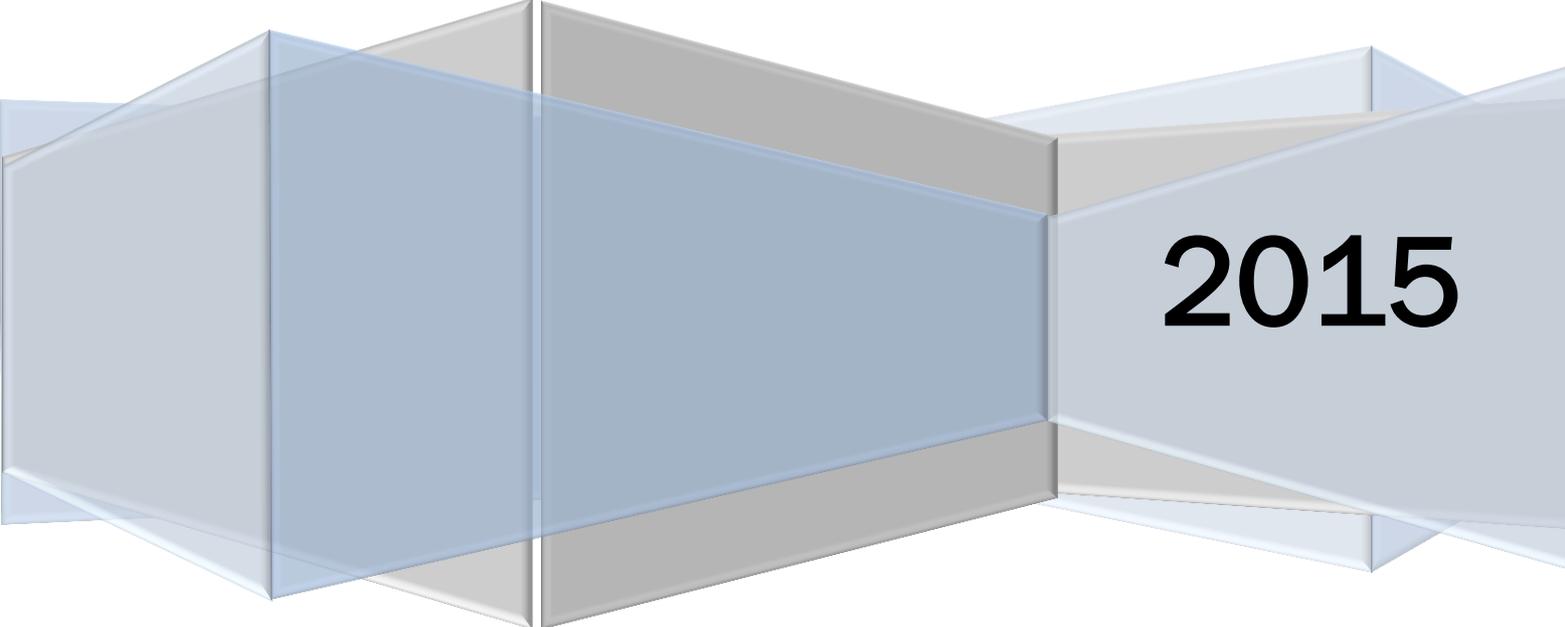




Exploring Transitions: Digging Deeper Roadshow Report

Autism Network Scotland,
in conjunction with Association for Real Change Scotland
and Scottish Transitions Forum



2015



Introduction

The Scottish Strategy for Autismⁱ is a ten year national plan to address the issues facing people across the entire autism spectrum, over the whole lifespan. Its recommendations impact upon all professions, across all disciplines involved in the provision of public services.

Put into place in 2011, the Scottish Strategy for Autism is now in its second phase: The Whole Life Journey. One of the goals of this phase is for people with autism to have “Access to appropriate transition planning across the lifespan.” This goal aligns with the outcome, “Active Citizenship: People with autism are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities.”

As part of the work towards this goal, Autism Network Scotland, in conjunction with Association for Real Change Scotland, carried out a series of roadshows across Scotland in 2014 and 2015 called **Exploring Transitions: Digging Deeper**. The events explored the work of the Principles of Good Transition 2 documentⁱⁱ and its suitability to autism-specific transitions.

We listened to what people told us about their transitions experiences where they lived, and what they thought could make a difference. We were particularly interested in hearing about transitions experiences in more remote and rural areas.

The following report contains a summary of what we heard from people across Scotland. We have broken our findings down into six key theme areas.

Events were held in Angus, Argyll and Bute, pan-Ayrshire, Dumfries and Galloway, Highlands and Islands (Inverness and Wick), Perth and Kinross, Scottish Borders, and Stirling and Clackmannanshire.

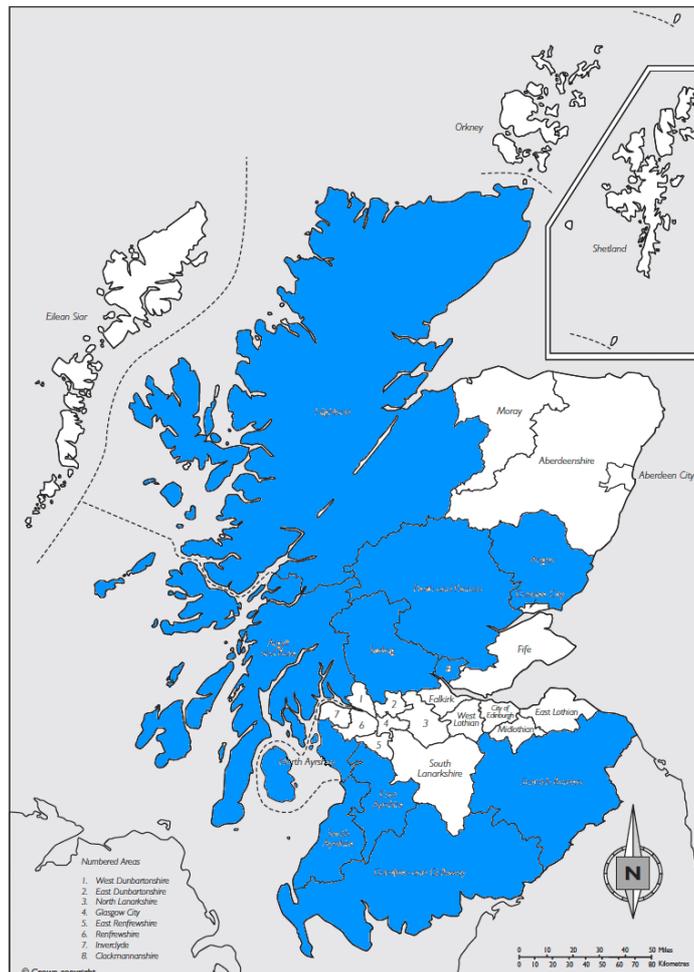


Figure 1 – map of local authorities where roadshows were held

The events centered on the review of the Principles of Good Transitions 2 document, produced by the Scottish Transitions Forum. The events gave attendees the opportunity to give their perspective on the document, and were attended by practitioners, people with autism and parents and carers.

Roadshow delegate profile:



Figure 2 – profile of delegates who attended roadshows

The roadshows covered three major topics:

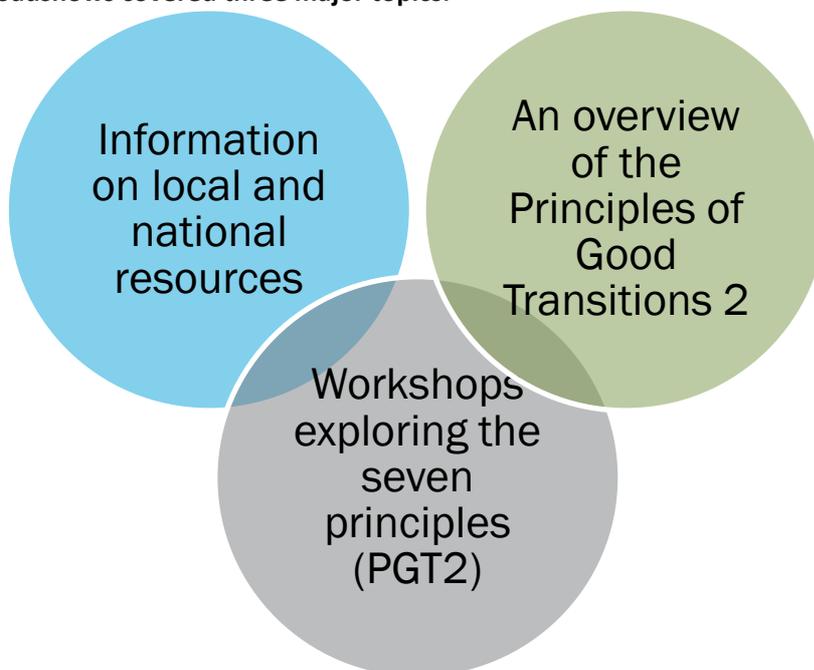


Figure 3 – topics covered at roadshows

Delegates attending the events were able to discuss how transitions work in their local areas, what is working well and what gaps exist. We specifically wanted to hear about the issues facing someone in transition living in a remote and rural area. Delegates some solutions and innovative ways they have overcome certain issues. We also heard from young people who are going through transitions. They gave us their thoughts on the process.

From the evidence gathered from delegates, we have identified six overarching themes which correlate with the Principles of Good Transitions 2. A section at the end of this report describes what we will do with this information.

The six themes:



Figure 4 – The six themes are based on the issues raised by delegates at the roadshows

Questions

These are some key questions that were discussed in the workshops:

- What is the difference between a ‘positive destination’ and ‘positive outcomes’ for young people, in line with the Children and Young People Act (Scotland)ⁱⁱⁱ and its definition of wellbeing? How can better support be provided to allow people to achieve positive outcomes?
- How do services and other providers capture the different aspects that make up an individual on the autism spectrum whilst ensuring the provision is autism-specific at the same time?
- How do we ensure that, in times of austerity and within the current financial climate, people are supported not just to have their basic needs met during the transitions process, but are supported to meet their full potential?

Key themes in more detail

We have taken each of the key themes and broken them down into more specific points. We have detailed the points that delegates raised with us and some of their suggestions for how transitions could be improved.

Theme 1: Processes

1.1 Person at the centre rather than the focus on the process

Many delegates stated that they felt the organisational process associated with transitions often takes priority over the individual needs of the young person. Plans and paper work are often focused on professional needs and parents said they are not accessible to the young people and families undergoing transitions. It is widely accepted that the entire transitions process should be person centered, but this was not always reported to be the case. It was felt that the communication needs of the young person are not always acknowledged which leads to them being excluded. At times the transitions processes were not very autism friendly or specific enough to address people's needs. We often heard from families that the practitioners working with them were doing a brilliant job and going above and beyond; however, they were limited by time and resources.

1.2 Lack of support for families and carers

Families told us they feel there is a lack of support for families and carers who are also undergoing the transitions process with the young people under their care. There is a big shift in understanding between child and adult services for parents and young people; for example, the terms used are different, and required paperwork changes.

Consideration needs to be given, along with the young person's outcomes, to parents with their own additional support needs, and families who are not in contact with services.



"Sometimes we need to be allowed to be a regular family"

1.3 Timeliness

Delegates often commented that the transition processes need to start early and continue throughout the persons lifespan. Information needs to be available and each step of the process explained in enough time for young people and those supporting them to understand it and explore how it can meet their outcomes. This early start will also help to build up key relationships that help support resilience. At the transitions stages after age 16, it was noted by parents that universities often don't let young people know expectations in enough time to allow a smooth transition into higher education. Adult services are also not coming on board early enough, which further affects the success of the plan.

Questions were frequently raised in relation to post-college/university; who supports this transition into rest of life planning and who has accountability for tracking related data.

1.4 Consistency and coordination within the transitions pathway

Delegates told us that they felt a positive transitions experience should not only depend on the skills and knowledge of the individual professionals involved, but rather on sound, deliverable pathways and processes. It was often raised that positive experiences were a postcode lottery and experiences differed greatly between young people and throughout local areas.

Delegates at the roadshows gave feedback on what they think would make improvements:

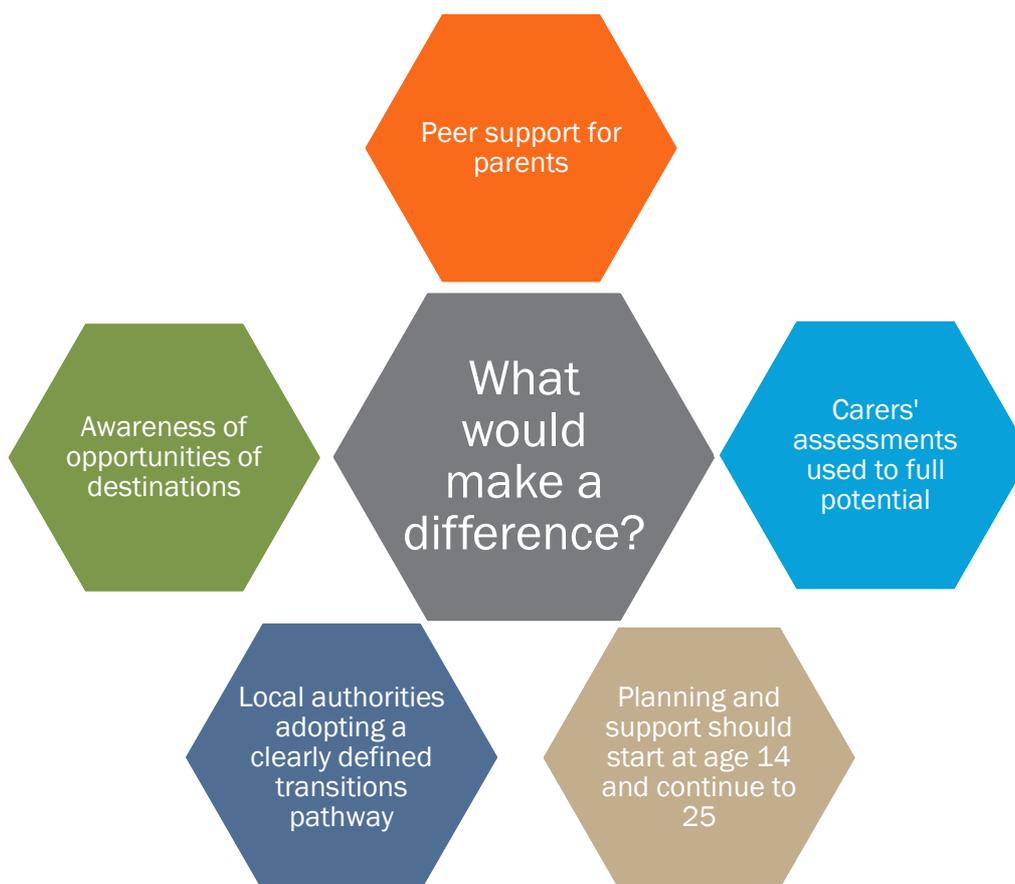


Figure 5 – Delegates' suggestions to improve processes

Theme 2: Options and choices

2.1 Limited Options

Options should not be limited to the availability of day services or college courses. Many stated that the skills, wishes and aspirations of each individual should be taken into consideration when identifying their future outcomes. It was felt that those who had gone to mainstream school had more choices compared to those who didn't. Both face similar challenges in accessing meaningful employment due to the stigma sometimes attached to the autism diagnosis.

"I want to be an astronaut"

2.2 Self-directed support (SDS) – is it being used to enable real choice?

It was felt by those attending that SDS^{iv} is not being used to its full capacity. It was felt that SDS Option 1^v, where the person chooses how to use their funds on supports of their choosing, could isolate people from their communities. SDS could address some of the issues around lack of specialist services in local areas.

2.3 Lack of positive destinations, particularly in rural locations

People should have a variety of options to allow them to make real choices. In more rural locations, people felt that there is often no or only one option for further or higher education and individuals have to travel a significant distance in order to access further options.

Delegates at the roadshows gave feedback on what they think would make improvements:

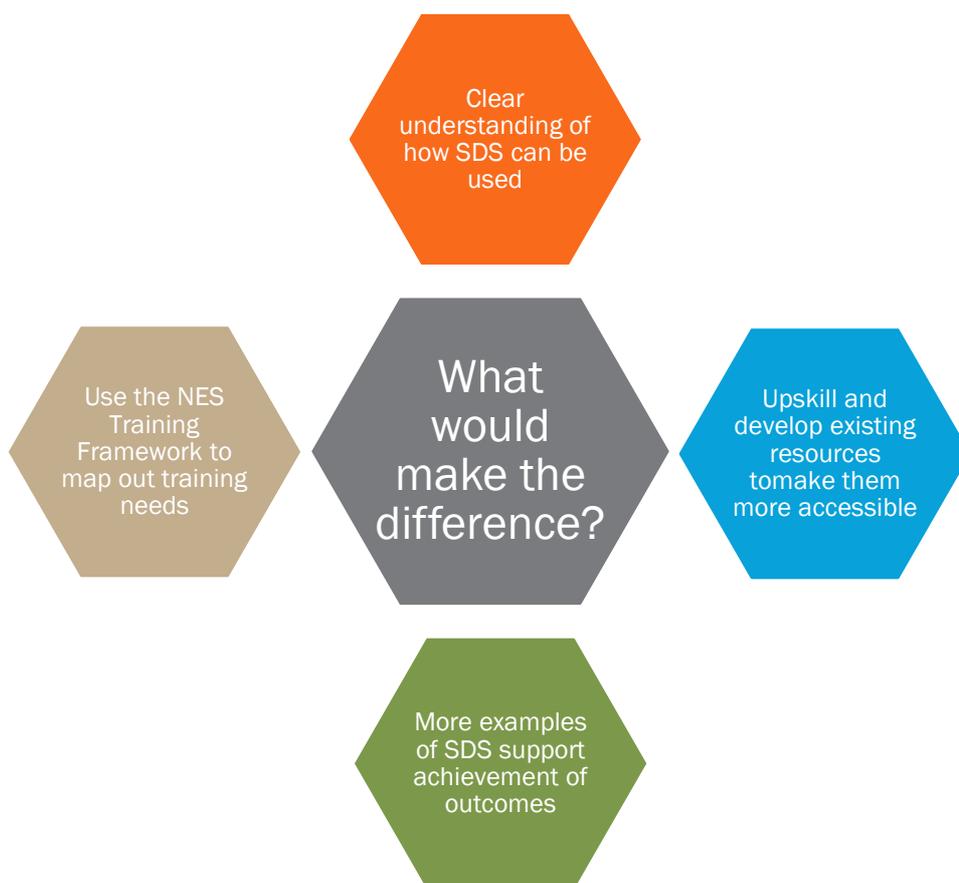


Figure 6 – Delegates' suggestions to improve options and choices^{vi}

Theme 3: Accountability

3.1 Lack of awareness amongst some professionals of autism and the transitions process

Delegates felt that some professionals involved in the transitions meeting don't always realise how much information the assessment encompasses or how many professionals may need to be involved.

Some young people can fail to achieve or sustain a positive destination because information is missed from the assessment or because autism-specific needs have been missed from the assessment.

"It's quite a struggle just now, not having people to immediately solve the problem"

A disconnect between cross-sector professional practice, policy and welfare also increased the negative impact of the transitions process when people with autism were involved.

In contrast, there were lots of isolated examples of practitioners going above and beyond to attend autism training on their own time. This had a positive impact on the transitions process.

3.2 Local authorities have to be accountable for successful transitions pathways

Parents often said they did not know who was responsible for ensuring their child's transition was properly supported. Without accountability for transitions pathways being held by a local authority, the possibility of improvement in this area was felt to be slim. This is wider than a sole focus on

the model of positive destinations, which recommends focusing on education, employment or training as indicators of a successful transition. Parents wanted someone to have responsibility to coordinate a wide spectrum transition programme that is inclusive of all services involved in transition and which focuses on the wellbeing of their child at the centre.

3.3 Policy and legislation needs to be joined up and simplified

Many professionals were confused about the different policies and legislation that impacts on transitions. Alongside accountability at local level, there also needs to be accountability at national and strategic level. Coordination across different policy and legislative strands and new statutory guidance would ensure that these different policies align with one another. Another suggestion was a “national transitions coordinator,” who would gather evidence from the different local authorities to ensure that transitions across health, education and social care are considered holistically.

3.4 Local authorities should be co-productive in relation to transitions

Many young people and carers felt removed from the process of transition and felt they weren’t always listened to about how things might be improved from their perspective. Oversight is needed at local and national levels to coordinate services, which take account of the views of young people and their families in a co-productive manner. Accountability was another concern; delegates would like to someone to oversee and be accountable for the coordination of transitions services in each local authority or region.

3.5 Joint funding between health, social work and education for transitions roles

Professionals told us that the division of resources and data protection responsibilities created barriers between joint working and successful transitions coordination. To overcome this, it was suggested that any roles that helped coordinate transitions should be jointly funded by the three services.

Statutory sector leads from health, education and social work all identified “lack of joined up working” as the biggest challenge to improving transitions.

3.6 Accountability for tracking data

Questions were raised about who was responsible for data tracking from pre- to post-age 16 transitions and how this may relate to Skills Development Scotland^{vii}, the Children and Young People Act (Scotland), Opportunities For All^{viii} and the data they capture. If young people are known to be moving through the system, resources should be in place to fully assist them when they move into adult services.

Delegates at the roadshows gave feedback on what they think would make improvements:



Figure 7 - Delegates' suggestions to improve accountability

Theme 4: Information and training

4.1 Sharing information between all involved in transitions process

Those attending often said they felt that information is not shared as well as it could be. A few barriers to this noted by delegates were the Data Protection Act^x and the implications of the relatively new Children and Young People Act (Scotland). Information parents received was noted to be inconsistent and parents report it did not fully address their needs.

4.2 Accountability for providing autism-specific information to parents, carers and young people

Some delegates felt that information is a postcode lottery depending on the knowledge of the workers involved, word of mouth or luck. It was understood that the local authority had a duty to provide this information but with resources being cut, it was very difficult for parents and young people to access local authority-specific information. The information provision gap has been somewhat filled by the third sector and One Stop Shops where they exist.

“If you don’t know what to ask, then what do you ask?”

4.3 One Stop Shop format very effective

It was noted at every event that those who had used the One Stop Shops were delighted with them and that the format of these was proving to be very successful in provision of information. It was further noted that a lot of people had heard about the One Stop Shops by word of mouth or through friends.

4.4 All involved in the transitions process should have clear knowledge and understanding

Many practitioners, parents and carers said that they felt they did not have enough information or understanding of the transitions process which became a barrier to a successful transition. All

involved in the transitions process including parents, third sector, education, health, social work, employment, voluntary, housing, allied health and welfare should have a clear understanding of the processes, success and barriers of transitions and the effect autism has on a transition.

Delegates at the roadshows gave feedback on what they think would make improvements:

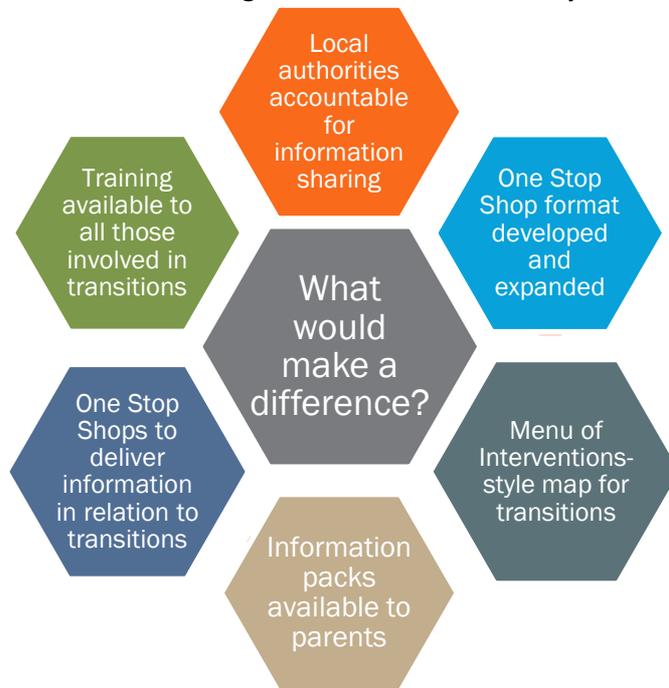


Figure 8 - Delegates' suggestions to improve information and training

Theme 5: Eligibility and unmet need

5.1 Eligibility is gatekeeping access to services

In every local authority people spoke at length about eligibility criteria. Due to the way eligibility criteria are structured and scored, very few families were eligible for a service. This was particularly true for people who had an autism diagnosis but not a corresponding learning disability or mental health support need (see item 5.3). This means that young people were unable to get the support they needed to succeed and maintain a positive outcome or destination. The Doran Review^x mentions the ambiguity of professionals with the desire to help but are unable to do so because the eligibility criteria prevent them from being able to offer any council-led services. This was echoed by delegates at the roadshows.

5.2 The stigma of diagnosis

The stigma of diagnosis was mentioned by many of those who took part in the focus groups. People faced stigma in gaining employment, college placements and access to training courses such as modern apprenticeships. A lot of people felt that they didn't want to go to a mental health service to be diagnosed with autism, and some felt that this conflated autism with being "crazy".

5.3 Unmet need amongst those who have autism but not a learning disability or mental health support need

Not everyone who has autism has a mental health concern or a learning disability. Due to this, services aren't tailored to help support them. They will also miss out on services due to not meeting eligibility criteria, as having autism alone is quite often insufficient to qualify for local authority support.

"What about my son, who only has autism, why should he miss out?"

Delegates at the roadshows gave feedback on what they think would make improvements:



Figure 9 - Delegates' suggestions to improve eligibility and unmet need

Theme 6: Resources and logistics

6.1 One Stop Shop model very effective

It was noted at every event that those who had used the One Stop Shops were delighted with them. The format is proving to be very successful in provision of support and access to resources, particularly at the time of diagnosis.

6.2 Advocacy is a key need

Advocacy was consistently raised as a key need throughout all local authorities for people undergoing transitions to understand their rights and to navigate what can be a difficult time. Advocacy is needed both for the young people themselves but also for the parents. Parents often stated that they felt lost in the process and felt they might end up getting something wrong because they didn't understand it. There is a lack of services to support parents in meetings if the parents themselves do not have an additional support need but may need guidance to navigate the transitions process.

6.3 Resources are not autism-specific

It was felt that many local resources tended to be geared towards supporting people with a learning disability. Practitioners felt they would benefit from training in autism in order to upskill and make the environment more accessible and appropriate for someone with autism.

6.4 Travel is a barrier to accessing positive outcomes

In rural areas, travel was consistently mentioned as being a huge barrier to access services, colleges, hospital appointments and other positive outcomes. In some cases, an appointment was a five-hour train journey away.

"There are some brilliant services but they are just too far away"

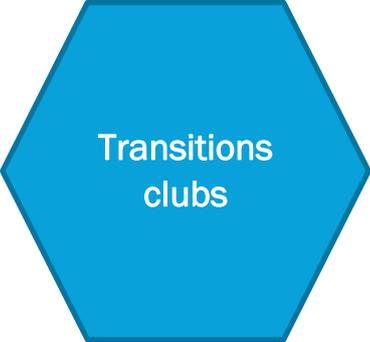
Delegates at the roadshows gave feedback on what they think would make improvements:



Figure 10 - Delegates' suggestions to improve resources and logistics

Examples of good practice

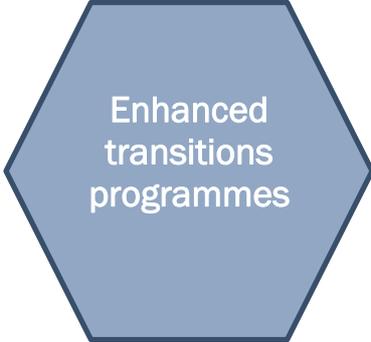
We heard lots of examples of good practice and innovative ideas and solutions:



Transitions
clubs



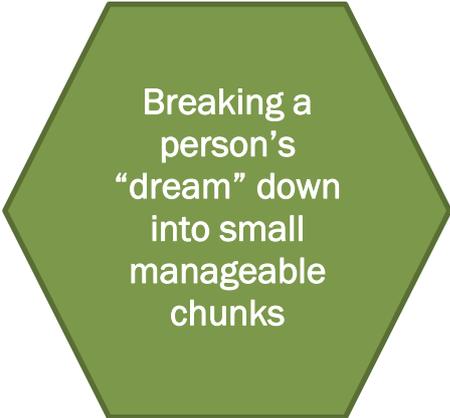
Transitions
open days
with all
information
in one place



Enhanced
transitions
programmes



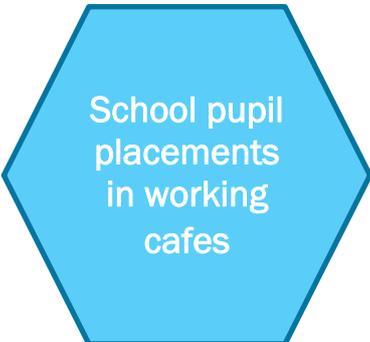
Summer
programmes
before
university
starts



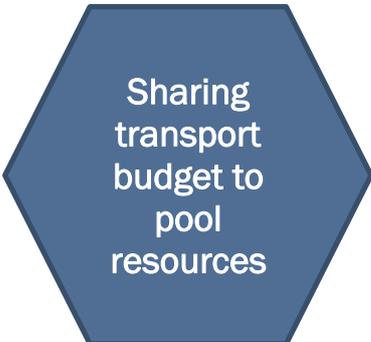
Breaking a
person's
"dream" down
into small
manageable
chunks



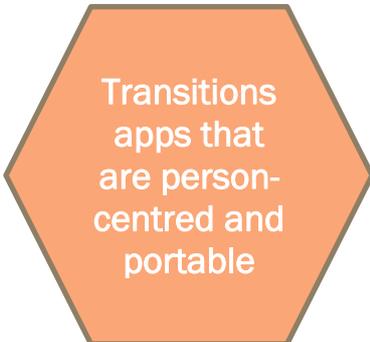
One Stop
Shops
holding
transitions
groups



School pupil
placements
in working
cafes



Sharing
transport
budget to
pool
resources



Transitions
apps that
are person-
centred and
portable

What happens next?

We know it is of key importance to do something with the information that people share with us. There are a number of things we will be doing with the information we collated and you can read about them below. If you would like to find out more about any of these points or if you would like to discuss them you can send us an email. Contacts details are at the end of the report.

Working Group 2

- We are members of Working Group 2 of the Scottish Strategy for Autism.
- The Goal of Working Group 2 is: Access to appropriate transition planning across the lifespan.
- We have reported back to Working Group 2 about what we've heard

To find out more about the Working Groups, [please follow this link](#). You can also [click here to read the minutes](#) of Working Group 2.

The National Autism Coordination Project

- We work closely with the National Autism Coordination Project (NACP)
- Their role is to ensure that local authorities implement autism strategies that are effective
- We have fed back to NACP about transitions in local authorities
- The September 2015 NACP event for lead officers will focus on transitions

For more information about the [National Autism Coordination Project, please follow this link](#). You can also [click here to read local autism strategies](#).

The Principles of Good Transitions 3

- The Scottish Transitions Forum is developing The Principles of Good Transitions 3 (PGT3)
- What we have heard will feed directly into this development
- We are looking at ways to produce a document that compliments the PGT3 and includes some specific information relating to autism

To find out more about the [Scottish Transitions Forum, please follow this link](#).

Transitions Virtual Network

- We have developed the Transitions Virtual Network
- It is free to join and you can share documents and information about transitions on this network
- It is a safe, protected environment for anyone with an interest in transitions
- This will mean you can keep up-to-date with what is happening in relation to transitions across Scotland

To become a member of the virtual network you first need to [fill out the online membership form](#). You will then be able to [view a list of the virtual networks](#) and choose the Transitions network.

End Notes with links to resources:

ⁱ Scottish Strategy for Autism -

http://www.autismstrategyScotland.org.uk/index.php?option=com_docman&Itemid=&gid=41&lang=en&task=doc_download

ⁱⁱ The Principles of Good Transitions 2 - <http://scottishtransitions.org.uk/wp-content/uploads/principlesofgoodtransition-arc-scotland.pdf>

ⁱⁱⁱ Children and Young People Act (Scotland) -

<http://www.legislation.gov.uk/asp/2014/8/contents/enacted>

^{iv} Self-directed support - <http://www.gov.scot/Topics/Health/Support-Social-Care/Support/Self-Directed-Support>

^v Self-directed support Option 1 -

<http://guidance.selfdirectedsupportscotland.org.uk/users/option1.html>

^{vi} National Health Service (NHS) Education for Scotland Autism Training Framework -

http://elearning.scot.nhs.uk:8080/intralibrary/open_virtual_file_path/i1923n4027869t/NESD0350ASDTrainingFramework-WEB.pdf

^{vii} Skills Development Scotland - <http://www.skillsdevelopmentscotland.co.uk/>

^{viii} Opportunities for All - <http://www.gov.scot/Publications/2012/11/7618>

^{ix} Data Protection Act - <http://www.legislation.gov.uk/ukpga/1998/29/contents>

^x The Doran Review - <http://www.gov.scot/Topics/Education/DoranReview>

Figures:

Figure 1 –altered map of Scotland. Original acquired from Transport Scotland,

<http://www.transportscotland.gov.uk/statistics/j251205-193.htm>

Figures 2 – 10: developed by Autism Network Scotland using data from **Exploring Transitions: Digging Deeper** events

Contact Us

We are always keen to hear from people. We can also provide paper copies of documents discussed in the report, including the Principles of Good Transitions 2.

If you would like to discuss anything in this report in more detail, you can contact us in the following ways:

Autism Network Scotland:

Phone: 0141 444 8146 (Lynsey Stewart)

Email: autism.network@strath.ac.uk and put “Transitions” into your subject heading

Visit our website: www.autismnetworkscotland.org.uk

The Scottish Transitions Forum and ARC Scotland:

Phone: 0131 663 4444 (Scott Richardson-Read)

Email: scott.read@arcuk.org.uk

Website: scottishtransitions.org.uk or arcuk.org.uk/scotland/



