



Walking Tall

Disability inclusion work

March 2019

The Fostering Network

The Fostering Network is the UK's leading fostering charity. We are the essential network for fostering, bringing together everyone who is involved in the lives of fostered children.

We support foster carers to transform children's lives and we work with fostering services and the wider sector to develop and share best practice. We work to ensure all fostered children and young people experience stable family life and we are passionate about the difference foster care makes. We champion fostering and seek to create vital change so that foster care is the very best it can be.

Our consultation project – Walking Tall

The Fostering Network in Scotland was awarded funding from the Big Lottery Fund for a two-year project named Walking Tall. The aim of Walking Tall was to consult primary school-aged children living in fostering households. This included both children in foster care and the sons and daughters of foster carers.

While working with children in the Walking Tall project it became apparent we were not capturing the voice of children and young people with more complex disabilities, those who cannot easily voice their views. This led us to ask: If we were not doing this was the voice of these children being captured at all in the foster care system?

We set out with the aims of:

- discovering if the voice of children and young people with complex disabilities was being heard
- exploring how foster carers are supported to look after children with complex disabilities
- producing some guidance to support foster carers working with children with complex disabilities.

A disability inclusion co-ordinator was appointed for six months to engage directly with children with complex disabilities and their foster carers to ensure that the views of children with disabilities were heard and any barriers to participation were identified.

What we did

We met with foster carers and, where appropriate, the fostered children of these foster carers to explore this topic over a six-month period. We also met with various services.

- 16 fostering families
- 14 meetings with services including SCRA
- 6 children with their foster carers

Foster carers

Meeting with foster carers was both humbling and inspiring. Hearing of the challenges they faced to get the support they and their young people needed highlighted the importance of work needing to be

done in this area. Very clearly, in every case, the voice of children with complex disabilities was not being heard.

Foster carers told us:

- ‘Fostering a child with disabilities can be like walking through treacle – nothing happens quickly enough, decisions are slow, diagnosis is slow and getting information relevant to care for the child non-existent.’
- ‘The voice of the child is important.’
- ‘The system is not designed to listen to these kids, [those working in the system are] not listening or finding a way to listen’
- ‘Children need to be listened to but not in a tokenistic way, don’t just wheel them in for the sake of it, it has to have meaning for the child. Needs to be participatory, involve them.’
- ‘Meetings are procedural not about children, why ask the social worker to speak first when they do not know the child?’
- ‘You must advocate for the child and keep pushing.’

Areas for development

We asked foster carers where and what they would like to see improved to support disabled children in foster care. They noted:

- Social workers need to be trained in working with children with severe and complex needs, so they can communicate with them, being familiar with communication tools and methods.
- Clarity around applying for Disability Living Allowance (DLA) and if a blue badge for the car can be applied for.
- Looked after children reviews must accommodate different ways of hearing from children with disabilities. One young person, who was non-verbal, was reported to have created a PowerPoint of his activities for a school meeting. He would be able to share this and change the slides. However, the looked after children review would not let him stay and did not watch his slideshow. Another foster carer reported that their young people never attended their looked after children review and no effort was made to capture their voice. Consequently, the foster carers are the voice of these young people. Efforts should be made to ensure young people with severe and complex disabilities are supported to develop and communicate as best they can. Ultimately, all those working and supporting children must learn how best to communicate.
- Children’s Hearings must accommodate different ways of allowing children with disabilities to communicate their views

- Clarity about who funds adaptations which are needed within the home to ensure the child's needs are appropriately met.
- Contact decisions must be more child focused. Examples were given of children having contact once a year with no knowledge or understanding of who they are meeting.
- Respite needs to be offered in a managed and appropriate way with better transport arrangements and only with people the children know.
- Support for sourcing and acquiring appropriate wheelchairs to significantly improve quality of life. Several families had self-funded better wheelchairs, with others self-funding adapted bikes and trikes to ensure fitness and stimulation. Disability Living Allowance (DLA) is not enough to cover such things.
- Fostering services supporting and signposting foster carers to increase their knowledge and awareness of activities and clubs which are accessible for children.
- Raising awareness of the availability of ENQUIRE, the Scottish advice service for additional support for learning. This can support carers and their children to increase their knowledge of children's rights within education and how best to support children with their education.
- Foster carers are supported to feel more confident in advocating for their child within the health care system and are supported to increase their knowledge of health matters, including how to self-refer to services such as physiotherapy and occupational therapy.
- Increased information and greater clarity around Continuing Care to enable foster carers to enhance their knowledge and feel empowered to support all young people with severe and complex needs to be offered continuing care where appropriate.
- Improved toilet and changing facilities at venues used by services including The Fostering Network. This was reported as a significant issue with some foster carers reported being advised by services to double pad children if they were going to an event where there would be limited toilet facilities.
- Foster carers need to be treated as professionals and a key member of the team around the child and should always be invited to professional's meetings.

Hearings and reviews

Scottish Children's Reporter Administration (SCRA) were very open to looking to ensure they were inclusive for all children. They said that they would readily work with foster carers to best get the voices of children heard, including using video, story boards and methods suggested by the foster carer. One foster carer spoke of the panel members proactively visiting the child's school to observe her, thus removing the need for her to attend a hearing.

There were some examples of social workers using a gaming system to get the views of the child prior to a care planning review, but for those with very limited communication methods there was a feeling that little is done to capture their views.

How do we get children's voices heard?

During this project we visited fostering homes and met with some wonderful young people with complex disabilities. For example:

It was a joy to walk into a room and, with the foster carer's guidance, take time to hand sign hello, be able to communicate and play musical instruments with a teenage girl. Despite being non-verbal and blind, she communicated through sound and visual clues which her foster carer was able to share with me and tell me that she was happy.

The foster carers were strong advocates for getting what this young person needed and ensuring she was involved in her care. The dedication to finding ways to communicate, discovering a love of music and using this as a powerful communication tool was inspiring.

The issue of communication lies very clearly with us and not the child - we must recognise that there are many ways of communicating and working with a child. The Children's Hearings and review systems must embrace and encourage this – foster carers spoke of being discouraged from bringing video footage of the young person or photos, yet these may be a key part of finding out about the child, their likes, dislikes and needs.

What would foster carers like to see put in place to allow children to communicate at hearings and reviews?

- Social workers and panel members are aware of how each individual child communicates and be given training in hand signing, Makaton, board maker. These techniques could then be used to build a relationship with the child. Social workers need to spend time with children, be in their environment and get to know them.
- Closer working between those involved in the child's life to ensure the child's views are being interpreted correctly.
- Use of video, photo book or photos on PowerPoint for presentation at meetings. These can show what the child has been doing and what they have achieved. If possible this should be presented by the child, if not then by the foster carers (who can also help interpret behaviour and expressions).
- Video footage can demonstrate how the young person interacts with his/her foster carers and how they make choices, showing level of understanding of foster carers around what the child or young person is communicating.
- Recognition given to the views and observations of foster carers who can give considerable insight into what children and young people need.
- Continuing Care should be promoted as many foster carers are willing to have young people with complex disabilities with them to 21 and some beyond. All too often services are moving young adults with disabilities to adult services and adult units, rather than allowing a gradual transition to appropriate adult services over time.

Guidance for foster carers with children with disabilities

Foster carers shared that they would welcome practical guidance and further supports to enable them to best advocate for children and young people with disabilities. It was noted that this should be available to foster carers when asked to take on a child. Below are some of the areas they identified, along with further information and links for other sources of support.

- Disability Living Allowance (DLA) and Personal Independence Payment (PIP)
- Blue Badge scheme
- Self-Directed Support (SDS)
- Continuing Care.

Disability Living Allowance (DLA) for children may help with the extra costs of looking after a child who:

- is under 16
- has difficulties walking or needs much more looking after than a child of the same age who does not have a disability.

They will need to meet all the eligibility requirements.

Personal Independence Payment (PIP) is for those aged over 16 and can help with some of the extra costs if the young person has a long term ill-health or disability. The amount given depends on how the condition affects the young person, not the condition itself.

Further information on these and other benefits can be found online: [gov.uk/browse/benefits/disability](https://www.gov.uk/browse/benefits/disability)

Blue Badge scheme

Foster carers can apply for a blue badge on behalf of a child or young person they care for. Also known as disabled parking permits, the scheme supports people who cannot easily get around by helping them park closer to their destination. Blue Badges are for people with severe mobility problems or those who pose a risk to themselves or others in traffic.

The Blue Badge may also be available if people have a shorter-term condition which is expected to severely affect mobility for at least 12 months. The scheme operates differently across the UK. If you are resident in Scotland visit: mygov.scot/apply-blue-badge/apply-for-or-renew-a-blue-badge-in-scotland/

Self-Directed Support (SDS) is Scotland's mainstream approach to social care. Self-Directed Support (SDS) puts the person at the centre of the support planning process and enables people, carers and families to make informed choices about what their social care support is and how it is delivered. It's not an add on or a separate way of doing things. It is the legal way in which all social care must be delivered and ensures that people who are eligible for support are given the choice and control over how their individual budget is arranged and delivered to meet their agreed health and social care outcomes. sdsscotland.org.uk

Continuing Care

A young person born after 1 April 1999 who is looked after in foster, kinship or residential care is eligible to remain in their current care placement until they turn 21. This is called Continuing Care and has been in place since April 2015.

If the placement cannot be maintained, or if it is in the young person's best interests to start an alternative placement, a welfare assessment must be provided showing why staying in their current placement would significantly adversely affect their wellbeing.

Any eligible young person ceasing to be looked after on or after they turn 16 can request Continuing Care. A young person receiving Continuing Care will no longer be defined as 'looked after' but will continue to receive the same support. When Continuing Care ends the young person is then eligible for Aftercare support until they turn 26.

[Guidance on Part 11 \(Continuing Care\) of the Children and Young People \(Scotland\) Act 2014](#)

[Continuing Care \(Scotland\) Order 2015](#)

Real life examples were given of young people being moved to adult services provision when they turned 18 with no offer of Continuing Care. To enable provision of Continuing Care the local authority must carry out a welfare assessment and must, unless it is not reasonably practicable to do so, seek and have regard to the views of the young person and take all reasonable steps to enable the eligible person to attend and participate in any meetings relating to the welfare assessment. This is a right of all young people but foster carers have shared that young people are not always consulted about their views.

It is imperative that foster carers are well informed to support the care planning for young people, and essential to ensure that planning is in place as early as possible.

Sources of further information

The following have been suggested by those who engaged with the project. Thanks also to Anne Wilson, Children's Health Scotland, for sharing wider resources and useful organisations.

Call Scotland help children and young people across Scotland to overcome disability and barriers to learning created by their environment, and to fulfil their potential. In addition to training and information they also have an equipment bank to enable children to try out equipment to ensure it works for them. Their website also includes information on Board Maker as a communication tool.
callscotland.org.uk

Children's Health Scotland (formerly Action for Sick Children Scotland) promote and campaign for children and young people's health rights and the highest standards of healthcare for all children across Scotland through partnership and policy work, information and support for parents/carers and their projects. They provide presentations, workshops, as well as a range of resources, communication and multi-sensory tools for children and adults to help children prepare for and experience health services including dental and hospital treatment. childrenshealthscotland.org

Contact (formerly Contact a Family) support families with a wealth of information on all aspects of disability for both carers and the practitioners who support them. Their services include an online medical directory, telephone helpline, information guides, support groups and workshops.
contact.org.uk

Disability Information Scotland (formerly Update) work with disabled people, their families, friends, carers and people who work in the sector. They help to guide people through the maze of disability information and offer information via a telephone helpline, online Scottish Disability Directory and a range of information guides and other resources. disabilityscot.org.uk

Enquire is the Scottish advice service for additional support for learning. They aim to raise awareness of children's rights to extra support in school, help families and schools work together to ensure children get the support they need and provide advice to children and young people who might be struggling in school. They provide easy to understand advice and information about additional support for learning legislation and guidance for families and professionals, help families find local education and support services and share practical tips to help families and schools work together and solve problems should they arise. They also provide telephone helpline, guides, factsheets and outreach work. enquire.org.uk

Genetic Alliance The Rare Resources project (formerly Fresh Steps) has developed a toolkit of information resources for families in Scotland who have received a diagnosis of a rare, genetic condition or who have an undiagnosed condition. The toolkit is a flexible resource with information and signposting to support services in Scotland. geneticalliance.org.uk

Salvesen Mindroom offer practical and emotional support to parents and carers of children and young people up to the age of 25 years with [learning difficulties](#). They also provide a range of services to [professionals](#), including advice, information and support and training workshops. mindroom.org

Supporting Disabled Children, Young People and their Families Scottish Government website (launched April 2019) provides a range of information on national policies, entitlements, rights and the different options for support available gov.scot/publications/supporting-disabled-children-young-people-and-their-families

Talking Mats (Consulting Children and Young People Resource) is a picture-based communication tool designed to help education staff listen and respond to the views of children and young people, including those with communication difficulties. It uses attractive and engaging symbols that can be used for consulting children and young people from three to adulthood. It has been developed to correspond with three different education stages, early years, primary and secondary. talkingmats.com

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