Intellectual Disability, Caring and Role Reversal

From being cared for, to caring for…

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Presentation outline

- Care Alliance Ireland: Who We Are
- (Brief!) History of intellectual disability and longterm care
- ID & Family Care: Changing demographics
- Policy and service challenges- PWID becoming Family Carers- Impacts
- Possible solutions?

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- National umbrella organisation for NFP organisations supporting Family Carers in Ireland
- 104 member organisations across Carer support, disability specific and broad community organisations
- Focus on policy, research and “macro advocacy” for Family Carers
- Support or member organisations so more resources can go to front-line work
- Member of Eurocarers and IACO

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- This presentation is from an Irish context
- I will use the term “Intellectual Disability” shortened as “PWID”

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ID & Longterm Care- Ireland

- History of residential care for PWID
- Workhouses- Hospitals- Congregated settings (institutions)- Community living
- Until 1970s/1980’s: significant no. of PWID in residential settings
- Currently 67% of PWID live at home with parents/siblings etc. (NIDD, 2015).

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Changing Demographics

- Life expectancy in general increased; Irish average 81.4 years
- Life expectancy for PWID increased significantly- many more living to 40+
- Parents of PWID are seeing their adult children age as they themselves age
- Creation of co-dependant care relationships

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PWID as Family Carers

- June 2015- a number of members came to us independently to highlight this issue
- No previous experience- developing issue- Very little written or understood
- December 2015- "Discussion Paper 3- Intellectual Disability, Caring and Role Reversal" published by Care Alliance (http://bit.ly/1LbFLtM)
- May 2016- expanded paper published in The Irish Social Worker

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Service Impacts?

- Challenging dominant discourse
  - Who is the “client”?
  - Who is the “carer”?
  - Does it matter?
  - How do professionals view this change?
- Provision of Accessible supports & information
  - Easy-to-read information & training for PWID
  - Information for PWID re: long-term care? Who makes that decision?
- Collaborative working
  - Carer Organisations & Disability Organisations working closely together
  - Challenge & tensions

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Policy Impacts

- Policy development strategies “talking” to each other
- Hospital/ GP policies re: discharge & discharge planning
- Accessing longterm care for parent may mean 2 individuals possibly inappropriately placed at increased costs- how to align to current community-focussed service provision?

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Solutions?

- Increased support for PWID from Carers organisations
- Change to dominant discourse- PWID do not always need to be “cared for”
- Tie policies together at high level (e.g. National Carers Strategy; National Dementia Strategy; National Disability Strategy) to acknowledge links between all.

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In conclusion…

- PWID living longer & taking up caring roles for aging parents
- Presents challenge to dominant discourse- cared-for becoming the carer.
- Impacts upon longterm care;
  - Supporting PWID to embrace caring role, with support, may mean later admission to longterm care
  - Not supporting PWID to care may then lead to two people inappropriately & needlessly living in longterm care- increased costs and contra to established policy

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thank you!

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