What is Advocacy?

A Collaborative Compilation led by Thom Kirkwood **AISee Collaborative**

An insightful take to mark the last day of my 50th cumulative years voluntary, professional and parental interface with autism, learning disabilities. Over that time I have come to realise what good advocacy is and is not and collaborated with many over the last few months to bring you this collective perspective as follows-

What Advocacy is -

- Standing alongside individuals and groups of people who may otherwise be marginalised with the danger their views and opinions would be disregarded or discounted.
- Speaking on behalf of people who are unable to do so for themselves and who have explicitly consented to their views being represented.
- Helping to articulate a person or groups viewpoint and desired objectives.
- Promoting and embodying the principles of natural justice laid out in Human Rights Legislation and related legislation where access to advocacy has been specified.
- Actively Listening to someone and striving to understand their point of view using a range of preferred communication methods where needed.
- Finding out what makes a person feel good and valued.
- Informing and empowering individuals and groups from a rights-based perspective.
- Consciously and consistently striving to Understand a person’s lived and living experience and supporting them to identify the systemic and structural barriers preventing them living a good life.
- Identifying and promoting similar causes and wherever possible strengthen individual and where appropriate collective action and networks.
- Helping individuals consider the potential range of choices they have in each situation and consider the potential consequences different choices might have for them, including fall back choices.
- Enabling a person to have control and agency over their life whilst addressing issues on their behalf if requested and with due consent.
- Always apply the guiding principles of; consultation, cooperation, communication, collaboration and co-production in all exchanges
- When relevant, help to frame personal problems as symptomatic of wider societal and community issues potentially requiring collective response, action or reform.
- Offer proportionate support or translation if an individual requires accessible information and how it relates to their desired choices and wishes.
- Supporting an individual or group decision about how information can assist in making informed choices.

What Advocacy is not (with added caveats) –

- Providing advice, or your own opinions
- Making decisions for individuals or groups
- Imposing own solutions on individuals.

- Making complaints – *(On occasion it can be about supporting an individual within a formal complaints processes to promote rights or identify unethical, unprofessional, discriminatory or unscrupulous practice by ensuring their voices are heard)*
- Helping fill in forms *(on occasions where there are linguistic, literacy or communication barriers providing it is about the individual their choices and their concerns etc.)*
- Mediation *(do not mix up mediation from constructive discussion where the advocate is relaying information to client, advocacy partner and then relaying a response, such practice is not mediation)*
- Counselling, psychotherapy *(on occasions it can be emotional support alleviating an individual's anxiety by utilising an individuals preferred communication technique)*
- Befriending *(it does however require a practioner to deliver with clear communicative approach to enable understanding and responsive communication)*
- Care and support work
- Consultation
- Telling or advising someone what you think they should do.
- Speaking for people when they are able to express a view
- Uncritically agreeing with everything a person says and complying with whatever an individual asks of you in the role of an advocate.
- Unconditionally reciting views or opinions which could conflict with professional codes of conduct, or other ethical, moral and legal restrictions.

Success in the world of public policy is currently defined by impact and outcomes.

When the use of the word 'outcomes' is applied within the advocacy, there can be differing definitions of whose desired outcomes are being promoted. Clearly the primary definition for us is a desired outcome for the individual or group accessing advocacy services. There are other desired outcomes defined by advocacy organisations, commissioning organisations and/or individuals.

The advocacy journey towards achieving a 'desired or preferred outcome' can often be challenging for all stakeholders. Some negotiated outcomes may not be entirely in line with the 'vision' some individuals may have been hoping to achieve in the future. The practice of negotiation and compromise may be a particular challenge for this community. It is therefore important to recognise that there are a wide range of neurodevelopmental disorders, and as such autism-informed advocacy requires an understanding of neuro-difference and a capacity to adapt communication in line with preferred individualised person-centred approaches. Supported by Principles of Good Advocacy Practice and Quality Assurance.

When striving for agreed and desired outcomes, an understanding of the different types of advocacies is crucial:

Types of Advocacies

One to one individual advocacy

This includes professional or issue-based advocacy. It can be delivered by paid or unpaid advocates. An advocate supports an individual to represent their own interests or represent the views of an individual if the person is unable to do this themselves. They provide support on specific issues and provide information but not advice. This can be both short and long term.

Another model of one to one advocacy is citizen advocacy. Citizen advocacy happens when ordinary citizens are encouraged to become involved with a person who might need support in their communities. The citizen advocate is not paid and not motivated by personal gain. The relationship between the citizen advocate and their advocacy partner is on a one-to-one, long term basis. It is based on trust between the advocacy partner and the advocate and is supported but not influenced by the advocacy organisation.

Peer advocacy can also individual advocacy. Peer advocates share significant life experiences with the advocacy partner. The peer advocate and their advocacy partner may share age, gender, ethnicity, diagnosis or issues. Peer advocates use their own experiences to understand and have empathy with their advocacy partner. Peer advocacy works to increase self-awareness, confidence and assertiveness so that the individual can speak out for themselves, lessening the imbalance of power between the advocate and their advocacy partner.

Collective or Group Advocacy

Collective Advocacy enables a peer group of people, as well as a wider community with shared interests, to represent their views, preferences and experiences. A collective voice can be stronger than that of individuals when campaigning and can help policy makers, strategic planners and service providers know what is working well, where gaps are and how best to target resources. Being part of a collective advocacy group can help to reduce an individual’s sense of isolation when raising a difficult issue. Groups can benefit from the support of resources and skilled help from an advocacy organisation.

Peer Advocacy

Describes an advocacy relationship between an advocate on the autism spectrum working to support another person on the spectrum to speak out or represent their wishes and views. An advantage of peer advocacy is that the advocate might have a deep understanding of the difficulties and experiences of the person they are advocating for, so trust and understanding are quickly established between the advocacy partners. A possible disadvantage is that some people on the spectrum have an impaired ability to see another person’s point of view, and a tendency to assume that others want, think, believe and know the same things that they do. There is a risk that the peer advocate actually advocates for him/herself rather than the individual concerned. This can be overcome by increasing the availability of trained peer advocates within existing advocacy organizations, enabling the advocate with ASD to develop listening and reflective skills and to leave their own agenda outside the advocacy partnership.

Self-advocacy

The aim of all models of advocacy is to help individuals gain increased confidence and assertiveness so that, where possible, they will feel able to self-advocate when the need arises. Much work of self-advocacy is about equalising power. As Pennell states 'Self-determination focuses on reforming systems to provide greater opportunities for choice and self-direction' Self-Determination and Self-Advocacy 'Shifting the Power' Pennell 2001. Supporting Outcome 2 Choice within the Outcomes and Priorities 2018-2021.

It has however, to be respected and appreciated, others have [different] perceptions and challenges, Power, Bartlett and Hall (2016) point out that self-advocacy and peer advocacy can often overlap with each other, with peer advocacy being made up of a group of self-advocates.

Professional Advocates

Are trained and/or qualified for the service they offer and they are paid for their services. They are not usually involved in any other way in the life of the person they advocate for, but have understanding and experience of autism and learning disabilities which enables them to work successfully with this group of children and adults, and to speak on their behalf.

Non-instructed Advocacy

Is the last resort in the field of advocacy and differs in that the advocate is expected to use a greater level of judgment than in instructed advocacy. Advocates will undertake non-instructed advocacy when an individual is not able to instruct another person to speak or act on their behalf and is not able to make their views or wishes clear in a specific situation. The advocate makes representations based on the perceived and theoretical preferences of the person with ASD. It is important for the advocate to get to know the person, to use observation and to reflect on what the person "tells" by their behaviour and mood, and to use information and advice from others who know them well. The quality of life measures that most people would find acceptable, together with relevant legislation and standards in social care are used as a baseline and compared with the quality of life of the person being advocated for. A knowledge and understanding of the autism spectrum is essential, as we should not expect that people on the spectrum will necessarily want or need the usual measures of an acceptable quality of life, such as holidays, friends and employment (although many people on the spectrum do).

"The non-instructed advocate seeks to uphold the person's rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspective." (Henderson R, 2007 p.7).

Legal Advocacy

Is carried out by trained lawyers or barristers who can represent people on the spectrum in the Criminal Justice System. The legal advocate assists the person in exercising or defending their rights, but this is not advocacy in the same sense as above. The theoretical basis in the legal arena is best interest in the law, not the best interest of the individual. For example, the law may work under guidance that cannot support the individual to pursue what they would choose, such as an independent or isolated lifestyle.

Human Rights Based Approach.

Advocacy is delivered with a human rights-based approach which is fundamentally about empowering people to know and claim their rights. This increases the ability and accountability of individuals and institutions who are responsible for respecting, protecting and fulfilling rights. This is also about parity in policy making as well as the day to day running of individualised service provisions.

In Scotland, your human rights are protected by The UK Human Rights Act, The Scotland Act and The European Convention on Human Rights ('the Convention'). Your rights are also protected by a range of international human rights laws which, although they cannot be enforced directly in Scottish courts, are monitored internationally.

The Human Rights Act 1998 ('the Act') brings most of the fundamental rights and freedoms contained in the European Convention on Human Rights directly into UK law. The rights included in the Act not only impact upon matters of life and death, but also affect the rights you have in your everyday life: what you can say and do, your beliefs, your right to a fair trial and other similar basic entitlements. Most rights have limits to ensure that they do not unfairly damage other people's rights. However, certain rights, such as the right not to be tortured, can never be limited by a court or anybody else. Cases based on the rights and freedoms in the Act can be argued in a UK court or tribunal. The Act also requires all public authorities, such as hospitals, schools, local authorities, courts, and some care homes to comply with those human rights. According to the Act, all other legislation should also be interpreted and applied in a way that is consistent with the rights included in the Act.

The Scotland Act 1998 established the Scottish Parliament and the Scottish Government. It ensures that neither the Scottish Parliament nor the Scottish Government can pass any law that is incompatible with the human rights contained in the Human Rights Act or the European Convention on Human Rights. This means that human rights must be respected and realised at all levels of governance in Scotland.

The European Convention on Human Rights was drafted by all the states of the Council of Europe, including the UK, and came into force in 1953. The Council of Europe was formed in response to the atrocities and cruelties of the Second World War and is a regional membership organisation for countries in Europe. The Convention is made up of a series of Articles. Each Article is a short statement defining a right or freedom, together with any permitted exceptions. The rights in the Convention apply to everyone in the UK.

The Scottish Human Rights Commission is an independent public body, accountable to the people of Scotland through the Scottish Parliament. The Commission has a general duty to promote awareness, understanding and respect for all human rights – economic, social, cultural, civil and political – to everyone, everywhere in Scotland, and to encourage best practice in relation to human rights. The Commissions full duties and powers are set out in the Scottish Commission for Human Rights Act 2006.

Note: The Bill of Rights Bill was introduced to parliament in June 2022. It has not been approved by parliament. If approved, as proposed with no amendments, it would repeal and replace the Human Rights Act 1998, which incorporates and makes the rights contained in the European Convention on Human Rights (ECHR) domestically enforceable.

Legislative Provision in Scotland

In Scotland there is a range of legislative provision (see infographic below) that underpin the desirability and provision of advocacy in Scotland. Few are autism informed.

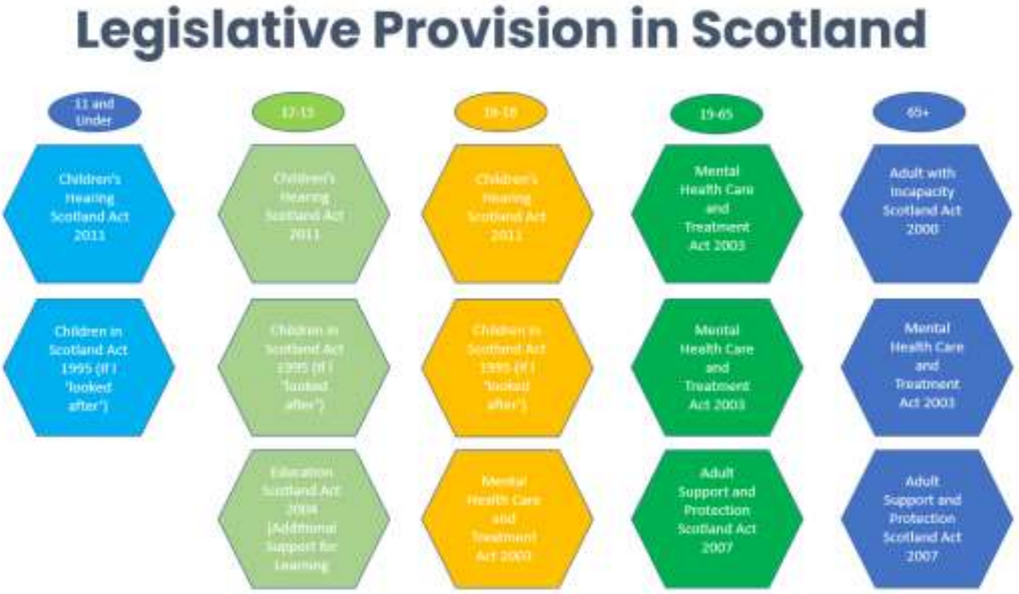


Image courtesy of the Autism and Advocacy Network.

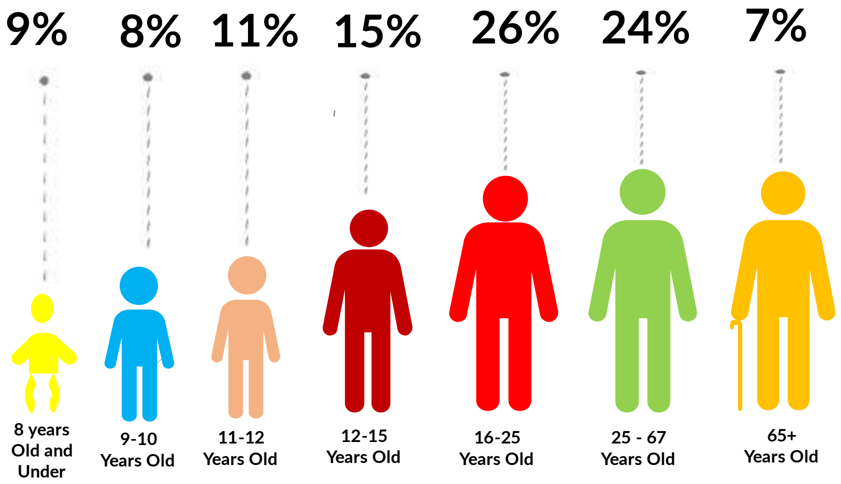
Over and above the aforementioned age specific legislations, the Self-Directed Support (Scotland) Act 2013 and the Social Security Scotland Act 2018 both can be of relevance to autistic people and their families and depending on eligibility criteria advocacy provision may be available.

Good advocacy is delivered by a variety of different organisations. A perspective from International Advocacy Practitioners Association, on work led by Suranne Muriston lead for membership and member engagement.

From this work one learns that Advocacy is global and significant, spanning age range see illustration one below.

Advocacy Delivery by Age Demographic

Member who deliver advocacy provision either professional and/or community /peer, were asked to provide a breakdown by client age

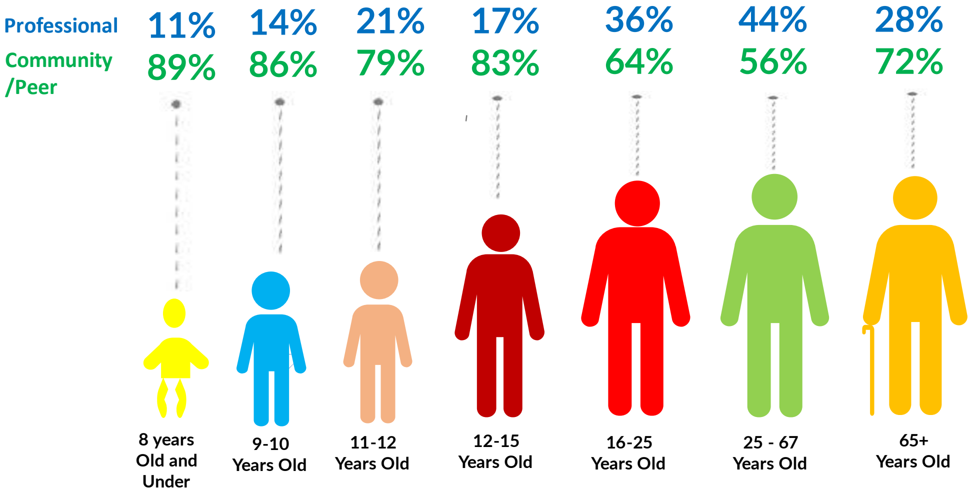


.The above results are from 37,468 members across 41 countries spanning 6 continents.

Provided by- International Advocacy Practitioners Association July2022 Table 1

We also learn of how advocacy delivery is split between professional, community/peer see illustrative table 2 below. The majority is delivered by community / peer.

Advocacy Split by Professional or Community/Peer



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Provided by - International Advocacy Practitioners Association July2022 Table 2

During this collaboration there are three legitimate concerns around non-legal advocacy that came to the fore, funding or lack there off, automatic opt-in, and training.

In regards to training, I am aware of five independently accredited advocacy training programmes, four by City and Guilds and one by ourselves at AISee Collaborative accredited by the Institute of Training and Occupational Learning and recognised by International Advocacy Practitioners Association.

I would like thank the contributors from across Argyll and Bute, Aberdeen and Aberdeen shire, Forth Valley, Dunbartonshire, Dundee, Dumfries and Galloway, Glasgow, Lanarkshire, Lothians, Perthshire, and Renfrewshire for their time and contributions.

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AISee – Advocating, Identifying, Solutionising, Educating and Empowering.

13th February 2024