

DISABILITY CONFERENCE SERIES

**A Program in the President's
21st Century Interdisciplinary
Conference Series**



During the 2004-2005 academic year, with generous support from the President's 21st Century Interdisciplinary Conference Series, the University of Minnesota Center on Aging, Center for Bioethics, Humphrey Institute of Public Affairs, Institute on Community Integration, and Disability Services, with assistance from the disability planning committee (see Appendix A), hosted a series of five conferences on disability-related issues (see Appendix B). These conferences brought together University faculty and community persons who share an interest in disability issues, stimulated dialogue between the two groups, recast disability issues in a new light, furthered our insights, and explored innovative solutions to improve the lives of persons of all ages with disabilities. The series also strengthened ties between the University and the disability community and built a foundation for ongoing collaboration and greater interaction that can lead to better programs and policies for persons with disabilities. This monograph includes summary highlights from the five conferences; research questions and unresolved policy issues stimulated by the conference deliberations; and suggestions for future University, disability advocacy community, and joint University-advocacy community activities.

UNIVERSITY OF MINNESOTA

CONFERENCE SERIES HIGHLIGHTS

“Balkanization” of Disability

Persons with disabilities receive support through a fragmented set of programs and services, with varying criteria for benefits and eligibility for services. This fragmentation, or “balkanization,” is particularly acute for individuals as they transition from childhood to young adulthood and from adulthood to age 65 and older. Mirroring the patchwork disability system, the disability community is comprised of multiple groups, often segregated by age and type of disability. Disability advocacy organizations similarly highlight these differences and often seek to advance their constituents’ perceived distinct interests. There are historical reasons and contemporary rationales for the fragmentation. Disabilities are different and persons with different types of disabilities have different priorities and needs. Some of these differences should be acknowledged, respected, and valued. Indeed, they are championed by some groups. The deaf community, for example, embraces its distinct “culture.”

Nonetheless, all persons with disabilities share basic needs such as housing, health care, and transportation. Disparities across disability programs for these services are difficult to justify. For example, almost all elderly persons with disabilities have health coverage (primarily through Medicare) whereas significant numbers of younger persons with disabilities remain uninsured. On the other hand, independent living services are more readily available for younger than for elderly persons with disabilities. Services that favor segregation over integration are rejected by younger persons with disability but are considered mainstream for older persons with equivalent types and levels of disability. On balance, the attitudes towards and the programs, care models, expenditures, and goals for people with disabilities differ substantially across age groups in ways that suggest ageism.

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As the demographic, social, and economics tides shift, it may not be advantageous to preserve the current fragmentation across disability programs and advocacy. Reducing the degree of fragmentation while recognizing that some differences are unavoidable and even to be valued is an important policy goal. Cross-cutting issues that address common, fundamental concerns, such as housing and health care coverage, deserve priority. Consumer-directed (or “consumer-driven”) care is promoted as one potential strategy to reduce disparities and improve society’s responses to persons with disabilities. The underlying philosophy is that since consumers are in the best position to identify and prioritize their needs, they should have more say in obtaining and directing the services they need. Despite the enthusiasm for consumer-directed care, however, relatively little is known of its impact on cost, quality, and access; and what is known comes primarily from small demonstration projects. Another, more basic strategy may simply be to enforce laws and regulations already on the books that promote the interests and protect the rights of persons with disabilities, such as requiring school systems to fulfill their special education responsibilities and providing them

with the necessary resources to do so.

Role of Advocacy

Much of current disability policy has been shaped by the actions of advocates. Most disability advocacy is linked to a single, specific disease or syndrome, and only a few advocacy groups, notably AARP, represent population groups. The disease-focused advocates have been differentially successful in gaining support for their causes. Many diagnosis-based organizations have promoted research and treatment over disability services and support, but some, especially those advocating for persons with developmental disabilities, have been dramatically effective in accruing resources for their constituents. Although most advocacy is diagnosis- and condition-specific, some disability advocacy organizations have worked with other organizations that share similar interests and needs. Ad hoc coalitions of disability organizations periodically form at the state and federal government level, but are rarely inclusive and usually disband once their limited purpose has been achieved.

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The advocacy situation differs for young and old. For children with disabilities, the primary advocates are their parents, who may feel responsible (correctly or not) for having created the situation, but also have a long-standing interest in the outcome, because the child will be around for a considerable period of time. The situation for older persons is different. Their natural advocates are their children, but the causal relationship is substantially different, and personal histories may play a much stronger role. Their period of disability is also typically much shorter. Although children may become actively involved in advocacy activities during the period of active care, they are less likely to sustain this involvement upon the death of the parent.

Perverse Economic Incentives

By almost any economic measure, persons with disabilities are less well off relative to the non-disabled population. Their assets and incomes are lower, despite income support programs. They are more likely to be unemployed. Many incur higher expenditures for health, transportation, and other basic necessities. These economic burdens are compounded by disability programs' conflicting incentives (e.g., returning to work may jeopardize an individual's health coverage).

Many disability policies are tied to labor force participation, including education, rehabilitation, health care, income support for those not able to work, income support for those retired from work, and equal access and opportunity to work and productively engage (special education, Supplemental Security Income [SSI], Social Security Disability Insurance [SSDI], Rehab Act, ADA, etc.). The goals, directly or indirectly stated, are to provide people with disabilities equal access to the labor force and equal opportunity to prepare for, engage in, and reap the rewards of work. Other economic goals of disability policy include easing the financial burden of disability and reducing the probability of disablement (e.g., by preventing health impairments or adapting jobs so that persons with disabilities can be gainfully employed). Disability policy also has non-economic goals, including equity and social justice goals (however these may ultimately be defined). Key challenges are to improve the economic well being of persons with disabilities while reconciling both the conflicting goals of disability policy and the competing demands for finite resources.

Current disability policies often fail to advance their own stated economic goals. The primary federal programs providing income support for working-age people with disabilities include SSDI and SSI. By design and in practice, these programs have perverse financial incentives. For example, the eligibility criterion – “inability to engage in any substantial gainful activity” – is a disincentive to return to work. The valuable health insurance coverage included as part of SSI’s and SSDI’s benefit packages may influence individuals’ decisions about establishing eligibility and remaining eligible for these programs. The “all-or-nothing” nature of the programs also functions as a barrier to expanding employment for persons with disabilities and to other policy goals.

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Exacerbating the employment difficulties for persons with disabilities is the lack of evidence that “disability-friendly” employers (i.e., employers who strive to provide equal opportunities for disabled employees, employees who become disabled, and job applicants) can remain economically competitive with their peers who do less for workers with disabilities. Employers generally do not view and accept costs associated with being “disability friendly” (e.g., accommodation costs, higher health insurance costs) as normal costs of doing business. Thus it may be unrealistic, in the current economic and social environment, to expect private employers to “do good” for employees and applicants with disabilities. These concerns underscore the current ambivalence regarding the role of private entities, particularly employers, in protecting and advancing the interests of persons with disabilities, just when the public sector is shifting more of this responsibility to the private sector.

Costs of Disability

There is little information on the total cost of disability in the US. The three primary sources of services, support, and assistance for persons with disabilities are: (1) a wide range of public programs, such as Social Security Disability Insurance, Medicaid, and special education for children with disabilities; (2) private programs, including health and disability insurance and private pensions; and (3) family, friends, and other informal (i.e., unpaid) caregivers. The total costs in the US for such services, support, and assistance are thought to be substantial; precise figures, however, do not exist. In 1986 total public and private disability expenditures in the US, combining the first two categories above, were estimated at \$169.4 billion, or 4 percent of the GNP.¹ More recent estimates are not available, but the expansion of disability-related programs and services during the past few decades almost certainly means that national disability expenditures now exceed 4 percent of the GNP. Estimates of the value of “unpaid” care for persons with disabilities are not available.

Including expenditures for health care in the estimate of total disability costs (as they are in the estimates above) is controversial. Some argue that health care is a core component of disability services and its costs should therefore be included. Others favor excluding health care expenditures since they are not unique to persons with disabilities – all persons incur such expenditures. Moreover, since some health care for persons with disabilities is for conditions unrelated to their disability, including

¹ M. Berkowitz and C. Greene, “Disability Expenditures,” *American Rehabilitation*, (Spring 1989): 7-15.
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health expenditures would overestimate total disability costs. This debate has important policy implications because expenditures for health care for persons with disabilities overshadow all other disability expenditures. For example, federal health care expenditures (primarily through the Medicare and Medicaid programs) account for approximately two-thirds of all federal expenditures for persons with disabilities.

A full accounting of the cost of disability would include direct costs, such as expenditures of private and public disability programs; indirect costs, including, for example, the cost of goods and services not produced by persons with disabilities because they are unable to work; “soft costs,” including, for example, the ‘cost’ of having a disability and of living with a disability; informal caregiver costs, including their opportunity costs; and the ‘cost’ of doing nothing (i.e., of not providing services). Such an accounting has not yet been performed.

Moral Foundation of Disability Policy and Programs

Improving disability policy is hampered by uncertainties over foundational issues such as:

- What should be the underlying framework of values to guide disability programs and policies?
- Are assuring equality of opportunity, full participation, independent living, and economic self-sufficiency for persons with disabilities, only legal requirements of disability policy or also moral imperatives?

The level of uncertainty on these issues varies across disability programs. Compared to other programs, the values framework underlying special education, for instance, is relatively clear. The public good that special education is designed to promote is explicit: The Individuals with Disabilities Education Act (IDEA), guarantees all children with disabilities the right to a “free appropriate public education.” Children are to receive such an education not because they meet some criteria of need or disadvantage; rather, a free public education is a legal right of all children – including those with a disability and those without.

Genetic Testing and Disability

Advancements in genetics will impact our understanding of, attitudes toward, and responses to health, illness, and disability. They will fundamentally alter the concept of disability and what it means to have a disability (e.g., is an asymptomatic person with a genetic predisposition for a disabling condition “disabled”?). They also raise other significant bioethical issues.

Genetic testing can offer a glimpse into someone's future health and provide unprecedented opportunities for prevention. Despite the pace of recent advances, however, the promise of genetic testing may be oversold. Accurate predictions of single gene disorders such as Huntington's Disease or Cystic Fibrosis are relatively straightforward. In contrast, testing for genetic “markers” that are linked with other conditions remains imprecise. For more complex conditions, such as carpal tunnel or physiological conditions like depression or anxiety, current genetic testing is not reliable at all. Moreover, having a strong likelihood of developing a condition says nothing about the extent of that condition.

Genetic testing also presents new challenges regarding the collection and use of information. Predictive information about common diseases could be misused by insurers, employers, and other

third parties. Life and disability insurers can now conduct rigorous genetic tests for a growing array of disabling genetic conditions during the course of underwriting potential applicants. Should they be able to exclude coverage for conditions and diseases based on these tests? Should genetic susceptibility to a condition by itself warrant coverage exclusion? If coverage is excluded, who should pay for the individual's care? Under what circumstances, if any, should employers or other third parties have access to personal genetic information? What additional protections, if any, are needed to prevent discrimination against employees with genetic markers that *could* lead to serious medical conditions down the road?

Balancing Competing Needs

As with all social policy, disability policy in the US exists in a context of scarcity: the needs of persons with disabilities will always exceed available resources. Relatively unexplored are the criteria and processes for allocating these finite resources across competing disability needs. Missing is a thoughtful discussion about balancing disability with other societal needs and the role of cost considerations when designing programs for persons with disabilities.

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Balancing competing needs is a constant challenge in special education. The IDEA provides all children with a disability the right to a “free and appropriate education.” Fiscal challenges in a context of finite resources are at the heart of the question of balancing access to educating disabled children and their non-disabled peers. Budget considerations (driven primarily by inadequate funding for achieving the IDEA's goals, according to some) have eclipsed all other aspects of the IDEA, creating tension between the individual entitlements guaranteed by the act and maintaining the viability of the school system for all children, as well as glossing over the impact of the act's strong preference for inclusion, or mainstreaming. Since the IDEA allows parents to be fully involved in developing the individualized education plan for their children with disabilities, another ethical challenge facing schools, families, and governments is whether the intensity of a parent's advocacy should affect the amount of services provided by a school system to a child with disability. Parents' level of assertiveness does not necessarily correlate with children's level of need.

The ADA prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. In employment, the ADA requires employers to provide “reasonable accommodation” to persons with disabilities who are employees or applicants for employment, unless such accommodation would cause the employer “undue hardship.” These concepts are among the most ambiguous and most litigated issues associated with this law. The clear trend in recent Supreme Court decisions on the ADA has been to interpret these two concepts in favor of employers. Consequently, defendants (typically employers) prevail more than 90 percent of the time in suits brought under the employment section of the ADA.

But the challenge of balancing the needs of disabled and non-disabled persons in the workplace may not be as daunting as it first appears. Many “reasonable accommodations” are under \$500, so they don't wind up costing an employer of any size that much money. Moreover, the

concept of “universal design” with adjustability for all workers can mitigate the problem when employers allege that a reasonable accommodation for a disabled worker would cause them undue hardship.

The ADA’s impact on employment varies across disabilities. For instance, since the law requires employees to disclose their need for accommodations, persons with conditions that carry a stigma, such as depression and other mental illnesses, may not benefit from the ADA. Such employees may be particularly unlikely to divulge their disability and ask for any accommodations from an employer.

Care versus Empowerment

Much divides health care professionals from the people with disabilities whom they serve. Health professionals often view disability as a physical or mental impairment *of the person*. They train and work in a health care system that emphasizes care for diseases that are bounded, do not need ongoing treatment, and can typically be cured. They focus on care and frequently still make unilateral treatment decisions.

In contrast, people with disabilities, and younger adults with disabilities in particular, posit the problem of disability as a social and physical environment that does not meet their needs. They come to this system with conditions that impact their lives more than their health, are long-lasting, and require management and accommodations but cannot be cured. They seek empowerment and want access to information to support their own decisions and to maximize control over their lives. As a result of these differences over goals, timelines, roles, and the meaning of disability, what health professionals provide may not always be what people with disabilities need. The differences may be most acute for younger persons with disabilities.

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The rationale for eligibility for services is similarly based on different premises with young and old persons with disabilities. Younger persons look to a basis in civil rights claims of denied access to opportunities. Older persons are more inclined to accept a disease-based model, where treatment is contingent on establishing a basis in malfunction. Rather than feeling entitled to assistance, older persons tend to be grateful for it, perhaps a reflection of endemic ageism, to which they subscribe.

“Care versus empowerment” captures the divide between health professionals and persons with disabilities, but it may be an oversimplification. Although care and empowerment differ, they are not necessarily in opposition. The goal is to find an appropriate balance. Also, clinicians don’t only provide care and patients don’t only seek empowerment. Sometimes patients, including those with disabilities, don’t want to be empowered but simply want – and need – to be cared for. Still, a narrow focus on care will not adequately address all dimensions of a person with disabilities’ “problem.” A cochlear implant for a deaf person, for example, may help the person hear, but does not address the social and psychological aspects of the person’s hearing impairment. Yet cochlear implants and similar strategies to “fix the problem” are the health care system’s standard response. Too often, the focus is solely on a person’s medical problem, ignoring the person’s emotional and social needs.

Many in the disability community argue a cultural divide separates persons with disabilities and clinicians. The two groups barely know each other and do not share a “common language” to talk about goals, expectations, and roles. The differences are magnified for persons with disabilities who are also members of a minority. The medical community has little access to the disability community. Interactions between the two occur during brief snippets – 7-minute clinic visits, for instance – that provide little opportunity to get to know and understand each other. The structure and financing of the health care system also hamper comprehensive and appropriate responses. Clinicians constrained by brief office visits do not have time to get to know their patients with disabilities. Further, they are typically paid for performing tests or procedures, not for talking with their patients. Persons’ disabilities may complicate their interactions with the health care system. For instance, a patient who is blind may need extra assistance getting up on the examining table. Persons with disabilities may take longer to recover from surgery. The system stumbles in addressing these simple and common occurrences.

However, focusing only on the inadequacies of the health care system may be disingenuous. The problem is more basic than money or time constraints. Clinicians should, but too often don’t, treat their patients with disabilities with respect and dignity, view them as persons instead of pigeonholing them based on their disability, and have the same expectations of them as they have of their other patients.

Bridging the Gap between Clinicians and Patients

The current push for change in health and supportive care programs in the public sector, driven primarily by fiscal constraints, provides an opportunity for positive change. Despite differences between persons with disabilities and their clinicians, there is significant agreement between these two groups on the outline of an improved health care system for persons with disabilities (e.g., a system that treats everyone with respect, responds to the whole person, provides appropriate care, and empowers patients). Although there is less agreement on how to move towards such a system, some strategies to bridge the differences appear obvious.

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Making patient-clinician encounters more productive and responsive to patients’ needs and expectations will require changes on both sides of the relationship. Clinicians will need to share power and information with their patients, value their insights about their condition, and involve them in all aspects of decision-making. Strategies to change clinicians’ perceptions and behavior must be sustained over time, such as repeated exposure to patients with disabilities during their clinical training. Since not every provider will be adept at treating persons with disabilities, an alternative strategy may be to concentrate care in the few clinicians who are, and to create well-recognized and accessible centers of excellence.

Persons with disabilities will need to assume more responsibility in managing their care and the medical consequences of their disability. As empowered patients they will need to adopt a more proactive role relative to the

health care system. To make the most of their brief encounters with clinicians, they will need to prepare for their office visits (rehearsing their questions, if necessary) and strive to keep the visit focused on their – not their clinician’s – agenda.

For practitioners in some medical-related disciplines, such as occupational therapy, the skills, competencies, and perspective needed in order to better meet the needs and expectations of persons with disabilities already form the foundation of their training. Their training blends scientific knowledge of the human body and mind with an understanding of the environment and the challenges and culture of disability. Other health care professionals may benefit by creating additional opportunities for partnerships and new care models that include disciplines with a comprehensive understanding of disability.

Other strategies to help bridge the gap between health care professionals and persons with disabilities include establishing a common language to articulate the problems, goals, expectations, and roles, and leveling the playing field by, for example, providing persons with disabilities access to the same information about treatments, options, cost-effectiveness and other aspects of their care as their clinicians. Most important, designing and implementing health care programs to better serve persons with disabilities must involve all stakeholders, including persons with disabilities.

Disability Policy Framework

Over the past two and a half decades, Congress has made a concerted effort to articulate in legislation the precept, goals, and major policies governing the treatment of people with disabilities (the “emerging disability policy framework”²). This framework can be used as a lens, guidepost, or benchmark to assess social policy from a disability policy perspective. It also provides guidance and insight to effectively develop, implement, and support home and community-based systems change initiatives and consumer-driven alternatives.

The new framework is based on a civil rights argument, where the underlying precept holds that disability is a natural and normal part of the human experience that in no way diminishes a person's right to fully participate in all aspects of society. Its focus is on fixing the physical and social environment to provide effective and meaningful opportunity to persons with disabilities; not on fixing persons with chronic conditions. The shift to the new framework for disability policy parallels shift from medical to social model of disability.³

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² See: *Using the Emerging Disability Policy Framework to Support Community-Based Systems Change Initiatives*. Robert (Bobby) Silverstein http://www.disabilitypolicycenter.org/docs/Using_EDPF_Systems_Change.doc

³ Many persons with mental disabilities embrace the medical model because it opens doors to services and resources. Most persons with other disabilities, however, reject this model because it locates the “problem” in them rather than in their environment. For them, the potential of increased resources that could result from placing disability under the health care system does not warrant adopting a model they have already rejected.

From the medical model perspective, disability is a mental or physical problem of the person. In contrast, the social model of disability frames the problem as a product not of the physical or mental impairment per se, but of the social and environmental barriers faced by persons with impairments, transforms the basis of viewing the different treatment of persons with disabilities in employment, access to public services, and other aspects of daily life into a form of discrimination and, in consequence, within the realm of civil rights protections. A model of disability that identifies the barriers to integrating persons with disabilities into the community as due, at least in part, to social practice and policies is essential to viewing disability discrimination as a civil rights problem. Identifying disability solely as impairment-related dysfunction of the person leaves the solution squarely within the purview of the health care system alone.

Young adults with disabilities (including some who are now in their 40s and 50s) have been the most vocal in arguing that disabled persons have been unfairly denied access to many of life's activities by virtue of their disabilities. They have used the social model to build their case that disabled persons are a segregated minority who deserve equal protection under the law. Differential treatment of persons with disabilities as a civil rights issue gathered steam throughout the 1970s and 1980s and culminated with the passage of the ADA in 1990, which draws heavily from previous civil rights legislation and has been hailed by supporters as a "minority group approach to disability policy issues."⁴ Conversely, older persons with disabilities remain staunchly in the medical model. For them, disability results from underlying disease, which is a concomitant of aging. Responses such as institutionalization, which have been rejected by young disabled persons, are still considered appropriate for older persons. Reflecting this difference, the deinstitutionalization movement is largely complete for younger persons with disabilities but has only just begun for the elderly with disabilities.

The social model of disability reinforces the notion that persons with disabilities share important commonalities. Similar types of disabilities occur across all age groups; that is, persons of any age can have physical disabilities, cognitive deficits, or mental illness. Regardless of the person's age, the need for accommodation, access, care, or services can be temporary, long-term, or life-long. The common denominator is the effect of the impairment or disabling condition on the individual's participation in normal daily activities. All persons with disabilities require, albeit to varying degrees, compensatory services, assistance, or accommodations

The ADA, which has functioned as the primary vehicle to advance the new policy framework specifies the four goals of disability policy as equality of opportunity, full participation, independent living, and economic self-sufficiency. However, the extent to which these goals have been attained vary across different populations with disabilities. Younger persons with disabilities have been at the vanguard of independent living and self-direction. Persons with mental impairments remain particularly unlikely to achieve economic self-sufficiency.

⁴ Protecting the civil rights of people with disabilities differs in fundamental ways from similar protection for other minority groups. Whereas protecting the civil rights of members of minority groups based on race, color, sex, national origin, and religion requires that they be treated the same as people in the dominant group, protecting the civil rights of persons with disabilities "requires that their differences be acknowledged and accommodated," L. Francis and A. Silvers, "Achieving the Right to Live in the World: Americans with Disabilities and the Civil Rights Tradition." In *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions*. Edited by L. Francis and A. Silvers (New York: Routledge, 2000) xii-xxx.

Future Disability Policy

In the coming decades, a variety of changes in the political, demographic, and economic environment will lead to a much more competitive policy climate, where various constituencies will battle for a constrained set of resources. The political basis for laying claim to these resources will vary in terms of philosophy. In the face of competing claims, there likely will be a greater call for accountability and equity based on common measures of need and the likelihood of success from interventions

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The growth in older persons combined with pressures to control federal and state budgets will place enormous pressure on budgets and thus set the stage for complex political maneuvering. The values and priorities of the Boomer population differ from those of currently elderly population but mesh with those of younger disabled adults. The Boomer population is more individualistic, more supportive of individual choice, and less likely to be satisfied with the current level, quality, and choice of services. They likely will bring a new vision of aging to both the disability population and disability ideology, breaking down stereotypes of aging as a loss and forwarding the concept of older adults as productive, engaged, and included in their communities as valuable resources and active citizens. Overlying the primary struggle, divisive “hot button” issues including stem cell research and assisted suicide may impact the political discourse and agenda. The interplay of these changes and issues with the goals of disability policy creates a complex and unclear political landscape.

The trend toward “self-sufficiency,” “personal responsibility,” and an “ownership society” will significantly affect disability policy. Future disability policies will be more likely to reflect an “all or nothing” approach, with eligibility for services and support resembling a cliff rather than a gradual slope. If current trends continue, overall spending for social supports will be more constrained, restricting services to only the most needy. Universal programs benefiting everyone (e.g., social security retirement income) will be more likely to retain support than special programs for subpopulations (e.g., social security disability insurance). Support for the safety net that everyone may need at some point in their lives will be stronger than for welfare programs, which are typically perceived to be for “others.”

Contemporary political discourse in many states is dominated by taxes and other cost considerations. As a result, disability policy is not driven by vision, principles, or values. The singular focus on financial issues hampers any creative dialogue of the needs, wants, and priorities of persons with disabilities and thus stifles any initiatives to improve disability policies and programs. For example, efforts in Minnesota and other states to move long-term care and disability programs into managed care are driven primarily by hoped-for, but not yet realized, cost savings.

RESEARCH QUESTIONS

The deliberations that come out of these conference sessions generated a number of potential research questions, which could be addressed by teams of researchers and pragmatic persons. These questions are offered as potential areas of exploration; they range from specific to general.

- To what extent, if any, has the fragmentation of disability harmed/benefited persons with disabilities overall, or particular groups? Who has been harmed/benefited and why?
- To what extent has the ADA reduced discrimination, expanded opportunities, and improved the lives of persons with disabilities? Does the ADA's impact vary across different populations with disabilities? What is needed to further advance the ADA's articulated goals?
- How will current political trends, such as greater personal responsibility, establishment of an "ownership society," and a more limited role of government, impact disability policy?
- How will the aging population and other demographic changes impact disability policy?
- How will "hot button" political issues influence future disability policy, programs, and advocacy?
- The future of Medicaid is in doubt; many states are cutting eligibility, others view the program as fiscally non-viable and seek to remodel the program or put a new system in place. What is the future of Medicaid? How will anticipated changes affect persons with disabilities?
- How a question is framed can make all the difference. How do the ways health professionals and persons with disabilities define the underlying problems affect the level of collaboration between the groups?
- What is the nature of the gap between the needs and expectations of people with disabilities regarding health care and the responses by health care professionals?
 - To what extent, if any, do health care professionals differ from people with disabilities on:
 - the appropriate conceptual framework for disability
 - the role of treatment
 - the goals of care (cure, condition management, accommodations)
 - the respective roles of providers and consumers
 - the appropriate balance between freedom and risk
 - research priorities
- How can health care professionals better communicate with and meet the needs of persons with disabilities?
- What models, if any, have successfully aligned health professionals' services with the needs of persons with disabilities?
 - How can these successes be transferred to other programs and settings?

- To what extent is genetic discrimination a reality? A legitimate fear?
- Are existing legal protections sufficient to “regulate” the permissible collection and use of personal genetic information?
- What are the levers to bring about change in disability policy? Who has the power to influence the levers? What are the sources of pressure for retrenchment?
- To what extent is the “all-or-nothing” nature of some disability programs a barrier to meeting desired economic goals?
 - How should this be changed? For example, should temporary benefits be employed to improve the incentives in income support programs for persons with disabilities?
- Disability groups have not historically been unified. Are conditions changing sufficiently to forge more sustained political alliances? What principles are held in common?
 - Are disability organizations better off uniting their political efforts or going it alone? When are coalitions feasible, advisable, essential, or counterproductive?
 - To what extent would joint efforts by aging and disability constituencies give political advantage to both groups?
- What are the barriers to greater cooperation among disability advocacy groups? What are the benefits and dangers of these goals? What could be gained or lost?

UNRESOLVED POLICY ISSUES

The active discussions within the sessions often generated more questions than answers. They also surfaced a number of important policy issues that deserve ongoing consideration.

- What is the obligation of society to persons with disabilities? What is the obligation of the private sector, the public sector, individual private entities (such as employers)? Who has responsibility for funding disability services?
- Do people with disabilities have a “right” to services/assistance/accommodations, or do they earn them? Does this depend on the type of service/assistance/accommodation?
 - What are the arguments for and against positing a individual’s “right,” as opposed to a societal obligation to provide or assure access, to (certain types or levels of) disability services/assistance/accommodations?
- Should disability programs providing the same benefit (e.g., personal assistance) to different populations (e.g., elderly, persons with developmental disabilities) be required to provide the same level and quality of service to all persons with the same level of disability regardless of its etiology?
- How should society balance the interests and needs of persons with disabilities with those of persons without disabilities in developing education, transportation, housing and other public policy?
 - For example, what criteria and factors should guide policies for inclusion (mainstreaming) in education?
- What role, if any, should cost considerations play in protecting or promoting the civil rights of persons with disabilities? Should “rights” claims trump cost concerns?
- How should finite resources for disability programs be distributed?
 - Based on efficiency, level of need, equality, outcomes, or some other criteria?
- How should state government be restructured to better protect and promote interests across disability groups? Should aging, disability (including DD), and mental health be in the same unit of state government?
- What should be the economic goals of disability policy? For example, restoring earning capacity, easing the financial burden of disability, reducing the probability of disablement, other?
 - How, if at all, should these goals differ depending on type or severity of disability, age of recipient, or other factors?
- To what extent should we be facilitating persons with disability in the workplace? What is the case for getting them meaningfully employed?
- How should health insurance programs be structured and financed in order to promote rather than conflict with the desired economic goals of disability policy?

- Should a person with a genetic predisposition for developing a disabling condition be considered “disabled” by him/herself, others, employers, insurers, society, etc.
 - When should such a person be considered disabled for the purposes of benefits eligibility? For the purpose of anti-discrimination under the ADA?
- Under what circumstances, if any, should a third party have access to personal genetic information?
- What are the boundaries of permissible collection and use of personal genetic information?

- What changes (e.g., in health professional education or in disability programs and policies) are needed so that health care professionals and the health care system are more responsive to the needs and priorities of people with disabilities?
- What are the essential elements of a disability program or service that would enable health care professionals to better meet the needs of persons with disabilities?

- What is the “right” framework for disability policy? What are its key features?
- How, if at all, should aging and disability policy converge?
 - How should advocacy efforts on behalf of elderly persons and persons with disabilities be structured? If changes are needed, what direction should they take?

- A variety of metrics have been proposed for measuring success in “improving” disability policy, including economic self-sufficiency, level of independence, enabling persons with disabilities to be able to do what they want to do, and compliance with existing standards (e.g., for accommodation). Which of these (or others) deserve priority?
- Are individual participation and choice essential goals for disability policy?
 - Should the range of choices available be based on consumer (or market) demands or on bureaucrats’ decisions?
- Is deinstitutionalization an essential goal?
 - What if individuals “choose” institutionalization?

- What strategies are needed to develop and implement a disability agenda that is more responsive to the needs, interests, and priorities of persons with disabilities?
- How should disability effort and advocacy be structured?
 - Should current patterns of fragmentation across programs and advocacy be maintained?
 - If changes are needed, what direction should they take?
 - How should the desired level of consolidation in programs and cooperation in advocacy be achieved?

NEXT STEPS

Defining the problem is always easier than defining the solution. It will be up to the disability community and academia, working independently and cooperatively, to design the solution. Improving the lives of persons with disabilities requires innovative policy and advocacy and changing the political paradigm to better respond to the needs of persons with disabilities. Although it may be possible to generate some additional revenue or savings (e.g., shifting from institutional care to home- and community-based care, downsizing nursing facilities, moving other services to less costly settings, and purchasing services based on “value”) it may not be possible to significantly increase the total pool of resources available for persons with disabilities.

“A prerequisite to changing the political paradigm for disability is to create ‘an aura of inevitability,’ to build the perception that the time for change has come and the status quo is no longer acceptable.”

The disability advocacy community can be powerful when it comes together, but such unity has occurred only infrequently. The most notable time was to promote passage of the ADA; even then, however, elderly persons with disabilities were not part of the coalition. The disability community is more likely to come together in order to protect or advance civil rights; in contrast, economic concerns have usually functioned as a wedge.

In the current environment, however, economic concerns appear paramount. There does not appear to be an untapped pot of money for disability. Advocacy in the context of constrained resources will be successful only through reasoned arguments or substantiated claims for greater efficiency (achieving better results with the same or fewer resources); by themselves, lofty arguments for fairness, social justice, or other moral values likely will be ineffectual. In the political arena in particular, arguments based on cost-efficiency, rather than rights or moral principles, hold more promise in loosening legislative purse strings.

A prerequisite to changing the political paradigm to better respond to the needs of persons with disabilities is to create “an aura of inevitability,” to build the perception that the time for change has come and the status quo is no longer acceptable. This requires combating the current skepticism that significant change in disability policy is even possible. Once that barrier is crossed, improving disability policy and programs will require a range of activities. Opportunities for future joint University-advocacy community activities include:

- Building University capacity to conduct disability research and policy analysis for the state. As demand for disability and long-term care services increases so will the pressures to allocate finite public resources more equitably and efficiently. The University could assist the state of Minnesota by researching the impact of policy

directions and decisions on persons with disabilities. It could also use the knowledge gained to help the state develop more appropriate disability policies and programs.

- Developing a comprehensive approach to integrate disability into health professional education throughout the Academic Health Center by expanding existing and developing new opportunities for health professional students to provide care to and interact with persons with disabilities.
- Expanding participatory research – a more collaborative approach to research that involves all partners in the research process and recognizes the unique strengths that each brings -- on disability issues in health care and public health.
- Creating education programs for persons with disabilities to improve their “health literacy” and self-management skills so that patient/clinician encounters are more productive and responsive to patient’s needs and expectations.

The University has begun to bolster disability education and research. In July 2005, the University of Minnesota’s Institute on Community Integration convened a multi-disciplinary group of University faculty and scholars to explore creating a significant academic presence on the University of Minnesota campus that could encourage and coordinate research and education in disability and its interface with aging. The 20-member group met on July 21, 2005 and identified a range of projects and activities that could engage the University faculty in collaborative effort. To build a foundation for such effort, the group will develop a conceptual framework for aging and disability outlining specific contextual areas such as policy, services, and technology; provide opportunities for members to share information on current research and related activities; and create a list-serve to share potential funding opportunities. Possible future activities include forming a University of Minnesota consortium on aging and disability, developing a set of guiding principles and operating assumptions, and clarifying the conceptual intersect of aging and disability and how it might play out on campus. The group may explore possible synergies with ongoing efforts to create a disability studies program at the University and other initiatives designed to raise the visibility of disability issues on campus.

APPENDIX A

Disability Conference Series Planning committee members

University of Minnesota

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Courage Center

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Minnesota State Council on Disability

APPENDIX B

Conference sessions

The “Balkanization” of Disability
October 15, 2004
Courage Center, Minneapolis

The Economics of Disability
December 1, 2004
Radisson Hotel Metrodome, Minneapolis

Ethics, Genetics, and Disability
January 20, 2005
Radisson Hotel Metrodome, Minneapolis

Care versus Empowerment
March 22, 2005
Radisson Hotel Metrodome, Minneapolis

The Politics of Disability
June 2, 2005
Radisson Hotel Metrodome, Minneapolis

The University of Minnesota is an equal opportunity educator and employer.