

CHAPTER 4: TO LOVE AND BE LOVED

“You’ve got to have something to eat and a little love in your life before you can hold still for any damn body’s sermon on how to behave”

Billie Holiday

Billy Holiday (1915 – 1959), known professionally as Billie Holiday, was an American jazz and swing music singer. Nicknamed “Lady Day”

WE ASKED AND YOU SAID

People with learning disabilities and/or autistic people often face barriers establishing and maintaining relationships. For many, the pandemic had made these difficulties worse, leading to feelings of isolation, anxiety, and mental health challenges. We asked people what was important to them about relationships and the opportunity to love and be loved and these are some of the responses.

Adult loving and sexual relationships are not prioritised and supported

Support services place barriers in the way of people living full social lives

Family relationships were not prioritised in the pandemic response, particularly for people living in congregate settings

Family relationships are often seen through the prism of support rather than loving family relations
Withdrawal of support

left families struggling, unpaid 'carers are financially underpaid and emotionally under supported'

There is a concern that services will not value people's relationships long term

Concerns about the quality of support available puts pressure on families worrying what will happen when they are no longer able to support their loved ones

Adult sexual relations are seen as a health issue rather than a right

HUMAN RIGHTS FRAMEWORK

The right to respect for private and family life is enshrined in ARTICLE 8 of the European Convention on Human Rights. It states that:

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

The UN Convention on the Rights of Disabled Persons provides a more detailed account of the rights of disabled people, particularly in relation to personal and intimate relations.

ARTICLE 23: RESPECT FOR HOME AND THE FAMILY

- 1 States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that: (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized; (b)

The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided; (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

- 2 States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.
- 3 States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.
- 4 States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.
- 5 States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

You can find more information about these rights [HERE](#)

HUMAN RIGHTS FRAMEWORK

IDEAS WE CAN WORK ON TOGETHER?

We have gathered ideas of things we can work on together to improve the lives of people with learning disabilities in the areas they, and their families, said are important to them.

People spoke strongly about the importance of respect and support for healthy family relationships. Also, opportunities to love and be loved, in the widest and most inclusive sense. These ambitions may be achieved through the following steps:

- We should ensure that the right to family life is embedded in service standards and commissioning. Formal support services would be required to make explicit reference, and adhere to, the supported persons will and preferences with regards to family relationships.

- Adopting an explicit Human Rights based approach to frame service design and practice development.
- Recognition that people with learning disabilities may require additional support to exercise their will and preferences in relation to sex, sexuality and relationships. Ensuring this support is available.

- Ensuring that people with learning disabilities and/or autism are aware of their sexual rights.

- Sexuality and relationships should become a mandatory focus in Care Quality Commission (CQC) inspections, in the Key Lines of Enquiry.

- All social care workers undertaking training on supporting sexuality and relationships, using a rights framework.

- Support providers adopting the No Bedtimes guide, ensuring people can develop and maintain friendships and relationships by attending events and activities evening, weekends and as late as the person desires.

- Adoption of the Stay up Late manifesto pledges by commissioners and support provider.

- REACH standards adopted as basic standards for supporting good lives and underpinning all service provision.

- Social workers and commissioners using rights based standards, such as REACH, to measure progress towards explicitly rights based practice.

WHAT GOOD MIGHT LOOK LIKE (HOW WILL WE KNOW WE ARE ON THE RIGHT TRACK)

GOOD EXAMPLE 1

Supported Loving is a human rights-based campaign, with associated network meetings, hosted by Choice Support. The campaign actively promotes the belief that people with learning disabilities and/or autism should be able to enjoy the same sexual and romantic freedoms as everyone else. The campaign highlights the fact that 3% of people with learning disabilities live as part of a couple compared to 70% of the general population.●

“For people with learning disabilities finding love is often more than just chemistry - it can come down to getting the right support from your staff”●

GOOD EXAMPLE 2

Stay up Late is a registered charity committed to promoting the rights of people with learning disabilities to live the lifestyle of their choosing. It is particularly concerned that people with learning disabilities, and autism, aren't able to Stay Up Late and do the things so many people, who don't need support, take for granted.

The charity recognised that people with learning disabilities often aren't able to lead full and active social lives because their support workers finish at 10pm. This means lots of people with learning disabilities leave events at 9pm.

Recognising that people with learning disabilities have the same right to stay up late and have fun as anyone else Stay up Late have campaigned to raise awareness of the issue, issuing a No Bed Times guide and a Manifesto for an Ordinary Life.

GOOD EXAMPLE 3

The British Institute of Human Rights (BIHR) promotes change through human rights by supporting people and organisations to use human rights advocacy and approaches in their everyday life to achieve positive social change. They work with people, with communities and with public bodies to develop greater understanding of the power and potential of human rights to transform lives.

GOOD EXAMPLE 4

Think Local Act Personal place an emphasis on building people's resilience and social connections using asset-based practice; building social networks, encouraging membership of community groups, creating opportunities for social interaction based on active contribution. They also encourage social workers to change the workforce culture to one that is 'strengths-based', promoting wellbeing, early intervention and prevention.

WHO DO WE NEED TO ENROL/ENGAGE?

There are many actions that flow from the ‘we asked you said’ and the ‘ideas that we can work on together’ that do not require high level government action. Citizen action and co-ordination can bring about many of the desired changes that will have a significant positive impact on the lives of people with learning disabilities and their families. One only need look at the Stay Up Late campaign to see what impact a small, committed group of people can have.

Building alliances of individuals, advocacy and campaigning groups, funders and human rights organisations around the issue of the right to love and be loved could have far reaching consequences. It will need a concerted commitment to dismantle the discriminatory service system barriers that inhibit opportunities for people with learning disabilities. Commissioners and regulators can play their part by requiring evidence of active support with this aspect of everyday life as standard.

NEXT STEPS/FIRST STEP

FOR SERVICE PROVIDERS

Support providers adopt the No Bedtimes guide.

Develop alliances of interested parties to promote the right to love and be loved, building on the good work undertaken to date.

FOR GOVERNMENT

Care Quality Commission (CQC) prioritise sexuality and relationships during inspections.

FOR COMMISSIONERS

Education, health and social care commissioners and providers need understand the right to a private and family life and ensure that this is incorporated into service standards and practice.

All social care workers undertake training on supporting sexuality and relationships, using a rights framework.

REACH standards should be adopted as basic standards for supporting good lives.

FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

A co-ordinated campaign to raise awareness of sexual rights among people with learning disabilities and or autism, families, and professionals.