



# Developing a physical and sensory disability strategy for Moray



On-line/paper survey for parents and young people

Responses – 17 (1 young person, 8 parents, 5 professionals, 1 community representation, 4 did not answer)

10 people interested in being further involved and information on the next two workshops has been sent to them.

## 1. What does living well and as independently as possible mean to you and/or your child?

Theme	Comment
Support	<ul style="list-style-type: none"> <li>• Highly important with the correct support.</li> <li>• For my child to be supported in finding strategies to help him manage his sensory</li> <li>• Being able to trust those working around our child. Knowing that professionals listen to what our needs are, what our concerns are and how best to utilise what is available to us.</li> </ul>
Inclusion	<ul style="list-style-type: none"> <li>• To know that where ever we go, that we can use facilities like families that have no disabilities can. Toilet facilities that are suitable for all disabilities, so that we don't have to lay our child on dirty toilet floors</li> <li>• Having the chance to take part in all activities with friends and family</li> <li>• Accessibility</li> <li>• That she is safe and healthy and able to be part of her community</li> <li>• Makes me feel normal like everyone else</li> <li>• Being able to be part of every day activities without discrimination/barriers</li> <li>• Being supported to learn skills and life skills to be able to achieve everything I am capable of doing.</li> <li>• A world without barriers.</li> <li>• It means everything. My son has severe Autism. He's only 4 but I already struggle to take him out into the community.</li> <li>• Freedom to live as a normal family. Inclusion but with resources as needed to help this.</li> </ul>
Family /communication/ other	<ul style="list-style-type: none"> <li>• Is very important, attempts to minimise impact on the others in the family</li> <li>• Essential</li> <li>• The ability to communicate</li> </ul>



## Developing a physical and sensory disability strategy for Moray



### 2. What helps you and/or your child to live well and as independently as possible in your community?

Theme	Comment
	<ul style="list-style-type: none"><li>• Support in place for my son which had had to be fought for.</li><li>• Major adaptations to home environment, access to community buildings etc with equipment-hoist, ramps etc.</li><li>• For professionals in school and after school activities to have an understanding of sensory disorder and it's impact on daily life</li><li>• Patience - people having time to ensure that you understand when communicating and not getting annoyed when you don't hear or understand them the first time.</li><li>• Support services to enable a child to access school/college/social and sporting events that most children take for granted.</li><li>• Good support services</li><li>• Additional support in school</li><li>• Direct Payments, carers, easy access to places</li><li>• Direct payments being able to pick your own carers</li><li>• NESS is very helpful and monthly sensory club</li><li>• Being involved in support/activity groups, input from schools, hearing tips from professionals and knowing that there is a network of opportunities, support, guidance and information to assist me and children.</li><li>• To be respected. To be listened to. To be welcomed into mainstream education so that children and their parents can learn about disabilities</li><li>• Good friends. Support at school.</li><li>• Educating the general public and children about additional needs. I find there really isn't much to do with my son when the weather is bad.</li><li>• Quick appointments, support in and out of home ir respite/school support and quality, affordable sn childcare so we can alsp work and contribute to society.</li></ul>

### 3. What, if anything, stops you and/or your child from playing as full a part in community life as possible?

Theme	Comment	What would help
<b>Social inclusion</b>	<ul style="list-style-type: none"> <li>• Few people in society can communicate in BSL with deaf children and adults</li> <li>• Lack of understanding and supporting particularly when he was younger as we had to seek support outside of moray</li> <li>• Again the patience of others when you cannot hear them clearly or properly the first time.</li> <li>• My child has panic attacks when we are out which put her at risk and people can be very judgemental so she does not like going out much</li> <li>• Not everyone is deaf aware, basic sign language and taking a little extra time makes a massive difference. I can't rely on people being vigilant to deaf awareness, people take for granted understanding and may think he understands but in fact he might be completely unable to grasp that task!</li> <li>• Others opinions. If your child needs extra care etc often not able to join in other activities because they don't have adequate care/training.</li> </ul>	<ul style="list-style-type: none"> <li>• Support</li> <li>• A greater awareness of what it is like to be deaf and also more provision of courses for hearing people to learn BSL. Demand currently would appear to exceed supply.</li> <li>• Greater visual aids resources available</li> <li>• People becoming aware that not everyone is like them and that they may have a hearing issue which may take them a little more time and effort. Deafness is not just an old person's condition.</li> <li>• Greater public awareness</li> <li>• More groups, clubs and social events being more deaf friendly</li> <li>• Educating local groups to be more welcoming and encouraging. Trialling to see if the child could manage to be involved and talking to other services to see if any supports could be set up,</li> <li>• Information on council or NHS website of all groups, events for or suitable for disabilities.</li> </ul>
<b>Access/facilities /equipment</b>	<ul style="list-style-type: none"> <li>• Equipped changing facilities, school environment adapted to accommodate larger equipment, level of support within school, lack of 3 sector organisations able to provide support in community</li> </ul>	<ul style="list-style-type: none"> <li>• Access to equipped changing facilities to be identified and location/opening times circulated. Encourage wider choice of organisations providing support in Moray.</li> </ul>



## Developing a physical and sensory disability strategy for Moray



	<ul style="list-style-type: none"> <li>• Lack of sports visual aids</li> <li>• Steps to cinema 2 Wheelchair users can't use it</li> <li>• Disabled toilets too small</li> <li>• Local groups such as school football teams, swimming lessons and guitar instructors who say 'NO' before they know what the child is capable of and are not prepared to support.</li> <li>• Play parks not having equipment for wheelchairs. Play parks not having suitable ground for wheelchairs. Unsuitable parking. Not knowing what is all out there.</li> <li>• Horrible road network around and in Elgin that makes it difficult to get from A to B without driving.</li> </ul>	<ul style="list-style-type: none"> <li>• Build new cinema on one level or with lift. Make disabled toilets bigger</li> <li>• Suitable play parks.....even one in Elgin that we could go to when we are there. Paths that might at least take us to a suitable swing instead of struggling to push through grass or even worse, woodchips.</li> <li>• Better road crossings.</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• It would be very unsettling.</li> <li>• Can't work as special needs childcare too expensive/hard to find. Social work never get back to you, regular respite very difficult</li> </ul>	<ul style="list-style-type: none"> <li>• To have NHS staff who work holistically and not just give out sheets of activities with no practical support</li> <li>• Training, funding</li> </ul>

### 4. What services support you and/or your child/family to live well and as independently as possible?

Theme	Comment
	<ul style="list-style-type: none"> <li>• Speech and language, audiology, ear nose and throat, sensory impairment service, Rowan Centre</li> <li>• Moray Council Sensory Education Service supports deaf/hearing impaired children and their families also children with visual impairment and their families. North East Sensory Services - a Charity has good links with the Sensory Education Service.</li> <li>• Community OT, education, social work, 3 sector i.e. Aberlour Options</li> <li>• We receive support from speech and language therapy, the Rowan centre, paediatrics, school and auxiliary</li> </ul>



## Developing a physical and sensory disability strategy for Moray



	<p>support</p> <ul style="list-style-type: none"> <li>• I don't have support but am the sister to a profoundly deaf brother who has got where he is mainly due to himself, family and from attending a School for the Deaf which was not in mainstream schools.</li> <li>• Visual support team</li> <li>• SALT, direct payments, sw, ed psych, rowan centre</li> <li>• Direct payments</li> <li>• Teachers of deaf and classroom assistants have a massive positive impact on my son's schooling out with NESS</li> <li>• School support and charity organisations</li> <li>• Physio OT MARS SALT Orthotics Advocacy Moray NHS</li> <li>• NESS. TMC. NDCS.</li> <li>• Quarriers OT/speech and language/seizure nurses/Rowan Centre</li> </ul>
--	---

### 5. What's good about them?

Theme	Comment
	<ul style="list-style-type: none"> <li>• They all provide support in different areas.</li> <li>• Knowledge of child, person centred approach</li> <li>• The school have been fantastic at trying to work with other agencies to provide appropriate support</li> <li>• Helpful and understanding</li> <li>• They listen and respond to child's individual needs and tailor her services</li> <li>• Means I can live on my own with the help of the carers I chose</li> <li>• He meets kids like him! He's not different there. They are trained to work with deaf people and no ques when things may need to be worked on</li> <li>• Schools are really good at organising packages of care for the young person while they are at school.</li> <li>• MARS provide wheelchair and see us whenever we ask to see them. SALT helps with communication problems and are very approachable. Orthotics team are friendly and helpful. Advocacy are so very very supportive, and</li> </ul>



# Developing a physical and sensory disability strategy for Moray



	<p>have helped us considerably.</p> <ul style="list-style-type: none"> <li>• NESS - good activities for kids. TMC - good support at school. NDCS - support with benefits</li> <li>• Helpful/knowledgeable</li> </ul>
--	--

## 6. What could be better?

Theme	Comment
	<ul style="list-style-type: none"> <li>• Talking to each other as I'm going in between all the services at the moment passing on the information.</li> <li>• More public awareness of hearing impairment and visual impairment and the implications of these on the individual.</li> <li>• Lack of services</li> <li>• Many. Respite. Support for parents. Training for families and staff that include practical suggestions. Auxiliary support and support for learning. Joined up working with other professionals</li> <li>• SALT I find massive gaps in care Deaf education, understanding</li> <li>• The transitions between leaving school and what happens next.</li> <li>• Communication! Too long waits for orthotic appointments. Lack of respect often. With such little spare time, it would be good to have a directory of places etc that could help. No childcare for disabled children....no clubs.....</li> <li>• Developmental Groups in 3-4 locations offering pre school support 0 - 3 yrs, of these only 2 can offer funded nursery placement, other than that no additional support facilities in education nursery settings, once school age can be supported in additional support needs bases from 5 - 19years.</li> <li>• Respite. Parents being involved in decision making regarding their child</li> </ul>

## 7. Any other comments

Theme	Comment
Partnership	<ul style="list-style-type: none"> <li>• It's challenging but it's only manageable if you are working together with services. I've had a battle on my</li> </ul>



## Developing a physical and sensory disability strategy for Moray



<b>working, training, respect and understanding</b>	<p>hands with different access to services for a very long time.</p> <ul style="list-style-type: none"><li>• There is a huge lack of understanding and support from professionals in Moray in comparison with other regions. We had to pay privately to access any hands on practical support which has shocked parents and professionals we have been lucky enough to make links with in Highland and Grampian. Moray continues to lag miles behind other regions which is incredibly frustrating as there are some pockets of fantastic work but they are few and far between with no apparent support from those higher up in education</li><li>• It can be very lonely</li><li>• Why do we have to pay bedroom tax when the council ask you to swap to a 2 bedroom because you are a wheelchair user</li><li>• My son will be getting French at school!!! It's a challenge learning British now he's trying a foreign language which he may grasp but then it will be changed to another language in P6. I even find at school transition is not provided to allow him time to grasp things. I feel initially people don't appreciate this life long disability</li><li>• People can feel very isolated and may not feel comfortable about getting in touch with organisations that could help.</li><li>• Having a child with a disability is a shock to the system initially, but is so rewarding and such a fantastic learning experience, but having to cope with so many different professionals is really really hard. So many different appointments, cancellations etc. Some staff are very nice, helpful and supportive and some are just down right rude and nasty. We need to be listened to!</li><li>• Don't have us having to park on main streets in Elgin with car door opening onto street, and often being shouted at, sworn at, to close the car door.</li><li>• Staff in your home need to be respectful. If a family and a professional just don't see eye to eye at all, then please let it be that they can just see someone else. Our solid family life has been ruined by some horrendously rude professionals....don't let them destroy families by being nasty just because they can....</li><li>• To have the skills and expertise to work with this population of children takes training and opportunity to develop skills, it is not realistic to think individual schools would be able to up skill for an individual child and be able to offer the level of support the child, family &amp; school require to be successful. Good intentions are not enough. Specialists are a very limited resource so use them smarter. It is not practical to make some schools environments suitable to all children's needs - it's a poor use of limited recourses.</li></ul>
---	--



## Developing a physical and sensory disability strategy for Moray



### 8. Listed are some issues around physical and sensory disability. Please rank them in order of importance

Issue	Average ranking
Access to good information and advice on managing my own/my child's health and wellbeing	8
Clubs and activities in the community for me/my child	7
Equality of access to service	7
Services which support me/my child at times of change e.g. transition to adult services	7
Having choice and control over the care and support services I/my child received	8
Equipment and adaptations which support me/my child to live as independently as possible	7
Care and support services which enable me/my child to live at home as independently as possible	7
For me/my parents to have sufficient childcare options to be able to have paid employment	2
Being able to get around by care, bus, walking or wheelchair etc	4
Access to support/advice and training for me/my parents	6
Support with employment, skills and learning for me/my child	3