

Litigation, Legislation, Research, and Advocacy for Accessible Healthcare for People with Disabilities

Nancy R. Mudrick, Ph.D.
School of Social Work
Syracuse University



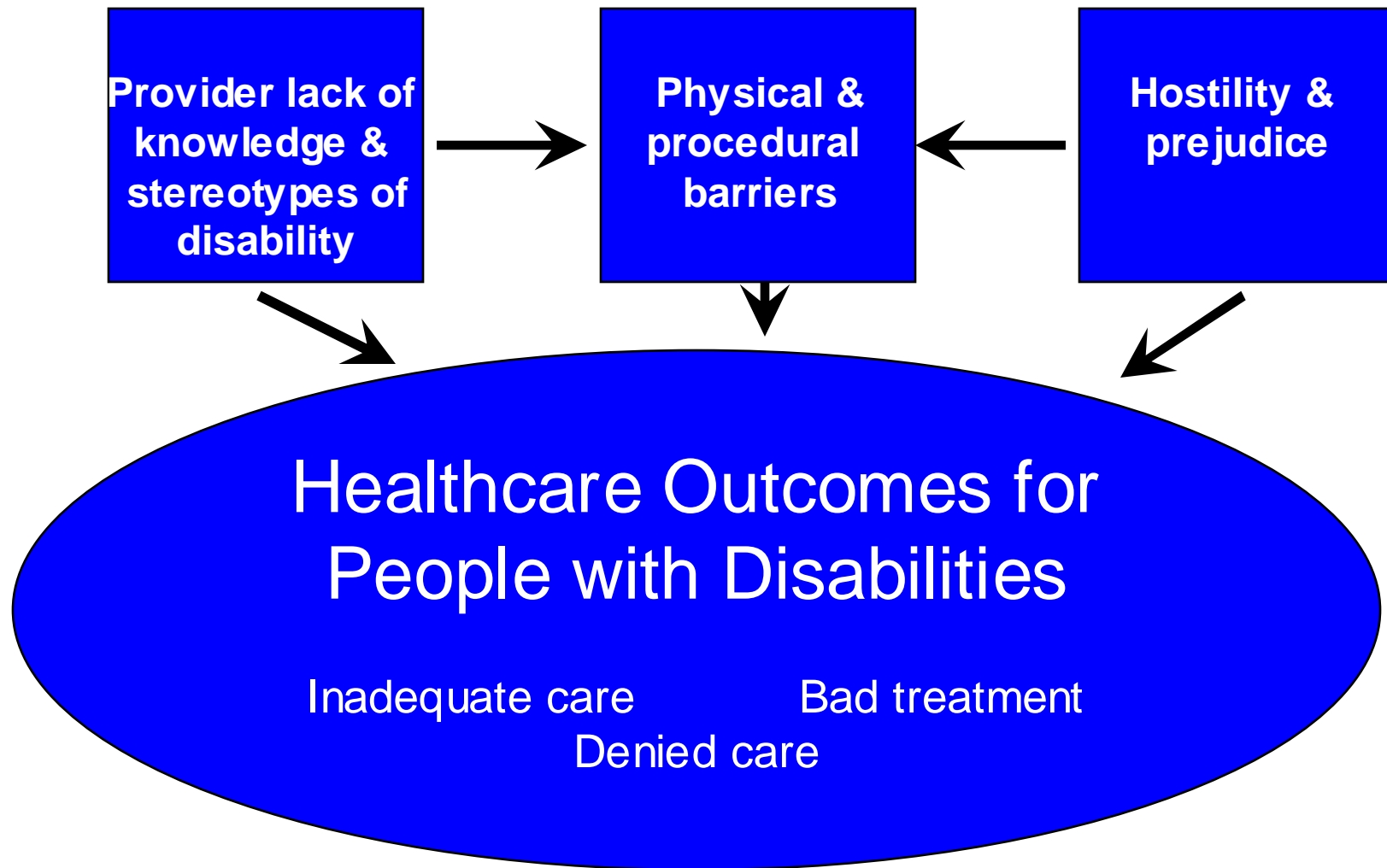
Healthcare Stories

Wheelchair user repeatedly examined in his chair

Young man with cerebral palsy goes 10 years between teeth cleanings & dental exams

Woman with a severe psychiatric condition complains repeatedly of stomach pain

Healthcare Experiences & Outcomes for People with Disabilities



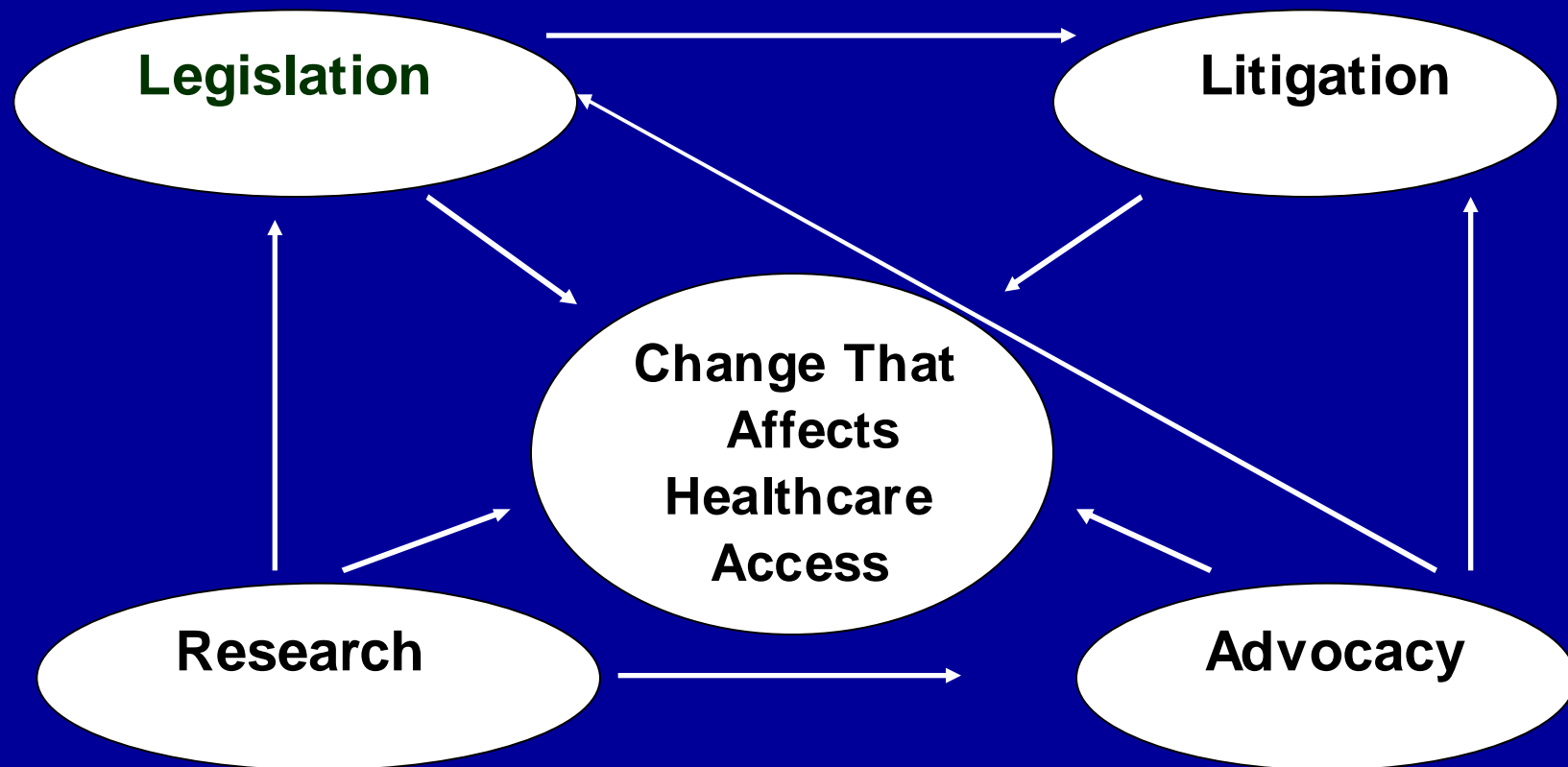
Examples of Outcomes

- Women with mobility impairments report lower rates of pap smears & mammography compared to all women
- People w/ disabilities report postponing needed care (especially referrals), and are less satisfied with care
- Deaf people have inadequate or no information about their conditions or medical treatment

Elements of Accessible Healthcare

- Architecturally accessible facilities
- Accessible medical equipment
- Policies for communication & access to information
- Policies for scheduling & waiting
- Procedures for conducting examinations
- Procedures for follow-up or referral
- Adequate insurance coverage for healthcare needs (including DME)
- System-wide flexibility for unusual needs

Multi-Sector Actors Influence the Outcome



Research

Funded projects produce a growing literature

Federally sponsored

National Institute on Disability &
Rehabilitation Research (NIDRR)

Agency for Healthcare Research & Quality
(AHRQ)

National Council on Disability (NCD)

Community & privately sponsored

Special Olympics survey

MCO monitoring & checklists

Research Focus & Methods

Quantitative profiles from large population surveys, receipt of standard screening & other procedures, satisfaction w/ care—surveys include people w/ disabilities

Qualitative interviews about healthcare experiences & access—people w/ disabilities

Small mail surveys of providers—physicians in specific geographic locations

Healthcare Access: Problems Identified

- Architectural barriers in healthcare facilities
 - Entrances, parking location, path of travel
 - Signage
- Lack of modification of procedures
 - Scheduling, appointment duration, waiting
 - Methods of obtaining information
 - Information provision & media, sign language interpreters

Healthcare Access: Problems Identified

- Provider office equipment
 - Adjustable height examination tables
 - Adjustable examination & diagnostic equipment
 - Accessible weight scales
 - Lifting aids

Healthcare Access: Problems Identified

- Provider training & disability cultural competence
 - Lack of knowledge to perform medical exam of person with a disability
 - Lack of knowledge for operation of accessible equipment
 - Lack of training for safe lifting & transfer
 - Unfamiliar with disability etiquette

Existing Applicable Legislation

Section 504 – Rehabilitation Act

Americans with Disabilities Act

- Title III: Non-discrimination by public accommodations. Medical facilities & providers are covered here
- Title II: Non-discrimination by state & local government entities. Should apply to Medicaid & Medicare insurers & MCO's

Litigation: Example

Metzler v. Kaiser Permanente (2001)

--Class action suit, settled out of court

--Kaiser Agreed to:

- Remove architectural barriers
- Install accessible medical equipment (esp. accessible weight scales & exam tables)
- Develop training programs, handbooks, & complaint system
- Review all policies to ensure they do not prevent access and meet the needs of patients w/ disabilities

Litigation: Example

Disability Rights Council et. al. v. Washington Hospital Center (2005) Hospital agreed to:

- Increase number & quality of accessible exam rooms, tables, & other medical equipment
- Revise policies & procedures to ensure patients receive assistance they need to eat, drink, & care for themselves
- Provide disability training for hospital staff

Litigation: Example

Numerous formal ADA complaints, private lawsuits, private settlements, & Dept. of Justice ADA enforcement agreements involving medical providers who fail to provide sign language interpreters

Hospitals, clinic facilities, doctor & dentist offices

Some agreements include compensatory damages & fines

Advocacy

--Work with health plans & providers for training, monitoring, or consultation

DREDF, Center for Disability Issues & the Health Professions

--Coalition advocacy for legislation under consideration

Disability Health Coalition (CA)

--Disability advocacy organizations

Special Olympics, Protection & Advocacy system, DREDF, AAPD, CIL's

Legislation Proposed

Promoting Wellness for Individuals with Disabilities Act of 2007 (S. 1050, H.R. 3294)

State health reform legislation (e.g., California)

What is Still Needed?

- Profile of accessibility from provider perspective
- Incorporation of disability access items in major data collection instruments to enable research on patients, insurers, and providers (e.g., NHIS, MEPS, CMS datasets)
- Monitoring of provider accessibility by payers (e.g., MCO's, Medicaid state & federal), licensing & accrediting agencies

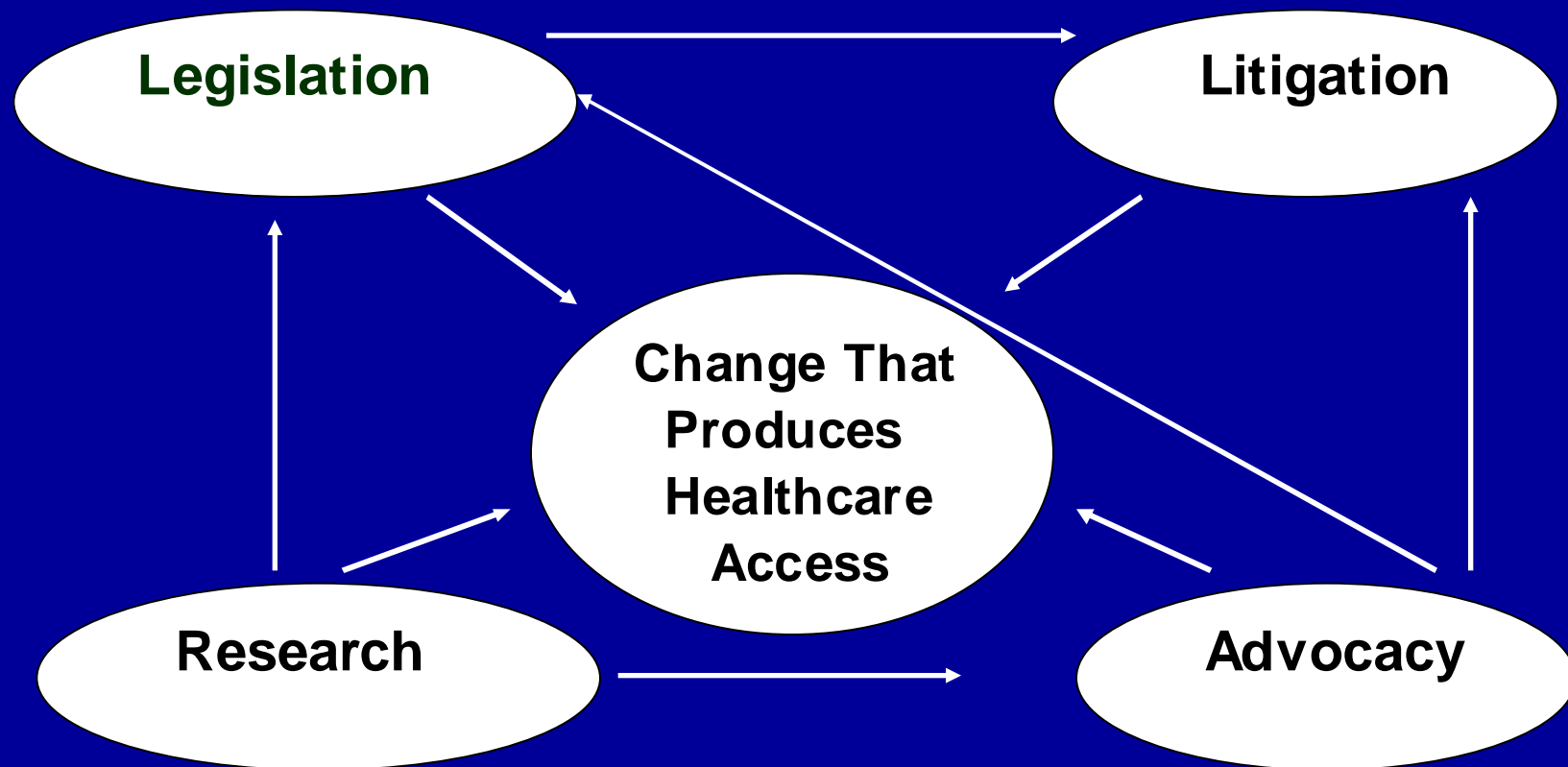
What is Still Needed?

- Physician knowledge, education, training: medical school curricula & continuing education
- Nurse and healthcare personnel training: disability cultural competence and safe utilization of assistive equipment
- Source for technical assistance to healthcare providers on methods & equipment for access

What is Still Needed?

- Affordable medical diagnostic & other equipment that incorporates universal design principles
- Stronger utilization of existing law (ADA) through compliance enforcement or litigation
- Mechanisms for producing cross-system solutions to problems involving different healthcare actors or sectors

Multi-Pronged Strategy for Bringing About Change



Potential Roles to Join the Effort

Researcher: social work public health
researchers are prominent contributors
(e.g., Parish & colleagues), but assistance
in studying provider behavior needed

Educator & trainer: public health
practitioners need specific training &
disability cultural competency

Potential Roles to Join the Effort

Public agency staff member: continued leadership to enhance governmental effectiveness is needed (e.g., at CDC and AHRQ, and by legislative, enforcement, and state & local agency staff)

Advocate: community-based organizations can infuse the issue into healthcare policy advocacy, task force & coalition work

Potential Roles to Join the Effort

Practitioner: healthcare providers and practitioners can work to ensure that their organizations ensure healthcare access; they can facilitate cross-system access through individual advocacy