



Comments made during families event at Cedarwood, Elgin, on 16.10.2014

Facilitated by: Moray Council, Moray Community Health and Social Care Partnership and Quarriers Carer Support Service.

1. What's the best way for you to access information, advice and support and physical on sensory disability and other related issues?

- Internet
- GP surgery
- Carers forum
- Information should be freely available in a booklet to know what's available and who to contact
- NAS. Good to get directed to reputable sites
- Facebook
- Personal phone calls and letters
- Good advice from epilepsy phone line in Inverness. Epilepsy nurses at Inverness excellent. Moray expertise at a local level would be good.
- Support networks – Quarriers are important
- By asking IT
- Have special schools. Integration is fine but doesn't work for every child. As school etc doesn't have all facilities/staff training etc.
- Just getting awareness out
- Accessing information etc is a nightmare. Difficult to find things that are specific to our area, or to Scotland. Internet and emails are the best way to find out anything. A database of local groups, people, professionals, therapies would be good and very, very helpful...it is very time consuming to be searching on the internet when you have a disabled child to care for.

2. How do we reduce the stigma and discrimination against those with physical and sensory disability in schools and our communities?

- Information, awareness raising in class
- Other parents and staff in shops – they don't understand autism and do give you disappointed looks
- Council should do more about autism awareness. Link with Glenn Morris access to services
- Difficult to get people to understand the condition it's so rare. No specialist support base up here. Online support is important – forums etc
- Need to raise awareness about mental health – people think my son is stupid
- Not enough support in schools – teachers vary in their ability to include and integrate my child
- Last year's teacher was excellent but this year's is not so good
- Waiting for a programme "Smart Moves" in school for 18 months
- School is good but they don't have the knowledge. They deal with epilepsy but they don't understand it. If school nurse was to listen to (epilepsy) experts
- School deals with epilepsy well - call it "day dreams" to explain it to children. I find this nice than epilepsy

- Better communication and information between school and home – asked for a diary and so did the speech therapist and they have refused twice
- School doesn't understand condition. Hard to retain information but has support
- I would start by making it easier to speak about school things with teachers and professionals. It always seems very 'secretive' in a way, as they don't seem to want to tell us. It helps us parents to feel confident in what we are doing and not feeling stupid. PTA and other parent groups should have knowledge of disability rules, so that if a parent of a child with disabilities asks about something then they should have the back up somewhere to find out how to help. There has to be more involvement with the regular children.... having separate class time should be kept to a minimum. It saddens me to see the additional needs kids out on a shopping trip for all to see.... why cant they be mixed with the other children? Parents need educating about disabilities of children, to realise that those children AND their parents like to be spoken to as well, and to be involved. Maybe Call Scotland passport system to be used more, with parents consent, to give out to families. Children might like to aim for certificates etc for learning more about and helping disabled children. Also if staff are not respecting the parents then no one in school will.

### 3. What are the key places where accessibility needs to be improved?

- Playbarn. Places with unfamiliar people, places with lots of people
- McDonalds is really disability friendly
- Christies in Fochabers is great but it would be better if they could lock the gate and make it safe
- A great idea would be to have a disabled friendly play day with extra supervision and safer exits
- Playbarn – parents attitudes is a barrier to accessing this service
- Family circumstances change and additional support needs to be in place
- Accessibility needs to improve in school transport. Buses should really be transporting, especially country children, in a bus that has other children in it.... It really is a big deal that a child goes to school on a bus on his own.... the joy he would have being with others! More accessible for all clubs..... its not good enough to have something to include special needs if, on the day of it, its discovered that there has not been the right training for a particular piece of equipment etc! Swimming should be advertised for disabled children like it is for other children. Took me months to finally get some pool time...shouldn't be so! More accessible afterschool clubs etc....and think about the country kids, we don't all live in Elgin. Please... better blue badge spaces, and lots more of them! Having to unload a child from a car to a wheelchair that is on the road! is not good enough, and having to put up with abuse and shouting from some drivers for doing so is even worse! Access to better toilet facilities...having to lay your child on a filthy toilet floor is not good....and how are we supposed to get them up off there afterwards....when we are told not to lift, use the hoist! Info on a web page maybe of where there are suitable walks for wheelchairs, play parks etc... Play parks should have equipment for all to use..... very little out there for our children.

4. What changes to housing, transport and equipment would make a difference to your child's life and that of your family?

- Get rails in house. Fencing for the garden would be useful so family could play safely. Council refused. It is hard to have my daughter stuck in the house
- Safety
- We could do with a larger house but wouldn't know where to start or go about doing this (I have 4 children).
- OT assessment
- Need to ensure housing is suitable – epilepsy no bath or stairs which are a hazard
- My five year old could benefit from support to get a break from my children with special needs. He misses out
- Be useful if partners could share information on what activities go on and how to find out more about them
- Go to Step by Step in Forres and Little Fish – these are too busy for my child. Need quieter, calming activity groups
- Key locks for doors. High fences
- Transport..... blue badge spaces, suitable buses for wheelchairs. Equipment .... too much red tape into getting equipment...form filling, meetings and then equipment takes sometimes months to come. If a parents know that a piece of equipment is going to be good for their child but it cant be funded, perhaps a voucher for part of the cost could be given to the parents, and then they can use it along with money of their own to get the equipment they need It is done in some parts of England. We should have the same rights and freedom to family life as any other family does.

5. How do we raise awareness in our schools and community about physical and sensory disability?

- Give schools information and ensure they are prepared and able to cope
- Better communication and partnership working between school and home
- Not tolerating teasing/bullying of vulnerable children
- Staff need more education. More ASN workers. Education in autism
- More awareness training for some teachers
- Staff don't have enough knowledge and skills to deal with autism in mainstream
- More auxiliaries/assistance in class where required
- Need more 1-to-1 support in schools - person centred – burn off energy. Early intervention
- All children needs education on inclusion at schools
- Classes doing themes about disabilities. Info about it on the school web page. Having a specific awareness day/s in school for any particular disability. Ask parents views and ideas on what they would like their school to be doing to raise awareness of their child's disability, if any at all.

6. How can we support young people with physical and sensory disability issues into further employment?



- Suitable workers
- Striking a balance – helping my child participate in everyday activities – swimming and skating – but keeping them safe

#### 7. What types of technology would benefit your child/you?

- Calming lights
- GPS type tracker gadget for wandering. Needs a good signal
- Alarms and sensors at different parts of house – doors, fridge, cooker, etc
- Difficulty getting the right information – too much on the internet. It's confusing
- It's difficult to know what is out there! New things coming out all the time, but often the parents are aware of all that's new for their child, as opposed to a professional that is acting for them as a group maybe..... Parents should be involved so much more. Parents should be told of anything that would benefit their child, and be allowed to donate money if they wish to purchase it.