Because of their disabilities, they did not know how to apply what they should have learned." The volunteer assigned to the case attended the parenting classes and facilitated action plans for the birth parents to implement when providing overnight care for their baby.

### Foster Parents

Many foster parent training programs do not account for chronic illnesses or severe disabilities, requiring foster parents to learn as they go. The stress and constant demands on their time to provide treatment can result in their inability to give the long-term care their foster children typically need. Changes in foster home placements further perpetuate breakdowns in coordinated medical interventions. Thus, volunteers may also need to advocate for services to support foster parents in their ability to provide stabilized care.

CASA director Hines often encounters foster parents in Dodge City, KS, and understands their extensive involvement in their foster children's lives. Foster parents must often drive at least three hours to Wichita or eight hours to Topeka to access Medicaid-funded specialized services for the children in their care. Dodge City is one of many rural and suburban areas that lack access to the comprehensive services necessary for chronically ill foster children who have Medicaid insurance.

Sara Cohen, the Georgia CASA volunteer and former foster mother with more than 40 years of experience, believes that well intentioned foster parents need help



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# Web-Based Resources on Illness/Disability

## American Academy of Pediatrics Committee on Early Childhood, Adoption and Dependent Care ([aappolicy.aappublications.org](http://aappolicy.aappublications.org))

The developmental issues important for young children in foster care are reviewed in the committee's publication *Developmental Issues for Young Children in Foster Care*. Additional topics addressed relate to parental roles and kinship care, parent-child contact, permanency decision-making and the components of comprehensive assessment and treatment of a child's developmental and mental health needs. Search for the publication title at the website above.



## American Bar Association (ABA) ([abanet.org/child/education](http://abanet.org/child/education))

The ABA Legal Center serves as a national technical assistance resource and information clearinghouse on legal and policy matters affecting the education of children in the foster care system. Especially useful is their *Special Education Decision-Making* series.



## American Lung Association—Asthma ([lungusa.org](http://lungusa.org))

*Open Airways for Schools* is the American Lung Association's elementary-school education program for children with asthma. *Open Airways* teaches children to understand and manage their illness so they can lead healthier lives.



## The Arc ([thearc.org](http://thearc.org))

The Arc is the world's largest community-based organization of and for people with intellectual and developmental disabilities. The national office and local chapters provide an array of services and support for families and individuals.



## Autism Society of America (ASA) ([autism-society.org](http://autism-society.org))

ASA, the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. The group increases public awareness about the day-to-day issues faced by people on the spectrum, advocates for appropriate services for individuals and provides the latest information regarding treatment, education, research and advocacy.



## Building the Legacy: IDEA 2004 ([idea.ed.gov/explore](http://idea.ed.gov/explore))

This site was created to provide a "one-stop shop" for resources related to the Individuals with Disabilities



Education Act and its implementing regulations. Resources and information are added as they become available.

## A Case for Action for Children and Youth with Disabilities in Foster Care ([ucp.org](http://ucp.org))



United Cerebral Palsy and Children's Rights partnered on this report, which provides a summary of research and other available information regarding children and youth with disabilities in foster care. The report documents the critical needs of the children and youth themselves and the status of the systems that serve them. From this site, search for "forgotten children."

## Center for Children with Special Needs ([cshcn.org](http://cshcn.org))



Find information on diagnoses, organize medical information with a "Care Notebook," create a plan of care, find support through others with similar experiences or look up community-based resources through Seattle Children's Hospital's web-based research portal. The information is aimed at parents, caregivers, professionals and individuals with special needs. Resources focus on children who have chronic physical, developmental, behavioral or emotional conditions such as asthma, cancer, autism or cerebral palsy.

## Disability Rights Education and Defense Fund ([dredf.org](http://dredf.org))

DREDF is a leading national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities. Their work includes training and education, legal advocacy and public policy/legislative development.



## National Center for Youth Law ([youthlaw.org](http://youthlaw.org))

NCYL uses the law to improve the lives of poor children. The organization works to ensure that low-income children have the resources, support and opportunities they need for a healthy and productive future. Much of NCYL's work is focused on poor children who are additionally challenged by abuse and neglect, disability or other disadvantage.



## National Scientific Council on the Developing Child ([developingchild.net](http://developingchild.net))

NSCDC is a multi-disciplinary collaboration comprising leading scholars in neuroscience, early childhood development, pediatrics and economics.



## Components of a Comprehensive Health and Development Assessment

An ideal assessment includes the following items:

- A complete physical exam, including provision of any necessary immunizations
- Screening for vision, hearing and presence of lead
- Intensive screening/monitoring for mental and emotional problems as well as cognitive and motor delays
- Referrals for preventive dental care and treatment
- Indicators of how the child handles peer relationships
- Indicators of how the child manages his or her behavior
- Indicators of how the child is coping with the changes in his or her life
- School status and progress reports

Source: New Hampshire Department of Health and Human Services. Available at [dhhs.state.nh.us/DHHS/FCADOPTION/FCHP.htm](http://dhhs.state.nh.us/DHHS/FCADOPTION/FCHP.htm).

understanding and succeeding with their care of chronically ill children: “They all want to love these children, but it will take a lot more than love,” she says. “Medical needs must be fulfilled around the clock. If I care about my CASA client, then I must make sure foster parents are supported in setting up routines and schedules.”

Change in home environment is what Jacquelyn McGinnis, PhD, professor of special education and former developmental disabilities interventionist in Livingston County, MI, observed as the optimum benefit for her clients. She recalls a former foster care client, a teenager with cerebral palsy who had limited mobility: “The foster parents welcomed any strategist who would come into their home to help their foster daughter accomplish the simplest of tasks, like turning on the radio,” McGinnis remembers. She considers CASA volunteers to be the professionals who can best help foster parents appreciate and promote “the child behind the tubes and crutches.”

## CASA Advocacy Within a Value-Added Model

No textbook or manual can adequately guide a CASA volunteer’s advocacy on behalf of children with chronic illnesses and severe disabilities. The nuances of disease and access to services require a determination to problem-solve the best course of action. The onset of intervention must stem from volunteers’ commitment to their clients first; but in reality this commitment often benefits birth parents and foster parents as well. The interdependence of these entities, along with therapists, physicians, social workers, caseworkers, judges and other service providers, demands CASA leadership that values all stakeholders. It is imperative that the CASA volunteer work closely in these cases with the social service case manager as well as other service providers. The ultimate goal should be to empower foster parents’ provision of safe, stabilized and high-quality care while ensuring that birth parents are prepared for this role should reunification occur. Specific activities to

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## Suggested Reading

- Pulsifer-Anderson, E. (2009). “Helping Families Understand and Manage Pediatric Gastroesophageal Reflux.” *Zero to Three*, 29(3), 50-59.
- Stahmer, A., Sutton, D., Fox, L., & Leslie, L. (2008). “State Part C Agency Practices and Child Abuse Prevention and Treatment Act (CAPTA).” *Topics in Early Childhood Special Education*, 28, 99-108.



consider include the following tips from CASA volunteers and other professionals:

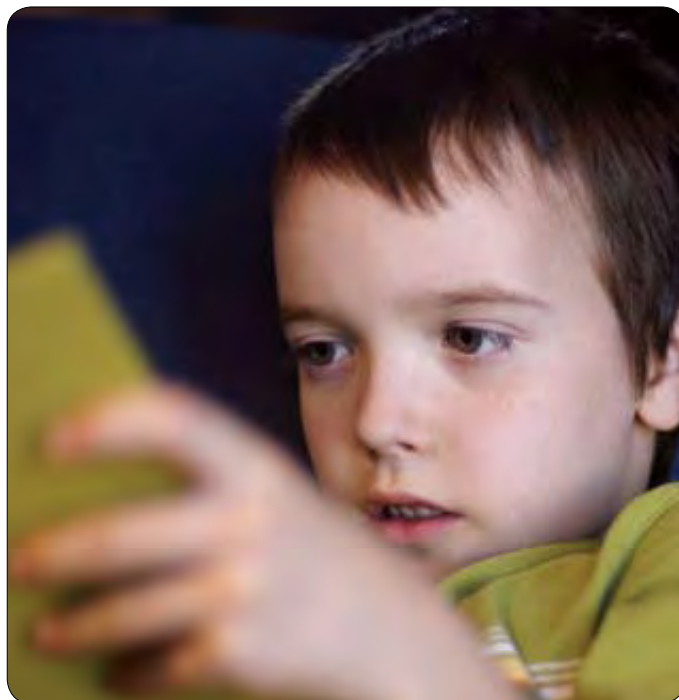
- Dr. Jacqueline McGinnis of Michigan asks volunteers to remember that all children communicate, even those with severe disabilities: "They may not use words, may not smile, may not be able to give yes-no answers, but if you keep looking, you will find their answer. Dignify your client by determining how he or she tries to communicate in his or her environment."
- Because of her extensive experience as a foster parent to children who were medically fragile, CASA volunteer Sara Cohen considers it imperative to synthesize and communicate service plan diagnoses and treatments to judges: "I consider it my job to paint the big picture so they understand why we are concerned when medical services are not implemented."
- Bridget James is the mother of one child with Asperger's syndrome and another with cerebral palsy who opened our story. As a CASA volunteer, she includes a picture of her client in her court reports: "I help judges realize that the 'problem' being discussed in the courtroom is not the child but what the child needs. I steer the conversation from blame to intervention."
- Kristen Hines of the Dodge City CASA program encourages volunteers to share medical history information with school teachers, within the bounds of confidentiality requirements. "Many times, teachers see only the behavioral issues. They may lack awareness about chronic illnesses affecting the behavior. They need to have the complete picture in order to do their job."

## CASA Volunteers with Chronic Illnesses and Severe Disabilities

Inviting adult volunteers with chronic illnesses or severe disabilities to assist with CASA programs can particularly benefit youth with similar conditions.

Most communities have government Offices of Developmental Disability Services. These agencies assist adults with their social security and other benefits necessary for maximizing independent living. Their staffs have access to information about disability conditions and treatment interventions. Adults with disabilities familiar with these services can help facilitate an exchange of information with CASA programs.

For example, an adult with Asperger's syndrome accesses health care and other benefits at a local Office of Developmental Disability Services. His awareness about his own disability and self-determination to independently function within the community have exposed him to resources and service providers. The local CASA program could tap into his expertise as they strategize an intervention program for a child with the same syndrome. In this manner, the CASA program models the very dignity they aim to achieve for the child.



## Conclusion

CASA volunteers who serve infants, children and teenagers with chronic illnesses and severe disabilities will most likely find themselves navigating uncharted waters. The demands will be continual and availability of resources scant. This reality will require advocates to play the role of investigator and to educate themselves about the illness or disability, oftentimes with the understanding that no other CASA volunteer in their program may have children with similar needs. In doing so, advocates must refrain from a one-size-fits-all mentality and engage in purposeful collaboration with interventionists, foster parents, birth parents and educators, all of whom will need support, advice or information pertaining to their provision of care. Above all, CASA volunteers need to claim their unique opportunity—the preservation of their client's dignity. They are the ones who can "label to enable" and set the tone for implementing services, not "fixing" children. When our CASA youth benefit from this dignity, finding their "amazing" will become a reality. 🗨️

*John Palladino, PhD, is an associate professor of special education at Eastern Michigan University. His research addresses the provision of educational services for youth in foster care. A former CASA volunteer, he is a licensed foster parent and adoptive father of two 10-year-old boys who were in the Michigan foster care system. Palladino also wrote the cover story on special education featured in the Winter 2007 issue of The Connection, which is available at [CASA.net.org/communications/connection-magazine.htm](http://CASA.net.org/communications/connection-magazine.htm).*





Robin McGraw (second from left) congratulates new training graduates.

## Robin McGraw Celebrates a New Class of CASA Volunteers

In February, Robin McGraw traveled to CASA of Los Angeles in Monterey Park, CA, to spend a day with the newly minted CASA volunteers from LA CASA's winter 2009 training program. Several of the volunteers found the CASA program as a result of the generous coverage our cause has received on the *Dr. Phil* show. McGraw spent much of the day observing the volunteers in training and interviewing several volunteers. She ended her day participating in the CASA volunteer swearing-in ceremony conducted by Judge Thomas Nash, 2006 National CASA Judge of the Year, and celebrating their joining the CASA and GAL family of volunteers. Segments of McGraw's visit were taped to air on a future *Dr. Phil* show.

"We so appreciate Robin taking the time to meet our volunteers and to help celebrate their swearing-in," said Theresa Luna, executive director of CASA of Los Angeles. "I know that hearing from Robin personally how important their work as volunteers is to our children meant the world to them. Thanks to the support of Robin and Dr. Phil, we have been experiencing the largest new CASA volunteer classes in the history of LA CASA. We are so grateful to them for helping us serve more children in need of CASA volunteers."

## Stigmatization of Foster Youth Addressed at New York City Event

The National CASA Association recently conducted two studies. The first was qualitative research examining self-perception of former and current foster youth (see "From the President" in the last issue of *The Connection*). The second was a quantitative national Harris online poll measuring public perception of children in care. This new research found that 83% of adults know little to nothing about the experiences of youth

in foster care. And when they do think of a youth in care, many adults envision a troublesome youth with no hope for a positive future. Despite this public perception, the focus group study found these youth recognize they have unique challenges, but they are determined to live "normal" lives. Amid these differing views, the question we need to answer remains "How do we fix this stigma?"

To address this question, National CASA in January conducted a roundtable discussion that included national media and members of the child welfare community. National CASA CEO Michael Piraino led the discussion in New York City. He was joined by best-selling author and long-time CASA supporter Anna Quindlen; National CASA spokesperson and TV personality Judge Glenda Hatchett; and former foster youth and author Julia Charles. Charles's book, *Surviving*

*the Storm*, was reviewed in the last edition of *The Connection*.

National media that attended the roundtable included CBS Television, NPR, PBS, *The Now Show*, *Parade Magazine*, *Time Magazine*, *Redbook Magazine* and the *Huffington Post*. Anna Quindlen spoke to her colleagues in the media, telling them: "National CASA has done important new research into how



(From left) National CASA CEO Michael Piraino, Anna Quindlen, Julia Charles and Judge Glenda Hatchett

these children are perceived—or stigmatized—by the public. It's heartbreaking data, but luckily the organization—and those of us in the media—are in a position to get the accurate story out there. As a reporter, I can't think of anything more important than setting the facts straight. As a mother, I can't think of anything more important than helping these kids."

Learn more about both studies at the home page of [CASAnet.org](http://CASAnet.org).

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## National CASA Annual Report Shares Volunteer Stories and Youth Perspectives

The 2008 National CASA Annual Report tells the stories of six children and the CASA volunteers who helped them find safe, permanent homes. The report also shares our organization's annual highlights and detailed financial information.

At the beginning of June, the annual report will be available both in print and online. To view the PDF, go to [casaforchildren.org](http://casaforchildren.org) and click on "About Us." To receive the printed version, contact Theresa Carleton at [theresa@nationalcasa.org](mailto:theresa@nationalcasa.org) or (800) 628-3233, ext. 253.




## National CASA Named One of America's Best Adoption-Friendly Workplaces

The Dave Thomas Foundation for Adoption, a nonprofit public charity dedicated to dramatically increasing the number of adoptions of foster care children in North America, announced on May 1 that National CASA was one of America's 100 Best Adoption-Friendly Workplaces.



Rankings for the Best Adoption Friendly Workplace list are determined by an analysis of a company's adoption benefits—financial reimbursement and paid leave—available to employees who adopt. The foundation compiled the results from survey data collected from 753 US employers. *Employee Benefit News*, a SourceMedia publication that is the leading source of information for benefits decision-makers, helped extend the survey's scope even further by inviting readers to participate.

"We continue to see increases in the number of companies establishing and enhancing adoption benefit policies," said Rita Soronen, executive director of the foundation. "Even with today's tough economy, we found that companies are dedicated more than ever to providing competitive benefits packages to help their employees when they adopt. It is one benefit that employers can add without negatively impacting the bottom line."

Today, more than 129,000 children in foster care are available for adoption in the United States. Most will spend nearly four years in the system before they are adopted. The release of the list helps the foundation increase foster care adoption awareness while celebrating those businesses that support adoptive families. To learn more about the foundation's work, go to [davethomasfoundation.org](http://davethomasfoundation.org). 



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Photo Submission Requirements: Please submit your best original photos. Digital photos are often not acceptable for print purposes. Connection staff will make every effort to return photos but cannot guarantee their return.

# 7 Tips for Advocating for Children with Disabilities and Chronic Illnesses

Krisan Walker  
Program Supervisor, North Carolina Guardian ad Litem Program  
18th Judicial District



The author with her two sons, Joshua (left) and Brandon

**V**olunteer advocates and care providers frequently have questions about how best to advocate for children with disabilities or chronic illness. Working with children who have many service providers and multiple needs may be daunting at times. Here are a few tips to best assess and advocate for the service needs of these children.

## 1. Familiarize yourself with the child's diagnosis:

It is important for key people involved in a child's life to have a basic understanding about the nature, diagnosis, cause and prevention of a disability or chronic illness affecting the child. With a basic understanding of the diagnosis, you will be better prepared to advocate for services, technology, medical care and education needs. Learn as much as you can about the diagnosis and how it specifically affects the child you advocate for. You can find helpful national organizations working on many diagnoses by doing a simple web search.

## 2. Watch for physical and behavioral changes:

Such changes can help you gauge how the child is adapting to a new situation. Ask the caregiver (or an older child himself) about disturbances of eating or sleeping. Physical symptoms such as frequent vomiting, diarrhea and skin rashes clearly call for a doctor's attention. But also watch for confusion or fear produced by unfamiliar events and situations. Problems with daily routine

can be a red flag that a child needs help. Watch for behavioral changes such as hiding, biting or frequent crying. Is this a sign that the child is unable to communicate needs and feelings? Try to find out whether the child has a favorite comfort item and when it is needed.

## 3. Seek out the opinions of those who know the child best:

You may not understand or be able to communicate with the child you are representing. In these cases, it is best to talk to the people who have known this child the longest. It may be a relative, a teacher or a school social worker who can explain to you how the child reacts in various situations. Ask them what can be expected and what would be signs for concern.

## 4. Educate yourself about local resources as well as your child's team of service providers:

Make sure to familiarize yourself with what is available in your community to meet the child's needs. The child you are representing may already have a capable team of service providers. Examples of providers are counseling/psychological service providers, early intervention providers, general and special education teachers, occupational therapists, physical therapists, speech and language pathologists, case managers, social workers, doctors, nurses and nursing assistants.

## 5. Know the child's education rights:

The Education for All Handicapped Children Act went into effect in 1978 and was replaced by the Individuals with Disabilities Education Act (IDEA) in 1993. The law requires states to provide a free, appropriate education to all children with disabilities regardless of the severity of their disability. Under the law, each child with a disability has an individualized education program that indicates what kinds of special education and related services she will receive. IDEA covers children with disabilities from ages 3 to 21, except in states that do not provide public education for children younger than 5 or older than 18. However, you may find your local school district provides programs for children 3 to 5 even when they are not required by state law to do so.

## 6. Know the role of the care provider:

While there may be other significant needs, the primary needs of a child with a disability are the same as those of all children: love and support. The care provider's goals are to foster independence and to help the child develop a sense of self-worth and personal fulfillment. Through therapy and play, care providers strive to help the child you serve deal with her disability while realizing her full potential. How much independence the child achieves depends, to a great degree, not only on the child's disability but on how responsive the care provider is at each stage.

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## 7. Focus on short-term goals:

All children reach plateaus in their development—times when they seem to stop moving forward or may even take a step back. This can be a particularly difficult time for children with disabilities or a chronic illness. In these situations, advocates do best to measure progress in inches rather than yards. When the child you serve reaches a plateau, it is helpful to look back on how far he has progressed. This may also be a good time to focus on short-term rather than long-term goals—finger-feeding, getting dressed or mastering toilet training rather than general readiness

for kindergarten. When care providers focus their energy on a single, short-term goal, a child with a disability or illness may begin to move forward again. By stopping to observe how the child copes with such challenges, how she adapts to new and greater demands, advocates and care providers can develop realistic expectations for the child.

There is much to consider when advocating for a child with a disability or chronic illness. Breaking down your challenges into manageable tasks can help you develop a strong, workable plan for effective advocacy. 🗨️

destructive behavior and had lower rates of depression. The approach holds promise for overcoming the disproportionately negative impacts of foster care on youth of color.

The project in this study was similar to the ways former CASA kids describe how their volunteers helped them. “I have goals,” they say, but they count on practical help from people they trust to support them in achieving their high hopes.

What if we took the senator up on his challenge to “solve big problems”? What if we were to create a practical vision of a nation-community working together to “parent” foster youth into adulthood? 🗨️



**As a CASA volunteer, you understand more than anyone what it means for children to have advocates in their lives.**

Please consider a gift in your will and help ensure that future generations of children benefit from your legacy. To find out how you can give for the future, please contact us today.

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## *Invisible Kids: Marcus Fiesel's Legacy*

by Holly Schlaack  
Advocacy Publishing; Blue Ash, OH, 2009  
201 pages

*"Read this book and you will understand how tragic it is when the needs of abused and neglected children are forgotten. Fortunately, Holly also offers practical ways you can help ensure they get what all children deserve—safe, permanent homes, with people who love them, secure in the knowledge that their futures are important."*

—Michael S. Piraino, National CASA CEO

As a child welfare professional, Holly Schlaack has had extensive experience working to ensure that the best interests of abused and neglected children are served. But when 3-year-old Marcus Fiesel's agonizing death hit the headlines, her work became even more urgent. She was motivated to write this book to address problems foster children face in an overburdened system, to expose the situation to a seemingly indifferent community and to challenge the reader to act so that positive outcomes for foster children become more common. Filled with case stories from the author's personal experiences, reinforced

by studies and statistics, this book describes the pitfalls and the successes of the foster care system. At the end, Schlaack lists a dozen ways to make a difference in the life of foster children, the "invisible kids" (see sidebar).

The central case study involves Marcus, a special-needs toddler who was rescued by the system from a negligent mother with an abusive boyfriend. He was then taken into the care of "qualified treatment foster parents." But after three months, Marcus's foster mother reported him missing. After some 2,000 people joined in a region-wide search, it was discovered that the foster parents themselves were responsible for his disappearance. Wanting to visit out-of-state relatives without Marcus, they had pinned his hands behind his back, bound him in blankets and packing tape and left him in a closet with a small fan to counter the 110-degree weather. Just about ready to leave, the foster mother ran back to the house to pick up something she had forgotten and came back saying, "He's freaking out." In spite of this, they drove off. Sometime during their absence, the boy died an agonizing death.

Schlaack notes a number of heroes in the book as well. The 2,000 people who looked for the missing boy demonstrated their goodness. She also mentions how CASA volunteers make a positive impact on children's outcomes. Schlaack gives credit to advocates who intervene to give children a second chance. She also describes ProKids Building Blocks, the successful program she began in Cincinnati to identify warning signs of risk of long-term cognitive and emotional problems in infants and toddlers.

But Marcus's martyrdom echoes throughout the book. What could have been done to avoid such an anguished ending? Who should

## **A Dozen Ways to Make a Difference**

There are many ways for us to help foster children, children who have become invisible or forgotten in our society. Holly Schlaack offers twelve. They do require time and commitment. But committing to any of these actions can help, even a bit, to change a life, improve the foster care system and prevent a tragic reoccurrence of what happened to Marcus.

1. Pay attention to stories relating to child abuse.
2. Spend some time researching child abuse.
3. Learn about the political process and how it influences decisions about abused and neglected children, particularly how government funds various agencies.
4. Vote for politicians who support funding and the development of programs for abused and neglected children.
5. Volunteer at community programs that help children who have been abused or neglected or children who are considered at risk.
6. Organize events to benefit foster children.
7. Volunteer at a local school.
8. Offer your professional services to a local nonprofit that serves children.
9. Find ways to support foster parents who have opened their hearts and homes to children.
10. Become a Court Appointed Special Advocate volunteer.
11. Become a foster parent.
12. Become a "forever family" for a child who desperately needs one.

be responsible for the "forgotten children" like Marcus? His foster parents met all the requirements the system demanded. However, as Schlaack, a mother of three herself, wrote, "The system can't save children. Adults save children. A community saves children."

So the question comes to, "What can we do?" This book challenges each of us to choose to care and take responsibility for children like Marcus so others do not die in vain. 📖

## **New Toolkit Measures Court Performance in Child Welfare**

The Children's Bureau and the US Department of Justice's Office of Juvenile Justice and Delinquency Prevention (OJJDP) have collaborated to produce the *Toolkit for Court Performance Measures in Child Abuse and Neglect Cases*. The purpose is to help dependency courts institute a system of performance measurement. The toolkit provides practical, comprehensive guidance on how to undertake performance measurement to improve child and family outcomes of safety, permanence and well-being and move toward more efficient and effective dependency court operations. The toolkit is designed to help courts establish their baseline of current practices; diagnose what areas of service delivery they need to improve; make improvements to their operations; track their efforts; and identify, document and replicate positive results. The kit may be ordered in its entirety or as individual publications by going to [ojjdp.ncjrs.gov/publications/courttoolkit.html](http://ojjdp.ncjrs.gov/publications/courttoolkit.html).

## **Implementation Centers Offer New Services to States and Tribes**

The Children's Bureau Training and Technical Assistance Network is expanding to include a number of new organizations that will provide additional information, training, technical assistance, research and consultation to support states and tribes in their efforts to improve their child welfare systems. Five of these new organizations are regional Implementation Centers that will facilitate peer-to-peer networking across state and tribal child welfare systems, host regional forums and support systems change projects. Learn more at [acf.hhs.gov/programs/cb/tta](http://acf.hhs.gov/programs/cb/tta).

## ***End Child Poverty—How Better Child Policy Makes for Better Poverty Policy***

Spotlight on Poverty, the advocacy website, recently published this commentary by William C. Bell, president and CEO of Casey Family Programs. Bell presents statistics that correlate poverty with a higher incidence of children entering the foster care system. He describes how Casey's 2020 Strategy—and specifically its goal to reduce the number of children in the child welfare system by 50% by the year 2020—requires us to “help redirect the course of life for the 7.7 million families living in poverty.” To see the strategy, visit [casey.org/AboutCasey/2020Strategy](http://casey.org/AboutCasey/2020Strategy). To read the commentary, go to [spotlightonpoverty.org](http://spotlightonpoverty.org) and search for “William Bell.”

## ***Using Family Group Conferencing (FGC) to Assist Immigrant Children and Families in the Child Welfare System***

Published by the American Humane Association, this issue brief highlights the key factors for consideration when using FGC as an approach with children whose families traverse national borders. FGC's benefits are illustrated through a case study by Casey Family Programs' San Diego office. Go to [americanhumane.org](http://americanhumane.org) and search for “immigrant children.”

## **Two New Chapin Hall Reports Available**

### ***Educating Homeless Children in Chicago: A Case Study of Children in the Family Regeneration Program***

This 2008 report by Amy Dworsky highlights the results of a study that examined the educational needs of a group of homeless children in the Chicago public schools. The research involved qualitative interviews with key informants familiar with the

problems facing homeless families with children in Chicago. It also included quantitative analyses of administrative data from the Chicago public schools and Inner Voice, an agency that provides services to chronically homeless families. Generally speaking, the educational experiences of these children were characterized by high levels of school mobility, academic difficulties and special education needs. The implications for how public schools and homeless shelters can work together to better address the educational needs of homeless children are discussed.

### ***Does Money Matter: Foster Parenting and Family Finances***

This 2008 paper by Cheryl Smithgall, Jan DeCoursey and Robert M. Goerge presents findings from a longitudinal qualitative study of Illinois foster parents. The research revealed a connection between how foster parents view their financial situation and the ways in which they understand and carry out their roles. The study illuminates the child welfare and family system dynamics that underlie the experiences of these families. Foster parents were found to have varying perceptions of their financial situation and were categorized into three groups: strained, managing and secure. Foster parents within these groups had distinctive views about their roles in identifying children's needs and helping them access services or recreational activities. Findings are discussed in the context of opportunities to support foster parents with the goal of meeting the needs of the children in their care.

To download both Chapin Hall reports, go to [chapinhall.org](http://chapinhall.org) and search by title. You must register at no cost in order to access the documents.



## Resilient Girls—Factors that Protect Against Delinquency

The January 2009 *Bulletin*, part of the Girls Study Group Series funded by the Office of Juvenile Justice and Delinquency Prevention, draws on data from the National Longitudinal Study of Adolescent Health. The Girls Study Group was created to provide a comprehensive research foundation for understanding and responding to girls' involvement in delinquency. This paper by Stephanie R. Hawkins, Phillip W. Graham, Jason Williams and Margaret A. Zahn describes how four factors—presence of a caring adult, school connectedness, school success and religiosity—affect girls' propensity toward delinquency. For the report, go to [ojp.usdoj.gov/ojjdp](http://ojp.usdoj.gov/ojjdp), click on *Publications* and look for the publication title.

## NSCAW Research on Child Welfare Populations

The National Survey of Child and Adolescent Well-Being (NSCAW) has recently released four research briefs analyzing outcomes for populations involved with child welfare. The briefs focus on infants, adolescents and caregivers of young children. Each draws from the longitudinal data collected by NSCAW to study the safety, permanency, well-being and receipt of services by children, youth and families who have been investigated for maltreatment by child protective services. They are:

1. *From Early Involvement With Child Welfare Services to School Entry: Wave 5 Follow-Up of Infants in the National Survey of Child and Adolescent Well-Being* (no. 10) examines outcomes for 962 children ages 5 to 6 who were younger than 1 year when they first came into contact with the child welfare system.
2. *Need for Adoption Among Infants Investigated for Child Maltreatment and Adoption Status 5 to 6 Years Later* (no. 14) examines the characteristics of and length of time to adoption for the same 962 children described above.

3. *Adolescents Involved With Child Welfare: A Transition to Adulthood* (no. 11) focuses on the needs of 620 young adults ages 18–21 who were involved in investigations of maltreatment when they were 12–15 years old.

4. *Depression Among Caregivers of Young Children Reported for Child Maltreatment* (no. 13) explores rates of depression among 1,244 mothers of children younger than 5 years old who were reported to the child welfare system.

All research briefs can be found at [acf.hhs.gov/programs/opre/abuse\\_neglect/nscaw](http://acf.hhs.gov/programs/opre/abuse_neglect/nscaw).

## Study Finds Stronger Ethnic Identity Predicts Greater Well-Being

A study of 83 Korean-born children adopted in the US found that as adults higher socialization to Korean culture predicted stronger ethnic identity and personal growth. Also, both higher levels of ethnic identity and more positive adjustment to adoption were associated with greater psychological well-being. "Identity Development and Psychological Well-Being in Korean-Born Adoptees in the US," by Susan Basow, Elizabeth Lilley, Jamila Bookwala and Ann McGillicuddy-DeLisi, was published in the most recent issue of the *American Journal of Orthopsychiatry* (volume 78, issue 4). The authors conclude that adoptive parents' provision of socialization experiences to their children adopted across race and culture facilitates their identity exploration and ultimately their psychological well-being. To access a free abstract or to purchase the full article, go to [psycnet.apa.org/journals/ort/78/4/](http://psycnet.apa.org/journals/ort/78/4/).

## Review Calls for Balance in Cultural Socialization of Adoptees


"A Theoretical Framework for Understanding Ethnic Socialization Among International Adoptees," by Jayashree Mohanty and Christina Newhill, offers a review of theoretical models that provide guidance for

understanding ethnic socialization of children adopted across race and culture and integrates research findings within these models. The report in the December 2008 issue of *Families in Society* (volume 89, issue 4), reviews three theoretical models (Erikson, Boykin & Toms and Rojewski & Rojewski). The authors emphasize the need to balance socialization to the child's birth culture/ethnic group with socialization to the mainstream culture and call for the development of specific recommendations as a roadmap for adoptive parents. To access a summary, go to [familiesinsociety.org/ShowSummary.asp?docid=3817](http://familiesinsociety.org/ShowSummary.asp?docid=3817).

## Manual Offers Guidance for Creating and Running Respite Care Programs

*Taking a Break: Creating Foster, Adoptive, and Kinship Respite in Your Community* was released recently by the Collaboration to AdoptUsKids. The 119-page manual was developed with the North American Council on Adoptable Children and the National Foster Parent Association; it can be accessed at [adoptuskids.org/resourceCenter/publications/respiteManual.aspx](http://adoptuskids.org/resourceCenter/publications/respiteManual.aspx).

## Adoption Competency Curriculum Available Online

The National Child Welfare Resource Center for Adoption has published its *Adoption Competency Curriculum* online. This curriculum is for training practitioners on issues relevant to the adoption of children and youth from the child welfare system. The *Trainer's Guide* and *Participant's Handbook* can be downloaded from [nrcadoption.org/acc/index.html](http://nrcadoption.org/acc/index.html). 

# Living Up to Our Claims: A Paradigm Shift from Recruitment to Retention

Lynda A. Williams, Executive Director  
Lisa Banks, Program Manager and  
Elisa Kosarin, Recruitment and Training Manager  
Fairfax Court Appointed Special Advocates, Fairfax, VA



September 2008 graduating class is sworn in by Judge Saxe of the Fairfax County Juvenile & Domestic Relations District Court. These CASA volunteers were selected under the CASA program's new recruitment and screening guidelines.

**“W**hile others may come and go, CASA volunteers provide the one constant adult presence that children need in order to survive.” Led by the voice of National CASA and repeated hundreds of times over across the country, CASA programs stake this claim to the public on their websites, in their newsletters, in their fundraising brochures and wherever they have a public voice.

Historically, our program has served more children than any CASA program in the Washington, DC, metro area as well as the Commonwealth of Virginia, and we have defined success by how many volunteers we recruited, trained and assigned to a case. A careful look at our data, however, suggested that the more relevant measure of success would be to calculate how many volunteers actually stay with a case until it is closed by the court. Therefore, we began to document the ebb and flow of volunteers in relation to the life of their assigned cases.

In tracking the number of volunteers leaving the program, we were shocked to discover that nearly 50% of them withdrew before their cases were closed. With this being so, how could we claim that our volunteers provided a constant adult presence in the lives of these vulnerable children? The stark realization that we were failing to provide what we claimed forced us to reexamine our priorities and change the way we conducted business. It became ever so clear that the *R* in retention weighed more heavily than the *R* in recruitment!

We revised the screening process by first identifying those volunteers who stayed with the program for many years and repeatedly took on new cases. Some even accepted more than one case at a time, a definite plus from a cost perspective given that we were committed to running our program within the boundaries of established best practices: a ratio of one supervisor for every 30

volunteers active on cases. What were the common characteristics, if any, of these long-serving volunteers?

To answer this important question, each of our five volunteer supervisors identified their “top ten” volunteers, and we uncovered their most common characteristics. This exercise revealed that our most reliable volunteers were: 1) retired or working only part-time; 2) over 40 years of age;

3) in supportive relationships; and 4) experienced in raising children. Armed with this information, we focused our recruitment tactics to reach people meeting the success profile (although we did not exclude other qualified applicants). Examples of where we placed targeted notices include high school parent-teacher associations, retiree groups and faith-based organizations. We also implemented a multi-step screening process that included mandatory attendance at an information session, a preliminary telephone screening interview and a face-to-face interview. During the in-person interview, we probed carefully for barriers to volunteer success such as inability to make the time commitment, family stressors, difficulty remaining impartial and trouble maintaining appropriate boundaries.

While developing a much more selective system, our enhanced

[continued on page 22]

## Dodging for CASA

**CASA of the South Plains, Inc.  
Lubbock, TX**

CASA of the South Plains' third annual Dodgeball Tournament was held recently in Lubbock. Three years ago, the local Starbucks had wanted to help raise money for the CASA program but wanted to do more than "just another golf tournament." So, together with Plains Capital Bank, Starbucks planned and implemented this event, which has grown from 15 teams the first year to 38 this year. The program's only overhead is renting the gymnasium (this year, there were two) and creating T-shirts, which are given to the volunteers who referee the matches, the sponsors—whose logos are on the back—and to the winning team. The tournament was "court-monitored" by Lubbock County Sheriff's Office employees, who volunteered their time to see that the game rules were properly enforced. The event provided much television exposure for the program—not only by the local FOX station, the media sponsor which fielded a team in addition to donating a great commercial, but by all the major networks. Next year promises to be even greater, with more than 50 teams expected to play in three gymnasiums.



## Fifth-Graders Raise Money for Children

**Piedmont CASA Inc., Charlottesville, VA**



A group of 5<sup>th</sup>-grade girls, as part of their service club at Saint Anne's Belfield School, decided to sell brownies for a charity and picked Piedmont CASA because they wanted to help other children who are not as fortunate. At their school assembly, the girls presented Ruth Stone, executive director, with a check and gave her a chance to talk about what a CASA volunteer does. It was a generous gift and a wonderful opportunity to garner a bit of publicity, especially while the program is recruiting volunteers. The girls, who call themselves the "Flying Blue Geckos," were also very excited to be interviewed on television.

## CASA Program Hosts Murder Mystery Fundraiser

**CASA of Jefferson County, Mt. Vernon, IL**

In a fundraiser for CASA of Jefferson County, actors from St. Louis's Murder Mystery Dinner Theatre performed *Mayhem in Mayberry* at the Holiday Inn. CASA of Jefferson County co-founder Judge George Timberlake emceed the evening, while another judge played the role of a suspect. As part of the action, some audience members, helping detectives solve this funny crime, got the chance to deliver lines. Others had to think up a quick alibi for the time of the murder, all while enjoying a delicious four-course dinner with wine. Nearly 200 guests raised approximately \$5,000. In addition to raising funds, Dawn Brink, executive director of CASA of Jefferson County, said, "CASA was able to raise awareness of the need for more volunteer advocates."



Actress Brenda Fowler and State Officer John Yard

## Nonagenarian Becomes Volunteer

**CASA of Parker County, Weatherford, TX**

Lois "Meme" Britton, one of Parker County CASA's newest volunteers, celebrated her 93rd birthday in March. After working as an architect in Odessa, TX, she retired to New Mexico where she started her own ceramics business at age 79. Three years ago, Britton moved back to Texas to be close to her grandson and his family. While busy with church activities and with her great-grandson, she decided to become a CASA volunteer because she feels her input and years of experience may help decision-makers choose wisely for the children the program serves. Together with her grandson's wife, Angela Gandy, the two new CASA volunteers serve local abused children.



Lois "Meme" Britton and her granddaughter-in-law, Angela Gandy

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marketing efforts have resulted in an increase in inquiries—allowing us ever-greater selectivity when admitting candidates into training. In 2006, 218 individuals inquired and 39% were enrolled. By 2008, inquiries had gradually increased to 543, but we only needed 10% of all prospects to enter training and be put to work. Based on the first quarter of this year, we project more than 700 inquiries for 2009, maintaining the 10% acceptance rate and resulting in the 70 new trainees we need. Of those who actually submit a formal application, only 50% are now admitted into training either because they withdraw during the interview process after reconsidering their commitment or because our staff screens them out as qualified volunteers. In previous years, we estimate that the number of applicants admitted was close to 95%.

A post-training interview with the program manager is the final step to achieving our retention goals. This short conversation presents an

opportunity to welcome newly trained volunteers to the Fairfax CASA family, thank them for the gift of time they are making and reiterate that the only irremediable mistake they can make is to leave a case before a child has achieved permanency. Looking new volunteers in the eye while expressing this unconditional expectation of their commitment is very powerful.

By incorporating these new recruitment and screening strategies over the past year, we have improved our annual retention rate of volunteers by 44% and have reduced the number of volunteers leaving the program without finishing their cases by 49%. In one year, the number of volunteers actively serving cases has increased by 23% to 127, with the number of children served growing by 14% to 257. Looking back, we can see that our paradigm shift has significantly increased the number of abused and neglected children who have a CASA volunteer consistently standing by their side. 📣

## Award

**CASA of Terrebonne, Houma, LA**, was awarded the Louisiana Association of Nonprofit Organizations Seal of Excellence for completing the *Standards for Excellence* certification program. The association's accreditation is based on fundamental values such as honesty, integrity, fairness, respect, trust, responsibility and accountability. According to Executive Director Stacey Martin, "Undergoing all of the difficult tasks required for the certification under the *Standards for Excellence* wasn't easy, but it was a worthwhile process for us. This seal shows we have taken every step to ensure we are serving the community and operating according to the highest standards of accountability in the most upright way, and we are proud to display it." 🏆



## 2010 National CASA Conference



Atlanta, GA • April 16-19, 2010  
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**J**oin us in the capital of the Peachtree State for the 29th National CASA Conference. Choose from more than 60 workshops, hear from leaders in their fields, and network with more than 1,400 peers from across the country. We guarantee you will go home ready to spring into action in pursuit of the best interests of abused and neglected children!

## CASA Volunteers from the Arctic



← **Winnie Nyhus** (right) and her Arctic tour guide beside *Mother and Child*, created by artist Eva Rybakken, which is part of *Children of the Earth*

Winnie Nyhus, a CASA volunteer from Will County, IL, went to the North Cape in Norway, at the very top of Europe, to visit the *Children of the Earth*, a unique monument dedicated to all children. An elementary school music teacher for 29 years, Nyhus retired in 2005 and became a CASA volunteer. Appointed in 2007 to the Will County CASA board of directors as the advocate non-voting member, she became a member at large the following year.

*"Every year, I learn more and am more determined to make that difference for a child. Illinois has CASA programs in only 35 out of 102 counties and remains one of the six states that does not fund the CASA program. We are working on both of these concerns."*

—Winnie Nyhus

## to Antarctica

### Karen Gibson in Antarctica

→ Karen Gibson, a former volunteer and continuing friend of Anne Arundel County CASA, MD, recently traveled to Antarctica. Bringing a copy of *The Connection*, she visited the Chilean Air Force research base on King George Island, where seven nations maintain research centers.

*"A funny side note of being a CASA is how our young daughter came to understand what I was doing when I went to visit my 'CASA kid' or meet anyone involved in the case. One day, sitting in her car seat, she held her toy and out of a quiet, contemplative moment said to me, 'Here mommy. I think your CASA child should have this to play with instead of me. I have enough toys.' My heart was so proud that she understood how important the work was for me."*

—Karen Gibson



Where do you take *The Connection*? Send us a photo of you or someone you know reading *The Connection* in a unique or interesting location. Since the *Connection* staff is especially interested in comments from readers, submissions including feedback about the publication are most welcome. Whether you are on an airplane or in a courthouse waiting room, help spread the word about this amazing way to advocate for children by telling others about the CASA/GAL cause. Pass along your copy of *The Connection*.

Send photos (min. 4" x 6") to:

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National CASA Association

100 W. Harrison

North Tower, Suite 500

Seattle, WA 98119

or email high resolution photos (300 dpi scanned at 4" x 6" size) to [theconnection@nationalcasa.org](mailto:theconnection@nationalcasa.org). Include your name, address, phone number, email address and photo location.

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### CASA Charm Bracelet—\$49

Wear this beautiful sterling silver charm bracelet and CASA charm with pride. For every purchase of the bracelet, \$5.00 will be donated to National CASA.

### Forgotten Children CASA Charm—\$19

Take a stand for foster youth! Add this commemorative charm to your CASA bracelet. Purchase this sterling silver CASA charm designed for the *Forgotten Children* campaign and \$2.00 will be donated to National CASA.



(back)

Visit [casaforchildren.org](http://casaforchildren.org) for a direct link to purchase these custom jewelry pieces!

#### GET CONNECTED!

The National CASA Association hosts several websites of interest to anyone who values promoting and supporting quality volunteer advocacy to help assure each child a safe, permanent, nurturing home. Visit the following sites to learn more.

##### Casaforchildren.org

The National CASA website is one of the strongest resources for recruiting new volunteers and supporters for state and local CASA/GAL programs. The website contains volunteer stories along with information on recruitment, public relations activities, news and donating to National CASA.



##### CASAnet.org

CASAnet is designed to meet the needs of CASA program staff and volunteers, including the advocate's library, program tools, updated information on national initiatives and other material for download.

##### Casaforchildren.org/JudgesPage

This webpage is dedicated to judges who hear child welfare cases. Content is valuable to other child advocates as well.

##### ShopCASA.org

A broad assortment of support materials and CASA/GAL promotional items is available through the ShopCASA site.







# Consistently Cheering for Our Children

Judge Glenda A. Hatchett  
National CASA Spokesperson

In the Winter issue of *The Connection*, I told you about the free “Parent Power” workshops I held last fall in nine US cities. While these presentations are aimed primarily at parents, I believe they contain valuable lessons for CASA volunteers and all adults who care about children. I call the first part of the workshop “The Three Cs: Concern, Consistency and Cheering for Our Children.” We covered *concern* in the last issue, so let’s examine the other two Cs.

*Consistency* can be summed up as “No means no means no.” The most common problem I encounter with parents can be illustrated by a frequently heard quote: “Well, Judge, I said ‘no,’ but then they kept asking me, and they wore me down, so I finally just gave in.” That is not the right response! If you know that the answer should be *no*, you have to stay strong. If you know that a co-ed pajama party does not meet the standards you have set in your household, then *so be it* that you are the only parent who stands firm. Children and teens honestly want consistent rules, in spite of what they may say.

The third C is my favorite: *Cheering for Our Children*. This is where we get to tell our own children, or those we serve as CASA volunteers, that we believe in them and expect greatness. Even when they do things that are inappropriate, we say, “I am disappointed in your behavior, and there are consequences for that. But I still believe in you.”

When my kids were young, I used to put notes in their book bags or tape them on the bathroom mirror. Now that they are older, they get emails and cell phone messages. But before they were old enough to understand, I was saying to them consistently, “I know that you’re destined for greatness.”

The homework I give parents for this part of the presentation is called “post their dreams.” And this is something that CASA volunteers can put in motion as well, with support from foster parents. I encourage you to sit

down and ask each child, “What is your dream for your life? If you could do anything in the world, what would it be?” Then I ask parents or foster parents to take a piece of paper and put the name of the dream in bold letters and tack it to the ceiling or over the child’s bed. *Journalist, pediatrician, teacher, artist*—whatever it may be. This sign becomes the first thing the child sees in the morning and the last thing she sees at night. And for the child who does not know what he wants to be, simply post “I want to be great.” He will figure it out. Of course, he may want to be a cowboy today and a scientist next week. It doesn’t matter. Just change the sign. The whole idea is to encourage our children to succeed.

CASA volunteers can support this dreaming process in children, whether for the far-off future or the here and now. For example, you might say to the child, “I just know you can make the squad (or the chess team or whatever short-term goal the child might have). And here’s how I can help you get there.” This kind of positive coaching is something all children need and is too often absent in the lives of youth in foster care. As an advocate, you can be key to making children understand that they are as good as anyone else and can achieve their aspirations through perseverance and hard work.

In the question-and-answer portion of one of my “Parent Power” presentations, a CASA volunteer said that she could not wait to help the children she advocated for to dream. She helped me realize that we can do this for youngsters who are not our biological children. After all, who needs to dream more than youth in foster care? It is *our* responsibility to send them the message that we care and we are cheering them on—wherever they find themselves now and whatever their dreams for the future may be. 📺

*The Honorable Glenda A. Hatchett is a nationally recognized authority on juvenile issues known for her award-winning television series Judge Hatchett and her book Say What You Mean, Mean What You Say! See her website for more information: [glendahatchett.com](http://glendahatchett.com).*

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## Invisible Kids— Marcus Fiesel's Legacy

By Holly Schlaack, this book tells the stories of many children and foster families, revealing practical approaches and real solutions. Reviewed in this issue. Includes an endorsement by National CASA CEO Michael Piraino.

Trade paperback; 201 pages.

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