

Principles of Good Transitions 3

2017



Autism Supplement

Autism Network Scotland

Husqvarna



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Scottish Transitions Forum

In collaboration with the Scottish Transitions Forum, part of the Association for Real Change (ARC) Scotland

www.arcuk.org.uk/scotland

www.scottishtransitions.org.uk



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Foreword

I am delighted to introduce the Autism Supplement to the Principles of Good Transitions 3.

This guide has been developed as a result of Scotland-wide consultation in relation to autism and transitions, and has been produced by Autism Network Scotland, in collaboration with the Scottish Transitions Forum, part of the Association for Real Change (ARC) Scotland.

This supplement is intended to improve access to appropriate transitions for autistic people as laid out in Outcome 4 of The Scottish Strategy for Autism Strategic Priorities which is that “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.”

The supplement identifies key practice considerations, tools and resources which, along with the seven Principles of Good Transitions, will ensure autistic people and their families have access to appropriate transition planning.

I am confident that practitioners from a diverse range of sectors will find this supplement an excellent tool for supporting autistic people with transitions. The supplement can also be used by parents and carers and autistic people.

I believe that it is only when we work together on improving practices do we deliver better outcomes for young people with autism.

Ms Maureen Watt

Minister for Mental Health



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Welcome to the autism supplement of the Principles of Good Transitions 3. Autism Network Scotland has produced this in line with the Principles of Good Transitions 3 written by the Scottish Transitions Forum which is part of the Association for Real Change (ARC) Scotland.

The supplement takes the seven principles and provides key considerations, examples and resources to allow these principles to be put into practice for an autistic person. The supplement has been informed by the ongoing work of *Working Group 2 of the Scottish Strategy for Autism and the Exploring Transitions: Digging Deeper report*.

In 2015, Autism Network Scotland and the Association for Real Change carried out a consultation exercise in remote and rural parts of Scotland. The consultation sought the views of autistic people, parents and carers and practitioners about what transitions are really like for an autistic person and what needs to be done to improve transitions.

The Scottish Strategy for Autism is in the second phase of its 10-year journey. This phase has four goals. Goal 2 is “Access to appropriate transition planning across the lifespan”. Working Group 2 has been tasked with meeting the aims of this goal.

The mid-term goal aligns with the Scottish Government’s strategic priorities for 2015-2017. Outcome 4 is “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”.

More information about the work of The Scottish Strategy for Autism, the strategic priorities, Working Group 2, and the other three mid-term goals and working groups can be found at www.autismstrategyscotland.org.uk

Using this supplement

This supplement is designed to be used in partnership with the Principles of Good Transitions 3 and to provide more specific information about how to get transitions right for autistic people and their families. The Principles document contains detailed information about what a transition is and the national picture in relation to transitions as well as information about the relevant legislation and practice across the spectrum of additional support needs. A list of tips and tools for putting the principles into practice can be found towards the end of this supplement.

Information about the links, resources and strategies detailed throughout this document can be found at the back of the supplement. Resources detailed in this supplement are national resources. Information on local resources is available from Autism Network Scotland.

Throughout this document the terminology used will be young autistic person. In 2015 the National Autistic Society published a research paper which concluded that while there is no single term that everyone prefers, a large percentage of autistic people endorse this terminology (Kenny, L. et al., Which terms should be used to describe autism? Perspectives from the UK autism community, 2015).

Autism Network Scotland

Autism Network Scotland is based at Strathclyde University and works in inclusive partnership with a range of stakeholders including autistic people, parents and carers, a range of autism service providers including national organisations and local authorities to provide a hub of impartial information and knowledge exchange in Scotland. In cooperation with Scottish Government and COSLA, the Network provides the secretariat for all meetings of the Scottish Strategy for Autism Governance Group, its Working Groups and aims to enhance coproduction across Scotland. The Network also works with local authorities to support the implementation of local area strategies.

A word on autism and transitions

Autism can have a big impact on the way a person experiences transitions. For everyone, transitions can be a scary, challenging time but for an autistic person these challenges and fears are often increased and complex. Transitions can often become a period of heightened anxiety and stress for autistic people and their families. It is therefore critical to get transitions right for autistic people.

It is important to recognise that transitions happen all day, every day, for example: moving from room to room, from activity to activity or from teacher to teacher. Autistic people may often need support with small, day-to-day transitions. It is just as important to get these right as it is to get the bigger transitions right. Establishing the best way to support smaller transitions can often help the bigger ones go more smoothly.

Transitions also happen across a person's lifespan; for example, moving house, bereavement, retirement or changes in relationships. Whilst this document focuses on the big transition from children's to adults' services, the principles should also be applied when supporting somebody through a smaller transition and through transitions across their lifespan.

Principle 1

Planning and decision making should be carried out in a person-centred way

- The hopes, dreams, aspirations and wishes of the young person should always be at the heart of the transitions plans.
- The specific communication needs of the young person must be taken into consideration. These may be quite complex and varied. They will be different for every individual.
- Extra time may be needed to ensure the young person is able to fully communicate their views in a meaningful way.
- Those involved in the transition planning must have a good knowledge and understanding of the young person and their way of communicating.
- Meaningful involvement also means ensuring that the young person understands the context of the communication.
- Staff involved in the planning process must have a good understanding of autism and the way it impacts on a transition.
- Independent advocacy must be considered throughout the planning process and the advocates must have a good understanding of autism.
- Consideration must be given to the health and wellbeing of the young person and how anxiety over the transition is impacting on them.
- Consideration must be given to the sensory needs of the individual when developing plans. These may be related to:
 - Sound
 - Taste
 - Touch
 - Sight (e.g. light, colours, patterns)
 - Smell
 - Pain
 - Over stimulation
 - Under stimulation
 - Awareness of the body position and movement



Principle 2

Support should be co-ordinated across all services

- Those involved in the transition planning must have a good understanding of autism and the way it impacts on transitions. Consideration should be given to training needs.
- The local area autism strategy must be taken into consideration when coordinating services.
- There should be representation in planning from those who have developed relationships with the young person and who have a good understanding of the strengths and skills as well as the challenges the young person faces. This should include parents and carers.
- There should be representation from adult services and those who will be involved once the young person leaves school. There is a key need for the young person to develop relationships with those who will become involved and building trust will take time.
- If the young person also has learning disabilities or other additional support needs, there should be relevant representation from these services.
- It is important to recognise when the young person has autism but not learning disabilities and this should be reflected in planning.
- If a transitions coordinator or a local transitions forum are involved, they should have an awareness of all opportunities, including those for young autistic people without learning disabilities.

Good examples in practice

Peter was due to leave school. Due to increased anxiety levels and personal circumstances, Peter did not feel ready to go to college, university or into employment. His school staff, parents, outreach worker and advocate worked with him to explore what a positive outcome would be for him. He said that he wanted to feel like a valued member of his community. Peter and his staff spent time looking at areas he would like to live in and the opportunities available to him. He got a flat and started various volunteering opportunities in his local community. In time Peter said that he felt he had become a valued member of his community and that he was living the life he wanted.

Principle 3

Planning should start early and continue up to age 25

- Due to the complex nature of autism and the impact it has on transitions, starting planning early is essential.
- Whilst planning must start early, there must be awareness that for some individuals, talking about change too far in advance will cause distress. It may be that the way the transitions process is communicated to the individual needs to change to take this into account.
- It is important that time is taken for the young person to build up trust with those involved in the process; for an autistic person this may take longer.
- Time should be given to explore the full range of opportunities available to the young person.
- Representatives from adult services should become involved early to allow time to build up relationships and develop an understanding of how autism impacts on an individual.
- The way autism impacts on an individual changes over time and can be influenced by many factors including anxiety, environment and health and wellbeing. This needs to be taken into consideration throughout the process.
- Extended support needs should be considered for the young person. This should include support with transport, support needed to increase skills and maintain positive outcomes and the changing impact that autism can have on an individual.

Good examples in practice

Sam struggled to communicate his wishes verbally. It took time for him to be able to express what he wanted and what his concerns or worries might be. Sam's transition planning started early. His staff and his family worked together and started having conversations with him about transitions and what this meant. Sam was a very good film maker so his family and staff encouraged him to make a film about transitions. This took time and involved Sam visiting new places and meeting new people to make them part of his film. Through this process, Sam was able to communicate what he wanted to do when he left school and was also able to share his worries about the future.

Principle 4

All young people should get the support they need

- Options and choices must also be made available to autistic people who do not have learning disabilities.
- Often small, low-cost interventions can allow a young autistic person to reach their full potential, for example having a student mentor at college.
- Advocacy is important. The advocate must have a good understanding of autism and the way it impacts on a transition. Information must be shared about what advocacy is available including for autistic people without learning disabilities.
- It is important to recognise those young people who do not meet eligibility criteria but who will need some form of support or for whom the transitions process may trigger increased anxiety.
- For some young people, the transition may mean living in supported accommodation or receiving social care support for the first time. Consideration should be given to:
 - The changes in responsibility which come with moving to accommodation without a guardian;
 - The change in relationship with family members if moving out of the family home;
 - Understanding the role of support staff in the person's life.
- Often the smaller things have the biggest impact on a person's ability to meet their outcomes. For example:
 - Transport – ensure that accessing transport does not become a barrier;
 - Managing your own time/study – this can often be a challenge for an autistic person;
 - Developing new relationships – this can also be a challenge and can impact on a positive outcome;
 - Getting used to new environments – there may be a range of factors that impact on an autistic person's ability to cope in new environments. It is important to take time to get to know the person, identify the factors that affect them, and develop strategies.

Good examples in practice

Janet had started a new place at university. Academically she was very able to complete the course. Janet had nine different lecturers and she struggled to remember the different communication methods and requirements of each one. The worry about this increased Janet's anxiety levels to the extent that she started to avoid going to lectures. Janet was given support to develop a communication aid which had a picture of each lecturer and then some key points that she needed to remember about that lecturer. Janet was then able to refer to this guide before each lecture and this reduced her anxiety levels, allowing her to complete the course.

Principle 5

Young people, parents and carers must have access to the information they need

- Information must be autism-specific and must also include information relevant to autistic people who do not have a learning disability.
- Information must be delivered in a way that is meaningful to the individual and their parents and carers.
- Information should be clear, straightforward and should not use complicated or ambiguous language.
- Information should be given at the time of need and based on the level of need. This may change throughout the transitions process.
- It is important to ensure the young person understands the information which is being given to them. This will involve a good understanding of that young person's communication needs and methods.
- Information may need to be provided in various different formats for example:
 - Visually e.g. through picture symbols, DVDs or talking mats
 - Written
 - Verbally/using auditory technology
 - Electronically
- If jargon or specific language cannot be avoided, consider including a guide to the language used.
- Remember that somebody saying "yes" does not always give a clear indication that they have understood the information in the context it was meant.

Principle 6

Families and carers need support

- Advocacy for parents and carers may be needed.
- Consideration must be given to the communication needs of the parents and carers.
- If there are other autistic children in the family, consideration needs to be given to how the transition will affect them.
- It is important that information being communicated to parents and carers is also relevant to young autistic people with no learning disabilities.
- Support may need to be given to allow parents and carers to support their child to communicate their own wishes effectively.
- It is important to remember that this is a transition for parents, carers and family members as well. Parents/carers and family members may experience heightened stress during the transitions process and this must be taken into consideration throughout the process.

Good examples in practice

A group of parents in a small town were finding the process of their children's transitions difficult. They felt that they did not have a lot of support available to them and that existing groups did not understand the impact that autism had on their children's transitions. The parents decided to set up their own, informal support group. They met once a month and the local authority provided them with a free place to meet. Here they were able to share information and suggestions and provide each other with support.



Principle 7

A continued focus on transitions across Scotland

- There should be a continued awareness of the ongoing work of the Scottish Strategy for Autism and the work of Working Group 2.
- Local autism plans should continue to include transitions as an area of focus.

Good examples in practice

The National Autism Coordination Project facilitates a collaborative of lead officers from across Scotland responsible for local autism plans. The collaborative meets regularly to share information and good practice and look at solutions to common barriers in relation to local autism planning. In September 2015 the focus of the collaborative event was on transitions. Lead officers were given the opportunity to hear about the Principles of Good Transitions 2 as well as the feedback from the Exploring Transitions: Digging Deeper report and consider how to develop their local plans to take this into consideration.

Tips and tools for putting the principles into practice

The tips and tools are listed below under the most relevant principle. However, most of the tips and tools could be used in relation to any of the 7 principles so it is recommended that you read through the full list. A list of resources and signposting to support with these can be found at the back of this document.

Principle 1 – Planning and decision making should be carried out in a person-centred way

- Visual aids (e.g. picture symbols, planners, photos of future destinations, mind maps, photos of people)
- Social Stories
- Films and videos of the transition
- Communication Passports and/or one page plans/sensory profiles
- Informal transitions peer groups - a way of opening up conversations about transitions and the future
- The NES training framework - can identify the training needs of those involved in the transition planning
- The Autism Toolbox - has a variety of information to guide communication with and supports for a young autistic person
- The My World Triangle has an autism-specific option.
- Environmental adaptations may be useful - for example consideration may be given to the colours of the walls.

Principle 2 – Support should be co-ordinated across all services

- The Scottish Independent Advocacy Alliance has details of all advocacy organisations across Scotland accessible to autistic people.
- The Scottish Strategy for Autism website contains information about local autism plans across Scotland.

Principle 3 – Planning should start early and continue up to age 25

- Informal transitions conversations can start early and develop over time and also be carried on at home by parents, carers and families.
- Informal peer transitions groups can start early to introduce the concept of transitions.
- Start small and build up – it may be that, before planning can begin, time first needs to be spent to support the young person to understand what a transition is.
- Some local authorities have developed transitions apps as a way of starting the transitions process and developing plans.

Principle 4 – All young people should get the support they need

- Buddy support or informal mentoring
- Transitions summer programmes at colleges and universities (Autism Network Scotland has a list of current transitions programmes in further and higher education)
- Visual aids (e.g. picture symbols, planners, scrap books, cue cards)
- Social interaction support groups
- Advance visits, photographs or videos
- The Autism and Employment website offers information and advice for autistic people, those supporting them and employers.
- Local area Menu of Interventions/resource maps can be used to identify existing local resources.
- Local Autism One Stop Shops can provide a variety of locally relevant information.

Principle 5 – Young people and their parents and carers must have access to the information they need

- Autism-specific resource packs containing resources, contact details and information about eligibility for resources
- Autism open information sessions are a way of getting multiple information systems together in one place.

Principle 6 – Families and carers need support

- Informal parents' support groups e.g. Facebook pages, coffee groups, online forums
- Information packs for parents
- The Scottish Independent Advocacy Alliance details advocacy organisations across Scotland available for parents

Principle 7 – A continued focus on transitions across Scotland

- The Scottish Strategy for Autism website contains information about local autism plans across Scotland.
- The National Autism Coordination Project can support with embedding transitions into local strategy implementation.

Resources and signposting

The resources listed below are national resources with a specific focus on autism. Information about local resources can be found by contacting Autism Network Scotland. Information about resources in relation to transition in general can be found in the Principles of Good Transitions 3, which is available on the Scottish Transitions Forum website.

Autism and Education Trust – information about the transitions toolkit and person centred planning tools can be found at <http://www.autismeducationtrust.org.uk/resources.aspx>

Autism and Employment Website – this is a forum for sharing information and good practice in relation to autism in the workplace as well as highlighting common challenges and promoting the benefits that autistic people can bring to the workplace. Information can be found at <http://employment.autismnetworkscotland.org.uk/>

Autism Initiatives – information about autism as well as services and support can be found at <http://www.autisminitiatives.org/where-we-are/scotland/>

Autism Network Scotland - information about local and national resources, local One Stop Shops, autism training resources, the Menu of Interventions and The National Autism Coordination Project can be found at <http://www.autismnetworkscotland.org.uk/>

The Autism Toolbox – a resource to support the inclusion of children and young people with autism spectrum disorder in mainstream education services in Scotland can be found at <http://www.autismtoolbox.co.uk/>

Autism and Uni – information about this European-funded research project that works with young people on the autism spectrum to help them navigate the transition from school into Higher Education can be found at <http://www.autism-uni.org/>

Communication Passports – information about writing communication passports can be found at <http://www.communicationpassports.org.uk/Home/>

Exploring Transitions: Digging Deeper – the report for this consultation can be found at <http://www.autismnetworkscotland.org.uk/files/2015/10/Digging-Deeper-Report.pdf>

My World Triangle – information about how to use the My World Triangle, which has an autism option can be found at <http://www.gov.scot/Topics/People/Young-People/gettingitright/national-practice-model/my-world-triangle>

NHS Education for Scotland Optimising Outcomes Autism Training Framework – information about the training framework, associated training plan and online resources can be found at <http://www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/autism-spectrum-disorder.aspx>

National Autistic Society – information about a wide range of autism related topics, including transitions and social stories as well as the Autism Helpline and Transition Support Service can be found at <http://www.autism.org.uk/>

Scottish Strategy for Autism - information about the national strategy and local strategies as well as information about Working Group 2 can be found at <http://www.autismstrategyscotland.org.uk/>

The Scottish Transitions Forum – information about the Principles of Good Transitions 3 and the work of the Scottish Transitions Forum can be found at <http://scottishtransitions.org.uk/>

SIGN guidelines - The Scottish Intercollegiate Guidelines Network has produced a national clinical guideline for – Assessment, diagnosis and interventions for autism spectrum disorder. The guideline can be found at <http://sign.ac.uk/guidelines/fulltext/145/index.html>

Scottish Autism – information about a wide range of autism related topics, including services and support as well as the Autism Advice Line can be found at <http://www.scottishautism.org/>

The Scottish Independent Advocacy Alliance – information about advocacy available in Scotland for autistic people and for parents and carers can be found at <http://www.siaa.org.uk/>

References

Kenny, L. et al. (2015), “Which terms should be used to describe autism? Perspectives from the UK autism community”, *Autism: The International Journal of Research and Practice*. This article can be found at <http://aut.sagepub.com/content/early/2015/06/10/1362361315588200.full.pdf+html>



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