



DESSA – Disability Equality Specialist Support Agency

Opening Statement to the Joint Oireachtas Committee on Disability Matters
3rd July 2024

Dear Chairperson, Deputies and Senators, DESSA, the Disability Equality Specialist Support Agency welcomes the opportunity to be here today. My name is Alice Griffin and I am Manager of DESSA. I am joined by Brian Miller, founding member of DESSA and currently Company Secretary.

DESSA is a national community development organisation which was established in 2001 to work within anti-poverty and social inclusion programmes to ensure that they were inclusive of disabled people. Our mission is to promote the social inclusion of disabled people and their families at community level by providing strategic capacity-building supports - advocacy, training and information provision to the community and voluntary sector and to disabled people and their families. By inclusion, I mean the full and active presence, participation and contribution of disabled people in settings and spaces of their choice alongside their non-disabled peers. Disabled people are first and foremost members of their local communities and given their lived experience and expertise have much to contribute.

We are committed to supporting the creation of inclusive and non-disabling communities by engaging with a range of civil society organisations – local development companies, family resource centres, Children and Young People’s Services Committee (CYPSCs), local access groups, advocacy organisation, both national and local and disabled persons’ organisation (DPOs). While DESSA is not a DPO, we work closely with the DPO Network, an alliance of 5 national DPOs. We also work with parent advocacy organisations in supporting the full realization of the CRPD in Ireland.

Over the years we have developed a range of innovative projects. In 2023 we launched an eLearning course called An Introduction to Disability Equality, Inclusion and Human Rights. The aim of this course is to support civil society organisation in developing their understanding disability as an equality and human rights issue which is an essential step in improving inclusion in our communities. I am happy to report that the course was one of the initiatives honoured at TUSLA's Excellence Awards scheme in 2024.

Today I will be speaking about two of our projects. The first is called the Empowering Parents programme – an advocacy and capacity building programme for parents of disabled children and young people and the second is a project called Community Inclusion, Capacity & Connection: A Community Development Approach to Local Area Co-ordination. Before I do this, I want to say something about how we work.

The community development perspective

We are a community development organisation. We understand Community Development to be a way of working that creates opportunities for those who experience exclusion and have their voices heard, to participate in decisions concerning them and to actively engage in social change.

It is an approach that promotes community empowerment and is the means to enhancing the inclusion of disabled people who have historically been disempowered, excluded and had no voice.

At the heart of our work is the belief that disabled people are citizens with rights, not objects of charity. The principles that underpin our work – human rights, social justice & equality, inclusion, empowerment and respect – are informed by the CRPD.

So, our role is to empower; raise awareness; connect people; and build networks of and between disabled people and community.

The Empowering Parents Programme

According to the Committee on the Rights of Persons with Disabilities "The role of parents, ... should be to assist and empower persons with disabilities to have a voice and take full control of their own lives." The DESSA Empowering Parents Programme seeks to do this. Developed in 2007, this is a capacity building programme supporting parents to develop

practical advocacy skills so that they can champion the rights of their children. More importantly, it supports parents to move beyond an understanding of disability that is rooted in tragedy, medical narratives, and paternalism.

Over an 8-week period, parents are encouraged to think differently about their child's impairment and see disability from a human rights perspective in accordance with the social model of disability. It supports parents to effectively communicate and engage with schools and disability services and to understand and influence policy. The policy piece is important. Parents need support to actively engage, develop and inform State policy on issues related to their children and young people. Many of the parents we work with are not linked to impairment-specific advocacy groups and so, do not get to hear about or input into relevant State consultations or policy arenas such as the development of the National Disability Strategy.

Parent advocacy groups are not DPOs but they are recognized by the CRPD Committee as having a role to play, based on their knowledge and experience, in the realization of their children's rights.

To date, 2,400 parents, grandparents and guardians have participated in the Empowering Parents programme and close to 10,000 families have been impacted by our advocacy and family support work since 2007. We continue to deliver this programme across the country, supporting parents to actively engage and partner with services and schools to create the best possible outcomes for their children.

The LAC Project

The second project I would like to speak to you about is the Community Inclusion, Capacity & Connection project – our interpretation of local area co-ordination (LAC). This project was developed by DESSA in 2015 and was delivered in County Leitrim in collaboration with a range of civil society organisations which we recognized as having a pivotal role to play in advancing the active participation and inclusion of disabled people within their local communities. These included Leitrim Local Development Company, Leitrim Disability Equality Network (a local DPO), Down Syndrome Ireland and their Leitrim branch, North Connaught Youth Services, Breffni FRC along with HSE disability services. The DESSA project

was one of 5 pilot projects funded through the Dormant Accounts Fund over an 18-month period from January 2016 to June 2017.

The LAC model was originally developed in Australia in 1988 and has since been replicated in other countries. It is a way of working with disabled people and families who experience exclusion by reinforcing natural and community supports that are flexible and individualised and is underpinned by the principles of self-determination, citizenship and rights, and inclusion. The LAC model entails a local coordinator working with a caseload of individuals with lived experience of disability in small geographical areas, across disability and age groups. The role of the LAC coordinator is to enable and support people to identify and attain personal advocacy goals, develop their self-advocacy skills and build supportive networks in the community. The coordinator brings together elements of personal advocacy; family support; community development; capacity building; and case management into one role.

The vision for the DESSA LAC project was that disabled people and their families would determine their own needs and goals, become leaders, decision makers and advocates in their local communities and live meaningful and happy lives. We recognise that disabled people are first and foremost members of their local communities, and have rights including the right to access and enjoy community life like all other community members.

The project sought to support people to explore and achieve meaningful opportunities in life. It was about enabling and supporting people to move beyond having a presence in the community to actively participating, contributing and developing leadership and collaborative roles in the community. It was also about building the capacity of the local community infrastructure.

The project was a huge success:

- 52 individuals were supported to identify and achieve personal goals - Some of the individuals supported went on to enroll in the Access and Foundation course in St. Angela's College, Sligo while others were elected on to Leitrim PPN and the local Disability Network.
- 40 community development organisations received training in disability competency, equality and inclusion

- 9 parents of LAC participants completed the DESSA Empowering Parents programme
- Disability inclusion became mainstreamed in local and community development agencies in Leitrim which led to more disabled people becoming volunteers, and training as youth leaders for example. And several individuals engaged with and informed Leitrim Local Link on transport access issue.
- Some LAC participants gave mainstreaming support to other disabled people so there was a ripple effect which led to an increase in the overall number of disabled people in Leitrim engaging in the mainstream.
- There was also a marked increase in networking and collaboration between disability services and local community structures which led to an increase in disabled people participating in mainstream activities.

Unfortunately, the project ended after the pilot phase however the learning and good practice can and should be used today.

Learning points

1. A community development approach to LAC, involving key agencies across community and disability services in partnership with DPOs is the most effective and sustainable way of enabling people who experience a disabling society to live ordinary lives.
2. The active involvement of DPOs in co-creating LAC is essential for it to be successful and sustainable and aligned with the CRPD.
3. LAC requires the intentional development of strong partnerships and collaboration across sectors.
4. LAC must be rooted in mainstream community with mainstream organisations. Community development organisations are an effective role model for mainstreaming, the realization of rights and are animators for social inclusion in partnership with DPOs.
5. And finally, the effective implementation of State disability policy doesn't happen in isolation. Community inclusion doesn't happen naturally. It requires a competent and committed Community & Voluntary sector that is resourced, skilled and accountable.

In conclusion, local area coordination is an effective model for creating real opportunities for disabled people to be part of inclusive communities in a genuine and meaningful way and in building local community capacity. It is time to reignite the DESSA LAC model across the country.

Thank you