

Whose life is it anyway?

The challenges of advocating for both people with intellectual disability and their family carers.

Zoë Hughes
Policy & Research Officer
Care Alliance Ireland

This presentation...

- Introduction
 - To presenter
 - To the topic
 - Disclaimer
- Outline of relevant policies
 - Irish context
 - National Disability Strategy & Implementation Plan
 - National Carers Strategy
- Personal reflection
 - Personal & professional
 - Challenges
- Conclusion

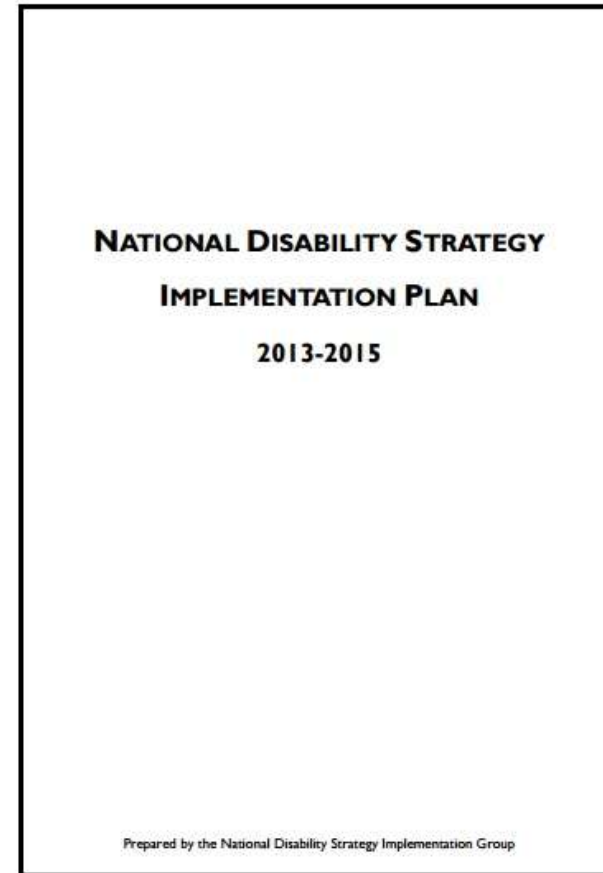
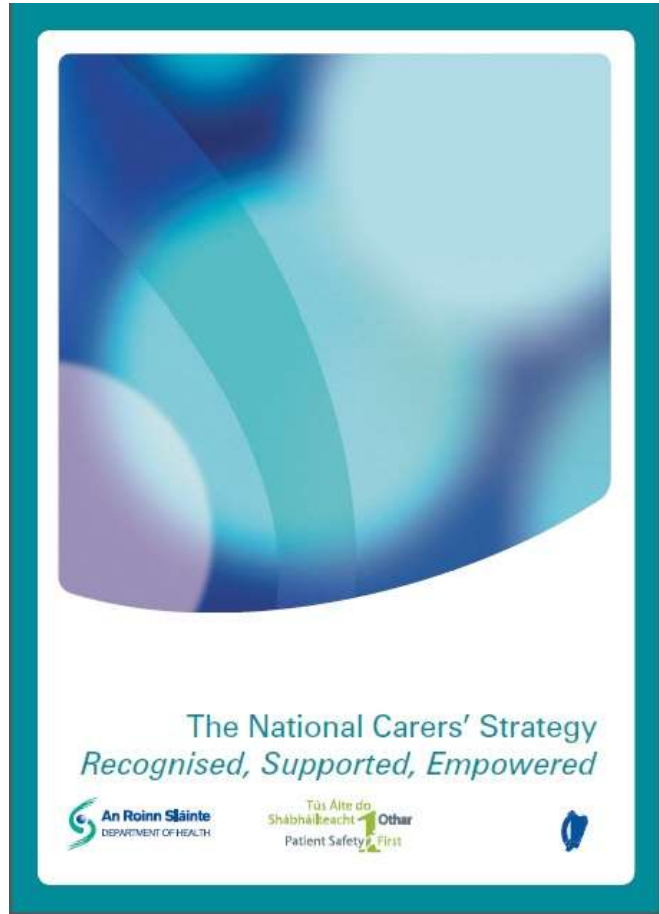
About me...

- Previous roles: not-for-profit, disability & academia/education
- Family member & supporter of my friends
- 20 years vs 9 months
- Have seen conflicts between PWD, their families and their “carers”
- Conflicts often personal but not assisted by policies at a macro level



Personal presentation with personal experiences

Irish Policy context



National Disability Strategy (& Implementation Plan)

- Launched in 2005- legislation & policy documents
- 2013-2015 Implementation Plan

"The National Disability Strategy is a whole-of-Government approach to advancing the social inclusion of people with disabilities." (NDSIP, 2012)

Family Carers & The NDS- Language

Word/ Phrase	Number of time used in the NDSIP
Family	0
Carer	0
Advocate*	0
Caregiver	0
Staff*	5
Support*	74

National Carers Strategy

- Published 2012
- Series of 48 actions with no particular implementation plan
- *“Carers will be recognised and respected as key care partners.”*

Policy Conflicts

- “Living an independent life” vs “Family Carers seen as partners in care”
- NDS push for parental & family involvement to be ‘minimised’
- NCS push for increased involvement

Personal “conflicts”

- Language use
- What “independence” means very different things for both groups
- Frustration re: communication- on ‘both sides’

Questions to ask

- Are Family Carers entitled to know the details of their relatives lives?
- When is it appropriate to challenge Family Carers on their desire to keep their children as “children”?
- What happens when a person with ID becomes the carer themselves? Who gets what information then?

Conclusion

- Personal experiences makes policy analysis stronger
- Useful to have experience of “both sides” at all levels:
 - Macro: have seen how policy decisions can be used as excuses in certain situations
 - Micro: have seen how policy directly effects individuals
- There should always be some struggle at a personal level when looking at policy- because policy impacts individuals, not merely “societies”

ThAnk you!

Zoe Hughes

Zoe@carealliance.ie