Covid-19 and IDD: Ethics

Petra Björne

PhD, R&D coordinator, researcher

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Conflicts of interest

- I receive funding for research from the Swedish Research Council for Health, Working Life and Welfare, in a project unrelated to the current topic.

- I have no conflicts of interest to declare.

Webinar outcomes

By the end of this webinar, participants will

- recognize how a pandemic can exacerbate healthcare inequalities
- understand that perceptions of intellectual disability and how a person with a disability is valued, can influence the healthcare provision
- advocate the importance that healthcare measures taken during a crisis cannot become the norm after returning to normality.

UN CRPD
Article 25

Access to general healthcare

Access to specialised healthcare

Provision same quality as for general population

”Prevent discriminatory denial of healthcare or health services or food and fluids on the basis of disability.”

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Ethics and health inequalities

- Some health inequalities are (usually) of no ethical concern
  - Variations and differences, random chance, biological vulnerability
- Health inequities: unfair inequalities stemming from injustice
  - Always of ethical concern
  - Depends on **how a person is valued**, theories of justice and society
  - Theories on reasons for health inequalities

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Health inequities

- We must recognise processes that are signs of devaluing and dehumanising a person
  - Eg. through service choices and quality of support
- Requires conceptual analysis

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“Vulnerability”

- General concept that requires clarification
  - Not static
  - Not an inherent property

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Compromised health

- Complex health problems
- Sedentary lifestyles
- Undetected health needs

- Cardiovascular disease
- Respiratory disorders
- Diabetes
- Obesity

- Reduced life expectancy

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"Vulnerability" (concept)

- Difficulties accessing appropriate and timely healthcare
- Lack of accessibility in general
- As well as access to special competence
- Lack of involvement
- Lack of cognitive and communicative support
- Lack of adaptation of physical environment
- Depending on support from staff or family who (usually) are not trained healthcare professionals

Vulnerability = inequity

- Vulnerability is a relationship between an individual and the environment
- Vulnerability is not inherent to a person with IDD
  - Healthy lifestyle choices can and should be supported
  - Healthcare provision can and should be adapted to the needs of people with IDD

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Conclusion so far

- People with IDD are not (intrinsically) at risk
- They are put at risk!
- Not recognising and preventing this is part of devaluing and dehumanising people with IDD

Enter Covid-19

Times of crisis and scarcity

- Stop breakdown in healthcare ***and*** keep vulnerable groups safe
- From individual healthcare to community perspectives
- Therefore individual needs are juxtaposed with community priorities
- Priorities change to "protecting the vulnerable ***or*** stop a breakdown in healthcare"

Blanket decisions based on diagnosis

- Engenders a sense of threat
  - For person and/or family and friends
- General population
  - “Othering” undermining social cohesion
- “Othering” reduces access to healthcare
  - Linked concepts: vulnerable, frail, not capable, QoL

    Is IDD even relevant?
  - Atypical symptoms or atypical expression of symptoms?

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Long-term consequences

- Medication to manage challenging behaviours not reviewed
- Backlog of medical attention
- Visiting regulations – institutionalisation
- Lack of transparency – increased restrictive measures
- De-sensitisation and normalisation of coercive measures
- Times of austerity – reduced social and medical support

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Some tools

Medical decisions are also ethical decisions

- Frame ethical concerns in as concrete and contextualised a way as possible!
- Who should be involved in a decision?
- How, not if, the person with IDD can be involved!
- What does “meaningful”, “benefit”, “QoL” mean when applied in this context, by/for/with this person?

- Never assume to know. Ask!

Thank you!

Petra Björne

petra.bjorne@malmo.se

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