Legal, Ethical, and Social Issues in Intellectual and Developmental Disabilities: Equal Access, Full Participation, and Inclusion

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Thought Questions

What do you value about or in your life?

Have you ever felt excluded?

Have you ever felt that you were denied your rights?

Have you ever felt discriminated against?
“I want to go through the same door as my friends”
– Micah Fialka-Feldman

“I am different, not less”
-- Temple Grandin

“A community that excludes even one of its members is no community at all.”
- Dan Wilkins
Today’s Focus

- Community Living
- Education
- Employment
- Legal Standing
- Medical Decisions
- Parenting
- Science

Benefits of inclusive communities
Disability as a natural part of the human condition
Inherent value and competence of all people
Disability Rights
Equal access
Diversity and intersectionality
Recognize contributions of people with disabilities
Poll Time!

What is your (primary) relationship to developmental disability?

1. Self-advocate
2. Family member
3. Service provider
4. Healthcare provider
5. Researcher
Acknowledgements

Language

• People first
• Identify first
Rights
Moral or legal entitlements or freedoms

Law

Beliefs

Ethics
Historical Context: Devaluing, Discrimination and Isolation

• Segregation
  – Denied opportunities to learn, choice
  – Abuse, neglect
Historical Context: Devaluing, Discrimination and Isolation

- **Guardianship**
  - Legal incompetence
  - Legal death
Historical Context: Devaluing, Discrimination and Isolation

• Eugenics
  – Compulsory sterilization

“It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. . . . Three generations of imbeciles are enough.”

- Buck v. Bell, 1927, paragraph 4
Disability Rights Emerges

Civil rights movement

“Separate educational facilities are inherently unequal.”
Brown, 397 U.S. at 495. (1954)

Independent living movement  Self-advocacy movement
Disability Rights Emerges

- Community living
- Protection from discrimination
- Equal access
- Full participation
Poll time!

What year were you born?

1.  1920-1929
2.  1930-1939
3.  1940-1949
4.  1950-1959
5.  1960-1969
6.  1970-1979
7.  1980-1989
8.  1990-1999
10. 2010-2019
Major Disability Rights Legal Victories

Rehabilitation Act - 1973
Brain Injury Association of America

Developmental Disabilities Act - 1975

Individuals with Disabilities Education Act - 1975

Americans with Disabilities Act - 1990

Olmstead - 1999

Conventions on the Rights of Persons with Disabilities - 2006

Tom Olin

ADA Network

Olmsteadrights.org
Community Living

- **Integration mandate**: deinstitutionalization, community-based services and supports

Figure 2
Medicaid long-term services and supports spending, by institutional vs. community setting.

Annual Medicaid LTSS Spending, in billions:

<table>
<thead>
<tr>
<th>Year</th>
<th>Home and Community-Based LTSS</th>
<th>Institutional LTSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>$57 (18%)</td>
<td>$76 (82%)</td>
</tr>
<tr>
<td>2000</td>
<td>$76 (27%)</td>
<td>$73 (73%)</td>
</tr>
<tr>
<td>2005</td>
<td>$107 (37%)</td>
<td>$63 (63%)</td>
</tr>
<tr>
<td>2010</td>
<td>$139 (48%)</td>
<td>$41 (52%)</td>
</tr>
<tr>
<td>2012</td>
<td>$142 (49%)</td>
<td>$51 (51%)</td>
</tr>
<tr>
<td>2013</td>
<td>$146 (51%)</td>
<td>$49 (49%)</td>
</tr>
<tr>
<td>2014</td>
<td>$152 (53%)</td>
<td>$53 (47%)</td>
</tr>
<tr>
<td>2015</td>
<td>$159 (54%)</td>
<td>$54 (46%)</td>
</tr>
<tr>
<td>2016</td>
<td>$167 (57%)</td>
<td>$57 (43%)</td>
</tr>
</tbody>
</table>

Community Living

- 13 states and DC have no state institutions
Community Living

Ohio
Living Arrangements of LTSS Recipients by Fiscal Year over Time

The number of Long-Term Supports and Services Recipients is for the IDD Agency in the state. Group settings (1-6, 7-15, and 16+) include ICF/IID, group homes, and other congregate settings.
Thought Question

What is community living?
What is not community living?
Education

• Free, appropriate education in the least restrictive environment

Education

Intellectually Disabled Student Wins Dorm Suit

December 29, 2009 · 6:00 AM ET
Heard on Morning Edition

JOSEPH SHAPIRO
Employment and Economic Independence

Figure 1. Number Served by IDD Agencies

- 638,568
- Non-work
- Facility-based work
- Integrated employment

StateData: The National Report on Employment Services and Outcomes • 2018
Employment and Economic Independence

Figure 6. Trends in Weekly Wages (in 2014 Dollars)*

General population
Other disabilities
Intellectual disabilities


StateData: The National Report on Employment Services and Outcomes • 2018
Employment and Economic Independence

STABLE ACCOUNT

✔️ Nationwide enrollment for individuals with disabilities
✔️ Tax-free savings plan for disability-related expenses
✔️ Save and invest without losing needs-based benefits

https://www.stableaccount.com/

Rhode Island Settles Case on Jobs for the Disabled

Steven Porcelli, second from left, worked in a sheltered workshop for about $3 an hour. In an agreement announced Tuesday, Rhode Island will help those with developmental disabilities find better jobs. Gretchen Ertl for The New York Times

WIOA
WORKFORCE INNOVATION OPPORTUNITY ACT

Charlotteworks

FALK | Syracuse University
Poll Time!

Think about a recent big or important decision you made ...

How did you make the decision?

1. On my own
2. I talked to people I trust
Decision-Making

I was told I had rights at the group homes, but that wasn’t true. JFS took them away. It was like I didn’t matter... like I didn’t exist. JFS took away my rights, my choices, my independence... A guardian is supposed to help me reach my goals.

Instead, I was kept away from my community, my church, and my friends. I kept telling everyone I was unhappy but no one listened to me.

I lost a year of my life being forced to stay in group homes and forced to work at a job I did not want.
Ethical Issues

Nothing about us without us

Home RedZazz T-Shirt Design - incurablehippie
Medical Decision-Making

Alexandra Huddleston for The New York Times
Medical Decisions
Parenting

“Sara Gordon” and “Dana” - Gordon family

The City College Libraries at the City College of New York
Inclusion in Science

Figure 1 Barriers to participation in precision medicine research

- Environmental accessibility
  - Transportation to healthcare facilities is difficult (52.94%)
  - The space and equipment in clinics and healthcare facilities are not accessible for me (56.18%)
- Communication
  - Information about medical research is not accessible to me (43.43%)
  - Communication with health professionals is difficult for me (44.28%)
- Economic
  - Transportation to healthcare facilities is too expensive (40.57%)
  - I can’t take time off from work to participate (13.29%)
- Attitudes of professionals
  - My health insurance may not cover the costs (27.43%)
  - Researchers and healthcare providers have stereotypes about people with disabilities (25.04%)
- Institutional
  - Precision medicine research might be used to harm people like me (39.88%)
- Concerns about PMR
  - Precision medicine research will not help people like me (41.58%)
  - Research may be used for studies I don’t approve of (40.34%)
- Personal
  - I have medical problems that would make it hard for me to participate (29.68%)
  - My family or legal guardian would not want me to participate (18.08%)

Inclusion in Science

Figure 2 - Facilitators of participation

- Having accessible locations for visits with researchers: 56.80%
- Having non-hospital settings for research visits: 44.20%
- Having study results communicated in understandable ways: 61.75%
- Having information about the study in easy-to-use formats: 11.28%
- Having free transportation to a medical center for the study: 61.21%
- Scheduling research visits on weekends or after work hours: 28.52%
- Knowing I will not have to pay for anything to be a participant: 58.96%
- Knowing health and life insurance wouldn’t cost more or be harder to get: 32.38%
- Knowing the study is respectful of people with disabilities: 57.96%
- Knowing researchers are aware of the needs of people like me: 65.07%
- Knowing that results of the research will help people with disabilities: 58.27%
- Providing access to new medications and treatments from the study: 39.57%

Inclusion in Science

• Protocols should avoid the risk of coercion and exploitation while maximizing autonomy and inclusion
• Researchers must make the consent process as accessible as possible
• If possible, offer multiple modes of participation to maximize inclusion of autistic participants with differing strengths and needs
• Do not assume that survey instruments validated with general populations, caregivers, or children are valid for use with autistic adults
• Create accessible qualitative interview guides
• Use proxy reporters only if direct participation is not possible, even with accommodations and supports

Nicolaidis, Raymaker, Kapp, Baggs, Ashkenazy, McDonald, Weiner, Maslak Hunter, & Joyce (2019). Practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. Autism, online first.
Inclusion in Science

Figure 9. Topic areas are defined by each question in the IACC Strategic Plan. The seven questions of the Strategic Plan are represented in the clockwise direction, beginning with Screening and Diagnosis (Question 1) and ending with Infrastructure and Surveillance (Question 7).
Inclusion in Science

Source: AASPIRE website
Inclusion in Science

If you had the chance, how would you want to participate?

- a. Help design the study: 50.31%
- b. Help choose research questions: 55.33%
- c. Help decide what kinds of research are conducted: 48.22%
- d. Help recruit other participants: 41.50%
- e. Help collect study data: 42.81%
- f. Help analyze the data: 32.84%
- g. Help decide what to do with study results: 24.50%

Study design 86%
Data collection 67%
Data analysis 33%
Policy 25%

Inclusion in Science

• Be transparent about partnership goals and choose an appropriate approach to match those goals.
• Clearly define community partner roles, consider who needs to be included on the team, and partner with people who are likely to help the project succeed.
• Create processes for effective communication and power-sharing.
• Regularly focus on building and maintaining trust.
• Collaboratively disseminate findings.
• Actively encourage community capacitation.
• Fairly compensate community partners for their work.

Ending Violations; Protecting Rights

• “Be the change that you wish to see in the world.” - Mahatma Gandhi

• What can you do to promote disability rights?
Acknowledgments – the Noun Project

• behavior modification by Bold Yellow from the Noun Project
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• risk by monkik from the Noun Project
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