

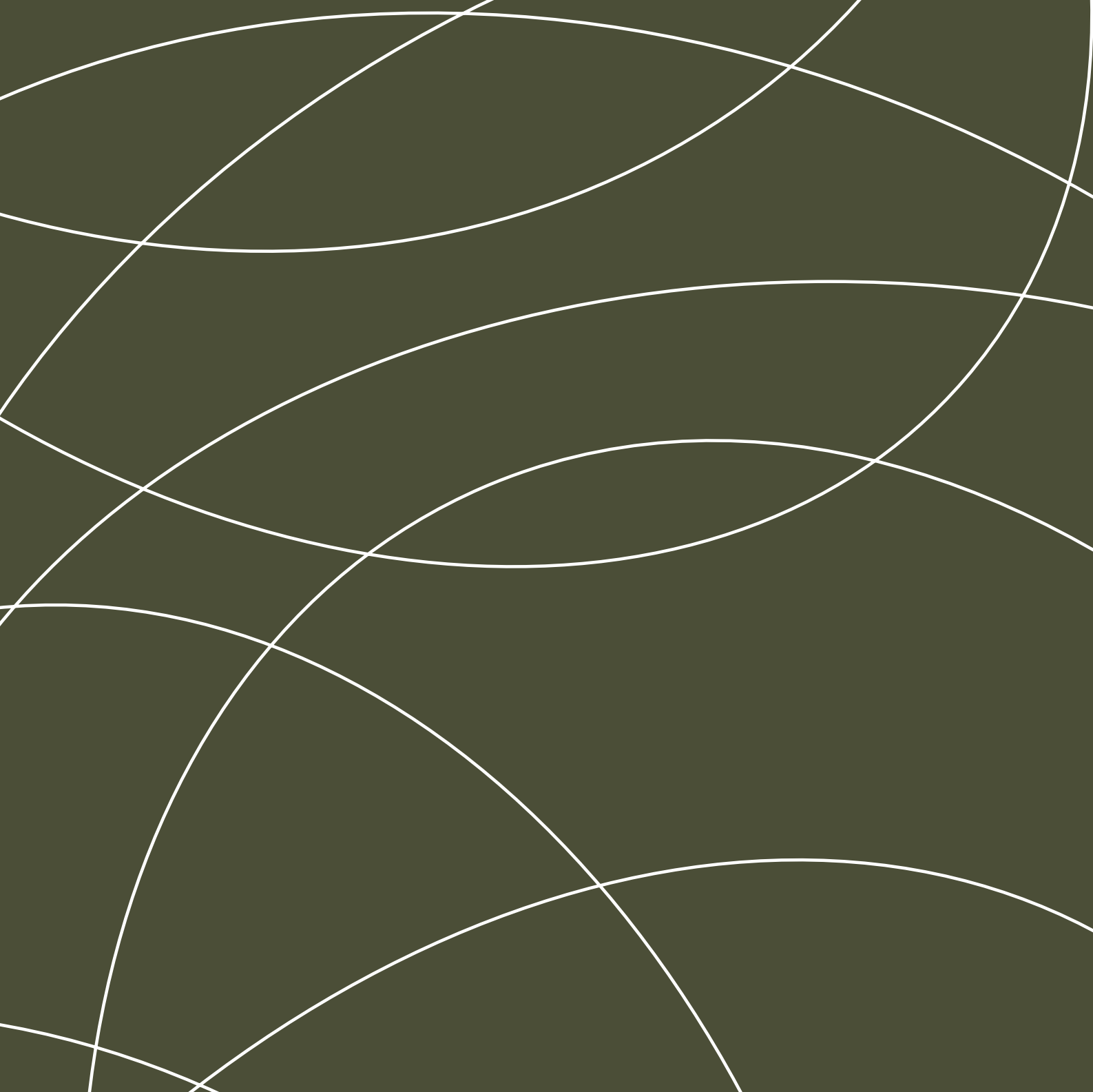
Principle 5:

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



Principles of Good Transitions 3

Scottish Transitions Forum
Second Edition 2019



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The Seven Principles of Good Transitions

1

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

2

Support should be co-ordinated across all services

3

Planning should start early and continue up to age 25

4

All young people should get the support they need

5

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

6

Families and carers need support

7

A continued focus on transitions across Scotland

Principle 5

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

This means information should:

- Clearly state what young people are entitled to during transitions
- Show what support is available
- Be inclusive of different communication needs
- Use common and agreed language

Information should clearly state what young people are entitled to during transitions

Young people, parents and carers should have access to information stating what support they are entitled to and what they can expect during the transition process. The right to information is included in many different legislative areas¹.

Practice examples such as those detailed in the recent NHS Accessible Information Standard and its associated Quality Checkers Programme show that information should be accessible, relevant and proportionate to the individual needs of parents, carers and young people. This is in line with the Equality Act 2010 and the UNCRC article 17.

Good sources of information are already available that help overcome some of these barriers. These include Enquire², Autism Tool Box³, Moving on Transitions Workbook⁴, English as an Additional Language resources⁵, LEAD Scotland (Linking Education and Disability)⁶ and Contact a Family⁷. Young people, parents and carers should be made fully aware of the information available to them.

The information provided should include the options that are available to young people, parents and carers who may be dissatisfied with transition planning or outcome. This may include accessing the Additional Support Needs jurisdiction within the Health and Education First Tier Tribunal for Scotland in relation to a failure to comply with the transitions duties in sections 12 and 13 of the Education (Additional Support for Learning) (Scotland) Act 2004, following complaints procedures relating to social care services, or the Complaints and Investigation powers with the office of the Children and Young People's Commissioner for Scotland. Information should also be available about the judicial process and signposting to good sources of legal advice, for example the Scottish Child Law Centre. Advocacy should be offered to help support this.

Right to complain

Young people and parents should know about their right to appeal via the This may include accessing the Additional Support Needs jurisdiction within the Health and Education First Tier Tribunal for Scotland (found under the Education (Additional Support for Learning) Scotland Act 2004, the duties for Children and Young People's Commissioner for Scotland, as laid out in the Commissioner for Children and Young People (Scotland) Act (2003) and the right to complain in the Children and Young People (Scotland) Act 2014).

In addition to the existing Enquire service that provides information and advice to children, young people and their parents, the Children and Young People (Scotland) Act 2014 now extends the powers of the Children and Young People's Commissioner for Scotland to allow them to investigate cases affecting individual children and young people. Before this change, the Commissioner was able to investigate only groups of children. This means that children, young people and their parents are able to ask the Commissioner to decide whether or not an individual's rights have been respected. This allows recommendations to be made.

Information should show what support is available

It is best practice that young people should be able to make informed choices about the support they receive⁸.

Asset mapping has been developed in some local authority areas to increase young people's awareness of the options available⁹. This is being developed in partnership with support agencies, local and national government and other statutory services to ensure all options are included.

Another approach to information provision is the 'Leaving School or College in Fife' leaflet developed by a partnership between ten voluntary and independent social care provider organisations. It outlines the range of support they provide to help young people and their parents and carers make a more informed choice about the organisations that may be best for them.

Menu of Interventions – Mapping Assets

The Menu of Interventions was produced as part of the Scottish Strategy for Autism. It sets out a series of 14 challenges that an autistic person may face and details what supports or interventions could be put in place to address them.

Autism Network Scotland has held asset mapping events attended by autistic people, parents, carers and practitioners from a range of backgrounds. Delegates were asked to take the 14 challenges and map out what was available locally from health, education, social care and the third sector. Services included social groups, employment support, speech and language therapy, local diagnostic pathways and information about local family supports.

Innovative forms of support were also considered, for example a local hairdresser who had a good understanding of autism, a shoe shop that offered 1:1 appointments for autistic customers and a dentist who would let patients take photos of the staff and building before their appointment. There were also autism-friendly sports clubs, cinema screenings and much more.

The information was collated and uploaded on to the Autism Network Scotland website in the form of an asset map which can be used by anyone.

Local transitions fairs are held in some areas to provide information about the range of services available. Examples include the transitions fair in Midlothian and 'Young Scots Got Talent' organised by Values into Action Scotland. Many local organisations, particularly in the third sector, are keen to be involved in delivering these events and have the capacity to improve the information available to young people and their families.

Given the importance of adopting joined up and person-centred approaches to supporting transitions, advocacy and information providers should consider broadening their scope to cover all matters that may affect people in transitions, rather than addressing specific areas of need.

Contact's Parent Information Resource

The Preparing Parents in Scotland for Transitions website provides resources developed with parents, for parents, to answer questions about transition and to help families make the right decision – including information about law, benefits and other essential information.

To explore the resource please go to **www.talkingabouttomorrow.org.uk**

Craig's mum's story

When my son Craig, who had profound and multiple learning disabilities and complex health care needs, reached the start of transition into adult services at aged 16, I looked at the life I wished for him after school, and which I believed he wanted. My husband and I were granted Welfare and Financial Guardianship so that we could legally make decisions on our son's behalf.

At the time Craig received Direct Payments and funding from the Independent Living Fund (ILF). I wanted him to have the opportunity to continue his personal development and also knew his school had a very good relationship with the local college. We discussed this option and the school staff supported our application for Craig to attend. Following a visit by Craig and I, he was enrolled and attended a drama class. He went on to participate in a part time course in cooking, drama and communication and disability sport, which meant he attended college for one and a half days per week.

We were considering other opportunities for Craig and I looked at local day centre opportunities, but sadly, at that time, he could not attend the one nearest our home as it was within a different local authority area. We chose our next option and Craig began a 3 day placement. However, the day centre staff were unable to provide the necessary one to one support, and so carers from an external agency were employed to provide this care. The agency was unable to provide one regular carer, so Craig received his personal care support from a number of different carers. He quickly became distressed with this arrangement. Following negotiation with the head of learning disability service, I managed to use a Direct Payment to employ Craig's lead carer to provide this care. This worked brilliantly for Craig.

Craig had received respite for one weekend every six weeks. However, when he turned 16, he was too old to access the service. We had to discuss what type of respite he would most enjoy. A respite centre had been identified and was available but I knew that Craig would not enjoy his time there. We met with Craig's care manager and through further negotiation agreed that a portion of his ILF and Direct Payment money could be used to pay for 2 stays of 5 days a year at an outdoor centre. This was a fantastic way for Craig to spend his respite time and was more fitting for a teenage boy. We were also able to arrange that his support at weekends would be provided by his home care staff so that he could access the things he enjoyed in the community. This included activities such as visits to the cinema, and classic car shows. We as parents also benefited from this arrangement, as we knew Craig was happy and well cared for, so it was a break for all of us. Every few months, Dave and I managed a weekend away while his carers looked after Craig in his own home. We were lucky to have a team that we trusted in every way.

Craig became more fragile and eventually fell seriously ill, requiring palliative care. His well-trained care team supported him in the hospital and then in our home 24 hours a day. Having this level of support enabled him, when able, to enjoy every day even when he could no longer attend his Day Centre. We were also able to renegotiate the day centre funding to be transferred into his Direct Payment package so that his lead carer could provide Craig support in our home. This holistically caring arrangement continued until he passed away in 2008 in his own home, with family and carers with him.

Information should be inclusive of different communication needs

It is a requirement to provide information in ways that are inclusive of the different communication needs of young people, parents and carers. This may include British Sign Language¹⁰, alternative audio and video formats, assistive technologies, board maker, easy read and Talking Mats. This approach is fundamental when working with the deaf, deafblind and blind communities or others with communication support needs.



Deaf Action: Why communication is important in transitions

Being deaf¹¹ puts extra pressure on children and young people in transition, especially when it is an unplanned move. In this situation, sourcing support for the communication preference is vital and completing assessments with the young person so that funding can be accessed to meet their needs.

An example of such a person is Jack, who moved into supported accommodation while he was finishing school. He had a clear aim for college and was supported by school to apply for courses. The transition social worker liaised with the college to ensure communication support workers were in place. We met with his school and new support staff through reviews and highlighted the need for more support with independent travel, as he would be travelling between his new home and college. It was important to Jack that he could do this and that he would be able to meet his friends.

School staff had said that he used Sign Supported English (where signs follow the grammar of English). I noticed that he tended to adapt his communication style for the person he was talking with for instance, using speech with a hearing person who did not know British Sign Language. He was skilled at this. I was aware that while he may say he understood what was said in these conversations it was probably not the case. We talked about this and he said he couldn't understand what was said back. His preferred language was in fact British Sign Language and he had developed fluency with this language through classes at school and conversing with friends. I had to ensure that booking BSL interpreters for regular key worker meetings was written into his care plan. This was to make sure he had full access to information and have his needs listened to in return.

An essential part of managing transitions is working with other professionals and agencies to raise deaf awareness and promote the use of interpreters so that services are accessible for deaf people.

Information should use common and agreed language

Many Scottish Transition Forum members have told us that the lack of an agreed and common language is one of the most fundamental challenges to achieving a shared understanding of transitions and more joined-up approaches. It is good practice to ensure that all information is, as far as possible, free from professional jargon.

There should be clear definitions of the terms that are shared and agreed across all professional sectors¹². For example, 'transition', 'key worker', 'transitions co-ordinator', 'learning disability', 'disability', 'learning difficulty', 'outcome', 'positive destination' and 'person-centred' can have different meanings depending on the professional background of the person using them. This leads to confusion among young people, parents, carers and professionals.

References

¹ Legislation around information can be found in:

- The Children and Young People (Scotland) Act 2014
- Education (Additional Support for Learning) (Scotland) Act 2004
- Children's (Scotland) Act (1995)
- Equality Act (2010), Protection of Vulnerable Adults Act, Adults with Incapacity Act and Guardianship processes
- Social Care (Self Directed Support) (Scotland) Act (2013)
- The Human Rights Act (1998) and its Associated Articles

Policy mentioning information provision is found in:

- NHS Quality Improvement Strategy
- Better Health Better Care Health Policy
- A Fairer and Healthier Scotland
- Realistic Medicine

² <http://enquire.org.uk/good-practice/2013-transition-information>

³ <http://www.autismtoolbox.co.uk>

⁴ Play back ICE

⁵ <http://www.educationscotland.gov>
inclusionandequalitiesadditionalssupportforlearning/eal/

⁶ <http://www.lead.org.uk>

⁷ <http://www.cafamily.org.uk>

⁸ Scottish Government (2013) Social Care (Self-directed Support) (Scotland) Act

⁹ Highlife Highland

¹⁰ British Sign Language (Scotland) Act 2015

¹¹ deaf here refers to deaf BSL users, deafblind, deafened and hard of hearing people

¹² Jindal-Snape, D. (2016) A-Z of transitions. Palgrave



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