

Together for Short Lives special educational needs and disability (SEND) project

Helping children who need palliative care to access education events, September 2015



Report of our findings from the events

As part of our Department for Education funded project to engage children's palliative care in the SEND reforms in England, Together for Short Lives hosted four regional events in September 2015. The events - held in London, Newcastle, Birmingham and Exeter - sought to improve the extent to which delegates' understood:

- what children's palliative care is, who needs it and who provides it
- why giving children and young people with life-limiting conditions access to education is important - including what education providers are legally obliged to do
- how life-limiting and life-threatening conditions can be managed in education settings in ways which are consistent with children and families' needs and wishes
- how education providers can support children who need palliative care, their families and other pupils and students who learn alongside them - including principles of best practice, roles and responsibilities of individuals, unacceptable practice and how to provide support before and after bereavement
- how education providers should engage with the health and social care services which provide children with palliative care, including those in the voluntary sector
- where education providers can go for the support and information they need.

The morning session of the workshops consisted of presentations and question and answer sessions with:

- a representative from Together for Short Lives' Practice and Service Development team
- a parent carer of a child with a life-limiting or life-threatening condition
- an education provider and/or a children's palliative care provider.

Delegates included commissioners and providers from health, education, social care, local authorities and children's palliative care providers. All the presentations from the six events are available on our SEND online hub at www.togetherforshortlives.org.uk/sendresources

What our delegates told us

The afternoon session of the workshops was a discussion session during which we asked delegates to consider four questions about the work in their local area to improve access to education for children with life-limiting and life-threatening conditions.

A summary of the key themes emerging from their responses is set out below. Please note that this is not an exhaustive list of all the comments made during the events.

What is working well (or would work well) in your school, early years or further education setting in terms of giving children with a life-limiting condition access to education?

Information sharing

- Regular liaison between schools, families and medical professionals.
- Information-sharing between partner schools, including specialised and mainstream schools.
- Local authorities creating and coordinating better information sharing networks.
- School nurse liaison, e.g. texting service for young person to school nurse.

Continuity of education

- Medical teams on school site.
- Schools providing short breaks services.

Person-centred approach

- Staff having a good understanding of the aspirations of young people.
- Parent participation and personalisation helping children to participate fully.
- Individualised learning plans.

“To integrate a child back into his class we’ve encouraged him to help us set up a Y5/Y6 Minecraft club, which is something he is an expert about and can physically do”

Principles of the reforms

- Education, health and care (EHC) plans are now more of a ‘working document’ and are dynamic.
- One page profiles (‘pupil passports’) are shared well.
- New code of practice is empowering for families.
- Pathways for assessment are identifiable.

Professional competencies

- Strong leadership.
- Staff who are committed and enthusiastic to meet the needs of children and their families.
- Flexible and part-time workers working around children’s appointments.

“A special school invites student nurses in to the school to see how they are working with children with complex needs and communicating with them”

Awareness

- General disability awareness has improved.
- Improved support for children and families currently in school.

Training

- Good condition-specific training in schools, for example:
 - a school held a cystic fibrosis school study day to inform and educate mainstream school staff
 - a school holds an acquired brain injury study day each year – all professionals involved in their care attend the training.
- Use of coaching in school to support staff to understand their own motivational goal for working with children with complex needs.
- Specialist training to support staff in schools.

Integration

- Strong liaison between home, school, tutors and hospital.
- SENCOs providing single point of contact in initial stages.
- Links between hospital teacher and staff in special schools.
- Access to subject specialists when children have to take time off school.
- Children's hospice well integrated within school.
- Strong networking with education, social care, health and voluntary sector providers.
- Outreach of staff in special school working to support pupils in mainstream schools.
- Learning disability team working well with children's services.

What challenges are you facing (or would be facing) in terms of giving children with a life-limiting condition access to education?

Attitudes

- Expectations of continued learning and development for the child don't extend into wider community.
- Some parents do not believe that their child can achieve; they are often exhausted through battles with authorities and consequently disempowered.

Information sharing

- Collaborative working is 'hit and miss'.

- Lack of information about support services and advice for:
 - families
 - professionals.
- Poor links with local children's hospice services.

Fear of litigation/failure

- Fear of litigation if professionals make mistakes or stray beyond usual remit of their role - for example, education professionals undertaking health procedures.
- Head teachers failing to identify which staff require training and rejecting offers to train teaching assistants to provide medical care.
- Fear of accepting children into school who will spend time out of school and have a negative impact on schools' attendance figures.
- Ofsted reports do not sufficiently acknowledge that not at all child development is academic.

Training

- Mainstream schools do not get sufficient support to train staff to care for children with complex needs.
- Staff are reluctant to engage in further training.
- Professionals can find it difficult to communicate and support bereaved families.
- There is insufficient time to train staff properly.
- Staff lack the confidence to share appropriate information about a child's condition to other children.
- Time-lag: It takes time to train new staff to meet a child's needs.

Resources

- Insufficient funding to provide specialised support.
- SENCOs do not have enough time to adequately co-ordinate each child's care.
- Gatekeeping of local authority budgets can cause delays.
- Schools often require, but do not have, specialist interpreters to overcome language and cultural barriers when communicating with families who have moved to the UK.
- Children's plans are not being put into practice due to time pressures.
- Minimum wage rises affect overall school budgets
- Lack of facilities to care for children with complex medical needs.

“Moulded seats are not suitable for some learners to be supported in a ‘learning’ position comfortably and the learner has been told that they are ‘unseatable’. This stops community learning.”

Joint working

- It is difficult to make sure that support continues after the young person leaves sixth form college.
- Finding a convenient time to bring together all of the professionals involved.
- Families' reluctance to engage with all parties as they are already liaising with lots of professionals.
- Reluctance of professionals to share information.
- Lack of understanding among medical staff of the importance of education - an overly clinical focus.
- Failure of health professionals to attend EHC planning meeting.
- Information sharing and confidentiality varies between local authorities, schools and hospitals.

Regional variations – provision of services

- Distances to some services from schools creates a 'postcode lottery'.
- Some schools are more proactive than others in pursuing training for staff.
- Some schools are more aware of local children's palliative care services than others.

Regional variations – criteria

- Inconsistent criteria between local authorities for eligibility for EHC plans.
- Lack of clarity in continuing care definitions.
- Paperwork and administrative functions vary between local authorities.
- Different funding arrangements and criteria in different areas.
- Lack of EHCP assessment for children who 'only have medical needs'.

Mental health

- Lack of early intervention for mental health issues.
- Lack of consistent understanding of mental capacity.

Growing population

- Difficulty in knowing where and how many families there are with children who need palliative care.

- Providing appropriate education as children with life-limiting or life-threatening conditions live longer - for example, supporting young people into college and then university.
- A greater number of children with complex conditions are now accessing education but there are insufficient staff to support them.

What will you do as a result of the event, both individually and organisationally - and by when?

Engaging with education providers

- Make links with hospital school.
- Consider how to support schools when children leave rehabilitative settings and go back into school.
- Encourage outreach from special schools to mainstream schools.
- Revisit the roles and responsibilities of schools and how they are supported by local authority to meet needs of children who need palliative care.

Communicating with families

- Provide more support for parents when child is not able to be in school.
- Find ways to support families to manage their personal budgets – help them with bureaucracy and give them time to enjoy time with their family.
- Ensure families are aware of local services available to them.

Engage with local VCS CPC providers

- Attend training sessions with local children's hospice service.
- Link with children's hospices to support children from a younger age into education.
- Contact all local services supporting children receiving palliative care – create links and think about partnership working.

Person-centred care

- Develop better transition plans including 'what's next' page for when child finishes school.
- Work with children to develop and understand their aspirations.
- Explore practicalities and potential insurance issues of providing teacher assistant or teacher support from mainstream schools for children who are at home.
- Create a council mission statement about what services and expectations families with children who need palliative care should have.

- Talk to families who attend services and ask what their experience has been and how things can be improved.

Training

- Ensure all SENCOs have a copy of training materials for the SEND reforms.
- Training to increase staff understanding of what their responsibilities are to support children with complex needs.
- Provide coaching for staff to understand their own strengths and weaknesses and to better support children.
- Set up a local 'children with medical care needs' conference.
- Continuing development of community support workers to understand importance of learning for independence.
- Further training sessions to encourage sharing of 'success stories' and best practice.

Identifying children with life-limiting or life-threatening conditions

- Reassess staff and resources in respect of number of children who need palliative care.

Improve joint working

- Network with professionals involved in children's palliative care.
- Develop a small team of parent, social worker and teacher to develop a named person accountable for the outcomes agreed in the EHC plan.
- Encourage communications between services.

Use Together for Short Lives' SEND resources

- Add Together for Short Lives' interactive education resource to local offer.
- Share all of Together for Short Lives' SEND resources:
 - with all schools in region
 - with higher education providers in the local area
 - on school website
 - with SENCOs

What else would you find useful to help you give children with life-limiting conditions access to education.

Training

- Additional training on how to implement joint working in local areas.
- Training to equip schools to train their own staff on how to improve access to education for children with complex needs.
- Local meetings to network and discuss how to support this group of children.
- Use school inset days to train staff to support these children.
- Special needs training for all teachers prior to qualification.

Guides and resources

- Pathway for young people without an EHC plan.
- Additional case studies of success stories or failures.
- Information on grants available to early years settings.
- A forum to share best practice.
- A map of health trusts and local authorities, showing how they overlap.
- Information on children's hospices and what services they offer in the community.
- SEND briefing updates (distributed by Together for Short Lives) to include opportunities to share best practice, e.g. Tweet chats, webinars.

Joined up working

- Improved links to health to identify families who have children with complex needs so that can be supported to access services.
- A national policy on how local and health authorities should work together.

Legal clarity

- A list of statutory expectations for pupils with highly complex needs.
- Advice on how to obtain funding, how much is reasonable to request and how funding decisions are made.

Mental health

- Improved support for children with mental health issues.

Reforms within educational settings

- Resources to employ specialist services, for example a specialised school nurse in a special school.
- Teleconferencing facilities to engage with children who are unable to attend school.
- Improvements to school buildings and facilities.

For more information

Please contact James Cooper, Public Affairs and Policy Manager at Together for Short Lives by email (james.cooper@togetherforshortlives.org.uk) or telephone (01179 897 863 or 0741 522 7731) or visit www.togetherforshortlives.org.uk