NO! to Another Carers Strategy

Claire Kenny & Fiona Weldon

December 11th December 24

Social Care Services – Setting the Scene

Historically our government has never taken Disabled Peoples needs into account – left us out of policy development and practice allowing non-disabled providers and umbrella organisations speak on behalf of us

Our government also assumes that the family have an obligation to provide any or even all the additional support that they need for their loved one - including providing 24-hour support + medical interventions without paid support or breaks – they're also forced into fighting for essential supports and services

We know that parents do play a significant role in society, but they need the provision of additional support services – whatever that looks like– parents just need to be parents

Ageing parents worry what will happen when they're gone

Carer's, Home Helps, HealthCare Workers, the Carers Allowance - comes out of the same funding pool – easier to get these types of supports than person centred supports in the form of Personal Assistance

Social Care Services – Setting the Scene

System of support is system centred – we are forced to fit into service provision - it is **over medicalised** – focuses on our perceived deficiencies – only peoples basic needs are supported via home-help, Carer Workers with minimal hrs – "**this is not living its only surviving"**

Relying on a family limits choice, limits freedom & puts other people in control of our lives – can create toxic relationships

We fear that where parents lobby for residential institutions this will increase demand - and that demand will inevitably lead to the "warehousing" of Disabled People regardless of level of support needs

Disabled People Are in Conflict With The Term “Care”

- Implies that all Disabled People need to be “looked after”
- Implies that either adults are being infantilised, or that Disabled People are “sick”- which shows how prevalent the medical model still is
- Assumes a power imbalance - the carer / paid or unpaid “looks after” someone who is unable to do make any decisions
- Healthcare needs are different to our support need. Some of us need healthcare professional support but most do not
- Personal Assistance Services are very different to access – even though the Disability Movement has proven over and over that this provision of support works

Jenny Morris

"Takes away our autonomy, and the assumption is that carers are in charge"

"Being reliant on family strips us from being mothers, dads, daughters, brothers, sisters, aunts, and vice vera"

The CRPD

- Ireland ratified the CRPD 2018 - ratified the optional protocol
- Article 19 recognises the equal right of all Disabled People to live in the community
- Article 4.3 states that DPOs must be involved in policy and legislation that effects our lives – must consult / co-create with us
- The Social Model of Disability frames the CRPD –impairment & disability are separate entities
- Independent living is about agency, self-determination, having real choice and be in control
- Disabled people must have the right to choose who supports them and at what times

Not in the Driving Seat - 2023

Examined the impact of reliance on family, highlighted the absence of research on the impact reliance on family has on Disabled People

Four emerging teams

1. **Spontaneity**
2. **Choice**
3. **Compromise**
4. **Privacy**

“PAS enabled Disabled People to have fun with their families and live spontaneously without planning too far ahead”

The Big Debate

For Disabled Children, Adults, Older People and Family Members – Win Win

- Define
- Legislate
- Invest
- Standardise
- Promote
- Collective Empowerment in the PAS NOW Campaign

ILMI Personal Assistance Campaign

Consultation to Co-Creation (CIC) Project

- Commissioned by the HSE in 2022 and published in 2024 - guidance document about enabling the effective participation of Disabled People in planning of the support services they use and in decision-making

- Further development of this work, the HSE has commissioned Inclusion Ireland, in collaboration with ILMI, to pilot and document models of good participation practice within HSE funded disability support services

Donegal, Sligo and Meath

Disabled People Must Take Control of State Funded Disability Services

Moving Disability Services From Segregation to Genuine Inclusion

Manifesto

- Until services are governed and managed by us “person-centred directed” policies will continue to pay lip-service to the needs of Disabled People
- Until Disabled Activists are controlling the disability industry, State funding will continually be funneled into systems which limit our choices
- Disabled People must be in control of the organisations that the State funds to provide our services
- Until that happens, State-funding will continue to be used to provide segregated services that limit our choices, paternalise us and deny us our rights to agency and choice in our lives

DPOs must be the Drivers for Change

Recommendations

- Parents + family roles must be valued, but not at the expense of Disabled People's experience of feeling infantilised or paternalised by the term "care"
- Must start to talk about systems of support (inside and outside of homes, in social, educational and employment settings) moving towards conversations about how we invest in inclusion – removal of barriers – everyone benefits – it's a **win win**
- Understand that language matters, it frames our thinking. Language can constrain our thinking and limit how we view groups of people. By always resorting to talking about "care" - Disabled People are without doubt demoted to a "passive role where their views are not regarded"
- We need to campaign for investment in supports that meet the needs of Disabled People to be part of the community, the needs of disabled people (regardless of impairment) and the needs of family carers will be met
- Independent Living should be about every Disabled Person, regardless of complexity of support needs, having what they need to live their lives to the fullest of their potential
- Parents need to expect more from clinicians, from our our educational system, our healthcare services, work with local & national DPO's

Appropriate supports will liberate Disabled People, and appropriate supports will also liberate families at the same time