

We Care Collective Written Submission: No Mother Left Behind

1. Introduction

1.1 We Care Collective

We Care Collective (www.wecarecollective.ie) was set up in January 2020 by mothers of children who have physical and intellectual disabilities, long-term health conditions, and neuro-diverse children, who require care over and above parenting typically developing children. During the pandemic, Special Educational Needs (SEN) and disability services were effectively withdrawn, meaning mothers provided extreme levels of care to our children with complex and serious needs without support or respite for over a period of eighteen months. The cost to mothers' and our children's mental and physical health was so apparent and appalling that we felt compelled to provide a voice for other marginalised mothers in our position by telling our stories in the media. We are currently affiliating to the National Women's Council of Ireland (NWC) to recognise mothering additional needs as a feminist issue and support their work in campaigning for a care-centred society and disabled women's rights.

1.2 Additional Needs Maternal Voices

We Care Collective's submission responds to the recommendations of the Citizen's Assembly on Gender Equality specifically from the perspective, experiences and needs of mothers of children with additional needs. Our responses will draw attention to how gender inequity intersects with ableism for women who parent children with disabilities. We Care Collective's submission concerns our urgent need for equality as mothers and women, rather than our children's needs, however these are of course gender relational given that services which support our children could alleviate the overwhelming and extreme burden of care currently forced on mothers.

We welcome many of the ambitious and commendable recommendations of the Citizen's Assembly on Gender Equality, but we were disappointed at the absence of marginalised maternal voices such as ours at the assembly and expertise on

mothering additional needs. This occlusion is surprising given that a 2011 Economic and Social Research Institute (ESRI) study on behalf of the National Council for Special Education (NCSE) estimated the prevalence of special educational needs in Ireland to be 25 percent and in-line with findings in the UK and the Netherlands.¹ These figures do not include infants, preschool children, higher education students and adult children being cared for at home. They also do not reflect the almost 4,000 children awaiting assessments of need (Children’s Ombudsman, 15 Dec 2021), or 21,317 children referred to CAMHS during the first eleven months of 2021 (HSE, 4 Feb 2022). According to the last census an additional 40,000 children were identified as having a disability from 2011-2016 alone. Research suggests that mothers, to a larger extent than fathers, take primary responsibility supporting these children².

1.3 Gendered and Forced Care Labour

We Care Collective have not identified ourselves as carers because we did not choose to become carers for our children. We have been forced into this additional, extreme and unsupported care work because of the lack of public childcare and chronic underfunding of disability services. This is also lifelong, forced care labour as our adult children will require extended additional support because they develop differently. For some of us it means the stress of parenting a child at a toddler stage developmentally for years beyond that typically expected, or even indefinitely. Mothers of children with additional needs’ care work is often overlooked because the additional disability care they provide for their children is conflated with their parenting role and differs significantly from that of caring for the aged or those with long term health conditions or physical disabilities. This makes mothers of children with additional needs a particularly marginalised group of women who require specific and urgent supports in order to live our lives again and participate fully in public life.

¹ Journal.ie, ‘One in four children have special educational needs – study’, 16 November, 2011: <https://www.thejournal.ie/one-in-four-children-have-special-educational-needs-study-281045-Nov2011/>, accessed, 22 March 2022.

² Kingston, Anna Karin, *A Different Maternal Journey; Living with Autism, Down syndrome and ADHD*. 2021: 11. <https://www.amazon.com/Different-Maternal-Journey-Living-syndrome-ebook/dp/B09L527KWD>

2. Definition of Care: The choice to work outside of the home and economic independence

We welcome the gender neutral wording and an emphasis on more State support for caring in the recommendation to amend Article 41.2 'Women in the home' of the Constitution, but this State support should not replace the right for mothers (parents) of sons and daughters with additional needs to participate equally in society on the same terms as everyone else. State supports such as Carers' Allowance and Domiciliary Care Allowance cannot substitute wages/salaries offered to mothers of children with additional needs who are forced to stay at home due to lack of service provision. Children with additional needs often have life-long conditions and will not reach developmental maturity of their peers, so mothers then become carers for their adult children who may have the developmental age of a young child. The language of 'care' is ableist as it is incapacitating the individual and generalising people into passive receivers of care rather than agents in their own rights. As a consequence, mothers (parents) are also reduced to care givers with no choices to participate equally in society.

2.1 Recommendations:

- Parents/mothers of children with additional needs (including adult children) who are either prevented from working outside the home or **choose to care additionally for their child or adult child, should be paid** to do so with the requisite pay, conditions, pension, training and equipment in line with professional carers, special education teachers, speech and language, occupational and physio therapists, and health workers (these are all the roles parents are expected to now take on due to substitution of parent training for individual therapies).
- Parents/mothers of children with additional needs who choose to return to work outside of the home should be enabled to do so by **the provision of public childcare inclusive of their children's additional needs, extended beyond early years to include the development diversity of our children** and with liaison with public disability services.

- **Parents/mothers of adult sons and daughters with disabilities should be considered in tandem with recommendations of supports for people with disabilities and not under a 'caring' rubric.** Supporting mothers (parents) to get their own lives back, the same way that parents of typically developing children do as they reach adulthood, will also enable adult sons and daughters with physical and intellectual disabilities to be supported to live quality lives away from their families. Individual needs of people with disabilities are currently totally dependent on parents. And when they die, siblings are expected to take over. It is often a drastic event in their lives when the parents die and they are moved to nursing homes. There needs to be **future planning where families and people with disabilities come together** for this purpose, **these policies need a radical overhaul**, and **we need public disability services.**
- Public disability services should include a **coordinator/key worker** who manages families' access and relationships with services as piloted in Sweden (<https://eurocarers.org/coordinator-support-for-parents-of-children-with-disabilities-in-sweden/>).

3. Domestic, Sexual and Gender-Based Violence

The recommendations in the Executive Report omit cases of domestic, sexual and gender-based violence in settings other than mainstream society, and is in this sense ableist. It is important to highlight that domestic violence also occurs in homes where sons/daughters with disabilities physically assault parents and siblings. Currently, these cases of violence cannot be alleviated by a police or court response because the perpetrators are under the age of 18 and/or have a disability.

Furthermore, there are cases where people with Intellectual Disabilities are both victims and perpetrators of domestic violence/sexual abuse (both within and outside residential settings), and tougher sentences will do nothing to help these marginalised people in our society. Support in these cases should nevertheless be addressed by mainstream society in legislation.

3.1 Child to Parent Violence

Research shows that up to 15 percent of cases of domestic violence in Irish courts are parents seeking protection from an adult child³. The authors found that there were no support services indicated for parents in such cases. The paper described such parents as "the most marginalised and vulnerable group at the family court" where the system fails their adult sons/daughters who have addiction, mental health, behavioural issues and brain injuries. Similarly, international research on child to parent violence have found high levels of victimisation among parents of children diagnosed with an autism spectrum disorder⁴.

Many Irish parents with dependent adolescent/adult sons and daughters with disabilities are also frequently victims of physical assault, but do not have the option of seeking protection/barring orders against their children if they are considered dependents on their parents. The lack of supports can have devastating consequences: two Irish mothers have died after being attacked by their autistic sons⁵.

Stigma prevents parents speaking openly about being assaulted by their children and in cases where the children have disabilities, service-providers will only provide residential supports in emergency cases. These cases entail either the death of parents, or the abandonment of the child by the parents in either respite facilities or hospitals in order to force residential service-provision. Ongoing, and not life-threatening domestic violence in these homes is otherwise ignored by society. The perpetrators in these cases are themselves victims of a society that fails them by not providing the appropriate support that is needed.

3.2 Recommendations:

- To end this type of domestic violence within the family home, **legislation needs to be in place to offer adequate services** to families who experience these particular difficulties. There needs to be an **open**

³ Conneely, O'Shea and Dempsey, *Irish Journal of Family Law* 2019 (4), 79-86

⁴ Johnson, Richert and Svensson, *Journal of Family Violence* (2022) 37:165–180

⁵ Susan Dunne, Kerry, 2013 and Lynn Cassidy, Wicklow, 2014

discussion which allows parents, and mothers in particular, to speak about their children's aggressive behaviours. Domestic violence support groups, disability groups and women's organisations must openly acknowledge this type of violence in homes.

- **Sexual abuse** where perpetrators and victims have intellectual disabilities needs to be included in recommendations for legislative changes.

4. Conclusion

Mothers of children with additional needs form a growing and particularly marginalised group of women in Irish society whose ability to work outside the home, to economic independence, and inclusion in mainstream society has been severely hindered by the lack of public childcare and disability services, and whose risk of violence and trauma from forced caring within the home remain substantial. The recommendations of the Citizens Assembly have the potential to give mothers of children the chance to live again, but in order for this to be fully realised these recommendations need to reflect the realities of our lives too and an interdependent approach to care. **Parents/mothers of adult sons and daughters with disabilities should be considered interdependently with recommendations of supports for people with disabilities**, rather than as if we live separate lives. The overwhelming responsibility for the care of children and adult children with additional needs must be relieved from individual families, where mothers are expected to 'sacrifice' their lives, and shared more equally with the State and society. **This must be reflected in the provision of inclusive public childcare and disability services.** As urged in the Assembly's strong open letter, as a society we must be courageous enough to prioritise the needs of the most marginalised in our society, particularly marginalised mothers such as ourselves, and embrace a more progressive taxation system and gender equality budgeting if we are serious about ensuring no Irish mother is left behind.