



INCLUSION IRELAND

National Association for People with an Intellectual Disability

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Written Submission

Joint Committee on Health and Children

Discussion on Advocacy Services

Thursday, November 26th 2015

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1. Executive Summary

The number of adverse events recorded by Irish hospitals and healthcare facilities in 2011 included 10,000 incidents of violence, harassment, aggression or abuse of patients.

Over 4,300 these incidents involved a physical assault on patients, including persons with disabilities.¹

The incidents of violence towards adults with severe to profound disabilities, as witnessed in the RTE Prime Time broadcast of the Áras Attracta care home in December 2014, are not isolated.

The numerous reports by inspectors from Hiqa and the Mental Health Inspectorate paint a picture of poor living conditions and bad practices across all types of residential centres.

In residential services Hiqa and the media have reported:

- “Inhumane and degrading treatment”
- Allegations of abuse.
- Multiple uses of restraint for often hours at a time.
- People not leaving the centre for nine months. These people committed no crime.
- People having no access to food for up to 15 hours.
- A lack of basic privacy and dignity.
- People are being chemically restrained.
- People’s civil and legal rights were not safeguarded.

In 2014, Inclusion Ireland conducted an analysis of the first 50 Hiqa reports and it concluded that the inspection reports present a picture of extensive non-compliance with regulations in areas such as health and safety, independent advocacy, restrictive practices and correct checking of medicines.

However, despite all of this, advocacy services for persons in receipt of health and personal social services is characterised by a lack of coordination, consistency and oversight.

There are no national standards or codes of practice for organisations providing advocacy services and funding for organisations providing advocacy is fragmented and ad hoc.

¹ Gartland, F. Irish Times, 11 October 2012. Retrieved from www.irishtimes.com/news/violence-against-patients-report-released-1.550016

The current system can be summarised in a number of points:

- There is urgent need for a broad spectrum of advocacy supports.
- There are no national guidelines or standards for advocacy provision.
- There is no national information campaign on the right to advocacy or how to access advocacy services.
- There is a little or no coordination of advocacy services.
- No funding exists for the development of a range of advocacy models.
- Funding for patient advocacy services has been cut in recent years.

With this in mind, Inclusion Ireland has a number of recommendations that it would like the Committee to consider:

- Inclusion Ireland proposes the establishment of a National Advocacy Authority. This new body would have responsibility for coordination and oversight for all advocacy services to persons in receipt of public services. Working alongside the existing public bodies (Hiqa, Citizens Information Board, Ombudsman, Children's Ombudsman and the Irish Human Rights Equality Commission).
- Inclusion Ireland recommends that such an authority would have responsibility for setting standards and developing codes of practice for advocacy services. Coordination and resourcing advocacy would be its remit.
- Inclusion Ireland recommends that one of the first tasks of such an authority would be to develop a national strategy for advocacy. This strategy would include provision of a broad range of advocacy models.
- Inclusion Ireland would recommend the introduction of a national signposting service under the aegis of the new body. This service would be modelled on the complaints signposting service operating in Wales.

2. About Inclusion Ireland

Inclusion Ireland is a national rights-based advocacy organisation that works to promote the rights of people with an intellectual disability and their families.

Established in 1961, Inclusion Ireland recognises people with intellectual disability as rights holders with entitlements and corresponding duty bearers and their obligations.

Inclusion Ireland works to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

Inclusion Ireland facilitates and provides various types of advocacy including representative advocacy, self-advocacy, parent advocacy and citizen advocacy.

Inclusion Ireland has a long tradition of supporting self-advocacy. We do this at the individual and groups levels.

At the individual level we support people to develop the skills, confidence and capacity to be their own advocates.

At the group and organisational level, we work to raise awareness and build the capacity of service providers to better understand and support self-advocacy.

3. Current Landscape of Advocacy

The landscape of advocacy services for persons in receipt of health and personal social services is characterised by a lack of coordination, consistency or oversight.

There are no national standards or codes of practice for organisations providing advocacy services. Funding for organisations providing advocacy is fragmented and ad hoc.

In the context of the proposals under consideration:

“Advocacy is concerned with getting one’s needs, wants, opinions, and hopes taken seriously and acted upon. It allows people to participate more fully in society by expressing their own viewpoints, by participating in management and decision making, and by availing of the rights to which they are entitled.”²

The type of advocacy described here should not be confused with the type of advocacy carried out by organisations (i.e. campaigning or lobbying). It also excludes the provision of legal representation or advice.

(i) Current service provision

A range of advocacy services are funded by the Exchequer and available to persons in receipt of health and personal social services.

These include advocacy services provided by the National Advocacy Service (NAS), the Irish Advocacy Network, Patient Focus, SAGE (Support and Advocacy Service for Older People) and EPIC (advocacy for children and young people in care).

These services are available to persons with disabilities, children and young people and older people. The models of advocacy provided by these community and voluntary organisations are varied.

These models of advocacy include peer advocacy, representative advocacy and citizen advocacy (a description of the common forms of advocacy is appended to this submission).

“All these forms of advocacy overlap and are not mutually exclusive: an individual could need self-advocacy or citizen advocacy over a period

² Commission on the Status of People with Disabilities (1996), A Strategy for Equality

along with professional [representative] advocacy to deal with specific problems.”³

Examples of the circumstances in which people can avail of different types of advocacy are appended to this submission.

Despite the investment in advocacy services in the community and voluntary sector, there is currently no coordinating or oversight body for advocacy development or its provision. There is no central funding stream. Funding is provided on an ad hoc basis. No public body has responsibility for developing standards or codes of practice.

(ii) Role of existing public bodies

Operating alongside the advocacy services provided by community and voluntary organisations are a number of statutory bodies with responsibility to either investigate complaints or provide support to persons to make complaints. These public bodies include the Office of the Ombudsman, the Office of the Children’s Ombudsman, the Irish Human Rights & Equality Commission (IHREC) and the Citizens Information Board (CIB).

An important new development will be the Decision Support Service (DSS) which will operate under the aegis of the Courts Service.

This new body – provided for in the Assisted Decision-Making (Capacity) Bill 2013 – will have a role in providing information and guidance, the development of codes of practice, and powers of investigation in respect of decision-making arrangements, under the Act.

However, none of the existing public bodies provide a signposting service to persons making complaints or requiring advocacy support in a broad range of situations and circumstances.

(iii) Advocacy in practice

The Irish Constitution recognises and respects the values of autonomy, self-determination and dignity. The right to self-determination is established in Irish law.⁴

³ Weafer, J. (2003), *Jigsaw of Advocacy*, Comhairle: Dublin.

⁴ A Vision for Change: Report on the Group for Mental Health (2006), p.25

Disability Act 2005

The Disability Act 2005 provides for the right of qualifying persons with disabilities to obtain the services of a Personal Advocate as provided for in Section 5 of the Citizens Information Act 2007. However, the relevant section of the Act has yet to be commenced.

Mental Health Act 2001

Although the Mental Health Act 2001 does not specify a right to a mental health advocate, A Vision for Change (2006), Ireland's national mental health strategy, recommends that all users of mental health services should have the right to the services of a mental health advocate.⁵

UN Convention on the Rights of Persons with Disabilities (UNCRPD)

The right to exercise decision-making capacity is embedded in International human rights law and reaffirmed in the UNCRPD.

Article 12 of the Convention guarantees the right of persons to participate to the fullest extent possible in decisions which concern them and to assistance to enjoy that right.

Ireland has signed the UNCRPD and legislation to enable ratification has been promised in 2016.

(iv) Self-Determination and Autonomy

To be "autonomous and capable of self-determination is a large part of what humans cherish in terms of liberty and independence"⁶ the Law Reform Commission has stated – and the right to self-determination and autonomy is not consistent with a best-interests approach.

The best interests approach is not aligned with modern human rights standards and is considered a subjective approach rooted in paternalism.

In a 2009 paper, Michael and Lana Kerzner illustrated the tensions surrounding rights to self-determination and autonomy saying "concerns have been expressed relating to the potential cost to personal safety, well-being and life itself in the name of autonomy."⁷

⁵ A Vision for Change: Report on the Group for Mental Health (2006), p.25

⁶ Law Reform Commission Report on Vulnerable Adults & the Law 2006

⁷ A New Paradigm for Protecting Autonomy and the Right to Legal Capacity

For people with intellectual disabilities and other so-called 'vulnerable' adults these concerns have been enough to curtail these fundamental human rights in the name of best interests; the dignity of risk or the right to failure does not apply to all.

The European Convention on Human Rights (ECHR) was given effect through the European Convention on Human Rights Act 2003 and although no new rights have been created, the Act should be considered by courts in line with our Constitution.

Article 8 of the ECHR provides a right to respect for one's private and family life and this broad-ranging article has been interpreted as protecting the right to personal dignity, autonomy and self-determination.

Article 40 of the Constitution provides that all citizens are to be held equal before the law and obliges the State to vindicate the personal rights of the citizen's life and explicitly includes the vindication of the life, person, good name and property of citizens.

The Supreme Court first enunciated the concept of 'unenumerated' rights in *Ryan v Attorney General* where it was held that 'personal' rights were not limited to the text of the constitution, but included other rights such as bodily integrity.

To date, the courts have identified 'unenumerated' rights including self-determination, bodily integrity, privacy, autonomy and dignity.

In the recent case of *MX v HSE* it was stated that while the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) had no direct applicability as Ireland has not yet ratified the Convention, "personal capacity rights ... now fall to be informed by the [Convention], as well as the principles enunciated in the judgments of the European Court of Human Rights."

In other words, when we discuss our personal rights (both enumerated and unenumerated) as per our Constitution, they are informed by Article 12 of the Convention.

Article 12 of the UNCRPD concerns Equal Recognition before the Law and requires States parties to promote legal capacity in all aspects of life and ensure that persons with disabilities have access to support required to exercise legal capacity.

It is fair to say that persons with disabilities have a right to individual support in exercising their personal Constitutional rights.

(v) Health and social care context

The Disability Act 2005 imposes a statutory requirement on public bodies to integrate their services for people with disabilities with those for other citizens. In some cases, assistance to access the service will be available to people with disabilities, following a request.

The HSE has appointed access officers across all Health and Social Care services. Access Officers are responsible for providing or arranging for, and co-ordinating assistance and guidance, to persons with disabilities accessing services provided by the offices and generally to act as a point of contact for people with disabilities wishing to access such services.

Patient advocacy is recognised as an important support for people when receiving medical care.

Doctors have recognised a duty to help patients to make decisions for themselves by giving them information in a clear and comprehensible manner and by ensuring that they have appropriate help and support.

The medical profession have stated that a patient is also entitled to be accompanied during discussions by an advocate of their own choice.⁸

A number of the functions of a patient advocate can be also carried out by an assisted decision-maker or co-decision maker such as accessing information, correspondence, making and articulating decisions relating to health or social care.

⁸ Medical Council Guide to Professional Conduct & Ethics for Registered Medical Practitioners 7th Edition 2009

4. The Need for a Broad Spectrum of Advocacy

Persons in receipt of health and personal social services should have access to a broad spectrum of advocacy.

The number of adverse events recorded by Irish hospitals and healthcare facilities in 2011 included 10,000 incidents of violence, harassment, aggression or abuse of patients.

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The incidents of violence towards adults with severe to profound disabilities, as witnessed in the RTE Prime Time broadcast of the Áras Attracta care home in December 2014 are not isolated.

The numerous reports by inspectors from Hiqa and the Mental Health Inspectorate paint a picture of poor living conditions and bad practices across all types of residential centres.

In residential services Hiqa and the media have reported:

- “Inhumane and degrading treatment”
- Allegations of abuse.
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In 2014, Inclusion Ireland conducted an analysis of the first 50 Hiqa reports and it concluded that the inspection reports present a picture of extensive non-compliance with regulations in areas such as health and safety, independent advocacy, restrictive practices and correct checking of medicines.

The Office of the Children’s Ombudsman has noted that 47% of complaints relate to Education and there is no advocacy service to

⁹ Gartland, F. Irish Times, 11 October 2012. Retrieved from www.irishtimes.com/news/violence-against-patients-report-released-1.550016

support young people who may end up excluded or denied their right to an inclusive education.

For persons with disabilities, access to a broad spectrum of advocacy was first recommended by the Commission on the Status of People with Disabilities as far back as 1996.

Building on the recommendations of the commission's report, the Goodbody report in 2003 recommended a three-stranded approach to advocacy for persons with disabilities, namely:

- A programme of support for organisations providing advocacy services and supports.
- An independent advocacy service with statutory powers.
- A community visitors programme for persons in long-term residential care.

None of the recommendations of the Goodbody report have been fully implemented.

- Funding for community and voluntary organisations providing advocacy services and supports has been cut in recent years.
- The independent advocacy service with statutory powers is provided for in legislation (Citizens Information Act 2007) but the relevant section of the Act has not been commenced
- The community visitors' programme for persons in long-term residential care has not been introduced.

5. The Need for a Coordinated Approach

There is little or no coordination between the advocacy services provided in the voluntary sector and the public bodies with responsibility for dealing with complaints or investigations of complaints. There is also a lack of coordination among the organisations funded to provide advocacy services to persons in receipt of health and personal social services.

There is clear evidence that current services are unable to meet demand. For example, the National Advocacy Service (NAS) for persons with disabilities only employs 35 advocates nationwide. About 3,500 people with an intellectual disability live in congregated settings – that is settings of 10 or more people living together, often in hospital or dormitory-type arrangements – a further 4,000 or so live in a community group homes or other residential settings.

Many of these smaller settings are, we know from Hiqa reports, little more than mini-institutions. Some 35 advocates on a national basis is wholly inadequate when we consider the scale of residential living alone.

Other types of advocacy support badly needed include family advocacy for parents of young children trying to access disability services and who are mistreated by local HSE or education settings; advocacy for parents who have an intellectual disability and who find themselves the subject of court proceedings and many other situations.

According to a recent report by the Office of the Ombudsman, people in receipt of health and personal social services are often afraid to speak up to complaint about health services. The Ombudsman has called for an action plan to ensure that people have access to an effective independent advocacy service.¹⁰

In her statement to the Joint Oireachtas Committee on Education and Social Protection in June 2015, Chairperson of the Citizens Information Board Ita Mangan called for “a coordinated approach to advocacy services across a number of areas but particularly in the context of the implementation of the assisted decision-making legislation and the needs of patients within the health services.”¹¹

¹⁰ Office of the Ombudsman (2015), Learning to Get Better An investigation by the Ombudsman into how public hospitals handle complaints.

¹¹ Statement to the Joint Oireachtas Committee on Education and Social Protection, Ita Mangan, Chairperson Designate, Citizens Information Board, 10 June, 2015.

6. Assisted Decision-Making and Advocacy

(i) Overview

The Assisted Decision-Making Bill will shortly replace the Ward of Court system under the Lunacy Regulation (Ireland) Act 1871 and will define capacity and enshrine a presumption of capacity.

The Bill will legislate for a functional approach to decision-making which is an ability to understand the nature and consequences of a decision in the context of available choices.

An individual can be said to lack decision-making capacity if he/she is unable to understand the information relevant to the decision, to retain that information long enough to make a voluntary choice, to use or weigh that information as part of the process of making the decision, or to communicate his or her decision.

Communication is defined as talking, writing, using sign language, assistive technology, or any other means or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.

A guiding principle for the Assisted Decision-Making Bill is the right of a person to make a so-called 'unwise decision' and that the wisdom or otherwise of a decision shall not invalidate it if the person has decision-making capacity. This is consistent with a move away from best interests and towards autonomy. The best interests approach is not aligned with modern human rights standards and is considered a subjective approach rooted in paternalism.

(ii) The need for Assisted Decision-Making

An individual who is in receipt of health or social care services may need an assistant decision-maker (or other support) in circumstances involving the following:

- Entry into a contract for care
- Managing of day-to-day finances including receiving state payments
- Payment of Long-Stay charges
- Decisions about medication
- Decisions about therapies
- Decisions about treatments

- Decisions about de-congregation / moving to the community
- Entry into tenancy arrangements with private landlord / housing association

(iii) Assisted Decision-Making Structures

Assisted Decision-Making will allow people to be supported to make decisions. There are several structures proposed, depending on the individual and the support required. An office within the Courts Service will be established called the Decision Support Service (DSS) and a Director of the DSS will be recruited.

At all times the past and present 'will and preferences' of the individual are to guide the decision-making process. This is a guiding principle of the legislation.

(iv) Assistant Decision-Maker

An assistant decision-maker can be any person of an individual's choosing. The Assistant supports the individual decision maker in gathering information relevant to the decision and communicating the decision. The Assistant does not contribute to the decision.

(v) Co-Decision Maker

Co-Decision Makers should be a relative or friend where a relationship of trust exists. Owners or employees of residential services, mental health facilities or nursing homes cannot be co-decision makers. A Co-Decision Maker supplements the individual's decision-making. Co-Decision makers make the decision jointly with the individual.

(vi) Decision-Making representative

A form of substitute decision-maker, the representative makes a decision on behalf of a person. The will and preference of the individual should always guide the decision. The representative should be a relative or friend where a relationship of trust exists. Owners or employees of residential services, mental health facilities or nursing homes cannot be decision making representatives.

(vii) Other Structures

The DSS will also have panels of special visitors, general visitors and court friends. A court friend is a person who assists the individual when an application is being made to court under the legislation. A special visitor or general visitor may be asked to visit an individual or their assistant, co-decision maker or representative and submit a report to the Director or examine any health record.

(viii) Relationship between Assisted Decision-Making & Advocacy

The role for advocacy in the communication of a decision is apparent, in particular for persons who are seen as non-verbal and may communicate in other ways.

On an International level, the Australian Capital Territory advocacy service (ADACAS) has stated that there are five key areas for decision-support.

- Building expectation to be a decision maker (self & peer advocacy)
- Learning about decision making (self & peer advocacy)
- Support to make a decision (citizen, patient & representative advocacy)
- Support to fulfill a decision (citizen, patient & representative advocacy)
- Advocacy for a decision (non-instructed advocacy)

Advocacy can also play an important role where an individual is having difficulty in having his / her legal capacity recognised.

Advocacy plays an important role where there is no natural support for a person whose decision-making capacity is under question or where there is disagreement.

The importance of building the confidence and capacities of individuals to be autonomous decision-makers cannot be understated and there is a significant role for self-advocacy and peer advocacy in the promotion of this aim.

7. Inclusion Ireland Recommendations

Inclusion Ireland has a number of recommendations that it would like the Committee to consider:

- Inclusion Ireland proposes the establishment of a National Advocacy Authority. This new body would have responsibility for coordination and oversight for all advocacy services to persons in receipt of public services. Working alongside the existing public bodies (Hiqa, Citizens Information Board, Ombudsman, Children’s Ombudsman and the Irish Human Rights Equality Commission).
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APPENDIX 1 – Common Forms of Advocacy and Key Features

(i) Representative Advocacy

Sometimes also referred to as independent advocacy. Provided as an independent service. Usually involves casework and complex issues that require specific knowledge and expertise. Trained advocates working to a code of practice. Usually a short-term intervention.

(ii) Self-Advocacy

A process of empowerment through which persons, individually or collectively, develop the skills and confidence to represent their own views and interests. Supported or facilitated by persons independent of providers of health and personal social services.

(iii) Citizen Advocacy

Volunteer advocates recruited from the community And providing advocacy to person resident in long-term residential care. The citizen advocate is matched with the individual on the basis of shared interests. Characterized by a long-term relationship.

(iv) Patient Advocacy

An independent person advocating on behalf of a patient. Provided in hospitals and other medical facilities.

APPENDIX 2 – Inclusion Ireland Advocacy Case Studies

(i) Refusal to enrol a child in school

Patricia is five years old and has a severe intellectual disability. She made great progress in pre-school. The psychologist with the local service provider assessed Patricia and said she would benefit most from attending the same mainstream school as her brother. The parents applied for a place in the local school. The school refused Patricia a place as they had a "right to refuse" clause in their enrolment policy. This veto was used despite a professional psychologist recommending this school.

(ii) The lack of therapy supports to children

Ann is a teenager with autism and a moderate intellectual disability. Ann is in severe need of speech therapy, occupational therapy and psychology. Due to communication and sensory issues, Ann displays behaviour that can be challenging. Despite numerous requests for therapy interventions by the parents and Ann's school, none have been provided for more than five years.

(iii) Restraint

Sophie attends her local special school and exhibits some behaviour that is challenging. The staff in the school physically restrains Sophie by holding her face down on the ground. This happened about 50 times per month. Sophie's parents asked the school to stop this practice and look at alternative responses. The school refused. In the end, Sophie was expelled from the school as her parents would not allow the continued use of restraint.

(iv) Lack of access to further education

Pat has an intellectual disability and applied to enter a Post-Leaving Cert course at his local mainstream Education and Training Board centre. Pat had to attend an interview to get a place on the course. Pat got no accommodations to attend this interview and had difficulty communicating with the interview panel. Despite meeting the academic criteria to attend this course, the interview panel decided that Pat did not have the academic ability to complete the course and refused him a place. The interview panel told Pat that there was a similar course with a local disability service provider.

(v) HSE-funded day services

Mary is a school leaver. Mary did not like the day service that was being offered by the local disability service provider. She wanted to access an individual budget to allow her more choice in the services she experiences. Mary was refused an individual budget to support her. The only choice available to Mary was either a day service that did not meet her needs or no day service.

(vi) Banking

James receives a Disability Allowance payment from the State. He wants to open a bank account to receive his weekly payment. James has had training from his local disability service provider on how to manage his money. The bank realise that James has an intellectual disability. They insist that he must have another person to open a joint account with him.

(vii) Relationships

Caroline and Paddy live in a residential service for people with an intellectual disability. They are in a loving relationship. The service provider is worried about the implications of the Criminal Law (Sexual Offences) Act. They believe that Paddy and Caroline could break the law if they engage in sexual intercourse. As a result Caroline and Paddy are not being supported to live together as a couple.

(viii) Congregated Settings

Mark lives in a congregated setting. He has lived there for almost 50 years. In line with government policy, Mark was being moved into a house outside of the congregated setting. Mark got no choice in this move. He was not asked would he like to share with other people, who he would like to live with, where he would like to live, or what type of home he would like to live in. Mark was placed with five other people with a disability. He did not like all of these people. His new home was 3 miles from town and not on a bus route. Mark feels more alone in his new home.

(ix) Medical procedures

Brigid has an intellectual disability and has great difficulty in communicating. Her doctor wants her to have an operation. Brigid cannot fully understand what this medical operation is about. Her family are very worried as the medical people will not discuss Brigid's medical care with them.

(x) Money issues

Tony lives in a residential service. The service decided to build a small link corridor between Tony's house and another one just beside it. The service took €4,000 from Tony's bank account to help pay for the work.

APPENDIX 3 – Advocacy Services in Other Countries

(i) England

People in England who meet certain criteria have a statutory right to access an independent mental capacity advocate under the Mental Capacity Act 2005.

The person must lack mental capacity which is the ability to make a decision. A person lacks capacity to make a decision if the cannot understand information about the decision, retain information long enough to make the decision, use information provided to make their decision or have the means to communicate their decision.¹²

Conditions that affect capacity include dementia, mental illness, learning disability and acquired brain injury.

¹² Making Decisions, the independent mental capacity advocate service, Office of the Public Guardian (UK), 2007.

These advocates provide support where there is a lack of capacity to make certain decisions such as for medical procedures or moving accommodation.

Under the Mental Capacity Act 2005, advocates have statutory powers to support and represent the person making decisions, meet with the person in private, access health and social care records of the person, and their report can form part of a decision making process.¹³

Where a decision relates to serious medical procedures, the advocate has a right to obtain a second medical opinion.

The Care Act 2014 extends the cohort of people who can access a statutory advocate. Where an individual has no person to support them, a local authority must make an advocate available to involve the person in planning their care, assessments or a safe guarding review.¹⁴

Advocacy under the Care Act has a role in supporting the person to be a part of assessing and planning their support needs and obtaining the care and support they need.

(ii) Scotland

In a similar manner to England, people in Scotland with a mental disorder have a statutory right to an independent advocate under the Mental Health Act 2003.

A mental disorder includes dementia, learning disability, mental illness and personality disorder. The person does not have to be receiving treatment or be detained under the Act to be eligible for advocacy support.

Local authorities and health boards must make independent advocacy available to persons with a mental disorder free of charge.

Where an individual is detained or undergoing treatment under the Mental Health Act, they must be informed of the availability of independent advocacy and every effort must be made to ensure the person can avail of this service.¹⁵

¹³ *ibid*

¹⁴ Guide to the Care Act 2014, Local Government Association, 2015.

¹⁵ The new Mental Health Act: a guide to independent advocacy: information for service users and their carers, Scottish Executive, 2005.

(iii) United States of America

Through the Development Disabilities Acts (1975-2000), 'Protection and Advocacy Systems' (P&As) have been established in every American state and territory. P&As are independent of service providing agencies¹⁶ and they carry out the following types of work:

Provide legal support to persons with a disability and helping them to navigate the legal system.

Support people to exercise their rights to make choices, contribute to society and live independently.

Monitor the move of people from institutions to live in the community. Ensuring people

Investigate cases of abuse and neglect in residential centres for person with disabilities.

Ensure people have access to inclusive education.

Provide training to services and policy makers on disability issues.

Assist in the development of self advocacy and raising rights (legal and social) issues that people with a disability face.¹⁷

(iv) Canada

The Ministry of Social Development and Social Innovation in British Columbia has appointed an Advocate for Service Quality.

The advocate's job is to assist people with a developmental disability and their families to access services and supports that are available.¹⁸

The Representative for Children and Youth Act gives all children in Canada a right to an advocate. For people with a developmental disability this right lasts up to their 25th birthday in some cases.

All children have and young people in British Columbia have a right to be safe, healthy, educated and heard and advocates in the office of the Representative for Children and Youth assist young people realise these rights.¹⁹

¹⁶ www.acl.gov

¹⁷ Factsheet: Protection & Advocacy Systems

¹⁸ <http://www.sdsi.gov.bc.ca/advocate/Index.htm>

¹⁹ <http://www.rcybc.ca/about-us/mandate/advocacy>

(v) Australia

In Australia, the National Disability Advocacy Program is funded under the Disability Services Act 1986.

Later legislation has introduced mandatory quality standards that all funded advocacy services must adhere to.²⁰

People covered under the National Disability Advocacy program include people with an intellectual disability, physical disability, sensory disability or a psychiatric condition.

People are supported to have a greater role in decisions that affect their lives, have greater economic independence and a more independent lifestyle.

The Disability Services Act requires that any funded disability program must support people with disabilities to exercise their rights and freedoms as set out in the UN Convention on the Rights of Persons with Disabilities.

This includes supporting people through individual advocacy, citizen advocacy, family advocacy, self advocacy and legal advocacy.²¹

²⁰ www.dds.gov.au

²¹ Quality Toolkit for the National Disability Advocacy Program, Government of Australia.