

**Getting it right for children & young people with Autism in Moray.
Key themes overview from our 'Listening and Understanding....' Survey
September – December 2020.**

As part of a desire to create positive change around autism and children and young people, a group of education, health, support services, people with lived experience and parent carers began to meet in Autumn 2020. This group included people from Moray Council, Health & Social Care Moray and Moray Wellbeing Hub CIC who host peer-support action for change in Moray. Before they formalised and widened membership, they wanted to clarify their focus and areas of action. To do this they created a survey to gain views from a range of people about support, asking young people with autism, their families and those that support them to share ideas and experiences.

The data from this survey is rich and, while it was not possible to analyse this fully, key themes have been drawn out to give the flavour of the responses by three of the group members with different viewpoints – education, social support and community. We hope the results will stimulate action and deepen the evidence to enable more resources and coproduction to create positive change.

Overview:

54 returns between 21/9/20 and 18/12/20 of which.

- 0 young people
- 26 family members
- 15 people who offer formal support
- ■ family members who also hold a formal role of support
- ■ individuals who had autism themselves. ■
- ■
- 28 gave email details regarding further involvement or discussion.

Formal roles of support

- 7 social / community professional (childcare practitioner, social worker, speech and language, other roles not given)
- 2 responding on behalf of a group (Independent Advocacy Group, and none given)
- 16 working in education (head and depute teachers, support for learning, support workers, teachers, pupil support, school counsellor)
- 1 both education and social /community professional.

Subsequently the Moray Autism Service who have direct contact with pupils with Autism facilitated a further 11 questionnaires to be completed by young people with Autism, who are currently using the service

Key themes from these young people

- **Not enough support before diagnosis or in the community or school.** We think that other people listen more once there is a diagnosis.
- **It helps me that I know I have Autism.** I want to be able to talk about it and find out more chat to others and be part of a group. We would chat to others now or in the future.
- The Moray Autism Service really helps and really gets us, they listen. Coming to the service has really worked well. In school no one recognised how much of a struggle it was, I was “thrown” into mainstream and couldn’t cope, no-one believed I was struggling. The Moray Autism service understand me and listened. **Not enough people understand Autism, there is no support except MAS.**

- **Some school experiences are ok**, no concerns, some pupils felt listened to
- **We don't know what support** is available to us in the community.
- What works well:
 - ✓ **People that understand Autism and can explain it to me**
 - ✓ **People and teachers that understand us and listen**
 - ✓ **Coming to Moray Autism Service**
 - ✓ **Sometimes we need time on our own**
 - ✓ **Having a quiet place if I need to calm down**
 - ✓ **Being involved in what's happening**
 - ✓ **Flexibility: less time at school, time to do our own thing, starting part time and building up**
 - ✓ **Being in a small group with people who understand me helps.**
 - ✓ **It helps me know ahead of time where I am going and what I will be doing.**
 - ✓ **I need other people to know when to stop talking to me!**

We would like more groups for people with ASD, schools should tell us what is available we could join a group and talk to others about Autism, we could help others who feel the same.

Autism assessment themes:

The survey asked about what was working well and could be improved in the current ADAPT process.

- **Multi-agency approach** works well and is valued by families
- However, there is a **lack of post-diagnostic support**
- A **directory of support** would be helpful
- **More information and support for young people** about their diagnosis is needed
- The **process and the timescales for assessment** need to be clearer
- **Early Intervention and support** before/during diagnosis – regardless of diagnostic outcome
- **Need for consistent level of knowledge and skills** for teaching staff re supporting autism
- **Agency support was valued but wasn't accessible to all** – access criteria need to be clearer
- **More awareness of female presentation** of autism is needed

Education key themes:

When questions were asked about Education for Children with Autism those surveyed understand that schools are trying hard to get it right and could identify good practice, but this is not consistent and can be a “postcode lottery”, they liked and want to see:

A “listening, proactive school” which includes and “promotes neuro-diversity” and is Autism Friendly. A consistent and pro- active team around the child, consistent staffing in place, consistency in approaches and communication methods.

This would be created from

- More funding, **support and specialist support**
- Knowledge, experience understanding and **training about Autism** for all staff from Early Learning and Child Care to Secondary school leavers.
- Knowledge of the **child's individual needs**
- Knowledge about the **school environment to support Autism**

- **Communication systems** and information sharing between families and Educational settings that promote a **shared understanding** of the issues, strengths, strategies for learning and entitlements of the child.
- **Reduce a culture of blame** – both ways or not being listened to / lack of communication.
- Better communication systems for learners and **consistency in approaches and strategies** used.
- Early Intervention and **support from an early stage**
- **Inclusion – children being liked and welcomed** and not segregated, strict bullying protocols, Autism social groups, more support for siblings
- **A flexible approach: The right support in the right and space** out-with and within the classroom –as and when required with a **flexible approach to timetabling**. More **work available on-line** so that home learning is more successful.
- Teaching wellbeing and **self-worth about Autism**

In order to support this respondents offered:

- **A wealth of experience**, information and knowledge which could be shared about **“what the children need”** and **“how life is as a learner with Autism”**
- Participation and volunteering in **parent support groups, Autism workshops** for all children and adults.

Community key themes:

When asked to review experiences of supports available within the **community**, respondents recognised that there are currently a small number of support groups and short life activities available however overwhelmingly there was a sense of a lack of resources within the community, and where there are resources available – a lack of communication. Parents especially were keen to be part of the solution and provide peer-support as well as promote in their networks services and supports.

*“There is no support in the community, and it is quite **isolating, we feel alone**”*

*“There **doesn't seem to be any support offered near us, or if there is there is no information given**”*

There was also a sense of a lack of understanding by the general public of what Autism is and a request that **“understanding of Autism needs to be more acknowledged within the community”**.

Ideas suggested to improve these areas included:

- **Improving community awareness** of what Autism is, quash the myths & educate, highlight female experiences as part of this.
- **More positive peer-support opportunities** for parents to meet up, for family groups and for young people as well. *“It would give him more confidence and help him make friends his own age... They need to be easy to access places, nice for kids, somewhere like the Youth Cafe.”*
- **Joint up working** so all parties are made aware of support groups. Including shared communications and advertising such as a **leaflet with information for parents**
- More **support to groups and services** that can offer workshops, clubs and peer-support
- Desire to see **new services** sensory light experiences, play therapy access, workshops for parents, autism speakers, varied hours for shopping quiet hours *“They always seem to be early on a Sunday morning. This can make it difficult as a family to attend if you have non ASD children as well.”*
- More opportunities with measures in place so **young people feel comfortable and involved**

- **Pre visits** to service/people *“Relationships have to be built generally prior to accessing some of the services to enable our children to get the most from it - our children generally don't want to feel different from others, they want to feel included”*
- **Fencing for parks**, ensuring spaces are inclusive for all. *“Even cooper park isn't safe when there a road right next to the play equipment!”*
- **Making best use of the natural environment**, walks and outdoor groups strongly mentioned as what works well.

Respondents offered a range of supports including:

- *“Could provide **information, advice** about communication needs”*
- *“I could **talk to people about my experiences**. I could help with informing & educating”*
- *“By **advocating** for all people on the autism spectrum”*
- *“Fundraise, **volunteer**, support at home”*
- *“**Attending and supporting** local events. Helping to **promote** the events through social media etc.”*
- *“Willing to **provide wellbeing walks, attend meetings to support parents, share knowledge, model and educate** on different approaches used for ASD children, **discuss strategies and routines** we use at home”*
- *“Talk about aspects of autism that can prevent young people taking part.”*