CAREdesign NEW YORK

PHP PARTNERS HEALTH PLAN

Provider Webinar: Reducing Heath Disparities in the IDD Community through “IDD-Tailored” Health Care

Presented by: Steven Merahn, MD, Medical Director

10/26/23

NEWS RELEASES

Tuesday, September 26, 2023

NIH designates people with disabilities as a population with health disparities

Designation, new research program and update to NIH mission are actions to ensure inclusion of people with disabilities.

Today, Eliseo J. Pérez-Stable, M.D., director of the National Institute on Minority Health and Health Disparities (NIMHD), designated people with disabilities as a population with health disparities for research supported by the National Institutes of Health. The decision was made in consultation with Robert Otto Valdez, Ph.D., the director of the Agency for

Today’s Objectives

- Consider how the “health disparities” designation should be implement in our care delivery systems
- Recognize that “standard operating procedures” for the non-disabled population may not support goal achievement for people with I/DD
- Understand some of the unique patterns of conditions, functional limitations, and risk factors for quality of health
- Explore some best practices for “healthcare” caring for people with I/DD

Health Disparities Experienced by People with IDD

- More likely to report being inactive and in poor health
- Shorter average life expectancy than the general population.
- Most common causes of death differ from the general population and show higher rates of mortality due to illnesses/conditions less likely to lead to death in the general population.
- Less likely to receive preventative screenings and vaccinations.
- More likely to have poorly managed chronic health conditions.
- Higher rates of diabetes, arthritis and cardiovascular diseases, including high blood pressure and asthma
- Higher rates of undiagnosed hearing and vision impairments.
- Higher rates of obesity.
- Higher rates of poor dental health.
- Higher risk of getting and dying from cancer
- Higher rates of prescribed psychotropic medication.
- People needing behavior support show higher rates of many disparities than others in the DD population

Chronic Condition/Disease	***NY State IDD Prevalence (% of population)***	***NY State Non-IDD Prevalence (% of population)***
Currently have ***asthma***	16.5%	7.8%
Ever had ***cancer***	6.8%	4.8%
Ever had ***COPD***	10.1%	3.0%
Ever had ***diabetes***	17.0%	7.3%
Ever had a ***stroke***	4.6%	1.0%

Source: Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability. Disability and Health Data System (DHDS) Data [online]. [accessed Jun 13, 2023]. URL: https://dhds.cdc.gov

Barriers to Health Equity for IDD

- People with developmental disabilities lack access to quality health care, with “health” broadly defined.
- Quality health care has a variety of components, so there are a multitude of individual barriers that contribute to a lack of access to quality health care for people with DD.
- Barriers to quality health care fall into several categories:
  - **Systemic barriers**
  - **Societal/attitudinal barriers**
  - **Barriers due to a person’s functional limitations related to his/her disability**
  - **Intersectional barriers influenced by factors other than a person’s developmental disability**

Systemic Barriers

- The US health care system was not designed to accommodate the specific needs of people with developmental disabilities, especially as the life expectancy for people with IDD increases.
- There is a lack of research into health disparities experienced by people with disabilities, including developmental disabilities.
- Public campaigns for health promotion are typically not inclusive of people with IDD.
- There are no curriculum requirements for undergraduate pre-med programs or medical schools to provide education that prepares medical professionals to understand and accommodate the specific needs of people with developmental disabilities.

Societal/Attitudinal Barriers

Attitudinal Barriers for People with Disabilities

People with disabilities face many barriers every day–from physical obstacles in buildings to systemic barriers in employment and civic programs. Yet, often, the most difficult barriers to overcome are attitudes other people carry regarding people with disabilities. Whether born from ignorance, fear, misunderstanding or hate, these attitudes keep people from appreciating–and experiencing–the full potential a person with a disability can achieve.

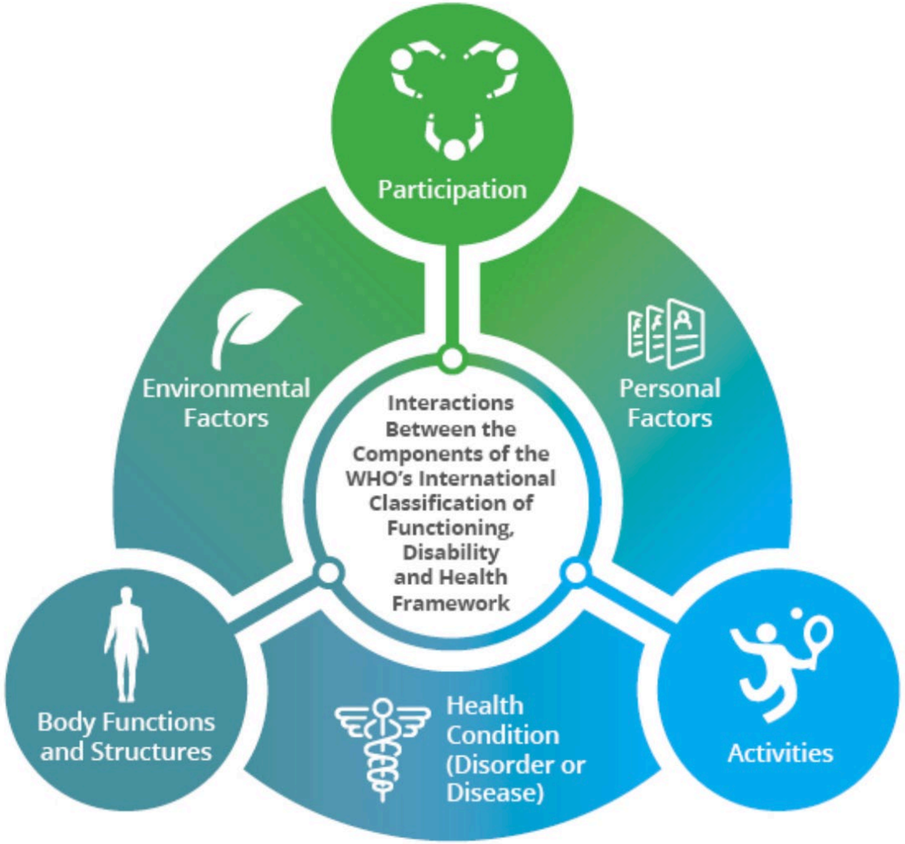
http://www.ncwd-youth.info/attitudinal-barriers-for-people-with-disabilities - National Collaboration on Workforce and Disability

- Societally, there are many stereotypes, misconceptions and prejudices towards people with DD.
- Medical professionals who have had little exposure to people with DD and little education specific to developmental disabilities often carry these attitudes.
- Societal lack of understanding related to the human and civil rights of people with DD continues to be a barrier to progress in many areas.
- Societal stigmas surrounding receiving psychiatric care or having psychiatric diagnoses may cause people with DD to avoid seeking specialty health care when they need it.
- People with DD and their families/advocates report that negative experiences with health care providers have made them less likely to seek medical care when they need it.

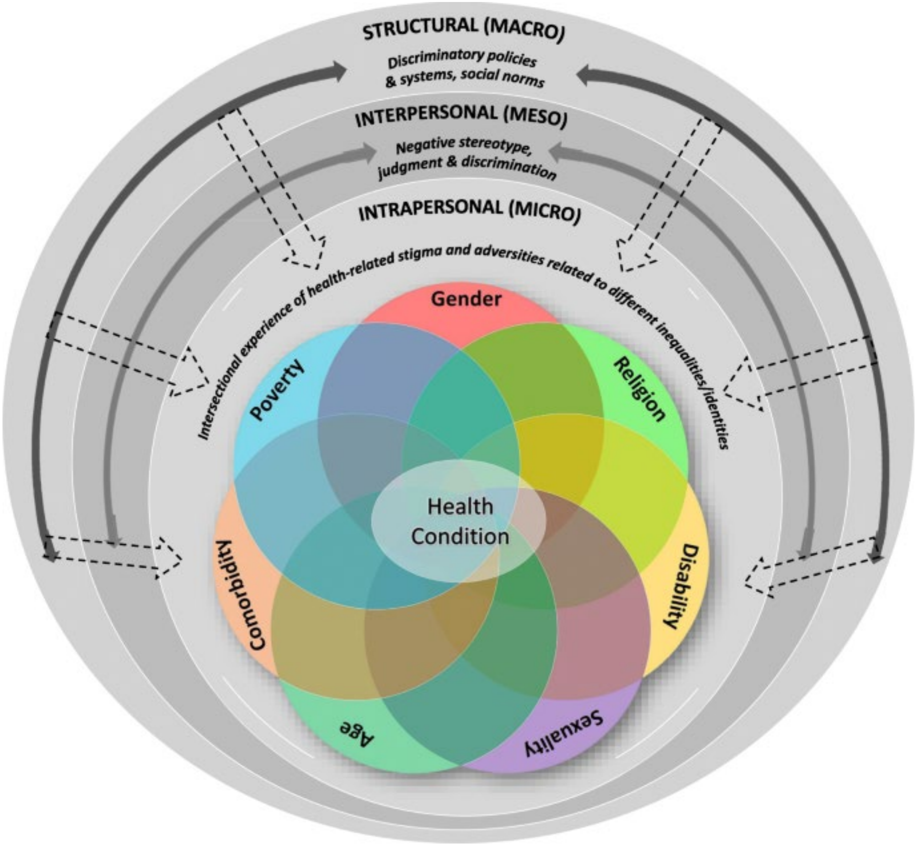
Barriers Related to Disability

People with developmental disabilities

- Often have functional limitations to their communication skills which create difficulty in communicating their needs to medical providers and understanding recommendations or instructions from their medical providers.
- Are three to five times more likely to demonstrate challenging behavior.
- May have physical disabilities, sensory processing issues and other needs. For example, medical centers, exam rooms and other physical environments where health care is provided are often not fully accessible to people who use wheelchairs or need to avoid bright lighting.



Intersectional Challenges



- When people with IDD also fall into racial and other minority groups that experience health disparities, the disparities they experience are compounded.
- There are numerous social determinants of health that contribute to health disparities that are very common in the IDD population, including:
  - Low income/socioeconomic status
  - Inadequate or inaccessible housing
  - Unemployment
  - Lack of reliable transportation
  - Lack of social connectedness
- Issues in these areas compound the already significant disparities experienced by people with IDD related to their disability.

Strategies to Address Disparities

- In the same way that there are a multitude of barriers to people with IDD receiving quality health care, there are also many recommendations and strategies to improve access to health care for people with IDD, in order to reduce the disparities in their lived experience.
- To fully address the identified barriers to quality health care for people with DD, change is needed on multiple levels of our healthcare system, including:
  - Systemic changes at a federal or nationwide organizational level
  - Systemic changes at a state or local level
  - Local changes that can be made by medical providers, healthcare systems and payers

Systemic Changes to Reduce Disparities

- At a national level:
  - %educe funding complexity and fragmentation of health care systems.
  - Recognition of people with IDD as a demographic group that experiences health disparities Efforts to make public health initiatives more inclusive and accessible to people with disabilities.
  - Creation and standardization of curriculum requirements for undergraduate medical programs and medical schools to ensure medical professionals receive education on the specific needs and human rights of people with disabilities.
- At a state or local level:
  - Continued efforts to address issues of poverty, inadequate housing and accessible transportation.
  - Efforts to make statewide or local public health initiatives more inclusive and accessible to people with disabilities.
  - Improve data collection on demographic information related to disabilities

But the IDD community requires distinctive competencies that are often missed.

Barriers to Health Care for People with Disabilities

HEALTH ENVIRONMENT
Absence of disability standards in provider training
Insufficient data on the health of people with disabilities
Lack of inclusive health promotion programs

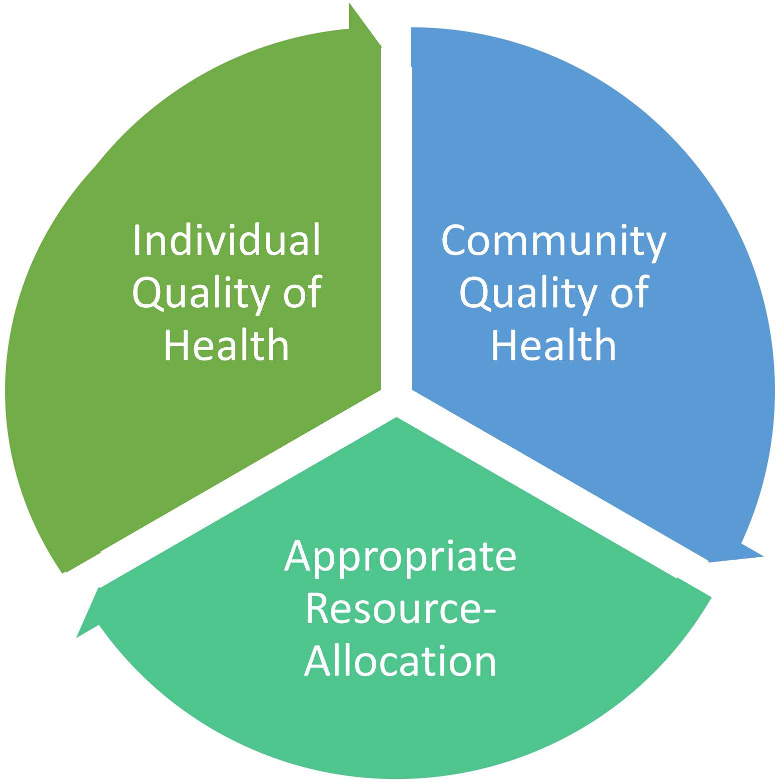
HEALTHCARE SYSTEM
Scheduling constraints
Payment and Reimbursement issues
Lack of age appropriate services and supports

CLINICAL PRACTICE
Inaccessible office and equipment
Lack of staff training
Communication barriers

PROVIDER
Lack of disability training
Incomplete knowledge of care coordination
Poor attitude

Robinson, A.C. (2018). *Barriers to Health Care for People with Disabilities* [Infographic]. Adapted from nisonger.osu.edu/wp-content/uploads/2018/07/Barriers-to-Health-Care-for-People-with-Disabilities.png

It’s Time to Take Triple Aim at IDD



Individual Quality of Health

Community Quality of Health

Appropriate Resource-Allocation

Historically, the medical model has been dominant.

It defines disability as an impairment or problem existing within the body or mind that can be identified by objective scientific or expert observations and ameliorated with the guidance or treatment of experts to help the person adapt and conform to the “normal” environment.

The social model challenges the medical model’s definition identifying disabled people as ‘defective’ and disabled lives as inherently inferior to nondisabled lives.

- From a social-model perspective, disability occurs when a person with an impairment interacts with physical or social environments that do not take the full range of human body variation into consideration and are unaccommodating or hostile as a result.
- In the social model, disability is a social construct, and disabled people are an oppressed minority group with unique histories and perspectives.

The Social Model of Disability

The problem is the disabling world

Badly designed buildings

Stairs not ramps
No lifts

Special schools

Few sign language interpreters

Discrimination

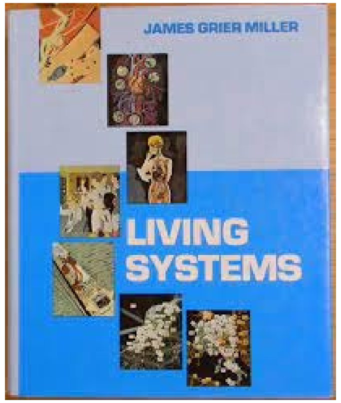
Inaccessible transport
No parking places

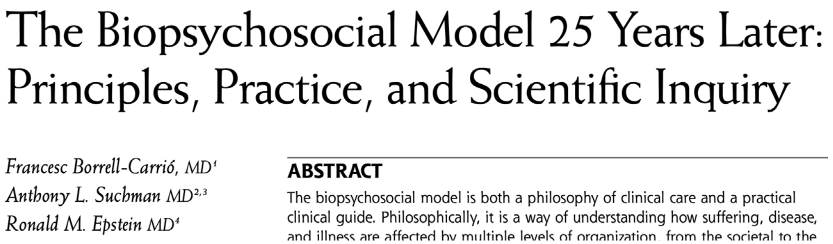
Isolated families

Poor job prospects

For this discussion….

- We are going to consider IDD through the lens of JG Miller’s Living Systems Theory, and its descendent, Dr. George Engel’s biopsychosocial model
- These models define health and well-being as harmony within the hierarchy of living systems.
    - **BIO = Body structures/Body functions**
    - **PSYCHO = Activities and participation (experience and behavior)**
    - **SOCIAL = Environmental factors (barriers and facilitators)**
- Illness, disease or disability are therefor the result of a force or perturbation at one of the levels that reverberates among and perturbs the functions of the whole.

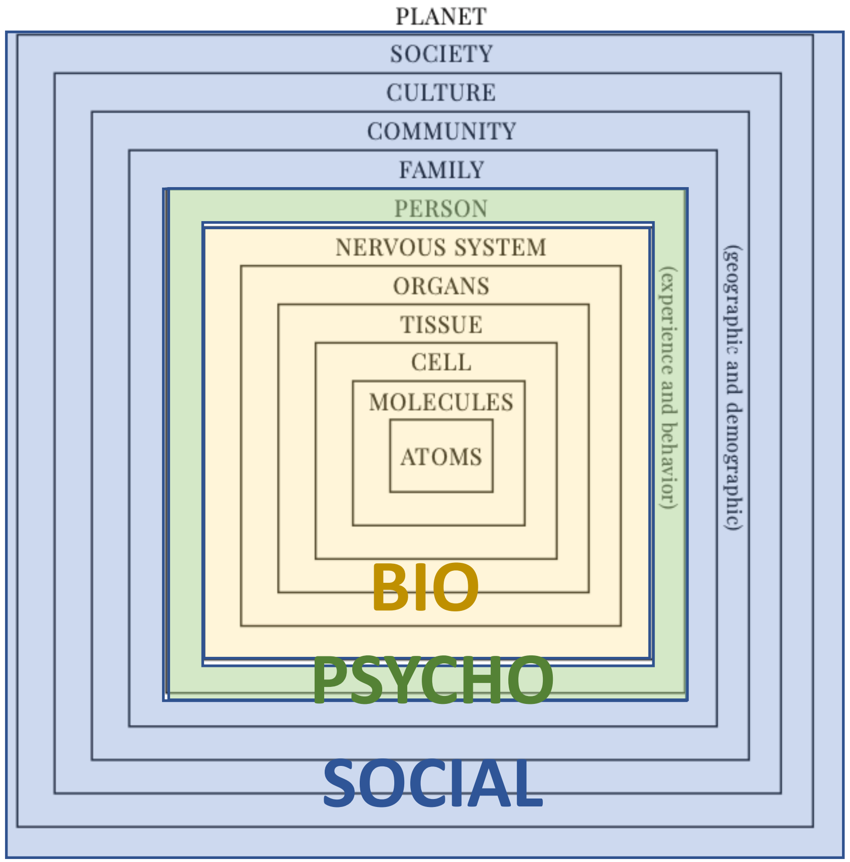



The Biopsychosocial Model 25 Years Later: Principles, Practice, and Scientific Inquiry

Francesc Borrell-Carrió, MD[1]
Anthony L. Suchman MD[2,3]
Ronald M. Epstein MD[4]

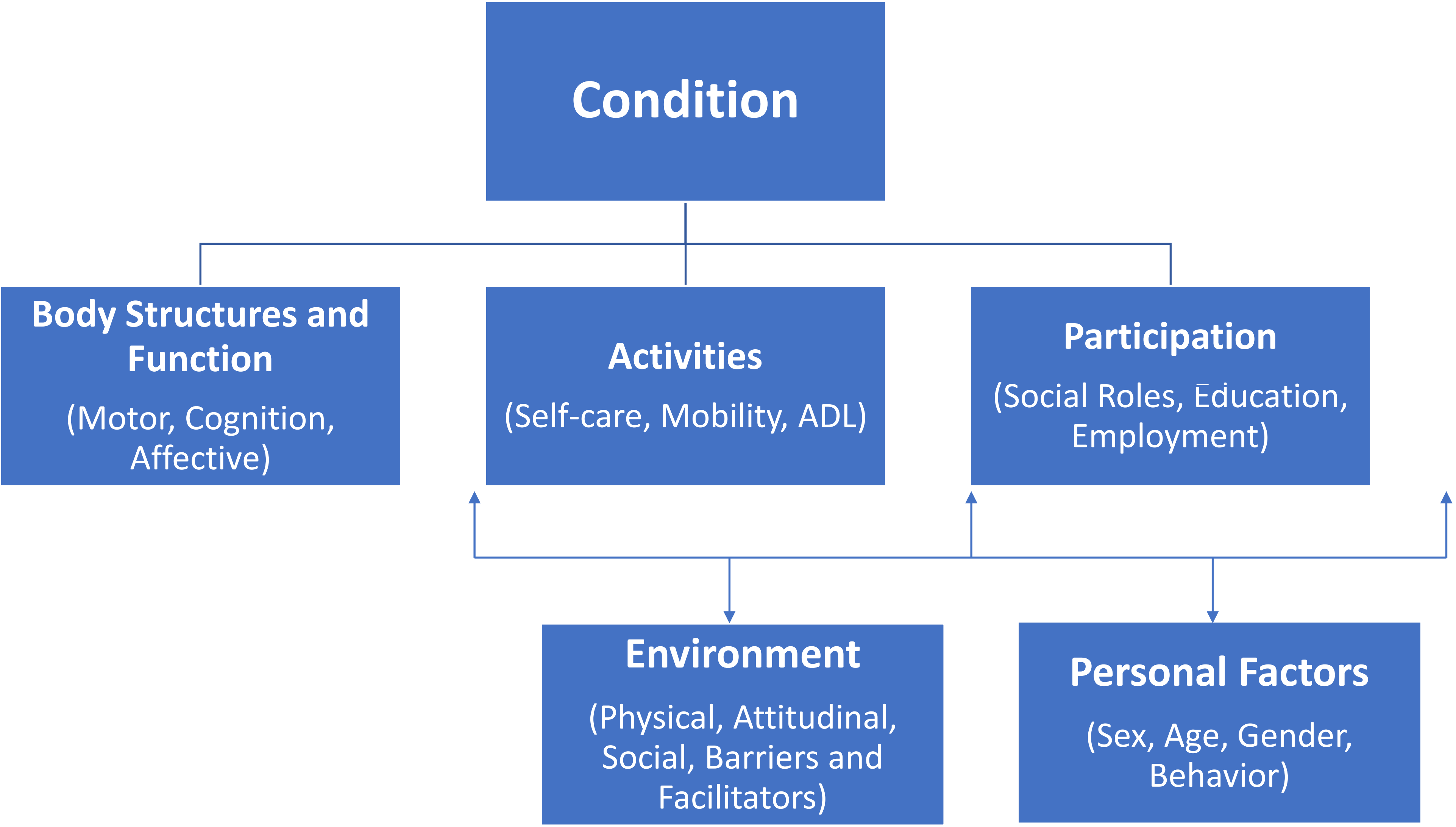
ABSTRACT

The biopsychosocial model is both a philosophy of clinical care and a practical clinical guide. Philosophically, it is a way of understanding how suffering, disease, and illness are affected by multiple levels of organization, from the societal to the



Hierarchy of Living Systems

Functional Capacity = Outcomes



Condition

Body Structures and Function

(Motor, Cognition, Affective)

Activities

(Self-care, Mobility, ADL)

Participation

(Social Roles, Education, Employment)

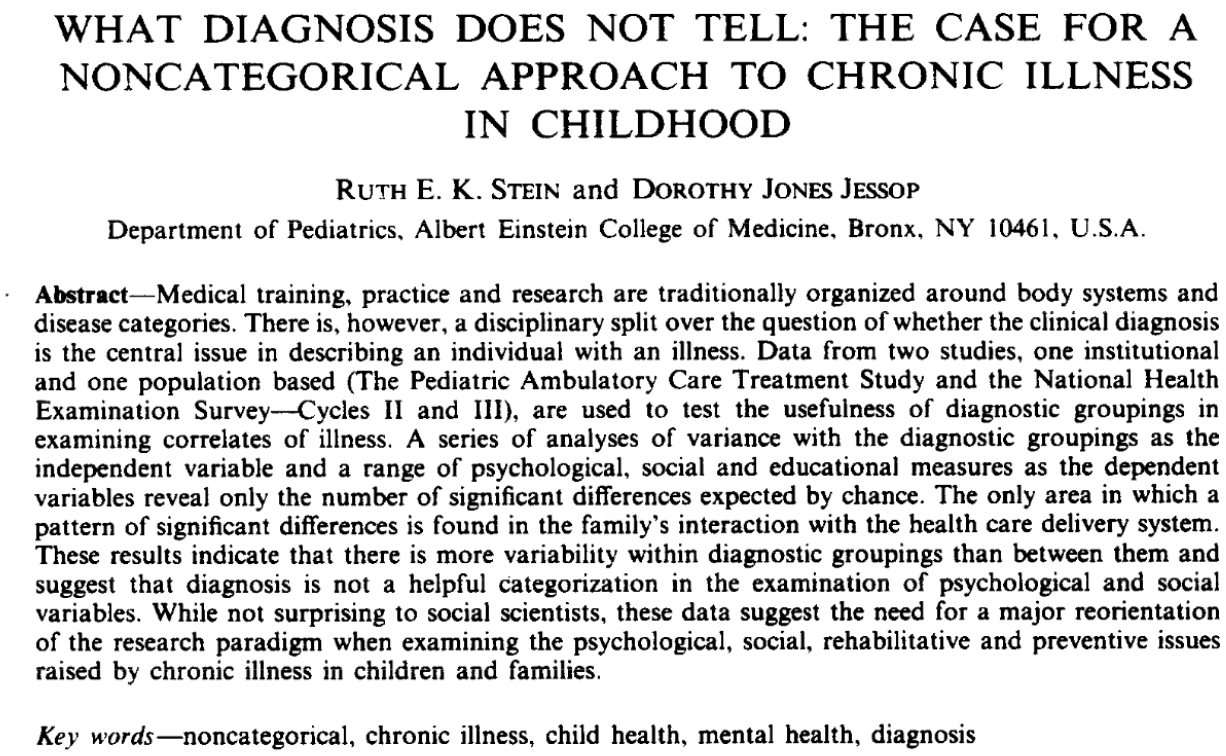
Environment

(Physical, Attitudinal, Social, Barriers and Facilitators)

Personal Factors

(Sex, Age, Gender, Behavior)

Which Means Diagnosis Doesn’t Matter



WHAT DIAGNOSIS DOES NOT TELL: THE CASE FOR A NONCATEGORICAL APPROACH TO CHRONIC ILLNESS IN CHILDHOOD

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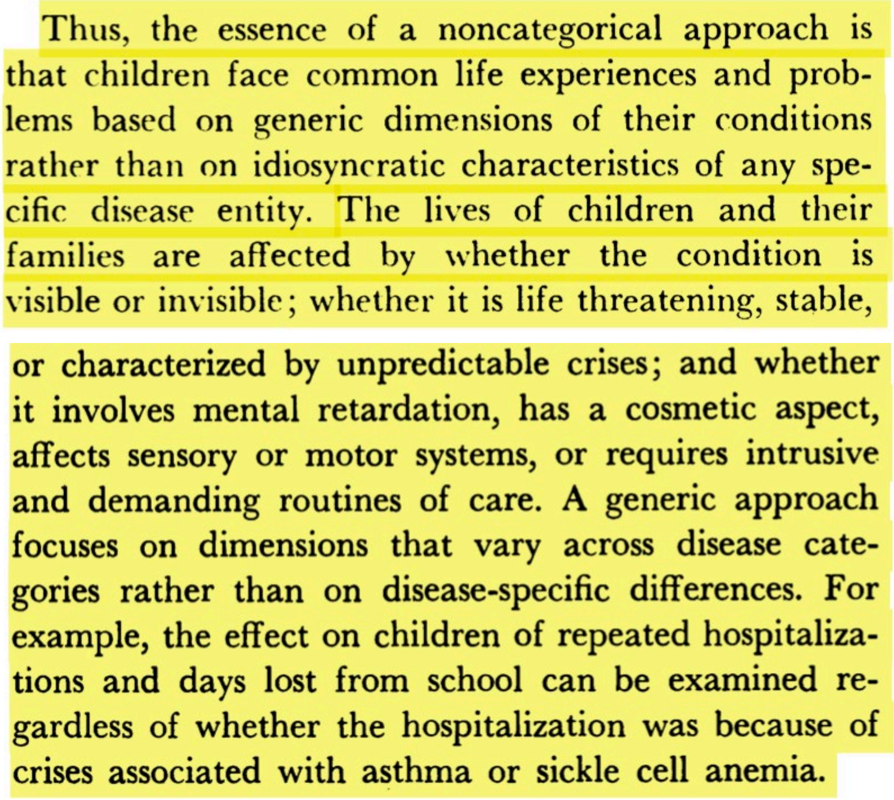
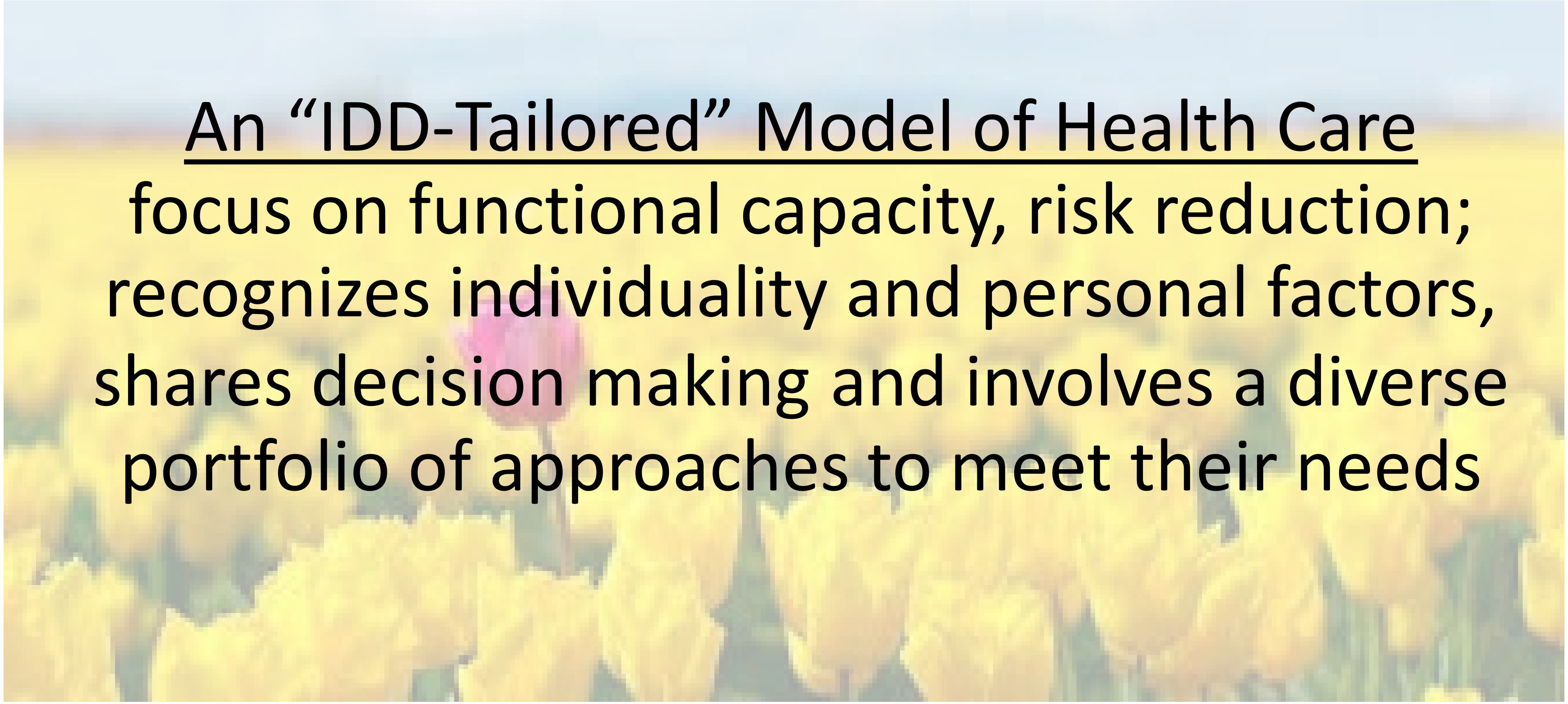
Abstract—Medical training, practice and research are traditionally organized around body systems and disease categories. There is, however, a disciplinary split over the question of whether the clinical diagnosis is the central issue in describing an individual with an illness. Data from two studies, one institutional and one population based (The Pediatric Ambulatory Care Treatment Study and the National Health Examination Survey—Cycles II and III), are used to test the usefulness of diagnostic groupings in examining correlates of illness. A series of analyses of variance with the diagnostic groupings as the independent variable and a range of psychological, social and educational measures as the dependent variables reveal only the number of significant differences expected by chance. The only area in which a pattern of significant differences is found in the family's interaction with the health care delivery system. These results indicate that there is more variability within diagnostic groupings than between them and suggest that diagnosis is not a helpful categorization in the examination of psychological and social variables. While not surprising to social scientists, these data suggest the need for a major reorientation of the research paradigm when examining the psychological, social, rehabilitative and preventive issues raised by chronic illness in children and families.

Key words—noncategorical, chronic illness, child health, mental health, diagnosis



Thus, the essence of a noncategorical approach is that children face common life experiences and problems based on generic dimensions of their conditions rather than on idiosyncratic characteristics of any specific disease entity. The lives of children and their families are affected by whether the condition is visible or invisible; whether it is life threatening, stable, or characterized by unpredictable crises; and whether it involves mental retardation, has a cosmetic aspect, affects sensory or motor systems, or requires intrusive and demanding routines of care. A generic approach focuses on dimensions that vary across disease categories rather than on disease-specific differences. For example, the effect on children of repeated hospitalizations and days lost from school can be examined regardless of whether the hospitalization was because of crises associated with asthma or sickle cell anemia.

Strategies for Medical and DD Providers



An “IDD-Tailored” Model of Health Care

focus on functional capacity, risk reduction; recognizes individuality and personal factors, shares decision making and involves a diverse portfolio of approaches to meet their needs

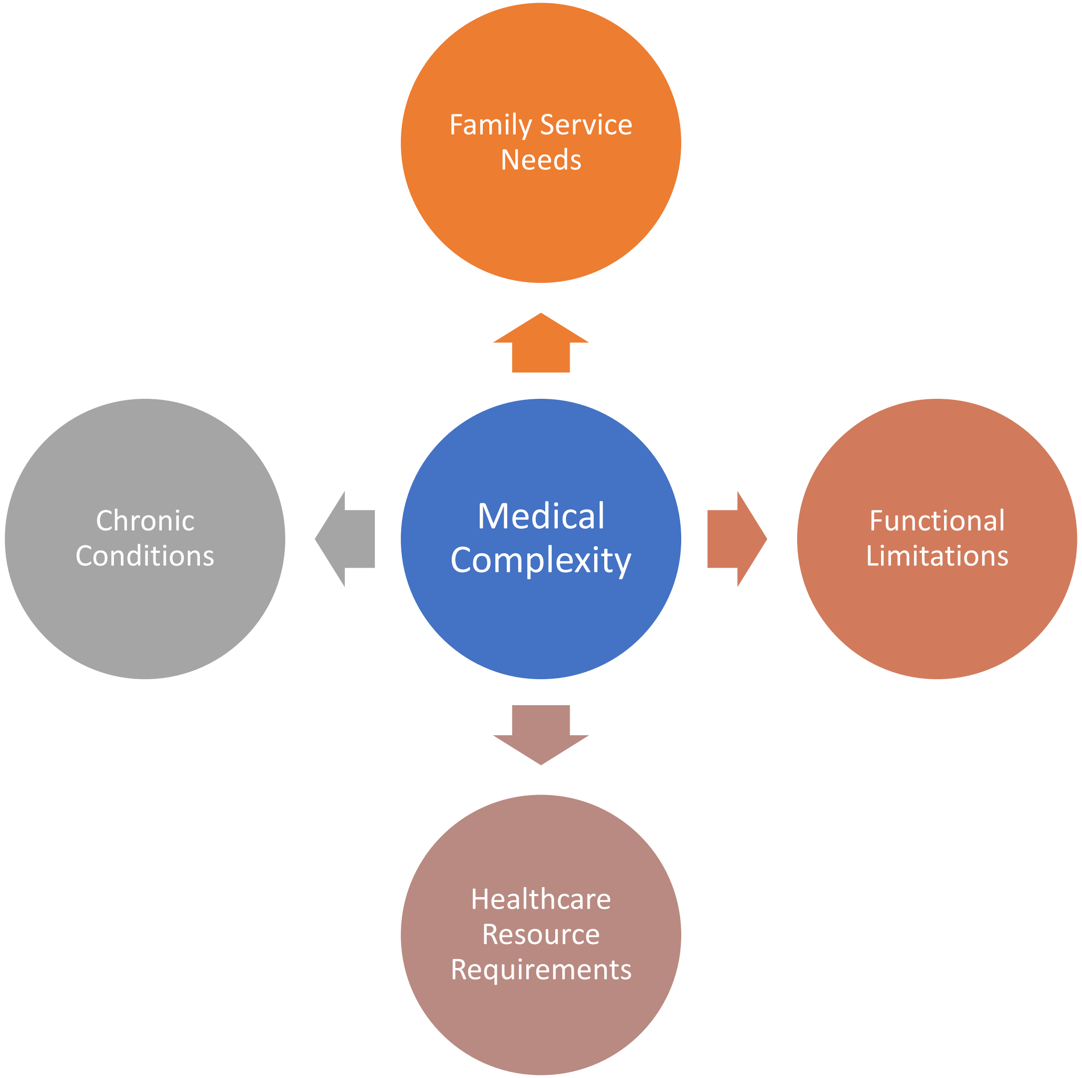
Changes at the Provider/System Level

- See each patient as a whole person, not just their disability.
- Embrace the WHO definition of health as a "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”
  - Life –course outcomes vs “Response to therapy”
- Adopt an IDD-tailored model of care
  - Baseline IDD-focused assessments of function and risk
  - Preventive/proactive interventions based on known IDD issues/challenges
  - Intensive primary care
  - Care coordination/care management
  - Surveillance for known patterns of risk/challenges
  - Orchestrate across all programs and resources available to support people with developmental disabilities in various aspects of daily
- Ensure that the physical environment in which health care is provided is accessible to people with all types of disabilities and that specialized medical equipment needed to treat people with disabilities is available.
- Encourage self-advocacy and self-determination for patients with DD

SPECIAL ARTICLES

Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives

Individuals with IDD deserve best practices for “Medically Complexity””



Family Service Needs

Chronic Conditions

Medical Complexity

Functional Limitations

Healthcare Resource Requirements

The Foundation of IDD-Tailored Care

- **Consider “whole life” needs beyond medical care and the influence of health status on participation in family and community.**
- **Work closely with your patient’s Care Manager to coordinate care, information sharing and support access to resources.**
- **Recognize challenges to communication and decision making.**
  - Adapt communication to meet the needs of people with IDD.
  - Check for understanding; expressive and receptive communication skills may differ in the same person
- **Factor in family/caregiver stresses and available resources/ capacity to actively participate in holistic care.**
- **Factor in communication and language diversity (sign language, hearing deficiencies, English as a Second Language/ESL, grade-school reading level materials) as well as ethnic and cultural considerations.**
- **Change in behavior is type of communication.**
  - In persons with IDD think first of common conditions (e.g., GERD, arthritis, pain, constipation,, wax in ears, social or environmental change) as a source of behavior change

The Basics

- **IDD-Tailored Annual Wellness/Well-Child Visit**
  - Schedule this visit in the first quarter of every year
  - Maintain a comprehensive list of chronic conditions, even if stable (supports accurate CMS acuity assessment)
  - Know patient-level risks
  - Plan risk-reduction for ambulatory care sensitive conditions (ACSC’s
  - Develop annual preventive services and risk/screening assessment
- **Follow-up Health Maintenance Encounters**
  - Preferably at least two additional visits a year
  - Additional visits based on needs, complexity, risk level.
  - Track and monitor chronic and ACSC’s.
- **Transitions-of Care Encounters (ED/Hospital Discharge)**
  - Facilitate receipt of discharge summary from Care Manager within 3 days of discharge
  - Engage Care Manager to facilitate scheduling of follow-up encounter.
  - Post hospitalization or emergency room follow-up should take place within 7 days of discharge; best practices to prevent readmissions is 3 days.
- **Dental Care**
  - Encourage patients and work with their Care Manager to ensure dental care; dental disease is among the most common health problems in adults with IDD owing to their difficulties in maintaining oral hygiene routines and accessing dental care.
  - Consider desensitization visits/ pre-visits for familiarization and comfort ahead of treatment appointment.
- **Immunization Maintenance**
  - Annual flu shots
  - Adequate pneumonia, RSV and Covid-19 protection
  - As appropriate HPV vaccine

Focus on function and risk, not just diagnosis

Conduct routine assessments beyond physical exam (falls, choking, ADLs, iADLs)

Screenings & Assessments

- Annual
  - Cancer Screenings (Colorectal, Breast, Cervical)
  - Falls Risk
  - Functional Status
  - Hearing/Vision
  - Mental Health Screening (anxiety, depression, loneliness)
  - Nutrition
  - Social Needs
- As indicated.
  - Apnea
  - Choking/Aspiration Risk
  - Cognitive/Dementia Screen
  - Osteoporosis Screening (age >66 + for any patient with limited ambulation)
  - Pain
  - Sensory Screening
  - Skin Risk
  - Substance Use/Abuse

Condition Management

Condition Management

- Hypertension
- Diabetes
- Cancer Screening
- Cardiovascular disease
- COPD/Asthma
- Epilepsy
- Psychotropic Medications

Preventive Services

- Dehydration
- Constipation
- Foot care
- Cerumen

Medication Management

- Manage polypharmacy; long-term use of certain medications are prevalent among people with IDD, known to cause largely preventable adverse drug events.
- Medication Review
  - Conduct with each HCM encounter.
- Comprehensive Medication Therapy Reconciliation (CMTR)
  - Review and return acknowledgement of CMTR from PHP Clinical Pharmacist

Advance Care Planning

- With their growing life expectancy, the numbers of older adults with IDD continues to expand, and community agencies and families now face the challenge of providing supports as these adults experience age-related changes.
- Adults with IDD are more likely to experience earlier age-related health changes, limited access to quality health care, and fewer financial resources.
- In addition, they are more likely to be living with parents into adulthood and have more limited social supports and friendships outside the family.
- This all speaks to the need for Advance Care Planning (ACP) in early adulthood for individuals with IDD.
- Getting started early sets the foundation for the individuals future, especially because the ACP is not a singular act, but an ongoing process that best practices say should be reviewed at least annually and/or with any significant change in status.

Lifestyle Considerations 1

Eating, Nutrition

- Monitor hydration status; even 95% of needed oral intake can result in a chronic “hypohyration” status with clinical consequences including infection risk (e.g..UTI), reduced wound healing,
- Monitor weight trends regularly and assess risk status using body mass index, waist circumference or waist-hip ratio measurement standards.
- Counsel patients and their caregivers annually regarding targets for an optimal diet and level of physical activity using general population guidelines by age. Advise patients regarding possible changes to their daily routines to meet these targets.
- Address modifiable risk factors for obesity such as medications and environmental or social barriers to optimal diet.
- For anyone who is not meeting nutrition targets, refer to interprofessional health promotion resources (eg, dietitians, support workers).

Physical Activity

- Physical inactivity is prevalent in patients with IDD.
- Address modifiable risk factors such as environmental or social barriers to optimal physical activity.
- Confirm participation or refer to community programs adapted for people with IDD
- Consider bone health risks associated with limited ambulation.

Smoking, Alcohol, Drugs

- Screen for tobacco use; provide or refer for appropriate medical or behavioral supports
- Screen for substance use; high risk of abuse is associated with mild IDD, persons who live independently, males, those with psychiatric disorders, and those with legal issues. Most common substances include alcohol, cannabis, prescription medications

Lifestyle Considerations 2

Safety

- Consider risks for the individual and adapt counseling accordingly (eg, adult with DD who has a propensity for pica, risk of elopement, or who uses a bicycle). Include caregiver stress.
- Monitor for signs of abuse, which may manifest themselves indirectly

Sleep

- Sleep problems (eg, difficulties settling, night walking, or early awakening) are common among adults with IDD and often result in increased caregiver stress
- If a problem has been identified, consider physical health issues (eg, GERD, pain, OSA), sleep environment, medications (eg, psychotropics, anti-epileptics), life experiences/stressors, psychiatric conditions.
- Assess for OSA in high risk patients with obesity, craniofacial abnormalities, certain genetic disorders (eg, Down syndrome) and neuromuscular disorders (eg, cerebral palsy).

Pain

- Assess for pain and its intensity with caregiver input and adapted tools.
- Pain and distress can manifest atypically in patients with limited communication and can be difficult to recognize.
- Common sources of pain include injury, dental caries, GERD, arthritis, constipation and urinary tract infections.

Sexual Health

- Discussions about sexuality may vary depending on the patient’s level of IDD. In patients with mild IDD, provide consistent messages repeatedly. In patients with moderate or more severe IDD, the discussion may be more with the caregiver, decision-making supporter or substitute decision maker.
- Ask male and female patients, their family, or other caregivers about the patient’s relationships, intimacy, and sexuality (eg, sexual behavior, gender identity, sexual orientation, genetic risks).
- Ask about self-stimulation and masturbation, in part to indicate to patients and caregivers these can be important topics.
- Explore family plans to address unintended pregnancy. In females and males at risk, ask if the patient and/or substitute decision maker wish to discuss the pros and cons of birth control.
- Perform breast and testicular examination in adults with IDD.
- For patients who have been sexually active, inspect the perineum for venereal warts and obtain cultures for STIs from the pharynx, rectum, and vagina as per guidelines for the general population (eg, every 3 months for patients having unprotected sex).
- To minimize or avoid the need for vaginal speculum examinations of women for whom this would be difficult, all at-risk patients should be given the HPV-9 vaccine.
- These examinations should follow a trauma- informed approach. Consider providing easy-to-read patient information leaflets, such as for cervical screening, or prostate screening,

Review of Systems

- **Eyes***:* *Vision*
- **Ears***:* *Hearing, Cerumen*
- **Mouth/Teeth***:* *Dental health (caries, gingiva), Swallowing, Aspiration Risk; GERD*
- **Neck:** *Thyroid*
- **Skin:** *Dermatitis, Eczema, Ulceration*
- **Abdomen:** *GERD*
- **Cardiovascular:** *CV risk, genetic associations, CHF*
- **Respiratory:** *Asthma, COPD, OSA*
- **Gastrointestinal:** *GERD, constipation, peptic ulcer disease, celiac disease, pica.*
- **Genitourinary:** *Urinary retention; peri-menstrual/menstrual issues*
- **Musculoskeletal:** *Foot care; Osteoarthritis, Scoliosis, Contractures, Spasticity, and Ligamentous laxity; Osteoporosis risk*
- **Neurological:** *Seizure management; change in gait, balance issues, parkinsonism, generalized weakness, somnolence; emerging/localizing neurological findings; dementia*
- **Endocrine:** *Thyroid, Diabetes*
- **Mental health:** *Differentiate behaviors that challenge (e.g., aggression, self-injury or irritability) from psychiatric disorders. Consider, especially before mental health diagnosis or drug treatment: physical causes (e.g., rule out infection, constipation, dental pain); environmental changes (e.g., changed residence, reduced supports, usual worker on holidays); and lived experiences (e.g., stress, trauma, grief).*

Bottom Line: The “standards of care” may not be standard for people with IDD

FROM THIS WEEKS NEW ENGLAND JOURNAL OF MEDICINE

”A staff member at my sister’s group home noticed the swelling in Deborah’s breast. She was giving her a bath. She phoned Deborah’s doctor, who came to the house.”

“The breast exam was not easy. Deborah, then in her early 40s, was intellectually disabled, non- verbal, and autistic.”

“Then came the day we sat in a basement office with Deborah’s oncologist and breast surgeon to review the options. Everyone, the doctors included, seemed flummoxed. **It was becoming distressingly clear that the standard of care — if it were to be responsive to Deborah’s needs — was simply out of reach.”**

“**I don’t know whether Deborah would still be alive had there been more information and guidance available. I am pretty sure that the family meeting would have been different if (someone) with expertise in working with intellectually disabled adults, had joined us in that basement office.”**

Standard of Care

Anna Reisman, M.D.

A staff member at my sister’s group home noticed the swelling in Deborah’s breast. She was giving her a bath. She phoned Deborah’s doctor, who came to the house.

The breast exam was not easy. Deborah, then in her early 40s, was intellectually disabled, nonverbal, and autistic. She shied away from touch. But this particular doctor had experience caring for intellectually disabled adults, so she allowed Deborah to lead. If Deborah wanted to walk, they walked. If she wanted to stop, they stopped. In this way, Deborah let her examine her breast a little here, a little there, a few seconds at a time.

It was cancer. When I spoke to my family, I focused on the positives. Deborah was lucky in many ways. She was relatively healthy. She had health insurance. She had access to excellent medical care, with a top cancer center nearby. She had doctors in the family — my husband and me — who would find the best specialists and help weigh the options. She had people who loved her and would gladly help her through this ordeal, including wonderful caregivers in her group home.

Then came the day we sat in a basement office with Deborah’s oncologist and breast surgeon to review the options. Everyone, the doctors included, seemed flummoxed. It was becoming distressingly clear that the standard of care — if it were to be responsive to Deborah’s needs — was simply out of reach.

The surgery Deborah needed was a radical mastectomy with lymph node dissection, which would require her to tolerate the presence of long plastic surgical drains, with the ends stitched under her chest-wall skin, for 2 weeks. Deborah liked to fiddle with things, and she might tug at the drains until they loosened or came out. If she felt pain or discomfort? It was hard to fathom how her caregivers would attend to symptoms that she didn’t have the capacity to describe.

Radiation sounded inconvenient but feasible: several weeks’ worth of daily drives to a radiation facility. Getting Deborah to these appointments would be no problem. But after she arrived? How could she understand that she had to lie completely still while the radiation was administered? She’d undergone minor medical procedures under light sedation. Here, she’d need daily general anesthesia to ensure complete immobilization. Each day: anesthetized, intubated, irradiated, extubated, woken up, and driven home. Even a compressed radiation schedule would have meant spending weeks sedated or groggy.

Chemotherapy seemed particularly cruel. Tolerating an IV would be difficult: someone would have to hold her arm while she resisted the painful needle and then MacGyver a contraption of gauze and wraps to keep the IV and its potentially toxic contents safe from a searching hand. A port? She would surely tinker with it and try to wiggle it free. And how could she understand that whatever misery ensued — nausea, vomiting, fatigue, mouth sores, numb or painful hands and feet — was something she had to endure in order to get well? How could she grasp that it was part of the treatment, covered by the informed consent that she was incapable of understanding?

Even if we could come up with a plan that incorporated all these treatments, a cure was unlikely. Yet we couldn’t imagine not trying. My other sister advocated for the standard of care, whatever it took. Eventually, we arrived at a compromise. We opted for what seemed the most humane option: a less extensive version of the surgery, with no chemotherapy or radiation. The surgeon would remove as much as she could, but not enough to necessitate surgical drains.

It seemed like the right choice. Deborah recovered and was soon back to her delightful self. And then, 4 or 5 months later, the cancer came back. Maybe it would have anyway. Or maybe it returned because we had cut corners.

Neither breast cancer nor intellectual disability is rare. According to the American Cancer Society’s 2023 Cancer Facts & Figures, an estimated 297,790 women in the United States will receive a new diagnosis of invasive breast cancer this year. With intellectual disabilities affecting roughly 1% of the U.S. population, that means that each year there must be at least a few thou-

Questions/ Comments