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Supporting inclusion of people
with cognitive disability



Community Participation:

Measurable Outcome or Buzzword?

Stacy Clifford Simpican

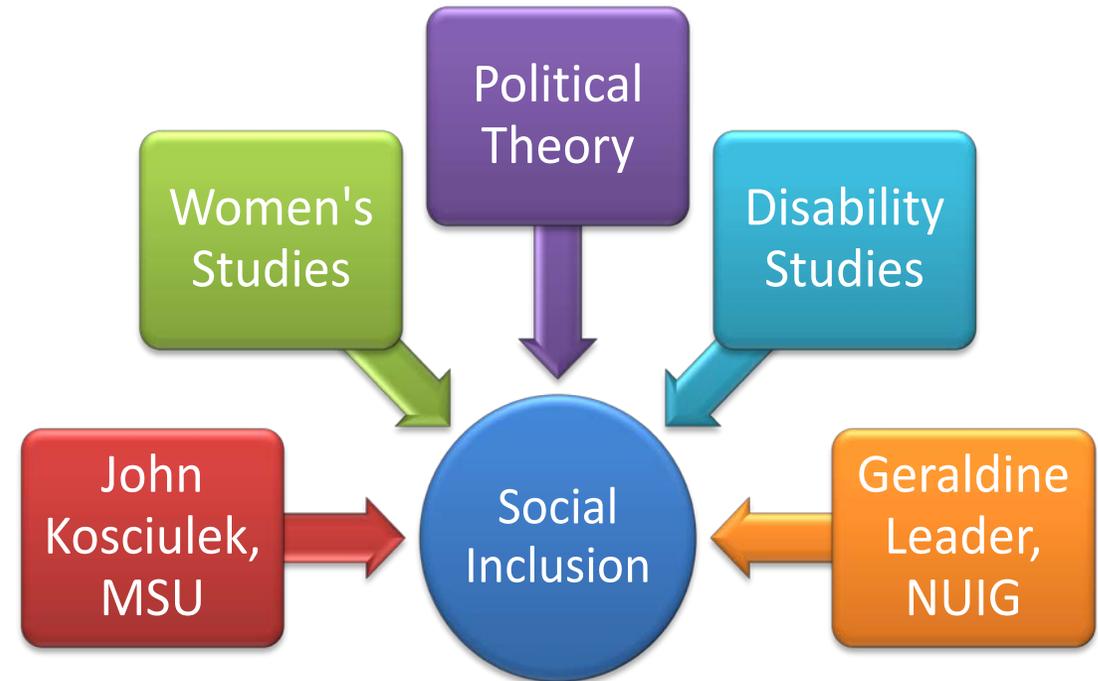
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Conceptual problems with community participation and social inclusion: what do these terms mean?

- Social inclusion lacks conceptual clarity
 - It is often used interchangeably with community participation
- Conceptual confusion may hamper the ability of multiple stakeholders to come together
 - Researchers, policymakers, professionals, staff, people with disabilities, & families
- Social inclusion and community participation are key components of national and international policies
- And, yet, research suggests that social inclusion and community participation remain elusive



What is Social Inclusion?

Co-authors Geraldine Leader,
John Kosciulek, and Michael
Leahy



Review article

Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation[☆]

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ABSTRACT

Social inclusion is an important goal for people with intellectual and disabilities, families, service providers, and policymakers; however, the inclusion remains unclear, largely due to multiple and conflicting definitions and policy. We define social inclusion as the interaction between two models: interpersonal relationships and community participation. We then propose a model of social inclusion that includes individual, interpersonal, community, and socio-political factors. We identify four areas of research that an ecological model of social inclusion can move forward: (1) organizational factors of social inclusion; (2) social inclusion of people with intellectual and developmental disabilities living with their families, (3) social inclusion of people with a spectrum of disability, and (4) the potential role of self-advocacy in promoting social inclusion.

Social Inclusion: Definitions, Terminology and Aims

Column 1: What is it?

Scope

- Access to or being accepted
- Staff, family, disabled people?

Settings

- Private or public

Depth

- Quantitative or qualitative

Column 2: What is not social inclusion?

Column 3: What is it for?

Individual benefits

- Happiness, skills, confidence, wellbeing

Group benefits

- Employment, abuse & poverty

Societal benefits

- Combatting negative attitudes

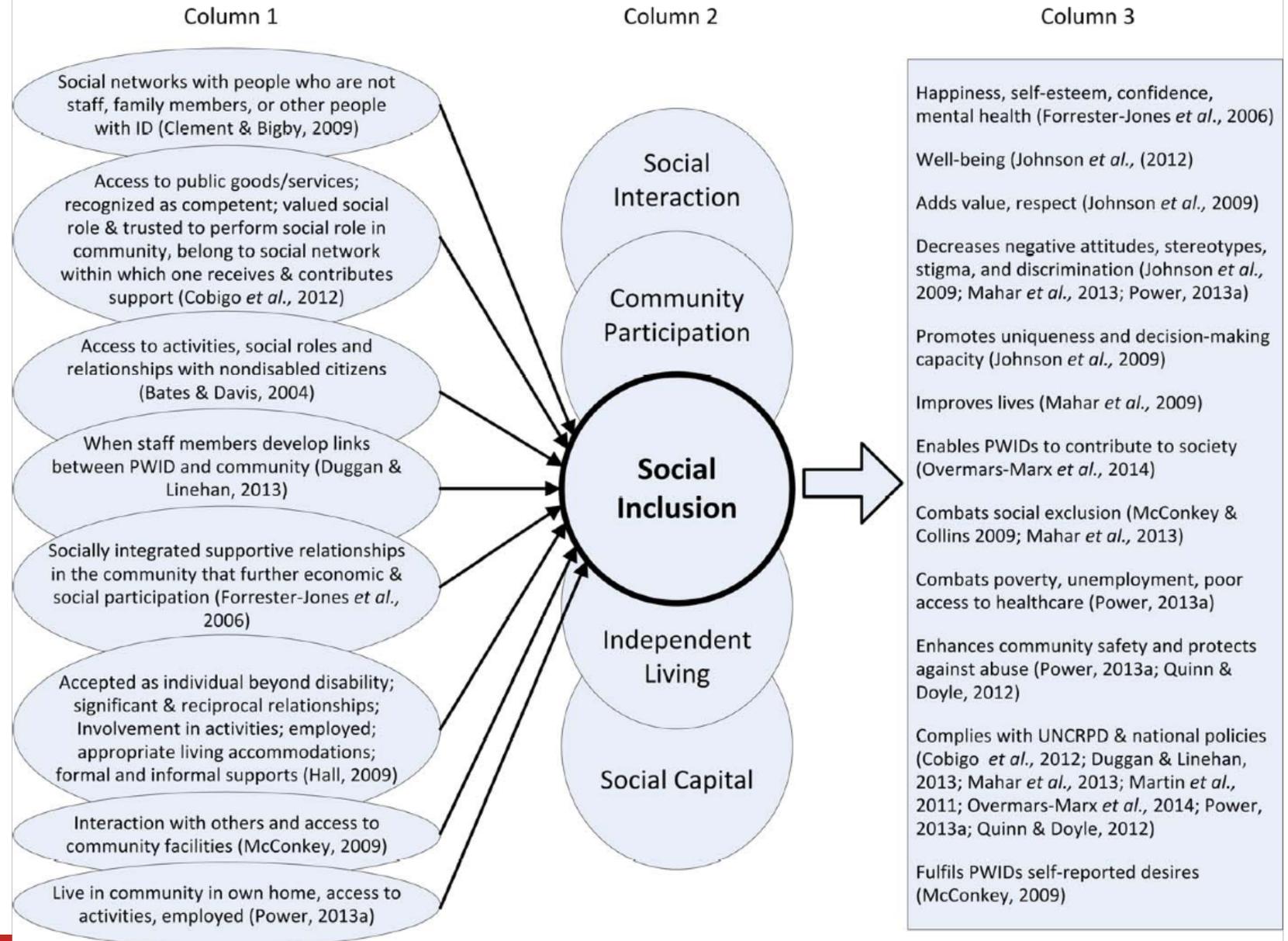


Figure 1

Two Interconnected Domains

Interpersonal relationships

Category

Structure

Function

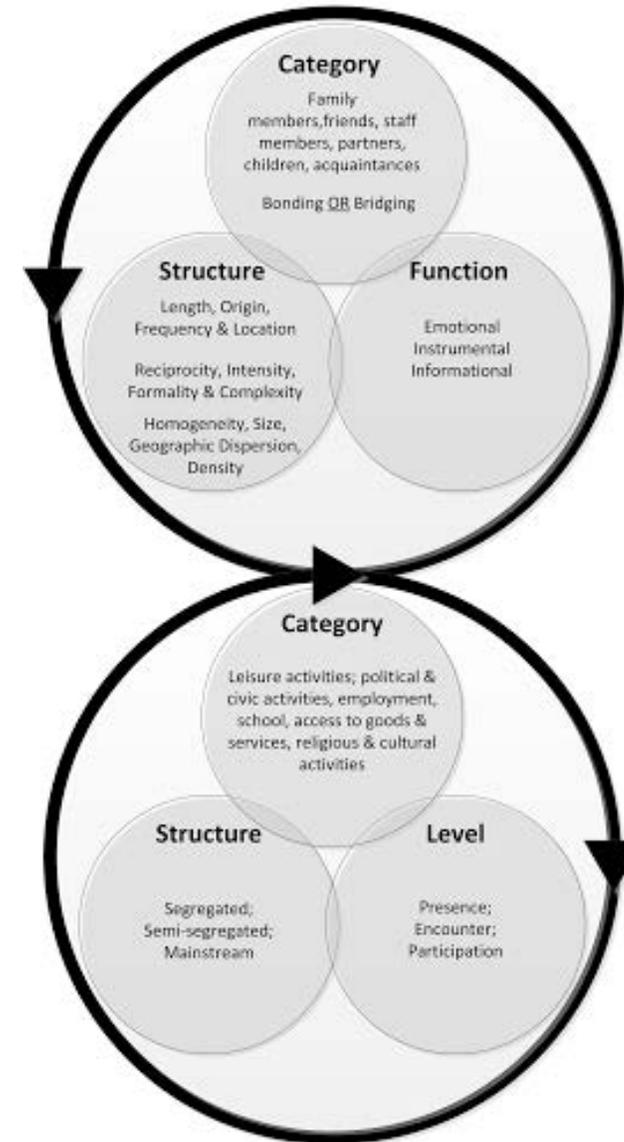
Community Participation

Category

Structure

Level

Interpersonal Relationships



Community Participation

Figure 2: A Model of Social Inclusion

INTERPERSONAL RELATIONSHIPS

1. Category

- Family members, intimate partners, friends, acquaintances, staff
 - Bonding or Bridging

2. Structure

- Length of relationship, origin, frequency & location of contact
- Network as a whole: size, homogeneity, geographic dispersion, and density

3. Function

- Emotional, instrumental, and informational

COMMUNITY PARTICIPATION

1. Category

- Leisure activities (hobbies, sport, art), political and civic activities, employment, consumption, religious and cultural groups

2. Structure

- Segregated
- Semi-segregated
- Mainstream

3. Level of involvement

- Presence
- Encounter
- Participation

Ecological questions

1. How do state policies affect organizations?
2. What are the attitudes of community members toward disability support organizations?
3. In what kinds of communities do people live?

And more...

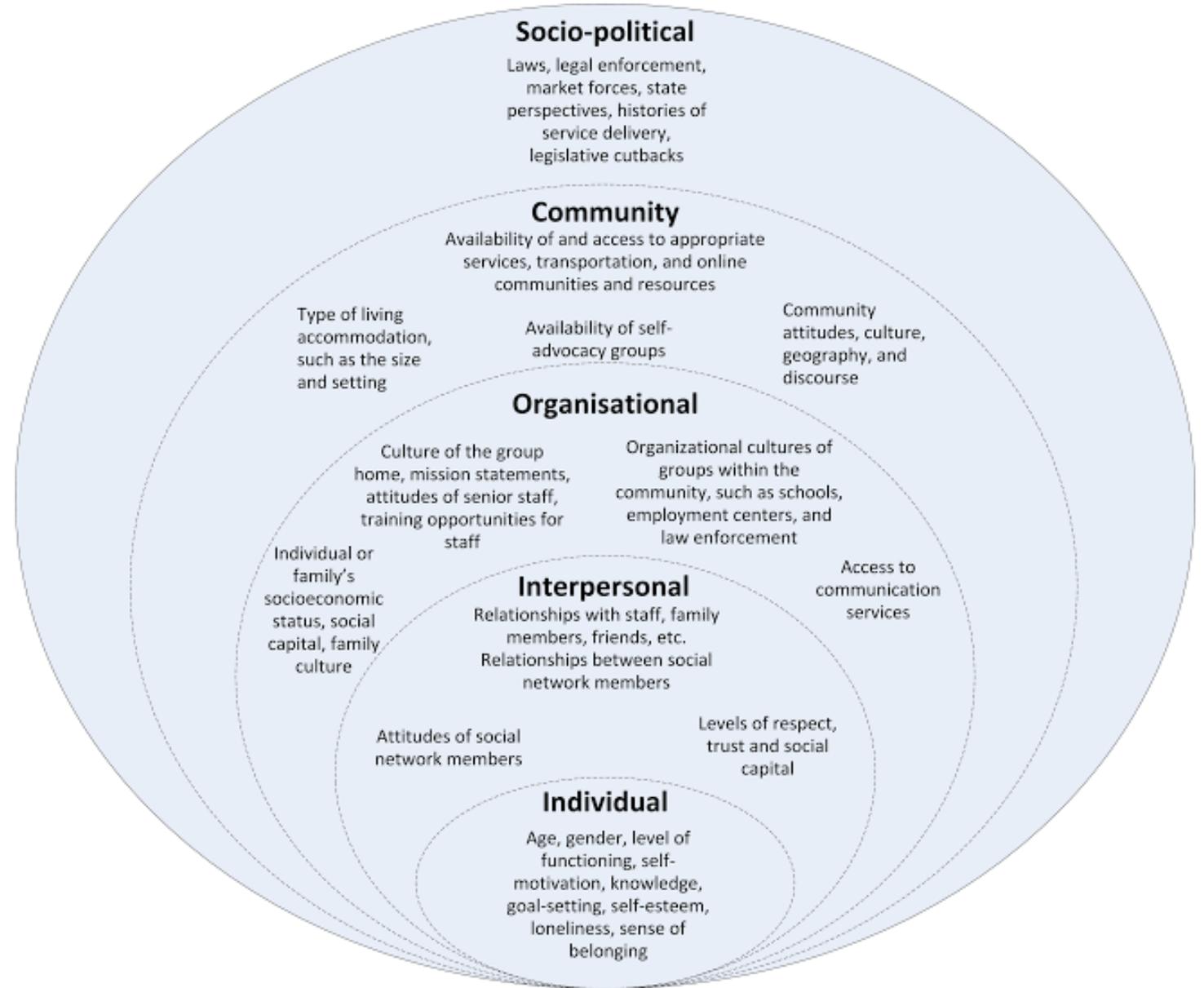


Figure 3: Ecological Pathways to and from Social Inclusion

What do we count?

Why do we *value* social inclusion?

Does *belonging* better capture our values?

Co-author Geraldine Leader

e University] at 13:05 25 June 2015

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Counting inclusion with Chantal Mouffe: a radical democratic approach to intellectual disability research

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As mandates for social inclusion of people with intellectual disabilities remain unfulfilled, many scholars question whether the concept of inclusion is to blame. Critics worry that quantitative measurements of inclusion miss what should count: a meaningful life gained from a sense of belonging. We argue that both concepts – inclusion and belonging – embody a communitarian ethos in which citizens mirror the values of their community. In contrast, Chantal Mouffe’s radical democratic approach to inclusion emphasizes the importance of difference and the inevitability of exclusion. Mouffe thus offers a way to broaden our approach to social inclusion in the twenty-first century.

Keywords: belonging; social inclusion; intellectual disability; community; radical democracy; identity

What gets counted?

‘Mainstream’ settings

People with mild to moderate intellectual disabilities

Communities that afford people a sense of belonging

Places that align with communitarian democracy

What gets discounted?

Segregated settings

People with more complex and challenging disabilities

Experiences that are more fleeting & transitory

Places that align with radical democracy

Radical Democracy

1. Power

- Democracy is not the absence of conflict, but open contestation
- Patterns of domination can be contested anywhere

2. Difference

- Idealizations of harmony threaten to silence difference

3. Passion

- Too much emphasis on consensus leads to apathy and disaffection with political participation
- Inclusion should evoke passion: anger, disappointment, rage, joy, excitement



Is our approach to social inclusion and community participation too broad?

Or is it too narrow?

Community Participation: Measurable Outcome or Buzzword?

Kathy Davis argues that a
“successful” social theory inspires
confusion

Successful theories have four
features:

1. Foundational concern
2. Novel twist
3. Generalists & Specialists
4. Ambiguity & Incompleteness

Intersectionality as buzzword

*A sociology of science perspective on what makes a
feminist theory successful*



Feminist Theory
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Kathy Davis *Utrecht University*

Abstract Since its inception, the concept of ‘intersectionality’ – the interaction of multiple identities and experiences of exclusion and subordination – has been heralded as one of the most important contributions to feminist scholarship. Despite its popularity, there has been considerable confusion concerning what the concept actually means and how it can or should be applied in feminist inquiry. In this article, I look at the phenomenon of intersectionality’s spectacular success within contemporary feminist scholarship, as well as the uncertainties and confusion which it has generated. Drawing upon insights from the sociology of science, I shall show how and why intersectionality could become a feminist success story. I shall argue that, paradoxically, it is precisely the concept’s alleged weaknesses – its ambiguity and open-endedness – that were the secrets to its success and, more generally, make it a good feminist theory.

Foundational concern

A successful theory “needs to be recognizable as ‘imperative’, ‘crucial’, or ‘key’ to understanding something that a particular audience holds near and dear.” (70)

Inclusion may be **THE** most important value in our field

Nothing
about us
without
us.

Novel twists

“Successful theories capture the attention of an audience by disputing or unsettling something that it had previously believed. They make unexpected connections between unlikely events in ways that the audience could not have imagined before.”
(72)

Today we will hear novel twists:

- Liquid modernity
- Convivial encounters
- Dogs as catalysts
- New interventions

Generalists and Specialists – bridging the divide

“The third characteristic of successful social theories is that they must appeal to a broad academic audience, bridging the gap between theory generalists and specialists.” (74)

Concepts in disability need to bridge between research, practice, and policy—like today’s roundtable.

Ambiguity & Incompleteness

“Pointing out the incongruities in a theory is the first step toward looking for ways to improve upon the original – an activity which is the bread and butter of theorizing. If ambiguity stimulates synthesis, then incompleteness can motivate an academic audience to elaborate or ‘test’ the theory by applying it to new areas of social life that were not addressed in the original theory (p. 297).” (76)

Today is evidence – our discussion across stakeholders will reveal the ambiguities in community participation, and how this incompleteness sparks research.

Are these four features good for theory *and* practice?

“Obviously, successful theories are not necessarily ‘good’ theories – and, indeed,..., the most successful theories are often not the best ones in the sense of being coherent or capable of providing encompassing or irrefutable explanations of social life.” (78)

Davis’s analysis of a “successful theory” pertained to academics *only*

- She measured success by the ability of academics to produce new research

Do her ideas apply to the academic field and practices around intellectual disability

- Success, here, is to improve the lives of people with intellectual disability

For many people, novelty and ambiguity can be frustrating

- Can we bridge what is good for research and what is good for practice and people with intellectual disabilities?

Thank you

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