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*in*SIGHT

THE OFFICIAL PUBLICATION OF THE ARC OF THE UNITED STATES

2008 Disability Policy Seminar

Advancing Disability Policy in an Election Year

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The Arc®

inSIGHT

THE OFFICIAL PUBLICATION OF THE ARC OF THE UNITED STATES

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The Arc

Mary V. Jordan, *President*

"Never doubt that a small, group of thoughtful,
committed citizens can change the world.
Indeed, it is the only thing that ever has." **— Margaret Mead**

Making Our Own Change

The outstanding attendance numbers at the 2008 Disability Policy Seminar in Washington, DC is a testament to how far we have journeyed toward being a powerful and potent voice for the disabilities rights movement. It is appropriate that the theme for the seminar was "Advancing Disability Policy in an Election Year."

This election represents a sea of change in this country. We have the opportunity to cast our votes for a new President and a swell of representatives; it is a unique time in history and our issues have never been more important. Since the passage of the Americans with Disabilities Act (ADA) in 1990, the rights of persons with disabilities were thrust into the national consciousness. And now nearly two decades later as Congress considers the restoration of the ADA, the power of the original law has been diluted.

Ironically, the restoration of the ADA has been met with opposition by President George W. Bush; it was his father President George H.W. Bush who originally signed it into law. In 1999, the Supreme Court defanged the law ruling that any "mitigating measure" (i.e. medicine, hearing aid, prosthesis and more) must be considered to determine if an individual's impairment severely limits life activity.

You can read more about the fight for the restoration of the ADA in "From Washington" in this issue of *inSight*. Participants to the Disability Policy Seminar received briefings on this issue and heard from many expert panelists. They agreed that Congress needs to fix the definition of "disability" so that the law covers all individuals who experience discrimination based on disability.

In addition to the ADA, the Disability Policy Seminar tackled a range of other issues that impact our constituency: Budget and Appropriations, Entitlements, Employment, Health, Housing, Social Security and the Developmental Disabilities Act.

One of the most important discussions at the seminar was Legislative Advocacy which clarified the reasons we were there and set a mandate for what we must do. Each of us as, advocates for change, must recognize the values grounded in policies affecting our constituency. Indeed, in order to achieve Full Participation, we must empower ourselves by making informed choices and exercising self determination.

Our advocacy has a clear purpose and indeed the attendant values of policies that impact persons with disabilities are also goals. Along with Full Participation, we strive for:

- Equal Opportunity
- Independent Living
- Economic self-sufficiency

Our advocacy, both individually and collectively is not limited to annual gatherings – our quest for full participation and equity is something we exercise every day, year after year. While an election year puts a punctuation point on our need to be informed on the issues it's also a call to action.

One need not be in Washington to have your voice heard. We make our voices heard everyday in our homes, our communities and across state and local chapters through the vital work that we do. Although, given the mandate of "Advancing Disability Policy in an Election Year," the seminar reminds us that information is power.

We can maximize our potential and make our voices louder. We can do this by making our voices a chorus just as The Arc of the United States, the American Association on Intellectual & Developmental Disabilities, the Association of University Center on Disabilities, United Cerebral Palsy and National Association of Councils on Developmental Disabilities did when they coalesced to organize this forum around shared vision and common goals. ■

Executive Director's Column

John Foley, *Acting Executive Director*

The Arc: Leading the Way with Family Support

The Arc was born out of the need by families to create an environment of mutual help and assistance to other families needing to find support and services for their child with developmental or other disabilities. At the local level families came together to find encouragement, assistance, advise and mutual support. Literally thousands of local chapters across this nation were organized to support families in their quest for a better life for their child.

The awakening of a sleeping giant in the 1950's ushered in an era of families reaching out to other families. These families organized thousands of classrooms in church basements, workshops in abandoned store fronts, and parent support groups in living rooms. Thus began the unleashing of parent power. Local chapters of these parent driven organizations came together to organize the state organizations which in turn came together to begin the national organization.

Family support is not new; it is integral to what The Arc was and is. Family support systems are somewhat analogous as chapters of The Arc have been driven by and for families for many years. What has happened is that as a result of the success of the parents working together, formal service systems assumed the responsibility for the operation of the family support services and networks. The resultant concern of families was that the systems were not empowering them to raise their children in their homes and further that parents did not have the enabling skills on how to advocate for their families at the individual and systems level.

"A corner has been turned. An organization run by families that provides leadership roles in advocating for and securing the adoption and implementation of family centered policies will become a reality. "

The Arc, driven by the passion and belief that parents can make a difference, set out on a course of action to develop a stream of funding that would enable parents to provide leadership in the design and improvement of family-centered and family controlled systems of family support services. Up to this point funding had never been made available for the express purpose of providing leadership and training by and for families.

A corner has been turned. An organization run by families that provides leadership roles in advocating for and securing the adoption and implementation of family centered policies will become a reality. For the first time we will have a National Clearinghouse and Technical Assistance Center. There will be local projects in as many states as funding permits. The Clearinghouse purpose will be to disseminate best practices, provide technical assistance to state and local projects, and offer training to parents from the perspective and the leadership of parents.

An appropriation of $2,000,000 has been made by Congress and will be available soon. This is only the beginning as the authorization level is up to $15,000,000. The Arc took a big step in the securing of the funding for this family driven project. The next step is in addressing the proposal with a keen sense of making life better for parents of children with disabilities everywhere.

The Board of Directors at the early March meeting directed me to prepare a response to the request for proposals soon to be issued. Our intent is to bring into collaboration organizations with a vision of working with The Arc as we endeavor to bring about a program that will have parents and families in leadership positions. ■

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Good Grief Does Not Depend on IQ

By Reverend Bill Gaventa, M.Div., Associate Professor,
The Boggs Center on Developmental Disabilities,
Robert Wood Johnson School, UMDNJ and Jeffrey Kauffman, LCSW

One of the powerful and wonderful parts of the documentary, *Praying with Lior,* mentioned in the last column, is the way that the grief and loss in Lior's family about the death of his birth mother are addressed directly and honestly as they prepare for his bar mitzvah. As he says at one point, "I wish and hope that my mom would come back on my bar mitzvah day."

In the past few years, there are a number of promising ways that grief and loss in the lives of children and adults with developmental disabilities are being recognized. The Last Passages Project and The Arc of New York, were pioneers in this. The AAIDD sponsored a powerful national conference in 2005. The California Arc was one of the key sponsors of a conference in October that drew over 300 people. Another is being planned in Delaware for October of 2008.

The Arc of the United States published the first of a new group of resources, the small booklet version of Charlene Luchterhand's book *Helping Adults with Mental Retardation Grieve a Death Loss* entitled *Mental Retardation and Grief Following a Death Loss: Information for Families and Other Caregivers.* 45 pp. $6.49. www.TheArcPub.com. There are a growing number of good resources which are also beginning to recognize that loss is not just about grief at death, but is often pervasive in life as a whole. (For a two page list of resources, email me at bill.gaventa@umdnj.edu)

Jeffrey Kauffman says it like this in a new column he is beginning with the AAIDD Religion and Spirituality Division newsletter:

"Loss is a part of life, and the way in which losses are responded to be a deep and abiding part of a person's inner life. In recent years there has been a growing awareness of the impact of loss experiences in the lives of those with intellectual disabilities. One's quality of life, sense of identity and behavioral expressions of self are greatly affected by losses. The support community is sometimes at a loss in understanding how to respond to losses.

Losses are also experienced throughout a person's life, and families are faced with many challenges in understanding loss experiences and providing support. Needing to anticipate losses in the family so that the person with intellectual disabilities will be best supported when, for example, a primary caregiver dies, leaves families with many concerns.

Grief occurs in reaction to death and in reaction to other life losses. Change in residence, change in employment, experiencing broken relationships or rejection are all losses and involve grief reactions. Loss-of-self experiences, such as feeling oneself to be different or stigmatized is likely to produce a grief reaction. Many life frustrations may trigger grief, which is expressed behaviorally.

Let's look a bit more closely at what this means — that behavior is an expressive language. Behavior communicates to others by gesture and dramatic action. Yelling, physical aggression, self-hurting, increased levels of compulsive behavior and so forth are common distress signal behaviors. When a person creates a disturbance in the social environment we may recognize an expression of grief.

Grief woundedness may abide long after a loss is remembered or associated with a behavior. So, distress behavior in the present may be related to long ago loss experiences. Expressions of grief may become part of a routine behavioral repertoire, linked up with everyday frustrations, and the loss that occurred long ago forgotten.

Many families implicitly understand the expressive meaning of behavioral languages. When, for example, a person withdraws and isolates either just after a loss, or even down the road, I advise that we consider the possibility that this behavior is expressing grief.

Recognizing the behavior as expressive of grief is a starting place towards supporting healing. Simply recognizing the expressive meaning of distress behaviors may, in itself, go a long way towards supporting mourning needs and strengthening the sense of connectedness.

One of the great ideas in Jeff's book, a *Guidebook on Helping Persons with Mental Retardation Mourn* is the possibility of doing a loss assessment as part of person centered planning, i.e., that service providers seek to understand the ways that a person has addressed loss in his/her family, culture, and religion, and then, together, plan how providers and families might address the inevitable losses in the future. Too many of us have had experiences where adults with developmental disabilities have been denied opportunities to participate in funerals or other expressions of grief and loss. That is just asking for trouble. Granger Westberg, author of the classic little booklet, *Good Grief,* notes "Grief denied is grief delayed. Grief delayed is grief denied." As Lior demonstrates in the film, his capacity to face and deal with his grief, with the support of others, turns out to be a gift to many others as well. Good grief does not depend on IQ. ■

2008 Disability Policy Seminar
Advancing Disability Policy in an Election Year

Over 500 self-advocates, families, advocates, professionals, care providers and policy makers converged on Washington, DC for the 2008 Disability Policy Seminar held in early March. Attendees gathered at the Hyatt Regency Washington on Capitol Hill for three days of briefings, workshops and meetings with their Members of Congress.

This was the 32nd consecutive year that The Arc has sponsored the Seminar. For the last several years, other cosponsors have joined us: the American Association on Intellectual and Developmental Disabilities, the Association of University Centers on Disabilities, United Cerebral Palsy and the National Association of Councils on Developmental Disabilities.

This year's Seminar theme "Advancing Disability Policy in an Election Year," explored the unique challenges and opportunities facing the Congress and White House as the 2008 campaigns unfold. In this, an election year, the Disability Policy Seminar was held at a crucial time for the disabilities constituency as Americans cast votes for a new President, a third of the Senate and the entire House of Representatives.

Presentations by experts, advocates, professionals, self-advocates and others focused on a range of issues from Medicaid, Long Term Services and Supports, Health & Wellness, Direct Support Workers, Employment, Education, Budget & Appropriations, the Developmental Disabilities Act, Housing, Social Security, Autism Spectrum Disorder and others. Brief overviews on key program areas on the first day were followed up with extensive

discussions on each on the second day.

"The annual Disability Policy Seminar has emerged as the premier event for those who advocate on public policy issues affecting people with disabilities and their families. The DPC provides participants with all the necessary information and tools to effectively advocate with the U.S. Congress and return to their home states armed with powerful and current knowledge," said Paul Marchand, Staff Director, Disability Policy Collaboration.

With the Capitol Dome in view, the conference site once again provided an inspiring setting for seminar participants to hear from national advocacy leaders. John Rother, Director of Policy and Strategy for AARP, one of the largest and most influential membership organizations in the country, delivered the keynote address. Rother stressed the importance of sustained personal contact with elected officials and their staff.

Rother addressed the aging population and the increasing number of those who will become disabled as they age. He noted that among the chief concerns of aging parents who have been lifetime caregivers is ensuring that their adult children with disabilities have appropriate supports and services when they can no longer provide care.

In a panel entitled "Community Organizing: Focus on Voting," Joe Meadours, a self-advocate and Director of People First in Sacramento, CA and Board member of The Arc led a discussion on the importance of voting. This timely discussion focused on the influential voice of the disabilities constituency in determining the outcome of the elections and voting for leaders that support favorable policies for those with disabilities and their families.

"Together, we have a powerful voice and there is no better time than during an election year

POLICY continued on page 8

POLICY continued from page 7

to make ourselves and our issues known. Elected officials and those running for office must be accountable for policies and funding that affect people with disabilities," said Meadours. "We must empower ourselves and cast our votes to make sure that the issues we care about are heard," he said.

Plenary sessions included Policy Updates from Marchand and DPC staff on the FY 2009 Bush Administration Budget Proposal, which includes cuts to Medicaid and Medicare. Presentations on the ADA Restoration Act elicited the greatest response from audience members. DPC discussed the original ADA which passed in 1990 with overwhelming support from both parties in both Houses. Presenters said that Congress needs to fix the definition of "disability" to ensure that the law covers all individuals who experience discrimination based on disability.

The 2008 Disability Policy Seminar also provided an opportunity to recognize outstanding individuals in the disabilities rights movement. Connie Garner, Policy Director for Disability and Special Populations for Sen. Edward M. Kennedy, was honored for her role in advancing legislation on disability issues.

Conference attendees were also introduced to the lives of two remarkable individuals, Diane Braunt and Kathleen Conour, who are the subjects of a documentary film, "Body and Soul: Diane and Kathy." This film is an intimate

portrait of two women with disabilities who are determined to live independent, non-institutionalized lives. The women also traveled to Washington for the Seminar to the delight of those who had seen the film. When DPC staffer Erika Hagensen met the two women, she exclaimed "You two are like rock stars!" For more information on the film, visit http://dianaandkathy.com/.

The most important event to take place during the Disability Policy Seminar was the full day set aside for attendees to meet with their elected officials in Washington. Having heard from leading public policy experts, disability advocates, and Congressional staff on key policies, Seminar participants were ready to lobby on the Hill. An estimated 250-300 Hill visits were made.

The annual Seminar is one of the most effective vehicles for The Arc, AAIDD, AUCD, UCP and NACDD to engage their extensive grassroots networks to advocate in a bipartisan manner for national public policies promoting the full inclusion of people with disabilities in our society.

To view the 2008 Seminar speaker presentations, please visit www.thearc.org and click on "Public Policy." ■

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Restoring the Americans with Disabilities Act for Mr. Littleton and Others

On July 26th, 1990, about 3,000 people gathered on the White House lawn: people with disabilities, families, advocates, and lawmakers. This day, like no other, held the promise of full participation, physical access to every part of community living, and an entrance into the workforce for people with disabilities who wanted to work. Because on this day, the first President Bush, with disability rights legend Justin Dart at his left, signed the Americans with Disabilities Act of 1990 (ADA) into law.

President Bush said the ADA would "break down the barriers of discrimination experienced by generations of Americans," and in many ways it has. But the full promise of employment for Americans with disabilities has not yet been realized. The employment rate of workers with disabilities is relatively unchanged, and 97% of the cases brought forward are either lost by the plaintiff or are never brought before the court.

Unlike other civil rights laws, people with disabilities who experience workplace discrimination first have to prove they have a disability before they can bring their case forward. The ADA says that a person with an impairment, a record of an impairment, or is perceived to have an impairment that affects a major life activity is considered "disabled" in the eyes of the law. Over the last 17 years, however, people have had an increasingly difficult time proving their disability.

If the definition of disability and protections from discrimination are written into law, how can that happen? All laws are tested and interpreted by courts, and judges' verdicts become the new lens through which laws are reinterpreted and applied.

The Supreme Court and district courts began to narrowly interpret "disability" and "major life activities." Based on these judgments, the disability status of an individual is now considered in his or her "mitigated state." In other words, individuals who take medication, use prosthetics or devices to mitigate or manage their disability well, are not considered disabled in the eyes of the court. This affects people with epilepsy, diabetes, amputation or limb loss, and others who could use a variety of means to function well in the nondisabled world.

For people with intellectual and developmental disabilities, their rights in the workforce have been most challenged by interpretations of "a major life activity." No one knows that better than Mr. Littleton. Mr. Littleton, a man in his twenties living with intellectual disability and receiving Social Security disability benefits, applied for a job to push carts and greet shoppers. It was agreed that his vocational rehabilitation job coach would join him in the interview, but once they arrived, Mr. Littleton's job coach was asked to wait in the hall. He did poorly in the interview and didn't get the job.

Mr. Littleton felt strongly that his rights had been violated, and he filed a case under the ADA. But he never got his day in court. Even before Mr. Littleton could discuss what he perceived as discrimination, the court said, "It's unclear if thinking, communication and social interaction are considered 'major life activities' under the ADA." According to the courts, despite what they referred to as his 'mental retardation,' Mr. Littleton did not have a disability. He did not qualify for protection under the ADA.

If someone with intellectual disability who meets the strictest definition of disability under Social Security doesn't qualify, who does? Not many. More and more, lawyers are refusing legitimate cases because they'll never get to court.

The National Council on Disability (NCD, www.ncd.gov), a bipartisan, independent Federal agency appointed by a Republican President, drafted a report called "Righting the ADA." This report aims to return the ADA to Congress' initial intent and protect the Mr. Littletons of the world. Among other recommendations, the NCD proposed that discrimination cases be judged "on the basis of disability" rather than putting the initial focus on "a person with a disability."

These recommendations have culminated in the ADA Restoration Act, introduced in the House and Senate on the 17th anniversary of the ADA. This bill, if passed into law, would put the focus where it should be — discrimination — so Mr. Littleton and others can focus on what's important: Employment. Participation. Dignity. Community membership. Getting the ADA Restoration Act enacted is one of The Arc's highest national legislative priorities.

For more information go to www.thearc.org. ■

Assuring Tomorrow - Today

You can join hands with all members of the Arc today and make a lasting contribution to our efforts to empower children and adults with intellectual and developmental disabilities by remembering the Arc in your will. Please call us today at (800) 433-5255, extension 451.

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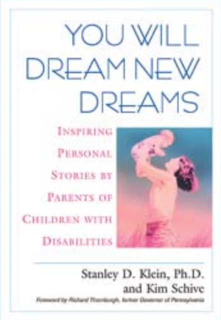
YOU WILL DREAM NEW DREAMS

Inspiring Personal Stories by Parents of Children with Disabilities

Stanley D. Klein, Ph.D. and Kim Schive

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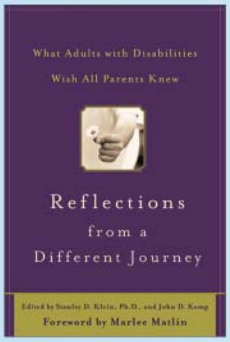
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PILCOP,
A Well-Kept Secret but a Treasure for The Arc

By James R. Wilson, Jr. and Quincy S. Abbott[1]

Over the years, many of our shared experiences have been celebrated through the pages of *inSight*. But we are betting that many people do not know about a singular organization that has, over the years, changed the world for all of us: the Public Interest Law Center of Philadelphia, or, as many of us know it, PILCOP.

Laboring in cluttered but sunny offices near Philadelphia's Independence Hall, this small band of lawyers (Tom Gilhool, Frank Laski, Judith Gran, Barbara Ransom, Max Lapertosa) has, over the past 30 years, fought hand-in-hand together with national and state chapters of The Arc around the country to bring major, groundbreaking cases that closed institutions, forced state governments to create and support community services, opened the public schools and struck down discriminatory zoning.

Tom Gilhool receives an honorary degree from Syracuse University at commencement last year.

We are not talking about one or two, or even five cases. We are talking about a legacy of cases that, when taken together, amount to a revolution. PILCOP lawyers have been there, either as lead counsel, behind the scenes assisting state Protection & Advocacy agencies, or representing individual members or chapters of The Arc in California, Connecticut, Delaware, Florida, Georgia, Alabama, Illinois, Michigan, Massachusetts, New Hampshire, New Mexico, Oklahoma, Pennsylvania, Rhode Island, Tennessee and Vermont.

Each of us met these fiercely dedicated lawyers in different states, one in Pennsylvania and one in Connecticut, but the passion and the results we experienced were the same. As those who have been around for a while know, approximately 200,000 people with developmental disabilities were typically warehoused under horrific conditions in state-run institutions. In Pennsylvania, PILCOP, hand-in-hand with the Pennsylvania Association for Retarded Citizens forced the Commonwealth of Pennsylvania to close the infamous Pennhurst State Hospital and create community services for those residents. PILCOP argued three separate times before the United States Supreme Court before that monumental first step was made, but that step spurred the establishment of community-based services as the law of the land in the Home and Community Based Services Amendments to the Social Security Act. In Connecticut, partnership with The Arc closed Mansfield Training School and developed a system of community services. By June 2006, the number of persons still living in large, congregate state-run settings was down from the high of 200,000 to approximately 45,000 people.

When the Pennsylvania Association for Retarded Citizens demanded that the public schools be opened, PILCOP lawyers secured court orders that not only allowed children into the school, but required the school to provide children a meaningful education. Those cases again took the country by storm, ultimately leading to the Education for All Handicapped Children Act, now the Individuals with Disabilities Education Act. This case, and the law that it inspired forever changed American education, not only for children with disabilities, but for all children, helping to create a more tolerant and open society.

PILCOP lawyers not only fought in court for chapters of The Arc, but they testified in state legislature and submitted "friend of the court" briefs in cases where a state or national chapter of The Arc wanted its voice to be heard. For example, in 1985 PILCOP submitted a friend of the court brief to the United States Supreme Court on behalf of the National Association for Retarded Citizens and chapters in Texas, Massachusetts and other organizations in a case that challenged a zoning law which excluded residential community services. PILCOP also submitted a friend of the court brief for the Connecticut Association for Retarded Citizens in support of a case brought by nursing home residents who were denied adequate care.

The secret, we believe, to the successes of these lawyers is the sound strategic counsel following the maxim of Tom Gilhool, former Chief Counsel of PILCOP and mastermind behind the above achievements. Tom would always say that litigation as a mode of social change should be used as one of many tools: like other initiatives by The Arc, litigation is one means to define the issues and secure appropriate change.

The passion, dedication and hard work of the PILCOP lawyers have not dimmed over time. In Pennsylvania, PILCOP lawyers, with the Arc of Pennsylvania, brought a lawsuit against the state Department of Education to force that agency to bring the state's 501 school districts into compliance with the IDEA. That case settled and today, with The Arc of Pennsylvania, the PILCOP lawyers keep vigilant watch over progress toward inclusive practices. In Tennessee, PILCOP lawyers continue to fight for improved and increased community services and closure of the state's large institutions. Here, PILCOP represents other organizations but The Arc partnership continues as The Arc of Tennessee filed a friend of the court brief to support PILCOP's efforts.

In honor of the retirement of Tom Gilhool, a symposium and celebration will be held in Philadelphia on May 12, 2008 to lay the foundation for PILCOP's future work and initiate a capital fund drive to support this future. You can find more information about PILCOP, the celebration and the capital fund drive at its website: www.pilcop.org.

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[1] Each of the authors is a past president of The Arc of the United States.

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For more information go to www.ncearc.org.

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The Puzzling Confession of Richard Lapointe

by Robert Perske

I'm sitting here "If the evidence shows that I was there, and that I killed her, then I killed her. But I don't remember being there."

I'm sitting here, staring north out my window toward my friend, Richard Lapointe who lives in a prison 100 miles away. He will call collect later. Then I will be driving up to see him the day after tomorrow. I cherish being one of his many friends for over 16 years. After all he has gone through, Richard needs all the friends he can get.

Good advocates for persons with intellectual disabilities – be they sensitive citizens or paid workers – are already swamped with commitments to the folks they work with and care about. But maybe – just maybe – if any of these advocates catch the flu, and have down time while waiting for the fever to end, they might find time to read the website www.friendsofrichardlapointe.com. The following sketches show why.


Richard Lapointe

CHILDHOOD: Richard Lapointe was born two months after the end of World War II, on October 18, 1945. He grew up in Hartford, Connecticut's Charter Oak Housing Project where most of the neighbor kids called him "Mr. Magoo." He was a pudgy child with an up-and-down thickness that even included his head. He wore thick glasses and, later, he wore hearing aids in both ears. Some of the kids in the projects taunted him because of the way he looked. Even so, those who lived close by were kind and protective. They did it because he seemed so soft and vulnerable. Nobody knew that he had a serious disability. They just saw him as likeable and friendly, but different like his cartoon character namesake.

EDUCATION: It wasn't much. He left school at an early age. When anyone asks why he left, he recites a well-memorized concrete answer: "The teacher said that I was only taking up a seat." Richard always recalls changes in his zigzag-but-progressive life with short concrete sentences. He never tries to explain himself by using larger abstractions like most people do.

DISABILITY: At age 15, a physician discovered that Lapointe had been born with Dandy-Walker syndrome, a congenital brain malformation. The vermis – a small piece of tissue that connected the cerebellum with both temporal lobes – was missing. It caused a buildup of cerebral fluid that enlarged his skull. To correct the buildup, he underwent five insertions and adjustments of shunts needed for draining the fluid. The syndrome affected many of his physical and mental functions – including his eyesight, hearing, stamina, muscle coordination, and the ability to learn certain social skills and abstract concepts. He only walks and never runs. When he stands up too quickly, he often experiences dizziness that he calls "a rush." Even so, when asked about his medical situation, his response is quick: "I'm a survivor. I survived five brain operations."

ADULTHOOD: For most of his adult life he worked as a dishwasher in numerous Manchester restaurants. He walked many blocks to work, faithfully did his shift in a restaurant, and walked home. He served as a volunteer in an organization for persons with cerebral palsy. It was at one of these meetings that he met his future wife, Karen, a person with cerebral palsy and epilepsy. They married and gave birth to a son named Sean. Although both mother and father possessed intellectual disabilities, they were well known as active members of Manchester's St. Bridget Roman Catholic Church – Karen in the women's Rosary Society, Richard in Knights of Columbus, and Sean attending the parochial school. They were regular at most of the special activities sponsored by the church. The family had been intact for ten years.

PICKUP: On July 4, 1989, Richard, then 42, his wife, Karen, 38, and their 9-year-old son, Sean, were happily preparing for an evening picnic and firework watching. It stopped at 4:30 p.m., when a police officer picked up Richard and took him to headquarters. Shortly after that the Lapointe family was destroyed.

SETUP: Upon entering the police station, Richard was walked past a number of posters attached to the walls – large charts, lists, and diagrams – with "Lapointe" written incriminatingly in large letters on all of them. Later, a detective testified that they were "props designed to reduce the suspect's inhibition for telling the truth." The posters were a waste of time because Richard could not read. Next, an officer read Richard his Miranda Rights and asked him to sign the accompanying waiver sheet – which he also could not read.

CONFESSIONS: After that, he was taken to an upper story room, where a detective told him that he brutally beat, raped and killed his wife's grandmother, 88-year-old Bernice Martin, and then set her cottage on fire. The crime happened better than two years and four months earlier, on March 8, 1987. During that time no significant arrests were made until they zeroed in on Richard. They did it when they learned that his blood, "Type A – Secretor," was the same as the perpetrator's – even though 28 percent of the rest of the male population possessed it as well.

During nine hours of interrogation, Richard gave three confessions. The first detective came out with a one-sentence confession that had been printed by the interrogator in large block letters: "ON MARCH 8, 1987, I WAS RESPONSIBLE FOR BERNICE MARTIN'S DEATH AND IT WAS AN ACCIDENT, MY MIND WENT BLANK." The detective went back for a second interrogation. This time he came out with 157 typed words. It ended with Richard saying, "If the evidence shows that I was there, and that I killed her, then I killed her. But I don't remember being there." Another detective went in for the third session. He came out with a hand printed 212-word statement.

All of the confessions were received during one-on-one sessions in a closed room. All were so dissimilar one might wonder if they came from the same person. Later, during the trial, forensic experts presented findings showing that the crime did not happen the way the police said it did. Also, none of the sessions were videotaped so that the judge and jury could actually see and hear what went on in that interrogation room until 1:30 the next morning.

TODAY: Richard at 62, is serving a sentence of "Life Without Parole Plus 60 Years." The only evidence that convicted him was his blood type and the three confessions. His family has disappeared from his life. Because of his wife Karen's disability, she also was dependant on others and relatives pulled her away.

FRIENDS: Richard's situation has drawn together a circle of friends. They began to appear in the courtroom on the very first day

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Ask the Expert

Health Care Transition

By Stanley D. Klein, Ph.D.

Q. We are worried about our fifteen year old daughter.

She has several on-going medical problems. It took us a long time to learn how to manage her medical needs, and work with her doctors. How can we help her take on responsibilities for her own health?

A. I turned to John Reiss, Ph.D., Associate Professor of Pediatrics, at the Institute for Child Health Policy (ICHP), University of Florida, to respond. Dr. Reiss writes: The process of helping youth with special health needs to be more in charge of their own care is called “Health Care Transition.” ICHP has developed several health care transition resources, including workbooks, training materials, pamphlets, and videos. These materials are available to download, at no cost, at http://hctransitions.ichp.ufl.edu.

I suggest the daughter and her parents watch the video titled “This is Health Care Transition.” In this 30-minute video, several adolescents and young adults discuss why they wanted to be more in charge of their own health care and what they did to gain the necessary knowledge and skills. This video, and our other materials, emphasizes the fact that, by knowing how to take care of themselves, they will be as healthy as they can be and will be able to do more of the things that they want to do: spend time with friends, be active in their community and pursue other goals. This video also emphasizes that transition involves a lot of planning and practice, and that it is never too early for youth to be more involved in their own healthcare.

Next, look at *Since You’re Not A Kid Anymore, Its Time to be More in Charge of Your Health*. This booklet, developed for teens in middle school, includes information about growing up with chronic conditions and what other teens have done to take a more active role in managing their health needs. It also includes activities that can help teens learn more about their condition, how to talk with their doctor(s), and ask questions when they don’t understand.

Your family can also complete our “Health Care Transition Training for Families and Youth.” You can access a free training program at: http://hctransitions.ichp.edu/ddcouncil. The training program provides information about the process of health care transition; the transition practices of health care providers and the educational system; health insurance; and how to assist youth, including those with intellectual impairments, to be prepared to transfer to the adult health care system. This program also provides instructions for completing a Health Care Transition Workbook and links to other resources.

There are three age-linked versions of the Health Care Transition Workbook, (ages 12-14; ages 15-17; and 18+). These workbooks are designed to help parents and their child work together: to look at goals for education, work and independent living; assess the adolescent’s level of independence in health-related activities; identify what parents are doing to support their teen’s health care autonomy; gather information about health insurance eligibility and providers’ age-related policies; and develop a healthcare transition plan.

You can download a Health Care Transition Workbook from our site, and then print it out. While the books are age-linked, you can use the 12-14 workbook if your daughter has an intellectual disability. While some young people with intellectual disabilities may not be able to take over full responsibility for self-care and medical decision-making, it is important to enable them to be as involved as possible. This includes spending some time alone with their doctors in order to ask personal questions that are important to them and practicing answering key questions about their health condition and needs with doctors they know in order to prepare for an emergency when they might have to interact with providers that they do not know. ■

Stanley D. Klein, Ph.D., answers readers’ questions about child development and family life. Dr. Klein is a licensed clinical psychologist and the co-editor of five books including Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew (McGraw-Hill, 2004) and You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities (Kensington, 2001). He is a frequent speaker at parent and professional conferences.

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AFP is partnering with The Arc of the United States to offer a special membership rate through May 31, 2008. When you join AFP, you are required to join at both the international and the chapter levels. Any employee of The Arc, no matter your experience level, may join AFP at the Introductory member rate of $100 plus applicable chapter dues.

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- The AFP First Course in Fundraising offers a complete overview of the development function, featuring state-of-the-art information and techniques. The first course is available online or as a two-day program.
- The AFP Essentials of Fundraising Series is a series of five 3-hour workshops hosted by AFP chapters and partners to develop basic fundraising skills within specific focus areas. It is designed to provide the key tenants of fundraising to small organizations and individuals new to the field or those expanding their responsibilities.
- AFP Audio and Web conferences provide exceptional opportunities to learn from and interact with experts in fundraising. Each 90-minute teleconference covers a specific topic, including: annual fund campaigns; major gift fundraising; fundraising during a crisis; stewardship; online giving; board development; and more.
- The AFP/Stanford Social Innovation Review Nonprofit Management Institute is an intensive two-day institute conducted by the world's leading experts and professors from the Stanford Graduate School of Business.
- Save the Date: The 2009 AFP International Conference on Fundraising, the largest gathering of professional fundraisers in the world, will take place March 29-April 1, 2009 in New Orleans, LA.

For more information on these and other AFP programs and services, please visit www.afpnet.org.

To Join AFP, please contact Lori Gusdorf, AFP Vice President of Membership and Chapter Services, at lgusdorf@afpnet.org for the special membership invitation. ■

Q. Can I support The Arc and also provide for my heirs?

A. Absolutely. In fact, a charitable gift made today may allow you to minimize taxes and increase the value of the estate distributed to your loved ones. It is never too early to start planning. Call us today at (800) 433-5255, extension 451. We will be happy to talk with you about the best options for you and your family.

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of his trial and thereafter. They officially organized themselves as "The Friends of Richard Lapointe." The Arc of Connecticut, so attracted by the advocacy of The Friends, offered them a home base and backup services. For 16 years, these friends have been present at every hearing held on his behalf. They visit him. They put money into his prison commissary account for snacks, birthday and seasonal presents. Some accept collect telephone calls. A core group of 24 remains in constant contact, but over 100 can be mustered for special forums.

NEW LAWYERS: After years of legal failures, Centurion Ministries voted to take over the case. This organization includes some of the nation's best investigators and attorneys. They have successfully reversed the wrongful convictions of over 40 persons who were headed for the death chamber or doing life without parole. They never take a case unless they are convinced that the prisoner is actually innocent.

ABYSS: By the time the Centurions took the case it was in a very deep legal hole. Six pro bono lawyers who came before mishandled exculpatory evidence in ways that it can no longer be used again in a court of law. A few examples of many follow.

Semen with game-over DNA in it was found at the crime scene, but it was used up in a failed testing process. Now, when over 200 wrongful convictions have been easily reversed by DNA tests, Richard's case will never be solved as easily. The Centurions knew that his case would have to be argued the old fashioned way.

During the earlier trial, the public defenders failed by putting Richard on the witness stand. They saw him as likeable with a childlike sense of humor, gullible and unable to recall facts discussed the day before. They thought that surely the judge and jury would see him that way, too. They didn't. It was this belief in his vulnerability that moved the defense lawyers to overlook other evidentiary issues that should have been argued.

No attention was paid to the burn time of the Martin cottage in the earlier hearings. Estimates from detectives and forensic experts ranged from 30 minutes to an hour. If any of these time estimates had been argued in earlier hearings, everyone would know

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for certain that Richard was home with his family during the time of the crime.

Defense lawyers failed to deal with an unidentified pubic hair that was found on Mrs. Martin's sweater. Later, the DNA testing of the hair showed that it belonged to neither Richard nor the victim.

No argument was presented over two gloves left at the crime scene, one on the bed and one on the floor. The gloves were much too large for Richard's hands and the DNA found on the inside did not belong to Richard.

SURPRISE WITNESS: During the last habeas hearing, in July, 2007, the Centurion lawyers put Karen on the witness stand. She and Richard faced each other for the first time in 18 years. Back on that fateful Fourth of July, a detective secretly wearing a "wire" interviewed Karen in the Lapointe home at the same time Richard was being interrogated in the police station. Everyone in the court listened to Richard's wife stave off repeated threats while insisting that Richard was at home with her and Sean during the time her grandmother was being murdered. That tape was not played in the evidentiary hearing of Richard's trial. As the tape was being played, Karen wept.

ANGRY JUDGE: Shortly after Karen's testimony, the defense rested. Then the prosecution requested that the judge dismiss the case. The judge ordered a recess so he could study the request. Two weeks later, he issued an angry ruling. He denied a new trial and dismissed the case. He was angry because the Centurion's petition was 83-pages long. He claimed that not one bit of evidence was now exculpatory according to the letter of the law. He claimed that the defense had abused "The Writ" of habeas corpus and they should never come back into court with this case again.

DETERMINATION: The Centurions were shocked by the decision at first. Then they went to work preparing a petition to the Connecticut Court of Appeals. A Centurion official said that they were "black and blue – but not bent." They vowed to never leave Richard's case until he walks out of prison a free man.

We, Richard's friends, stand behind the Centurions. In spite of what has been said in the courts, we know Richard. We know he never beat Mrs. Martin in the face with his fists. He never took a piece of cloth, formed a ligature rope around her neck and cinched it tightly with a knot that only a trained boy scout might tie. He never lashed together her wrists so tightly in the same fashion. He never ripped the clothes off of the lower part of her body. He never raped her with a blunt object. He never masturbated on the bed and carpet. He never used a blunt object for a second time to strangle her. He never burnt the handle off of a knife. He never carried her 160-pound body into another room and set her cottage on fire in three different places. He never sprinted for the normal equivalent of five city blocks to his own home so he could sit down with his wife and son and watch the Sunday night National Geographic feature on TV – with no blood or the smell of smoke or any dishevelment of his clothes.

Today, judges are being pressured to cut back on habeas corpus hearings. They claim to be doing it according to the letter of the "law". But what about "justice?" If the judge and Richard had ever been in an elevator stopped between floors for an hour, his ruling would have been different. Or if Richard had been the coach of the Connecticut University basketball team instead of an indigent man with a disability, would he still be in jail? Obviously, the "law" and "justice" can be two different things. ■

Please Let Us Say Thank You

Bequests are warmly welcomed, but receipt is often tinged with sadness, particularly when we have had no chance to say "thank you." If you decide to make a provision for The Arc in your will, you deserve our acknowledgement and appreciation. If we are in your plans, we would like to say "thank you" and welcome you as the newest member of our Heritage Society. Please call us at (800) 433-5255, extension 451 and we will be happy to enroll you today.

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