A GUIDE TO FUNDING DISABILITIES AND SPECIAL NEEDS

Creating a more inclusive community

JEWISH FUNDERS NETWORK

Table of Contents

Introduction

The Jewish Funders Network's mission is to help maximize the quality and impact of Jewish philanthropy. Our members believe that philanthropy has the power to change lives and repair the world. By being strategic and thoughtful in our giving, we can ensure that our philanthropy realizes our visions and fulfill our promise.

But making strategic funding decisions can be incredibly difficult; we may not always know how to achieve the impact we seek. Members of our network often say that it's easier to make money than to give it away, which is why educating donors on how to be effective funders is at the core of our mission.

As a field, disabilities and special needs is particularly challenging: the multiplicity of choices can be overwhelming; different approaches bewildering, and the number of organizations puzzling. With so much complexity, funders sometimes skip the important due-diligence and research steps, and the quality of the funding—and therefore the field—suffers.

This book is an attempt to provide some guidance to funders seeking to invest in this important area. Commissioned by our peer network of funders committed to disabilities and special needs, it is, we believe, a valuable step to creating a more informed and more impactful philanthropy in this important area. We hope it serves as a tool, for those already investing in this field, to help fine-tune your grantmaking, and equally important, inspires others to delve into this challenging and rewarding area.

This book sits at the crossroads of JFN's most important values: networking; philanthropic excellence; strategic giving, and Jewish ideals. In our tradition, a book is a living thing. It evolves with the comments and additions from its readers, and we invite you to give life to this book, enrich it with your own experience, and share your perspectives—comments, feedback, and suggestions—with us. We hope it provides a valuable tool for your funding.

Andrés Spokoiny
President and CEO,
Jewish Funders Network

FROM THE EDITOR

This guide was commissioned by the Jewish Funders Network to meet a growing and pressing need in the Jewish community. Because Jews with disabilities are, increasingly, part of our sense of communal responsibility, the Jewish Funders Network is bringing together funders who share a commitment to Jews of all ages with disabilities of all kinds. But, of course, we are interested not merely in individuals, but in families, in Jewish institutions, in Jewish communities and in the community at large.

When a child with a disability is born to a family, what do we want our community to say to that family? Do we want to say, with our words and actions both, that we are here for your child and your family, that he or she is welcome as part of the larger community? Do we want to say that our schools, houses of worship, community centers, vocational services, and other services are here for your child and for you? Or do we want to say by our words and actions that we will find a special place for your child, but away from others, separate from the rest of our community, isolated from his or her brothers and sisters?

Increasingly, our communities are saying to families and to people with disabilities themselves: you are a part of us and we will find ways to support you in being part of our communities. This is what inclusion is all about.

During the Civil Rights movement, we insisted that people of color not be kept apart, discriminated against, or forced to sit in the back of the bus. We are now saying the same thing to Jews with disabilities. Actually, we are saying it to all people with disabilities.

This small volume represents an effort to keep the focus on including people with disabilities and their families and integrating them into our communities. From time to time, as new ideas present themselves, and as research, policy, and practice evolve, additions will be made to keep funders apprised of the latest ideas, trends and findings. I hope that you find this volume useful as we continue our efforts to support organized philanthropy in its collective resolve to demonstrate how our community's support can make a difference in the lives of all of its members.

Steven M. Eidelman
Newark, Delaware, July 2012

1 Federal Disability Policy

ALLAN I. BERGMAN

OVERCOMING DISCRIMINATION AND STIGMA

The civil rights movement by and for Americans with disabilities and their families began with the 1969 right to education class action lawsuit in federal district court, Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania. This was the moment the "social good" approach to services shifted into a "rights model" that continues to evolve today. When the litigation was filed, youth with disabilities in Pennsylvania (and other states) who were not toilet trained or could not speak and demonstrated "inappropriate behaviors" were deemed ineligible for public school education. These children, often placed in state institutions, were called all manner of names: crippled, afflicted, deaf and dumb, insane, crazy, maniac, psycho, demented, disturbed, Mongoloid, retard, idiot, imbecile, and moron.

In its 1927 majority opinion by Justice Oliver Wendell Holmes in Buck v. Bell, the US Supreme Court declared that involuntary sterilization was constitutional. "Carrie Buck is a feeble minded white woman who was committed to the State Colony (for Epileptics and Feeble Minded in VA), is the daughter of a feeble minded mother… and the mother of an illegitimate feeble minded child…. It is better for all the world if, instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind…. Three generations of imbeciles are enough." (Ironically, it was the eugenics movement in the US that laid the foundation for the medical experimentation in Nazi Germany.)

Rabbi Judith Z. Abrams documented the use of similar stigmatizing and dehumanizing terminology in her authoritative review of Jewish traditional teachings, which have placed an emphasis on "purity" and the need for da'at. Da'at, cognition or knowledge, is associated in the soul with the process of memory and concentration. The perceived lack of da'at had significant implications for the exclusion from Temple rituals for individuals with mental illness, deafness, blindness, and an intellectual disability that continued for many generations. The exclusion of children with disabilities from Jewish religious education, activities, and lifecycle events continued well into the twentieth century. To this day, the movement toward inclusion in Jewish life has tended to either parallel or follow the advances in the world at large.

THE RIGHT TO EDUCATION AND ITS ENHANCEMENTS

The PARC case argued that children with disabilities were entitled to an education under the equal protection clause of the 14th Amendment in the US Constitution. It further argued that since the children had not committed any crime for which they could justifiably be deprived of liberty, they were entitled to due process before being removed from the mainstream and compensatory services in order to be able to return to the mainstream as soon as possible.

Twenty-six additional rights-to-education federal class action lawsuits were filed and won by the plaintiffs. These cases laid the foundation for the passage of the Education for All Handicapped Children's Act of 1975, now known as the Individuals with Disabilities Education Act (IDEA). That law guarantees to all children with disabilities between the ages of three and twenty-one years a constitutional right to a free, appropriate public education of special education and related services (e.g., therapies, assistive technology and devices, nursing services) in the least restrictive environment, which includes maximum interaction with their peers without disabilities. This includes children educated in religious schools. However, for children to receive free, appropriate public education

in religious schools, the school must be willing to work with the public system for a child to receive therapy and other ancillary services.

From 2009 to 2010, public schools provided special education services to 6.48 million students ages three to twenty-one with identified disabilities; 13.1 percent of all students. We have no demographic data to suggest that the proportion of Jewish children with disabilities would be statistically different.

As a result of IDEA amendments in 1997 and the passage of the No Child Left Behind ACT in 2001, schools have placed a greater emphasis on performance and accountability for all students, including students with disabilities. Many states and districts are changing their styles of teaching and the materials they use with students, trading in traditional text-heavy materials for curricula created with the "universal design for learning" philosophy. According to the National Center on Universal Design, this model "provides a blueprint for creating instructional goals, methods, materials and assessments that work for everyone – not a single, one-size-fits all solution, but rather flexible approaches that can be customized and adjusted for individual needs."

FROM SCHOOL TO ADULT LIFE

This brings us to another significant shift: from traditional compliance-oriented rules that value process to an emphasis on accountability for educational outcomes. This development was further encompassed in the 2004 Transition amendments to IDEA, which apply to the student's individualized education plan (IEP) beginning at age fourteen, or earlier if the school chooses. The law defines transition as: "designed to be within an results oriented process, that is focused on improving the academic and functional achievement of a child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; is based on the child's needs, taking

into account the child's strengths, preferences and interests, and; includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living and functional vocational evaluation." Notably, the preferred outcomes do not include day habilitation, sheltered workshops, or group homes.

VOCATIONAL REHABILITATION AND INTEGRATED EMPLOYMENT

The first Civilian Rehabilitation Act was enacted in 1920 to provided funds for Americans with physical disabilities for vocational guidance, training, occupational adjustment, and placement services; it has been reauthorized and amended on numerous occasions since. In 1986, a new section created Supported Employment, establishing a program to assist state agencies to develop and implement supported employment services for individuals who need ongoing support to earn minimum wage or above. The amendment also sought to eliminate sheltered workshops, which has not yet occurred. The definition of Supported Employment is: "Competitive work in integrated settings for (A) individuals with severe disabilities for whom competitive employment has not realistically occurred, or (B) individuals for whom competitive employment has been interrupted or intermittent as a result of a severe disability and who, because of their disability, need ongoing support services to perform such work." The key components of Supported Employment are integrated employment, paid work, individualized services and supports, and ongoing supports.

The 1992 amendments to the Rehabilitation Act deleted the historical third criterion: "that there is a high probability that the provision of rehabilitation services will result in substantial gainful activity." In its place, the following language was inserted: "Individuals with disabilities, including those with the most severe disabilities, are generally presumed to be capable of engaging in gainful employment and the provision of individualized vocational rehabilitation services can improve their ability to be gainfully employed. Individuals with disabilities

must be provided with the opportunities to obtain gainful employment in integrated settings." The 1992 amendments also promoted the development of individual career plans and not just "job placement." More recently, the field of employment for individuals with the most significant disabilities has expanded to include the development of both customized employment and microenterprises (businesses owned and operated by individuals with disabilities).

The overwhelming professional and advocacy preference today is for community integrated employment, not segregated employment. In fact, several states have developed state policy declaring Employment First, as the priority use for public funds for adult day supports for individual with all types of disabilities. Washington State became the first to do so in 2006, and Kansas and Utah followed in 2011. In six states, 40 percent or more of individuals with developmental disabilities receive day supports in integrated employment, including Washington, Connecticut, Michigan, Delaware, Oklahoma, and South Carolina.

THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

This legislation, enacted in 1970 and reauthorized in 2000, provides funding for a state Council on Developmental Disabilities, a Protection & Advocacy System, and a University Center for Excellence for Individuals with Developmental Disabilities in each state and territory. The target population of this legislation is defined as: "Individuals whose disability occurs prior to the age of twenty-two, is expected to last a lifetime and require assistance and supports for substantial functional limitations in at least three of the following areas of major life activities: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency."

The law also defines its key goals for this population with the most significant disabilities: "1) Inclusion- the acceptance and encouragement of the presence and participation of individuals with developmental disabilities by individuals without developmental

disabilities in social, educational, work and community activities; 2) integration- exercising the equal right of individuals with developmental disabilities to receive and use the same community resources as are used by and available to other individuals; and, 3) self-determination- activities that result in individuals with developmental disabilities, with appropriate assistance having, a) the ability and opportunity to communicate and make personal decisions; b) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, support and other assistance individuals desire; c) authority to control resources to obtain needed services, supports and other assistance the individuals require; d) opportunities to participate in, and contribute to, their communities; and, e) support, including financial support to advocate for themselves and others, to develop leadership skills through training in self-advocacy, to participate in coalitions, to educate policymakers and to play a role in the development of public policies that affect individuals with developmental disabilities."

CENTERS FOR INDEPENDENT LIVING AND THE REHABILITATION ACT

The Rehabilitation Act amendments of 1973 established a funding formula for independent living centers. Today there are over 500 such centers in the country, led by people with disabilities. The purpose of such centers is to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities and to integrate them into the mainstream of American society. The centers focus on civil rights, the independent living philosophy, and inclusion. Each center must provide: individual and system advocacy; information and referral; peer support; and independent living training.

The ten principles of independent living are: civil rights; consumerism; de-institutionalization; de-medicalization; self-help; advocacy; barrier removal; consumer control; peer role models; and, cross-disability. The centers and their members are best known for their motto: "Nothing about us without us!"

THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

Over the past several decades, great advances have been made in the understanding of mental health and substance abuse. The contemporary approach to services and supports for individuals with these disabilities is termed the Recovery Model. As a result of several years of stakeholder participation, the 2012 revised stakeholder consensus definition published by SAMHSA is: "A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential."

The four dimensions that support a life in recovery are: "1. Health: overcoming or managing one's disease(s) or symptoms – for example, abstaining from use of alcohol, illicit drugs, and non-prescription medications if one has an addiction problem – and for everyone in recovery, making informed healthy choices that support physical and emotional well being; 2. Home; a stable and safe place to live; 3. Purpose: meaningful daily activities such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income, and resources to participate in society; and, 4. Community: relationships and social networks that provide support, friendship, love, and hope."

The guiding principles for Recovery are: "Recovery emerges from hope; Recovery is person-driven (self determined and directed); Recovery occurs via many pathways; Recovery is holistic; Recovery is supported by peers and allies; Recovery is supported through relationships and social networks; Recovery is culturally based and influenced; Recovery involves individuals, family, and community strengths and responsibility; and, Recovery is based on respect."

AFFORDABLE AND ACCESSIBLE HOUSING AND HOUSING DISCRIMINATION

For individuals with disabilities, one of the most daunting barriers to achieving a self-directed and community integrated life is limited access to decent, affordable, and accessible housing in safe neighborhoods. Emerging policy and practice support individualized supported living with the individual(s) and/or family owning or leasing the home and no more than four people with disabilities living in the same home. (This, indeed, is the policy of Money Follows the Person Grants with federal Medicaid matching funds administered by the Center for Medicare and Medicaid Services.) Communal living in segregated apartment houses and six to eight person (or larger) "group homes" is no longer considered "good or best practice." Several sets of national indicators of quality look at states in terms of individuals living in settings of three or fewer. The following states provide support to 85 percent or more of the individuals in their system in settings of three or fewer: Nevada; Vermont; Arizona; New Hampshire; Idaho; Colorado, New Mexico; California; Hawaii; Pennsylvania; Georgia; Kentucky; Washington; and, West Virginia.

The Fair Housing Act, administered by the Department of Housing and Urban Development, was amended in 1988 to include individuals with disabilities as a protected class against housing discrimination in renting, purchase, mortgage financing, and availability of tenant/homeowner's insurance. In passing the law, Congress intended to ensure that persons with disabilities have the same rights to use and enjoy housing as do other persons. "Generalized perceptions about disabilities and unfounded speculations about threats to safety are specifically rejected as grounds to justify exclusion." The Act specifically excludes a person with a disability "whose tenancy would constitute a direct threat to the health or safety of other individuals or whose tenancy would result in substantial physical damage to the property of others." It also excludes sex offenders and users of illegal controlled substances.

The law further defines discrimination as: failure or refusal to permit structural modifications of a property that is or will be occupied by a person with a disability at that person's expense; and, the failure or refusal of the landlord or homeowners' association to make "reasonable accommodations" in rules, policies, procedures, and services if such an accommodation is necessary for the person with a disability to benefit from the housing. Subsequent regulations have clarified

that public benefit checks, such as Supplemental Security Income, Social Security Disability Insurance, and veterans' benefits must be construed as income no different from someone's wages for the purpose of credit worthiness for rental or purchase.

ASSISTIVE AND ENVIRONMENTAL TECHNOLOGIES

"As technology has come to play an increasingly important role in the lives of all persons in our country, in the conduct of business, in the functioning of government, in the fostering of communication, in the conduct of commerce, and in the provision of education, its impact upon the lives of the more than 50,000,000 individuals with disabilities in the United States has been comparable to its impact upon the remainder of the citizens of the United States. Any development in mainstream technology should have profound implication for individuals with disabilities in the United States" (findings of the Assistive Technology Act of 1998).

The Assistive Technology Act (Tech Act) was first enacted as the Technology-Related Assistance Act of 1988. It is intended to provide Assistive Technology to persons with disabilities so they can more fully participate in education, employment, and daily activities on a level playing field with other members of their communities. The Tech Act covers individuals with all types of disabilities across the lifespan and in all aspects of their lives. The statutory definition of assistive technology device, unchanged since 1988, is "…any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities."

Assistive technology devices include items such as:
- Power and manual wheelchairs, scooters, canes, walkers, and standing devices
- Augmentative communication devices (speech generating devices), voice amplifiers, and speech recognition devices
- Durable medical equipment and medical supplies, such as patient lifts and incontinence supplies

- Orthotics and prosthetics, such as hearing aids, electric larynxes, artificial limbs
- Accessibility adaptations to the home, workplace, schools, and other places (e.g., ramps, stair glides, lifts, grab bars, flashing smoke detectors, level doorknobs, and environmental controls)
- Special equipment to help people work, study and engage in recreation, such a enlarged computer keyboards, reachers, amplified telephones, magnifiers, voice recognition software, and adaptive sports equipment
- Accessibility modifications in the community, such as audio systems on public transportation, talking ATMs, and voting machines for individuals who are blind
- Smart phones and tablets with increasingly numerous apps that increase autonomy, independence, and empowerment and reduce costs for and intrusiveness of personal care or direct support workers

(The above is taken from the National Dissemination Center for Children with Disabilities http://nichcy. org/laws/ata/)

Current law provides funding for fifty-six Assistive Technology Act Projects (ATAP); one in each state and territory. The ATAPs provide a place where people with disabilities, families, advocates, and providers can go for demonstrations of products they may be interested in obtaining including a device on loan at low or no cost, low-cost loans for their purchase, and information and referral on these items.

The statutory definition of Assistive Technology Device was amended into the following federal laws in order to assure the access to public funding when appropriate: IDEA, both Parts B and C; the Rehabilitation Act; and, the Developmental Disabilities Act. In most states, Medicaid can pay for a range of assistive technologies.

THE AMERICANS WITH DISABILITIES ACT AND THE OLMSTEAD DECISION

The landmark Americans with Disabilities Act (ADA) of 1990, a civil rights law prohibiting discrimination

based on disability in employment, publicly funded services, and public accommodations has the following findings: "Individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotecting rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities." The law declares four goals for each individual living with a disability: equality of opportunity; independent living (having choices and control); economic self-sufficiency; and full participation. The goals are, by law, non-negotiable regardless of severity of disability. Moreover, although some of the terminology used by each of the disability categorical programs cited above is different, the fundamental constructs are the same and all are fully compatible with the goals of the ADA.

A significant case under the ADA was resolved by the 1999 Supreme Court ruling in L.C. and E.W. v. Olmstead. Lois and Elaine, two women with the "dual diagnoses" of intellectual disability and mental health disability, wanted out of a state institution in Georgia. Everyone agreed that they did not need to be there; however, the state of Georgia said that it had used all of its community funding from its Medicaid Home and Community Based Services Waiver and that the women could continue to receive appropriate services in the institution. The Court ruled, 6-3, with Justice Ginsburg writing for the majority, that Title II of the ADA forbids unjustified isolation of people with disabilities. Today New Hampshire, Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii, Maine, Michigan, Oregon, Indiana, and Alabama are institution-free for individuals with developmental disabilities and another ten states have less than 100 individuals residing in state facilities. The data are very clear: except for forensic situations, no one with a developmental disability needs to be in an institution. We know how to provide individualized services and supports for everyone to live in a home in the community with housemates of their choice.

The Court's decision affirmed much of the purposes and findings of the ADA and the key Title II

regulation promulgated by the US Department of Justice: "A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." On June 26, 2011, the 12th anniversary of the Olmstead decision, the Department of Justice issued a policy paper https://www.ada.gov/olmstead/q&a_olmstead.pdf on segregation and integration with operational definitions for clarification and guidance. This is a must-read for funders. Most recently, a class action lawsuit was filed by self-advocates in Oregon regarding their right, under the ADA, to receive supported employment services in integrated settings rather than funding for sheltered workshops. The Department of Justice has entered the case and affirms that the ADA and Olmstead apply to all publicly-funded services and not just to residential services.

The federal government states that nearly 19 percent of the population, about 54 million people, are protected under the ADA. Among families in America, 20,874,130 families – 29% – have a family member with a disability. We have no data to suggest that this ratio does not hold true for Jewish families.

Of the people with disabilities who are fifteen years and older:
• 3.3 million use a wheelchair
• 10.2 million use a mobility aid such as a cane, crutches, or a walker
• 1.8 million are unable to see printed words or are blind
• 1 million are deaf or unable to hear conversations
• 2.5 million have difficulty having their speech understood by others
• 16.1 million have limitations in cognitive functioning; have a mental, emotional or behavioral health disability; or a developmental disability

Sadly, people with disabilities live in relative social isolation. Compared to people without disabilities, individuals with disabilities are much less likely to work full or part-time (21% vs. 69%); less likely to socialize with close friends or relatives; less likely to go to places of worship; and, less likely to go out to eat.

(For the above, the author is indebted to David Ferleger, "Disabilities and the Law," The Federal Lawyer, September 2010, p. 27.)

Twelve percent of individuals with non-severe disabilities between the ages of 25 and 64 live in poverty. Meanwhile, 27 percent of those with severe disabilities of the same ages live in poverty, compared with 9 percent of the population with no disability.

In the Jewish community, the greatest barriers we face are neither physical access nor accommodations. Nor are they financial. They are attitudinal, and in that sense, since we cannot legislate attitudes, are no different from those in the disability world at large.

QUESTIONS FOR FUNDERS AND GRANTSEEKERS

Education
- Are children with disabilities included and accommodated in classes with their age peers without disabilities?
- Are transition year (ages 14-21) IEP goals and objectives dedicated to both academic and functional skills leading to independent living, productivity and community integration?
- Do staff members have training in Positive Behavior Supports as an alternative to punishment and the use of seclusion (time out) and restraints (physical, mechanical, or chemical)?

Adult Supports
- Do individuals have meaningful choices in how they spend their day?
- Does each person have a plan that has been developed by and with the person with a disability and the circle of supports he/she has assembled?
- Are supports integrated into the community?
- Are community integrated activities organized in very small groups (two to three people with disabilities with one of two staff) so as not to draw attention and stigma to the individuals?

Employment Services and Supports
- Is competitive, integrated employment at minimum wage or above the goal for all?
- Are benefits planners available to assist the individual with a disability and/or his/her family

with understanding employment, income, assets and benefit protection?
- Are employment and career plans built upon the individual's aspirations, strengths and preferences rather than merely attempting to fill vacancies in the usual places of "food, filth, and flowers"?

Housing and Supports
- Does the person choose where he or she lives?
- Does the person(s)/family have control of the housing by rent, lease, or ownership?
- Does the person choose with whom they live?
- Does the person/family interview, select, evaluate, and, if necessary, terminate the personal-care or direct support professionals?

Assistive and Environmental Technology
- Does the organization have knowledge of the full range of technologies and their case-by-case applicability for the individuals for whom they provide services?
- Does the organization maintain a formal relationship with the Assistive Technology Act Program in its state?
- Does the organization employ staff or consultants who are well versed in the assessment of assistive technologies?

Quality Improvement and Data on Outcomes
- Does the organization have a mission statement and set of guiding principles consistent with current statutory values?
- Is the organization committed to continuous quality improvement in its services?
- Does the organization collect outcome data on individuals in the areas of increased independence/ self-direction, employment/productivity, and community integration?
- Does the organization use peer interviews to obtain feedback and input from its customers?

REFERENCES

To locate the legislation referenced in this chapter, see http://thomas.loc.gov/home/thomas.php

For more on federal legislation that concerns individuals with disabilities, see http://nichcy.org/laws

2 Legal Rights of People with Disabilities

ARLENE S. KANTER

HISTORY & OVERVIEW

In 1990, Congress passed the Americans with Disabilities Act (ADA) which guarantees the right of children and adults with disabilities to equality and non-discrimination. This historic law extends the protections provided in Section 504 of the Rehabilitation Act of 1973, which also prohibits discrimination against people with disabilities, but only in programs that receive federal funds. Section 503 of the Rehabilitation Act also prohibits discrimination by federal government contractors and subcontractors with contracts of more than $10,000.

The ADA more broadly prohibits discrimination by state and local governments as well as by private employers (of at least 15 employees). It prohibits discrimination in most areas of life, including access to employment (Title I); access to state and local services and programs, including public transportation (Title II); access to public accommodations, commercial facilities and public services operated by private entities (Title III); and telecommunications access (Title V). In 2008, the ADA was amended to make it easier for people with disabilities to qualify for protection under the ADA, particularly in the employment context.

Several rights are not included in the ADA: access to housing (because the Fair Housing Amendments Act of 1988 already prohibits discrimination in housing); access to airline carriers (because the Airline Access Act prohibits discrimination by US and foreign air carriers); and certain issues related to communication access (because the Telecommunications Act requires manufacturers of telecommunications equipment and providers of telecommunications services to ensure that such equipment and services are accessible to persons with disabilities). In addition, although the ADA may cover access to public buildings that serve as polling places, two other federal laws provide

additional protections to people with disabilities in the voting process: the 1984 Voting Accessibility for the Elderly and Handicapped Act, and the 2002 Help America Vote Act.

Similarly, the ADA does not apply to pre-school, primary and secondary education because the Individuals with Disabilities Act (originally enacted in 1975 as the Education for All Handicapped Children's Act) addresses the rights of school children through secondary school. Additional federal laws, not discussed here, govern the federal government's anti-discrimination obligations as well as federal benefits programs such as Supplemental Security Income (for people who have no work history), Supplemental Security Disability Insurance (for people who have a work history), and Medicaid and Medicare, which provide cash assistance and health insurance for eligible children and adults with disabilities.

State laws may add to the benefits and protections provided by federal laws, but, according to principles of federalism, state laws may not limit the scope or coverage of federal laws. In the context of education for children with disabilities, for example, states have enacted their own laws and regulations implementing the IDEA. No state, however, may deny children and families their rights under the IDEA. In addition to these federal laws, some areas of law are covered only by state or local laws. These include criminal laws, mental health laws, guardianship laws, and local zoning laws.

In some instances, the Supreme Court–as well as lower federal and state courts–have issued decisions that have clarified federal and state laws and interpreted the US Constitution and its application to people with disabilities. To take one particularly far-reaching example, in Olmstead v. L.C., the Supreme Court held that people with disabilities have a right to receive services outside of institutional settings and

that states must develop plans to provide services to support people with disabilities in the community.

Yet unlike other groups who face discrimination, such as people of color and women, people with disabilities have not been determined by the Supreme Court to be entitled to special protection under the Equal Protection Clause of the 14th Amendment. Therefore, laws that infringe upon the rights of people with disabilities will be evaluated by courts using a lower standard of review: the state must show only that the law has a rational relationship to the purpose served.

In addition to federal and state statutes (laws) and common (case) law, the US recently signed the 2006 UN Convention on the Rights of People with Disabilities (CRPD). This Convention, the first disability-specific treaty in the history of the UN, was signed by President Barack Obama on July 30, 2009 and transmitted to the Senate for ratification on May 17, 2012. To date, 114 countries have ratified the CRPD.

POLICIES AND PRACTICES

The ADA and other US disability laws are based on civil rights laws that were enacted to protect other groups. These laws both prohibit discrimination and guarantee access and accommodations. In the employment context, employers are not required to provide accommodations if doing so will create an "undue burden." When it comes to the built environment and access to public and private services and programs, however, modifications may be required. Here, no such "undue burden" defense is generally provided. The only "defense" against providing modifications is if they are not "readily achievable." In order to enforce the rights provided in the ADA, individuals must file an administrative complaint and/or complaint in federal (or state) court. In some cases, prevailing parties may receive injunctive relief [unclear phrase] as well as damages. The US Department of Justice is also authorized to investigate and pursue cases on behalf of people with disabilities who allege discrimination under the ADA.

Most recently, the Department of Justice has taken an active role in pursuing the rights of people to be

included in the community through enforcement of the Supreme Court's decision in Olmstead v. L.C. Although the ADA does not prohibit institutions, nursing homes or group homes, per se, the Supreme Court in Olmsted v. L.C. held that it is discriminatory to require individuals with disabilities to enter institutions in order to receive the services they need. As a result, the Department of Justice has investigated, filed, or participated in cases in 21 states to require them to develop community alternatives to institutions and to provide support to people with disabilities in the community. Most recently, on April 20, 2012 the Department of Justice entered a case in Oregon (one of the most progressive states), alleging that the state's system of sheltered workshops for people with disabilities violated the ADA's integration mandate. That mandate, cited in Olmstead, provides that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

The IDEA, on the other hand, is not a civil rights law like the ADA, but a "spending law." It authorizes federal funding to states once the state agrees to provide a "free and appropriate public education" to qualified children with disabilities, ages three to twenty-one. In 2004, the IDEA was amended and renamed the Individuals with Disabilities in Education Improvement Act. In order to receive an "appropriate" education and related services under the IDEA, the child's educational performance must be "adversely affected" as a result of one or more impairments[1].

This does not mean, however, that a child has to fail in school in order to receive special education and related services. According to the IDEA, states must make a free appropriate public education available to "any individual child with a disability who needs special education and related services, even if the child has not failed or been retained in a course or grade, and is advancing from grade to

1 Definitions of "a child with a disability" vary from state to state. In general, the term "child with a disability" includes a child with one or more of the following impairments (in order of prevalence): specific learning disabilities, speech or language impairments, intellectual disability (until 2010 referred to as mental retardation), emotional disturbance, other health impairments, multiple disabilities, autism, orthopedic impairments, deafness, or hearing impairments, blindness or vision impairments, traumatic brain injury, and deaf-blindness. At the discretion of each state, "child with a disability" may also include children ages three through nine and preschool age children (ages three to five) who are experiencing developmental delays in certain areas and therefore require special education and related services. See 20 U.S.C. §1401 (3)(b)(i)-(ii).

grade." This requirement also applies to children who attend private schools, including religious schools, and, depending on the state, to students who are homeschooled. In the 1982 Rowley case, the Supreme Court held that school children are entitled only to a "basic floor of opportunity" and not to the opportunity to maximize their educational potential. Since the 1997 reauthorization of the IDEA, courts have held that IDEA should provide a meaningful education that will lead to independent living and economic self-sufficiency.

For children with disabilities who attend Jewish day schools (considered private schools under the IDEA), access to services under the IDEA is governed by state law. Most states, such as New York, ensure that parents have a legal right to place their children in independent or religious schools or instruct their children at home in order to satisfy the state compulsory education law. However, about dozen states, including New York, have enacted the "Blaine Amendment," which prohibits the use of state funds at "sectarian" schools. Nonetheless, children with disabilities are entitled to receive services under the IDEA so long as their parents make a written request. Further, under the 2004 version of the IDEA, the local educational agency (LEA) that services areas in which private schools are located is required to identify children with disabilities; engage in timely and meaningful consultation with the private school and parent representatives to determine the special education and related services that the LEA will provide; and "expend a proportionate share of federal funding on servicing this population of students." The LEA is also required to maintain data on the number of children who are placed in private schools by their parents. In some states, the local school district may also be required to provide transportation for children with disabilities who attend Jewish day schools.

Under the IDEA, all parents of children with disabilities who qualify for IDEA services, regardless of whether their child attends a public or private school, have the right to meet with the school staff to develop an Individualized Education Program (IEP) for the child, which must be reviewed at least annually. If the parties do not agree on the IEP, the parents have the right to pursue a "due process hearing" and subsequently to file a case in court, for which attorney fees are available for parents who prevail. Having said that, however, few parents are aware of their rights. Even for the most educated and resourceful parents who are aware of their rights, securing appropriate services for their child is often a time-consuming and frustrating task. As a result, many states have developed programs that support parents in advocating for their children's educational rights such as the New York state-wide program of parents centers. Others partner with a university-based program, such as the Syracuse University Parent Advocacy Center. In addition, in recent years, not-for-profit legal organizations as well as private attorneys have begun to specialize in this area of law. Syracuse University College of Law has created the first joint-degree program in law and disability studies to equip its graduates with experience in representing parents in IDEA cases as well as in other areas of disability law.

LEADING EDGE CONCEPTS

Although a significant portion of the American population are people with disabilities (as many as 15 percent by recent estimates), for most of our nation's history people with disabilities have been excluded and marginalized and regarded as defective. Society's response to them was confinement, neglect, charity, and/or medical treatment or rehabilitation. Today, disability is no longer seen as a purely medical problem but as an issue that demands societal action and intervention. In what is commonly referred to as "the social model of disability," disability is now considered a product of the interactions between the individual and the physical and social environment. Consequently, efforts to assist people with disabilities focus today not on charity and medical intervention alone, but also on efforts to advance the human rights and self-empowerment of persons with disabilities as well as to promote programs that incorporate person-centered planning, inclusion, and universal design.

It is worth examining each of these concepts in turn:

Human Rights
The Human Rights Model recognizes the inherent equality of all people, regardless of disabilities or

differences, and affirms that people with disabilities are entitled to full inclusion and equal rights. It focuses less on functional impairments than on the limitations of a society that categorizes who is normal and who is not. The Human Rights approach adopts the social model of disability, as discussed above, and challenges the view that people with disabilities are objects of charity or in need of services and treatment. It regards limitations placed on people with disabilities by their social and physical environments as violations of their human rights, and seeks to protect the rights of people with disabilities to make informed decisions about their own lives.

Self-Empowerment

Perhaps the most important development in the field of disability law in the past decade has been the rise of the self-advocacy and self-empowerment movement. Many people with all types of disabilities now participate in the planning of their own lives and are no longer satisfied if others make decisions for them without their input. This movement strives to enable all people with disabilities to live as independently as possible, to make as many choices about their own lives as possible (and to know what choices exist), and to exert as much control over their own lives as possible. Similarly, person-centered planning and programming now requires service providers to include the client in decisions about treatment and services, including where he or she will live, what treatment he or she will receive, and where such treatment and services will be provided. As the slogan puts it, "Nothing About Us Without Us."

Full Inclusion

In recent years, people with disabilities—together with their non-disabled allies, friends, and family members—have advocated for the right of children and adults with disabilities to be included in all aspects of life. State-of-the art education policies and practices have moved from segregation to mainstreaming and integration to inclusion as current the goal for all students with disabilities. In the area of housing and community living, programs will be positively evaluated if they provide typical housing, with supports as needed; and employment policies and programs aim to offer supported employment rather than sheltered workshops.

Universal Design

The ADA and its predecessors, the Rehabilitation Act and IDEA, refer to accommodations and modifications to ensure access. But these terms are being replaced by the concept known as Universal Design (UD). UD was coined in the early 1970s by Ronald Mace, the founder of the Center for Universal Design at North Carolina State University. He defined UD as the design of products and environments to be usable by all people to the greatest extent possible. (For more information, see The Center for Universal Design http://www.ncsu.edu/project/design-projects/udi/ or Institute for Human Centered Design http://www.humancentereddesign.org.) Today, the principles of UD support the adaptation of the environment to a wide range of users.

When such adaptations are made at the outset, they save the expense of later retrofitting. For example, adding a ramp at the entrance of a building (or having only a ramp) may be seen as an accommodation for a person using a wheelchair, but it also provides a benefit to a child on a tricycle or a parent pushing a carriage. "When the ramp is integrated into the architectural and landscape designs from the outset, aesthetics of the building are not compromised, but the 'usability' by the public has been broadened." (Id.)

BEST PRACTICES

Throughout the country, state and local government offices collaborate with non-profit organizations and university-based programs to develop models that promote these leading edge concepts. Funders no longer reject requests from advocacy programs in favor of funding only direct (non-legal) services. Many funders now appreciate the importance of advocacy in ensuring quality services.

THINGS TO AVOID

From the funders' point of view, programs and projects that fail to address the concepts discussed above, particularly in reference to person-centered

planning and supported housing and employment, should be viewed with skepticism. That is not to say that all programs that segregate people with disabilities are unworthy of attention. Surely some deaf children prefer attending schools for deaf children rather than their neighborhood school. Nonetheless, funders that perpetuate the status quo by supporting institutions, institution-like housing (even when it is "nice" housing), and segregated employment and programs are likely to meet opposition by the disability rights community.

Take, for example, the current worldwide campaign to end the institutionalization of children. This campaign, developed by Disability Rights International http://www.disabilityrightsintl.org urges governments and private funders to stop providing funds to support institutions. Similarly, Inclusion International's Global Campaign on Article 19 http://www.ii-livinginthecommunity.org/ seeks to include all people with intellectual disability in the community.

As the success of programs based on these values becomes known, people with disabilities as well as their family members have not only acknowledged the important role advocacy plays in improving and ensuring quality services to people with disabilities, but have begun to embrace inclusive, rights-based, person-centered, universally designed models of services delivery.

ADDITIONAL RESOURCES

American Disabilities Act (ADA)
http://www.ada.gov

Individuals with Disabilities Education Act (IDEA)
http://idea.ed.gov

UN Convention on the Rights of People with Disabilities
http://www.un.org/disabilities

Disabled People's International
http://www.dpi.org

Global Partnership on Disability and Development (GPDD)
http://www.gpdd-ponline.org

International Disability Alliance (IDA)
http://www.interntationaldisabilityalliance.org

Jewish Special Education International Consortium
http://www.jsped.org/

Gateways: Access To Jewish Education
http://www.facebook.com/
GatewaysAccessToJewishEducation

Syracuse University Center on Human Policy, Law, and Disabilities Studies/Disability Law and Policy Program
http://disabilitystudies.syr.edu
http://law.syr.edu/academics/center-and-institutes/
disability-law--and-policy-program

Universal Design
http://www.ncsu.edu/project/design-projects/udi

The Disability Rights Fund (DRF)
http://www.disabilityrightsfund.org

Wellspring Advisors LLC – Catherine Hyde Townsend, Program Officer, International Human Rights, 410 Broadway, 23rd FL, New York, New York 10018-5023, Tel +01 646 214-7741| Fax +01 212 609-2633. Email: chtownsend@wellspringadvisors.com

3 Early Childhood Education

BARBARA J. SMITH

This chapter uses the term "early intervention" (EI) as encompassing the array of services and policies established for improving the developmental trajectory of young children with special needs, birth to age eight, and their families. "Early childhood special education" (ECSE) is the profession that establishes the parameters for professional standards, program standards, and approaches, and embodies the theoretical and scientific foundations for the field.

EARLY CHILDHOOD EDUCATION HISTORY

Although ECSE and early intervention evolved from the fields of early childhood education (ECE) and special education, it is more than the sum of these two parts; it now represents a distinct body of professional knowledge, practice, and policy.

ECSE shares with ECE the theory that early childhood is a distinct period of human development characterized by approaches to learning and interpreting the world differently from those of adults. ECSE and early intervention also embody the ECE notion that development is sequential but responsive to environmental factors that affect that sequence or trajectory. Twentieth-century writers and theorists have posited that a child's development is affected not only by "nature," or the innate characteristics of the child at birth, but also by "nurture," or environmental factors.

Early education movements in the early 1800s emphasized these concepts as well as the role early education could play in ensuring an educated citizenry. In the first systematic developments in the US, kindergartens were established in order to foster social and emotional readiness for formal schooling. With the advent of more women working outside the home, and particularly with the women's suffrage movement in the early 1900s, other forms of ECE developed. Nursery schools primarily established by

and for middle-class families put additional focus on social and emotional development of young children.

In the 1930s and 1940s, the Great Depression created high unemployment and World War II created the need for women to work outside the home in order to fill jobs left by men who were serving in the military. The federal government provided funding for child care so that women could work in war related industries. Views about ECE and the availability of ECE settings continued to evolve with the women's equity movement. The Equal Pay Act of 1963 and Titles VII and IX of the Civil Rights Act of 1964 ushered in equal rights for women and girls in education and employment, as well as a growth in child care opportunities. But even as these dramatic developments expanded early education, children with disabilities received little attention.

SPECIAL EDUCATION HISTORY

The second foundation of ECSE and EI is the field of special education. At roughly the same time period in the nineteenth century that theories associated with early childhood emerged, the interest in atypical human development became visible. The 18th and 19th century theories on the influence of environmental factors on young children's development also began to inform our understanding of the developmental trajectory of people with disabilities.

At the turn of the 20th century, with the expansion of public schooling in the US, the field of special education emerged. It made clear that learning and development are not fixed but rather can be affected by the environment, including education. Over the next four decades, testing of recruits for the World Wars revealed that many people with disabilities were living typical lives. As veterans with war-related

disabilities came home, the view of disability began to change. The result was a growing recognition of the need to provide support and services.

In the mid 1960s, researchers found that by enriching the early experiences of young children with disabilities, their learning trajectories of could be dramatically altered for the better. Others argued that intelligence is not fixed, develops early, and is affected by early experiences. This scientific and theoretical foundation, along with strong support from the Kennedy administration, led states to enact legislation that expanded educational programs for children with disabilities. Still, special education and early intervention services were largely confined to volunteer efforts and provided to children with disabilities in settings separate from their non-disabled peers.

THE ROLE OF POLICY

As noted above, along with the theoretical and scientific advances in the mid-1960s, public policy began to play a key role in the expansion of services and the development of systems for special education, early childhood education, ECSE, and early intervention. While research findings were establishing the importance of education in the lives of young children with disabilities, services were voluntary rather than part of mainstream education. Advocates began to turn to policy makers in an effort to establish more adequate services for young children with special needs.

Public policy came to play two major roles in ECSE and EI: encouraging states and localities to provide services while offering guidance about best practice; and requiring states to provide services and to establish systems for doing so. By the mid-1960s, research on the effects of early experience and child development led to two path-breaking federal initiatives that provided incentives and guidance to states.

The first, Project Head Start, was enacted in 1964 under the Economic Opportunity Act as a part of the Johnson administration's "war on poverty." Head Start aimed to provide early intervention for young children at risk for school failure due to poverty.

In 1972, Head Start programs were required to allocate 10 percent of enrollment to children with disabilities. This requirement not only resulted in the first national early intervention services for young children with disabilities, but also made a national statement about the importance of serving young children with disabilities together with their typically developing peers rather than separately.

The Handicapped Children's Early Education Program (HCEEP), the second major policy milestone during this period, was enacted by Congress in 1968 to develop research and demonstration projects aimed at discovering new and better approaches to working with young children with disabilities.

While HCEEP was helping to foster the field of early intervention and ECSE, other important developments were already on the horizon. By the mid-1970s, it was estimated that one million school age children with disabilities were not receiving an education. Building on the precedent set in the 1954 Brown v. Board of Education ruling, which established a right to equal education for all children regardless of race, the 1970s saw several court cases and other policies advance the right to education for children with disabilities. In 1971, the landmark Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania lawsuit established the right to education for all school age children with mental retardation. The following year, in Mills v. Board of Education, the court in the District of Columbia established a right to education for all children with disabilities of school age.

These court cases found that under the equal protection clause of the 14th Amendment to the US Constitution if education is provided by the state to one group, it must be provided to all. The interpretation of the equal protection clause was evolving from ensuring equal access to the same resources, to "equal access to differing resources for equal objectives." State legislatures and other court cases followed suit, and children with disabilities were winning the right to an education, due process during important decisions such as assessment, diagnosis, and placement in special education, and to have services provided in the "least restrictive environment."

This right to education movement culminated in the 1975 Education for All Handicapped Children Act, created by amendment to the Education of the Handicapped Act (later named the Individuals with Disabilities Education Act, or IDEA). This new law mandated states to provide a free, appropriate public education to all school-age children with disabilities in the least restrictive environment and according to a written Individualized Education Program (IEP). While not requiring states to serve very young children, it offered states financial incentives to provide preschool education to children with disabilities younger than age six.

In 1984, based upon research findings on the efficacy of early intervention services and the social value of supporting families and children, Congress established a new program that provided federal funds to states for planning, developing, and implementing statewide services for children with disabilities from birth to five years. Again, this was not a mandate, but an incentive program. At that time, about half the states provided early intervention and education services to some portion of the population of young children with disabilities, ages three to five, with ten states providing some services from birth.

Building on these state efforts, and based on an accumulation of the federally funded efficacy research and development of effective practices and services under HCEEP, Congress passed the Education of the Handicapped Act Amendments of 1986. These amendments created what is now known as IDEA, Part C, for infants and toddlers with disabilities, and IDEA, Part B, Section 619, for preschool aged children with disabilities. This law required states to lower the age from six to three for a free appropriate public education to children with disabilities under Part B. It also established a voluntary early intervention program for children with disabilities (or at risk for disabilities) from birth through age three under Part C.

In the 1980s and 1990s, few major federal initiatives addressed early intervention, though there have been amendments to IDEA refining some of the early childhood provisions. However, Early Head Start was established for birth to two year olds. Like the program for three to five year-olds, it required

10 percent enrollment of children with disabilities. Funding for IDEA and Head Start has increased but is still not sufficient to appropriately serve all eligible children. A major milestone was the passage of the Americans with Disabilities Act (ADA) in 1990. Though not early childhood legislation, it bans discrimination in public services such as child care and other early childhood settings. It was through the ADA, therefore, that children with disabilities gained the right to enter into many natural settings.

RESEARCH-BASE

Two national professional associations advance standards of practice in early childhood education. The National Association for the Education of Young Children (NAEYC) is the professional association for "regular" early childhood educators. The Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC) advances professional standards, programs standards, and public policies that promote best practices for optimizing the developmental outcomes of young children with special needs, including children with disabilities and children at risk for disabilities.

Based on the best available research, both organizations have developed standards of practice for young children and young children with special needs, including disabilities or at-risk for disabilities. The DEC Recommended Practices, for instance, are the result of the most recent comprehensive literature review in EI/ECSE. The EI/ECSE field has an extensive research base in teaching strategies that promote good outcomes. There is a growing recognition that with this substantial research base, services and programs for young children with disabilities should use evidence-based practices to ensure that children and families are getting the most effective services available.

LEADING-EDGE CONCEPTS

Professional Development
One approach to enhancing quality is to establish training, professional development, and technical

assistance programs that support the use of effective practice at the local level. Currently, however, few states provide such programs. Often, states provide support only for short-term training sessions. A growing body of research suggests that training alone, without on-site coaching to provide opportunities for application of new strategies with feedback, does not adequately change current practice by service providers. To achieve adoption of effective practice and strategies, providers need to receive information on the new practice, be provided with an opportunity to apply that practice, and receive supportive feedback.

Adopting evidence-based practices, in other words, requires on-site coaching. To achieve this type of professional development and technical assistance, states need to develop policies and resources that may not yet be in place. This further requires a paradigm shift for states to establish and support such intensive technical assistance and training systems for early childhood programs. In some cases, this would require a comprehensive systems-change, including resources, systems, and quality assurance mechanisms (such as certification and licensing) as well as data collection and evaluation systems tied to quality improvement efforts.

Inclusion

By the 1990s, there was not only legal precedent for inclusive services, but also a recognition that providing effective services and supports to young children with special needs and their families should be conducted in normal settings with typically developing peers. This concept of "inclusion" has been a focal point of early intervention and ECSE for the past twenty years. A large body of research demonstrates that children with disabilities served with typically developing peers develop and learn at least as well--if not better--than those served in segregated settings.

Inclusion has major ramifications on policies, on personnel preparation, and on local, state, and federal programs. One of the implications has been to bring the ECSE and ECE fields together, not as one field but as two coordinated fields of knowledge. The two professional associations, DEC and NAEYC, are working together to establish a shared vision of inclusion, and to promulgate personnel and program recommendations for how to teach all children together.

EVIDENCE-BASED PRACTICES (EBPS)

For two reasons, there is today an increased recognition that strategies to promote learning and development in young children with disabilities should be based on the best available evidence that the strategies will result in optimal learning and outcomes. The first reason for this is a move toward greater accountability. A second reason is an ethical one: if we know of practices that will promote good outcomes, how can we ethically continue to use unproven practices?

Professional development therefore ought to focus on teaching EBPs; it should include training at the pre-service (e.g., two- and four-year colleges and universities) and in-service level, as well as technical assistance services. Training and technical assistance providers also have the responsibility to support practitioners in identifying evidence-based practices for implementation across a broad range of settings. They must know which practices are effective and how to teach providers practices so that they can implement them appropriately. The challenge for states is to fund and support such effective professional development efforts.

THINGS TO AVOID

- Funding services delivered in non-inclusive settings
- Funding programs in which consumers do not have input into their design
- Funding projects that are not evidence-based

THE ROLE OF FAMILIES

In all services for people with disabilities, families are an integral factor and should be involved in all decisions including program planning and evaluation. In the case of early childhood services or initiatives,

families must be considered the consumer as much as the child. In family-centered services, all plans, programs, and all services to be provided to the child must be co-designed by the family. The family of a young child is the child's voice. Because the family knows the child best, it can help design services better than professionals who do not know the child as well. The reach of the intervention is extended if the family knows the strategies and can carry them out at home. Services should be provided in a family-friendly way and in a manner that can be easily embedded in a child's natural routines, including play.

Suggestions for the role of families in the grant awarding process:
• Families should help select grantees
• Families should help to craft an overall vision for funding in this area
• Families should serve on advisory boards of funded projects

QUESTIONS FOR FUNDERS

• In your funding initiatives, do applicants need to describe the inclusion of persons with special needs?
• Do you require prospective grant recipients to identify the evidence base for the services and programs they propose?
• Do you ask prospective grant recipients how they will involve parents and other consumers in their plans?

REFERENCES

Bauer, A M., Johnson, L. J., Ulrich, M., Denno, D.M., & Carr, V.W. (1998). "A history of working with and for children." In L. Johnson, M. LaMontagne, P. Elgas & A. Bauer (Eds.) Early childhood education: Blending theory, blending practice. Baltimore, MD: Brooks.

Blasé, K. (2009). Technical assistance to promote service and system change: Roadmap to effective intervention practices. Technical Assistance Center on Social Emotional Intervention. www.challengingbehavior.org. Downloaded, 2/1/10.

Bloom, B. S. (1964). Stability and change in human characteristics. New York: Wiley.

Darragh, J.C. (2010). Introduction to early childhood education. Upper Saddle River, NJ: Pearson.

DEC/NAEYC. (2009). Early childhood inclusion: A joint position statement of the Division for Early Childhood (DEC) and the National Association for the Education of Young Children (NAEYC). Chapel Hill: The University of North Carolina, FPG Child Development Institute.

Fixsen, D. L., Naoom, S.F., Blase, K.A., Freidman, R. M. & Wallace, F. (2005). Implementation research: A synthesis of the literature. Tampa, FL: University of South Florida, Louis de la Parte Florida Mental Health Institute, the National Implementation Research Network (FMHI) Publication #231.

Hunt, J. M. (1961). Intelligence and experience. New York: Ronald Press.

Joyce, B. & Showers, B. (2002). Student achievement through staff development (3rd ed.). Alexandria, VA: Association for Supervision and Curriculum Development.

Mallory, B. (2007). "Early childhood special education." In R. New & M. Cochran (Eds.) Early Childhood Education: An International Encyclopedia. Westport, CT: Praeger.

Rous, B. & Smith, B. (2011). "Key national and state policy implementation issues." In C. Groark, S. Eidelman & S. Maude (Eds.) Early Childhood Intervention: Programs and Policies for Special Needs Children, Vol. I: Policies and Procedures. CA: Preager.

Sandall, S., Hemmeter, M., Smith, B., McLean, M. (Eds.) (2005). DEC Recommended Practices: A Comprehensive Guide for Practical Application. Longmont, CO: Sopris West Publishing.

Shonkoff, J. P. & Meisels, S. J. (2003). Handbook of early childhood intervention. New York, NY: Cambridge.

Smith, B. & Rous, B. (2011). "Historical Perspectives," In C. Groark, S. Eidelman & S. Maude (Eds.) Early Childhood Intervention: Programs and Policies for Special Needs Children, Vol. I: Policies and Procedures. CA: Preager.

Smith, B. & Bredekamp, S. (1998). "Foreword." In L. Johnson, M. LaMontagne, P. Elgas & A. Bauer (Eds.) Early childhood education: Blending theory, blending practice. Baltimore, MD: Brooks.

Smith, B. J. (1988). "Early intervention public policy: Past, present, and future." In Jordan, Gallagher, Hutinger, & Karnes (Eds.), Early Childhood Special Education: Birth-Three. Reston, VA: Council for Exceptional Children.

Weintraub, F. & Abeson, A. (1976). "New education policies for the handicapped: The quiet revolution." In F. Weintraub, A. Abeson, J. Ballard & M. LaVor (Eds). Public policy and the education of exceptional children. Reston, VA: Council for Exceptional Children.

4 Special Education
GORDON L. PORTER

Families of children with special needs face the challenges typical in their communities, but they also face the added strains of obtaining an appropriate education for their child. A child may have significant needs based on physical, intellectual, behavioral, or mental health factors. Such needs bring extra challenges to the family and consequently to the education institutions.

Special education services have been developed to meet these challenges. Applicants for funding may request support for programs that are either:

• New or have enhanced special services or facilities
• Programs that focus on fundamental changes to special education

Such changes would create a balanced program that provides personalized support and instruction in an inclusive context.

There has been tremendous growth of special education over the last few decades. In many cases, it is the greatest cost driver in the education system. The number of children in publicly-supported special education programs in the United States increased from 8.3 percent of the student population in 1976/77 to 13.2 percent in 2008/09.

This same trend is at work in Canada. Between 2005 and 2010, in one large urban school district in Canada the overall student enrollment fell by nearly 27,000 students. But in the same period, more than 5,000 more students were placed in special education programs.

This trend offers funders an opportunity to support innovative programs with a more sustainable approach to effectively meet student needs.

HISTORY

Children with disabilities often need specific supports and accommodations to assure their success. Traditionally, these supports have been offered in special programs and services that have isolated the children and caused social divisions between them and their peers.

Since the 1970s, educators have developed ways to serve children with disabilities effectively in schools and classrooms with their non-disabled peers. This effort of inclusion offers the most appropriate approach because it focuses on bringing extra supports and capacity into the regular school and classroom rather than taking the child out.

POLICY

US policy for special education mandates that children are provided with Individualized Education Plans (IEPs). Effective and appropriate instruction for each child is based on individual plans that maximize personal development. At the same time, the plan maintains and facilitates social and community inclusion.

PRACTICE

An inclusive special education program is supported by practices that permit the school and the teacher to identify, develop, and implement child-centered strategies. These strategies are designed to meet the individual student's needs for growth in cognitive, social, physical, and emotional areas.

Strategies cover a range of practices, for example:
• Schools should plan, assess student needs, support teachers, engage in problem solving as well as

collaboration, and partner with families and community agencies that provide children's services or work with families

- Classrooms should incorporate flexible instructional strategies, differentiation, co-teaching, team teaching, peer strategies, and support cooperative learning; use a range of visual, auditory, and tactile modalities; and utilize Howard Gardner's Multiple Intelligence Model that focuses on a pedagogy that engages students in visual, logical, kinesthetic, interpersonal, musical, and other distinct abilities.

RESEARCH-BASED

Children with disabilities do best when their individual needs are met. Needs are best met in a setting that maximizes interaction and contact with other children their own age. To accomplish this, both the child and teachers need support. When provided, this support achieves positive outcomes.

LEADING-EDGE CONCEPTS

The most instrumental concept is to create collaborative teams within the school. Several teachers share responsibility for planning and carrying out instruction for a group of students that include those with special needs. In some cases, this involves team teaching or co-teaching. Collaborative teams can also involve a specialist teacher assisting a regular classroom teacher as required.

The strategy is to introduce support and capacity into the classroom rather than pulling out individual students. This strategy simultaneously builds the capacity in the regular classroom for a child with special needs and strengthens the teacher's capacity to enhance learning for other students.

BEST PRACTICES

Best practices are linked to specific strategies that assure collaboration among teachers and professionals, as well as interventions based on the specific needs of individual children.

In the first example, a community school assures collaboration by holding grade level meetings of teachers and support staff at a scheduled time at least once a week. Teachers inform the resource teachers about the challenges they are having with specific students. Then, the team identifies a strategy to intervene and provide support.

The resource teacher with the most knowledge and experience with the identified need provides the support. Specialists or experts from outside the school are called on when needed, but they contribute as a member of the team. The teacher gets the needed support and the student achieves increased levels of success. As a result, both the teacher and the team are better prepared to meet similar needs in the future.

As a second example, a high-school geography teacher demonstrates a practice most commonly described as differentiated instruction. The teacher engages all the learners in his heterogeneous class in the same general concepts. At the same time, the teacher accommodates differences in learning styles and cognitive levels among the students.

If teachers use Howard Gardner's Multiple Intelligence Model, with its emphasis on the range of intelligences children have, teachers can better engage students at different levels and with varying ways to effect input and output. The result is a flexible approach to lesson design that effectively meets the needs of a diverse range of learners.

THINGS TO AVOID

The most important thing to avoid is to isolate a child from the mainstream of the educational system. Avoid such stand-alone programs or interventions. Isolating any child from the school diminishes the school in the long term. Isolation does not build school capacity or sustainability.

Promoting inclusion enhances the social development of both the child with a disability and his/her non-disabled peers. The diversity of our communities, if it is embraced, can be used to build a positive and accepting school climate that yields social benefits for every student.

ROLE OF FAMILIES

Families are critical to any child's success in school. Family involvement is even more critical for children with disabilities. Families need to be treated as partners and not as consumers of a service.

Families need to:
- offer their insights and knowledge about their child's needs
- monitor and give feedback to the educators who work with their child
- demonstrate their determination that their child will gain the skills, the competencies, and the relationships in school that will result in a meaningful life in the family and community when they are no longer in school
- be nurtured and supported in the many functions demanded of them

QUESTIONS

For Grantseekers

- How will your project encourage children with disabilities to achieve higher levels of social and academic inclusion?
- Does your project strengthen families and enhance community supports? If so, how?
- Will your initiative strengthen the core educational program to accommodate diversity, or will it enhance an alternative service option?

For Funders

- Will the project increase capacity in such a way that the applicant/agency/school can serve children with disabilities better in the future?

ADDITIONAL RESOURCES

The European Agency for Development in Special Needs Education was established by member countries to act as their platform for collaboration regarding the development of provision for learners with special educational needs.
www.european-agency.org

TASH promotes the full inclusion and participation of children and adults with significant disabilities in every aspect of their community, and eliminates social injustices that diminish human rights.
www.tash.org

Inclusive Education Canada provides training information and opinions on providing quality educational services to children with disabilities or other special needs.
www.inclusiveeducation.ca

The Council for Exceptional Children (CEC) works internationally to improve the educational success of individuals with disabilities and/or gifts and talents.
www.cec.sped.org

Inclusion International is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide.
www.inclusion-international.org

5 Community Living and Supports

STEVEN EIDELMAN & AMANDA RICH

For the past forty years, disability rights advocates, including people with disabilities and their families, have fought hard to advance the belief that people, regardless of their disability status, have the right to live in the community, in regular housing, with the supports that they need to be successfully included in the community. Advocates and self-advocates (people with disabilities themselves) have had great successes that can be seen through the dramatic rates of deinstitutionalization from both large, state-run, residential institutions and to a lesser extent nursing homes, as well as the increase in community presence of people with disabilities. By and large the question has shifted from "is supporting people with disabilities in living the community the right thing to do?" to "what are the right ways to support people with disabilities in living rich, integrated, and connected lives in their communities?" and "what are the right policies to enable to communities to provide those supports?"

HISTORICAL DEVELOPMENT

Prior to the mid-1800s, most people with disabilities primarily received support from their families. Those whose families could not provide support did not survive or were sent to live in poorhouses. Integration into community depended in part on one's ability to participate in farm labor. The mid- to late-1800s marked a burgeoning interest among physicians, educators, and social reformers in the nature of what was then called "idiocy" and in how "idiots" were fairing in society. Some shed light on the appalling conditions to which people with intellectual and developmental disabilities were consigned and encouraged local governments and private donors to invest in the education and treatment of people with disabilities. Disability was seen as a medical illness that should be managed by professionals. Those professionals maintained that the best care for people with disabilities could only be provided by

professionals in settings that were separate from other parts of the community.

The next eighty years saw rapid growth of large training schools and institutions for people with disabilities in the United States, Canada, and Europe. Institutional care was often marked by a loss of contact with family members and others outside of the institutions, a lack of choice and control over one's life, and the denial of basic civil rights.

In the 1960s and 1970s, exposés on the dehumanizing conditions faced by people who had been institutionalized prompted massive efforts on the part of disability rights advocates to move people from institutions to their communities. It likewise prompted the development of funding streams, primarily through Medicaid, in an effort to improve the quality of institutions and provide people with the funding needed to live in their communities. (For more information on the rise of institutions and the history of disability see the Minnesota Governor's Council on Developmental Disabilities. http://www.mnddc.org/parallels/index.html)

According to new ways of thinking about disability support that emerged from the Scandinavian countries, people with disabilities should lead lives that are normalized–lives comparable to those in their communities without disabilities (see http://thechp.syr.edu/Genius.pdf). Decent lives, some argued, could not be provided in institutional settings.

The movement to support people with disabilities from institutions to the community has made significant progress. In 1990, over 131,000 people [worldwide? In the US?] with intellectual and developmental disabilities were housed in large, state-run institutions. By 2005, that number dropped to 40,532. About 92 percent of individuals with intellectual and/or developmental disabilities who

receive residential services are supported in settings of sixteen people or fewer (Larson, Ryan, Salmi, Smith & Wuorio, 2010 http://rtc.umn.edu/docs/risp2010.pdf). Indeed, a number of states have closed all of their publicly funded institutions for people with intellectual and developmental disabilities. By 2009, eight states and the District of Columbia (Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, West Virginia) no longer had a large state institution (Larson et al., 2010 http://rtc.umn.edu/docs/risp2010.pdf).

However, in 2007, just two states – Vermont and Alaska – had more than 95 percent of the individuals with intellectual and developmental disabilities served living in their own homes, in their family's home, or in settings with three or fewer residents. In addition, between 1990 and 2000, the number of state-run psychiatric hospitals decreased by 17 percent. (For a review of deinstitutionalization of people with mental illness, see the Kaiser Commission on Medicaid and the Uninsured's report: http://www.nami.org/Template.cfm?Section=About_the_Issue&Template=/ContentManagement/ContentDisplay.cfm&ContentID=137545)

The progress, while significant, has been slower for those with physical disabilities and complex health needs. The housing task force of the Consortium of Citizens with Disabilities found that nearly 430,000 non-elderly people with disabilities in the United States, about 14 percent of total residents, were residing in nursing homes or public-funded mental health facilities. In the United States, 16,000 nursing-home residents were children and young adults with disabilities, ages 0-30. (For data on housing for people with physical disabilities, see the Consortium for Citizens with Disabilities Task Force on Housing Report: http://www.tacinc.org/resources/data/pricedout/)

BEST PRACTICES

Although the concept of best practice continually evolves, it is generally agreed that best practice for supporting people with disabilities living in the community is rooted in values that respect individuals' dignity and autonomy and recognize disability and interdependence as a normal part of the human experience. Best practice emphasizes economic self-sufficiency and self-directed, independent, and fully participatory living within communities. The United Nations Convention on the Rights of Persons with Disabilities (CRPD), which has been ratified by most countries, has adopted many of these values. Article 19 of the convention states that people with disabilities should have the right of to choose where and with whom they live.

Services that utilize best practice support individuals' and families' physical and social inclusion, choice and control over one's life (including financial and support service decisions), health and safety, and opportunity to contribute to one's community. Best practice also recognizes the cultural diversity of the people supported, and values the people who directly provide the support services.

The United States, Canada, and Israel, as well as other developed countries, are home to many organizations that provide high-quality services and supports to people with disabilities. In the United States, dozens of such organizations support all of the people they serve, regardless of the severity of disability, in a home owned or rented by the person who uses their supports. In this way, a disabled person maintains the ability both to change residence without impacting the support services he or she receives and to change support providers without impacting his or her residence.

There is another element to best practice: an individualized support plan that each person and each family helps to create around their strengths, preferences, and needs. Organizations that provide services are seen as bridges to the community and help the people they support build meaningful relationships within their community. Direct care providers are valued as perhaps the most important components of their organizations and are given meaningful input into organizational decisions.

Yet physical presence in the community is only one aspect of inclusion. Full inclusion includes having

meaningful experiences and relationships with others in the community. Quality services involve supporting people with disabilities in developing meaningful relationships with others in their communities. Quality housing alone does not equal quality of life. Pervasive loneliness is continually cited as a major problem in the lives of people with disabilities, regardless of the size of their residential setting (though there some evidence suggests that people are less lonely in smaller-sized residences and family homes).

Best practice also involves supporting individuals and families in having choice and control over all aspects of their lives, from mundane decisions like what to eat to major ones like where and with whom to live; how to spend money; and how and by whom to be supported. This also means that people are supported in gaining the information and experiences necessary to make informed decisions.

Far from all support services have embraced this practice. For instance, in a study conducted in Pennsylvania from 2003-2004, 65 percent of adults receiving residential services reported having no input regarding where they lived (Feinstein, Levine, Lemanowiz & McLaughlin, 2005 http://disabilities. temple.edu/publications/docsDL/ID114_IM4Q_ INFO_SHEET.pdf). Of those who did report having a say on where they lived, 66 percent reported not having looked at any other options other than where they were currently living, 76 percent did not choose their housemate, and only 31 percent had a key or way of entering their house when they wanted (Feinstein, et al., 2005). Pennsylvania is generally considered a "progressive" state for people with disabilities.

The benefits of community inclusion and autonomous choice are by now well-documented. (For a review on the benefits of community based supports, see the policy research brief "Behavioral Outcomes of Deinstitutionalization for People with Intellectual and/or Developmental Disabilities: Third Decennial Review of U.S. Studies, 1977-2010" http://ici.umn. edu/products/prb/212/212.pdf by the University of Minnesota Research and Training Center of Community Living.) The Council on Quality and Leadership www.thecouncil.org found that people

with intellectual and developmental disabilities who chose where and with whom they lived; chose where they worked; and chose their services, were more likely to be free from abuse and neglect, and three times more likely to perform varied valued social roles. Seventy percent of families that include a member with intellectual disabilities receiving community-based supports reported that those supports usually or always made a positive difference in their family member's life (National Core Indicators, 2010 http://www.hsri.org/files/ uploads/publications/NCI_Annual_Summary_ Report_2009-10.pdf). Services and supports that promote community involvement and inclusion correlate with higher levels of choice, independence, self-determination, and self-worth for people with disabilities and their families.

Building a support service plan around an individual's wants and needs enables organizations to provide more culturally competent services by allowing for flexibility and individualization. A person-centered approach creates a holistic picture and builds supports around the wants and needs of individuals and families served rather than "putting" the individual in open service slots. There are many tools to help organizations engage in this process, some of which are laid out by Cornell Universities' Employment and Disability Institute http://www.ilr. cornell.edu/edi/pcp/.

Support organizations, as well as state and federal programs, must recognize the importance of families in long-term support for community living for people with disabilities. Seventy-five percent of adults with intellectual and developmental disabilities live at home with their families. This proportion has increased significantly between 1998 and 2004, and the trend is likely to continue as people with disabilities live longer and budget shortfalls grow. (For a review, see the University of Albany's report, "Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities: A Tool Kit for State and Local Aging Agencies" http://www.albany.edu/aging/ IDD/documents/aidingoldercaregivers-toolkit.pdf.)

Across many states, there are long waiting lists for out-of-the family home placements for adults

with intellectual and developmental disabilities, as well as for paid in-home supports. In response, many families take on the role of service delivery systems. Yet families receive a disproportionally small share of the public spending allocated to disability care services. (The State of the States in Developmental Disabilities http://sos.arielmis.net/index.php/all-disabilities/overview report reviews this material.) Spending for families providing support for a person with a developmental disability increased [in which period?] from 1.5 to 4 percent of total resources spent by state MR/DD agencies. This is still a disproportionately small share of spending, especially considering that families caring for members with developmental disabilities incur significantly higher out-of-pocket expenses than other families. The relationship between those providing services and family members is often contentious. Services using best-practice find ways to work collaboratively with family care-givers to meet the needs of those receiving services.

Separating housing from support services helps promote choice, control, and self-determination. When housing is separate from support services, an individual has both the ability to move out of an unsatisfactory living situation without interrupting support services and the ability to change service providers without having to move. Support provider organizations may help the individuals they serve in utilizing low-income housing programs that are not specifically designed for people with disabilities to meet their housing needs.

Under US law, individuals with disabilities are entitled to funding for institutionalized care. However, states retain considerable flexibility in deciding how funding for home-based and community-based services will be used. Many states utilize a "Money Follows the Person" program http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html for certain people who receive state-sponsored services. In these programs, the funding for long-term care is not connected with any particular service provider, but accompanies the person needing it, allowing them to spend it on the types of support services that they want and need.

Although people living in community-based settings that promote choice and control are more likely to live free from abuse and neglect, they also enjoy less access to preventative health care than people in institutional settings. According to the American Association of Health and Disability http://www.aahd.us/about/, reasons for this include a lack of information and lack of accessibility of community-based health services.

Although increased independence and choice translate into higher quality of life for people with disabilities, it is important that people also have education and access to information about their healthcare needs and services that can support them. The Centers for Disease Control and Prevention http://www.cdc.gov/ncbddd/AboutUs/human-development-disability.html offers ways to reduce disparities in health care access for people with disabilities. Support service providers may need to work with advocacy organizations to help educate community-based health service providers about how best to meet the needs of all people in the community, including those with disabilities. Working with advocacy organizations will help support service providers inform those who use their services on how to access preventive health services.

Best practice in supporting people with disabilities in their communities is an evolving concept. It involves recognizing that support services, civil rights of people with disabilities, and opportunities for self-direction are integrally intertwined. Individuals with disabilities who are supported to live lives with informed choice, control, and meaningful connections with others in their community enjoy a higher quality of life. Support service organizations that build individualized support plans, provide services that are separate from housing, and help educate existing community service agencies on meeting the needs of all citizens are more likely to promote these ideals.

Organizations that provide person-centered services and help individuals with disabilities and their families live full, connected lives within their communities are still the exception rather than the rule. Many individuals with disabilities still live in restricted congregate settings with limited control

over their lives and limited connections to others in their communities. We should not be building more group homes and large congregate facilities. There is no proof that "economies of scale" is a valid concept in providing supports for people with disabilities.

QUESTIONS FOR FUNDERS

- Are individuals able to choose where and with whom they live, or are they assigned "slots" as vacancies become available? Do people see other options when making this decision?
- Does the organization value natural, meaningful relationships with others in the community? Does the organization have practices in place to support the cultivation of such relationships?
- Do the people who are being supported and their families take an active role in creating their support plan? Are the support plans built around the person's interests, wants, strengths and needs?
- Do the people using supports have the ability to hire and fire those who are paid to support them?

ADDITIONAL RESOURCES

Baxley, D. L, Janicki, M. P., McCallion, P. & Zendell, A. (n.d.). Aiding older caregivers of persons with intellectual and developmental disabilities: A tool kit for state and local aging agencies. Retrieved from http://www.albany.edu/aging/IDD/documents/Aiding_older_caregivers.pdf.

Braddock, D., Hemp, R., Rizzolo, M.C., Haffer, L., Tanis, E. S., Wu, J. (2011). The state of the states in developmental disabilities 2011. University of Colorado. Retrieved from http://sos.arielmis.net/index.php/all-disabilities/overview.

Centers for Disease Control and Prevention (2012, April). Health care access: Reduce disparities in health care access for people with disabilities. Retrieved April 23, 2012 from http://www.cdc.gov/ncbddd/AboutUs/human-development-disability.html.

Cooper, E., O'Hara, A. & Zovistoski, A. (2011). Priced out: The housing crisis for people with disabilities. Report from Consortium for Citizens with Disabilities, Housing Task Force. Retrieved from http://www.aucd.org/docs/policy/PricedOut2010.pdf.

Cornell University IRL School Employment and Disability Institute: Person Centered Planning Education Site. Retrieved April 23, 2012 from http://www.ilr.cornell.edu/edi/pcp/.

Independent Monitoring for Quality: What is Independent Monitoring for Quality? Retrieved April 23, 2012 from http://disabilities.temple.edu/publications/docsDL/ID114_IM4Q_INFO_SHEET.pdf.

Koyanagi, C. & Judge David L. Bazelon Center for Mental Health Law (2007). Learning from history: Deinstitutionalization of people with mental illness as precursor to long-term care reform: Report to the Kaiser Commission on Medicaid and the Uninsured. Retrieved from http://www.nami.org/Template.cfm?Section=About_the_Issue&Template=/ContentManagement/ContentDisplay.cfm&ContentID=137545.

Lakin, C., Larson, S. A. & Kim, S. (2005). Behavioral outcomes of deinstitutionalization for people with intellectual and developmental disabilities. Policy Research Brief, Research and Training Center on Community Living. University of Minnesota. Retrieved from http://ici.umn.edu/products/prb/212/212.pdf.

Larson, S., Ryan, A., Salmi, P., Smith, D. & Wuorio, A. (2012). Residential services for persons with developmental disabilities: Status and trends through 2010. Research and Training Center on Community Living Institute on Community Integration College of Education and Human Development University Minnesota, Minneapolis, MN. Retrieved from http://rtc.umn.edu/docs/risp2010.pdf.

Money Follows the Person (MFP). Retrieved April 23, 2012 from http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html.

National Core Indicators Program. (2010). National Core Indicators: Annual Summary Report 209-2010. Retrieved from http://www.hsri.org/files/uploads/publications/NCI_Annual_Summary_Report_2009-10.pdf.

O'Brien, J. (n.d.). The genius of the principle of normalization. The Center on Human Policy, Syracuse University: NY. Retrieved from http://thechp.syr.edu/Genius.pdf.

The Council on Quality and Leadership. Retrieved April 23, 2012 from http://www.thecouncil.org/.

The Minnesota Governor's Council on Developmental Disabilities: Parallels in time. (n.d). Retrieved April 23, 2012 from http://www.mnddc.org/parallels/index.html

United Nations (2007). Convention on the rights of persons with disabilities. Retrieved April 23, 2012 from http://www.un.org/disabilities/convention/conventionfull.shtml.

6 Transitions to Post-Secondary Education and Adulthood

MEG GRIGAL & DEBRA HART

HISTORY

Since the early 1990s, special education focused on what students (ages 16-21) with disabilities need to transition successfully from high school into adulthood. The kind of transition services students received and the location where they received them varied depending on their disability label and associated low expectations. The more significant a student's disability, the more segregated his or her instructional setting tended to be. Transition services focused primarily on job training activities. These were often contrived and artificial, seldom led to real paid jobs in the community, and placed little emphasis on preparing students with disabilities for higher education.

Despite an increased focus in secondary education on preparation for employment, people with disabilities, especially students with intellectual and developmental disabilities, face significant challenges. They are less likely to be employed; work fewer hours; and earn less that other disability groups. Although individuals with disabilities with at least some college education are employed at double the rate of people with just a high school diploma (Gilmore, Bose, & Hart, 2001), college continues to be omitted from transition planning for youth with disabilities. Along with students with intellectual disabilities and those on the autism spectrum, youth with developmental disabilities are among the least likely groups to enroll in postsecondary education.

POLICY

The policies that guide school to adult transition for youth with disabilities are derived from a variety of disparate and sometimes contradictory systems. The services provided by public and private schools vary greatly state to state, and often from school district to school district. Transition education, which is derived from the Individuals with Disabilities Education Act 2004 (IDEA), is impacted by the testing and reporting requirements of No Child Left Behind. Policies guiding adult services and employment support are governed by the Rehabilitation Act (subsumed in the Workforce Investment Act), the Americans with Disabilities Act, and the Developmental Disabilities Bill of Rights Act of 2000. Many young adults with disabilities are also dependent upon the Social Security and Medicaid benefits systems. Finally, postsecondary education services rely on the Higher Education Opportunities Act and the provision related to accommodations and equal access in the ADA and Section 504 of the Rehabilitation Act amendments.

Given this diverse and somewhat incongruent legislative landscape, it will come as no surprise that policies guiding practice between these various systems are not always well aligned. One prevailing theme, however, is evident across each piece of legislation and its supporting policies: inclusive environments for learning, working, and living in the community provide the best and most effective context for people with disabilities. Separate, segregated programs in K-12 education, higher education, employment, and community living do not reflect the values or outcomes supported by legislation and policy. Therefore, best practices in all adult transition and postsecondary education services can and should ensure that people with disabilities are not segregated, separated, or limited to "specially designed" environments.

PRACTICE

Current transition and rehabilitation practices focus on what youth with disabilities, ages 14-26, need to transition successfully from high school to adulthood. IDEA 2004 requires that schools work with students with disabilities (age 16-21) and their families to conduct a transition assessment. Based on the assessment's results, they are required to develop a transition plan that identifies the students' post-school goals in the areas of education, employment, and community living. This transition plan must list measurable annual goals. Best practices emphasize a person-centered, inclusive, and outcome-oriented service that ensures every student with a disability has the opportunity and support to become competitively employed in an integrated setting, pursue a postsecondary education, and contribute to and engage in meaningful ways in typical community settings once they leave high school (TEAM Act 2011).

Employment

The majority of transitioning students with disability receive some type of vocational training or work-based learning experiences while in high school to help them focus their personal career goals, and gain work-related skills. Yet youth with developmental disabilities too often end up not going to college or getting paid jobs; instead they go to sheltered workshops in sheltered environments, and earn sub-minimum wages (Grigal & Hart 2010; NDRN, 2011). Paid work while in high school is the most consistent predictor of paid work as an adult. Therefore, programs that support the acquisition and retention of paid work for youth with disabilities while still enrolled in high school are those that will most likely result in that desired outcome.

Postsecondary Education

The last decade has seen the emergence of new postsecondary opportunities for students with developmental disabilities. There are now over 250 college initiatives for students with these disabilities. But this is still a very small number of college options compared to the thousands of colleges available to students with other and without disabilities. This innovative practice recently received some additional support via amendments to the Higher Education Act, and new initiatives are currently being developed and implemented nationwide, though not all of these programs reflect inclusive practices. Some postsecondary education programs have created "Special Ed" colleges with classes attended only by students with disabilities. Other more inclusive options have found ways to successfully integrate students with developmental disabilities into typical college classes with typical college peers. These programs reflect the current legislative guidance and ultimately provide the best chance of encouraging students with developmental disabilities to become valued members of their learning communities.

RESEARCH-BASE

Employment

Youth with developmental disabilities are one of the least likely groups of students to obtain paid employment or to enroll in postsecondary education four years after high school. The Department of Labor's May 2012 statistics indicate that the employment rate of youth with disabilities age 16 to 19 is at an appalling 10.5 percent. Only 34 percent of young adults [with disabilities?] age 20 to 24 are employed.

Postsecondary Education

Postsecondary education leads to increased employment opportunities and higher wages. Individuals with disabilities who have had any postsecondary education are employed at double the rate of people with just a high school diploma (Gilmore, Bose, & Hart, 2001). Yet postsecondary education is often omitted from transition planning for youth with intellectual disability. Though the goal of attending college is a predictor of employment, only 11 percent of students with intellectual disability list this goal on their education plans. Data from the National Longitudinal Transition Study-2 indicate that only 2.3 percent of out-of-school youth with intellectual disabilities in 2009 were enrolled in any kind of postsecondary education institution and only 39 percent of youth with any disability are enrolled in higher education (NLTS-2, 2009).

Postsecondary Education as a Path to Employment

The number of postsecondary education programs and services for students with disability in colleges

across the country has increased, according to Think College www.thinkcollege.net. Preliminary research on postsecondary education for developmental disabilities demonstrates improved employment and self-determination outcomes (Migliore, Butterworth, & Hart, 2009). A recent study documented that students with developmental disabilities in college attended ninety-five different typical college courses and 83 percent held paid jobs in integrated community settings. Students with intellectual disability worked an average of 18 hours per week and earned an average of $7.90/hour. Upon exit, 89 percent of students with developmental disabilities intended to take more courses in a college or other adult learning environment; 84 percent exited with a paid job; and 91 percent exited connected with a community rehabilitation provider (Grigal & Hart, 2010b). This is extremely exciting, as going to college in the 21st century has become a minimum requirement for obtaining a decent job and succeeding in the workforce.

In the end, all students with disabilities should be able to attend college and to succeed there. A successful collegiate experience raises expectations of everyone, not least the student herself.

LEADING-EDGE CONCEPTS

The following describes various leading-edge models of practice that are being implemented throughout the country in order to effectively prepare students with disability for life after high school.

Access to Postsecondary Education
Students with developmental disabilities receive the same benefits from postsecondary education as individuals without disabilities (Grigal & Hart, 2010). Providing access to adult learning experiences in college settings better prepares students with intellectual disability to understand the benefits of furthering their education once they leave high school.

One leading-edge model of practice is to provide students with disabilities access to postsecondary education both during and after high school, as many students with developmental disabilities

remain in high school until they are 21 years old. College-based transition programs, often called dual enrollment programs, offer the opportunity to access college courses and campus work experiences while continuing to receive services from the educators most familiar with the individuals (Grigal & Dwyre, 2010; Hart & Grigal, 2010). Tuition for courses is sometimes paid for by the local education agency and sometimes paid for by the family, depending upon state and local policies. Federal law does not prohibit the use of IDEA funds to support access postsecondary education if this goal is included in students' education plans.

Think College www.thinkcollege.net suggests that postsecondary education for youth with developmental disabilities can act as the perfect nexus for the transition experience, providing opportunities for personal growth and development, interesting learning options, higher levels of responsibility, access to adult learning and working environments, increased career opportunities, and expanded social networks (Grigal & Dwyre, 2010). However, there is a great deal of variability in the types of services provided and anticipated outcomes of existing college programs throughout the country. Not all programs provide the same level of access to college courses or paid employment (Hart, Grigal & Weir, 2010). Additionally, student access to such experiences is dependent upon program options being available in their community.

Commitment to Paid Work
Paid employment during high school is the hallmark of high-quality transition experiences; students with paid employment during high school are more likely to be employed as adults. Without the support to gain paid employment in high school, many students with disabilities remain unemployed as adults. Students who participate in paid employment before graduation build resumes reflective of their skills and experience before leaving high school.

BEST PRACTICES

Several leading-edge policies and models of practice reflect this commitment to paid work, including

Employment First principles, the Project Search Model, and the Transition Service Integration Model.

Employment First http://www.employmentfirst.net/ is a national movement that includes a presumption of employment for all and integrated competitive employment as the expected outcome and not the exception. As part of a growing grass roots movement to establish Employment First initiatives nationwide (e.g., Oregon, Tennessee, Washington, California, Indiana, Minnesota, Georgia, North Dakota, Wisconsin, Missouri), many states have worked with their APSE chapter or other entities to establish an Employment First policy.

Project Search www.projectsearch.us is a comprehensive three-part program providing employment and education opportunities for youth and adults with intellectual disability that includes a high school program, a vocational clinic, and an adult education program. More than 120 businesses in thirty-nine US states and several countries have already adopted the Project Search approach. Sixty partnerships around the globe are working to implement this model for the youth with intellectual disability in their local communities.

In the Transition Service Integration Model (TSIM), http://www.ncset.org/publications/viewdesc. asp?id=705 school systems subcontract with private agencies at the point of transition to facilitate individualized employment (Luecking & Certo, 2002). TSIM is designed to combine the resources of school and adult systems in sharing the costs of a student-driven approach to transition planning, resulting in integrated employment with wages paid directly by the employer. The intent of TSIM is a seamless transition in the most literal sense. That is, youth are working in jobs they will keep upon graduating from school and they are supported in these jobs by the same staff and same adult agency. Thus, the first day after school looks the same as the day before.

These changes in postsecondary education—including the full implementation of employment first principles, and a presumption of employment for all—may increase the level of community inclusion, broaden the range of choices that students and families

currently have, and significantly increase workforce participation for individuals with disabilities. For this to occur, local and state education agencies, providers, advocacy groups, consumers, and the general public must understand the need for change and the desire for equality—in learning and in employment alike—of students of all abilities.

THINGS TO AVOID

Above all, funders should avoid programs or proposals that segregate people with disabilities. Too often, and sometimes with the best of intentions, those seeking to create access to jobs or postsecondary education have created special places and programs for people with disabilities. These places often end up being deemed the only choice for individuals with disabilities and their families and the "go to" option for educations and rehabilitation providers. Or they are designed to get people "ready" for work. Extensive research demonstrates that readiness is a fallacy and that helping transitioning students into real work is a more effective approach.

Segregated Work Programs
A 2011 National Disabilities Rights Network www.ndrn.org publication, Segregated and Exploited, identifies the barriers to employment that people with disabilities face and dispels myths about their capability to be fully employed, equally compensated, and integrated into workplaces and communities. The report indicates that "in the best of situations, sheltered environments, segregated work, and the sub-minimum wage do not truly provide a meaningful experience for workers with disabilities. Workshop tasks are often menial and repetitive, the environments can be isolating, and the pay is often well below the federal minimum wage. In the worst situations, the segregated and sheltered nature of the lives of workers with disabilities leaves them vulnerable to severe abuse and neglect."

Segregated Postsecondary Education
No studies conducted since the late 1970s have shown an academic advantage for students with developmental disabilities educated in separate settings. Yet substantially separate postsecondary

programs continue to be propagated throughout the country, largely because creating a separate curriculum for individuals with disabilities is far easier than developing structures and policies that support equal access to existing inclusive postsecondary education.

ROLE OF FAMILIES

The postsecondary education and occupational aspirations of youth with disabilities are more closely associated with their perceived efficacy than with their actual academic achievement (Wagner et al., 2007). Therefore, students with developmental disabilities will do only as well as they are expected to do. If parents and teachers indicate to students with developmental disabilities that they don't expect students to get a well-paying job, attend college, or live independently, it's likely that the student will fulfill those expectations.

Youth with disabilities are in general much less likely to be expected by their families to continue their education after leaving high school. Additionally, poor employment and community living outcomes for individuals with developmental disabilities have made families and professionals identify a need for improved secondary special education and transition services that would result in inclusive post-school outcomes. College programs for students with developmental disabilities should be guided by standards of practice aligned with higher education principles (Grigal, Hart & Weir, 2011) to ensure access to the academic, social and employment opportunities that higher education provides. While there has been growth in the number of institutions of higher education that have opened their doors to students with intellectual disabilities, there remains a critical paucity of PSE options from which students and families may choose.

Students without disabilities enjoy an immense array of higher education choices. The same is not true for students with an intellectual disability. There remains a need to increase the number of postsecondary education options so that students and families have the choice of going to college in their home community or away to school. To this end, the field needs to disseminate information that clearly describes the different pathways into higher education for students with developmental disabilities. The discovery that students with developmental disabilities go to college often evokes a quizzical response: "How is that possible?"

Families most often receive information about what is possible for their child with a disability from professionals in the medical, education, and disability systems. Therefore, it is crucial that those guiding families in the medical community, the education community, the rehabilitation, and the disabilities service communities have up-to-date information about what is possible for transitioning youth with disabilities. If professionals offer only low expectations and the same sad, stale options-- congregate living, no education, and sheltered work-- how are families to know that there are alternatives?

Public awareness of inclusive education and work options have begun to emerge, thanks to initiatives like Think College http://www.thinkcollege.net/featured-videos and Think Beyond the Label http://www.thinkbeyondthelabel.com/. But sustained efforts must be made to get the best information about higher education and employment options into the hands of those who support and guide family members. Only in this way will youth with disabilities have the best chance of attaining their best possible future.

QUESTIONS

For Grantseekers
• Does the applicant propose inclusive postsecondary education and/or integrated competitive employment?
• What was the role of family members in proposal development and what will be their role in the ongoing project?
• What was the involvement of people with disabilities in the development and evaluation of your proposed project?

- How will this project ensure the development of self-determination skills for students with disabilities?
- What are your plans for professional development for project staff?
- How will this project be sustained beyond the funding period?
- How innovative is the proposed project, and how will it result in inclusive post-school integrated paid employment and/or inclusive postsecondary education for students with disabilities?
- Are their other postsecondary education initiatives for students with disabilities in the proposed geographic area for your project?

For Funders
- To what extent do we support the concept of integrated competitive employment for all students?
- Does supporting students with disabilities in higher education align with our mission statement?

REFERENCES

Gilmore, D. S., Bose, J., & Hart, D. (2001). "Postsecondary education as a critical step toward meaningful employment: Vocational rehabilitations role." Research in practice, 7(4), retrieved from http://www. communityinclusion.org/article. php?article_id=44. 27

Grigal, M., Hart, D. & Weir, C. (2011). "Framing the Future: A standards-based conceptual framework for research and practice in inclusive higher education." Think College Insight Brief, Issue No. 10, Boston, MA: University of Massachusetts Boston, Institute on Community Inclusion. Available at http://thinkcollege.net/standards

Grigal, M., Dwyre, A., (2010). "Employment activities and outcomes of college-based transition programs for students with intellectual disabilities." Think College Insight Brief, Issue No. 3, Boston, MA: University of Massachusetts Boston, Institute on Community Inclusion. Retrieved from http://www.thinkcollege.net/publications

Grigal, M. & Hart, D. (2010). Think college: Postsecondary education options for students with intellectual disabilities. Paul H. Brookes, Publishing Co., Baltimore, MD.

Hart, D. & Grigal, M. & Weir, C. (2010). "Think College: A Snapshot of Postsecondary Education for Students with Intellectual Disabilities Across the United States." Think College Fast Facts, Issue No. 2. Boston, MA: Institute for Community Inclusion, University of Massachusetts Boston. http://www.thinkcollege.net/images/stories/FF2_F.pdf

Luecking, R., & Certo, N. (2002). "Integrating service systems at the point of transition for youth with significant disabilities: A model that works." National Center on Secondary Education and Transition (NCSET), Information Brief, 1(4). Available at http://www.ncset.org/publications/viewdesc.asp?id=705

Migliore, A., Butterworth, J., & Hart, D. (2009). "Postsecondary education and employment outcomes for youth with intellectual disabilities" (Fast Facts Series, No. 1). Retrieved from http://www.thinkcollege.net/component/docman/doc_download/8-fast-facts-issue-1-pdf

NDRN. (2011). Segregated and exploited. A call to action. The National Disability Rights Network. Retrieved from www.ndrn.org.

Wagner, M., Newman, L., Cameto, R., Levine, P., & Marder, C. (2007). "Perceptions and expectations of youth with disabilities. A special topic report of findings from the National Longitudinal Transition Study-2 (NLTS2)" (SRI Project P11182). Retrieved from www.nlts2.org/reports/2007_08/ nlts2_report_2007_08_complete.pdf

7 Aging and Disability

STEVEN EIDELMAN & AMANDA RICH

For the first time in history, the life expectancy of people with significant disabilities, including intellectual and developmental disabilities, is comparable to that of people without disabilities (see an overview by Tamar Heller, 2010 http://ici.umn.edu/products/impact/231/2.html). In 1940, the average life expectancy of people born with Down Syndrome, for instance, was twelve years. Today, the average life expectancy of people with Down Syndrome in developed countries is sixty years, according to the Down Syndrome Medical Interest Group http://www.dsmig.org.uk/library/articles/DS%20demography%20life%20expect.pdf. This means that parents and siblings can expect to share their lives with a loved one with disabilities for many years, and that it is likely that people with intellectual and developmental disabilities will outlive their parents. Some 75 percent of adults with developmental disabilities live at home with family members.

The rates of out-of-home placements of children and adults with disabilities have decreased dramatically in the United States and many other countries over the past 40 years (Stancliffe & Lakin, 2011 http://ici.umn.edu/products/prb/151/default.html). In most households, family members serve as the primary providers of support for people with intellectual and developmental disabilities. Of people with serious mental illness, 25 percent live at home with their family; among those who do not live at home, 20 percent receive financial support from their families (Hall, Graf, Fitzpatrick, Lane & Birkle, 2003 http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_Public_Policy/Policy_Research_Institute/TRIAD/TRIAD_Summary_Sheet.pdf). Unpaid family caregivers often are the sole providers for many people with long-term care needs, including those with lifelong disabilities. In families who use formal, paid service systems to provide care, such care is typically provided in the family home. Family care comes at a great savings to society (Feinberg

et al, 2011 http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf). In the United States, families provide over $257 billion in unpaid, direct support, which nearly equals Medicare spending in 2002 and surpasses spending on Medicaid for the same year [any chance of more current numbers?]. Aging families have changing support needs and families that never utilized formal supports may need to as circumstances change. As the WWII generation fades, little is understood about the willingness and abilities of the generation born in the 1950s and 1960s to provide similar levels of support as they, themselves, age. We are only recently appreciating the roles that siblings play in the adult lives of their brothers and sisters with disabilities.

Of the families providing care for their family member with disabilities, many are aging, and with aging, often come changes in the needs of the entire family. Of the 75 percent of individuals with developmental disabilities who live at home with family, 25 percent live with caregivers who are over the age of sixty, and many are developing their own needs for support. (For a description of family caregivers, see AARP's Caregiving in the United States 2009 http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.) For some aging families, this is the first time that they will look to formal support providers to meet their changing needs and it is important that those professionals understand best practice in supporting aging families.

PLANNING AND COORDINATION OF SERVICES

Many parents of adults with disabilities worry about what will happen to their son or daughter when they are no longer able to provide care. Few have made formal plans for the future and even

fewer discuss the plans with the family member with the disability (Heller & Caldwell, 2006 http://www.wrightslaw.com/info/SibsFuturePlanning.pdf). Within the developmental disabilities community there is some argument whether to focus on the individual or the family. A framework called "person-centered" planning and thinking empowers the person needing the future care plan, as well as family members, to create a holistic view of what they would like their future to look like and create steps to make that vision a reality (Cornell University ILR School Employment and Disability Institute Person Centered Planning Education http://www.ilr.cornell.edu/edi/pcp/).

Siblings are often involved in this process. Although there is great variation across families, many typically-developing siblings of an adult with disability anticipate providing increasing support as they, their parents and siblings age. Yet parental caregivers are often reluctant to discuss concrete expectations of the sibling in future care. (For information regarding the support available for siblings of people with disabilities, see the Sibling Leadership Network http://www.siblingleadership.org/category/sibs-in-the-news/.) Person-centered planning may create a forum to make the family conversation easier. Rather than limit itself to financial or residential planning, person-centered planning encourages individuals and families to consider other aspects of a quality life, including employment, recreation, transportation, social, and legal considerations, including guardianship and its alternatives.

Legal complications are not the only challenge that families face when planning for the future. Even as families look forward, many must simultaneously grapple with past interactions with service systems, other family members, fears, and expectations. Some baby-boomer families fought a system and society that told them that they should institutionalize their loved one with a disability, and many harbor a mistrust of that system, especially after the horrors of some of the congregate living facilities came to light in the 1970s and 1980s. Some families report a general mistrust of the service system, and a reluctance to initiate contact even when resources are needed. Even though it is a complex and ongoing process, having a plan in place can offer relief in times of crisis.

Though planning for care needs for older adults and adults with lifelong disabilities are similar processes, the plans themselves may look considerably different. Future planning in families with elderly members may need to anticipate care needs for one to two decades. A plan for care for someone with a lifelong disability may need to anticipate changing contexts for well over sixty years. Plans for individuals with lifelong disabilities may center on the individual obtaining a valued role within the community, whereas planning for older adults without lifelong disabilities may rest on maintaining their place in the community and for a shorter term horizon.

Quality programs support families in thinking about and planning for future care needs. Some particularly effective programs that have utilized peer support and involved other families with a member with disability in facilitating conversation about holistic plans for their future (Heller & Caldwell, 2006 http://www.wrightslaw.com/info/SibsFuturePlanning.pdf). Families can share stories of what helped them in the planning process, what barriers they faced, and how they negotiated challenges. The programs also made a legal professional available to discuss legal and financial matters as well as experts to provide information on community living and long-term care. (For a review of future planning, see The Arc's A Family Handbook on Future Planning http://internet.dscc.uic.edu/forms/ARC_FuturePlanning.pdf.)

LATER IN LIFE NEEDS AND OPPORTUNITIES

Typically, the aging service networks and the disability service networks have not frequently interacted. With the rapid growth of the population of aging families with disabilities and their unique health care and service needs, more collaboration is required. (For a review of recommendations on facilitating this collaboration, see Bridging the Aging and Developmental Disabilities Service Networks: Challenges and Best Practices http://www.acf.hhs.gov/programs/add/BridgingReport_3-15-2012.pdf.)

Individuals with lifelong disabilities have a higher risk of developing other chronic conditions. For instance,

people with cerebral palsy are more likely to develop degenerative joint diseases and osteoporosis later in life. People with Down Syndrome are more likely to develop Alzheimer's disease than people without developmental disabilities. People with developmental disabilities may also be more likely to develop secondary conditions such as obesity and type-two diabetes. Further complicating age-related concerns, people with developmental disabilities have less access to preventative health services and adequate health care in general. Community health care and health promotion providers require support in becoming more accessible to people with disabilities and in encouraging them to attend health screenings and prevention programs.

Though many people with intellectual and developmental disabilities are unemployed, many who work in supported or sheltered work settings may wish to retire as they age. Aging networks, such as senior centers, may offer resources to support community participation later in life, through volunteer opportunities, community activities, and recreational and lifelong learning opportunities.

Programs that support aging families should also coordinate and utilize services across the low-income, aging, and disability communities. Community programs for the elderly such as transportation options, meals on wheels, and resources offered at the senior center may be beneficial to many aging families, including those with disabilities. Disability related organizations may help programs outside the disability community learn how to make their programs more accessible for community members who have a variety of abilities.

END OF LIFE PLANNING

Many individuals with disabilities eventually leave the family home and live in community-based or nursing home care. Like all people, people with intellectual and developmental disabilities and people providing support face decisions around end of life care, including medical treatment, resuscitation

orders and pain management. The quality of end of life care depends in part on the availability of palliative care, or care that eases pain, and the extent to which families and professionals are aware of the special needs at the end of life. (For a review of how person-centered thinking can help inform end of life planning for people with developmental disabilities, see Person Centered Planning and Communication of End-Of-Life Wishes With People Who Have Developmental Disabilities, Kingsbury, 2005 http://learningcommunity.us/documents/pcp.eol.journal.pdf.)

Many programs that serve aging adults with disabilities and their families do not integrate end of life care. This can cause additional stress not only for the individual at the end of life, but also for their loved ones and support providers. In a survey of community-based agencies that serviced older adults with developmental disabilities, only about half said they would provide hospice and home based care towards the end of life. Less than half of organizations stated they provided end of life care training to staff.

Agencies reported several challenges in providing quality end of life care. These problems included state and federal regulations about levels of care; approval of waivers for additional equipment and staffing; reimbursement issues, including the regulatory reimbursement pressure to fill residential beds quickly; shortage of direct care staff; and liability concerns. Some agencies also reported conflicts between staff and family and a lack of cultural competence as an issue. End of life care and decisions regarding this care are made easier when there is coordination in services across support and medical care providers and family members, open lines of communication, and interpersonal support that may include family members, religious leaders, medical providers, and service providers.

Quality services should encourage the individuals they serve, family members, and other loved ones to incorporate decisions regarding end of life care into the planning process.

QUESTIONS FOR FUNDERS

• Do programs that support aging families help families to make comprehensive plans for their future?
• Do programs that support aging families help make connections and utilize resources between the disability and aging resource networks?
• Do programs that support aging families have plans in place to help families, direct-care workers, and individuals with disabilities in addressing end of life concerns?
• Do programs that support aging families include siblings in the planning process?
• Do programs support both the person with a disability and the family's wishes and needs?

REFERENCES

Cornell University ILR School Employment and Disability. Person centered planning. Retrieved form http://www.ilr.cornell.edu/edi/pcp/.

Down Syndrome Medical Interest Group (nd). "Down's syndrome demography." Retrieved from http://www.dsmig.org.uk/library/articles/DS%20demography%20life%20expect.pdf.

Factor, A., Heller, T., Janicki, M. (2012, March). Bridging the aging and developmental disabilities service networks: Challenges and best practices. Institute on Disability and Human Development: University of Illinois at Chicago. Retrieved from http://www.acf.hhs.gov/programs/add/BridgingReport_3-15-2012.pdf.

Feinberg, L, Reinhard, S. C., Houser, A., & Choula, R. (2011). "Valuing the invaluable: 2011 update the growing contributions and costs of family caregiving." AARP Insight on the Issues. AARP Public Policy Institute. Retrieved from http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf.

Hall, L. L, Graf, A. C., Fitzpatrick, M.J., Lane, T., and Birkel, R.C., Shattered Lives: Results of a National Survey of NAMI Members Living with Mental Illnesses and Their Families TRIAD Report, NAMI, Arlington, VA, 2003. Retrieved from http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_Public_Policy/Policy_Research_Institute/TRIAD/TRIAD_Summary_Sheet.pdf.

Heller, T. (2010). "People with intellectual and developmental disabilities growing old: An overview." Impact, 23, 1-35. Retrieved from http://ici.umn.edu/products/impact/231/2.html.

Heller, T. & Caldwell, J. (2006). "Involvement of adult siblings of people with developmental disabilities in future planning." Disability Research Brief, 2, 1-2. Retrieved from http://www.wrightslaw.com/info/SibsFuturePlanning.pdf.

Kingsbury, L. A. (2005). "Person centered planning and communication of end-of-life wishes with people who have developmental disabilities." Journal of Religion and Health, 9, 81-85. Retrieved from http://learningcommunity.us/documents/pcp.eol.journal.pdf.

National Alliance for Caregiving & AARP (2009, November). "Caregiving in the U.S. 2009." Retrieved from http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.

Sibling Leadership Netword (nd). "About us." Retrieved from http://www.siblingleadership.org/about/.

Stancliffe, R.J. & Lakin, C. (2004). "Costs and outcomes of community services for persons with intellectual and developmental disabilities." Policy Research Brief 14(1). Minneapolis: University of Minnesota, Research and Training Center on Community Living. Retrieved from http://ici.umn.edu/products/prb/151/151.pdf.

The Arc & Rehabilitation Research and Training Center on Aging with Developmental Disabilities Department of Disability and Human Development College of Applied Health Sciences University of Illinois at Chicago. (2003). A family handbook on future planning. S. Davis (ed.). University of Illinois at Chicago. Retrieved from http://internet.dscc.uic.edu/forms/ARC_FuturePlanning.pdf.

8 Healthcare for Individuals with Intellectual and Developmental Disabilities

RICK RADER

So take good care of your n' fashot/whole beings…
Deuteronomy 4:15

From earliest times, virtually every society has considered people with intellectual disability (what used to be called mental retardation) to be not "whole." As a result, little or no effort was expended in insuring their health and wellness. They were variously perceived as sick, subhuman, menaces, objects of pity, burdens, or holy innocents (Wolfensberger, 1988 http://thechp.syr.edu/Genius.pdf). In each case, this attitude justified societal indifference, cruelty, and institutionalization. The healthcare model was an extension of this triumvirate.

This indifference, coupled with the abbreviated life expectancy of people with intellectual and developmental disabilities (ID/DD) meant that the bulk of medical care was provided by pediatricians with no plans to oversee the transition to adult care. The outlook for successful medical intervention--particularly for those with genetic syndromes--was bleak. As a result, caring for individuals with special needs held little attraction for the best and brightest physicians. Most medical care was provided by institutional physicians, well out of sight of mainstream medical standards. As life expectancies rose, the largest segment of this vulnerable population were adults, not children.

Historically, most individuals with intellectual and developmental disabilities lived at home. The 1980s saw a push for those living in state institutions to return to their communities. Yet the medical infrastructure was ill equipped to meet the complex needs of this vulnerable population. Little was known about the health characteristics and concerns related to the number of rare disorders represented in this population. (By definition a "rare disorder" is one with fewer than 200,000 cases in the United States. There are over 6,000 rare diseases, many of which have "intellectual disability" as a component.) Few physicians, dentists, and nurses received clinical experience in treating people with complex disabilities. As a result, they were reluctant to provide care, often deferring treatment for years.

While each individual is unique, those with intellectual and developmental disabilities are often challenged with the following health-related conditions:
- Seizure disorders: six times more prevalent in the ID/DD population
- Challenging behaviors: often resulting from an inability to express and communicate anxiety, fears, needs, pain, desires; seven times more prevalent in the ID/DD population
- Co-existing mental-health issues: five times more prevalent in the ID/DD population
- Polypharmacy: typically receive three times the number of drugs, often due to clinically unjustified legacy prescribing and inappropriate use of drugs to control behaviors
- Sensory processing disorders: inability to interpret and integrate sensory input; seven times more prevalent in the ID/DD population
- Osteoporosis: resulting from non-ambulation, seizure medications, bone density disorders; two times as prevalent in ID/DD population
- Movement disorders: three times the prevalence in ID/DD population
- Oral health: source of associative relationship to systemic disease; four times the prevalence in ID/DD population
- Loneliness: social affiliation and social engagement has been found to be neuro-protective as well as cardio-protective (see definitions below)

- Incontinence: both urinary and fecal; twice as prevalent in the ID/DD population
- Constipation: three times as prevalent in the ID/DD population
- Obesity and associated disorders: six times as prevalent
- Chronic pain: often resulting from muscular-skeletal and neuro-muscular disorders like Cerebral Palsy
- Dementia: people with Down syndrome are at a 60 percent higher risk to develop Alzheimer's disease

Definitions
- Neuroprotective: serving to protect neurons from injury or degeneration.
- Cardioprotective: that which serves to fortify, maintain and strengthen both the structure and mechanics of the heart.
- Social affiliation: the need to feel a sense of involvement and "belonging" within a social group.
- Social engagement: active involvement in the community and with other people, not for the sake of being involved, but to accomplish something of meaning.

In addition to the above, many of the genetic conditions carry a plethora of co-existing health concerns that impact the heart, lungs, kidneys, blood, GI, skin, and reproductive organs. Those with intellectual and developmental disabilities are also vulnerable to the myriad diseases of civilization (cancer, diabetes, heart disease, depression). It's a scenario that has plagued advocates, policy makers, public health officials, healthcare providers, legislators, researchers, parents, families, therapists, and support staff. Great strides are still needed to close the disparities gap.

Research literature supports the following historical and intuitive realities:
- People's attitudes about people with ID/DD hover between indifference and neutrality. Most people want them to be treated with respect and dignity but would not seek them out as companions, either in the workplace or in the community.
- People with ID/DD account for higher than average healthcare burdens (more and longer hospital stays, visits to the emergency rooms, higher medication usage, more dependency on devices, specialized equipment, rehabilitation stays, nursing coverage).

- Most medical and dental students have not received formal training in ID/DD healthcare; most medical students (and postgraduates in residency training) feel they are not competent to effectively treat people with ID/DD, but most would be interested in treating them if they had the skills, experience, and knowledge.
- Few if any "questions" relating to the medical care of patients with ID/DD appear on the national boards (used to license physicians and dentists); thus medical and dental educators are not encouraged or incentivized to include this in their curricula.
- Healthcare providers who have participated in volunteer healthcare encounters (screening, educating, treating patients with ID/DD) often report very positive, satisfying experiences and express interest in additional opportunities.
- The "business model" for providing care in traditional medical practice settings does not encourage including this patient population in the normal practice flow.
- Among the healthcare professions there is a "stigma" directed towards providers who have dedicated their careers to people with ID/DD. ("It must be very gratifying to work with those people," or "Guess he couldn't make it with real patients.")
- Healthcare is a vital component in the support structure to allowing people with ID/DD to thrive in the community; it is an indispensable vehicle towards competitive employment, community inclusion and the initiation of natural supports and relationships.

LEADING-EDGE CONCEPTS

Healthcare students need early exposure to both the concepts of ID/DD as well as opportunities to engage with patients with complex disabilities. Once physicians and dentists begin to practice, it is virtually impossible to reorient them to including this population in their practice base.

The medical education community (e.g., curriculum developers, deans, clinical mentors, examination/board certification policy makers, funders) must have high-level "ownership" of the benefits and advantages of teaching medical/dental/nursing students, post-clinical fellows, and residents about ID/DD healthcare. An incentive would be to provide school

loan forgiveness or loan discounts for clinicians who treat the ID/DD population.

Reimbursement must be commensurate with the additional time required to treat and educate patients with ID/DD. Applying the patient-centered medical home model requires care coordination which places additional resource burdens on medical practices, clinics, and medical organizations. One cannot rely on the warm fuzzy feelings of treating marginalized populations as a sustainable model. The mission needs an appropriate margin to insure continuity of care.

BEST PRACTICES

Total Immersion Clerkships

Total immersion clerkships embed medical and dental students in community agencies for a week, during which students observe, participate and begin to understand the big picture of what constitutes needed supports to sustain people with ID/DD in the community. This clerkship allows them to understand the myriad roles of caregivers, families, therapists, clinicians, teachers, vocational counselors, house managers, and recreation/sports coaches. It puts medicine in its proper perspective – not the center of the universe but as a vital component in assisting individuals to make their own contributions.

Healthcare Screening for Athletes with Special Needs Programs

These programs recruit volunteer medical, dental, nursing, allied health students, and veteran clinicians to provide healthcare screening in various disciplines for athletes involved in competitive games on local, state, regional, national, and international levels. They provide the newcomer with the opportunity to experience the challenges and rewards of interacting with an individual with ID/DD. The programs allow the volunteer clinician, at his/her own pace, to become further involved with the hope that it will serve as encouragement to consider incorporating patients with ID/DD in their practice.

Parents Teaching the Doctors

These programs employ parents of children with special healthcare needs as teachers, instructors,

and mentors to medical students and residents. The programs select and train parents as faculty members at medical schools and teaching hospitals and allow them to present their stories at Grand Rounds. This provides needed insights to doctors who may only see these individuals for fifteen minutes twice a year. It also allows physicians to better understand the steady flow of stressors, frustrations, and obstacles produced by school systems, insurance companies, medical centers and administrators. The parents teach how to take a meaningful social history as well as require a home visit to enable the doctors and students to get an appreciation of the dynamics of a home with a child or grown adult with developmental disabilities. Research has provided indices of success to gauge the changing attitudes of medical residents who have participated in this "parents as teachers" program. The parents are paid by the teaching hospital, thereby demonstrating their role as bona fide faculty members.

Things to Avoid

It does not work to provide operating funds to programs that would not be sustainable without that funding stream. We do not need additional programs that fold up their tents when funds are depleted. Only sustainable models should be considered. Models that would benefit by expansion, further research or opportunities for collaboration would be attractive. Avoid programs that simply rehash known bodies of knowledge. We have accumulated enough research to understand the pratfalls and failings of existing systems.

ROLE OF FAMILIES

Parents have always been the lynchpins in the area of healthcare for people with intellectual and developmental disabilities. They hound clinicians to see their kids, pursue researchers to continue to look for treatments, lobby politicians to create legislation to provide medical coverage and security, and demand to be seen, to be heard, and to be respected. Parents change definitions, doorway specifications, belief systems, and myths. Families need to continue to have representation in curricula, protocols, systems, outcomes, benchmarks, and next steps.

Questions For Funders

- Why is specialized training for physicians needed? Shouldn't a competent physician be able to treat anyone especially since there is no treatment or cure for these developmental disabilities?
- What measures can be put in place to ascertain if specialized training has been effective and beneficial?
- Because people with developmental disabilities represent a small percentage of the population doesn't it make more sense simply to create several specialized nationwide clinics instead of trying to train every physician to care for a small group?

ADDITIONAL RESOURCES

American Academy of Developmental Medicine and Dentistry
www.aadmd.org

Special Olympics Health Athletes Program
http://www.specialolympics.org/healthy_athletes.aspx

Project DOCC (Delivery of Chronic Care)
http://www.projectdocc.org

9 Employment for People with Disabilities

DAVID MICHAEL MANK

The change in thinking about community employment for people with disabilities can be summarized in this way

From impossible to possible…
From possible to beneficial….
From beneficial to allowed…
From allowed to preferred…
From preferred to expected….

… to the same standard as everyone else.

(Mank, D. M. (2008) Alderbrook 2007 Journal of Vocational Rehabilitation 29 (2008) 53-62.)

Being a person with a disability in the US most likely means you are poor and unemployed. The US Department of Labor estimates that people with disabilities (all disabilities) have a 21 percent participation rate in the workforce, compared to 69 percent of the US adult population. While estimates vary and depend in part on disability label, it is entirely and sadly accurate to equate disability with poverty and unemployment.

At the same time, we also know that people with disabilities are capable of working and want to work. This is a relatively recent discovery. As late as the 1970s, the prevailing belief about people with disabilities, especially people with intellectual and developmental disabilities, held that they were unable to work in regular jobs in community settings.

Scanning the last fifty years of daytime services for people with disabilities, especially people with developmental disabilities, shows an evolving emphasis toward personalized and employment oriented outcomes, and a progression from segregation and non-work toward integration and community employment. Fifty years ago, we assumed that people with disabilities were unable to work. Beginning in the 1970s, as we discovered better methods of instruction,

assistive technology, and new ways to support people in community employment settings, we discovered that people with disabilities are capable of work.

As a result, services too began to evolve. Initially, daytime services for people with disabilities were, quite simply, a safe place for people to spend their time with very little expectation of productive activity of any kind. In large part, these segregated daytime settings were smaller re-creations of institutional settings and psychiatric hospitals where people were grouped together without individual choices. As the abilities of people with disabilities were discovered, services evolved to create a segregated setting where people could learn activities of daily living and some work-related skills. These activity centers were supplemented by segregated, sheltered workshops where people with disabilities were congregated and worked on tasks from contract work acquired by the service organization. Starting in the 1980s, services to support people with disabilities in community employment emerged. More recently, employment services are evolving to match people's interests and abilities to specific kinds of work, and more recently to customized employment where work in integrated settings is tailored to a person's ability and interests.

But while thinking has evolved and some services now focus on individualized jobs, the majority of people with disabilities, especially those with developmental disabilities and people with serious mental illness, remain in segregated non-work settings or in segregated sheltered workshops. As a result, supported community employment has not yet substantially replaced segregation, as evidenced by the very low employment participation rate in the labor force.

Despite an acknowledgement that segregated settings result in neither employment nor integration, they remain the most common service. This is in part because funding and policy implementation are not

aligned with community employment. But whatever else they may or may not be, these segregated programs are predictable and reliable. As a result, families and residential support agencies rely on them for services for a set number of hours each day. And this has become another obstacle to change.

At the same time, repeated surveys show that the vast majority of people with disabilities want to work. Numerous needs assessments show employment in the top three concerns of people with disabilities along with health care and transportation. Self-Advocates Becoming Empowered (SABE), a national advocacy organization comprised of and run by people with disabilities, issued a call for the end of segregated day settings and sheltered workshops by 2015.

While current practices have been slow to evolve, an emerging national policy promotes full integration and community participation for people with disabilities. Important policy is represented in the Individuals with Disabilities Education Act (IDEA) from the 1970s; the Vocational Rehabilitation Act which promotes integrated employment and now specifically prohibits sheltered work as an employment goal; the Americans with Disabilities Act (ADA) of 1990, often said to be the civil rights legislation for people with disabilities; and the Developmental Disabilities Act, which promotes independence, integration, and productivity for people with intellectual and developmental disabilities. In addition, the Supreme Court's 1999 Olmstead decision ruled that forced segregation in state institutions is illegal and that people have the right to move from a segregated, institutional setting to a community setting with financial resources following them. In combination, this wave of legislation and Supreme Court finding clearly set a standard of full community citizenship for people with disabilities in all aspects of life, including employment.

And yet, despite the clarity of legislative and judicial intent, people with disabilities are still largely unemployed and in poverty.

At the same time, pockets of employment exist for people with developmental disabilities in some states. In a few states, the community employment rate for people with developmental disabilities is more than double the national average. In nearly every state, it is possible to find pockets of excellence where a small number of people with significant disabilities are employed in good jobs in the community at high wages. This demonstrates the capabilities of people with disabilities and shows that there is a knowledge base for intervention and support to create individual employment outcomes.

RESEARCH BASE

The research base for assisting individuals includes studies over several decades that establish best practices for:
- individual assessments of interests and abilities (sometimes called "Discovery") and individualized job development procedures
- procedures for analyzing jobs and work tasks
- teaching self-management skills
- travel trainings
- positive behavior supports
- assistive and other technology
- instructional methods
- developing employer and natural supports in the workplace
- transition from school to employment
- customized employment and self-employment

LEADING-EDGE CONCEPTS

Achieving the worthy goal of employment for the vast majority of people with disabilities will require several steps. First, there is a tremendous need for the aggressive and widespread use of known techniques and best practices. This calls for training and support to agencies responsible for assisting individuals with disabilities to get and keep jobs in the community. Second, agencies must work with individuals and families, when people do go to work, to manage social security benefits as income increases. This is a complicated area of a needed "safety net" while also having an incentive to work while reducing benefits. Third, we need a better science of widespread implementation of known best practices. The pockets of excellence that exist show what is possible; what is needed are methods to implement known methods in

every community and for every person with a disability who can work and wants to work. Finally, we must improve funding structures for supporting community vs. segregated employment. As long as funding favors segregation, segregation will prevail--despite known best practices, despite the abilities of people with disabilities to work, and despite the fact that people with disabilities prefer real jobs with real wages.

THINGS TO AVOID

While considering investments to improve the employment rates of people with disabilities, there are several things to avoid. First, approaches which group people together in employment are impossible to personalize and usually result in lesser employment and integration outcomes. Second, stereotyping people with disabilities into certain kinds of jobs in such a way that fails to recognize each individual's unique combination of interests and abilities. To target only certain kinds of jobs is to ignore individual needs and gifts. Third, goals and strategies that are satisfied with only a few hours of work per week are a guarantee of continued poverty and under-employment. While dealing with social security benefits is complex, working more than half-time and nearer to full-time is the path to true integration and a living wage.

ROLE OF FAMILIES

For several reasons, families' role in employment of people with disabilities is a major factor in future success. First, families should know what is possible, and be supported in aspiring toward employment for their family member. Second, families know their member well, and likely better than people in any service system. Hence, their support and knowledge of their loved one is integral to planning and supporting employment outcomes. Third, families can support other families in similar situations and can share stories that may offer both guides for success and suggestions in solving problems. Fourth, families are the best ambassadors in the public policy arena, and can work to align state and local policy and funding formula with employment outcomes.

In summary, employment is the greatest possible gift for any member of society, and the single most important path to community membership and full citizenship. People with disabilities are wholly capable of working productively in fully integrated settings. They clearly and repeatedly express their interest in working and in contributing to society. Existing strategies show that the knowledge base exists for securing and maintaining employment for people with disabilities. Finally, it is in the best interest of society and every community that people with disabilities work and contribute instead of simply being consumers of services.

QUESTIONS FOR GRANTSEEKERS

- How will this project improve employment outcomes?
- How will this project make use of, or improve upon, current best practices?
- How will the impact of this effort extend into the future?

ADDITIONAL RESOURCES

Association of People Supporting Employment First (APSE)
www.apse.org

Self-Advocates Becoming Empowered
www.sabeusa.org

Institute for Community Inclusion, University of Massachusetts
www.communityinclusion.org

Training Resource Network
www.trn-store.com

Virginia Commonwealth University Rehabilitation Research and Training Center
www.worksupport.com

10 Rehabilitation

MARK JOHNSON

HISTORY

Physical medicine and rehabilitation dates back to World War I and includes the creation of the medical field called physiatry. During World War I, "physical reconstruction services" were used to improve the functioning and independence of injured soldiers.

During World War II, the noted philanthropist Bernard Baruch formed the Baruch Committee, which included a subcommittee on rehabilitation. The Committee produced a blueprint for the growth, development, and promotion of physiatry, and awarded funding to develop physiatry training programs at select universities in physical medicine and rehabilitation. Founded in 1949, the American Board of Physical Medicine and Rehabilitation (ABPMR) remains in existence today.

In 1970, the National Institute on Disability and Rehabilitation Research (NIDRR) created Model Systems Centers Programs in spinal cord injury (SCI), and today there are fourteen Centers. In 1987, Model Systems Program Centers for traumatic brain injury (TBI) were created by NIDRR with sixteen centers functioning today. Model Systems gather information and conduct single- and multi-site research with the goal of improving short- and long-term medical, functional, vocational, and quality-of-life outcomes for individuals with brain and spinal injuries. Model System grantees prospectively collect data for national registries in order to track and predict the long-term consequences of SCI and TBI. Collaborative multi-center grants allow for more rigorous clinical trials to identify efficacious treatments and to conduct research in the areas of medical rehabilitation, service delivery, health and wellness, and short- and long-term interventions. Each Model System is also charged with disseminating information and research findings to individuals with brain and spinal injuries, family members, health-care providers, educators, policymakers, and the general public.

POLICY, PRACTICE, ROLE OF PATIENTS AND FAMILIES

A regular hospital treats a one-time illness or injury, usually on a short-term basis. Its purpose is to meet the patient's immediate medical needs and then discharge patients to their home or other setting. A rehabilitation hospital, in contrast, provides assessment and treatment that includes a variety of daily therapeutic interventions to return the patient and family to the highest possible level of independence. The main focus is to maximize a person's recovery medically, physically, emotionally, cognitively, and communicatively. Goals are to learn new strategies and understand disability. Families are an integral part of the process as they learn new lifestyles, changes in their loved one's needs, and how to support and manage care.

The sentiment captured in the motto "don't make decisions about me without me"– often shared by those recovering from traumatic injury and illness – is at the heart of a growing push by patients and families to play a more active role in healthcare decisions. Patient/family-centered care is endorsed by the Institute of Medicine and other health care agencies as an integral component of quality care.

Four main principles guide patient/family-centered care:
- Dignity and respect: including patients and families in care planning and decision making in a way that values and reflects individual choices, preferences, values, etc.
- Information sharing: presenting complete and unbiased information in a timely fashion and in multiple and accessible formats
- Participation: ensuring that patients are not just allowed to participate, but feel engaged and involved in planning to meet their individual needs
- Collaborating: working in partnership not just in

the delivery of care, but also in helping to inform program development, research, facility design, and even staff education

While the spirit of patient/family-centered care is applied by clinicians every day, in practice a variety of issues can interfere. A patient's awareness of difficulties and family members' feeling overwhelmed can lessen their engagement in treatment. On the one hand, the challenge is to help the patient and family understand treatment goals, and to persuade them that if the goals are not followed the result will be high medical acuity and associated healthcare systems costs (e.g., skin care, taking important medications). On the other hand, to be successful the interdisciplinary team's goals must reflect the values and day-to-day preferences of patients and families.

It is also critical for patients and families to provide input and feedback on clinical programs. Consumer Advisory Boards are just one way that patients and families can be involved in program evaluation and planning. Surveys are another. The Institute for Patient and Family-Centered Care http://www.ipfcc.org/ has a survey that can be used to assess a rehabilitation hospital's culture for patient/ family-centered care. The survey can evaluate what is working and provide recommendations to improve person-centered care. These efforts encourage patients and families to be more actively involved, thus improving overall outcomes and satisfaction.

A snapshot of how patient/family-centered care works:
• Collaborative and individualized goal setting
• Development of an assessment scale to determine post-discharge safety risks among patients with SCI and/or TBI; developed with input and testing from family members to ensure items were meaningful and usable
• Ongoing, hands-on training
• Peer support
• Learning resource center with up-to-date information about rehabilitation and recovery
• Community re-entry activities for families; guidance on how to adapt and advocate in the community where mobility and cognitive issues can remain challenging
• Temporary housing and spaces for families to relax and recharge during their stay

LEADING-EDGE CONCEPTS

Cure
Paralysis results from a disconnection between the central nervous system (the brain and spinal cord) and the body. Sometimes, as in the case of trauma, nerve cells are affected by some outside force. In other cases, including diseases such as multiple sclerosis or transverse myelitis, the breakdown of the nervous system comes from within.

Biomedical research hopes to return function to people who have lost it. A generation ago, the notion of a "cure" for spinal cord injury or other paralyzing conditions was unthinkable. The central nervous system was simply not thought to be fixable. Few scientists invested their careers in what was considered a dead end area of research.

Today, however, the field of restorative neuroscience is expanding. There are more scientists working on brain and spinal cord dysfunction now that at any time in history. Even the most conservative researchers no longer believe that a damaged or diseased nervous system cannot be treated. Clinical trials for innovative treatments and therapies will steadily increase in coming years.

Our knowledge of the brain and spinal cord is far beyond what it was, but still limited. Many discoveries are still needed to assure that treatments are effective and safe. There is much work to do, but also much reason for hope.

Cognitive Rehabilitation Therapy
The Brain Injury Interdisciplinary Special Interest Group (BI-ISIG) of the American Congress of Rehabilitation Medicine (ACRM) http://www.acrm.org/ defines cognitive rehabilitation therapy as a "systematic, functionally-oriented service of therapeutic cognitive activities, based on an assessment and understanding of the person's brain-behavior deficits." "Services are directed to achieve functional changes by (1) reinforcing, strengthening, or reestablishing previously learned patterns of behavior, or (2) establishing new patterns of cognitive activity or compensatory mechanisms for impaired neurological systems" (Harley, et al., 1992, p.63). If

skills cannot be relearned, then new ones have to be taught to enable the person to compensate for lost cognitive functions.

The Locomotor Training (LT)

LT is the result of research begun decades ago. This program, currently working with individuals who have incomplete cervical and thoracic injuries, involves suspending patients in harnesses over treadmills while therapists move their legs to simulate walking. Not all participants achieve the same results, but all experience changes as a result of the therapy. There are improvements in participants' function – including trunk control, endurance, speed of walking when possible, and balance – which translate into better ability to perform activities of daily living and reduced dependence on caregivers. There are also demonstrable improvements in cardiovascular, pulmonary, and bladder function, and increased bone density.

Quality of Life

A focus on quality of life issues is equally important. Value-added programs give patients the resources to re-learn activities of daily living and achieve the goals they set for themselves post-injury, including returning to home, school, and work. Goals may also include regaining the ability to enjoy life through social events, hobbies, and leisure activities, as well as providing for themselves and their family. The value-added programs aid patients in regaining their life and rebuilding their hope, but are often not reimbursed by private or public insurance. Research shows that these programs are essential in a patient's recovery and directly contribute to the much greater than average clinical outcomes achieved by our patients, which lead to greater independence for the patient.

Examples of such programs include:
- Animal assisted therapy in which the therapist uses trained dogs to assist the patient to achieve daily physical and occupational therapy goals
- Assistive technology like a wheelchair clinic (helping people who need wheelchairs to make an appropriate choice); an adaptive driving program (helping people with disabilities and the elderly to drive safely or be transported safely); and an

adaptive computer and electronics program (helping people with disabilities use computers with adaptive controls or with specialized techniques)
- Back-to-school programs that train students' compensatory learning and studying techniques and advocate for the full inclusion of adolescent patients returning to school
- Injury prevention that provides outreach to the community to promote safety and injury prevention, disaster preparedness, and response
- Peer support that provides role models to share coping skills; serve as support so that patients/families feel less alone; demonstrate functional skills and activities; and share specific information on disability-related issues including disability rights and community resources
- Therapeutic recreation that facilitates physical, cognitive, and social functioning through leisure counseling, leisure skill instruction, and community reintegration with the goal to return the individual to as independent, active, and healthy a lifestyle as possible
- Vocational services that evaluate the patients ability to return to work and advocate in the workplace for the patient, insuring the necessary reasonable accommodations are made available to successfully return to employment post-injury
- Other community-based programs like Teleheath medicine, personal support training programs, and community transition programs for preventing re-hospitalizations

Treatment
- Innovative practices for cost-effective outcomes
- Innovations that include use of information and communications technology (internet, mobile apps, social media) and social support networks to augment traditional health and social services
- Innovations that focus on promoting health, wellness, and continuing recovery of people with disabilities. These efforts might focus on techniques and technologies for exercise (e.g., use of Functional Electrical Stimulation, body-weight support, robotics) and peer support
- Innovations in cognitive and behavioral supports
- Use of robotics in functional recovery after disability (e.g., exoskeletal orthosis)

THINGS TO CONSIDER

- Funding programs that involve consumers in meaningful ways on boards, as staff, and as volunteers
- Funding programs that embrace patient/family-centered care
- Funding programs that demonstrate the benefits of a coordinated system of rehabilitation and habilitation
- Funding programs that conduct and publish peer-reviewed research that improves people's lives
- Funding programs that are able to identify, evaluate, and translate evidence-based findings into clinical practice
- Funding programs that systematically evaluate their outcomes and have a formal process for integrating findings to improve quality care
- Funding programs that focus on home and community-based services (long-term services and supports)
- Funding programs that focus on collaboration with other stakeholders
- Funding programs that develop products such as consumer information and other educational materials, and distribute them widely and effectively

QUESTIONS FOR FUNDERS AND GRANTSEEKERS

- Is the organization accessible, accommodating, and inclusive of people with disabilities?
- What, if any, are the organization's current advocacy efforts?
- Please provide a list of stakeholders and community partners in achieving your mission.

- What are your target benchmarks for program outcomes? What is your process for evaluating and improving outcomes?
- How successfully do you manage the transition of your patients back to their community? Back to work/school/productivity?
- How does your organization bridge the gap in quality of care once patients leave your organization and return home?
- How do you involve the family in a patient's rehabilitation?
- What value-added programs do you offer that go above and beyond those reimbursed?
- What role does peer support play in your continuum of care?

ADDITIONAL RESOURCES

The American Board of Physical Medicine and Rehabilitation
https://www.abpmr.org

National Institute on Disability and Rehabilitation Research
http://www2.ed.gov/about/offices/list/osers/nidrr/index.html

The Institute for Patient and Family-Centered Care
http://www.ipfcc.org/

American Congress of Rehabilitation Medicine
http://www.acrm.org/

11 Inclusive Recreation

JAMES H. RIMMER

HISTORY

Inclusive recreation is a relatively new concept that reflects the need for societies, communities, and organizations to promote opportunities for people with disabilities to become recreationally engaged with non-disabled members in the same community. This may involve using paths and trails for hiking and biking; joining a local walking club; participating in lifetime sports such as golf and tennis; or joining a fitness center for access to the facilities' programs, equipment, and services. Many good local programs support inclusive recreation in communities across the United States. Unfortunately, these are often the exception rather than the rule.

Entrenched socioeconomic disadvantages and structural, programmatic, and attitudinal barriers have severely restricted the ability of people with physical, intellectual, and sensory disabilities to engage in recreational pursuits. Barriers such as cost, transportation issues, inadequate support services, lack of professional training in disability, and inaccessible parks, playgrounds, and equipment are some of the reasons why people with disabilities are not obtaining regular amounts of recreation compared to non-disabled community members.

Existing Healthy Communities/Community Transformation programs, funded by the US Department of Health and Human Services since 2003, focus on policy, environmental, programmatic, and infrastructure changes to promote active living, including various recreational activities (e.g., biking, walking, jogging). This is an opportune time to promote inclusive recreation across communities that are building physical activity environments that facilitate greater rates of walking, biking, and use of indoor and outdoor recreational facilities among non-disabled community members.

POLICY

The Americans with Disabilities Act (ADA), signed into law in 1990, is designed to prevent discrimination in various sectors including recreation. Title III of the ADA, Public Accommodations, makes reference to recreation. Public or private recreation facilities must provide reasonable accommodations for people with disabilities, which in most cases involves making a certain segment of the facility accessible to a member with a disability (e.g., purchasing an arm ergometer for someone who cannot use their legs to perform aerobic exercise). While the term "reasonable accommodation" will be interpreted differently by each community based on need, interest, or resources, the intent of the ADA is to ensure that people with disabilities have access to some portion of recreational services offered to the general community. From a human rights perspective, Article 30 of the Convention on the Rights of Persons with Disabilities http://www.un.org/disabilities/convention/conventionfull.shtml states that adults and children with disabilities must have access to recreational, leisure and sporting activities in both inclusive and disability-specific settings.

PRACTICE

There are three key elements required for promoting inclusive recreation: access, participation, and adherence. Access refers to the built environment (e.g., fitness facilities, exercise and recreation equipment, parks, trails). Participation relates to the actual execution of the recreational activity (e.g., playing golf with an accessible golf cart, performing yoga with the necessary adaptations to obtain an equivalent experience as non-disabled members of the class). Adherence denotes the sustainability of an activity, which is associated with its level of enjoyment and engagement.

Access involves physical access – entering and exiting the building; allowing full use of available facilities; allowing access on and off the equipment; having information available in various formats; etc. A more subtle aspect of access is information on the availability of facilities, services, programs, and equipment.

Participation goes beyond physical access and use of universal design to develop modalities of recreation that are both beneficial and satisfactory for people with disabilities. While access is primarily concerned with availability of opportunities for recreation, leisure, and exercise activities, participation is primarily concerned with the usability of those opportunities. For a person with a disability, simply having access to a facility (e.g., swimming pool, weight training room, or exercise equipment) is necessary but not sufficient for a successful outcome. For example, someone who has a disability may be able to get into an exercise room but have little or no success with participating in programs that are available with the existing equipment (e.g., circuit training class such as CurvesTM). A pool lift allows someone to enter the water (access) but is of little use if the person is unable to participate in the aqua-aerobics class due to a lack of adaptive equipment. Group exercise classes (e.g., Tai Chi, Pilates, yoga, aerobics), team sports (e.g., basketball, softball), exercise rooms (e.g., cardio and strength equipment), and outdoor recreation activities (e.g., cycling, climbing) often must be modified for people with disabilities to allow them to have satisfying and beneficial experiences.

Adherence denotes the sustainability of an activity. To realize the full benefits of inclusive recreation, an individual must participate regularly. Some of the most effective strategies for increasing adherence to beneficial recreation and exercise programs involve varying the types of activities or activity locations and developing social support networks for the physical activity. While adherence to an appropriately physically active lifestyle is a chronic problem for most people, it presents substantially greater difficulties for people with disabilities because of limited opportunities with regard to access and participation.

BEST PRACTICE

Recognizing the gap in inclusive recreation programs and the health disparities associated with disability, the Centers for Disease Control and Prevention (CDC) and other federal agencies have funded many excellent health and wellness programs that feature elements of recreation and physical activity for people with disabilities. Examples include Living Well with a Disability http://www.livingandworkingwell. org/, a ten-week wellness workshop for adults with disabilities; Steps To Your Health http://www.sciodh. com/materials/#Training-Manuals, a ten-week health education program for adults with physical and cognitive disabilities; Healthy Lifestyles http://www. ohsu.edu/xd/research/centers-institutes/institute-on-development-and-disability/public-health-programs/ healthy-lifestyles.cfm, a health and wellness program for adults with intellectual disability; adaptations of the Chronic Disease Self-Management Program http:// patienteducation.stanford.edu/programs/cdsmp.html for select disability groups; and Health Matters http:// healthmattersprogram.org/products/, a health education program for adults with intellectual disability.

Many local communities (including Boulder, Colorado and Portland, Oregon) provide inclusive recreation services for community members with disabilities. Canada is an international leader with some of the best inclusive recreation programs in the world.
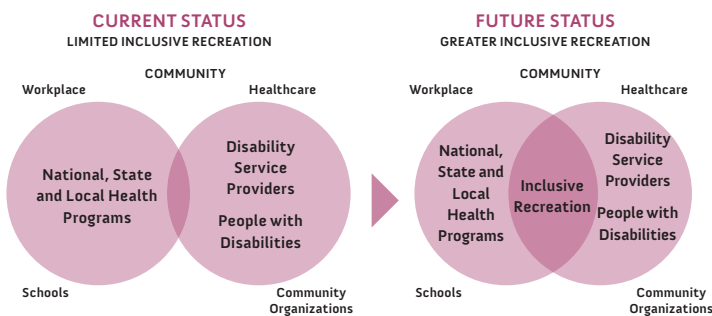
RESEARCH-BASE

The research on inclusive recreation is limited. Currently, most of the programs that are offered in communities across the U.S. are more practice-based than evidence-based. Given the importance of recreation in optimizing health and wellbeing of people with and without disabilities, there is a critical need for more empirical research on how inclusive recreation affects key health outcomes in people with disabilities.

LEADING-EDGE CONCEPTS

While specialized recreation programs have enormous value in improving the health of people with disabilities

in the short-term, long-term sustainable health improvements require the necessary supports (e.g., transportation, trained staff, accessible information, facilities) that will allow people with disabilities to engage in community recreation services. As illustrated in the figure on this page, recreation programs for the general population and those for people with disabilities currently tend to be developed and delivered within separate spheres of activity. The left side of the figure shows how this parallel structure results in inefficient use of resources and inadvertently promotes images of people with disabilities as "different." The right side depicts how communities should view inclusive recreation as part of the structure of community-based services for all members. Inclusive recreation must be an integral part of the workplace, healthcare facilities, schools, and community organizations. One major way to achieve this is by strengthening partnerships and building capacity among non-disability health organizations so that more communities will understand how to develop programs and services that meet the needs of community members with disabilities.

CURRENT STATUS
LIMITED INCLUSIVE RECREATION

FUTURE STATUS
GREATER INCLUSIVE RECREATION

THINGS TO AVOID

The ADA provides strong support for inclusive recreation. Family members and program staff interested in facilitating the integration of youths, adults, and seniors with disabilities into community recreation programs must be persistent and never accept "no" as an answer for excluding people with disabilities from "mainstream" recreational programs, venues, and services. People with disabilities and caregivers pay local taxes and are entitled to the same types of recreational services offered to the general community.

FUNDING SUGGESTIONS

Communities interested in promoting inclusive recreation often find that local charitable organizations and Jewish philanthropies will provide small grants for the purchase of adaptive recreation equipment. On the national level, the Christopher and Dana Reeve Foundation http://www.christopherreeve.org/site/c. ddJFKRNoFiG/b.4425935/k.6491/Quality_of_Life_ Grants.htm provides quality of life grants for children and adults who have some form of paralysis.

ROLES OF FAMILIES

Family members who are caring for a child, adult, or senior with a disability should educate themselves on how to obtain recreational services for a family member with a disability. There is an enormous amount of literature available on the internet for supporting families who want to proactively get another family member with a disability involved in inclusive recreational activities in their community. Families who have a member with a disability should also reach out to other families who have a child or adult with a disability to reduce the isolation that many such families experience.

REFERENCES

Fried, G. (2005). "ADA and sport facilities." In H. Appenzeller (Ed.), Risk management in sport: issues and strategies (2nd ed.) (pp. 289-302). Durham, NC: Carolina Academic Press.

National Center on Physical Activity and Disability www.ncpad.org

Rimmer, J. H., Riley B, Wang E, Rauworth A, Jurkowski J. (2004). "Physical activity participation among persons with disabilities: barriers and facilitators." American Journal of Preventive Medicine, 26(5), 419-425.

Walsh, R. (2011). "Lifestyle and mental health." The American Psychologist, 66(7):579-92.

12 Synagogue Inclusion: Do Not Separate Yourself from the Community

SHELLY CHRISTENSEN

"We are an Inclusive Congregation where individual differences are accommodated, accepted and appreciated, and where all members of our Synagogue Community participate together."

These words grace the main entrance of a synagogue that embraces inclusion of people with disabilities and their families. A beautiful artwork, created by artist Mordechai Rosenstein, was dedicated during Jewish Disability Awareness Month http://www.facebook.com/JewishDisabilityAwarenessMonth in February 2011 as part of a celebration that was thoughtfully carried out to acknowledge each person's strengths, gifts, and contributions to the synagogue.

This congregation and many others have begun to recognize that Jews with disabilities and their families have the right to participate in meaningful ways, to express their spirituality, and to gain access to worship, social, educational, and recreational activities across the lifespan. Choosing where and how to participate are the hallmarks of self-determination. Synagogues must be open to engaging people with disabilities in congregational life. The road to successful inclusion begins with raising awareness and educating synagogue members and staff to eliminate the barriers that prevent participation.

Judaism has much to say about the spirit of inclusion. Abraham, recovering from his own brit milah, sat in his tent, flaps wide open on all sides (Gen. 18:1-10). Upon seeing three strangers approach, he rose and welcomed them in the tradition of honor and respect by washing their feet. Sarah prepared a meal of the best grains and meat that they had to offer. Abraham and Sarah's hospitality was rewarded with the news that Sarah would give birth to a son.

Moses, reluctant to accept the mantle of leadership, told God that he could not assume this role because he was "slow of speech and slow of tongue" (Ex. 4:10). God saw the leadership qualities in Moses that would lead the Israelites out of slavery and on their long journey to the Promised Land. Moses did not believe his own strengths could outweigh his speech disorder. God finally said to him: "Who gives man speech? Who makes him dumb or deaf, seeing or blind? Is it not I, the Lord?" (Ex. 4:11).

Torah teaches us that each human being is created B'tzelem Elohim, in the Divine image (Gen. 1:27). It is this spark that makes us human. This particular text can help us find the common ground to honor individual spirituality and the connections to our sacred traditions and communities.

Hillel said "Al tifrosh min hatzibur. Do not separate yourself from the community" (Pirkei Avot 2:5). In our own recent history, Jewish parents were frequently advised to place children with disabilities in residential treatment centers, where they were too often left and forgotten. Having a child with a disability was a shonde (something of which to be ashamed). In a tradition deeply rooted in education and high achievement, having a child with a disability, especially one deemed "uneducable," was a source of grief and isolation. In Jewish communities it was as if people with disabilities were invisible.

Accessibility to the synagogue posed a tremendous barrier. Buildings were simply not designed to accommodate people who used wheelchairs and other mobility devices. Synagogue buildings and sanctuaries were literally built so people would have to make "aliyah" or go up staircases to reach the inside of the building and the bimah. These

long staircases were a feature of twentieth century synagogue architecture that symbolized exclusion of those people who could not use them.

Several events in the early 1980s would eventually influence sacred community inclusion. First, people with disabilities were leaving institutions to live in community-based housing. Sacred communities were not particularly welcoming and the stigma of shame still existed in Jewish communities. Most people of this era did not automatically turn to the Jewish community for support. Second, the demands for synagogue inclusion by parents was heightened when the landmark Education of All Handicapped Children, later renamed the Individuals with Disabilities Education Act (IDEA), was signed into law in 1975. As IDEA began to change the way children were educated, by the 1980s Jewish parents began to demand that synagogues and community schools include their children. It made no sense that their children were receiving a secular education in the least restrictive environment, but were not accepted into synagogue schools.

Parents' efforts were often met with resistance from synagogue professionals who believed that inclusive education would require financial resources that were not in the budget. Besides, some schools reasoned, "we have no children with disabilities in our congregations." This denial of need and the unwillingness to provide a Jewish education to children with disabilities drove parents and their children away from the synagogue and often from the Jewish fold altogether.

As a result of prevailing attitudes toward people with disabilities of all ages, inclusion remained elusive. Parent advocacy resulted in the formation of special-education programs that were a part of many community boards of Jewish education or provided the impetus to start separate agencies to provide special-education services to synagogue and day schools. Over time, these separate agencies have raised the level of quality education for children with disabilities. It was time to look past childhood and at inclusion of teens and adults.

In 2001, a medium-sized Jewish community was awarded a grant to develop an entire inclusion program devoted to collaboration between synagogues and agencies. The grant funded a study to determine the strengths and weaknesses in serving people with disabilities, as well as the attitudes and perceptions of community members, professionals, and family members. The grant also funded a full-time staff position to lead this initiative. Rather than providing direct service to people with disabilities, the program supported them by collaborating with synagogues to develop practices and change attitudes to reflect openness and respect for all individuals. The goal of the program was to allow all people, regardless of ability, could actively participate in worship, as well as in social, educational, and recreational activities in the Jewish community.

Strategies and best practices were developed along the way. Building relationships with rabbis, lay leadership, and staff professionals was critical to success. Not surprisingly, clergy were glad to have a community partner who could help them work through the challenges that they admittedly were facing in an effort to be inclusive without really understanding what that might mean to each individual and family. This collaborative model also enabled development of inclusion committees in each synagogue. Lay leaders from each committee also represented their organization on a community-wide board which provided a safe place to discuss barriers and ways to mediate them.

The inclusion model includes professional assistance to develop and train inclusion committees as well as to assist in developing goals and implementation strategies that hold organizations accountable for results. Before long, inclusion became a community-wide priority for funding and programming. Synagogue inclusion committees are dedicated to raising awareness and advocating the elimination of barriers that block meaningful participation for someone who has a disability.

Functions of inclusion committees can include:
• Assessing current practices in all facets of congregational life
• Developing a mission statement for synagogue inclusion

- Creating a vision and strategic plan
- Working with professional staff, congregational committees, and members of the board to weave inclusive practices throughout the synagogue
- Maintaining a website, and publishing weekly or monthly bulletins, service programs, invitations to events, and registration materials for all programming
- Determining that services are comfortable and accessible, locating the best lighting, acquiring large print and Braille prayer books and Torah commentaries, and ensuring that assistive listening devices are in working order. Ushers should be trained in these matters
- Evaluating practices such as announcing page numbers from the bimah, allowing people to rise or sit as they prefer
- Offering "walk throughs" for individuals who want to see where they will be worshipping or attending classes to alleviate anxiety
- Allowing for sensory breaks and creating a quiet and comfortable space for parents to take their children or for adults to go to when they need to get away from buzzing florescent lights and the low hum of microphones
- Developing programming for Jewish Disability Awareness Month and promoting JDAM throughout the congregation
- Advocating for best practices including person-centered planning, person-first language, and self-determination
- Ensuring that people with disabilities have a voice in synagogue life and can participate in all aspects of congregational activities including life-cycle events, worship, social, educational, and leadership

Self-determination is as important in a sacred venue as anywhere else. Stephanie tried to join a synagogue for over fourteen years. Calls and voicemails to synagogues went unanswered or she was told that she couldn't get in the building because she uses a wheelchair. Finally, she found a rabbi who wanted to meet with her. Rather than make assumptions about what she could or couldn't do because of her disability, the rabbi asked what was important to her as a Jew. She had quite a list of things that would give her a quality experience! Together Stephanie and the rabbi formed a partnership that made

her feel as though she belonged. Now she chairs a committee, participates weekly in Torah study, attends services, and regularly shares Shabbat dinner with fellow congregants.

The Jewish Special Education Consortium, founded in 1986 to provide collegial support to special education leaders, designated February 2009 as the first national JDAM http://www.facebook.com/JewishDisabilityAwarenessMonth. JDAM is a unified effort among Jewish organizations worldwide to use common programs to raise awareness and foster inclusion of people with disabilities and their families. In just four years, JDAM became part of the annual programming and is supported by the major synagogue movements, Jewish Federations of North America, and the Association of Jewish Family and Children's Agencies. Raising awareness blossomed into making inclusion a priority.

But raising awareness is just one of two key components of inclusion. The other is learning what works along the way. One well-intentioned practice is to help people with disabilities engage by creating a program or activity without including them in the planning. Synagogues must adopt the attitude that we don't do things for people with disabilities; we do things with them.

Synagogues should be careful about offering segregated programming for people with disabilities and their families. One synagogue offered an inclusion havdallah service but invited only people with disabilities and their families. No one even thought about creating a havdallah service which is conducive to using the different senses and learning preferences and inviting the entire congregation to experience the service.

Remembering to include people with disabilities and their families in life-cycle events can offer a warm invitation to families that feel excluded. Jonah attended religious school in a class for children with autism spectrum disorders. One day a letter came from the rabbi asking parents to arrange the bar or bat mitzvah date for their child. Jonah's mom Beth did not respond; she believed that because her son did not speak, he would not be able to read from the

Torah and participate in the service. Her rabbi called her a few days later, noting the absence of Jonah's bar mitzvah from the calendar. Beth related that this phone call made her feel that her entire family was wanted and that her son's relationship to Judaism was strengthened by a single phone call.

Some communities hold inclusion conferences for community members and synagogue professionals. But many conference planners do not consider follow-up programming and strategic planning. The result is disillusionment by community organizations and members. Conference planners must also remember to include people with disabilities in any and all planning.

The role of families must not be underestimated. When a child is diagnosed with a disability, parents are often deeply concerned about how the disability will impact their own hopes and dreams for their child. Dreams of raising the next generation of Jews, of having a bar and bat mitzvah ceremony, seeing the child standing under the chuppah are compromised or disappear entirely. Clergy must be trained in seminaries to counsel parents through this difficult time and to reach out and be with them for the spiritual aspects of the journey. Research shows that people with disabilities feel lonely and isolated at a much higher rate than other community members. Knowing that their synagogue and Jewish community accept and value them reinforces the sense of belonging to a community that is so important to inclusion.

The Chassidic master HaYehudi HaKadosh said, "Good intentions alone, not accompanied by action, are without value. The main thing is the action, as this is what makes the intention so profound" (Rabbi Yaakov Yitzchak of Przysucha quoted in Itturei Torah, Sh'mot 10:24, p. 84). In that spirit, our sacred community's responsibility is to manifest good intentions into practices that empower us and enhance our communities. Let us start by building inclusive congregations where people with disabilities feel a sense of belonging and purpose.

QUESTIONS FOR FUNDERS AND GRANTSEEKERS

- What are the strengths and assets of the synagogue (community) that can support people with disabilities and their families? What is working? What is needed to fill in the gaps?
- What opportunities are there in existing programming and what do you envision needing to provide satisfactory outcomes?
- What programs and resources already exist in the broader Jewish and secular community? In what ways can community organizations collaborate and build partnerships?
- Provide a plan including vision, outcomes, timeline and resources needed. What outcomes do you expect?
- As a funder, what do you want to achieve with this grant?

ADDITIONAL RESOURCES

Christensen, Shelly. The Jewish Community Guide to Inclusion of People with Disabilities. Jewish Family and Children's Service of Minneapolis, 2010. www.jfcsmpls.org/inclusion

Pinsky, Mark I. Amazing Gifts: Stories of Faith, Disability, and Inclusion, The Alban Institute. 2012.

Prosser, Ora Horn. Esau's Blessing: How the Bible embraces those with Special Needs. Ben Yehuda Press. 2011.

Strauss, Jane. A Part or Apart? Photographic essays of people who have disabilities active in their Jewish community. www.apartorapart.com

American Association on Intellectual and Developmental Disabilities Religion and Spirituality Division
http://www.aaiddreligion.org/

Jewish Special Education International Consortium
www.jsped.org

Jewish Community Inclusion Program for People with Disabilities, a program of Jewish Family and Children's Service of Minneapolis
www.jfcsmpls.org/inclusion

Person-Centered Thinking and Planning, an introduction by Michael Smull and Helen Sanderson
http://www.elpnet.net/documents/pctandplanning.pdf

Person-First Language, explanation of, articles and information by Kathie Snow http://www.disabilityisnatural.com/explore/pfl

Wehmeyer, Michael L. "Self-Determination and Individuals with Significant Disabilities: Examining Meanings and Misconceptions" http://www.beachcenter.org/Research/FullArticles/PDF/SD4A_Self-Determination%20and%20Individuals.pdf

Author Biographies

Allan I. Bergman is an accomplished nonprofit community agency provider and association executive with over 40 years of experience at the local, state and national levels. He is a nationally recognized leader in influencing federal and state policy relating to best practice services and supports for children and adults with disabilities in the "most integrated setting" consistent with Title II of the ADA and the integration mandate of the Olmstead Supreme Court decision. Bergman brings over 30 years of expertise in Medicaid, Medicare, and managed care policy, practice and financing including the Affordable Care Act; school transition services and community integrated supported living and employment. He established his consulting practice in 2010. Bergman also brings the perspective of a father and step-father of two adult daughters with disabilities; one in her own apartment with supports and a part-time integrated job, and one with more intense support needs living in a four-person home with a fully-integrated set of day supports.
aibergman@comcast.net

Shelly Christensen, MA, is an author, speaker and change leader for inclusion of people with disabilities in religious communities. Since 2001, she has served as Program Manager of the award winning and cutting-edge Minneapolis Jewish Community Inclusion Program for People with Disabilities. Shelly literally wrote the book on inclusion of people with disabilities. The Jewish Community Guide to Inclusion of People with Disabilities provides a comprehensive approach to cultivating welcoming and inclusive congregations and community organizations based on Jewish values. In 2008, Shelly co-founded Jewish Disability Awareness Month, which is today widely observed throughout the United States and Canada. She co-chairs the Union of Reform Judaism Access to Lifelong Learning Task Force. She is a graduate of the National Leadership Institute on Developmental Disabilities. In 2010, Shelly founded Inclusion Innovations, a consulting organization that collaborates with Jewish communities and institutions to build capacity so that people with disabilities and their families can live meaningful Jewish lives of their own choice in all aspects of community life. Shelly and her husband Rick are parents of three sons, one of whom has Asperger syndrome.
shelly@inclusioninnovations.com
www.inclusioninnovations.com

Steven M. Eidelman is the H. Rodney Sharp Professor of Human Services Policy and Leadership at the University of Delaware. He is also the Executive Director of the Joseph P. Kennedy, Jr. Foundation, a leader in philanthropy on behalf of people with intellectual disabilities. Eidelman is a past President of the American Association on Intellectual and Developmental Disabilities (AAIDD), and a former Executive Director of The Arc of the United States. He volunteers as Senior Advisor to the Chairman and CEO of Special Olympics International. He is also on the Board of The Open Society Institute's Mental Health Initiative, focusing on deinstitutionalization and community supports for people with intellectual disabilities in Central Europe and the Former Soviet Union. His recent efforts have focused on leadership development for practicing disability professionals and on implementation of Article XIX of the United Nations Convention on the Rights of Persons with Disabilities, focusing on deinstitutionalization. He was the state government official in charge when Pennhurst State School and Hospital were closed and has served as an expert witness on Olmstead-based deinstitutionalization litigation. His research interests focus on professional development of disability professionals.
sme@udel.edu

Meg Grigal, Ph.D., is a Senior Research Fellow at the Institute for Community Inclusion, University of Massachusetts, Boston where she co-directs Think College. She serves as the Co-Principal Investigator for four [?] national grants: the Center on Postsecondary Education for Students with Intellectual Disabilities, funded by the National Institute on Disability and Rehabilitation Research (NIDRR); the National Training Initiative, funded by the Administration on Developmental Disabilities; the Consortium for Postsecondary Education for Individuals with Developmental Disabilities; and the Office of Postsecondary Education National Coordinating Center for the Transition Programs for Students with Intellectual Disabilities (TPSID) Model Demonstration Programs. Prior to joining the ICI, Dr. Grigal was a Senior Research Associate at TransCen, Inc. where she served as the Principal Investigator and Director of the OSEP funded Postsecondary Education Research Center (PERC) Project www.transitiontocollege.net and the Co-Principal Investigator of the NIDRR Center on Postsecondary Education for Students with Intellectual Disabilities www.thinkcollege.net. Dr. Grigal currently conducts research and provides evaluation and technical assistance on exemplary practices for supporting students with disabilities in community, employment, and postsecondary settings. Her previous experience includes the administration and supervision at the University of Maryland of over $3.3 million federally funded personnel preparation, research, and outreach grants. She has co-authored two books on postsecondary options for students with intellectual disabilities and has conducted and published research in the areas of postsecondary education options, transition planning, families, self-determination, inclusion, and the use of person-centered planning techniques.
meg.grigal@umb.edu

Debra Hart, Ph.D. is Director of Education and Transition for the Institute for Community Inclusion at the University of Massachusetts, Boston. She has over 30 years of experience working with youth and adults with disabilities, their families, faculty, and support professionals. Currently, she is the Principal Investigator (PI) for three national postsecondary education grants. Together, these projects conduct research to better understand characteristics and outcomes of postsecondary education options for youth with intellectual disabilities, provide training and technical assistance to enhance existing PSE initiatives, and expand the choice of a postsecondary education for youth and their families nationwide. Additionally, she is the PI for the Equity and Excellence in Higher Education, a project focused on implementing a model for faculty development that provides teachers the tools and knowledge to make their courses accessible to a wider range of students, including students with disabilities.
debra.hart@umb.edu

Mark Johnson, M.Ed, is Director of Advocacy, Shepherd Center, Atlanta, Georgia. He is a nationally recognized advocate for people with disabilities, and a frequent contributor to policy issues impacting them. The Shepherd Center is a leading provider of rehabilitation services in the region. Mark holds a M.Ed. in Guidance and Counseling from the University of North Carolina at Charlotte, and is a graduate of the Leadership Denver Program and Atlanta Regional Commission (ARC's) Regional Leadership Institute. He has extensive background in independent living and rehabilitation, and is a Past President of the Fund for Southern Communities, a progressive fund that supports social change in NC, SC and GA.

Mark is a founder of ADAPT www.adapt.org. ADAPT is a national grass-roots advocacy community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom. He has received numerous awards for his advocacy and leadership including Georgia Trend Healthcare Hero (2009), Betts Award (2007), the New Mobility Person of the Year (2001) and the Jefferson Award for Outstanding Community Service, North Carolina.
mark_johnson@shepherd.org

Arlene S. Kanter is the Syracuse University College of Law's Bond, Schoeneck & King Distinguished Professor of Law and Meredith Professor of Teaching Excellence. She is the founder and director of the College of Law's Disability Law and Policy Program and the co-director of the Syracuse University Center on Human Policy, Law, and Disability Studies (CHPLDS). The CHPLDS is an expansion of the Center on Human Policy which was founded in 1974 as the first university-based, multi-disciplinary academic center dedicated to research, advocacy, and public education on issues of inclusion and equality for children and adults with disabilities.

Kanter writes and lectures extensively on domestic and international disability law, mental health law, and (special) education law. In 2001-06, Professor Kanter was invited to help draft the UN Convention on the Rights of People with Disabilities (CRPD). Since its adoption in 2006, she has worked with governments and organizations on developing laws and policies to comply with the CRPD in many countries, including Egypt, Ghana, India, Israel, Italy, Jordan, Mexico, Turkey, and Vietnam.

Kanter has published over 100 articles and book chapters, as well as the first casebook on international and comparative mental disability law. Her most recent article, "There's No Place Like Home: The Right of People with Disabilities to Live in the Community Under Instructional and Domestic Law," appears as the lead article in the Israel Law Review. Her upcoming books are Disability and Human Rights, soon to be available from Routledge Press, and Righting Educational Wrongs: The Intersection of Disability, Law and Education, forthcoming from the Syracuse University Press. Professor Kanter is also the founder and editor of the international electronic SSRN Journal on Disability Law.

In 2009-10, Kanter was named a Fulbright Scholar at Tel Aviv University. In 2010-11, she was named the Distinguished Switzer Fellow by the US Department of Education's National Institute of Disability Rehabilitation Research, and conducted a comparative project on inclusive higher education in Israel and the United States.

Kanter was a visiting scholar at Tel Aviv University Law Faculty in 2010, and at Hebrew University Law Faculty in 2011. Professor Kanter has served as a consultant to the Israeli Commission on Equal Rights of People with Disabilities, the Joint Distribution Committee's Disability Division's Israel Unlimited Project, and Bizchut, Israel's Human Rights Center for People with Disabilities. She developed a project with the National Insurance Institute on creating centers to support students with disabilities in higher education, which has been adopted by twelve colleges and will be adopted by twelve to fifteen additional colleges and universities throughout Israel in 2012. **kantera@law.syr.edu http://law.syr.edu/faculty/facultymember. aspx?fac=72**

David Michael Mank, Ph.D., is the Director of the Indiana Institute on Disability and Community at Indiana University, Indiana's University Center for Excellence on Developmental Disabilities. In addition, he is a Full Professor in the School of Education, Department of Curriculum and Instruction.

As a writer and researcher, Mank has an extensive background in the education and employment for persons with disabilities. He has authored or coauthored dozens of articles and book chapters. His interests include transition from school to work and community living. He has been involved in several lawsuits regarding deinstitutionalization and the movement from segregated to integrated employment services.

Since 1985, Mank has had responsibility for grant writing and management of numerous state or federally funded projects in which he has been the Principal Investigator, Director or Co-Director. Mank holds a master's from Portland State University in special education (1977), and a doctorate in special education and rehabilitation from the University of Oregon, Eugene (1985).

Mank is a member of the editorial boards of the Research and Practice for Persons with Severe Disabilities (TASH), the Journal of Vocational

Rehabilitation, the Journal of Disability Policy Studies, and Siglo Cero. He is Associate Editor of the journal Intellectual and Developmental Disabilities.

He served on the Board of Directors of the American Association on Intellectual and Developmental Disabilities and is Past President of the Association of University Centers on Disability (AUCD). He was one of the founding board members of Association for Persons in Supported Employment (APSE). He is a member of the Board of The Arc of Indiana. He has received the Franklin Smith Award for National Distinguished Service from The Arc of the United States.
dmank@indiana.edu

Gordon L. Porter, C.M., is a consultant, trainer, researcher, and teacher. He has worked on inclusive education projects with UNESCO, the OECD, and the World Bank. He has taught at the University of Maine at Presque Isle, the University of Prince Edward Island, the University of Calgary, McGill University in Montreal and Ryerson University in Toronto. Porter is Director of Inclusive Education Canada. He is co-editor of Exploring Inclusive Educational Practices through Professional Inquiry (SENSE Publishing, 2011).

Porter was inducted as a member of the Order of Canada in November 2010. In 2007, the Canadian Education Association gave him the Whitworth Award for Education Research to recognize his substantial contribution at both conceptual and practical levels to building inclusive classrooms. In 2009, he was awarded a Doctorate Honourus Causa, from the National Pedagogical University of Peru. He conducts training and consultation on inclusive education in countries in many parts of the world, most recently in Portugal, Germany, Spain, Peru, Columbia, and Ethiopia.

Porter led a review of inclusive education in New Brunswick for the Ministry of Education. The report, Strengthening Inclusion, Strengthening Schools, was released by the NB Department of Education and Early Childhood Development in June 2012.
glporter@nbnet.nb.ca

Rick Rader, MD, is a physician cross-trained in internal medicine and medical anthropology. He is the Director of the Morton J Kent Habilitation Center at Orange Grove, Chattanooga, TN, where he is engaged in the creation of novel healthcare programs for people with developmental disabilities. Rader is the Editor in chief of Exceptional Parent Magazine, the leading publication for parents of children with special needs, where he has contributed over two hundred articles. He is a founding member of the American Academy of Developmental Medicine and Dentistry and serves on the board of the American Association on Health and Disability. He was the first appointed Special Liaison for Family Healthcare Concerns at the President's Committee on People with Intellectual Disabilities. He has advised four former Surgeon Generals in the area of health and disabilities. He is an adjunct professor of Human Exceptionality at the University of Tennessee-Chattanooga.
habctrmd@aol.com

Amanda J. Rich is an assistant professor of sociology and human services at York College of Pennsylvania. She was awarded a PhD in human development and family studies by the University of Delaware in 2012. She earned a Masters degree in special education and applied behavior analysis at Columbia University. Amanda is a family advocate and her research interests focus on social justice and families with developmental disabilities, international disability rights, family diversity, inclusive communities, pedagogy in human services, and family supports.
arich1@ycp.edu

James H. Rimmer, Ph.D, is a Professor in the School of Health Professions and the first Lakeshore Foundation Endowed Chair in Health Promotion and Rehabilitation Sciences at the University of Alabama at Birmingham. He currently serves as director of the UAB-Lakeshore Foundation Research Collaborative and Director of the National Center on Health, Physical Activity and Disability. For the past 30 years, he has been developing and directing health promotion programs for people with disabilities

aimed at reducing obesity, increasing physical activity and improving nutrition in youths, adults and seniors with disabilities. His research interests explore the use of new and emergent technologies in developing behavioral and environmental strategies to promote beneficial physical activity and healthful weight management in youths and adults with disabilities. He was the director of the National Center on Health, Physical Activity and Disability since 1999 and was one of thirteen members of the Physical Activity Guidelines Advisory Committee that was commissioned to establish national US guidelines in physical activity in 2008.
jrimmer@uab.edu

Barbara J. Smith, Ph.D., is a Research Professor, School of Education and Human Development, University of Colorado, Denver. Her areas of interest include early intervention, early childhood special education, and early care and education policies and program development, leadership, professional development systems and collaboration. She held early childhood and early childhood special education positions for the past thirty five years including: early childhood teacher; Executive Director of the Division for Early Childhood (DEC) of the Council

for Exceptional Children; Policy Specialist, Council for Exceptional Children (CEC); and Program Specialist, US Office of Special Education Programs. Barbara has worked with NAEYC and other early childhood leadership organizations to help shape quality inclusive early childhood environments and the policies and guidelines that support them including serving on the NAEYC Commission to develop the current program accreditation criteria. She has published widely on the topic of EC policy and systems, presented testimony to state legislative and Congressional committees, and has provided consultation to states and collaborative state cross-agency teams. She has worked extensively on collaborative planning for interagency systems development and has published a related book A Road Map for Facilitating Collaborative Teams.

She currently serves as faculty on two national training and technical assistance centers related to children's social emotional development and challenging behavior: the Center on the Social and Emotional Foundations for Early Learning (CSEFEL), and the Technical Assistance Center on Social Emotional Intervention (TACSEI). She is the Director of Pyramid Plus: The Colorado Center for Social Emotional Competence and Inclusion.
barbara.smith@ucdenver.edu