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Isn't getting old getting old? An analysis of issues in ageing with a lifelong disability

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Objectives

- Understand the organisational and advocacy issues associated with ageing with lifelong disability
- Explore the experience of a range of service users
- Identify the challenges facing service providers/ advocacy organisations in understanding and meeting the support needs of their service users as they age.

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Outline

- Background to the issue
- Ageing with a Lifelong Disability - UNSW Student Project
- Findings
- Conclusions

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Participating agencies

- The Futures Alliance and five member organisations
 - The Spastic Centre NSW
 - UnitingCare Disability
 - Ability Options Limited
 - McCall Gardens Community
 - Sunnyfield
- Three disability related peak bodies
 - Mental Health Coordinating Council
 - Physical Disability Council of NSW
 - Interchange Respite Care

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Background

- Number of older people with intellectual and psychiatric disability quadrupled between 1993 and 2003
- People with early onset disability, such as intellectual disability, experience the ageing process at an earlier age than the general population (AIHW, 2000).
- Ageing and disability do not overlap in current theory, policy or practice leaving the issues poorly understood.

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Method

- 9 'snapshot' studies conducted by UNSW students from July-Oct 2009, focusing on specific agency concerns, but relevant to the overall project
- Mixed method – including one-to-one (31) and paired interviews (4), focus groups (6) and an online survey (40)
- 104 participants including:
 - 47 management or direct service workers in disability or ageing sector organisations
 - 57 people with disabilities

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Limitations

- Broad and exploratory
- Sample taps only Sydney-based non-profit agencies who had expressed concern with issues of ageing and disability
- Not representative of breadth of disability sector agencies at local, state or national level
- Student project – time limited
- Snapshots are limited in scope, depth and complexity

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Implications for services

- Services required to provide increasing support to service users
- Limited opportunities and resources for staff development particularly in relation to:
 - Physical
 - Communication
 - Psycho-social needs of service users
- Innovative ways of addressing needs happening locally but experiences are not shared across the sector.

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Findings

- 9 projects with individual agencies each had their own individual aims, specific contextual background, methodology and findings
- Findings reported here are combined from all 9 studies and present overall themes in relation to:
 - Implications for older people with disability
 - Implications for services
 - Implications for policy

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Implications for policy

- Currently major gaps and disjunctures in policy between Commonwealth and State responsibility leads to inflexibility in service provision and people ageing with a lifelong disability 'falling through the gaps'
- Philosophical differences
- Service gaps
- Responsibility and advocacy

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Implications for older people with disability

- Universal experience of ageing
- Presence of lifelong disability compounds disadvantage and leads to greater complexity of issues
- Age-related changes:
 - Health and social support
 - Finances
 - Place
- Minimal planning for the future

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Conclusions

- Connections between ageing and disability are complex
- Innovative local practice is current primary service response
- Need for coordinated action at the lobbying and policy level
- Lobbying for policy and practice change needs to be underpinned by a strong evidence base.

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Recommendations

- Developments in advocacy, policy and practice could include
 - Workforce training in both disability and ageing sectors
 - Development of future planning (financial, legal etc) processes for ageing service users
 - Development of more sensitive assessment tools
 - Crisis and minor incident care response models
- Further research could address:
 - Prevalence of and projections of older people with lifelong disability
 - Financial Implications for disability and aged care services and carers
 - Grief and end of life issues for older people with lifelong disabilities

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