

Good practice for supporting people with complex behaviour

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Main focus

- Persons with intellectual disability
- Context: group homes and day programs in the community
- Expressing distress, fear, protest, pain, sorrow, grief, sensory overload, boredom, etc. through behaviours that are labelled as challenging or of concern
- Often subjected to restrictive practices: chemical, mechanical, physical, environmental restraint, and seclusion
- Or neglect

Vulnerability

- Vulnerability is not an intrinsic attribute
- Living in a challenging environment
- Or challenged by the "support" that is provided

- Survival in an unfriendly, even hostile environment
- Disadvantaged, with compounded disadvantages

- Included in the value system of the normative society, or
- Empowered to participate in shaping the norms?

- Can moral actions be legislated?

Shared vulnerability

- Interviews with 96 care staff, 17 front-line managers
 - All commented on high staff and manager turnover
- Staff:
 - Abandoned by the organisation
 - Advocates for the persons they support
 - Are expected to get the work done (and not care too much)
 - “We have to scream our heads off”, “They don’t care unless it hurts them”
- Front-line managers
 - Administration and budget
 - “My staff are the experts”
 - Seem to know of rather than actually know service users

(Mis)aligned ethics

- Staff report more restrictive practices (RP) than managers
- Staff identify their own role and the role of the organisation in reducing RP
- Managers don't identify their own role in reducing RP

- Staff “care about” and “care for” the persons they know and spend time with
- The organization, as represented by front-line managers, is often more engaged in “getting the care done”
- That is, social connectedness does not seem aligned with administration

Capable environments as framework?

- Organisation
 - Priorities, alignment throughout the organisation?
- Service
 - Staff support, training and supervision?
 - Methods available to translate into action?
- Persons with intellectual disability
 - Quality of support?
- Research
 - Identify gaps in research and create research questions?

Capable environments

- Support for communication
- Opportunities for choice
- Consistent and predictable environments
- Relationships with family and friends
- Positive social interactions
- Mindful, skilled carers
- Support for participation in meaningful activity
- Encouragement of more independent functioning
- Personal care and health support
- Provision of acceptable physical environment
- Effective management and support
- Effective organisational context

Capable environments

Support for communication

Opportunities for choice

Consistent and predictable environments

Translation

- Alternative & augmentative communication
- Active support
- Practice leadership
- PBS?
- TEACCH/structured teaching?

Capable environments

Relationships with family and friends

Positive social interactions

Mindful, skilled carers

Translation

- Acknowledging social relationships and friendships
- Focus on and enabling structures for quality of life
- Trauma informed care

- Active support? Practice leadership? AAC? PBS?

Capable environments

Support for participation in meaningful activity

Encouragement of more independent functioning

Personal care and health support

Translation

- Active support
- Communicative and cognitive support
- TEACCH/structured teaching?
- PBS?

Capable environments

Provision of acceptable physical environment

Effective management and support

Effective organisational context

Translation

- Knowledge throughout the organisation
- Front-line leadership
- Organisational culture
- Transformational leadership?

Conclusions

- Staff in, e.g., group homes and day programs continuously make sense of legal, social and ethical requirements
- Staff need support in this sense-making in an organisation they see as fit for purpose and capable to address the complexity of every day interactions
- Implementing an “evidence-based method” will not provide sufficient support
- Ethics, norms and values have to be discussed and navigated on a continuous basis throughout the organisation
- Staff need to know that the organisation cares

Capable environments as framework!

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- Persons with intellectual disability
 - Quality of support!
- Research
 - Identify gaps in research and create research questions!

Thank you!

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