




**“He is just like a two-year-old”:
Controversial?**

An exploration of using age analogies to understand people with severe and profound intellectual disability

ASID National Conference 2023
Valuing Different Perspectives
Date: Friday, 24th November
Time: 11:30am – 1pm



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Main messages

People with severe and profound intellectual disability need to be better understood

Using age analogies may or may not be helpful for understanding individual experiences

Using age analogies is a complex, contentious issue

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“Persons with PIMD are among those people who force disability studies to reflect upon the meaning and significance of impairment, and the diversity of the disability experience.”

p 181, Vehmas & Mietola, 2021

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Research & gaps



Ethical & philosophical



Clinical and personal experience



Discussions with experienced others



You...



Future written paper?

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“We would argue that concepts like ‘adult status’ or ‘age-specific-needs’ are unintelligible in the case of young persons with PIMD unless the qualities and cultural meanings attached to different age categories are unpacked properly. Age categories need to be analysed in order to make visible the cultural ideals and norms linked to them”.

- P. 114, Vehmas & Mietola

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- Using “age equivalence” descriptors
- The typical age at which particular skills are seen
- Applying it to people whose chronological age is much older
- Putting myself in precarious position of different perspective



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Common sense...

Whose common sense?

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A map for 20 minutes...

"He's just like a two-year-old"

- The story

Parent voice

- Saying – rejecting the saying

People with severe or profound intellectual disability

- Cognition, communication, "challenging behaviour"

Breaking down the issue

- Saying as derogatory – saying is supporting

Snapshot of "professional" thinking

- Against use of analogy – supporting use of analogy

Disability support workers

- Delivery, use and misuse of age analogies

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“He’s just like a two-year-old”

- Told to me by a parent-advocate
- About a father talking about his adult son
- Discomfort

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Why might a parent say this?

- “Earl invariably defaulted to particular interaction with Zachary: ‘ My son, he is twenty-six. Cognitively, he is like a two-year-old. This morning I cam home from the fire station, I went to his bedroom, he wasn’t awake yet, and he sits up and looks at me with a huge smile on his face and he goes, ‘aaiieeee.’ An I lay at the end of his bed and he turns and drops his head into my left should and rolls back and forth, going ‘aaiieeee’ and I’m like, if that’s not love, what is?’ Earl didn’t elaborate beyond the specificities of the moment. It was as though he assumed everybody he told these stories to would grasp their significance”.
 - Jackson, p 73
- “The numbing monotony of caregiving and social isolation and exhaustion that permeate caregivers’ experiences can lead to internal inconsistencies, and sometimes human and moral tragedy”.
 - Jackson p 157
- The profound adjustment from the expected role of parenting – everything is shaken
 - Feder, 2020

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Why might another parent feel discomfort?

- Concern of low expectations
- Inaccurate estimations
- Overshadowing of life experience
- Incoherence with bodily age
- Social justice implications
- “Normalisation”

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A divergence from typical...

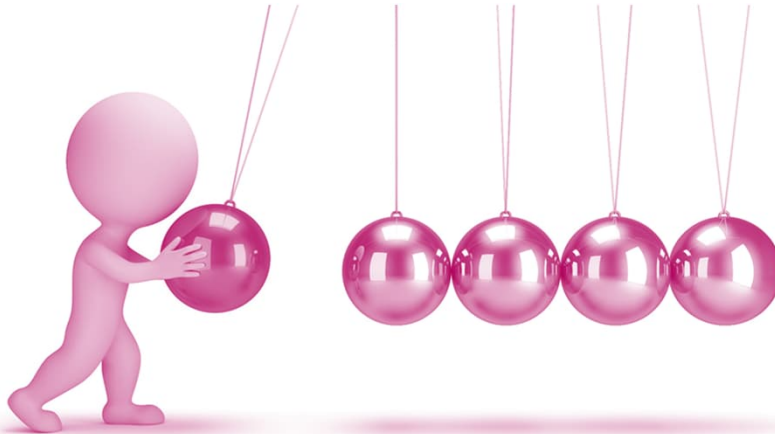
“Paul frequently berates himself for not talking to Pearl more often. He tells me that she has no means of effectively communicating her thoughts or feelings. “How long would you talk to your kid without any feedback whatsoever?” he asks. ‘A week? Twenty-two years?’ He laments feeling guilty over not talking to her more: ‘ I don’t talk to her I can’t talk *with* her.’ Paul feels this as a moral failing, because ‘parents are expected to talk to their children’. Yet despite the silence that enfolds them. Paul recognizes that they share an experiential connection. Throughout my time with them, I noticed they were frequently in physical contact with one another. Below the threshold of these conceptual understandings of how parents are ‘supposed’ to interact with their children there is a more primordial form of communication at play between their bodies.”

Jackson, p 73

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- “Takoda’s continued social alienation and misrecognition by others, that is, his frequent relegation to the outskirts of social and moral belonging, are inseparable from the emotional pain, exhaustion, and vulnerability to suffering that mark my experiences as his caregiver”
 - Jackson, p 148
- Ethnography, phenomenology
 - Skarsuane, Simmons, Grace, Jackson, Vehmas, Antaki & Finlay, Bos

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“but shouldn't you ask them?”

“Even disability activism has worked on the terms of those who are articulate and has excluded individuals with PIMD and other conditions who have very limited capacities to express their own voice. If the principle ‘nothing about us without us’ is strictly applied, and if nobody else has the legitimacy to speak for person with PIMD than themselves, they will have no voice, no social standing whatsoever”

- Vehmas & Mietola, 2021, p. 175

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People
with
profound
intellectual
& multiple
disability



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- Diagnosis
- Cognition
- Communication
- Sensory
- Physical
- Medical
- Emotional
- Challenging behaviour
 - Poppes, 2016 a & b - self-injurious and stereotypical 82%, withdrawn 98%, aggressive/destructive 45%: support staff difficulties attributing behaviours cause
- Participation

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- Dominant view
 - Behaviours outside of cultural norms - serve communicative function
 - Behaviours that need to be changed
 - "Rights based model of Positive Behaviour Support" – person-environment, conditions of life equivalent to non-disabled peers, inclusion Leif et al 2023
 - ? Superficial and inconsistent incorporation of the developmental needs?
 - ? Rare consideration of cognition and communication?
- Another way viewing behaviour with developmental lens
 - Delay – can be explained by development delay requiring a developmentally informed responses – including acceptance and support
 - Deviance – can't be explained by typical development

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- Some behaviours of people with profound ID can be explained as adaptive and cognitively explainable
 - Behaviours as self-determination
 - Behaviours as self-regulating
 - Behaviours as harmful
- The responses of supporters can be coherent or incoherent to cognitive/communicative level
 - Provide regulation support, response to distress, empathy
 - “give the person space”

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“Person with PIMD are a group of people that troubles the cultural conventions and expectations regarding age”.

- P. 131 Vehmas & Mietola, 2021

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“All in all, our research participants were clearly able to develop social interaction and reciprocity in their own individual ways. However, since they needed support in virtually any activity, they were unable to create social lives on their own. Their interest and capacity to relate to others was possible only through one people’s recognition and active measures”.

- P. 100, Vehmas & Mietola

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Two-year old: Breaking it down

- “Like a two-year-old”
- General perceptions of a two-year-old may be negative
- Infantilisation: not fully human? rights?
- Mismatch can occur when chronological skills equate with developmental skills (expecting a child to behave above their development)
- Adulthood

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- Contemporary infant mental health
 - Skilled infants
 - Supported infants
- Examples
 - Vasudevi Reddy – humour
 - Ed Tronick – regulation
 - Trevarthen – intersubjectivity
 - Beebe – attachment
 - Siegel – neurobiological

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- Not allowed to use age analogies
- “Prerequisite skills” being used as gatekeepers to service provision
- Ruled out with normalization movement
- Treated as a tacit “common sense” to not use
- Not inline with dominant agenda of autonomy and independence
- Tendency towards dedifferentiation
 - “shift away from regarding cognitive impairments as the origin of difficulties experienced by people with intellectual disabilities and, instead, regarding their difficulties as socially produced and common to all people with disabilities”
 - Clegg & Bigby, 2017

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- The biggest thing you're not allowed to talk about in the intellectual disability area is.....

intellectual disability.

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A complex relationship with shame

- "Act your age"
- Parental shame – violating a rule of expected behaviour
- Societal shame
- Professional shame

- Ableism - Campbell – any separation from the "ideal citizen" is viewed as a negative thing

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"Professional" thinking: using analogy

- Some professionals have developmental training
- Use varies from: superficial, quasi-use (using but not openly), stage use, to explicit age use
- Using the concept to:
 - Understand the person from a different lens
 - Guide supports equivalent to cognitive age supports
- Requires a nuanced understanding of development
 - (history of tools / models being meaningless / floor effects)


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"Professional" thinking: using analogy

- Broad views of incompetence can obscure the micro-competencies – the analogy can uncover competencies
- To accept that different aspirations are acceptable (e.g., sucking the facewasher, flicking the pages of a magazine)
- Helpful to move past "multisensory" passive formulation currently dominant

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Examples of use: Social Emotional

- Social-emotional development scale SED-S
 - Sappok, Zepperitz, Hudson... Došen
- Attachment, neurobiology informed
- Needs: physiological, safety, autonomy, social, self-esteem
- Skelly – “Reality orientation” – support engagement, and provide comfort and reassurance

0-6 Months Emotional Development

Proximate explanation for:
Deciding where to go & what to do (based on what the task is)
“UP” the person to the activity (if not physically there automatically).
Do not wait for decision making (responding to a cue, gesture, hungry, wet, tired, or left alone).
Focus on non-verbal cues in the environment.

Create safety by:
Being within sight at all times in the space (not out of reach as possible).
Meeting personal care needs without requiring a response from the person.
Constant speech tone.

Support engagement by:
Initiating interaction.
Activities as props for reaching, not solely learning.
Lots of eye contact.
Engaging in early responses or comments.
Not expecting sustained attention.

Provide comfort and reassurance by:
Addressing physical discomfort immediately.
Keep eye contact while reassuring the person.
Talk in reassuring tone without expecting formal understanding of what is said.
Considering what was distressing the person.
Doing the thinking for them as a unit.

6-18 Months Emotional Development

Proximate explanation for:
This is when attachment patterns appear to children development they have to feel safe to explore.

Create safety by:
Being closely available to prevent accidents.
Meeting personal care needs.
Have “light” eye contact aware from thoughts and focused to activities but don't expect the person to make or comment on things!


Proximate explanation for:
Keep providing the structure and activity plans.
Provide different environments as well as learning goals, but some skills where possible encourage exploration of the immediate environment with toys.
Check in but not interfere.
Expect frustration and some “baffled” but not to be upset or angry (e.g., “No, that’s not yours”).

Support engagement by:
Following the person but letting them act for themselves.
Activities across areas for reaching, not solely learning.
Provide eye attention (i.e. Make eye contact to the person, then to the object or activity, then quickly back to them).
Talk in a tone to them.
Engaging in eye “Recovery” / “Attention” as appropriate.
Following only BEST attention to an object before continuing exploration.

Provide comfort and reassurance by:
Addressing physical discomfort immediately.
Keep eye contact while reassuring the person.
Talk in reassuring tone without expecting formal understanding of what is said.
Considering what was distressing the person.
Doing the thinking for them as a unit!


- “Emotionally connecting to the fact of very limited intellectual abilities can cause discomfort for care staff, professionals and family members and can seem like an insult or even a form of discrimination or prejudice.... Whichever method is used to explain the reality of the person’s abilities, it must also be delivered in an empathic way, and with the express intent of accurately identifying what new learning is really fair to expect”
- Skelly, 2016

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Intensive Interaction (Nind & Hewett)


- Intensive Interaction
 - Using mother-infant interaction patterns
 - Using imitation, anticipation building, pause, attunement
 - Building evidence for enhancing social communication and well-being
 - Also been used in dementia support
 - Fundamentals of communication




Enjoying being with another person




Developing concentration & attention span




Doing sequences of activity with a person




Taking turns in exchanges




Sharing personal space




Using & understanding eye contact, face expressions, physical contact & other



Using vocalizations with meaning




Regulating & controlling arousal levels



Emotional & physical development

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Examples of use: FAS-D

- The uneven profile of skills is understood and supported
- Diane Malbin - Neurobehavioral Model
- Values and values clashes


Primary characteristic	Values, expectations	Interpretation / feelings	Intervention	Secondary symptoms	Accommodations: Building on strengths
Dysmaturity	Act your age	Being a baby, lazy, not trying, frustrated	Punish	Anxiety, anger	Think younger
Memory problems	Remember	"Should" know!! Angry frustrated	Remove privileges	Anger, frustration	Accept need to reteach, based on learning strengths
Slow processing	Value speed - think fast	Not trying, withholding on purpose	Speed up, yell, embarrass	Shut down, fear, avoidance, withdrawal	SLOW DOWN Use fewer words

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Formal further education (rare in Australia)

- Further education opportunities for people with PIMD are viewed as islands of learning
- Programs based on developmental skill progression and support for next skill
- Run in contrast to usual programs
- Orchard Hill College, England
- Weston College, England
- Carpenter, B et al. 2015



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“Of course, they have some elements of behaviour which could in some circumstances be described as ‘baby-like’: toileting, extreme egocentrism, difficulties feeding themselves, etc. but they are not babies... They have life experiences, quite complex feelings, hormones. In some cases they are nearly 6ft tall and extremely strong... We should never ignore this, and describing them as ‘like babies’ should not be used as an excuse to just ‘babysit’ them”

P24-25, Colley, 2013

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Using the analogy as part of approach

Can

- Frame present skills
- Support and preserve use of skills
- Explore next skills
- Direct the supports needed
- Shaping an accessible world cognitively, communicatively, sensorially and emotionally
- Be safer and more effective
- Think of person differently

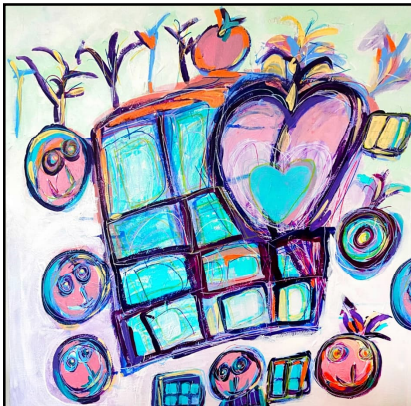
Does not mean

- Dressing like a child
- High-pitched condescension
- Legitimising power relations over the person
- Restricting opportunities
- Viewing the person as having no skills or hope
- “Eternal child”
- Babysitting...

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- Sharing of information between allied health and DSW
- Need to shift from “care work” to skills and relationships
- “Re-minding” (Vehmas & Mietola)
 - Permission to use age analogies
- Delivery of analogy
 - “A person has skills that are similar to a typical x month-old, that might have particular meaning, and require support in line with...”
 - Relating to their children at different ages, and supports needed
- Use and misuse of the knowledge

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Valuing different perspectives

22 - 24 November 2023
Crown Promenade Hotel, Melbourne

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research to practice

Can we value this different perspective?

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- Clegg, J., & Bigby, C. (2017). Debates about dedifferentiation: twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group. *Research and Practice in Intellectual and Developmental Disabilities, 4(1)*, 80-97. <https://doi.org/10.1080/23297018.2017.1309987>
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- Vehmas, S., & Mietola, R. (2021). *Narrowed lives: Meaning, moral value, and profound intellectual disability*. Stockholm University Press. <https://doi.org/10.16993/bbl>