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?
Care Alliance Ireland

• 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
• This presentation is from an Irish context

• I will use the term “Intellectual Disability” shortened as “PWID”
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).
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
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


• May 2016- expanded paper published in The Irish Social Worker
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
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?
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.
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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