



LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE



Epilogue – Change and Continuity for People with Intellectual Disabilities

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Post Kew

- Study that evaluated the closure of Kew –MLG 2005-2008 – since continuing research on group homes and services for people with intellectual disabilities including some of Kew homes
- Finally, closed in 2008 had been downsizing since 1990s with people progressively been moving out
- 100 people remained on site in new group homes clustered on part of the site
- Others in small group homes in the community – managed by state government now NGOS
- **What happened to people who left Kew – changes in their lives ?**
- **What have been the changes and continuities more generally for people with intellectual disabilities since that time –in terms of experiences, policy and practice?**

What happened to people who left Kew – changes in their lives

- ‘Making life good in the community’ project funded by DHS
 - Qualitative study life of 26 people in five of the new group homes moved from 2005
 - Summarised in book *Group homes for people with intellectual disabilities*, (Clement & Bigby 2010)
 - Subsequently, analysis of culture in these homes compared to ‘better group homes’
 - Outcomes survey – changes in quality of life of the former residents – pre move and 12 months post move

Findings

- Much improved material conditions in new homes
 - small scale, no more than 5 people, dispersed in the community – own bedroom – sprinklers – heating, own clothes, regular day activities
- Unequivocally better quality of life - just like all research on deinstitutionalisation shown
- Significant positive changes: homeliness; exercise of choice, use of community facilities, person/social responsibility; the size of social networks.
- Significant reductions in maladaptive behaviour, depersonalisation and block treatment
- But networks small and contact with family declined - only 28% of people have weekly contact someone outside without intellectual disability
- Continued to live in a ‘distinct social space’ comprised of staff, family and other people with an intellectual disability



- <https://www.youtube.com/watch?v=xwXD6lilhU&t=1s>

Changes in the lives of people who moved from Kew

- Variability among groups – those in known locality - larger networks including non co resident friends with intellectual disability
- Despite the focus on active support and community participation during the closure - low levels of resident engagement in domestic activities, relationships with people without a disability, and involvement in community organizations
- Homes categorised as underperforming in terms of – community inclusion, engagement, choice and control
- Culture – similar to that of the institution - but less harsh and extreme
 - rigid routines - staff centred and inflexible – getting up, meals, going out during the day
 - block treatment - regarded as a group rather than individuals ‘ the guy’s ’ group activities and outings
 - depersonalisation - less evident – did have own clothes, pics, names - some stifling of individualisation
 - social distance from staff - ‘not like us’ , different utensils, spaces, toilets
- Culture compared poorly to that found in later study of better group homes

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Many changes since our original research looking post move

- NDIS more than doubled funding for disability services - new individualised ways of organising support
- Stronger policies about rights such choice and control and supported decision making
 - *But many people with intellectual disabilities don't have informal support networks needed to advocate for getting best type of plan or to support decision making*
 - *People with intellectual disabilities are one of the groups that have benefitted **least** from NDIS*
- Traditional group homes being superseded – perhaps this was the case even before Kew closed
- More housing and support options and greater choice to leave the family home or remain there
 - *But Relatively few people have left group homes*
 - *Quality of support in group homes has dropped over the last 4 years – remains considerable variability*
- Greater recognition of the significance of hearing directly from people with intellectual disabilities about their own lives and in policy and service design
 - *But Are voices of this group loud and representative enough? –is influence commensurate with size? not obviously part of the conversation dominated people with physical and sensory without cognitive impairments and its not clear who represents those with more severe and profound intellectual disability*
- Increasing dominance of social model and *much less differentiation of people with intellectual disabilities from all people with disabilities* - less concern about practice specific to people with intellectual disabilities

What continues to be the same as the Kew experience

- Significant disparities in quality of life - particularly, employment, social inclusion, life expectancy and health
- High rates of abuse and neglect by services established to care or educate
 - Testimony and case studies as part of the Royal Commission hearings
- Broken government promises - two clear ones from Kew were promise of shared common facilities on Kew site to help inclusion and memory of the site –broken with sale of last 3 historic building in 2021 and promised relocation to avoid an enclave in bottom right- hand corner
- Ambitious but unfulfilled public policies – continuing failures of implementation – NDIS multiple reviews about problems with way it operates. - evident that promised tier 2 has not eventuated and National Disability Strategy great ambitions about mainstream inclusion not followed through with funding
- Family members strongest allies and advocates - services cannot replicate their commitment
- There continue to be many people with intellectual disabilities without strong family or other informal networks or others who can advocate for them, get the most from NDIS plans, support their decision making – help to move to more individualised accommodation - Funders such as the NDIS and Services are not concentrating on building social connections or high-quality services that take account of the unique needs of this group.
- Theme of the book continues as people with intellectual disability continue to be the subjects of failed ambitions of government

References

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