

Human rights in both health care and social care are all about ensuring everyone has access to the care they need without discrimination

Health & Social Care

Submission to Select
Committee 1

The Equality & Human Rights Commission
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EXECUTIVE SUMMARY

Human rights in both health care and social care are all about ensuring everyone has access to the care they need without discrimination. This includes the right to

- access health and/or social services,
- privacy and confidentiality, and
- be treated with dignity and respect.

This document sets out to examine the current (although rapidly changing) Health and Social Care eco-system on St Helena, taking into account its unique economic situation, its remoteness and the population demography and numbers.

The EHRC makes the following recommendations which are given context below.

Recommendations

Recommendation 1 – Adult Social Care legislation be enacted as a matter of urgency.

Recommendation 2 – A review of the Welfare of Children Ordinance be carried out within the next Legislative Council.

Recommendation 3 – A robust protocol be established for the monitoring of care of patients in mental health facilities in South Africa.

Recommendation 4 – St Helena Government extends the OPTCAT to St Helena, as soon as practicable.

Recommendation 5 – The regulations for statutory sick pay be reviewed and the days allowed be increased annually until there is parity with the public sector.

Recommendation 6 – Consideration be given to a local National Insurance scheme or similar.

Recommendation 7 – consideration be given to developing accommodation suitable for couples. Couples should not be split up if one or both need care or respite. There is a business opportunity for the development of retirement homes.

Recommendation 8 – the introduction of robust anti-domestic abuse legislation which makes coercion and other non-physical abuse a crime by the end of this Legislative Council.

Recommendation 9 – An independent review of the Children's home and its staffing arrangements including a risk assessment should be carried out to identify and/or reduce risks to both children and staff and to identify training needs.

Recommendation 10 – Long term care needs of adults being cared for at home by elderly parents be assessed and a plan for future care be made. This will give carers peace of mind and SHG chance to plan its longer-term delivery requirements.

Recommendation 11 – Overnight Respite care be reinstated as soon as staffing allows. This must be a priority.

INTRODUCTION

Human rights in both health care and social care are all about ensuring everyone has access to the care they need without discrimination. This includes the right to

- access health and/or social services,
- privacy and confidentiality, and
- be treated with dignity and respect.

It's about making sure that health and social care is available, accessible, acceptable, and of good quality for everyone. This paper summarizes the current law which is insufficient and ineffective and desperate the situation on St Helena from the evidence supplied by clients. The EHRC cannot divulge any personal information, nor can it outline scenarios which may lead to someone being identified however what is contained in this document can be evidenced if required.

The EHRC understands the difficulties of providing health and social care on St Helena with only around 4,000 people many of whom have care needs it is almost impossible to recruit, train and keep sufficient carers. Again, due to our small population we cannot afford, staff or maintain the specialist services that are available elsewhere. We cannot, for example build, staff and run a mental health facility which may only be in use for a few weeks a year.

That said, government cannot deny the people of St Helena their right to a reasonable standard of health and social care.

The EHRC calls on our government to define the standards of care we can expect through developing and enacting strong legislation and open, transparent and robust policies in line with international human rights standards and the Constitution of St Helena, Ascension and Tristan da Cunha.

We acknowledge that the people who come to us are the ones for whom the system has, in their opinion failed them, we rarely hear the success stories. The bravery of those that do come forward is creditable but also gives an indication that there are those who do not complain but whose experiences are disappointing.

WHAT IS THE RIGHT TO HEALTH?

Key aspects of the right to health

The right to health is an inclusive right. It includes the right to access to health care and the provision of hospitals etc and it includes the equal opportunity of access for all.

The right to health also contains freedoms. These freedoms include the right to be free from non-consensual medical treatment, such as medical experiments and research or forced sterilization, and to be free from torture and other cruel, inhuman or degrading treatment or punishment.

The right to health contains entitlements. These entitlements include:

- The right to a system of health protection providing equality of opportunity for everyone to enjoy the highest attainable level of health, whatever their Constitutionally protected characteristics¹;
- The right to prevention, treatment and control of diseases.
- Access to essential medicines.
- Maternal, child and reproductive health.
- Equal and timely access to basic health services.
- The provision of health-related education and information.
- Participation of the population in health-related decision making.

Health services, goods and facilities must be provided to all without any discrimination. Non-discrimination is a key principle in human rights and is crucial to the enjoyment of the right to the highest attainable standard of health. All services, goods and facilities must be available, accessible, acceptable, of good quality and available in sufficient quantity. They must be physically and financially accessible for all sections of the population, including children, adolescents, older persons, persons with disabilities and other vulnerable groups and as well Accessibility also implies the right to seek, receive and impart health-related information in an accessible format (for all, including persons with disabilities), but does not impair the right to have personal health data treated confidentially.

The facilities, goods and services should also respect medical ethics and be gender-sensitive and culturally appropriate. In other words, they should be medically and culturally acceptable.

¹ ST HELENA, ASCENSION AND TRISTAN DA CUNHA CONSTITUTION ORDER, 2009, C21, sex, sexual orientation, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, age, disability, birth or other status.

They must also be scientifically and medically appropriate and of good quality. This requires trained health professionals, scientifically approved and unexpired drugs and hospital equipment.

WHAT IS THE RIGHT TO SOCIAL CARE?

Social care plays a critical role in protecting our fundamental human rights.

It protects our right to life and to be free from poor treatment, by helping us to meet our basic needs like eating, drinking, washing, dressing or taking medication.

It promotes our dignity, supports our relationships with others, and helps us to have independence, connection and community. Ultimately, social care means that whatever our needs or age, we can live our lives in the way we choose to.

Like health care it should be available to those who need it without any discrimination. All services, goods and facilities must be available, accessible, acceptable, of good quality and available in sufficient quantity. They must be physically and financially accessible for all sections of the population, including children, adolescents, older persons, persons with disabilities and other vulnerable groups and as well:

- Everyone with social care needs can get the support they need to live a dignified life. The system should be sufficiently and sustainably funded to achieve that
- Care should be personalised and tailored to individuals' needs, including needs related to their protected characteristics
- Social care services should be easy to navigate and help people to make informed choices. The individual should have choice and control
- Services must anticipate the needs of disabled people, and any adjustments required, including independent advocacy
- Services should allow the individual connection with the community.

LEGAL PROTECTIONS

The European Convention on Human Rights (ECHR) applies to St Helena this is reflected in the Constitution (see below). The Chief Justice of St Helena has directly applied the standards set by the European Courts to a recent case on Island.²

Constitutional Protections:

Clause 6 – Protection of the right to life

Clause 7 - Protection from inhuman treatment

² CRUYFF GERARD BUCKLEY Plaintiff -and THE ATTORNEY GENERAL OF ST HELENA ON BEHALF OF THE CROWN (HOME AFFAIRS DIRECTORATE), 10 October 2024, p25.

Clause 13 - Protection for private and family life and for privacy of home and other property

Local Legislation:

The Welfare of Children Ordinance 2008

Mental Health and Mental Capacity Ordinance 2015

In the considered opinion of the EHRC, both pieces of legislation are out of date and in urgent need of updating to properly protect the human rights.

More urgently robust and effective Adult Social Care legislation must be passed to clearly define and protect the rights of vulnerable adults. This should include the concept of a positive obligation to make reasonable adjustments and provisions for those with disabilities. The EHRC understands that work has been carried out on this over several years, but at the time of writing it has no knowledge of how this has progressed.

Several international United Nations (UN) human rights treaties have been ratified by the UK Government and extended to St Helena, which means we are expected to reflect these in domestic legislation, policy and guidance.

Key relevant treaty provisions include:

The International Covenant on Economic, Social and Cultural Rights (ICESCR) includes Article 11 (right to an adequate standard of living) and Article 12 (right to physical and mental health). This means that the SHG is committed to recognising and taking steps to realise the rights of those with care needs and their carers to have an adequate standard of living and to enjoy the highest attainable standard of physical and mental health.

The SHG has not incorporated these treaties into our legislation, so they are not directly enforceable in our courts, but they do represent legally binding obligations on SHG in international law and can be used to interpret rights under the European Convention on Human Rights. SHG would also potentially be in breach of the Partnership agreement with UKG defined in the Constitution.

SHG must also actively consider the Convention on the Rights of the Child (CRC). For example, all decisions made across government should be in the best interests of children. There should be recorded reasoning behind decisions.

CROSS-CUTTING ISSUES

Lack of legislation for adult care – As mentioned above there is no legal framework for adult social care. The Health and Social Care Portfolio have no legal framework on which to base their actions, services and policies. The corollary to this is that clients do not know to what they are entitled nor how to access that entitlement.

In the considered opinion of the EHRC this lack of legislation is a potential breach of several of the rights listed above, including the right to redress and the right to information.

Recommendation 1 – Adult Social Care legislation be enacted as a matter of urgency

Welfare of Children Ordinance - This legislation was being developed 20 years ago, and it is no longer fit for purpose. Best practice has changed.

For example, children are allowed to marry (with parental consent) and have children themselves at 16. Child marriage is not acceptable under the CRC. The marriage age in the UK is 18.

There is a need for consideration and public discussion on whether we need a “Romeo and Juliet” law or policy. St Helena does not have a close-in-age exemption in its legislation. Close in age exemptions, commonly known as "Romeo and Juliet laws", are put in place to prevent the prosecution of individuals who engage in consensual sexual activity when both participants are significantly close in age to each other, and one or both partners are below the age of consent.

Because there is no close-in-age exemption, it is possible for two individuals under the age of 16 who willingly engage in intercourse to both be prosecuted for statutory rape, although this has not happened. Similarly, no protections are reserved for sexual relations in which one participant is a 15-year-old and the second is a 16- or 17-year-old

Recommendation 2 – A review of the Welfare of Children Ordinance be carried out within the next Legislative Council

Mental Health Ordinance – People sent to South Africa for treatment, cannot access our Court system, and St Helena has no jurisdiction in South Africa. The patients may not have capacity to act for themselves. We cannot protect vulnerable Saint Helenians from here.

Recommendation 3 – A robust protocol be established for the monitoring of care of patients in mental health facilities in South Africa.

Any facilities here that hold non-voluntary patients/clients must be protected by Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or

Degrading Treatment or Punishment (OPCAT) as should any overseas facility to which our Courts send our vulnerable people who are not voluntary patients.

OPCAT is an international human rights treaty adopted by the United Nations in 2002 and entered into force in 2006. This has been ratified by UKG and the FCDO is keen that it is extended to all its Overseas Territories.

The main objective of OPCAT is to prevent torture and other forms of ill-treatment in places of detention, this includes anywhere where people are held without their own consent, for example the Mental Health ICU at the hospital and the Dementia Unit at the CCC and the Prison. It establishes a system of regular visits to such places by a statutory committee with powers to act to prevent torture and other cruel, inhuman, or degrading treatment or punishment.

Recommendation 4 – St Helena Government extends the OPTCAT to St Helena, as soon as practicable.

HOSPITAL

The EHRC currently has 14 clients who are complaining about the excessively long wait for treatment overseas which is having life changing impacts on their lives from losing jobs, missing out on promotion, living in pain, to fear of leaving the house. This is now improving due to the promise of additional funding from UKG.

The financial impact for the long-term sick and their families can be devastating particularly as the entitlement to sick pay is only 5 days per annum in the private sector.

Recommendation 5 – The regulations for statutory sick pay be reviewed and the days allowed be increased annually until there is parity with the public sector.

Recommendation 6 – Consideration be given to a local National Insurance scheme or similar

The EHRC has had many complaints about the costs involved in visiting the hospital and repeat visits to collect prescriptions. Recently when an elderly man was ill on a Sunday he went to hospital by taxi as he can no longer drive. He knew there would be an out of hours charge but felt so concerned he went anyway. He saw a nurse and the doctor (who was in the hospital) was given medication and told to return to outpatients the next day. Over that week he attended for an X-ray, scans, blood tests and a further doctors appointment necessitating four more return-taxi fares. A total of £60 from a BIP payment of £80. If the EHRC had not found assistance for this man, he would not have been able to go for all his tests and may not have been diagnosed. Information on medical fee exemption policy is not publicised and therefore when he gets his bill he will have had the additional costs of those tests too.

The EHRC understands that the hospital must function with limited resources and that scenarios like this are almost unavailable however lack of information on the medical fees exemption policy and the reduced pharmacy hours are exacerbating the situation.

Complaints received about health care

Year	Total Number of New Complaints Received	Number of New Complaints about Health Received	% of total complaints
1 st April 20 – 31 st March 21	141	10	7.1
1 st April 21 – 31 st March 22	79	9	11.4
1 st April 22 – 31 st March 23	103	20	19.4
1 st April 23 – 31 st March 24	51	12	23.53
1 st April 24- 30 th September 24 (6 months)	28	8	28.6

As shown in the table above the number of complaints on health care has increased every year since 2020. The factors involved in this are many and complex:

1. In 2022 the EHRC was contacted by patients of Dr Sergio, all these complaints were referred to the Public Solicitor.
2. In 2022/23 there were contacts requesting help obtaining pain relief and CBD oil
3. 3 complaints have been received about chemotherapy drugs not being available one lady waited 3 months
4. In July and August 2022, 20 issues around Covid and reopening the island were raised
5. There have been 9 complaints about the availability of key drugs and being issued out of date medication (Naproxen, omeprazole, contraceptive pill, insulin to name but a few.)
6. Up to last year there were many complaints about the lack of assistance by MSO in South Africa, people left without food, no assistance with personal care, “loss” of property and money while in hospital. These have now ceased, there have been no complaints about the new service provider.

7. The biggest issue by far currently is the long wait for medivac to South Africa. Which is now beginning to be addressed.
8. We have received 2 complaints from people who obtained a diagnosis in South Africa and were told they could be treated immediately but the hospital management here refused the treatment, and they had to return home.

SOCIAL CARE

Community Care Centre

In recent months the EHRC has not received any new complaints about the care in the CCC despite the difficulties with staffing levels. In the past we have had complaints of violence by staff and ill treatment. These have been raised with the Minister and the Director in general terms (the victims did not want to be identified) and passed to the relevant authority.

The EHRC is concerned that the amount of accommodation available is not meeting the needs of the aging population. We understand that on occasions elective surgeries have been delayed due to the number of elderly people being kept in hospital as there is no room at the CCC. With an aging population demand for support from social care will inevitably increase. This could lead to challenges under the Constitution.

It is important that those in care are treated with dignity; the residents in the CCC must be allowed the freedom and the privacy they would have in their own homes. For example, to choose when to get up and when to go to bed and how they occupy their time. Couples also have a right to be together and remain together this is true even in our later years. Currently the CCC has no double rooms and the accommodation at Deasons and Cape Villa will not accommodate two people comfortably.

Recommendation 7 – consideration be given to developing accommodation suitable for couples. Couples should not be split up if one or both need care or respite. There is a business opportunity for the development of retirement homes.

Sheltered Accommodation

No complaints or concerns raised in recent months.

Domiciliary Care

This is an area of deep concern to the EHRC. When someone has the capacity to make an informed decision, they have the right to choose to stay in their own home and they should be assisted to do so. The level of assistance the state will provide should be defined in law and equally available to all. As discussed above there is no legislation,

however the EHRC is aware that despite very limited financial and human resources Adult Social Care work to spirit of the UK Care Act.

Parents and carers of loved ones with disabilities being cared for at home must also be supported and know what support they can rely on. While care plans and assistance are in place the EHRC is often contacted by our clients who have been let down due to early morning staff meetings which mean the client has to remain in bed, sometimes in wet/dirty nappies until someone arrives to help with bathing and dressing. Carers are often running late meaning they have insufficient time to clean, hang out washing or assist with cooking and personal care.

People cannot make informed decisions and organise their lives if there are no protections and no legal duty to fulfil an agreed care plan. This is why the EHRC stresses again that the people of St Helena need the protections of an Adult Care Ordinance.

The Safe Haven and Children's Home

The Safe Haven service is excellent but there is currently no support or refuge for men suffering domestic abuse.

There is a desperate need for robust anti-domestic abuse legislation which makes coercion and other non-physical abuse a crime.

Recommendation 8 – the introduction of robust anti-domestic abuse legislation which makes coercion and other non-physical abuse a crime by the end of this Legislative Council.

The Children's home is a difficult issue with potential for various human rights abuse claims if certain circumstances were to arise. This is due entirely to the circumstances of St Helena and a criticism in any way of the management or staff. We are a small community, and we cannot have all the facilities a larger island or country may have. Therefore, children of both genders, various ages and with varying social care needs share the same space. Limited staff numbers mean carers working alone with difficult children or young people. Protecting the varying needs and rights of each young person in the home is a delicate balancing act. Not only must children be protected, but the staff also need to be able to properly protect themselves too. The Portfolio have a duty of care.

Recommendation 9 – An independent review of the Children's home and its staffing arrangements including a risk assessment should be carried out to identify and/or reduce risks to both children and staff and to identify training needs.

Respite Care

The EHRC has several clients with problems accessing respite care, both day care and overnight assistance. Since the closure of Barn View in 2015 there has been no overnight

care for many clients. Some carers, mainly parents, have not had a night out together or a full night of sleep for over nine years. We have parents in their mid-60's through to over 80 years old coping day and night without a break. Even if their loved one goes to Day Care those few hours only give chance to catch up on the household chores.

There seems to be no plan for what will happen when they can no longer go on. There is no residential care for younger adults with high support needs.

Recommendation 10 – Long term care needs of adults being cared for at home by elderly parents be assessed and a plan for future care be made. This will give carers peace of mind and SHG chance to plan its longer-term delivery requirements.

Day Care

has also raised some complaints from Social Care clients:

There appears to be a reluctance to drive to certain places to collect clients

1. Wheelchair accessible cars are in short supply, and it appears frequently off the road.
2. There used to be a variety of activities for the elderly and disabled living at home. Carers would take them shopping, to meet friends, to visit graves or the library or to look at the sea. Now everyone must go to the CCC for day care. As one client put it, "Why would I want to spend the day looking at people and seeing my future?"
3. Because staff start at 8.00/8.30 am and must be on the bus home at 4pm the length of time some people spend at Day Care is very short. By the time someone has driven to Longwood, Levelwood, Sandy Bay or Blue Hill to collect a client and they arrive at Day Care, the clients feel it is almost time to go home.

Support for unpaid carers

Services should recognise the vital role of unpaid carers and work in partnership with them. In this context the EHRC means people in receipt of carers allowances of either £80 or £40 per week, based on the tasks they must perform rather than the time they spend caring.

Unpaid carers play a critical role in supporting individuals who are unable to fully care for themselves due to illness, disability, age, or other factors. Recognizing their vital role and working in partnership with them is crucial for several reasons:

1. **Enhanced Care Quality:** Unpaid carers often provide consistent, personalized, and compassionate care. They understand the needs, preferences, and routines of the individuals they care for, which can lead to better outcomes and higher quality of life.

2. **Cost-Effective:** Unpaid carers save public services a significant amount of money by providing care that would otherwise need to be funded through professional services or full-time residential care. Acknowledging and supporting unpaid carers can help alleviate the financial burden on healthcare and social services systems.
3. **Holistic Support:** Services can offer more comprehensive and coordinated care by collaborating with unpaid carers. Carers can provide valuable insights into the individual's condition, progress, and needs, leading to more effective and tailored interventions.
4. **Emotional Support and Well-Being:** Unpaid carers often form strong emotional bonds with those they care for, providing not just physical but also emotional support. Recognizing their role helps in maintaining the emotional well-being of both the carer and the cared-for individual.
5. **Carer Well-Being:** Carers themselves need support to manage the physical, emotional, and financial challenges of their role. Services that work in partnership with carers should provide resources, training, respite care, and financial assistance, reducing the risk of carer burnout and improving their overall well-being.
6. **Early Intervention:** Carers are often the first to notice changes in the condition of the person they care for. By working closely with carers, services can respond more quickly to emerging issues, preventing crises and reducing the need for more intensive interventions.
7. **Empowerment and Inclusion:** Recognizing the contribution of unpaid carers and involving them in decision-making processes empowers them and fosters a sense of inclusion and respect. This can lead to more effective care planning and a stronger partnership between services and carers.

Unpaid carers are an indispensable part of the care system on St Helena, if they all said they could no longer cope our already stretched care system would break. More must be done to recognise these people's contributions and working collaboratively with them enhancing care quality.

Recommendation 11 – Overnight Respite care be reinstated as soon as staffing allows. This must be a priority.

CONCLUSION

The EHRC understands the difficulties of providing health and social care on St Helena with only around 4,000 people many of whom have care needs it is almost impossible to

recruit, train and keep sufficient carers. Again, due to our small population we cannot afford, staff or maintain the specialist services that are available elsewhere. We cannot, for example build, staff and run a mental health facility which may only be in use for a few weeks a year.

That said, government cannot deny the people of St Helena their right to a reasonable standard of health and social care.

The EHRC calls on our government to define the standards of care we can expect through developing and enacting strong legislation and open, transparent and robust policies in line with international human rights standards and the Constitution of St Helena, Ascension and Tristan da Cunha.