



# National Study with Family Members Caring for People with Intellectual Disabilities in Ireland

## What this study was about



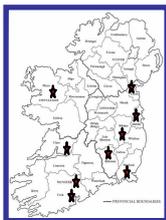
- Finding out what life is like for families
- Involving families in doing research and making research a collaborative process between researchers, people with intellectual disabilities and their families
- Finding out how to make support services for families better

## Working with families as co-researchers



- Family members were asked to be involved in doing the research
- Forty-four family members were trained to be co-researchers
- Four mothers and one father worked alongside the NIID researchers and together they led meetings with parents

## How we found out what life was like for families



- Over 600 families volunteered to participate in the research
- We arranged for families who wanted to participate to meet together in 'focus groups'
- The 'focus groups' happened in Charleville, Clonakilty, Drogheda, Dublin, Ennis, Kildare, Kilkenny, Rosslare and Westport
- Seventy family members took part in the focus groups and were asked to tell us how life was for them
- The families told us about their lives and we recorded what they said
- We analysed what the families said about their lives

## What we found out about inclusive research with families as co-researchers



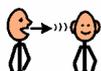
- The co-researchers acted as role models for other participants helping them to feel safe and speak frankly about their lives
- The co-researchers gave valuable insights that helped the focus groups run more smoothly
- The parents felt that being co-researchers helped to empower them and to develop their skills in listening to parents
- The parents felt that the skills they gained could help them to begin to make changes in their own localities and to take the findings to policy makers

## What we found out about family life



- Life for families with a member with intellectual disabilities can be very much like the lives of families who don't have a member with intellectual disabilities
- But life for these families has many 'ups and downs' with times when things are good and times when things are hard

## Life is good when families...



- feel supported and listened to (by services, professionals, their family and friends and other parents of children with disabilities)
- get adequate and timely respite services
- get adequate support and intervention for their family member with challenging behaviours

## Life is good when the family member with intellectual disabilities...



- is in good health
- is getting good services and support
- has opportunities to make friends and have relationships
- has opportunities to develop skills and interests during the day through activities, education and employment
- is getting the best out of life

## Life is not so good for families when...



- professionals, service providers and the wider community have negative attitudes and beliefs about disability.
- there is a lack of or poor quality respite, therapy and community services
- services and professionals don't listen to parents or tell them what is happening
- services and professionals fail to acknowledge and respect families' expertise and their wishes
- there is lack of information about entitlements and services
- there is insufficient support for their family member with intellectual disabilities when they are having problems, for example health problems or challenging behaviour
- they are neglected or disappointed by wider service systems, policy-makers and the government
- they have to fight for services and supports and continually having to advocate for their family
- they have to rely solely on informal family networks
- they feeling exhausted, tired and lonely

**In summary, life is good when families have opportunities, good quality support and are happy and healthy. When life isn't so good, it is often because of the limitations and challenges that the families encounter.**

## Families also talked about their development through life...



- 'Letting go' and being less protective of their child/young adult with intellectual disabilities
- Parents planning for their adult child's future support once they are gone
- Concerns and fears about their family member with intellectual disabilities developing romantic and sexual relationships

## What parents thought should happen now



1. Empower parents to form reliable alliances with service professionals and service systems
2. Develop nationwide parent to parent networks
3. Make information on entitlements and services easier to access

### Who wrote this summary report



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### Contact Us

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