



Opening Statement

Leap is a family-based, non-profit organisation that assists families of children with disabilities to take action for an inclusive life. We work with families, people with disabilities, their supporters, and allies. We focus our efforts on increasing expectations of what is possible in the lives of people with disabilities. We work with families with children with intellectual disabilities. We believe that the ordinary is the most precious of all, that “special” does people very few favours. We know that an ordinary life, a typical life produces better outcomes for people than segregated pathways.

We believe that much of what is good in life is not in the currency of money, that we can lose years, decades even, in the struggle to obtain more services and more resources and that ultimately, our children’s life is here and now. Many families of children with disabilities and their representative groups are clear on what they are against and what is not working – but less clear on what they are for and what is working. We believe that:

- Families who have a family member with a disability need support to not only survive but to thrive. To achieve this, we explore the idea of what a “good life” looks like with families through visioning and planning.
- We assist families to develop and articulate a strong and compelling vision of a good life. We do this to counter the culturally held low expectations of people with disabilities.

- We assist families to plan so that the elements of a typical life are more likely to be present as a child grows to adulthood.
- We encourage families to aim high and to focus on an ordinary life with valued roles.

This work involves ongoing conversations with families typically held around the kitchen table. Since the start of the pandemic these conversations have moved online and happen through our family Leadership webinar series or our online visioning and planning sessions.

- 1.) Developing A Vision of An Ordinary Life for Your Family Member.
- 2.) An Introduction to Inclusive Education.
- 3.) Celebrating Families – sharing stories.
- 4.) Supported Decision Making for children & young people with disabilities.
- 5.) Guest webinar 1 – Safeguarding the Future.
- 6.) Guest webinar 2 – Family Advocacy.
- 7.) Planning for life after school.
- 8.) Creating Community In the street where you Live - Cormac Russell.
- 9.) Getting a life not a service: How to utilize Individualised funding.

As a family-based organisation, we assist families to:

1. Figure out what we can do ourselves.
2. What we can do with others.
3. Where we need outside help.

We focus on belonging, relationships and valued social roles. Many families have found this approach has a better track record than relying on services to figure it all out.

This is not only important at crucial life stages like starting a new school or leaving school, but also when considering leisure and lifestyle options for our children, such as joining clubs and other groups. We believe it is essential to connect with other families and to work with people who are positive, have high hopes and are creative, and who have managed to create good lives for their own family member.

We encourage families to only dip their child's toe in special or segregated services and not to immerse them in these services. We know that the earlier a child deviates from the ordinary life path, the more difficult it is for them to return to it. For example, if you attend a special school, the opportunity to partake in typical milestones, such as work experience or having a part-time job are often lost. This makes it extremely difficult for a young person to re-join the typical life path on leaving school.

Why does this matter?

As we can see from the OECD report on Disability, Work and Inclusion in Ireland (2021), Government interventions in Ireland aimed at increasing the employment rates of disabled people are well intentioned but failing strategies. Data up to 2018 shows only 34% of people with disability are employed, with much lower rates of people with intellectual disability and people with autism in employment.

One example of a successful employment project is RISE located in Washington, USA, where 70% of people with developmental disability are in open employment. Research from RISE shows that the younger a person with disability enters the labour market, the more likely they are to stay in open employment for the rest of their working life. (RISE 2021)

RISE has established that the optimal age for people with disability to commence paid employment is thirteen years of age. Embedding young people with disabilities in ordinary valued roles in community, such as part-time work, is one of the most powerful ways to ensure that they do not live their lives on benefits, living in the shadows and experiencing loneliness and profound social exclusion, as is the case for many people with intellectual disability today.

Creating a positive and hopeful vision for the future, a vision that is supported by others, is vital to moving in the right direction.

In our work with families, much of what people say makes a good life, is not provided by services. Leap believe that children's (and adults') fundamental needs are for inclusion, participation, relationships, value and respect. These needs are best met in community when the person is embedded in a network of positive relationships.

We have a number of recommendations for the Committee today. These recommendations we believe contain many of the enablers of good lives, typical lives, valued lives. Our recommendations centre on resourcing children and families to stay on the inclusive life path, personal budgets, promoting innovation and the creation of inclusive neighbourhoods.

When the majority of the voices in this space are service providers lobbying for more funding, what gets lost is the simple truth; that the majority of people with intellectual disabilities are supported throughout their lives by their families.

Thank you for listening to us today, we are happy to now take any questions.



Infographic: Hilary Cottam