



AN INTRODUCTION TO YOUR RIGHTS TO HEALTHCARE

INTRODUCTION

All Australians (including those on the autism spectrum) have rights to access high quality and safe healthcare. These rights are described in the Australian Charter of Healthcare Rights, written by the Australian Commission on Safety and Quality in Healthcare (and available at [http:// www.safetyandquality.gov.au/national- priorities/](http://www.safetyandquality.gov.au/national-priorities/)).

In explaining health rights we have co-produced this document that is relevant to people on the autism spectrum, their supporters, and health professionals. This has been a challenging but thought provoking task.

The Australian Charter of Healthcare Rights describes seven rights related to healthcare services including Access, Safety, Respect and Privacy, Communication and Participation, and Comment. Each right is described and our experiences as an adult on the spectrum and a public health researcher are shared. We hope that in describing these rights we will assist with understanding and communication.

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What are human rights?

Human rights recognise the inherent value of each person. They are based on principles of dignity, equality and mutual respect, which are shared across cultures, religions and philosophies. They are about being treated fairly, treating others fairly and having the ability to make genuine choices in our daily lives. Respect for human rights is the cornerstone of strong communities in which everyone can make a contribution and feel included.

These arose from the United Nations Declaration of Human Rights:

<https://www.humanrights.gov.au/about/what-are-human-rights>

One set of rights are healthcare rights.

Where are healthcare rights identified?

Healthcare rights are described in the Australian Charter of Healthcare Rights. These were developed by the Australian Commission on Safety and Quality in Healthcare (<http://www.safetyandquality.gov.au/national-priorities/>). These rights are afforded to all members of society.

What does the Charter tell us?

The Charter written by the Australian government is a reference point to help clarify the rights of all people to safe quality healthcare.

In explaining the Australian Charter of Healthcare Rights (<http://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/>), we describe some of the practical and attitudinal issues associated with seven rights (access, safety, privacy and respect, communication and participation, and comment) that are likely to be of interest to people on the spectrum, their supporters, and health professionals.



1. ACCESS

All people have the right to access quality healthcare within or close to their own communities, even in rural areas.

What are practical concerns regarding access?

Structural barriers (e.g., location of services/activities) may exclude adults on the autism spectrum from opportunities and access to services. Another concern is inadequate provision of public or community transport to allow access.

What are attitudinal concerns regarding access?

An example of an inappropriate attitudinal response is when agencies providing services perceive poor access, perhaps due to inadequate public transport or individuals not being able to drive, as merely “unfortunate” and something to be accepted rather than changed.

2. SAFETY

All peoples’ rights to safety and safe and high quality healthcare should be respected. Everyone has the right to feel safe from physical, sexual, verbal, emotional, psychological and financial abuse at all times.

All people on the autism spectrum have the right to quality healthcare with appropriate provisions made to ensure their safety and maximum independence, physical, mental, social and vocational ability, full inclusion and participation in all aspects of life”. (Visit <http://www.un.org/disabilities/convention/conventionfull.shtml> for UNCRPD Articles 25 & 26).

What are practical concerns regarding safety?

Practical concerns include those related to physical and sexual safety. Also important is environmental wellbeing taking into account sensory issues that affect many people on the spectrum (e.g., lighting, noise, sensitivity to overwhelming odours, harsh and/or irritating fabrics/surfaces, and visual overload from television or radios).

What are attitudinal concerns regarding safety?

Attitudinal concerns may be associated with lack of respect for the dignity of the individual. This may result in individuals being treated as inferior, intimidated or embarrassed. People on the spectrum have the right to feel physically, emotionally and psychologically safe in their interactions with health and medical professionals.



3. RESPECT AND PRIVACY

Those on the autism spectrum have the right to privacy and confidentiality concerning their personal health documentation and discussion of health issues by health professionals should occur in a private space.

Respect affords individuals physical, mental, and emotional dignity within an environment that fosters self-respect; and recognizes different needs according to age, gender and ability.

There is no place where exploitation, financial abuse, or age or gender based violence is acceptable.

(Visit <http://www.un.org/disabilities/convention/conventionfull.shtml> for UNCRPD Articles 15, 16 and 17.)

What are practical concerns regarding respect and privacy?

Respect is maintained if individuals are allowed to make informed decisions and that those decisions are accepted without question.

Any participation in medical or scientific studies should occur only with the informed consent, without pressure, of the person on the spectrum.

What are attitudinal concerns regarding respect and privacy?

Attitudinal concerns are those that fail to appreciate the individual's intrinsic worth.

Achievements should be neither unfairly dismissed nor met with exaggerated praise, instead of a natural, honest, respectful response that recognises ability. Appropriate recognition and acceptance will overcome feelings of unintended humiliation that accompany being either patronized or ignored.



4. COMMUNICATION AND PARTICIPATION

Communication includes spoken, signed, gestural, visual and other forms of non-spoken languages. Suitable forms should be used to inform people on the autism spectrum and/or their carers about the available health services, treatments, options <http://www.un.org/disabilities/convention/conventionfull.html> and costs in a clear and open way. (Article 2).

What are practical concerns regarding communication and participation?

Practical concerns can include:

- a) physical environments that are not conducive to communication due to the person on the autism spectrum's sensory sensitivities;
- b) the communicator not being adequately equipped to facilitate appropriate communication, due to a lack of knowledge of the various non-verbal modes employed by those on the spectrum;
- c) misunderstanding due to the lack of "active listening" on behalf of the healthcare provider.

The provision of more time to allow for "active listening" and, if needed, time for the individual to consider their options, may maximise greater communication and informed participation.

What are attitudinal concerns regarding communication and participation?

These concerns often result from a lack of awareness and understanding of autism among the general community, health professionals, and agencies providing services.

False assumptions about people on the spectrum are often made. Failure to recognize the abilities and experiences of people on the spectrum can cause frustration and distress to both parties in their attempts to communicate effectively.



5. COMMENT

The right and opportunity to comment on healthcare services should be provided to all people including those on the autism spectrum and their carers/representatives.

What are practical concerns regarding comment?

Service providers may not be receptive to addressing grievances, placing the individual and their representatives in an unmanageable situation; particularly in the case where it is impossible to find another service provider.

What are attitudinal concerns regarding comment?

People on the spectrum may feel they have enough challenges, without the added pressure of having to personally advocate for their rights, fearing misunderstandings could result in unforeseen and undesired consequences.

Having to deal with bureaucracies and those providing care may be intimidating and fear of being viewed as a troublemaker can inhibit both those on the spectrum and their representative/s from communicating their needs.

A service's refusal to acknowledge a grievance or to be dismissive of a concern may impede communication and participation in healthcare decisions. Building an understanding of autism will help overcome these difficulties for people on the spectrum and health professionals when trying to understand each other.



References

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