

# It Takes Two to Tango

**Jennifer Clegg**

**Honorary Associate Professor University of Nottingham**

**Retired Consultant Clinical Psychologist**

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# On taking a relational perspective in an individualist culture

- Moral order of ID judgemental & excessively certain (Gleeson, 2010; Clegg et al 2010) interventions remarkably unchanging (eg bvt Clegg & Lansdall-Welfare 2003)
- ‘Stuck’ discourses sedimented in historical & institutional meanings: ideology taken-for-granted, questioners judged to be morally wanting (Danziger 1997)
- Rubber-band thinking most likely response to innovations: autonomy trumps all
- Unfolding an alternative view, without judging others & diminishing possibility of change, requires appreciation everybody doing their best as they see situation

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# Inclusion: asking the right Qs?



Latour (2013) two types of academic inquiry: address

1. **Mistakes of the senses:** use or develop instruments to see more clearly (MRI, systematic reviews)
2. **Mistakes of direction:** moments of hiatus when a community decides its questions no longer fertile & seeks new ones

(Clarke & Clarke 1958 from 'What is ID?' to 'How can life experiences of PwID improve?')

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**Clegg, J. Murphy, E. Almack, K. Harvey, A. (2008). Tensions around inclusion: reframing the moral horizon.**

J App Res ID, 21, 81-94.

- Assumed inclusion policy could support people to become actively involved in society, but our data indicate it is not doing so
- Parents these severely disabled young people identified two alternative aspirations for policy: **activity** and **relationality**

Conclude:

- Current inclusion policy ignorant of the way people with and without disabilities create meaningful lives (see also Power & Bartlett 2015)
- Inadequately theorised

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# Alan Clarke (1976)

## BPS presidential address



**“The history of research in mental handicap is full of examples ... of poor practice stemming from inadequate theory”**

- Practice “requires research that will show how to devise and maintain environments that ... promote well-being.”
- “Only when ... we begin to examine the characteristics of the environment that contribute to immediate happiness and well-being will we get our priorities right.”

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## ■ Is there a mistake of direction?

Over 40+ yrs neoliberal individualist *autonomy, rights, choice* vastly improved living conditions **BUT human relations problems continue**

- Interactions go wrong & scandals occur: in public and private hospitals *but also in the community*
- Staff in CB services experience high rates of assault
- Parents experience high rates of stress & ill-health, ↑ as they get older
- PwID experience social isolation & ↑ risk of mental ill-health

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# Society does not understand learning disability

Smellie, 2009



Everybody just freezes. Everybody is just embarrassed. Gray2002

Interacting with somebody who has ID undermines social skills, destabilizing certainties about identity (Meininger 2008)

Need to create new spaces of encounter that “invoke new meanings and a new way of acting in life and society... where people with disability can meet others in such a way that mutual strangeness can be faced up to ... connections in which difference and strangeness remain” (Meininger2013:35)

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# It Takes Two to Tango: Outline

- Invitation to suspend belief that only individual *rights, autonomy, choice & empowerment* are important; to understand how if relationships not theorized they can have no conceptual presence, & change begins at home
- Relational theorists/ies
  - Buber
  - Deleuze
  - Social Pedagogy
- Relational practices
  - Discovery Awareness
  - Enabling Environments
  - Community Psychology
- Building our own Enabling Environment

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# All real living is meeting

## Buber (1937) I and Thou

- When *thou* is spoken the speaker... takes his stand in relation (4)
- Relation is mutual. My *thou* affects me and I affect it
- The person becomes conscious of himself as sharing in being

## Deleuze's ethical triple shift (Braidotti 2012)

- Away from single individual achievements towards enduring relationships
- Away from moral rules to practical action
- Away from negative judgement towards affirmative living

ie from things to processes:

*important concepts* are not nouns (autonomy, inclusion) but *verbs* (belonging)

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# Impediments 1: professionals & parents



- Mothers feel scrutinised and judged by professionals (Todd & Jones 2003).
- In contrast to relatives persons w. dementia SWs regard parents of PwID to be seeking own advantage not best interests of son/daughter (Glendinning et al. 2009)
- Services not attuned to parents' emotional & practical needs (Faust & Scior 2008)
- 51% PwID at home during parents' midlife, 39% when parents in their 60s when sig:
  - more depression
  - less frequent visits with friends and family
  - more functional impairments
  - poorer Health-Related QoL (Mailick-Seltzer et al 2011)
- ***“On the whole there is a power gulf between professionals and parents .... (that) gets in the way of the human being involved.” (HoPC Mittler 2009)***

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## Impediments 2:

### ■ Professionals & residential staff

**“Institutions differ in their patterns of care because they are differently organized, and because the structure of the organization acts as a constraint on what can be achieved” (King, Raynes & Tizard 1971: vii).**

- Resident abuse connected to both poor management & poor staff support. Complexity of caring for PwID & CB underestimated. (Martin 1984)
- 93% PwID diag.d w psychiatric disorder show aggression (Tsiouris+ 2011).
- Long-term exposure to aggression results in emotional exhaustion and depersonalization (Hensel, Lunsky, & Dewa 2012)
- Staff need help to acknowledge & manage their feelings, repressed feelings displaced onto criticising organisation (Storey, Collis & Clegg, 2011)

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# One practical-theoretical answer: Social Pedagogy



## Cameron (2013)

Social pedagogues share life-space with person, establish genuine interest in and curiosity about them, do things together that build mutual interests.

Relationships not instrumental but first and foremost ethical: encounters occur for their own sake, rather than to change behaviour or explain rules.

Intend to establish trust so pedagogue can accompany person through their difficult situation: present but also future-focussed

Organisation supports relationships and reflection on them; encourage creativity, spontaneity, joy

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# Petrie 2013: Head, heart and hands



- Pedagogues see whole self as a person in relationship
- Practical – can share many aspects of person’s daily life and activities
- Person’s associative life important: foster and make use of the group
- Emphasis on team work – valuing contributions of others in bringing up children, supporting vulnerable adults – other professionals, parents, community members
- Orientation to everyday life, and how actions develop the whole of society (*Bildung*)
- Pedagogues supported to reflect both on practice & to draw theory into practice

**British social pedagogy needs to envisage the ideal relationship between vulnerable people and society, drawing on its own understandings of social culture**

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# Discovery Awareness: Heijkoop



## A method for tuning in to personhood, revealed and developed through relationships

- Study feelings, expectations, thoughts, doubts, insecurities, worries, contacts and cooperation which person w. ID brings to meetings with important others
- Also feelings, expectations, thoughts, doubts, insecurities, worries, contacts & cooperation important others bring to meetings with the person
- Method enhances awareness of how 2 sides fit & misfit
- **Conversation adopts open & interested attitude without blaming or shaming**

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# DA: videoanalysis

## Heijkoop & Clegg, IMH

- The opening: what is it like to be with this person?
- First viewing session: in silence – watch yourself watching
- First impression: what struck you?
- Second viewing session: Each person's distinct perspective is given space for exploration, valued without struggle towards agreement. Constant shifting between what can be seen and heard and the meaning (not explanation) that can be derived from it.
- Conclusion: What stayed in mind? What will each participant explore when next with the person?

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# Webb, J. Pilnick, A. Clegg, J.

R: .hhh [It's ] almost as if she was see:king with the low tone and like saying (0.2) the way she actually said (0.3) oh im al↓right as if she wanted then (0.4) for Camille to say (0.5) oh ↑why what's the matter↓(0.7) indicating to sort of say (0.5) well I'm al↓right (0.7) but giving out the signal of (1)

D: [°I'm not alright°]

R: [Well I'm not ]

D: [Hmmm]

R: [I'm] not alright (0.2) and I need you to ask me.  
(2)

R: That's what I interpreted from that

S: So she's seeking, (1)

R: Yeah

S: someone to enquire after her [further]

R: [yes: ]

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# Enabling Environments (EEs)

- ❖ UK Royal College of Psychiatry award, drawing on research into therapeutic communities
- ❖ Healthy psychosocial environments for everybody – staff, services users, families, visitors
- ❖ People in them oriented towards growth and development of one another & themselves

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## EEs: Places where...

- Positive relationships promote well-being for all participants
- People experience a sense of belonging
- All people involved contribute to the growth and well-being of others
- People can learn new ways of relating
- That recognise and respect the contributions of all parties in helping relationships

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# Definitions of Psychological Mindedness

- Originated psychotherapy with Applebaum 1973
  - interest in own psychological states and processes , &
  - ability to reflect on/have insight into them
- Heightened awareness of these in a non-judgemental environment enables people to become more Psychologically-Minded
- Psychologically-Minded people find it easier to connect with and attune to others

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# Mindfulness, E.I., Attachment

- **Mindfulness** understanding and practicing ‘accepting awareness’ in order to enhance ability to be ‘present’ to others.  
*Evidence: Reduced aggression and restraint in ID (Singh et al 2006, 2009)*
- **Emotional intelligence** (Bar-On 1997 EQ-i)
  - Intrapersonal; Interpersonal; Stress management; Adaptability; General mood*All ID care staff who volunteered to learn EI developed ability and understanding (Zilmans et al 2011)*
- **Attachment** *Irrespective of attachment status, all ID care staff who volunteered for a video-feedback coaching to improve relationships benefitted (Schuengel et al 2010)*

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# Collect stories about how people facilitate relationships

- ❖ Rick Perrrier's table
- ❖ Drumming workshops
- ❖ Inform Theatre on Rethinking Learning Disability website (Chris Philo, Murray Simpson & Ed Hall)

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# Community Psychology Kagan et al 2011



## Social justice

Stewardship

Community

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# Resist the Pollyanna approach

Stop asking *How can we insert PwID into society?* and hoping that enough demonstration projects by able PwID supported by charismatic staff will roll out. Instead ask

## ***How can relationships between PwID and society change?***

- Expand research beyond the horizon of relatively able, independent, & healthy members of self-advocacy groups – requires a shift in funding priorities
- Professionals and researchers involve residential staff: through DA rather than ‘training’, by seeking accreditation as an Enabling Environment
- Professionals and researchers involve parents to explore community contact
- Use community psychology/action strategies to start building connected societies

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# Create and sustain our own Enabling Environment



1. Enable ID practitioners to find safe ways to explore, create, innovate
2. Work through the implications of a relational model
  - ❖ Reduce staff churn and placement breakdowns: person should not feel like a hot potato
  - ❖ Social pedagogy: build relationships through ethical encounters, imagine and enact a good relationship vulnerable people ↔ society (encounter – Bigby & Weisel 2011- vs intensity)
  - ❖ Tune in using DA in order to ground attempts at being a community intermediary (Schelly 08)
  - ❖ How can families stay connected to son/daughter without their health suffering?
  - ❖ Combine media campaigns: Photographs; “Just say hi”; with community initiatives
3. Commission for connectivity
  - ❖ Debate single-person services where a few people get lion’s share of resource

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