

Policy on the Protection and Promotion of Human Rights in Intellectual Disability Services

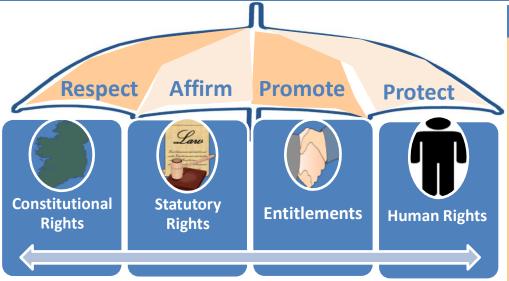
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This policy remains in force until such time as it is reviewed and approved by the Board of Community Services CLG.

Policy on the Protection and Promotion of Human Rights in Intellectual Disability Services

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Responsibility for implementation	Rights Policy Review Committee Regional Directors All employees of Saint John of God Community Services clg (Intellectual disability services only)	
Responsibility for evaluation and audit	Designated Rights Policy Review Committee Rights Review Committees Human Rights Committee	

Policy on Rights Protection & Promotion of Rights



Rights Review Committee

- Leads safeguarding, supporting & exercising rights
- Assists Management in ensuring human rights practices
- Acts as interface between group & individual needs

Considers

- All restrictions
- If benefits & risks balanced
- If due process followed

Ensures

- Review mechanism in situ
- Informed consent
- Least restrictive/most therapeutic approach
- Restrictions are temporary
- Director aware of restrictions
- Rights audit conducted & reviewed

Produces

- Recommendations
- Confidential minutes
- Annual report

Committee Chair

Accept referrals & assign

responsibility

- Convene quorate, minuted & emergency meetings
- Manage membership & update Director
- Facilitate discussion of referrals
- Facilitate majority consensus
 & minutes dissent
- Written response to referrals
- Advise & recommend on external restrictions
- Annually update Director



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1. Policy Statement

It is the policy of Saint John of God Community Services clg (SJOGCS) to respect, affirm, promote and protect the Human Rights of each individual with an intellectual disability to whom we provide services and supports.

2. Purpose

The purpose of this document is to acquaint all service-users including their families as appropriate, employees, members of Human Rights Committees, and advocates, of the Human Rights Based Approach process that is in place in SJOGCS. This process strives to promote and protect the rights of adult service users in the context of the Vision, Mission and Values of SJOGCS in line with all relevant Conventions, legislative requirements and recognised best practice.

3. Scope

This policy applies to all in SJOGCS in supporting a Human Rights Based Approach within SJOGCS. This includes adult Service-users, employees, members of Human Rights Committees, Advocates and Volunteers etc.

4. Definitions

4.1 What are Rights?

Rights are entitlements which we have either obtained or are inherent.

• Human rights are in place by virtue of us being human. They are considered inalienable (you cannot lose them), indivisible (equal in importance) and interdependent (they interact and are part of a total framework of rights). Human rights were first recognised on a global scale in the United Nations Universal Declaration of Human Rights (UDHR) in 1948. Despite numerous Conventions which followed after the UDHR, the rights of persons with disabilities were continuously contravened, with the numerous existing conventions failing¹

¹ Gerard Quinn, Theresia Degener et al, Human Rights and Disability – The current use and future potential of United Nations Human Rights Instruments in the Context of Disability (United Nations 2002).

the 'world's largest minority'. To address this, in 2005, The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations in 2006.

- Constitutional Rights or Fundamental Rights are bestowed on us through various means, for example, Articles 40 44 in Bunreacht na hÉireann (Personal Rights, The Family, Education, Private Property and Religion). Not all fundamental rights are contained within the Constitution, for example, there is no explicit right to privacy. However, Irish Courts have recognised the personal rights contained in the Constitution imply the right to privacy.
- Statutory Rights are rights set out in law and can only be changed through the legal process. Changes in the law may alter these rights. These laws include The Equal Status Act (2000–2004), Employment Equality Act (1998), Comhairle (Amendment) Bill (2004), The Mental Health Act (2001), The Education Act (2004), The Disability Act (2005), the Citizens Information Act 2007 and the Assisted Decision Making (Capacity) Act 2015.
- **Entitlements** are built up through custom and practice e.g. privilege days, free car parking. They are not legal and are discretionary, for example, entitlements granted by an employer or Government.

4.2 Human Rights Based Approach

A Human Rights Based Approach (HRBA) is an established framework and set of guiding principles for ensuring that human rights are upheld in organisations or services that adopt this approach.

The application of a human rights culture takes on additional significance in the provision of services and supports to people with intellectual disability. Services face the challenge of providing care and support, keeping people safe and well, facilitating independence, autonomy and community inclusion, while ensuring that individual rights are protected.

² Gerard Quinn, Centre for Disability Law & Policy NUI Galway Submission on Legal Capacity to the Oireachtas Committee of Justice, Defence & Equality p86 available at

defence_and_equality_.pdf accessed 28/04/2016

³ Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, 76th plen. mtg., U.N. Doc AIRES/61/106 (Dec. 13, 2006).

The application of a human rights approach within Intellectual Disability Services faces the challenge of balancing the provision of care and support within safe environments while also facilitating autonomy and community inclusion.

The Human Rights Committees can serve as the stabilizing force that allows this conflict to be resolved.

The guiding principles in a Human Rights Based Approach are as follows:

- **1. Express link to rights:** Identifies and names the rights that the person may or may not be in a position to exercise.
- **2. Participation:** The principle of participation identifies barriers that exist which limit the person in terms of exercising rights.
- **3. Empowerment:** The principle of empowerment explores how the person can be enabled through the selection of appropriate supports and environmental changes.

The main aim of service provision is to facilitate each person to live valued and fulfilling lives. Key to this is self-determination, sufficient support to live life to the full, a restriction free and a restraint free environment, adequate financial resources and protection of one's possessions.

- **4. Non-discrimination:** The principle of non-discrimination ensures that persons with disabilities are not discriminated against on the grounds of their disability that all people are treated equally.
- **5. Accountability:** Ensure that policies and procedures are in place to support effective delivery of rights and entitlements to service users.

4.3 Consent

The HSE National Consent Policy notes that the 'ethical rationale behind the importance of consent is the need to respect the service users' right to self-determination (or autonomy) – their right to control their own life' ⁴

⁴ National Consent Advisory Group. National Consent Policy. Dublin: Health Service Executive (HSE); 2013, p20 (accessed 15/04/2016) available at:

 $[\]underline{http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National_Consent_Policy/consenttrainerresource/trainerfiles/NationalConsentPolicyM2014.pdf}$

The policy defines consent as:

The giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication in which the service user has received sufficient information to enable him/her to understand the nature, potential risks and benefits of the proposed intervention or service. ^{5, 6}

This definition requires the provision of accessible information to service users, in a manner that is accessible for each person, and as such may require the information to be provided in document, audio or DVD format.

4.4 Informed Consent

For consent to be valid, the service user must:

- Have received sufficient information in a meaningful accessible manner about the nature, purpose, benefits and risks of any intervention/service or issue;
- Not be acting under duress;
- Understand what the intervention/service is;
- Understand why the intervention/service is proposed;
- Understand the nature of the proposed intervention/service;
- Understand the benefits and risks of having or not having the intervention/service;
- Understand other interventions/service options available;
- Balance the information and arrive at a decision;
- Have the capacity to make and communicate the particular decision with the support of meaningful accessible communication aids where necessary.

4.5 Capacity

Capacity is often divided into legal capacity and mental capacity. The HSE National Policy on Consent defines capacity as the' ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made'.⁷

⁵ National Consent Advisory Group. National Consent Policy. Dublin: Health Service Executive (HSE); 2013 (accessed 15/04/2016) available at:

 $[\]frac{http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National_Consent_Policy/consenttrainerresource/trainerfiles/NationalConsentPolicyM2014.pdf}$

⁶ This is also the definition used by Health Information and Quality Authority. Supporting people's autonomy: a guidance document. Dublin 2016. (accessed 15/04/2016) available at: https://www.hiqa.ie/publications/supporting-people/E2/80%99s-autonomy-guidance-document

⁷National Consent Advisory Group. National Consent Policy. Dublin: Health Service Executive (HSE); 2013 p12 (accessed 15/04/2016) available at:

 $[\]underline{http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National_Consent_Policy/consenttrainerresource/trainerfiles/NationalConsentPolicyM2014.pdf}$

The United Nations Committee on the Rights of Persons with Disabilities discussed the two different forms in their General Comment on Article 12 of the CRPD, which relates to equal recognition before the law:

'Legal capacity and mental capacity are distinct concepts.

Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society.

Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.'8

The Assisted Decision-Making (Capacity) Act 2015, when commenced, will provide a statutory framework within which requirements for assisting and supporting individuals, who require it, to make legally binding decisions, and decisions about their affairs. Under this Act, capacity means decision making capacity.

The Act will result in the functional approach to capacity being used, and an individual's capacity will be assessed on the basis of his or her ability to understand the relevant issues at the time a decision is to be made, i.e. does the person have capacity to make the decision? This approach recognises that there can be dimensions and complexities involved in different types of decisions, and that any cognitive support needs are only relevant if they impact upon decision making. 10

This means that a person's capacity shall be assessed on the basis of his/her ability to understand, at the time a decision is to be made, the nature and consequences of the decision in the context of the available choices at that time (issue specific and time specific).

Each decision is issue specific and time specific, and each time a decision is to be made, it is to be treated as a stand-alone issue and time specific issue.

4.6 Due Process

The Council for Quality and Leadership (1996) defines due process as "The guaranteed opportunity to protest, to be heard, to be informed, to consent, and to have the determination

⁸ United Nations (UN) Convention on the Rights of Persons with Disabilities. General comment No. 1. Article 12: Equal recognition before the law. Committee on the Rights of Persons with Disabilities: Eleventh session; 2014. P4 available at www.ohchr.org/Documents/HRBodies/CRPD/GC/DGCArticle12.doc (accessed 20/04/2016).

⁹ <u>www.williamfry.com</u> Assisted Decision-Making (Capacity) Act 2015, available at http://www.williamfry.com/newsandinsights/news-article/2016/02/08/assisted-decision-making-(capacity)-act-2015 (accessed 20/04/2016)

¹⁰ Health Information and Quality Authority. Supporting people's autonomy: a guidance document. Dublin 2016. P29 (accessed 15/04/2016) available at: https://www.hiqa.ie/publications/supporting-people%E2%80%99s-autonomy-guidance-document

to restrict rights made by an impartial jury". The concept of due process is intended to protect people from exploitation or undue restriction of rights.

A commitment to due process requires that people always be informed, where possible, in advance, when service actions will limit individual actions.

Due process ensures:

- 1) The right restricted has been identified.
- 2) The consent of the individual/advocate has been obtained to restrict the right and also to review of the right restricted
- 3) The individual is supported to clarify the importance of the right to them and to present their case.
- 4) The restriction is the least restrictive and most therapeutic for the Individual.
- 5) The investigating body is impartial i.e. the Human Rights Committee
- 6) Rights issues are dealt with in a timely fashion.
- 7) A consistent approach is used.
- 8) A plan and supports are in place to reinstate the restricted right and this is monitored on an ongoing basis by the Human Rights Committee until such time as the right is reinstated.
- 9) The training of all relevant staff in the restriction and related support prior to implementation and post use of the restriction.
- 10) The extent of due process matches the importance of the rights to the individual.
- 11) Identification of factors influencing the decision e.g. health and safety.
- 12) A review mechanism adequately protects the individual.
- 13) The individual has the right, and is supported to appeal ¹¹ with legal representation if necessary.

4.7 Confidentiality relating to the Human Rights Committee

Confidentiality means the non-disclosure of information relating to a service-user except to another authorised person.

In the context of a Human Rights Committee (HRC) the protection of the identity of the person is at the discretion of the individual. Therefore, the individual will choose if their name will remain private or be known by the committee.

¹¹ Bob McCormack, 'Fair Play! The Basic Rules for Fair Procedures for People Supported by Disability Organisations'

⁽Frontline Ireland: Dublin, Ireland) No 75: 2009, p12-13 available at http://frontline-ireland.com/wp-content/uploads/2014/12/frontline75.pdf accessed 20/04/2016.

The Human Rights Committee shall always protect and maintain confidentiality in relation to all referrals, discussions and decisions reached by the committee. Where the person's wishes for confidentiality are unclear, the default position which the HRC shall take is that the person wishes to remain anonymous.

4.8 Restrictive Practices

Saint John of God promotes a restriction free and a restraint free environment. However, it is also recognised that on occasions, within society, community, and services, situations exist where total freedom to act, do or decide is not possible. Restrictions may occur as a result of laws, community or group norms, or the needs of other people. These limitations may exist for all those cared for and supported by our services. Rights may be restricted within services where an individual's actions harm or have the potential to harm others, where an individual's behaviour or activity is viewed as immoral by society, or where the individual's health may deteriorate if action is not taken.

The National Standards for Residential Services for Children and Adults with Disabilities Standard 3.3 (Health Information and Quality Authority (HIQA), 2013) requires that, "People are not subjected to a restrictive procedure unless there is evidence that it has been assessed as being required due to a risk to their safety and welfare". See HIQA 2013 section 3.3 for further information.

In relation to restrictions that are put in place for behavioural reasons, these must be in line with SJOGCS's Positive Behaviour Support Policy, be the least restrictive and most therapeutic, and be in place for the shortest possible time. A reinstatement plan is required to illustrate the plans for removal of any restrictions, and this can be evidenced through a person's Behaviour Support Plan.

5. Human Rights Committee

The Human Rights Committee (HRC) is a committee that is established in each service for people with intellectual disability in SJOGCS. Its function is to promote and protect the rights of people receiving services and supports. This committee is held accountable to understand due process and best practice and to question every situation in which a person's rights, for any reason, are restricted.

It is also the function of this committee to promote a Human Rights Based Approach (HRBA) within the service.

The dual function of the Human Rights Committee is to promote a HRBA and to review rights restrictions. The HRC will be guided by Terms of Reference.

5.1 Terms of Reference – Human Rights Committee

To promote the human rights of adult service users receiving service from St. John of God Community Services Ltd. through:

Practice Support,

Supporting staff to understand and recognise that people have rights. Practice support
can be provided through mentoring in the work place and rights based practice support
clinics, if required.

Information sharing,

- Information sharing through participation at conferences, workshops etc.
- Sharing documentation and tools that relate to rights such as audit tools.
- Through service representatives from HRC's participating on the HMHQ Human Rights Committee.
- To conduct and participate in a Rights Audit within the service or request such an audit to be conducted. A rights audit should be conducted annually.

Education and Training.

- Providing information sessions/workshops in an accessible format to service users.
- Providing information and training sessions for families and staff.

5.2 Review of Rights Restrictions

In relation to the review of rights restrictions the committee should review present and proposed restrictions:

- 5.2.1 To identify the rights issue in each case, the restriction and the parties involved.
- 5.2.2 To ensure that all the information necessary to make an informed decision is obtained.
- 5.2.3 To make recommendations based on the information provided at the time of information gathering.

- 5.2.4 To communicate the committee's recommendations to the individual concerned, to their Supervisor, where relevant, and to the Regional Director/General Manager
- 5.2.5 Address the findings of any rights audit conducted in the service.
- 5.2.6 To provide a summary report annually to the Regional Director/General Manager, the Quality and Safety Committee and the SJOGCS Human Rights Committee.
- 5.2.7 To liaise directly with the Regional Director/General Manager when presented with restrictions imposed on the person by any agency external to SJOGCS.

6. Roles and Responsibilities

All rights restrictions should be notified to the Human Rights Committee.

6.1 The Human Rights Committee

- 6.1.1 Supports the Service in the promotion of rights and also the identification and removal of rights restrictions for people availing of its services and supports. If a safeguarding issue comes to the attention of the committee, the committee must ensure that the safeguarding process is being followed with immediate effect.
- 6.1.2 Assists management in ensuring human rights promotion and protections are evident and effective within their services through practice support, information sharing, education and training.
- 6.1.3 Reviews present or proposed restrictions.
- 6.1.4 Determines if there is an appropriate rationale for the existing or proposed restriction.
- 6.1.5 If the restriction is imposed for medical or behavioural reasons, ensure that the least restrictive, most therapeutic approach has been taken for the shortest possible time and that less restrictive alternatives have proven to be ineffective. Ensure that there is a plan in place to reinstate the right restricted.
- 6.1.6 Act as an interface between the person and the organisation.
- 6.1.7 Considers if due process and excellence in practice was followed. Ensures that a review mechanism for all restrictions is in place.
- 6.1.8 Ensures informed consent was obtained in line with regulatory requirements and best practice.

- 6.1.9 Makes recommendations to the Regional Directors/General Manager in relation to individual cases where rights are restricted. These recommendations may include:
 - That the restriction is retained subject to regular review.
 - The restriction is retained subject to specific modifications by the relevant personnel.
 - Recommendation for total review of the restriction.
- 6.1.10 Ensures the Regional Director/General Manager is made aware of rights restrictions imposed on people by external agencies and services.
- 6.1.11 Reports on their activities in an annual report to the Regional Director.
- 6.1.12 Maintains confidential minutes of all meetings ensuring that note is taken of any safeguarding concerns that may have arisen and how such issues were addressed by the committee.
- 6.1.13 Requests that rights audits are conducted and addresses the findings that emerge.

6.2 The Chair of the Human Rights Committee (HRC)

- 6.2.1 The Chair of the HRC must be external to the service and work in this role in a voluntary capacity.
- 6.2.2 Convenes Committee meetings at least on a bi-monthly basis but preferably once a month.
- 6.2.3 Plans and discusses, with the committee, rights promotion and how it should be carried out within the service. Uses audit data, HIQA reports, HIQA notifications and any other rights related material that comes to the attention of the committee to inform practice in this area.
- 6.2.4 Receives feedback from committee members on rights promotion work that is taking place within the service.
- 6.2.5 Accepts referrals on behalf of the Committee. All referrals submitted to the chair should be received and retained within the service.
- 6.2.6 Ensures a quorum for each meeting is at least two-thirds of the membership if reviewing rights restrictions.

- 6.2.7 Accepts all notifications of rights restriction practices from Persons in Charge (PIC). All notifications for review should be submitted to the chair and retained within the service.
- 6.2.8 Appoints a sub-committee, as required, between planned meetings in the case of urgent referrals to the Committee that need to be investigated.
- 6.2.9 Advises the Director of changes in membership of the Committee and requests member replacement as required.
- 6.2.10 Provides a bi-monthly/monthly report to the chair of the Quality and Safety Committee on the promotion and protection activities of the Human Rights Committee.
- 6.2.11 Ensures confidential minutes of each meeting are maintained and stored within the service in a secure place.
- 6.2.12 On receipt of a referral appoints a Committee member to contact the service user/advocate/applicant and relevant others to gather information on the rights restriction and report this information back to the committee.
- 6.2.13 Facilitates open discussion and review of each individual rights referral.
- 6.2.14 Facilitates the committee reaching a majority decision, noting dissenting views in the minutes.
- 6.2.15 Ensures that a written response is sent to the referral source, copied to the area supervisor (if appropriate) and to the Regional Director/General Manager.
- 6.2.16 Advises the Regional Director/General Manager where a rights referral has been made regarding a restriction imposed by an external agency to ensure this is handled with due regard for inter-agency co-operation.
- 6.2.17 Through the Regional Director, makes recommendations to the external agency regarding rights restrictions that have been imposed by that agency.
- 6.2.18 Delegates a committee member to write letters on behalf of the chair (which will be disseminated by the administration support personnel) detailing recommendations to service users, support staff and the director.

6.3 The Deputy Chair of the Human Rights Committee

- 6.3.1 A Deputy Chair may be appointed by the Chair, with the approval of the Regional Director/General Manager. Where possible, this person should be external to the service.
- 6.3.2 The Deputy Chair may be required to assume the role of Acting Chairperson on occasions when the chair is absent. This must be notified to the Regional Director/General Manager.
- 6.3.3 The Deputy Chair may not assume the role of Acting Chairperson for any period longer than 3 calendar months.

6.4 Administration

- 6.4.1 Administrative support should be provided to the Human Rights Committee by the local service.
- 6.4.2 The administrative support person should facilitate efficient and timely completion of all referrals processed and support the work of the Chairperson of the Human Rights Committee with regular liaison and communication.
- 6.4.3 Updates and maintains the Human Rights Committee Database of referrals and collates all necessary paperwork.
- 6.4.4 Liaises with the chair in relation to referrals and provides relevant documentation for consideration at committee meetings.
- 6.4.5 Schedules all meetings and prepares and distributes agenda for same.
- 6.4.6 Records and circulates minutes of all meetings including a summary of the decision making discussions in relation to the referral.
- 6.4.6 Distributes the recommendation letters for service user and director following case discussion and decision making process.

6.5 The Regional Director / General Manager

- 6.5.1 Appoints a Human Rights Committee for a renewable term of three years.
- 6.5.2 Ensures Committee membership comprises 60% from within the service, the other 40% from external agencies, community members, family members, etc.
- 6.5.3 Ensures membership is no greater than 10 members.
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- 6.5.4 Ensures membership includes the Chair of or a representative from the Positive Behaviour Support Committee. If this is not feasible, the Director must ensure that the committee evidence that they liaise with the PBSC on a monthly basis.
- 6.5.5 Ensures every three years that at least one-third of the membership steps down to facilitate rotation and appointment of new members.
- 6.5.6 Ensures that Committee members are appropriately inducted into their role as members of the Committee.
- 6.5.7 Assists the work of the Committee by acting on recommendations.
- 6.5.8 If unable to act on the recommendations of the Committee, the Director must clearly advise the Human Rights Committee of the reasons why in writing.
- 6.5.9 Meets the Chairperson of the Committee at least annually to review the activities of the Committee.
- 6.5.10 Reviews and monitors with the Quality and Safety Committee, Management Team and Positive Behaviour Support Committee aggregate data regarding rights restrictions and develops a service response.
- 6.5.11 Acts as an interface between the Committee and external services/agencies involved in imposing a rights restriction on an individual.
- 6.5.12 Through their service representative ensures that the SJOGCS Human Rights Committee is kept informed of trends and issues arising which may require a corporate response.
- 6.5.13 To support rights promotion, ensures all staff receive appropriate training on rights promotion and protection.
- 6.5.14 Appoints a Human Rights Committee at Hospitaller Ministries level where representatives of the service's Human Rights Committees are present to support and maintain a consistent approach across all of SJOGCS.

6.6 The Service-user

- 6.6.1 Service users should be made aware of their rights through the rights promotion work carried out within their service. All service users have the right to be made aware of their rights in an accessible format that they understand.
- 6.6.2 All service users should receive training, attend workshops and have the opportunity to participate in rights forums both within their service and at national level.
- 6.6.3 Seeks, with support where required, to have their rights restriction removed or reduced. This may be achieved by using the complaint process or other avenues.
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- However, where these options have been exhausted or where they are not appropriate, the service user should be supported in making a referral to the Human Rights Committee.
- 6.6.4 Having gone through the complaints process where appropriate and possible, the service user should receive support to present their case to the Human Rights

 Committee in writing, on DVD or through any other medium the person usually uses to communicate effectively.
- 6.6.5 Where necessary, is supported and encouraged to engage an external advocate to assist with their representations to the Human Rights Committee.
- 6.6.6 Has the right to appeal the recommendations of the Committee or the decision of the Director in each case.

6.7 The Advocate

- 6.7.1 To support the service-user in using all options to have their rights restriction removed or reduced prior to making a referral to the Human Rights Committee.
- 6.7.2 Supports the service-user in making the referral for review before the Committee.
- 6.7.3 Assists the service-user in communicating and presenting their individual case to the Human Rights Committee.

6.8 The Keyworker and Support Staff

- 6.8.1. Familiarise themselves with the Policy on Human Rights Promotion and Protection.
- 6.8.2. Through the person-centred process, promote rights and explore and highlight the responsibilities that may be associated with the exercise of rights.
- 6.8.3 Educate and support the person to understand and exercise their rights and responsibilities through the use of appropriate augmentative communication where necessary.
- 6.8.4 Assist the person in eliminating or reducing any rights restrictions that may be in place.
- 6.8.5 Support the person to engage an independent advocate where appropriate.

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- 6.8.6 Support the person to make a referral to the Human Rights Committee with or without the assistance of an advocate.
- 6.8.7 Any employee in their role as advocate for an individual may process their concerns regarding a rights restriction directly to the committee in writing.

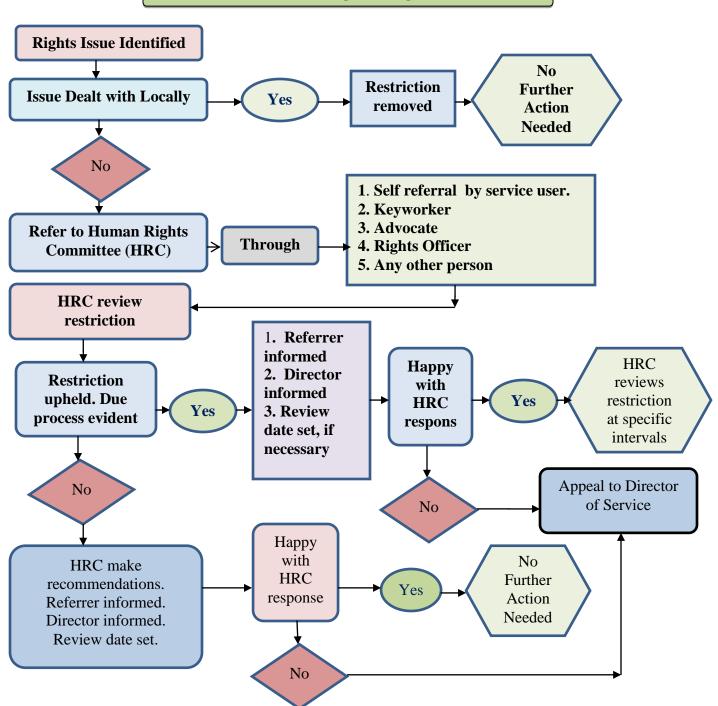
6.9 The Supervisor

- 6.9.1 Familiarises herself/himself with the Policy on Human Rights Promotion and Protection
- 6.9.2 Ensure that a human rights based approach to services and supports is upheld and nurtured in their areas of responsibility
- 6.9.3 Ensures that recommendations are upheld and completed in a timely manner. Ensures that all staff and volunteers operating under their direction are familiar with this policy document, Our Charter of Rights and with the referral documentation.
- 6.9.4 The Supervisor/PIC should report all rights restrictions that they are aware of, including those that have been reported to HIQA, to the Human Rights Committee.

7. Referral to Human Rights Committee

- 7.1 Accessible Referral forms are available at designated areas throughout the service;
- 7.2 When completed the referral form is posted to the Chairperson at a pre-designated address

8. Process for Dealing with Rights Issues



Process for Dealing with Rights Issues

SJOGCS11 Policy on the Protection and Promotion of Human Rights in Intellectual Disability Services.

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9. Procedure – The Review Process at the meeting

- 9.1 Following receipt of the referral the Chairperson will appoint a committee member to contact the service-user/advocate/relevant others to make arrangements to meet for the information gathering process, bearing in mind the confidential nature of the process, with a view to reporting back to the committee.
- 9.2 The information gathering should be conducted by two members of the committee, one internal who may have been the initial contact person as per the point 9.1, and one external, where possible.
- 9.3 The committee members may arrange to meet a number of people, depending on the detail required and the scope of consent obtained.
- 9.4 The service-user is invited to attend the committee meeting and may be accompanied by a family member/key worker/advocate if they so wish. Alternatively, they may choose not to attend or they may nominate a representative to attend on their behalf.
- 9.5 If the service user has given consent, a staff member will be invited to attend the committee meeting for the review of the restriction.
- 9.6 The committee will endeavour to respond to an individual referral within 8 weeks of the information gathering process;
- 9.7 A judgement by the Chairperson is made if it is deemed that the referral requires immediate action. A sub-committee may be appointed to deal with urgent applications between planned meetings.
- 9.8 Committee members will review a copy of the documentation for consideration prior to the meeting. Following the meeting, this copy is returned to the Chair for shredding.
- 9.9 The committee will review the referral at their monthly meeting and process a response directly to the referee (service-user/advocate) and to the relevant supervisor, if consent has been obtained. A copy is also forwarded to the Regional Director/General Manager
- 9.10 Based on a review of the documentation, the HRC may recommend one of the following actions:
 - Endorsement of the restriction that is in place, ensuring that due process is followed.

- Endorsement of the restriction that is in place contingent upon specified modifications by the relevant team.
- Recommendation for total review of the restriction that is in place.
- 9.11 The service-user/advocate may appeal a recommendation of the Committee to the Regional Director/General Manager. The Regional Director/General Manager, having considered all facts and met with all relevant parties, will issue a final decision.
- 9.12 The committee's recommendations will be a majority decision, with dissenting views noted.
- 9.13 Minutes of the HRC meetings will be approved by the membership. Copies of the minutes and a copy of all material relevant to each case will be kept by the service only.
- 9.14 The Chairperson/representative of the Positive Behaviour Support Committee (where present in a service) is invited to share information with the committee regarding the status of individuals who have a current restrictive strategy in place to manage their behaviours of concern.
- 9.15 Where it is evident following a Rights Audit that many restrictive strategies or practices are at present used within a service the following priority area will be addressed:
 - Restrictions for the management of behaviours of concern, e.g. medication, mechanical devices, locked doors, physical holds etc.

	-•
Appendix 1. Human Rights Committee Notice for Service-User Inform	nation
A Human Rights Committee is now in place in Service	
The committee meets monthly to review any Rights issues that users, or your advocate have brought to their attention.	you, as service-
Committee Members:	

Appendix 2. Human Rights Committee - Consent Form

Accessible Information and Consent Form for Referral

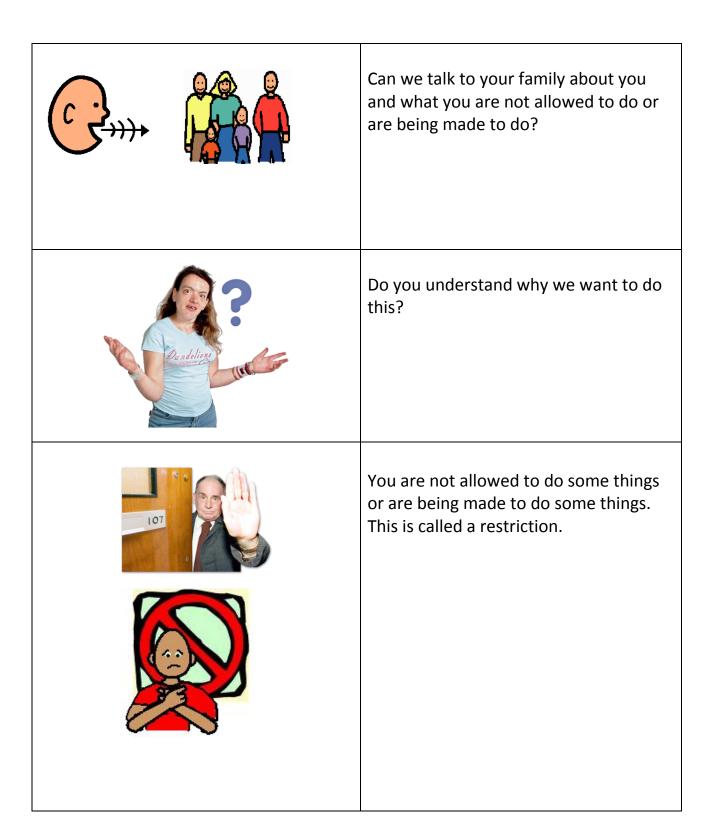
If you would like the Human Rights Committee to look at something you are not allowed to do, or are being made to do, we need you to fill this form in.



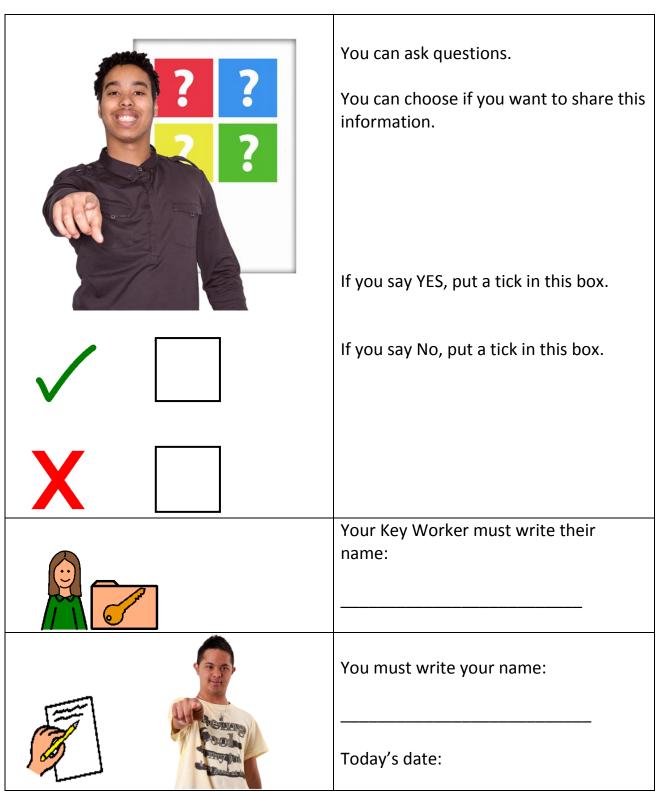


SJOGCS11 Policy on the Protection and Promotion of Human Rights in Intellectual Disability Services.

Document Reference No. SJOGCS11. Revision No. 3. Approval date 29/09/2016







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Appendix:	3. Referral For	m
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Referral Form

This form is to be completed by the person making the referral or by the person supporting the referral maker to ensure the required information is provided to the HRC. The person supported has the right not to have their name revealed to the HRC. However, the person also has the right to present their referral in person to the HRC.

Does the person object to giving their name to the HRC at this time?

Yes / No

All discussions by the HRC remain confidential to the HRC and the Director of Services.

Name of person whose right is restricted:					
Name of person making referral, if					
different:					
Contact Details of					
person restricted:					
(Address & phone					
number)					
Name of Advocate if					
different to person					
supporting:					
What is the right at issue and					
how is it being restricte	ed?				
How does the restriction					
impact on your life?					
Were you consulted before the restriction was			vas imposed?	Yes	No
were you consulted before the restriction wa		rus imposeu:	103		
Did you consent to the restriction?			Yes	No	

Determining Due Process Please complete this form including as much detail as possible.

1 Good Reason	What is the reason why the right needs to be restricted now? (What are the risks if not restricted? Is there a risk assessment – if so, please attach.)
2 Least restrictive	Is the right restricted in the least possible way? (If so, how? What else was tried?)
3 Plan in place	Is there active work going on to try to support the person to become more independent / less restricted over time? (Tell us what they are, e.g. skills teaching.)
4 Reviewed regularly	If the restriction is being reviewed, who is reviewing it and how often is this happening?
5 Consent of Person	Is the person (or their advocate(s)) okay with the current situation and support plan? Who is the person's advocate? (Family etc.)

How long has this restriction been an issue for you?					
Have you used the complaints process to make a complaint? Yes				No	
If yes, to whom did you	make the complaint?				
How was your complain supported?	nt				
What would you like to see happen?					
Who else have you told about this issue? (Name and contact details)					
Is your family involved in this process?					
If not, would you like your family involved in this process?					
Is there any other information you wish to provide for us?	0				
	act with you and other people invinformed recommendation?	olved if we need	d further	Yes	No
Sign:Individual restri	cted	Date:			
Sign: Person support	ing	Date:			
Relationship to individual restricted: Please include any additional information which you feel is relevant to this referral					

Address of HRC

Your referral has been received by the Chairperson of the Human Rights

Committee (HRC) regarding ______. Here is what will happen next:



The HRC Chairperson will ask a committee member to find out more information. This person is the Information Gatherer.



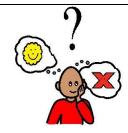
The Information Gatherer may speak to you or your key worker and important people in your life.



You may be invited to come to the HRC meeting. You can bring someone to support you and you can tell us about the restriction upon you.



If you do not wish to come to the meeting, the information gatherer will tell the HRC about your concerns and it will be discussed at the HRC meeting.



The HRC will then recommend one of the following:

- Agree with the restriction as due process has been followed
- Agree with the restriction if certain changes are made
- Recommend a full review of the restriction

If no further information is needed, and if a decision is reached, a member of the HRC will contact you and tell you what decision the HRC came to and how they reached this decision.



The decision will be sent in writing to you/your key worker and the Regional Director/General Manager.



You can ask for a Follow-up Review by the HRC if you want.





It is important that you are satisfied with the feedback.



If you are not happy you can appeal to the Director/General Manager of your Service.

Thank you for taking the time to make a referral to us,

Yours sincerely

Chairperson, Human Rights Committee cc. Key worker

Appendix 5. Checklist for Restrictions imposed for Behavioural Reasons.

This checklist is for the information gatherer to ensure due process has been followed where a restriction has been imposed based upon behaviours.

Behaviour Question	Answers			
What are the rights that are				
restricted for this person:				
Are there any other rights				
restrictions in place for this person?				
If yes what are those restrictions?				
Are the rights of others sharing the				
same environment with this person				
restricted as a result of this				
restrictive intervention?				
Name the behaviour that is of				
concern:				
Name the intervention(s) used to				
manage this behaviour which				
restricts the person's rights e.g.				
Environmental management,				
Medication, Restraint etc.				
How often has this restriction being u	sed in the past three			
months?				
Was the restriction approved and if so by whom?				
Has this person a Positive Behaviour Support (PBS) plan in				
place?				
Date of implementation of PBS plan:				
Date of last review of PBS plan:				
Last date of score of Periodic Service Review (PSR):				
Percentage % of score of PSR:				
Is the behaviour that is focused on in the PBS plan the same behaviour Yes / No				
for which the restrictive intervention is being used?				

If the answer is yes then is the person using their functionally equivalent (FE) skill?	
How many incidences were analysed and what % of incidences confirmed the hypothesis (now the FE skill)?	
If the answer is no then - has a new functional assessment been conducted?	

Appendix 6. Additional Information required if the restriction is in the case of Physical or Mechanical Restraint

This form is to be used in conjunction with the Information Gatherer form by the designated persons gathering information, where appropriate.

Physical restraint: The use of physical intervention (by one or more persons) for preventing the free movement of a person's body.

Mechanical restraint: The use of mechanical restraints such as devices or bodily garment for the purpose of preventing or limiting the free movement of a person's body.

Questions	Comments
Name the right restricted?	
What is the impact of the	
restriction on the individual?	
What is the impact of the	
restriction on others?	
What restraint is being used?	
Why is a restraint being used?	
How often & when is it used?	
How long is restraint applied for	
each time?	
How is it monitored?	
How and when was it reviewed and	
by whom? What document is	
available to show this?	
What factors influenced the	
authorisation and use of the	
restraint?	

Who consented to this procedure: the person/family member/advocate/other?			
What other measures/alternatives were considered to address the issue?			
Has a Risk Assessment been carried			
out? Is there a copy for us to see?			
Is there a restrictive reactive strategy in place? Is there a copy for us to see?			
Are there plans/therapeutic supports	in pla	ce to reinstate the right?	Yes/No
Is there a BSP in place?		Yes/No	
(a) Is the behaviour for which the r in the person's BSP?	estrai	nt is being used the behaviour targeted	Yes/No
(b) If not, has a functional assessm	ent be	en conducted on this behaviour?	Yes/No
Date of implementation of BSP:			
Date of latest review of BSP:			
Is the person being taught to use a full If not, why?	inction	nally equivalent skill?	Yes/No
What are the risks if the restraint is not applied?			
What has been done to minimise the restriction?			
Signed:	_	Date:	
Signed:		Date:	

Appendix 7. Information Gathering for Psychotropic Medication

This form is to support the designated information gatherers to collect information where a rights restriction involves **psychotropic medication**. This form is to be anonymised **– do not use any service users name within**.

Date Investigated:		
Information Gatherers:		
Questions		Comments
When did this person last att	end a	
Psychiatric Clinic and is there	e a	
document recording this?		
What medication has been		
prescribed? How often is it to	aken?	
When was the medication fir	st	
prescribed?		
When was the medication las	st	
reviewed and by whom?		
Describe the behaviour for w	hich the	
medication has been prescribed.		
What functional assessments		
been carried out, by whom and on		
what behaviours? What documents		
are on file to support this?		
Is there a Behavioural Suppo		
plan in place to support the person		
regarding the behaviour he/s		
now receiving medication for		
date is the most up to date v		
What are the known, usual s	ide-	
effects of the medication?		
What side-effects have been	noted	
and recorded?		
How is this medication monit	tored	
and recorded?		
Has the person/family memb		
consented to this medication	1?	

What rights restrictions have been	
imposed as a result of this	
medication?	
What supports are in place to	
reinstate the right?	
What alternatives to using	
Psychotropic medication have been	
considered in terms of management	
of behaviours?	
PRN (as needed) Medication	
Time (as neceed) included	
What is the rationale for	
administering PRN medication?	
What are the criteria for which PRN	
medication is to be administered?	
Is there a signed up to date protocol	
for the administration of PRN	
medication available to see?	
Sign:	Sign:
Information Gatherer	Information Gatherer
Date:	Date:

Appendix 8. Information Gathering

This checklist is for the designated information gatherer to see if due process was followed during the imposition of a Rights Restriction. This form is to be anonymous – do not use any service user's name within.

All parties must be offered the opportunity to report the rationale for the restriction as described. Information gatherers should liaise with the relevant supervisor, advocate and service user

Date Investigated:	
Information Gatherers:	
Location:	
Additional forms required:	
Questions	Comments
Please describe the restriction and how this impacts the individual and their life.	
	anical or involves psychotropic medication, complete the ion is for behavioural reasons, complete the Behaviour
What are the reasons/ evidence for the restriction?	

Describe any teaching supports that have been put in place.	
What else has been tried and what were the results?	
Do you think this particular action is the least restrictive?	
What is the impact of the restriction on other people?	
Does it restrict the rights of others? Or protect others?	
Did the individual consent to the restriction being put in place? If not, why not?	
Is the individual's family aware of the restriction?	
Was the Complaints Process used and, if so, what was the outcome?	

Who is responsible for implementing and monitoring the restriction, e.g. staff/ behaviour support committee?	
How is it reviewed? Please show supporting documentation.	
Additional Information if required	: Physical Interventions and Restrictions
Is there a comprehensive written restrictive reactive strategy in place and available to see?	
Is there a Risk Management Strategy in place and available to see?	
Additional comments can be	added on the reverse of this page.
Sign:	Sign: Information Gatherer
information Gatherei	intormation Gatherer
Date:	Date:

Appendix 9. Clinical Team Information Request Form

Application from the Chairperson of the HRC to the Clinical Team for information relevant to a restriction review.

Please return this form in a sealed envelope, to the Chairperson of the Human Rights Committee (HRC).

It will be kept on the HRC file of the above named person.

This file is kept securely by the designated committee member from the HRC.

Only those on the list below will see this information:

- 1. Human Rights Committee Chairperson/Vice Chairperson
- 2. Designated HRC Information Gatherer
- 3. Human Rights Committee (if relevant and only in an anonymised format)
- 4. Director of Service (if relevant and required in the appeals process)
- 5. Person supporting this referral (if required)
- 6. Person Supported/Service User

Name of Person Restricted:
(Key Worker) supports this Person.
The following restrictions are being reviewed by the HRC:
List restrictions; list any other relevant information:

Information Sheet

Name:	
Profession:	
Date:	
Rights Restrictions being reviewed.	
Discussed with:	
Can you briefly outline any input you have had in reviewing the above restriction (i.e. when, outcome, dates reviewed, barriers to progress, etc.)?	
Can you outline what further recommendations you have in relation to your input as it relates to the above review of this rights restriction?	
If you cannot, for professional reato meet with representative(s) of presentation of relevant informations.	
Any other comment(s)	

Appendix 10. Checklist for HRC prior to making Recommendations

Case ID: ____/___

This checklist is for HRC members to ensure all required information and forms have been completed, prior to the HRC making a recommendation.

Restriction:	
Requirement:	Yes/No
Is there a completed HRC Referral Form on file, including consent?	
Is there a copy of the acknowledgment letter on file?	
Assigned HRC members:	
Has an Information Gatherer Form been completed by the assigned HRC members?	
Was a Physical/Mechanical Restraint Form required and, if so, filled in?	
Was a Behavioural Restriction Form required, and if so, filled in?	
Was a Clinical Team Information request made by the HRC Chair and, if so, was a completed form received and placed on file?	
Has the Case Discussion Form been completed and presented to the HRC?	
Is there any other information now required before a recommendation is made?	
Recommendation:	
Date for review:	

Appendix 11. Human Rights Committee Decision Making Form

Identification No:
Date Received:
Committee members present:
Summary of issue:
Response/Recommendation:
Signed:
Chair
Date:

Appendix 12. Capacity/Consent

Capacity and information have been identified as elements important to informed consent. 'Capacity' refers to the ability of the individual to engage in the decision making process. 'Information' concerns the individual's access to the facts necessary to make a decision and the person's ability to understand the facts and circumstances relevant to a given situation. For consent to be voluntary there must be no coercion or threats of negative consequences for withholding consent (Turnbull, 1977).

To obtain informed consent the individual must demonstrate that he/she can:

- Understand the information relevant to the decision in question
- Retain that information
- Use or weigh that information as part of the process of making the decision
- Communicate his or her decision

Currently, in the absence of legal capacity legislation and guidelines, services respect the individual's right to make decisions and implement a policy of presumption to capacity to consent.

Capacity is issue specific and time specific. If the individual has reduced capacity to make a decision, support is provided to the individual to make the decision. The individual's capabilities in each aspect of the decision making process must be assessed based on experience and knowledge. Real choice can only be made when there is adequate awareness of alternatives and the consequences of the options available.

If consent is difficult to obtain, the individual's natural support network/advocate is consulted and consent requested. Informed consent must be obtained in all issues regarding medical treatment.

Circumstances where the person is considered to lack capacity to consent might include situations when:

- The individual does not know that they have a decision to make;
- The individual does not understand the choices available or the consequences of those choices;
- The individual cannot communicate their decision.

Appendix 13. Principles Underpinning the Delivery of Quality Services Using a Human Rights Based Approach (HRBA).

The application of a human rights culture takes on additional significance in the provision of services and supports to people with intellectual disability. Services face the challenge of providing care and support, keeping people safe and well, facilitating independence and community inclusion while ensuring that individual rights are protected. The balance between individual growth and personal safety needs to be continually gauged. The Human Rights Committees can serve as the stabilizing force that allows this conflict to be resolved. Key principles for consideration, within a HRBA include:

13.1 Express link to rights:

Identifies and names the rights that the person may not be in a position to exercise. In relation to adherence to this guiding principle these guidelines include the following standards and processes that link to a HRBA.

13.2 Participation:

The principal of participation identifies barriers that exist which limit the person in terms of exercising rights

13.2.1 Choice and Personal Growth

Choice must include the notion of prior experience, real options and opportunities, and the act of choosing. Each individual is supported to take on an active role in the design of their lives and support services.

13.3 Empowerment:

Explores how the person can be empowered through the selection of appropriate supports and environmental changes.

13.3.1 Environmental Context

The main aim of service provision is the empowerment of each person to live valued and fulfilling lives characterised by the achievement of personal outcomes in settings typical of the community in which people live. Key for each individual is control of their life, sufficient support to live life to the full, support in the least restrictive environment, adequate financial resources and protection of their possessions.

13.4 Non-discrimination:

The principle of non-discrimination ensures that persons with disability are not discriminated against on the grounds of their disability.

13.5 Accountability: Ensure that policies and procedures are in place to support effective delivery of rights and entitlements to service users.

Appendix 14. Restrictive Practices

- 14.1 Within society, community, and services, situations exist where total freedom to act, do or decide is not possible. Limitations may occur as a result of laws, community or group norms, or the needs of other people. These limitations exist for all those cared for and supported by our services. Rights may be restricted within services where an individual's actions harm or have the potential to harm others, where an individual's behaviour or activity is viewed as immoral by society, or where the individual's health may deteriorate if action is not taken. In relation to restrictions that are put in place for behavioural reasons, these must be in line with policy, be the least restrictive and most therapeutic for the shortest possible time. The person's Person Centred Plan (PCP) should be reviewed and functional assessment conducted if the issue is not addressed through PCP and the wheel of optimal living (see policy on Positive Behaviour Support).
- 14.2 The determination of whether an action is a restriction is based on a thorough review of a number of circumstances.

Questions may include:

- 1) Was anything done to discourage or prevent the individual exercising their right?
- 2) Was the individual denied assistance to exercise their right?
- 3) In applying a restriction, is there certainty that the individual's right could not be assured in any other manner?
- 4) What was the motivation for applying the restriction?

Often rights are restricted unintentionally. This may happen particularly where expectations and routines are established over time, especially in environments that are structured and people are supported in groups. These situations may not take individual differences and preferences into account and as a result established practices ignore or limit individual rights. These practices may result in the individual feeling disempowered, for example, having to be ready for bed at a set time or being denied access to food and drink because doors are locked, etc. Awareness raising and supporting residents in accordance with Regulations and HIQA standards should highlight such unintentional restrictions and create a pathway to the timely removal of such restrictions.

14.3 Due Process

A commitment to due process requires that people always be informed in advance when service actions will limit individual actions. Due process ensures:

- 1) The right restricted has been identified.
- 2) The consent of the individual/advocate has been obtained to restrict the right and/or to review the restriction
- 3) The importance of the right to the individual is clarified.
- 4) A plan and supports are in place to reinstate the restricted right.

- 5) The restriction is monitored regularly to ensure the need for continuation.
- 6) The training of all relevant staff in the restriction and related support prior to the implementation of the restriction.
- 7) The extent of due process matches the importance of the rights to the individual.
- 8) Identification of factors influencing the decision e.g. health and safety.
- 9) A review mechanism adequately protects the individual.

14.4 The following human rights concepts apply in the management of a rights restriction:

- 1) Progressive realisation taking steps, to the maximum of available resources, with a view to achieving progressively the full realisation of the right by all appropriate means.
- 2) Proportionality establishing a balance between the rights of the individual on the one hand and the rights of others on the other hand. The restrictions on an individual's rights must be strictly proportionate to the legitimate aim that they pursue.
- 3) Transparency the process of devising, deciding and applying restrictions must be open and accessible, with appropriate participation of stakeholders.
- 4) Clarity the restriction in question must be formulated with sufficient clarity to enable the person/persons most likely to be affected by it to understand it.
- 5) Understanding individuals must be fully informed and demonstrate understanding.
- 6) Accountability: Adherence to the principle of accountability ensures that the person is receiving the service he/she requires and that the roll out of that service is measured in accordance with best practice standards.

14.5 Best Practice

Best practice is developed by services that constantly seek the most effective and responsible treatment training and support. These practices are a constantly evolving process. Best practices may be represented by emerging alternatives with respect to how things are done presently.

Professional judgements from subject matter experts, within and outside the service, may assist in evaluating effectiveness. Best practice ensures the most effective non-restrictive approach is taken in supporting individual outcomes.

14.6 Freedom from Harm

In defining safety as the ability to effectively cope with the environment, it is important to weigh the cost of absolute safety against the opportunity to interact with the environment, which may impose an element of risk. The Human Rights Committee examines the ability of the individual to effectively cope with their environment without the imposed restrictions, examines the risk as compared to the opportunities, looks at ways in which the individual's need for independence can be supported in a safe and healthy way and ensures there is an acceptable balance between choice and personal safety.

14.7 The Best Interest of the Person

The person's best interest forms the basis for decision-making, advocacy and therapeutic supports. The interface between group/organisational needs and preferences, and those of the individual, is central to the work of the Human Rights Committees.