



Submission to the UN CRC Committee

On Group Homes as a form of Alternative Care for Children with Disabilities

Introduction:

The Preamble to the UN Convention on the Rights of the Child (CRC) states:

the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding

It has long been known that detachment from families causes children profound distress and negatively impacts upon their later lives¹. Also well-established is the negative impact of institutional care on children².

Globally, there are still two main life-trajectories for disabled children: inclusion in the private life of the family or exclusion from family life in various types of institution. I am certain that the Committee on the Convention on the Rights of Children (henceforth ‘the Committee’) is concerned about policies and practices limiting opportunities for children with disabilities to develop and sustain familial relationships. The attention that the Committee is giving to the issue of alternative care for children is welcome and I am thankful for this opportunity to feed into their deliberations vis-à-vis provision of such care for children with disabilities.

I seek to make a helpful intervention into the complex debate regarding the use of *group homes* as a form of alternative care. Given the commitment of the Committee to child protection and flourishing, I am confident members will approach the issue of group homes *carefully* and *cautiously*. In this submission I outline why such an approach is justified. I offer *sociological* rather than legal analysis.

Reason 1: lack of agreement over the definition of a group home

Establishing key terms helps to determine the boundaries of any debate. Unfortunately, meaningful exchange of views has been hampered by the absence of a universally agreed definition of group homes. The result is a fuzzy controversy.

Alternative terms such as ‘small group homes’, ‘small family homes’, ‘family-like care’ and ‘small-scale residential care’ appear across policy-documents, reports and research. It is not clear whether these describe the same thing.

Group homes provide care to a small number of children. This appears to be widely agreed. However, even a cursory glance through relevant literature reveals that there is no agreement regarding what constitutes a ‘small number’ – figures varying wildly, from 2 to 40 children.

Further, there is no one ‘type’ of group home: some are located within neighbourhood settings (just a *usual house on a usual street*), whilst others are physically removed from local communities. There are stand-alone group homes and those that cluster to form ‘children’s villages’. There are group homes that

¹ J. Bowlby (1951) *Maternal care and mental health: a report prepared on behalf of the World Health Organization as a contribution to the United Nations programme for the welfare of homeless children.*

² See library of sources at: <https://bettercarenetwork.org/library/particular-threats-to-childrens-care-and-protection/effects-of-institutional-care> (viewed 30.06.21)

have therapeutic aims - some of which exist at the therapeutic/secure-care nexus, providing care for children with mental health issues alongside children who have been placed into secure care via the criminal justice system (CJS). Such homes blur the boundaries between alternative care and care for young people in the CJS. The term is also sometimes used to describe what might more accurately be termed *temporary shelters* for children orphaned or dislocated from their families during a national emergency (e.g. conflict or natural disasters).

Adding to the complexity, there is little agreement over how to classify group homes. Are they an institutional form of care? The recent *Lancet Commission on Institutionalisation and Deinstitutionalisation*³ seems to be unsure. In June 2020 the Commission published its Report in *The Lancet Psychiatry* journal, stating:

For the purposes of this Commission, we define an institution as a publicly or privately managed and staffed collective living arrangement for children that is not family based. These institutions include orphanages, children's institutions, group homes, infant homes, children's villages, and similar residential settings for children. (My emphasis)

The same month their Recommendations were published in *The Lancet Child & Adolescent Health* and here they reversed their position distinguishing 'small group homes' from 'institutional care', arguing that 'institutional care' should be progressively eliminated, but that this does not include group homes.

This is a debate characterised by *vagueness* and *ambiguity*. Such uncertainty can be dangerous in policy and practice fields. In medicine vagueness and ambiguity have been shown to result in reduced adherence to guidelines and increased variation in clinical practice⁴. Without a clear definition of a group home and effort to reduce ambiguity in this area, there is a risk that State Parties will not adhere to any guidelines issued and there will continue to be much variation in practice vis-à-vis the use of group homes as a form of alternative care.

Reason 2: uncertainty regarding concepts of 'the family' and 'family-like'

According to proponents of group homes they are 'family-like'. This, they argue, is what distinguishes them from an institution and makes them a suitable form of alternative care. The Committee on the Convention on the Rights of Persons with Disabilities (CRPD)⁵ disagrees:

'Family-like' institutions are still institutions and are no substitute for care by a family.

To help navigate this aspect of the debate, we need a more in-depth discussion about 'family'; to be conscious of increasing family-diversity, yet understand what characterises a family *at its most fundamental level*. This will help us to understand *how* and *to what extent* group homes are like/unlike a family. Two avenues are worth exploring: first, the rich history of sociological research into the family; (b) second, research that captures *children's* views on family.

History and culture shape our understandings of the concept and there is no such thing as a 'typical family', nevertheless there is widespread agreement amongst sociologists that the family⁶:

- is a social group;

³ Details of the Commission and its reports available at:

<https://www.thelancet.com/commissions/deinstitutionalisation> (viewed 30.06.21)

⁴ S. Codish, R.N. Shiffman (2005) 'A model of ambiguity and vagueness in clinical practice guideline recommendations.' *AMIA Annu Symp Proc.* 146-50.

⁵ UN CRPD General Comment No. 5. Available at: <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx> (30.06.21)

⁶ See e.g. D.J. Cheal (2002) *Sociology of Family Life* or D.Chambers (2012) *A Sociology of Family Life: Change and Diversity in Intimate Relations*.

- is characterised by relationships that are more intense than many/most others;
- is *at best* composed of people who love and care for one another (regardless of blood-ties);
- is *at best* a site of and for acceptance and social inclusion;
- involves connection, bonds, attachment and obligations between members;
- involves life-time membership even if not life-time interaction.

Research informs us that children understand families in similar ways⁷. From a child's point of view, love, care, mutual respect and support are the key characteristics of family. They define the latter as people 'related to me' in some way (which does not need to be biological). What matters to children is the quality of the relationships within a family. They want to feel that their family listens to them, takes them seriously and values them. They look to family for emotional security and to provide affective support.

Before reaching any decision over the suitability or otherwise of group homes for children with disabilities (or indeed any child), I suggest that we must be satisfied that we have answers to the following questions:

- How 'family-like' are they? To what extent do they replicate the sociological and children's understanding of 'family'?
- In what ways are they *unlike* families and what are the consequences for children of growing up in settings that are 'like' families, but *not* families?
- How *unlike* a family can residential care be, before it is of concern or before it becomes an institution?

Moving to endorse group homes before resolving these questions would, I suggest, be risky.

Reason 3: should we be concerned about the nature and quality of 'evidence' being cited in this debate?

I draw to the attention of the Committee to two types of evidence that has been/is being employed within the group homes debate, which I believe need to be considered *carefully* and *cautiously*:

(a) **Research conducted by/on behalf of, funded, facilitated or otherwise endorsed by organisations that run or fund group homes:** even when such research has been undertaken by reputable researchers, such studies should be approached with organised scepticism due to the well-documented factor of 'funding effect' or 'sponsorship effect'⁸. Any correlation between research findings and funding/sponsorship source is never definitive evidence of bias, but is *prima facie* evidence that bias may exist.

(b) **Research conducted into the impact of residential care or institutionalisation upon children conducted by researchers from the medical and psy-sciences:** even when conducted with good intentions, such research is often shaped by these discipline's preoccupation with 'normal/abnormal' child development. Unfortunately, there is a long history of legislators and policy-makers giving more weight to research conducted by the medical and psy-sciences than to those of other disciplines or to the perspectives and experiences of disabled people themselves.

Research 'on' rather than 'with' children with disabilities, adopting an overly-medicalised deficit-model approach and perpetuating a pessimistic, tragedy perspective on their lives and futures, is problematic. Such studies neglect children's quality of life and subjective wellbeing. Further, there is evidence of

⁷ For example, see V. Morrow (1998) *Understanding Families. Children's Perspectives*.

⁸ S.Krimsky (2012) 'Do Financial Conflicts of Interest Bias Research?: An Inquiry into the "Funding Effect" Hypothesis', *Science, Technology, & Human Values*, 38 (4) pp. 566-587.

'scientism' within institutionalisation/deinstitutionalisation research, leading to a narrow range of research designs and measures. Many in the medical and psy-sciences hold that the 'gold standard' methodology is *quantitative* and the only credible measures are those that are *quantifiable* e.g. psychometric tests and or measures of height/weight or head circumference. The latter is often presented as a proxy for neural growth (brain development). Such studies and measures tell us little about children's lived experiences, their identities, abilities or desires/aspirations. Further, some of the measures themselves are contested (e.g. head circumference)⁹.

Again, the Lancet Commission is a case in point. Composed of 22 of the world's leading experts on the reform of care for children, it did not include anyone from the fields of Social Work, Social Care or Social Scientists with relevant expertise. A more transdisciplinary team might have prevented the Commission's:

- Relative neglect of the experiences of children with disabilities;
- Problematic suggestion that 'dedicated specialist therapeutic settings' (i.e. segregated settings) are a preferable placement for children with disabilities;
- Decision to exclude studies where there was 'no useable statistical data'. Had the Commission included qualitative studies there is a chance that their review might have encompassed at least some studies that captured the views and experiences of children themselves.

Reason 4: can we reasonably conclude that 'bad' group homes are just the 'few bad apples'?

There is little research that has found unequivocally 'positive' outcomes for children living in group homes. Caveats abound. For example, an Israeli study¹⁰ found that outcomes for young people who grew up in group homes were generally positive, but raised concerns about group home alumni's educational underachievement, low incomes and high rates of male involvement in the criminal justice system.

There is also literature that is more obviously critical of group homes. Issues raised are on a spectrum from less-than-optimal care through to mistreatment and abuse. Where mistreatment and abuse has been uncovered, victims are often children with disabilities.

Reports by Human Rights Watch (HRW)¹¹ and Disability Rights International (DRI)¹² make grim reading. HRW found that in Serbia children and young people with physical disabilities were living in group homes in inaccessible buildings, there was over-use of psychotropic medication to control behaviour and many children were not receiving education. DRI found that in Bulgaria children with disabilities were living lives of isolation and neglect, exposed to violence, sexual abuse and bullying.

Academic research points to additional concerns (indicative list only):

- A 2008 study in **Botswana**¹³ investigated children's experiences of life in group homes, clustered in a village-style arrangement and run by an established NGO. The authors highlight concerns over turnover of staff serving as 'Mothers'. Children described instances of perceived excessive

⁹ L. Nicolaou, T. Ahmed, Z.A. Bhutta et al. (2020) 'Factors associated with head circumference and indices of cognitive development in early childhood. *BMJ Global Health* 5.

¹⁰ M. Schiff and R. Benbenishty (2006) 'Functioning of Israeli group-homes alumni: Exploring gender differences and in-care correlates', *Children and Youth Services Review*, 28 (2), pp. 133-157.

¹¹ HRW (2006) "*It is My Dream to Leave This Place*". *Children with Disabilities in Serbian institutions*. Available at: <https://www.hrw.org/report/2016/06/08/it-my-dream-leave-place/children-disabilities-serbian-institutions> (viewed 30.06.21)

¹² DRI *A Dead End for Children. Bulgaria's Group Homes*. Available at: <https://www.driadvocacy.org/wp-content/uploads/Bulgaria-final-web.pdf> (viewed 30.06.21)

¹³ G. Morantz & J. Heymann (2010) 'Life in institutional care: the voices of children in a residential facility in Botswana', *AIDS Care*, 22 (1), pp. 10-16.

verbal and corporal punishment; having limited contact with their own families; and inadequate community interaction;

- A 2013 study in **South Africa**¹⁴ found that young people living in group homes reported communication barriers between staff and residents. They found it difficult to discuss HIV, sex, and substance use with childcare workers. Childcare workers did not talk to them about their parents' deaths, separation from family, or other painful events;
- A 2020 study in **Canada**¹⁵ found that restrictive interventions (restraint, seclusion and time-outs) are frequently used in group homes and have potential adverse effects amongst an already traumatised population;
- A 2020 study in **Norway**¹⁶ found there was no consistency in staffing in group homes – staffing flexibility was prioritised over child wellbeing. When children became attached to a member of staff this was perceived to be a 'problem'. Staff spoke 'over the heads' of children, reducing them to their medical diagnoses and objectifying them. Private tasks were addressed in public spaces, compromising children's dignity.

Given the extent and geographical spread of this evidence, I would urge the Committee to reject any arguments that poor examples of group homes are but 'a few bad apples'. That would be too easy/comfortable a conclusion, I fear.

Reason 5: are we at risk of getting distracted?

Important though the debate about group homes is, I suggest that it must not distract our attention from two important issues:

- Why so many children with disabilities are in alternative care;
- Why children with disabilities are seen as 'hard-to-place' in adoption or foster care.

Poverty, plus a lack of access to free or affordable community-based health, education and social services are placing families of disabled children into crisis and contributing to the placement of disabled children into alternative care. Research from the US highlights increasing concern regarding the incidence of natural caregivers voluntarily abdicating custody because they lack adequate resources to address their young person's mental health issues¹⁷. There is also evidence that in Brazil, Mexico and Peru disability is a factor in determining whether a child is in alternative care and increases the likelihood that they will remain there throughout childhood¹⁸.

A 2007 study from Sweden¹⁹ of families of children with autism or learning disabilities paints a picture of families under enormous pressure, inadequately supported; of parents suffering total exhaustion, social isolation and anxiety about the impact of the family situation on their other children. Whilst parents

¹⁴ D.F. Nestadta et al (2013) 'HIV+ and HIV- youth living in group homes in South Africa need more psychosocial support', *Vulnerable Child Youth Studies*, 8 (3), pp. 195–205.

¹⁵ A. Matte-Landry, D. Collin-Vézina (2020) 'Restraint, seclusion and time-out among children and youth in group homes and residential treatment centers: a latent profile analysis', *Child Abuse & Neglect*, 104702. Available at: <https://doi.org/10.1016/j.chiabu.2020.104702> (viewed 30.06.21)

¹⁶ I. Fylkesnes (2021) 'Institutional talk and practices: A journey into small group-homes for intellectually disabled children', *Disability & Society*, 36 (6), pp. 999-1020.

¹⁷ W-Y. Chow (2014) 'Youth in Group Home Care: Youth Characteristics and Predictors of Later Functioning', *The Journal of Behavioral Health Services & Research*, 41 (4), pp. 503-19.

¹⁸ C. Gale (2016) *Alternative Child Care and Deinstitutionalisation in Central and South America*. Available at: <https://www.sos-childrensvillages.org/getmedia/db7219d2-635c-43bf-b386-1f2c9a1669e4/Central-and-South-America-Alternative-Child-Care-and-Deinstitutionalisation-Report.pdf> (viewed 30.06.21)

¹⁹ Y. Benderix, B. Nordström, B. Sivberg (2006) 'Parents' experience of having a child with autism and learning disabilities living in a group home: a case study'. *Autism*. 10 (6), pp. 629-41.

expressed relief at the move of their child into a group home, they also felt much guilt. The authors argue that early intervention programs adapted to the special needs of each family might have helped prevent these families placing their child into residential care.

Early intervention programs can be effective. A 2001 US study²⁰ tested the efficacy of a program supporting children with significant emotional and behavioural difficulties and their families (REPARE-*Permanency through Adoption and Reunification Endeavors*). This was based upon empowerment, ecological family development and community development. Children spent time 'out' of the family home, but not 'away' from the family. Families were brought into the program. The findings suggest that there are ways in which families can be better supported to learn the skills and become empowered to support their children, even where children may have very challenging behaviours and high levels of distress. REPARE resulted in better outcomes in terms of stability. The authors defined stability as children returning to stable, family-based care (with biological or adoptive parents, kinship care or foster care).

The Ubuntu team at the London School of Hygiene and Tropical Medicine²¹ agree that early intervention is vital. They have developed, implemented and evaluated two participatory programs *Getting to Know Cerebral Palsy* and *Juntos* ('together' in Portuguese), which offer training to parents of children with complex needs, develop connections amongst families (peer support) and improve community-support. They are currently offering their training in over 30 countries.

Additionally Cantwell et al²² document case-studies of good/better practice – programs designed to keep families together – including initiatives developed in low/er income countries. Fewer resources need not be a barrier to improved services. For example, they describe a national program in Nepal. This multi-strand initiative included: improved healthcare, helping parents to communicate with children who have hearing impairments (teaching them sign language), advocacy for inclusive education, disability-awareness campaigns (to tackle stigma in wider society), a disability ID card to assist families to access allowances, a drive to include disabled children in clubs/leisure activities and micro-finance initiatives to help parents economically.

Whilst providing better support for families is essential, there will always be some children with disabilities requiring alternative care – for example children who have been subjected to neglect or abuse. Unfortunately, children with disabilities are often viewed as 'hard-to-place' into adoption or foster care and this can become a self-profiling prophecy. A 2015 Scoping Review²³ into the international literature on permanence for disabled children and young people through foster care and adoption revealed that amongst relevant services there was a 'lack of expertise, but plenty of pessimism' regarding achieving permanency for disabled children. The review found that such pessimism is unnecessary - disabled children can be successfully placed with adoptive and foster parents. What is required is systemic change – the right policies, services, programmes and professional practices – to make this happen.

²⁰ M.J. Landsman, V. Groza, M. Tyler and K. Malone (2001). 'Outcomes of family-centered residential treatment'. *Child Welfare: Journal of Policy, Practice, and Program*, 80 (3), pp. 351–379.

²¹ Link to the website for this project: <https://www.ubuntu-hub.org/> (viewed 30.06.21)

²² N. Cantwell, J. Davidson, S. Elsley, I. Milligan, N. Quinn (2012). *Moving Forward: Implementing the 'Guidelines for the Alternative Care of Children'*. Available at:

https://strathprints.strath.ac.uk/43093/1/Final_English_Version_of_Moving_Forward_Handbook.pdf (viewed 30.06.21)

²³ V. Welch, C. Jones, K. Stalker & A. Stewart. (2015) 'Permanence for disabled children and young people through foster care and adoption: A selective review of international literature'. *Children and Youth Services Review*, 53, pp. 137-146.

Recommendations

To conclude, I would like to recommend the following to the Committee, that they:

- Consider *carefully* and *cautiously* the nature, quality and independence of the evidence presented to it by lobbyists;
- Take care not to prioritise evidence and knowledge derived from the medical and psy-sciences to the neglect of that from other sources;
- Avoid making statements that endorse group homes (be that active or ‘soft’ endorsement) and instead call for more research in this area. Such research needs to: (a) be properly independent; (b) advance beyond the use of medical and psychological measures of child-development, to encompass a far wider array of indicators of children’s ‘flourishing’; (c) position the voice and experiences of disabled children at the centre of inquiry, employing inclusive, child-centred methodologies.

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