

Principle 6:

Families and carers
need support



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 6

Families and carers need support

This means:

- Family wellbeing needs to be supported
- Advocacy should be available at the start and throughout transitions

Family wellbeing needs to be supported

Young people's relationships with their family can be complex, particularly where parents or carers have an ongoing role in providing personal assistance and where disability related allowances or benefits are an important contribution to the household income. The needs and roles of family members and carers are also likely to change as the young person they care for grows up. Parents and carers are usually central to the continuing care of young people with additional support needs and are the people most likely to provide guidance and support during transitions.

This role may present considerable challenges. Many parents and carers feel they must fight for support and can experience 'burn out' as they deal with the many new challenges associated with transitions. Too often, parents and carers describe their experience of supporting a child through transition as like 'falling off a cliff' or a 'black hole'¹.

'Families need support. You've had five days a week "respite" [from school services being provided], and then suddenly you're faced with seven days a week all day. Normally when your kids leave home you get a "second life". We find it can be like going back to the baby or pre-school stage. It's like a backwards step.'

Transition project worker, voluntary sector, "Where Next?"
STF Evaluation (2015) p16

The Carers (Scotland) Act 2016² commenced in April 2018 and extends and enhances the rights of carers. This Act provides better and more consistent support to carers so they can continue to care, if they so wish, in good health and to have a life alongside caring. Likewise, young carers should have a childhood like their non-carer peers. Carer's assessments have been replaced by Adult Carer Support Plans, and Young Carer Statements have been introduced to identify personal outcomes and any support needs. A carers' charter has been developed as part of the legislation, setting out the rights of carers as provided for in or under the Carers Act. In addition, there is an expectation that young carers will be supported to transition into the adult caring role as the young carer statement is transferred to an Adult Carer Support Plan. Please speak to your local carers centre about this.



Liam's Mum's story

When things started getting more intense with Liam's care I needed help. I did have a close family and my parents to help but they did things their way, which led to arguments that didn't help with my stress levels. My social worker was aware of the situation but was limited in the options she could offer. Barnardo's home from home was mentioned but I felt finding someone I trusted with Liam and all his needs was way out of our reach! I remember saying I wanted something like an extended family that would be on Liam's and my side. Someone like a second granny or auntie, but how would this ever be available? I didn't want Liam out of my life, I wasn't ready to let him go but how could we carry on?

Then I met Jenny and Dave and it all came together! How amazing to meet a family who knew all about community services, how to access them for people like my son and could offer this and more. They could offer Liam opportunities that I was not in a position to offer. Their experience of being parents and caring for their own son Craig, and Jenny's involvement with PAMIS, meant that they were able to provide support for Liam and us as he transitioned from children to adult services. Jenny has guided us in the right direction to services such as accessing Self-directed Support, appropriate day centre provision and even College. Jenny and Dave understand Liam, can follow his communication and identify what he is saying by his body language. Their provision of respite support and latterly accepting Liam full time, once Liam and I were ready, has been a great help.

Transitioning from child services into adulthood and adult services is such a daunting time for all families who share our circumstances. However, Jenny and Dave welcomed us to become part of their family and we very much welcomed them into our family too.

Jenny and Dave's experience, knowledge and understanding gained from looking after their own son has allowed them to see and support Liam as a valuable individual young man.

People look at our situation and ask, "how did you manage to have all of this in place for your son?" Of course, without the flexibility, choice and control offered under Self-directed Support and everyone working hard to make it work we may not have such a successful story to tell. I feel Liam is a very lucky young man who has been gifted an amazing extended family and future adult life filled with opportunities. I just wish every family in my situation could be as lucky as we have been in successfully sharing their son's or daughter's caring role and the special relationship we now have with Jenny, Dave and their family. Liam and I have been blessed.

Good practice

Parents have reported that, where they exist, peer support networks are highly valued. However, networks developed while children are at school can be difficult to maintain after they leave. The ability of parents and carers to establish and maintain peer support should be considered in the development of support packages for young people.

The strategies below have been developed to help alleviate stress on families and carers during transitions:

- Encouraging positive expectations and working with doubts about community and social life post-16
- Clear communication and transparency about the transitions process at all times
- Talking about transition in positive and creative ways and as a time to celebrate moving into young adulthood
- Preparing parents and carers for the planning process by providing early information sessions from age 14. If information is timely and accurate, parents and carers will have a better

chance to engage with the transitions process

- Supporting parents and carers to understand and acknowledge that those they care for have their own choices to make as they move into adulthood and support all involved to make informed choices
- Increasing the availability of peer support networks
- Offering training in stress management techniques such as relaxation exercises and meditation
- Using appropriate short break and respite services
- Supporting carers to build resilience, self-efficacy, and self-esteem
- Ensuring parents have continued access to a single point of contact
- Ensuring that parents receive information and are supported to complete carer's assessments and consider relevant legal processes such as Guardianship Orders.

More information about support for family wellbeing and other areas can be found through Contact³, a charity for families of disabled children.

Advocacy should be available at the start and throughout transitions

It is best practice for advocacy to be made available to all young people in transition and their parents and carers, particularly if they have concerns about having their voices heard. It should not only be available when difficult decisions must be made. At present, references to advocacy services under the Education (Additional Support for Learning) (Scotland) Act 2004 are for parents and young person's (16+) only (section 14 as detailed in the Education (Additional Support for Learning) Codes of Practice⁴. Changes introduced by the Education (Scotland) Act 2016 include a national support service to provide advocacy for children with additional support needs in relation to rights under the 2004 Act.

The information about how to access advocacy is available from the Scottish Advice Service for Additional Support for Learning - Enquire.

The offer of advocacy should be made at the start of transition, age 14, and be available to at least age 25. This is especially relevant for those who are looked after, care-experienced, and those being considered for a Guardianship Order.

References

- ¹ NOP (2003) A survey of the views and experiences of young disabled people in Great Britain, conducted by NOP on behalf of the Disability Rights Commission, DRC: London; Morris (1999) Hurling into a Void JRF: York; and Heslop, P et al. (2002) Bridging the Divide at Transition: What happens for young people with learning difficulties and their families? BILD: Glasgow
- ² http://www.legislation.gov.uk/asp/2016/9/pdfs/asp_20160009_en.pdf
- ³ <http://www.cafamily.org.uk/>
- ⁴ As detailed in the ASL Act codes of practice for those who undertake a tribunal <http://www.gov.scot/resource/doc/348208/0116022.pdf>



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