

SIAA Response

Scottish Strategy for Autism

December 2017

1. How can we ensure autistic people and their families enjoy healthier lives?

Currently there is no legal right for individuals with Autistic Spectrum Disorder (ASD) to access assessment. It is imperative that the diagnostic process for individuals with ASD is free, accessible and that individuals are notified of their legal right to independent advocacy under section 259 of the Mental Health (Care and Treatment) (Scotland) Act 2003. This will help individuals with ASD to know their rights, understand the options available to them and to access other services and sources of support.

It is important to note that though the assessment process for children is different to that of adults, children with ASD also have a legal right to independent advocacy.

It is also essential that the assessment process is clear, accessible and consistent across local authority/NHS board areas.

Support and services (including mental health services) need to be well signposted, co-ordinated and collaborative. It is essential that health and social care professionals involved with individuals with ASD implement a human rights based approach, and that GPs take a proactive approach as individuals may have problems identifying health issues.

We recommend that the hospital passport scheme be made available to individuals with ASD in health and social care environments to help them convey their specific needs, their preferred communication methods and persons they would wish to support them. This scheme promotes greater agency and helps to ease the process.

Health and social care assessments should reflect an accurate picture of the needs of the individual, and be conducted by professionals who have a solid understanding of the individual and of ASD. It is vital that those individuals with ASD are adequately assessed and should other conditions manifest, that they are sufficiently diagnosed, treated and monitored.

It is vital to provide families, carers and others who may be involved in the lives of individuals with ASD with sufficient information on accessing education, training and employment, housing and independent living, finance, social activities, quality of life and relationships. There should also be support available specifically for carers in the form of financial assistance, short breaks/respite and other services that can help them to lead healthier lives.

Robust qualitative data from personal experiences of individuals with ASD on the uptake of services would help researchers to understand which services contribute to a good quality of life and what areas require development.

2. How can we ensure autistic people have proper choice and control over the services they use and in their lives more generally?

It is essential that a human rights based approach is applied to social care plans for individuals with ASD, and that support and services are tailored to their unique set of needs in order to enable them to make their own choices and decisions. An emphasis should be placed on building capacity and supporting individuals with ASD to lead fulfilling lives.

Supported Decision-Making can enable individuals to know their rights, to consider their options and to make their own choices regardless of capacity. It allows individuals independence, agency and respect as equal citizens.

Independent living can support individuals with ASD to have proper choice and control over the services they use and about their lives as a whole.

There have been concerns around the uptake, transparency and implementation of Self-Directed Support and we feel that this strategy presents an opportunity to address these concerns and to ensure that eligible individuals are notified of their rights; that SDS implements the PANEL principles and that sufficient funding is provided in order to meet the needs of the individual, allowing them to thrive not just survive.

3. What can we do to ensure autistic people can live independently?

Independent living services should incorporate a human rights based approach ensuring that individuals with ASD have the same rights as any other citizen. The twelve pillars of independent living should be implemented to enable individuals to lead independent, fulfilling and healthy lives. The pillars are as follows:

- Appropriate and accessible information
- An adequate income
- Appropriate and accessible health and social care provisions
- A fully accessible transport system
- Full access to the environment
- Adequate provision of technical aids and equipment
- Availability of accessible and adapted housing
- Adequate provision of personal assistance
- Availability of inclusive education and training
- Equal opportunities for employment
- Availability of independent advocacy and self-advocacy
- Availability of peer counselling

Local authorities, health and social care partnerships, integrated joint boards and voluntary sector organisations need to ensure that transitional support takes a human rights based, pro-active and engaged approach that takes into account the wishes and needs of the individual, and provides the minimal disruption possible – this could be achieved through the design and implementation of equality and human rights impact assessments.

4. How can we ensure autistic people are active citizens, fully integrated and able to participate in their communities and society?

By cross referencing the Human Rights Act with the Equalities Act and building a human rights based approach into all services, the Scottish Government would help to ensure that autistic people are active citizens, fully integrated and able to participate in their communities and society.

Children with ASD have a legal right to education and to any additional support that they may require. It is essential that education professionals (from early years' to higher education) have an awareness and understanding of autism and that educational institutions have sufficient funding to provide the support that individuals with ASD need in order to reach their potential.

Support to access employment is vital in helping individuals with ASD to be active members of society. This assistance needs to continue and be tailored to help the individual within their work environment, ensuring that employers have all the training, information and tools necessary in order to best support the employee.

Co-production would be a good method to involve individuals with ASD in the shaping, delivery and reviewing of public services.

It is essential that any adaptations made by communities (autism friendly screenings, quieter shopping times etc.) work to integrate individuals, not segregate them.

5. What one single thing could the Scottish Government do to improve autistic people's lives?

By ensuring that individuals have access to independent advocacy, the Scottish Government could significantly improve the lives of people with autism.

To highlight the impact that independent advocacy can have on the lives of individuals with ASD we have included two case studies from The Advocacy Project in Glasgow:

Case Study 1 (Miss P) Glasgow Integrated service

Miss P contacted her local Autism Resource Centre and was informed by a staff member about advocacy support as she stated that she was experiencing exacerbated anxiety and stress about an upcoming appearance as a witness in court.

It was important for the advocate to explore the communication needs because due to Miss P's condition she experiences difficulties with verbal and nonverbal communication which includes the understanding and processing of information. Miss P also has epilepsy and is prone to seizures.

Miss P was invited into the office to attend an appointment face to face; as this was her preferred method of communication as well as emailing her advocate.

Miss P told her advocate that she had witnessed a physical assault and had to provide a statement to the police which has led to her now needing to attend court as a witness. Miss P states that she has never had to attend court before, and is worried about this as she can't remember details of her statement and finds it difficult to attend new places and navigate processes.

The advocate and Miss P form an advocacy service agreement which details agreed actions and support which documents Miss P's desired outcomes which are:-

- Reduce symptoms of stress and anxiety and ensure the wellbeing of Miss P's mental and physical health

- Ensure the options are fully explored with Miss P in relation to her having to attend and be supported with process with any reasonable adjustments being made which take into account her condition

The advocate supports Miss P to contact the clinical team and GP to gather the necessary evidence detailing Miss P's condition and requests a letter requesting 'soul and conscious' excusal from court. The GP was of the view that due to Miss P's condition she should be considered as a 'vulnerable witness' and with special measures in place Miss P can attend court. The special measures offered at court included; a 'supporter' for the court and access to the adult's statement prior to giving evidence. Miss P in agreement with this and feels this will help reduce her anxiety and stress.

The advocate supports Miss P to contact the Procurator Fiscal with request for special measures and witness services are put in place which secures Miss P a supporter at court as well as access to her statement in advance of her attendance.

Advocacy outcomes reported;

- Reduced stress and anxiety and improved wellbeing
- Views were listened to and heard
- Exercised choice and preferred options

Case Study 2 (Mr X) Glasgow Integrated service

Mr X contacted The Advocacy Project by email and states that he is struggling to access services in his local area. He has contacted his local council but has not had a response. Mr X states he is exhausted as he is experiencing barriers to accessing information & support which is having a detrimental impact on his wellbeing. He indicates that he is struggling to cook for himself, is feeling isolated, and unsure of any social groups in his area which he would be keen to get involved with. Mr X states that he suffers badly from sensory overloads and struggles with communication on the phone. Mr X has aspirations to attend further education but feels that this is not possible without support.

The advocate invites Mr X for a face to face appointment and agrees supports with Mr X to:

- Access information about his diagnosis and sensory overload
- Contact the local council in relation to their response to Mr X in order to explore needs assessment
- Liaise with the local Autism Resource centre in relation to local groups and activities in the local area
- Contact the local college and attend meeting to discuss additional support needs available

Mr X reports that he is attending college with support of a minute taker. He is also aware of local services and reports he is feeling more confident and in control.

Advocacy outcomes reported;

- Improved social inclusion and avoided segregation
- Improved aspirations
- Increase confidence, personal control and autonomy

The Scottish Independent Advocacy Alliance (SIAA) is Scotland's national membership body for advocacy organisations. The SIAA promotes, supports and defends independent advocacy in Scotland. It aims to ensure that independent advocacy is available to any person who needs it in Scotland.

SIAA is a Scottish Charitable Incorporated Organisation Charity number SC033576

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