



Submission to the Twenty-seventh Session of the Human Rights Council Universal Periodic Review of the United Kingdom of Great Britain and Northern Ireland

September 2016

Brighton and Hove Impetus is a charity that helps vulnerable adults who are dealing with loneliness and isolation because of age, disability or poor mental or physical health. We achieve this by providing services such as befriending, advocacy and other support. We help clients make the right connections in their community, build skills which improve lives and wellbeing and we do this through a large network of over 300 trained volunteers.

Impetus supports almost 1000 people every year across a range of services. We work with older people, adults with learning disabilities, autism spectrum conditions, mental and physical health problems and other support needs.

The organisation has a track record of providing quality services and is accredited by the mentoring and befriending Approved Provider Status. In 2016 Impetus was awarded the Queens Award for Voluntary Service. Impetus is funded by a range of statutory sources, charitable trusts and foundations and public donations.

Website: <http://www.bh-impetus.org/>

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1 Executive Summary

- 1.1 Between 2013 and 2015, of the cases where Brighton and Hove Impetus provided specialist independent advocacy to parents with learning disabilities, 78% went on to care proceedings and 100% of those care proceedings resulted in the removal of a child. Impetus' direct experience is limited to Brighton and Hove, yet this is an issue across England.
- 1.2 Parents with learning disabilities are legally entitled to support to be able to fulfil their parenting role and to meet the good enough standard of parenting. The current system does not provide or enable such support, which violates the right to family and disregards the best interests of the child.
- 1.3 Parents with learning disabilities are put through an assessment system that is often not adjusted to reflect their disability, meaning most cases are destined to fail and equate to a violation of the right to a fair hearing.
- 1.4 These assessments often lead to care proceedings, at which point it is highly likely that one or more children will be removed from the parent. The failure to accommodate the parents' special needs and the inevitable outcome of care proceedings related to a parent with learning disabilities violate the right to freedom from discrimination and the rights of persons with disabilities, particularly regarding women with disabilities, and the best interests of the child.
- 1.5 This is at great financial cost to the public authorities, which calls into question whether the public authorities are acting reasonably according to their maximum available resources.
- 1.6 The lack of support and failure to accommodate for vulnerabilities prevents parents with disabilities from appealing decisions and exercising their right to an effective remedy.
- 1.7 It has also been found that 56% of parents with disabilities that have been subject to care proceedings and consequently had a child removed from their care have reported suicidal ideation or attempts relate to the case. Despite knowing of this real and immediate risk and the vulnerabilities of these adults, the public authorities have not put reasonable support mechanisms in place to tackle this issue, which is contrary to their obligations under the right to life.
- 1.8 Brighton and Hove Impetus recommends that the UK government ensures that adequate, effective and efficient ways of supporting parents with learning disabilities are introduced as standard across the UK. These steps are

required by the UK's obligations under the UDHR, the ICCPR, the ICESCR, the CEDAW, the CRC and the CRPD.

2 Equality and Non-Discrimination

- 2.1 Section 3(1) of the Human Rights Act 1998 (HRA) requires that domestic legislation “so far as is possible to do so... must be read and given effect in a way which is compatible with” the European Convention on Human Rights (ECHR). Section 2 of the HRA requires a court or tribunal determining a question connected to the ECHR “must take into account” the jurisprudence of the European Court of Human Rights. Section 6(1) of the HRA places a statutory obligation on public authorities to not “act in a way which is incompatible” with the ECHR. One such requirement is for public authorities and the courts to have due regard for Article 14 of the ECHR.
- 2.2 Section 29 of the Equality Act 2010 imposes a duty on service providers, to the public or section of the public, to provide a service without discrimination and to make reasonable adjustments. Section 149 of the Equality Act 2010 imposes duties on public authorities and persons who perform a public function to eliminate discrimination and to promote equality of opportunity.
- 2.2 The Care Act 2014 provides for entitlement to support if: a) an individual has a long-term disability; b) support is needed regarding two of the enumerated outcomes or more; and c) there would be a negative impact on the individual’s well-being. The listed outcomes include: a) maintaining family relationships; and b) carrying out caring responsibilities for a child.ⁱ
- 2.3 The Department of Health (DoH)’s ‘Good Practice Guidance on Working with Parents with a Learning Disability’ (2007) recommends accessible, clear, co-ordinated and tailored referral, assessment, support and independent advocacy.
- 2.4 These statutory duties and good practice are not being implemented for parents with learning disabilities, due to a lack of adequate and effective support, and a failure within the existing system to accommodate learning disabilities. Between 2013 and 2015, 78% of the clients supported by Brighton and Hove Impetus were subject to care proceedings. For the cases that got to this stage, 100% resulted in the removal of the child and 26% had previously had a child removed.
- 2.5 Brighton and Hove Impetus has highlighted the issue on a number of occasions since early 2015 to local public authorities. Shared Lives, an award-winning long-term placement pilot scheme for parents with learning difficulties in the South West of England offered to work with other local authorities on a similar scheme in March 2015, but this was not taken up.

2.6 Brighton and Hove Impetus recommends that the UK government:

- a) respect inherent dignity, individual autonomy, including the freedom to make one's own decisions, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of parents with learning disabilities and their children; equality of opportunity; accessibility; and equality between men and women;**
- b) take all appropriate measures to eliminate discrimination on the basis of sex and/or impairment by any State agent, person, organisation or private enterprise;**
- c) take all appropriate measures to ensure and promote full realisation of all human rights and fundamental freedoms for all parents with learning disabilities and their children. These measures are legislative, educational, administrative, cultural, political, linguistic and others. These measures may be temporary or long term and should overcome *de jure* and *de facto* inequality; and**
- d) ensure all relevant public authorities and their employees are fully aware of how the Care Act 2014 applies to parents with learning disabilities, at all relevant stages.**

3 Right to Life

3.1 Between 2013 and 2015 of the parents with learning disabilities that Brighton and Hove Impetus provided with specialist independent advocacy, 56% reported suicidal ideation or attempts related to their case following care proceedings. The public authorities should be aware of the vulnerability of parents with disabilities and should have known the real and immediate risk that this decision would have had on their mental health and posed to their life. However, the support required to mitigate this risk is not provided.

3.2 Brighton and Hove Impetus recommends that the UK government:

- a) take all reasonable steps to support parents with disabilities in effectively addressing suicidal ideation or attempts.**

4 Right to a Fair Hearing

4.1 In addition to international human rights provisions, the right to a fair hearing is protected in domestic law under the HRA, which makes Article 6 of the ECHR directly applicable. This obligation extends from the process leading to a court case, such as meetings and case conferences, through to the court case. The failure to take reasonable steps to address the inequality of arms that exists and to accommodate a parent's disability violates this right.

4.2 Brighton and Hove Impetus recommends that the UK government:

- a) take all reasonable steps to ensure equal access to a fair, public, independent and impartial hearing for parents with learning disabilities. This includes making reasonable adjustments to accommodate disability and increasing independent advocacy capacity;**
- b) take all reasonable steps to ensure equality of arms for parents with learning disabilities;**
- c) recognise parents with learning disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others. To abolish the substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against parents with learning disabilities;**
- d) ensure that the right of parents with disabilities to legal capacity is not restricted on an unequal basis with others. A person's status as a person with a disability must never be grounds for denying legal capacity or any other international human rights. Perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity;**
- e) provide parents with learning disabilities with access to support in the exercise of their legal capacity. This support must respect the rights, will and preferences of parents with learning disabilities and should never amount to substitute decision-making. Significant efforts must be made to determine the will and preferences of an individual. If after such efforts it is not practicable to determine the will and preferences of the individual, the 'best interpretation of will and preferences' must replace the 'best interests'**

determination in relation to adult parents with learning disabilities. Parents with learning disabilities must have the right to refuse support and terminate or change the support relationship at any time; and

- f) create appropriate and effective safeguards for the exercise of legal capacity with the primary purpose of ensuring the respect of the person's rights, will and preferences. The safeguards must provide protection from abuse on an equal basis with others, including undue influence; and**
- g) require the establishment of a joint protocol between local authorities' Adult Services and Children's Services in the UK for referrals and support service for parents with learning disabilities.**

5 Right to Family and Private Life

5.1 In addition to the relevant international human rights law standards, Article 8 of the ECHR imposes an obligation on State actors to respect the right to family and private life. This provision is directly applicable at a domestic level under the HRA. The Care Act 2014 requires maintaining family relationships and caring responsibilities for a child to be considered.

5.2 The high percentage of cases that result in a child being removed from a parent with learning disabilities show that these domestic, regional and international obligations are not being implemented.

5.2 Brighton and Hove Impetus recommends that the UK government:

- a) respect, protect and fulfil its legal obligations under domestic, regional and international law, particularly in relation to the right to family. This includes ensuring that the relevant public authorities are acting in accordance with human rights standards.**

6 Rights of the Child

5.1 International standards require that decisions are made in the best interests of the child. The lack of support for parents with disabilities within the current system assumes that it is in the best interests of the child to be removed from their parent. It does not enable a fair judgment to be made and discriminates against a child for having a parent with learning disabilities.

6.2 Brighton and Hove Impetus recommends that the UK government:

- a) respect, protect and fulfil its legal obligations under domestic, regional and international law, particularly in relation to the best interests of the child. This includes ensuring that the relevant public authorities are acting in accordance with human rights standards.**

7 Rights of Women

7.1 Women with learning disabilities are disproportionately affected by the inadequate system that currently exists regarding decisions concerning their children.

7.2 Brighton and Hove Impetus recommends that the UK government:

- a) recognise that women with disabilities are subject to multiple discrimination. This includes direct discrimination, indirect discrimination, discrimination by association, denial of reasonable accommodation and structural or systematic discrimination. Measures should be taken to ensure the full and equal enjoyment of women with learning disabilities for all human rights and fundamental freedoms;**
- b) take measures to ensure the full development, advancement and empowerment of women with learning disabilities;**
- c) abolish existing laws, regulations, customs and practices that constitute discrimination against women with learning disabilities;**
- d) adopt and apply the measures needed to secure the development, advancement and empowerment of women with learning disabilities. This involves a) systematically**

mainstreaming the interests and rights of women with learning disabilities across national plans, strategies and policies concerning women, childhood and disability as well as in sectoral plans, concerning gender equality, access to justice and social protection; and b) targeted and monitored action aimed specifically at women with learning disabilities;

- e) support and promote the creation of organisations and networks of women with learning disabilities and the promotion and support for women with learning disabilities to take leadership roles in public decision-making bodies at all levels; and**
- f) promote specific research on the situation of women with learning disabilities, in particular research on the impediments to the development, advancement and empowerment of women with learning disabilities, in all areas related to them.**

8 Rights of Persons with Disabilities

8.1 International human rights standards and domestic lawⁱⁱ require that persons with disabilities are not discriminated against and that reasonable adjustment is made to ensure persons with disabilities are not disadvantaged and able to live life to the full.

8.2 The current system for choosing whether a child can remain with their parent who has a learning disability often makes no adjustments to offer the reasonable support that is required by international and domestic law. This has resulted in discrimination against parents with disabilities. As the figures collected by Brighton and Hove Impetus show, it is likely that such cases will develop into care proceedings (78% of cases handled by Impetus between 2013 and 2015), at which point it is guaranteed that the child will be moved into care (100% of the 78%).

8.2 Brighton and Hove Impetus recommends that the UK government:

- a) respect, protect and fulfil its legal obligations under domestic, regional and international law, particularly in relation to the rights of persons with disabilities. This includes ensuring that the relevant public authorities are acting in accordance with human rights standards;**

- b) take measures to raise levels of awareness about the rights of parents with learning disabilities and their children not only among public officials and State agents, but also among the population at large; and**
- c) closely consult with and actively involve parents with disabilities, through their representative organisations, in the development and implementation of legislation, policies and other decision-making processes.**

9 Right to Effective Remedy

9.1 The same issues at the decision-stage – lack of support and lack of adjustment to accommodate special needs – continue at the remedial stages meaning that an effective remedy, as required by international human rights law and the HRA, under Article 13 of the ECHR, is not vindicated for parents with learning disabilities.

9.2 Brighton and Hove Impetus recommends that the UK government:

- a) ensure that parents with learning disabilities have access to effective remedies, which are appropriately adapted so as to take account of the special vulnerabilities of these categories of person;**
- b) investigate violations against parents with learning disabilities and their children promptly, thoroughly and effectively through independent and impartial bodies;**
- c) make adequate reparation to parents with learning disabilities whose rights have been violated; and**
- d) take measures to prevent a recurrence of a violation of the rights of parents with learning disabilities and their children. This may require the provision for and implementation of provisional or interim measures to avoid continuing violations and to endeavour to repair at the earlier possible opportunity any harm that may be caused by such violations.**

10 Economic Social and Cultural Rights

- 10.1 International standards require that a State takes reasonable steps within its maximum available resources regarding ICESCR rights. The figures indicate that decisions are made on the basis of prejudice against parents with disabilities, as opposed to acting in accordance with human rights obligations and economic sense.
- 10.2 It is calculated that the current assessment and legal process is £74,371 per parent with a learning disability, per removal of a child. If an appeal against the decision is successful precedent has set compensation at £20,000. A fostering or special guardianship package is an additional £85,045 per year.ⁱⁱⁱ
- 10.3 The Medway Council's Valuing Parents Support Service has been identified as an alternative approach. This costs £8,450 per family per year. A more comprehensive support service is the Shared Lives placement, which includes specialist parenting support. This costs £47,738 per year.^{iv}
- 10.4 Brighton and Hove Impetus recommends that the UK government:
- a) **take all reasonable steps to the maximum of its available resources to deliver the specialised parenting support services required to adequately support parents with learning disabilities and to protect their children. This includes ensuring that such services are not subject to retrogression and where the available resources are demonstrably inadequate, that the UK government strives to ensure the widest possible enjoyment of the relevant rights under the prevailing circumstances;**
 - b) **monitor the extent of the realisation, or non-realisation, of the rights of persons with learning disabilities and their children, and to devise strategies and programmes for the promotion of these rights, irrespective of resource constraints; and**
 - c) **Establish an efficient and effective Specialist Support Service for parents with learning disabilities in areas the UK where it currently does not exist; and**
 - d) **Extend the option of Shared Lives to all parents with learning disabilities in the UK.**

i Sections 1, 9 and 13, Child Care Act 2014; Department of Health, 'Care and Support Statutory Guidance: Issued under Care Act 2014' (DoH, 2014), at section 6.

ii Human Rights Act 1998; Equality Act 2010; Care Act 2014.

iii Karen Broadhurst et al, 'Capturing the Scale and Pattern of Recurrent Care Proceedings: Initial Observations from a Feasibility Study' (University of Manchester, 2014); Lesley Curtis, 'Unit Cost of Health and Social Care' (PSSRU, 2014), at 95; Impetus, 'Improving Support for Parents with Learning Disabilities in Brighton and Hove Submission to Brighton and Hove Fairness Commission' (Impetus, 2016), at 3-5.

iv Impetus, 'Improving Support for Parents with Learning Disabilities in Brighton and Hove Submission to Brighton and Hove Fairness Commission' (Impetus, 2016), at 4-5.