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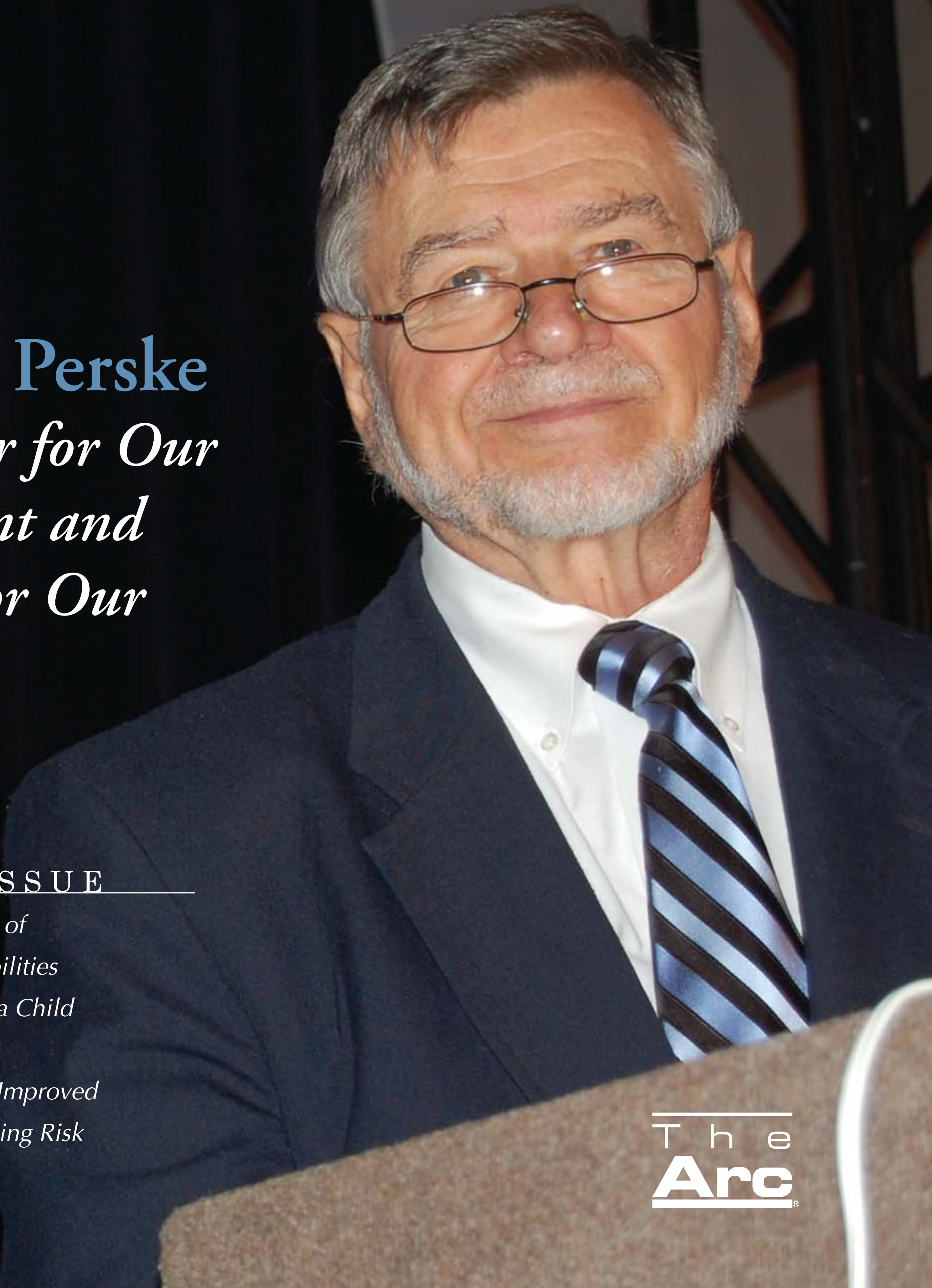
*in*SIGHT

THE OFFICIAL PUBLICATION OF THE ARC OF THE UNITED STATES



Robert Perske

A Mentor for Our Movement and Friend for Our Souls

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The Arc®

inSIGHT

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The Arc

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Mary V. Jordan, *President*

*"Change your opinions, keep to your principles;
change your leaves, keep intact your roots."* **—Victor Hugo, Author**

The Arc Moves Forward

As we reach the close of 2007, we pause to reflect on the year that was. Many of us are astonished with the speed with which a year can pass and ask each other to confirm our own intuitive feeling that time seems to have passed quickly indeed. At Thanksgiving, we are reminded of our blessings and are grateful for family, friends and good health. With the holiday season in full swing in December, we are filled with seasonal cheer and warm celebrations.

The start of the New Year is typically a time for change and new beginnings; we turn the calendar to mark the start of a brand new year at midnight and then prepare to face a new day.

The rich history of The Arc and the people who have written that history with their accomplishments and achievements knew that change would be inevitable for our movement to continue to move forward. Decades ago, our founders knew that a new day would come when they planted the seeds for the passage of ADA and IDEA. The founding families of The Arc knew that their hard work would be the foundation for positive changes and advancement to take place in the lives of people with disabilities and their families.

The New Year brings changes to leadership within The Arc of the United States. In mid-November, The Arc of the United States announced that Executive Director Sue Swenson would step down at the end of the year. Sue was named Executive Director of The Arc of the United States in 2005 and is a nationally and internationally recognized advocate for people with intellectual and developmental disabilities and their families. I want to acknowledge Sue's many contributions to our movement. Her advocacy on family support and her leadership on international disabilities rights greatly advanced our cause.

The Board of Directors for The Arc asked John Foley to step in as Acting Executive Director to work on transition at our national headquarters in Silver Spring, MD. I am grateful to John for his service to The Arc and I am confident that his distinguished 40 year long history with the organization makes him a most able steward. John's service in this capacity will provide support to the Board and streamline the process of identifying a new Executive Director.

Many of you may be familiar with John through his work with The Arc across the country over the years. He was a founding member of The Arc of Saunders County, Nebraska. Subsequent to that he served as the Executive Director of The Arc of Nebraska, as Regional Representative for The Arc of the United States, and was Chapter Consultant from 1975-80. John served as the Executive Director of The Arc of New Mexico from 1988 until he retired in 2001. In the summer of 2001, he re-joined The Arc of the U.S. as Chapter Consultant. He and his wife Violet are the parents of an adult daughter with disabilities.

John will help to ensure that the organization continues on course and that the transitional period is a smooth and seamless one.

The Board will commence a comprehensive search process to find a new Executive Director for The Arc. And during the next six months we will engage in a thoughtful and thorough assessment to identify an individual who will help us continue to move forward.

John shares with me a commitment to maintaining the momentum of our work on behalf of individuals with intellectual and developmental disabilities and their families. And with your continued support, The Arc can move forward with a keen eye toward being of better service to those we serve as we make life better for persons with disabilities and their families. ■

Executive Director's Column

John Foley, *Acting Executive Director*

The Arc: A Brilliant Idea

The Arc, what a brilliant idea for persons with intellectual and developmental disabilities and their families. I came into the organization as a parent of a young child who needed a free and appropriate education. After some prodding of the public school system's superintendent, we were told that in order for Belinda to receive an education, she needed to be placed in an institution.

Thus began our quest to provide our daughter with the necessary tools she would need to receive an education outside of an institutional setting. After speaking to members in our community, we learned about the Dodge County Association for Retarded Citizens, located in a county some distance from our home. Years before, parents had united to form this organization and the Association did have a program which would meet Belinda's needs.

Further research led us to the Nebraska Association for Retarded Children and we called upon them to inquire about possible assistance. This Association's director met with members of the community and shortly thereafter the Saunders County Association for Retarded Children was organized. We were on the way. A few months later the new chapter formed the SCORe (Saunders County Organized for the Retarded) school.

Soon after, the Nebraska chapter asked me to serve on their Board; three of our members were sent to Chicago to attend a two day leadership training session sponsored by the National Association for Retarded Children.

All three levels of the organization – the local, state and national – have played a significant role in the formulation of a powerful moment in our family's life. Now, I ask, is that real today? You bet it is. Perhaps not in the same way as the organization has matured, but our mission and purpose are still the same – to make life better for people with intellectual and developmental disabilities as well as their families. The name has changed over the decades, but the reason for our existence has not.

Although we are The Arc of the U.S., our reach is wider and collective concern far deeper. We should be vocal and active on disabilities issues in this country with the knowledge that our work has resonance abroad. The news from Serbia and Bulgaria is most distressing. We have gone through our own dark night in our own country and old photos provide evidence of the dehumanization of people with disabilities in our nation's history. Burton Blatt's landmark photo essay "Christmas in Purgatory" was a ground breaking and attitude shaking plea for attention. Furthermore, recent photojournalists have also been alerting us to the terrible conditions that exist in these nation's institutions for persons with intellectual disabilities. These photos are just as powerful as Mr. Blatt's in sending the rest of the world a very important message with regard to these horrendous institutional conditions. The entire world now knows that change comes when parents are empowered and provided with the tools and support required to make the world a better place for their children.

What a difference a group of organized parents can make in the lives of their children with intellectual and developmental disabilities. We must try to assist parents in other countries as they try to defy the odds and gain momentum in their efforts to create better conditions for their own family members. We must encourage them, share our stories of successes as well as our failures. Finally,

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Celebrating Habits of the Heart

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

Two things happened last Thursday that brought together the title of this reflection. First, Peter Gerhardt from the Organization for Autism Research led one of the Developmental Disabilities Lecture Series coordinated by The Boggs Center in New Jersey, this one on the topic of supporting young adults on the autism spectrum as they transition from youth to adulthood. Part of his talk focused on the absolute importance of social skills in helping people to get and keep jobs and to develop/maintain good co-worker relationships. He gave some wonderful examples of how co-workers, once briefed on ways they could best support someone with autism (e.g., Don't expect an answer to the "How are you?" question every day, but absolutely celebrate it and respond more when it does happen) had transformed some work situations to places that co-workers, instead of gossiping about the employee with autism, had friendly competitions with each other on who would get the most number of responses to verbal questions. It was, clearly, a matter of reinforcing new and good habits in a work setting, both on the part of the person with autism and the co-workers.

Peter also noted that many such social rules are ones most of us learn from things we have observed and learned over the years, but for people with autism and other developmental disabilities, they may need the "rules" explicitly spelled out for them and certainly reinforced. We just learn them again when we forget. He used an example that helped remind me why someone seemed cross with me recently when I was in too much of a hurry, and tried to step on an elevator in our building before she got off. I broke one of those unwritten elevator rules: "Let the other people off first!"

That same evening, our New Jersey Coalition for Inclusive Ministries had its sixth Awards and Celebration Dinner. We use the dinner to give small awards to individuals, congregations, organizations, and others who have worked hard to make sure individuals with disabilities are included in the life and service of congregations. Most of them are people who would not get recognized anywhere else for that work. Some might say that we should not have to recognize that kind of valued behavior, because it is what the church or synagogue should be doing. Theoretically, that is right. But tell that to some of our awardees and their nominators who spoke in moving, eloquent terms about what their work, and this recognition (our collective "Thank you!) meant to them. Some brought spouses, parents and whole groups from their congregation. Many will go back and say to their congregation, "You know that ministry we started that we were not sure about earlier? And some of you still have questions about its value. We just got recognized by a statewide organization for it!" In a room full of white, black, and other colors, Christians of many stripes and different Jewish denominations; clergy, laity, choirs, religious educators, families, direct support professionals, social workers, and self-advocates; and rich, poor, and all in between. It was a pretty amazing celebration of the ways that people with disabilities can indeed help create new communities.

The thread between those two events is perhaps obvious. As we enter into this end of year holiday season (or throughout the year), are there people in faith communities with whom you are connected who need to be recognized and thanked for the gift of their awareness and work? Does your chapter of The Arc recognize congregations as part of annual award ceremonies? We do it for employers, for schools, for professionals, for self-advocates, for legislators, for parents, and others. In our New Jersey experience, recognition usually leads to profound individual statements about what this inclusive ministry has meant to them, and the gifts that people with developmental disabilities and their families have brought to their lives, their faith, and their congregation.

The lesson is simple but one we so often forget. To help new initiatives and actions become habits, we all need positive reinforcement. We all need people who notice, and people who say "Thank you." That goes for clergy, religious educators, youth group leaders, church and synagogue leaders as well. If they are just beginning to learn new patterns of behavior that moves them beyond their "disability" of not knowing how to include people with disabilities, then we need to make sure they receive "positive behavior support" in whatever form is most appropriate. It is not too hard to develop a vision about the importance of inclusive faith communities and spiritual supports, but we all need to be intentional about translating those visions into real habits of the faithful (no matter what brand!) and of their hearts.■

Planning to Leave a Legacy

You can strengthen your commitment to a healthy society that includes individuals with intellectual and developmental disabilities today, and ensure that your voice will be heard well into the future by including The Arc in your will. Please call us today at (800) 433-5255, extension 451 for more information.

A Mentor for Our Movement and Friend for Our Souls

Leigh Ann Davis, M.S.S.W., M.P.A.

It's not everyday that you meet someone who changes you, someone who inspires you to become more than you thought possible, and someone who ignites inside of you a passion to step way out of your comfort zone and help someone you barely even know.

It was my second week on the job and I was feverishly searching for experts on criminal justice and developmental disability issues to provide input on a project I was working on at The Arc's national headquarters. Let's face it, nobody had ever heard of me and had no reason to want to spend time educating me about the issues. I made many phone calls that week, and while some were fruitful, many were not. My final call was the one that would change everything. This one phone call started a fire in me that continues to drive my work at The Arc, and it started a friendship with arguably one of the finest mentors known to the disability field: Robert Perske.

Mr. Perske (let's call him "Bob" for short since he prefers things simple) readily provided me with phone numbers, historical information and numerous articles that were not written in any book or available on the internet. His willingness and even eagerness to help out a youngster like me (I was 24 at the time and fresh out of my graduate program) was surprising, and I graciously accepted every morsel of information he was willing to give. What perhaps seemed like a small act of information-sharing to him turned out to be a life-changing experience for me. He tapped something in me that was just waiting to blossom, an avenue to reach out to others in great need.

But I am not the only one who has been inspired by his passion for justice, his unashamed quest to bring light to often minimized issues and his ceaseless drive to bring attention to often forgotten victims of the criminal justice system. How has he inspired us? Let us count the ways…

- One reporter with "U.S. News and World Report" stated, "Perske is a one-man clearinghouse on people with mental disabilities with legal problems… he has quietly devoted his life to showing how the criminal justice system is unfair to those with mental disabilities."

Advocates from The Arc of Pikes Peak in Colorado who have worked closely with Bob on criminal justice issues add:

- "He taught us how to look at the justice system with peace. He told us that anyone who truly believes in people with disabilities can advocate on the streets, in the jails, in the courts, or on the phone because all it takes is the passion and the drive for justice."
- "Bob has been the voice for people who have no voice long before it was hip, slick and cool."
- "People who can not protect themselves need to have some-

Perske receives The Arc's 2007 Lifetime Justice Advocacy Award.


Perske's mentees from The Arc of Pikes Peak Region

one fighting for them all of the time and there is no time to rest because our job is far from done. He taught us that."

- "He's the reason I have the drive I have. He truly is the hero for people with disabilities who end up in an unfair justice system."

Advocates with The Arc of Aurora in Colorado also realize Bob's significant and vital impact within this area of advocacy. They add, "Bob Perske's lifelong work with and on behalf of people with developmental disabilities involved in the criminal justice system is a real inspiration to us all. He has promoted, in a dignified yet forceful manner, a dialogue about justice where others walked away. No life or person is unimportant to Bob and he single handedly reminds the world of that. Some people question if angels are real, those folks only need to meet Bob to know that angels are not only real but they walk with us."

Last month at The Arc's 56th national convention, Bob Perske was honored with The Arc's 2007 Lifetime Justice Advocacy Award. The Arc family not only celebrated his advocacy work that spans nearly three decades, but we also celebrated something a bit more personal – his 80th birthday. As we all broke out in song to the familiar "Happy Birthday to You," we smiled with great admiration for the man who turned out to be not only an incredible advocate for people with disabilities, but also a much needed, trusted and valued friend to countless thousands.

Bob's lifelong quest for justice for people with intellectual disabilities reminds me of another beloved and cherished advocate with similar hopes for another forgotten people of his day. William Wilberforce (1759-1833) was credited with ending the British slave trade. In response to so many people who were against freedom for people of color, even after learning about the many injustices and abuse they faced as slaves, he said, "Having heard all of this, you may choose to look the other way... but you can never say again that you did not know."

Bob Perske is the William Wilberforce of our day. Reminding us that we are responsible to tell others about injustices once they are brought to our attention. When I first realized people with intellectual disabilities were up against such enormous challenges in the criminal justice system, I knew I could not simply turn my head and walk away. Bob not only had that affect on me, but on so many of us within The Arc and beyond. We will always be grateful to Bob for being such a strong mentor for our movement, and precious friend for our souls. ■

Leigh Ann Davis, M.S.S.W., M.P.A. is the Assistant Director of Professional & Family Services with The Arc of the U.S.

2007 Convention Awards

The Distinguished Research Award
Dr. Wayne Sailor,
a Professor of Education
and Associate Director of
the Beach Center for
Disability at
The University of Kansas

The President's Award
Quincy Abbott, past
President of The Arc of the
US & Chair of The
ArcLink Board

The Boggs/Mitchell Award
The Arc of Northern Bristol

Mr. & Mrs. Alex Ziring Award for Distinguished Research
The Arc of New Mexico

The Bill Sackter Self-Determination Award - Two Winners
Heidi Myhre
Johnnie Mae King

Media Excellence Award
WCBS/The ARC of Essex
County

The National Conference of Executive Directors of The Arc (NCE) held its annual awards dinner on Wednesday, October 10th in Dallas, Texas. For a complete list of winners, please visit www.ncearc.org.

Protecting Our Services and Supports

Disability advocates often see legislation as the main vehicle to protect and advance the interests of people with disabilities, their families/caregivers, and service providers. There is, however, an equally important vehicle that tends to receive less attention from advocates – regulatory reform – which can be used for or against our interests.

As the Bush Administration winds down in its final year, it is seeking to accomplish through regulatory reform what it has not been able to achieve through legislation. One of the Administration's main objectives has been to cut costs for the $346 billion federal/state Medicaid program. It has sought to do so by limiting program eligibility and reimbursement for services for the 50 million citizens with disabilities and/or low income enrolled in the program. The Administration states that it is seeking regulatory changes to the Medicaid program in order to curb abuses and to require states to pick up a greater share of the tab.

The Administration is taking this backdoor regulatory reform approach to cost cutting because it is far easier than through legislative reform. To begin with, the federal legislative process is more transparent and better understood by the public than is the regulatory process. Congressional hearings, press conferences, and other media events can bring attention to legislation in a way that does not happen for regulations. Such public attention often brings greater advocacy efforts and results in Members of Congress opposing legislation that would harm their constituents.

While most disability advocates' attention has recently been focused on the high profile bills like the State Children's Health Insurance Program (SCHIP) reauthorization, the Disability Policy Collaboration's staff has also been fighting the battle of regulatory change waged by the Bush Administration.

Two particular proposed regulations have been the focus of our efforts – the so called "rehab option" regulation and the school-based administrative and transportation costs regulation. On August 13, the Centers for Medicare and Medicaid Services (CMS) published a notice of proposed rulemaking (NPRM) that would amend the definition of Medicaid rehabilitation services to prohibit payment for habilitation services. The Administration is seeking to save $2.2 billion over five years by cutting habilitation services. CMS indicates that it will work with states to transition habilitation services to other authorities in the Medicaid program, such as the Section 1915(c) Home and Community Based waivers or the new Section 1915 (i) Home and Community Based option. However, the problem with shifting these services to other authorities such as these is that services could then be capped and means tested, and states could be allowed to maintain waiting lists. The proposed rule appears to prohibit people with "mental retardation and related conditions" from receiving any services through the rehabilitation option.

This "rehab option" regulation will hit some states much harder than others. For example, Massachusetts could lose more than $100 million a year and make it harder for tens of thousands of people with disabilities and other low-income groups to get healthcare, according to state officials, analysts, and advocates. This is because some states, like Massachusetts and New York, fund critical habilitation services for community living such as day habilitation, behavior development, and sensorimotor training, while other states do not.

The second Bush Administration Medicaid regulation of great concern to The Arc is the September 7 NPRM restricting schools from being reimbursed for certain administrative and transportation costs for students with disabilities. The Administration is seeking to save $3.6 billion over 5 years by cutting these services. The Arc strongly opposes this draconian approach to reducing school districts' inappropriately billing Medicaid. The vast majority of school systems affected by these cuts will have only one option – to reduce services to the children. We believe that CMS should instead focus on enforcing its current rules against the relatively small number of school districts that engage in fraudulent billing practices.

Fortunately, Congress has the authority to delay the implementation of regulations through a legally authorized postponement known as a "moratorium." A moratorium buys Congress time to review the regulations closely and propose needed revisions through legislation before the regulations go into effect.

Such regulatory policy making is not limited to the Medicaid program and is being taken even further by federal agencies. There have been numerous instances of agencies inserting language into regulations that substantially impacts programs, drawing increasing ire from Congress. For instance, the Senate Judiciary Committee recently held a hearing on federal agencies' practice of inserting into regulations language that removes consumers' ability to sue under state law those corporations whose products cause harm. Witnesses provided examples of federal agencies inserting preemption language into regulations, thereby usurping both expressed congressional intent and state law. Among the witnesses was the President of the National Conference of State Legislatures, who provided several examples of CMS trying to change Medicaid statutory intent by issuing rules without congressional authorization or consultation with state and local governments.

The Disability Policy Collaboration staff are taking a two pronged approach to restricting the Administration's proposed regulations – it has 1) drafted comments to CMS in concert with our coalition partners outlining our concerns with the proposed regulations and 2) worked with Members of Congress and their staff to ensure that the moratoria on the proposed regulations are included in legislation that gets signed into law before the regulations have a chance to take effect.

"The Medicaid program continues to be a target for cost containment and deficit reduction. Too often, this is tried with little or no regard for the hurt it will cause the recipients of services. In the matter of the two current proposed rules under consideration both will have a devastating impact on children and adults with intellectual and developmental disabilities," said Paul Marchand, the Staff Director of the The Arc and UCP Disability Policy Collaboration. "Parents and advocates must always remain diligent and active in protecting the services and supports we have worked so hard to achieve. Challenges like this surface all the time and we must never waver or be caught off guard." ■

IRS Charitable Rollover

The IRA Charitable Rollover provision included in the Pension Protection Act of 2006 allows individuals age 70½ and older to make charitable donations of up to $100,000 from Individual Retirement Accounts (IRAs) and Roth IRAs without having to count the distributions as taxable income. ***That provision is set to expire in December 2007.*** *Please remember The Arc when making giving plans from your IRA.*

The Decoding of Lana Morris

Authors Laura and Tom McNeal's fourth novel "The Decoding of Lana Morris" describes the evolving friendship of a girl called Lana Morris with four developmentally disabled teenagers in a Nebraska foster home. This husband and wife writing team were in large part inspired by their personal experiences with persons with disabilities and by Laura's volunteer work with a chapter of The Arc.

"I should confess first of all that I was an earnest but ignorant observer when I went to The Arc with the express purpose of doing research for this book. I wanted to understand how to help, but I fumbled a lot. I think that initially I made the mistake of treating the adult consumers like children – a benevolent and well-meaning mistake, but a mistake just the same. I came to understand the purpose of The Arc by degrees, by watching the job coaches and the consumers over time," Laura said.


Laura and Tom McNeal

When the couple began writing the novel, Tom wrote the first scenes based on his personal recollections with neighbors and relatives who had cared for children with Down Syndrome. Laura read a newspaper article about The Arc, and spurred by her desire to write truthfully about her characters, she contacted a local chapter in California where they reside and began volunteering two days a week to help and to observe.

Laura juggled her role as the mother of young school-age children with her role at The Arc where she principally worked with job coaches on starting a program making crafts that consumers could sell. She also visited consumers at their workplaces at grocery and sporting good stores.

"I was continually inspired by the job coach who permitted me to join her in these activities, and I was deeply moved by the cheerful way that consumers went about their jobs. I was also daunted by the difficulties they faced. Often, I was more daunted than they were, and that's what we tried to express in our book: the existence of an intelligence that surpasses ordinary adult understanding," Laura said.

"The Decoding of Lana Morris" evokes "The Wizard of Oz" through magical elements, yet Laura's experiences working with The Arc rooted the book in the realities of daily life for persons with disabilities. "I was profoundly moved and disturbed by the struggles of the 30 and 40-year-old adults who spent their days learning to count money, to make a $2 purchase at Wal-Mart, or to make dinner from a mix. They faced a world that I found unbearably forbidding, but they faced it, by and large, with a grace and acceptance that I have never possessed," she said.

When her children got out of school for summer break, Laura stopped working with the center, but her wish to remain involved in the disabilities movement burns strong. "I would be misrepresenting my abilities, though, if I said that I have much to offer the community of developmentally disabled adults other than my intense desire to see the world freshly as they do, and to make, through writing, that view of life accessible to others," Laura said.

The McNeals are generously donating ten percent of their royalties from the sale of the book to The Arc by way of thanks to the consumers and job coaches who inspired them.

"The Decoding of Lana Morris" *is published by Knopf, a division of Random House, and is available wherever books are sold. The authors can be reached at www.mcnealbooks.com.*■

FOLEY continued from page 2

we must share the success of our organizational mechanics.

In our own country we have miles still to go before people with intellectual and developmental disabilities are fully included in society and parents are provided with the support they so desperately need and deserve. The Arc truly has a mission here and elsewhere to do justice and bind up the hurt of children and adults in our own nation's institutions or in a foreign nation. We can only do this when we carry out the charge on the local, state and national levels of the organization to create a single effort in building partnerships and changing attitudes.

As you know, change occurs slowly and will only take place when parents join forces and become the frontline advocates of their children. Parents are the ones who will tear down the walls and barriers that exist in our country and abroad. Only when we are empowered will we be able to become the true agents of change for our movement. ■

Assuring Tomorrow—Today

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

The Demography of Intellectual Disabilities: What the Beans Tell Us

Dr. Glenn Fujiura

I had the good fortune of working with David Braddock on his State of the States Expenditure study after graduation. The study, which is still ongoing, was in the early stages of developing a database on public spending for intellectual and developmental disabilities (IDDD) services. At that time, RI Senator John Chaffee was leading efforts to reform the institutional bias of the Medicaid program and we were sharing our data with agencies that were developing different program options. During a conference call a federal analyst questioned our cost projections under an expanded waiver, asking, "Wouldn't that create a 'woodwork' effect?" "A what?" we asked. "You, know, would the waiver be so appealing that people will come out of the woodwork?"

Now the fact that many persons with IDDD were underserved and that most lived with their families was part of the conventional wisdom for the field. We accepted this as a fact, but we really did not know much *about* it. The analyst's comment stuck with me. The lack of information appeared to hold consequences for the development of policy. Exactly who was out there? How many? Where were they? These were basic questions about demography, the measurement of populations.

While a common perception of demography is one of endless factoids, the discipline emerged from a desire to identify social problems and stimulate reform.[1] Early demographers in fact, referred to themselves as "political arithmeticians" and later "moral statisticians." Not much has changed in the intervening centuries; reform remains close to the surface of the numbers. While demography cannot reveal much about the lives and daily dramas of IDDD, it can reveal much about the status and prospects of IDDD in society.

It's not just about the label; it's also about the need.

The conventional starting point for demographics is an estimate of the target population. Based on my own research and careful review of the literature, I can assert with great confidence that the prevalence of IDDD in the US is 6 per 1,000, or 1 per 100, or 3 per 100, or . . . all of the above.[2] There are a number of definitions of "intellectual disability," based on intelligence tests, adaptive behavior, need for supports, or some combination thereof, and each one results in vastly different population totals. Which is the correct one? As the great philosopher Yogi Berra once said, "If you come to a fork in the road, take it." IDDD is not a "thing" possessed by some and not by others, but rather a set of characteristics shared to varying degrees and in varying forms and combinations across the population.[3] Definition should be guided by purpose and since there are multiple purposes for identifying IDDD there is a need for different definitions.

It's not just about the person, it's also about family.

For all the attention (and resources) devoted to long-term residential care, the fact is that the vast majority of persons with IDDD live with their families.[4] Thus, while a substantial body of research has documented the whereabouts, well being, costs, and status of the few residing in institutions, nursing, group and other alternatives, the demography of family remains one of the great unknowns for the field. Here are some observations about families:

- Approximately 90% of Americans with an IDDD live in a family setting, the vast majority with their parents or other relatives, and smaller proportions living with a spouse or in their own residence.
- Families with a member with IDDD tend to be older, larger in size, and generally less well off

financially. There are no national estimates of non-reimbursed out-of-pocket spending on behalf of family members with IDDD, but studies suggest it is considerable, running into the thousands of dollars per year.

- The value of family living is enormous; while no analysis has been conducted for IDDD, a recent study estimated the "market value" of family care for all types of disability at $306 billion in 2004.[5]

It's not just about now; it's also about the future.

While our ideas about IDDD have changed over the years, we often think of the underlying population, however defined, as something static and fixed. But all populations are dynamic; changes in IDDD are closely linked to larger forces such as aging, increased diversity, and changing patterns of risk. What trends are of greatest interest to IDDD?

- There is no trend more important than the aging of America and the aging of families. Estimates of the proportion of IDDD families with a primary caretaker over 60 years of age range from 25% to 30%, depending upon data system and IDDD definition.[4] The magnitude of aging family members providing supports is a new challenge to our systems of care.
- The lower average income for families supporting a member with IDDD at home is due in large measure to the high proportion of single parent, primarily female-headed households in the group. Because of the variable quality of child care available to poor and low-income mothers and lack of access to health care, there are significant numbers of children with IDDD at significantly elevated risk for adverse outcomes.[6]
- The American labor force is changing. Significant shortages in health care and direct-service workers loom because of spiraling demand for labor required by the expansion of elderly care support systems set against a declining population of younger workers. IDDD services may be confronted with unprecedented labor shortages. Our current minimum wage approaches may not suffice to attract and sustain an adequate workforce.

It's not just about us; there is a big world out there.

Most everything we know about the circumstances of IDDD comes from the nations of North America, Western Europe, Australia, and the established market economies of Asia. It is remarkable what little we know about the rest of the world. Why should we care?

- The vast majority of the world's population, 82% of all humanity, lives beyond the borders of the wealthy, developed nations. Even if we were to exclude the two most populous nations — China and India — the proportion of the world's population in the less developed nations still stands at 72%. Nearly all of the world's population growth through 2015 (92%) will occur in the poorer nations of the world.[7]
- Among middle and lower middle income nations, publicly supported services are limited and depend heavily on the work of non-governmental organizations (NGOs) funded through religious or other international organizations. In the world's poorer nations, there are few if any public services outside of the largest cities.[8]
- While there are vast differences in the lives of persons with IDDD between the developed nations and the middle and low income nations, persons with IDDD are universally marginalized in their countries.
- In the poorest nations, persons with IDDD rely on traditional tribal or village-based accommodations, and family and kinship relations. If there is one clear global message, it is this: the lives of persons with IDDD are defined by the tens of millions of parents, siblings, relatives, friends, and other benefactors.[9]

There is a management expression that goes, "What gets counted gets noticed. What gets counted gets done." The "simple" act of counting and describing something can have a profound and sometimes galvanizing impact on policy making. The development of an official federal poverty line in the 1960s for example, helped transform American policy. In our own field, national statistics on institutional living and segregated schooling deeply influenced the shape of

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Dining Out with a Child with a Disability

By Stanley D. Klein, Ph.D.

Q. Are there guidelines for dining out with a child with a disability?

A. My goal for any activity a family does together is that the activity is enjoyable for everyone and no one participates unwillingly. In many families, this will require careful planning and negotiations. It may be an impossible goal in families with children at different developmental stages unless some family members are able to compromise.

In dining out, there are community expectations for appropriate behavior and dress that require different skills on the part of diners, with or without disabilities. Then, there are special considerations depending on a child's specific disability.

Let's consider the possibilities for enjoyment in three different kinds of restaurants. "Fast food" restaurants have minimal behavior expectations and dress codes. Food is quickly available and minimal eating skills and manners are needed. It is permissible to wander, make noise and even be messy. It is also acceptable to need help with eating or forget about using utensils. Since food is relatively inexpensive, parents are usually less concerned about children being picky or not finishing a meal. Also, these establishments usually have readily accessible parking, entryways and bathrooms and may even have play areas. While dining out in a fast food restaurant may not be an adult's idea of "dining out," it is a good place to begin with any child. Pre-school children enjoy "fast food" restaurants as do older children, teenagers and many adults.

More is expected of patrons at "family style" restaurants. While dress codes may still be minimal, some ability to wait patiently for the food to arrive and be relatively quiet and well behaved is expected. Although it is acceptable to assist children who need help with eating or cutting, skill with utensils is also expected. It is also acceptable to feed anyone who needs to be fed. In these settings, many families avoid booth seating because they know their children do better with some distance between one another. Most school-aged children and teenagers can be comfortable with their parents in these settings.

Expectations at "fancy" restaurants are more demanding. Adult level skills are needed because diners usually have to dress better, wait longer and behave in a more "mature" ways. Some adults and many children and teenagers do not enjoy such settings.

There are special considerations needed for some children. For children who are unable to sit still, are easily distracted, or are likely to speak loudly or make noises, restaurant dining will be difficult and may not be enjoyable. Some families that include a child with such behaviors designate a willing family member or friend to be prepared to go for a walk with the child when necessary.

For children (and adults) with mobility disabilities, parents can check, in advance, on the physical accessibility of the restaurant including parking, entering and exiting the restaurant, getting to comfortable seating and using the bathrooms. To do such an inspection, explain your concerns to the restaurant manager and ask to be shown around. Bathrooms often need especially close inspection to be sure that there is ample space and privacy for individuals who use wheelchairs and/or need special assistance. While businesses have made progress in accessibility, whenever possible, it is advisable for parents to visit in advance.

Children who look "different" or behave in "unusual" ways are likely to attract attention in a restaurant. Any family that includes a child likely to attract attention such as staring, pointing or questioning by other diners needs to be prepared. Usually, other people are curious and/or uncomfortable. While another person's discomfort is that individual's "problem," families need to discuss such situations in advance and decide how they want to respond. For some families, this aspect of dining out may require the most planning and even rehearsals. ■

Stanley D. Klein, Ph.D., answers readers' question 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.

2007 National Convention

Photos from The Arc's 56th Annual Convention include (clockwise from top): Sackter Award winner Heidi Myhre, The Arc of Greater Twin Cities; Dancing in the Lone Star to salsa band; Plenary speakers Jason Kingsley, Emily Kingsley and Mitchell Levitz; President Mary V. Jordan and Pauline Medrano, Councilmember, City of Dallas; Convention attendees enjoy opening reception; Convention Business Session with the Board of The Arc; and Former Presidents of The Arc, Jim Gardner and Leo Berggreen.

Protect Your Federal Benefit Payments – Switch to Direct Deposit with Go Direct®

This holiday season, The Arc is working closely with ***Go Direct***®, a national campaign sponsored by the U.S. Department of the Treasury, to encourage anyone receiving Social Security or Supplemental Security Income (SSI) by paper check to switch to direct deposit. It's a small but important step you can take to safeguard yourself against financial crime, such as check fraud and identity theft.

Protect yourself from check fraud and other crimes

Each month, millions of Americans with disabilities receive Social Security, SSI or other federal benefit payments either directly or through a trusted caregiver — such as a parent or other relative. In many cases, these payments come in the form of a paper check, which is less safe and convenient than direct deposit. Consider the following information:

- Financial crimes such as robbery, fraud and even identity theft are prevalent during the holidays – and senior citizens and individuals with disabilities can be targeted.
- Last year alone, about 58,000 Treasury-issued checks — totaling an estimated $56 million — were forged.
- A recent government survey found that 45 percent of Americans say they have been a victim of identity theft or know someone who has.
- When there's a problem with a Social Security payment, nine times out of ten it's with a paper check, not a direct deposit payment.

By switching to direct deposit you can eliminate the risk of delayed, lost or stolen checks and help protect yourself or a loved one against identity theft and fraud.

Simplify your life

Direct deposit can also help you simplify your life. It is more convenient than paper checks because the money goes straight to your account on payment day and is accessible from almost anywhere. This means one less errand to arrange and one less thing to worry about. It's no wonder that 96 percent of those who use direct deposit report a positive experience, and that virtually all of the people who switch to direct deposit never to go back to paper checks.

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Signing up for direct deposit is free, quick and easy – it takes just a few minutes. Simply call the toll-free ***Go Direct*** helpline (800) 333-1795 or sign up on ***Go Direct's*** secure Web site: www.GoDirect.org (www.DirectoASuCuenta.org, in Spanish). Within a few minutes, you can have the peace of mind that comes with direct deposit. Please have the following information on hand when you call ***Go Direct*** to enroll:

- Social Security number
- Bank or credit union's routing number (on the bottom of your personal check)
- Bank account number (on an account statement or bottom of your personal check)
- Spelling of your name exactly as it appears on your federal benefit check
- Amount of your most recent benefit payment
- Check number from a recent benefit payment or your claim number from the paying agency

Don't have a bank account, but want an alternative to paper checks?

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New 'Arc@Work' Program Directed At Improved Training and Reducing Risks

The Arc@Work
A workforce development collaboration…
The Arc, College of Direct Support
Philadelphia Insurance & Colonial Agency

COLLEGE OF DIRECT SUPPORT
AN INTERNET-BASED COLLEGE FOR DIRECT SUPPORT PROFESSIONALS

PHILADELPHIA INSURANCE COMPANIES

The Arc of the U.S., Philadelphia Insurance Co. and the College of Direct Support (CDS) have joined together in a new program – Arc@Work – to provide the highest quality of service and supports to individuals and families through training and safety awareness.

The program was kicked off during the recent Arc of the U.S. national conference in Dallas.

Here's how the program works.

Member chapters of The Arc of the U.S. are eligible for a 5% discount on liability and commercial insurance underwritten by Philadelphia Insurance Companies if 50% of the chapter's employees complete the first six specified online courses for Direct Support Professionals provided by the CDS. Participating in the CDS through Arc@Work provides chapters of The Arc with an annual license fee to utilize the CDS online curriculum as part of their staff training programs, and at a special price well below the price offered directly through the CDS.

The price for an unlimited number of employees and volunteers in the respective chapters to use the CDS curriculum is $38 per person served by the chapter plus an annual administrator's fee of $2,800, which provide the learning management administrative functions for a designated administrator for the CDS program.

"The College of Direct Support Learning Management System provides all employees with the highest quality on-line training curriculum developed in subject areas that have been identified as most important for people in direct support roles," said Michael Coburn, the chief operating officer of The Arc of the U.S.

"CDS has partnered with The Arc and Philadelphia Insurance to help all chapters of The Arc incorporate the highest quality and most comprehensive on-line training program so that all of your employees have access to training any time and any place that is best for them," said Bill Tapp, National Director of the CDS. "We know that your direct support staff members work odd hours, making it difficult to implement a comprehensive and continuing training program for all staff. Arc@Work can easily be implemented and administered which gives your chapter a world-class highly effective staff training and development program through the CDS."

Coburn also said that "Chapters of The Arc will be eligible for this discount at renewal time, which can save them thousands of dollars on your annual business and liability insurance premium."

If a chapter is not currently a customer of Philadelphia Insurance, The Arc has appointed Colonial Insurance Agency – an independent agency – to work with those chapters on an assessment of potential savings through this program. Philadelphia Insurance will help chapters obtain the most comprehensive insurance coverage at the best price. "If it is determined that a chapter of The Arc would benefit from The Arc@Work program, Colonial will work with them to transition coverage to Philadelphia," Coburn said.

"Chapters that currently hold Philadelphia Insurance company policies can immediately take advantage of the insurance savings program. The chapter's broker and a regional representative of Philadelphia Insurance Company will work to optimize savings for the chapter," Coburn explained.

Philadelphia Insurance has identified 11 courses within the CDS curriculum that will help all employees of Arc chapters safeguard against accidents and other risks and perils associated with the work done on a daily basis. Philadelphia's risk management professionals believe that the training staff receives through CDS will make the workplace safer and provide a higher level of safety for employees and the people each chapter serves and supports.

Tapp explained that chapters of The Arc may also want their DSPs to consider participating in the National Alliance for Direct Support Professionals (NADSP) National Credentialing Program to recognize and reward employees. "It is well known that professional recognition helps increase morale and self-esteem for employees in any profession – there is great need to honor and recognize those who dedicate their time serving and supporting people with intellectual and developmental disabilities," he said.

Information on the NADSP program can be found at www.nadsp.org.

To learn more about The Arc@Work program and how it can be implemented for your chapter, contact Elizabeth Muniot at The Arc of the U.S. by calling 301-565-5456 or by email at muniot@thearc.org. ■

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state and federal IDDD programs.

One of the great challenges for IDDD is that it is often not counted and as a consequence is frequently unnoticed. This is true both in the U.S. as well as globally.[10] While the integration of general disability into national census and survey programs has improved in recent years, IDDD is actually becoming less visible than in past years in our statistical systems.

My very first professional presentation occurred just months after joining the State of the States project. We reported IDDD spending data results at a national conference; David Braddock did most of the work but allowed me my five minutes of glory. At the end of the session, a colleague of my former advisor came up to the stage; I expected a compliment or words of encouragement. Instead, he scowled as he reeled off a list of criticisms: “No theories. No statistical models. Where are the determinants? This is just bean counting!”

I was crushed. Bean counter. What an insult.

But as the months passed, I saw firsthand the power of basic descriptive data. There were stretches when our project received daily requests for data from advocates, legislative offices, policy makers, and news media. There was a need for the data.

I became a very proud bean counter.

Dr. Glenn Fujiura is an Associate Professor of Human Development and Director of Graduate Studies for the Department of Disability and Human Development, College of Applied Health Sciences at the University of Illinois at Chicago.

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