



LTCAS

LONG-TERM CONDITIONS
ALLIANCE SCOTLAND
people not patients

Seen and not Heard?

Exploring issues facing children and young people living with long term conditions



“It’s basically... making other people know what it’s like to be you. Put them in your shoes.”

Young person – ‘Seen and not Heard’ Film

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Introduction

The long term conditions agenda has moved on apace over the past few years. In 2008 LTCAS and the Scottish Government jointly produced “GauN Yersel”, the Self Management Strategy for Long Term Conditions in Scotland which brought with it the Self Management Fund for Scotland. More recently the first long term conditions national action plan (‘Improving Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan’) was published.

Within this agenda LTCAS members have frequently raised concern that children and young people may be overlooked. Children and young people are often affected differently by long term conditions, tend to use a different range of services from adults, and have distinct needs.

It is a basic right of disabled children and young people, and those with long term conditions, to be included and to enjoy equality of opportunity with their peers. Supporting people to develop self management skills at an early age will improve their quality of life, opportunities and help reduce future complications.

There is also a need to work with children and young people to help tackle the negative societal attitudes that persist towards disability and long term conditions.

To begin to explore how the needs of children and young people can be met, and how children’s policy and long term conditions policy can be joined up, LTCAS has taken forward a range of activities:

- Established a **working group** comprising organisations from the long term conditions, disability and children’s sectors
- Gathered existing evidence of **children and young people’s views and experiences**
- Recorded **digital stories** with children and young people
- Developed the **‘Seen and not Heard?’ conference**, held in November 2009 and addressed by the Minister for Children and Early Years

This report brings together this work to-date. It includes the key points arising from the ‘Seen and not Heard?’ event and provides a brief overview of policy relevant to children and young people living with long term conditions. The report focuses on three themes which were identified by the working group: school education; mental health and wellbeing; and transitions.

LTCAS and the working group hope to work with children, young people and families to take forward the recommendations in this report with relevant decision makers.

Recommendations – Summary

Issue	Recommendations	Key agencies
<p>For policy and practice to succeed in this area, children and young people's voices must be heard at individual, local and national level.</p>	<p>Improve access to advocacy services by acting on the findings of 'Advocacy makes you feel brave; Advocacy support for children and young people in Scotland' (Susan Eilsley/Scottish Government 2010).</p>	<p>Scottish Government Advocacy organisations Organisations working with children, young people and families.</p>
<p>Lack of awareness and negative attitudes towards disability and long term conditions</p>	<p>Improve and increase school-based work to increase awareness, and tackle negative attitudes towards, disability/long term conditions.</p>	<p>Scottish Government Learning and Teaching Scotland Equality and Human Rights Commission (EHRC) Scotland LTCAS/voluntary sector.</p>
	<p>Develop teaching resources on disability and long term conditions to be used within the 'health and wellbeing' element of Curriculum for Excellence e.g digital stories, powerpoints and templates for class work. An example exists in England (developed by Diabetes UK and others) that could be built upon.</p>	<p>Learning and Teaching Scotland LTCAS/voluntary sector Schools and Education Authorities.</p>
	<p>Tackle bullying related to disability or long term conditions.</p>	<p>EHRC Respectme</p>

Recommendations – Summary

Issue	Recommendations	Key agencies
<p>Pupils with long term conditions often report not being fully supported in school. The approach to support varies significantly across Scotland and parents still report being asked to administer medicines to their child/children while they are at school.</p>	<p>Provide in-service training to school staff on “GauN Yersel” The Self Management Strategy for Long Term Conditions in Scotland.</p> <p>Consider extending the scope of accessibility strategies to explicitly include schools’ policies on supporting pupils with long term conditions.</p> <p>Review how effectively the ‘Administration of Medicines in Schools’ guidance is being implemented, particularly in settings such as extra curricular activities, nursery education and the non-statutory education sector.</p>	<p>LTCAS/voluntary sector Schools and Education Authorities</p> <p>Scottish Government</p> <p>Scottish Government</p>
	<p>Improve links between schools and long term conditions voluntary organisations, including through greater co-ordination between voluntary organisations, so that: Pupils have greater access to support provided by the voluntary sector Schools have greater access to awareness raising activities Schools can be supported to facilitate peer support/education in relation to disability and long term conditions</p>	<p>LTCAS/voluntary sector Schools and Education Authorities Parent Councils</p>

Recommendations – Summary

Issue	Recommendations	Key agencies
	<p>Improve accessibility of extra-curricular activities and settings including staff training.</p>	<p>Scottish Government EHRC Scotland Schools and Education Authorities For Scotland's Disabled Children (FSDC)</p>
	<p>Review whether there is adequate health expertise available within schools (e.g. school nurses), particularly in the context of pupils with increasingly complex needs accessing mainstream education.</p>	<p>Scottish Government</p>
<p>Support and services are often fragmented and unable to respond to children and young people holistically.</p>	<p>Examine inequalities in outcomes for children and young people who are disabled or have long term conditions and are experiencing other issues such as being looked after, living in poverty or being bullied.</p>	<p>Scottish Government LTCAS/voluntary sector FSDC</p>
	<p>Continue to develop approaches such as personalised budgets to enable children, young people and families to design holistic packages of support that best meet their needs. Children, young people and families should be reflected in the 'Self Directed Support Strategy 'currently being developed.</p>	<p>Scottish Government LTCAS/voluntary sector FSDC</p>

Recommendations – Summary

Issue	Recommendations	Key agencies
<p>Children, young people and parents do not have sufficient access to online information and support.</p>	<p>Work with children and young people to establish where they would access information online. As part of this consider development of an 'NHS Inform' for children and young people.</p>	<p>NHS 24 LTCAS/voluntary sector Organisations working with children, young people and families</p>
<p>Living with a long term condition often has a significant impact on a child or young person's mental health and wellbeing.</p>	<p>Add information on long term conditions to Parentzone and Learning and Teaching Scotland websites and to GLOW.</p>	<p>Learning and Teaching Scotland LTCAS/voluntary sector FSDC</p>
	<p>Increase awareness among children, young people, parents and professionals of the links between long term conditions and mental health issues.</p>	<p>Scottish Government LTCAS/voluntary sector Organisations working with children, young people and families</p>
	<p>Embed mental health and emotional support in any policy relating to children and young people who are disabled or have long term conditions.</p>	<p>Scottish Government Education Authorities</p>
	<p>Build on efforts to tackle stigma and make it easier for children and young people to talk about mental health and wellbeing.</p>	<p>'see me'</p>

Recommendations – Summary

Issue	Recommendations	Key agencies
<p>Children and young people do not have sufficient access to support to help them cope with the emotional impact of disability or long term conditions.</p>	<p>Improve the expertise of relevant health practitioners so they can consider mental health needs as a matter of course.</p>	<p>Scottish Government NHSScotland LTCAS/voluntary sector</p>
	<p>Improve access to voluntary sector support, peer support and psychological services (including for children and young people in hospitals). This will require better signposting between NHS and voluntary sector.</p>	<p>Scottish Government NHSScotland LTCAS/voluntary sector Child and Adolescent Mental Health Services (CAMHS)</p>
	<p>Roll out 'mental health first aid' type training for everyone coming into contact with children and young people who are disabled or have long term conditions.</p>	<p>Scottish Government NHSScotland</p>

Recommendations – Summary

Issue	Recommendations	Key agencies
<p>Despite significant attention the process and outcome of transitions is frequently difficult for children, young people and families.</p>	<p>Rationalise the current range of guidance on transitions into core cross-sector guidance that includes information on resources to help with the transition process.</p>	<p>Scottish Government</p>
	<p>Ensure all disabled young people and those with long term conditions have access to a key worker (as defined by the CCNUK Key Worker Standards).</p>	<p>Scottish Government Care Co-ordination Network UK (CCNUK)</p>
	<p>Improve school-based careers advice available to children and young people who are disabled or have long term conditions.</p>	<p>Scottish Government Careers Scotland Access to Work</p>
	<p>Work with employers to share good practice, raise awareness of long term conditions/disability and challenge discrimination.</p>	<p>Scottish Government EHRC Scotland LTCAS / voluntary sector Employers organisations Business organisations Unions</p>
	<p>Adopt the recommendations of the recent CCNUK/SNIP event 'Into the Void – the Emotional Impact of Transition upon Young Disabled People' (held September 2009).</p>	<p>Scottish Government CCNUK Special Needs Information Point (SNIP)</p>

Recommendations – Summary

Issue	Recommendations	Key agencies
<p>There is a lack of data about the outcomes of transitions and how these compare with the aspirations of children, young people and families.</p>	<p>Introduce a system of monitoring the outcomes of transition compared with the young person’s original aspirations. For example in relation to housing, education, employment, support services and quality of life.</p>	<p>Scottish Government FSDC LTCAS</p>
<p>Adolescents often fall between child and adult services with neither properly meeting their needs.</p>	<p>Monitor the extent to which adolescents are inappropriately placed on child or adult wards and develop a strategy to reduce, and ultimately end, this practice.</p>	<p>Scottish Government NHSScotland</p>
	<p>Build on models such as the Teenage Cancer Trust Unit at the Beatson and ensure adolescents are properly catered for within the new children’s hospitals in Edinburgh and Glasgow.</p>	<p>Scottish Government NHSScotland NHS Greater Glasgow and Clyde NHS Lothian</p>
	<p>Consider development of a specialist nurse role for children and teenagers living with disability or long term conditions.</p>	<p>Scottish Government NHSScotland</p>

Policy Context

Policy Context

This section provides a brief overview of key policy and legislation affecting children and young people who live with long term conditions. It is not an exhaustive or definitive list.

General policy

United Nations Convention on the Rights of the Child (UNCRC)

www.unicef.org/crc

The UNCRC is the international framework setting out the fundamental rights of all children and young people. The UK ratified the UNCRC in 1991 and has since passed various pieces of legislation bringing the Convention's principles into law.

Article 23 of the UNCRC states the right of disabled children to "a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community". This article also outlines the rights of disabled children to support and services including "education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities...".

Article 24 of the UNCRC states a child's right to "the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health".

Getting it Right for Every Child

www.scotland.gov.uk/Topics/People/Young-People/childrenservices/girfec

Getting it Right for Every Child is a programme aimed at improving outcomes for all children and young people. It is a framework for all services that children, young people or parents come into contact with.

The main aims of the programme are:

- A common, co-ordinated framework across all agencies that supports delivery of appropriate, proportionate and timely help to all children as they need it
- Streamlined systems and processes, efficient and effective delivery of services focused on the needs of the child
- A common understanding and shared language across all agencies
- A child-centred approach
- Changes in culture, systems and practice across services for children
- More joined up policy development

Policy Context

Early Years Framework

www.scotland.gov.uk/Publications/2009/01/13095148/0

The Early Years Framework was developed by the Scottish Government and COSLA along with a range of other partners. The framework recognises the importance of the earliest years (from conception to eight years) and is intended to bring increased focus to this area.

The framework supports other key policies including Getting it Right for Every Child and the Equally Well programme. Its emphasis is on improving the ability of services to prevent crisis and intervene early with appropriate and effective support.

Education

Education (Additional Support for Learning) (Scotland) Act 2004 (amended 2009)

www.opsi.gov.uk/legislation/scotland/s-acts2004a

This legislation places a range of legal obligations on education authorities. It replaced what was known as the 'special educational needs' or SEN system and was intended to be more inclusive and recognise all additional needs regardless of their cause.

Under the Act education authorities must identify, meet and keep under review the additional support needs of all children and young people for whose school education they are responsible.

The Act contains provisions specifically relating to young people leaving school. This section requires a range of agencies (including local authorities, NHS Boards, Careers Scotland and Further/Higher Education institutions) to help schools plan for a young person's transition.

This Act also gives children, young people and parents a range of rights and access to mediation, dispute resolution and the Additional Support Needs Tribunal.

For advice and information about the Education (Additional Support for Learning) (Scotland) Act please contact Enquire, the Scottish Advice Service for Additional Support for Learning (www.enquire.org.uk).

Policy Context

Curriculum for Excellence

www.ltscotland.org.uk/curriculumforexcellence/index.asp

Curriculum for Excellence aims to achieve transformation in education in Scotland by providing a coherent, flexible and enriched curriculum for pupils aged 3 to 18. The curriculum provides the framework for school education across Scotland and aims "to enable each child or young person to be a successful learner, a confident individual, a responsible citizen and an effective contributor".

Curriculum for Excellence includes a section on health and wellbeing which states:

"Learning in health and wellbeing ensures that children and young people develop the knowledge and understanding, skills, capabilities and attributes which they need for mental, emotional, social and physical wellbeing now and in the future...

Learning through health and wellbeing promotes confidence, independent thinking and positive attitudes and dispositions."

This section also identifies as an outcome that children and young people should achieve:

"As I explore the rights to which I and others are entitled, I am able to exercise these rights appropriately and accept the responsibilities that go with them. I show respect for the rights of others...

I recognise that each individual has a unique blend of abilities and needs. I contribute to making my school community one which values individuals equally and is a welcoming place for all."

Happy, Safe and Achieving their Potential

www.scotland.gov.uk/Publications/2005/02/20626/51543

This report of the review of guidance support in schools sets out ten standards for personal support that all children and young people can expect. It covers primary, special and secondary schools and clarifies the role of school staff and other agencies in providing support to pupils. It also gives examples of different approaches to providing personal support in schools.

Policy Context

Administration of Medicines in Schools guidance

www.scotland.gov.uk/Publications/2001/09/10006/File-1

This guidance clarifies the respective responsibilities of the health service and education authorities and schools on managing health care in schools. It provides good practice guidance on the administration of medicines in schools aimed at enabling children with medical needs to participate as fully as possible in mainstream education.

According to the guidance a healthcare plan should be drawn up by parents, the school and appropriate medical staff. This should set out what will happen if the school does not have staff available to administer medicines (for example due to staff absence or changes). Where possible parents should not be called upon to administer medicines while their child is at school.

Schools (Health Promotion and Nutrition) Act 2007

www.opsi.gov.uk/legislation/scotland/s-acts2007a

The Schools (Health Promotion and Nutrition) (Scotland) Act 2007 imposes duties on schools to be 'health promoting' and meet nutritional standards.

Health

NHS Quality Strategy

At the time of writing the NHS Quality Strategy was still in development. A draft of the Quality Strategy was produced for consultation in late 2009. According to the draft the aim of the Quality Strategy is "to make Scotland one of the leading countries in the world in healthcare quality".

The strategy proposes achieving this by focusing efforts in three areas:

- Putting **people at the centre of care**
- Continuing to improve the **safety** of patients
- Increasing **clinical effectiveness** of care and treatment provided by NHSScotland and in partnership with other public and third sector bodies

Policy Context

The aim is to ensure:

- **Caring** and **compassionate** staff and services
- Clear **communication** and **explanation** about conditions and treatment
- Effective **collaboration** between clinicians, patients and others
- A **clean** care environment
- **Continuity** of care
- **Clinical** excellence

Better Health, Better Care: National Delivery Plan for Children and Young People's Specialist Services in Scotland

www.scotland.gov.uk/Publications/2009/01/16113840/0

The National Delivery Plan for Children and Young People's Specialist Services in Scotland sets out the national infrastructure for sustainable specialist children's health services. This includes services provided in specialist children's hospitals as well as in district general hospitals and in the community. The plan sets out a programme of service development supported by additional funding of £32m over three years (2008-11).

A number of immediate priorities are identified within the plan:

- Cancer services
- Cystic Fibrosis
- Rheumatology
- General Surgery of Childhood
- Inherited Metabolic Diseases
- Gastroenterology
- Child and Adolescent Mental Health Services

Long Term Conditions

Improving Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan

www.sehd.scot.nhs.uk/mels/CEL2009_23.pdf

The Long Term Conditions Action Plan was published in June 2009. It sets out a broad range of actions to be taken by the Scottish Government, NHS, voluntary sector and others to improve the lives of people living with long term conditions.

“Gaun Yersel” The Self Management Strategy for Long Term Conditions in Scotland

http://www.ltcas.org.uk/self_man_gaun.html

The Self Management Strategy was published jointly by LTCAS and the Scottish Government in September 2008. The strategy is informed by the lived experiences of people with long term conditions. It calls for:

- People to have more access to high quality information about their condition and its impact on their life
- People to have more access to support, including peer support
- Increased provision of emotional and mental health support for people with long term physical conditions
- A change in culture so that people – those receiving and those delivering services – have the confidence and capacity to work together as partners
- Better partner working by NHS, voluntary sector and local authorities

The strategy also resulted in the Self Management Fund for Scotland. This £4m fund has been available to voluntary and community organisations to develop work that supports self management. Several of the funded projects are aimed specifically towards children and young people.

Cross-cutting Issues

Cross-cutting Issues

Recommendations

- Improve access to advocacy services by acting on the findings of 'Advocacy makes you feel brave; Advocacy support for children and young people in Scotland' (Susan Elsley/Scottish Government 2010).
- Examine inequalities in outcomes for children and young people who are disabled or have long term conditions and are experiencing other issues such as being looked after, living in poverty or being bullied.
- Continue to develop approaches such as personalised budgets to enable children, young people and families to design holistic packages of support that best meet their needs. Children, young people and families should be reflected in the Self Directed Support Strategy currently being developed.
- Work with children and young people to establish where they would access information online. As part of this consider development of an 'NHS Inform' for children and young people.

"It's been really nice to get to know everybody, and realise that you're not the only person in the world that has arthritis."

Arthritis Care in Scotland: Joint Potential DVD

- Issues affecting children and young people with long term conditions have **not been sufficiently recognised**.
- The **voluntary sector can contribute significantly** to supporting children and young people, particularly through creating opportunities for **peer support**.
- Improving the lives of children and young people with long term conditions requires '**mainstream**' support and services to be more inclusive. It also means increased **specialist** support. Children and young people often want to meet others with similar experiences but t the same time
- Greater **integration** of, and **signposting** between, services is key to this agenda. Policy and services must view children and young people holistically and respond to their full range of needs.

Cross-cutting Issues

- Tackling **lack of awareness and negative attitudes** towards disability and long term conditions must be a priority.

"A boy said to me once, he's said things like "oh, hurry up and die" and "what are you doing here cos we know that you're going to die" and stuff like that..."

So [there should be] something to let other teenagers understand that, yeah, there's something wrong with you but you're not necessarily going to die just because you've got an illness, and also to help them understand it could happen to anyone. It could happen to, like when they have children it could happen to one of their children."

Young person – 'Seen and not Heard' Film

"I think maybe a TV campaign would work more. The easiest way to educate people about asthma or other illnesses is a TV campaign."

'In their own words' Asthma UK Scotland Report 2008

- There is a need for greater **equity** in the support available across different areas of Scotland.
- More opportunities for **cross-sector networking** – such as the 'Seen and not Heard' conference – are needed.
- **Good practice** needs to be identified, shared and rolled out.
- **Key workers** can play a vital role for disabled children and young people and those with long term conditions.
- There is a great deal of **policy** in this area but questions about how successfully and consistently it is being implemented.

Cross-cutting Issues

"I think that young people with long term conditions find it difficult to kinda speak out because they don't think they can. I think you're patronised more if you've got a disability or additional need. People kind of make you feel as if 'oh well, they're speaking for me so I don't think I should speak'."

Gemma – 'Seen and not Heard' Digital Story

- The voice of children and young people must be at the heart of **policy and practice** in this area.
- At **individual level** the views of children and young people must be listened to and respected, even where these views differ from those of parents or professionals. Advocacy services are important to enable some children and young people to have their voices heard.
- Support should be based on the principles of **self management**. Support plans should focus on the individual needs of a child or young person and on empowering them to take control and cope with the impact of their condition on their life.
- Work needs to be done to increase children and young people's awareness of their **rights**.

Theme One

School Education

School Education

Recommendations

- Improve and increase school-based work to increase awareness, and tackle negative attitudes towards, disability/long term conditions.
- Develop teaching resources on disability and long term conditions to be used within the 'health and wellbeing' element of Curriculum for Excellence e.g digital stories, powerpoints and templates for class work. An example exists in England (developed by Diabetes UK and others) that could be built upon.
- Tackle bullying related to disability or long term conditions.
- Provide in-service training to school staff on 'Gaun Yersel' The Self Management Strategy for Long Term Conditions in Scotland.
- Consider extending the scope of accessibility strategies to explicitly include schools' policies on supporting pupils with long term conditions.
- Review how effectively the 'Administration of Medicines in Schools' guidance is being implemented, particularly in settings such as extra curricular activities, nursery education and the non-statutory education sector.
- Improve links between schools and long term conditions voluntary organisations, including through greater co-ordination between voluntary organisations, so that:
- Pupils have greater access to support provided by the voluntary sector
 - Schools have greater access to awareness raising activities
 - Schools can be supported to facilitate peer support/ education in relation to disability and long term conditions
- Improve accessibility of extra-curricular activities and settings including through staff training.
- Review whether there is adequate health expertise available within schools (e.g. school nurses), particularly in the context of pupils with increasingly complex needs accessing mainstream education.
- Add information on long term conditions to Parentzone and Learning and Teaching Scotland websites and to GLOW.

School Education

Attitudes and the need to raise awareness

"A lot of schools have this anti-bullying policy, and 'we don't have bullying in our school' and I just thought you obviously do and you obviously don't do anything about it.

I think the issue is a lack of understanding and... the reason... is that disability awareness isn't part of the personal and social education curriculum in schools and personally I believe it should be...

I remember one of our young people from Haggeye (youth forum) done a presentation about visual impairment in her school and before she done that she was being really badly bullied and after that the bullying stopped because everyone understood it."

Gemma – 'Seen and not Heard' Digital Story

"I think PSE [Personal and Social Education] teachers should take more notice of things other than drugs and alcohol and stuff. They never ever talk about things that most people have like asthma or eczema."

'In their own words' Asthma UK Scotland Report 2008

- Lack of awareness and negative attitudes are among the **biggest challenges** faced by children and young people with long term conditions.
- Disabled children and young people and those with long term conditions often **feel 'different'** from their peers. They may be treated differently or be 'singled out' as a result of having to sit out of certain (often Physical Education (P.E.)) activities or having to take medication at school.

School Education

- **Teachers do not always know how to best support** pupils with long term conditions. As a result they can be anxious about dealing with a health-related issue (for example an asthma attack or seizure) or can be overprotective. In some cases parents are asked to come into schools during the day to give medication or to accompany their child on school trips. This is limiting for the parent – particularly if they work – and often makes the child or young person feel embarrassed, childish or singled out.

“One teacher refused to allow a snack during choir rehearsal. The pupil fainted and was removed from the choir.”

‘Getting our act together’ Diabetes UK Scotland Report 2007

- Children and young people living with long term conditions are often coping with a range of difficult, complex issues and this can **undermine their ability to concentrate** on school work.
- Children and young people may **miss school** due to medical appointments or hospital stays.
- Teachers sometimes **have lower expectations** of children and young people who are disabled or have long term conditions. This in turn can undermine individual pupils’ expectations of themselves
- **Schools offer significant opportunities** for supporting children and young people, building self management skills and raising awareness about long term conditions and disability.

“What really got me down was with the education side, like with the teachers putting you down and they’re like ‘you can’t do it, you’re not capable’... which has got me really down because I just felt like ‘I’m useless, I can’t do anything’... I think it would be ideal for the teachers to know more so that they don’t judge you just by looking at you and thinking ‘oh, she’s disabled’.”

Young person – ‘Seen and not Heard’ Film

School Education

Improving support within schools

“At primary school the staff did understand my condition. They were given training about my condition and they were given all the equipment they needed to support me...”

When I moved onto secondary school it was like everything was there in primary school and as soon as I stepped into first year it was gone.”

Gemma – ‘Seen and not Heard’ Digital Story

“I’m not very confident that if I had an asthma attack, a bad asthma attack, the teacher or my friends would know what to do.”

‘In their own words’ Asthma UK Scotland Report 2008

“Every term you should be able to talk to your teacher about your asthma so they know how bad it is or if it’s getting better. The child could help educate them.”

‘In their own words’ Asthma UK Scotland Report 2008

- The level of **support varies** significantly according to which school a person attends, or which local authority they live in.
- Teachers are under **time pressures** and need to be better supported to in turn support pupils with long term conditions.
- Some **conditions are not recognised** as being sufficiently serious as to require the pupil to have a support plan.
- **Support is not always planned** far enough in advance and instead is often ‘reactive’.
- Schools offer a **vital opportunity** to provide children, young people and families with access to support. They are ideally placed to help children and young people with long term conditions to develop confidence and overcome fear and anxiety.

School Education

Joining-up services

- Although there is a drive to join up services for children and young people – particularly through Getting it Right for Every Child and the Education (Additional Support for Learning) (Scotland) Act – there is still a **need to improve the extent to which this happens on the ground.**
- The experiences of many children, young people and families remains one of being dealt with by different **silos** and having to co-ordinate support themselves.

Theme Two

Mental Health and Wellbeing

Mental Health and Wellbeing

Recommendations

- Increase awareness among children, young people, parents and professionals of the links between long term conditions and mental health issues.
- Embed mental health and emotional support in any policy relating to children and young people who are disabled or have long term conditions.
- Build on efforts to tackle stigma and make it easier for children and young people to talk about mental health and wellbeing.
- Improve the expertise of relevant health practitioners so they can consider mental health needs as a matter of course.
- Improve access to voluntary sector support, peer support and psychological services (including for children and young people in hospitals). This will require better signposting between NHS and voluntary sector.
- Roll out 'mental health first aid' type training for everyone coming into contact with children and young people who are disabled or have long term conditions.

"The consultant said to me 'make sure you're going out, and don't just stay in your house, you need to make sure you're up moving about, it'll make you feel better going out and stuff'.

And I was like, yeah, you're probably right but you know fine well that it takes me all my time to go in the shower, I have to get my mum to do my hair, she doesn't do it the way I want her to do it, she's rubbish at it... then she has to help me get dressed. Then I need to think about where we're going, is there parking next to where we're going, what kinda seats I'm sitting in, am I going to have to stand in a queue... All these kinda things.

I'm like, do you know, it's actually if you're feeling really rubbish... I'd just prefer to stay in the house and not deal with this hassle."

Arthritis Care in Scotland: Joint Potential DVD

Mental Health and Wellbeing

“When I was younger... not looking after my own diabetes, which was my fault but it started to get me feeling down and depressed. Being more upset... because I couldn't be allowed to do certain things, “oh you can't do this, you can't do that” and in a way, I think I was taking it out on myself.

It didn't make things easier the fact that I was a teenager and my hormones were all over the place but as I was approaching my end years of my teenage phase I was diagnosed of suffering from severe clinical depression. Most of the doctors or health care professionals that I saw blamed my diabetes. I too blame my diabetes as part of it but also I'd lost my dad's dad and my mum's mum within six months of each other.

The first time I tried committing suicide was when I was fourteen.

I still remember the day, counting out my tablets, which were my dad's tablets and I thought 'oh, I'll take fifteen and one for good luck'. I'd had a difficult day at school because I was trying hard to catch up what I had missed because of being ill. And I ended up having an argument with my brother... It was quite difficult for me all round.

Also my diabetes was quite high, my blood sugar levels were high, so I think that makes you feel all grumpy and agitated and aggressive as well and it's just I didn't stop to think what to do, what not to do, I just thought 'you know, I can't be bothered with all this and I'm better off dead'.

So I took the tablets and didn't even tell anyone, went to bed in the evening and the next thing I knew I was in hospital on drips and things... when the paediatrician came round I just got told 'If you're going to do anything like this in the future then tell us beforehand'. And, I listened to him and then I thought 'Yeah right, I'm gonna tell you the next time I'm going to do this' because that's the last thing I want is anyone to save me if I wanted to die...

I don't think there was any help really available. I mean, that was my first overdose at fourteen and I took plenty more after that and it was when I was eighteen that severe clinical depression was actually diagnosed.”

'Shazia—'Seen and not heard' Digital Story

Mental Health and Wellbeing

Living with a long term condition often has a **significant impact on a child or young person's mental health and wellbeing**. There can be a complex range of factors involved in this:

- Feeling different from peers
 - Low self esteem (sometimes linked to a condition or medication affecting physical appearance)
 - Being isolated, having less access to social opportunities or being treated differently
 - Being bullied as a result of being disabled or having a long term condition
 - Feeling a lack of control
 - Having to cope with implications of a condition, for example painful or life threatening symptoms/treatments or the possibility of reduced life expectancy
 - Physiological effects of medication on mental health
 - Having to cope with complex treatment regimes or decisions
- There has been **little focus** on the relationship between long term physical conditions and mental health issues for children and young people.
 - The impact on mental health may vary at **different points in a child or young person's life**. For example there may be additional stress at times of school exams, transitions, life events or around medical procedures.

"If you don't have the confidence, the self-esteem and all that... what have you got to focus on... if you're too scared to do anything all you've got left is your condition underneath that's just kinda eating away at everything... and you start to really resent it..."

But if you can deal with your life better and you're more confident to go out there and do things... get the job you want, or finish your schooling or whatever then dealing with your arthritis becomes secondary and you become so much better at it."

Arthritis Care in Scotland: Joint Potential DVD

Mental Health and Wellbeing

“My friends, they don’t have any idea. No clue at all. They think it’s just like a wee small sort of thing. That makes it even more annoying almost. If you did get depressed or sad about it you want someone to talk to. I got mine from my mum so I can always go to her but say you don’t want to talk to your family. If your friends don’t know anything about it they could as well just laugh in your face and then that would leave you with nowhere to go.”

‘In their own words’ Asthma UK Scotland Report 2008

Support and services

“Being diabetic and depression, I think there’s always been a lack with doctors recognising if you’re diabetic you could end up with psychological problems. It’s more aware now but I still think there’s still a big gap in people recognising that there could be even a slight complication of depression.

There are forms that... you get given when you go for check up appointments [as an adult] which are to basically do with depression and anxiety.

I think it’s helpful if even these questions could... be given to parents of children and they could interact with their children and answer these questions. I think that would be a start in picking up any psychological problems in young children.”

Shazia – ‘Seen and not Heard’ Digital Story

Health services often **focus on the medical** aspects of people’s conditions and give insufficient attention to emotional or social issues.

Children and young people **need greater access to support – including peer support** – to deal with the impact of disability or long term conditions on mental health and wellbeing.

There is a wealth of information and support available from the **voluntary sector**. However, currently this is only accessed by a minority of those who could benefit.

Mental Health and Wellbeing

"I didn't know about the British Heart Foundation until... a couple of months ago and if I knew about it... ages ago I would have probably been more confident in college and school and stuff like that."

Young person – 'Seen and not Heard' Film

"...even though this [voluntary sector run weekend] is not branded as a self management course, it gives you the life skills you need to be able to manage your condition with confidence and you don't get that in hospitals because hospitals are busy places and doctors don't have the time to spend with you to tell you... how you can boost your confidence..."

I know from doing the courses that my confidence levels have been boosted and the things that you go on to do after the weekends are maybe things that you never thought you could do...

At the end of the day all we need them [health professionals] to do is just tell their patients about it. Just give them a leaflet, point them in the direction of the website"

Arthritis Care in Scotland: Joint Potential DVD

Mental Health and Wellbeing

- There is a **need for supportive environments** (including within health services) that support good mental health and wellbeing and allow children, young people and families to feel comfortable talking about emotional issues.
- **Families**, particularly parents, may also need support to cope with a child or young person's diagnosis/condition. Some of the stress experienced by the child or young person can come from concern about the impact on their family.

"...so say you're worried about something... somewhere you [can] go that's not the doctors and not the hospital, that you don't have to be really serious. Somewhere you can go to tell someone if you're worried about something, and just to talk to them."

Young person – 'Seen and not Heard' Film

Theme Three

Transitions

Transitions

Recommendations

- Rationalise the current range of guidance on transitions into core cross-sector guidance that includes information on resources to help with the transition process.
- Ensure all disabled young people and those with long term conditions have access to a key worker (as defined by the CCNUK Key Worker Standards).
- Improve school-based careers advice available to children and young people who are disabled or have long term conditions.
- Work with employers to share good practice, raise awareness of long term conditions/disability and challenge discrimination.
- Adopt the recommendations of the recent CCNUK/SNIP event 'Into the Void – the Emotional Impact of Transition upon Young Disabled People' (held September 2009).
- Introduce a system of monitoring the outcomes of transition compared to the young person's original aspirations. For example in relation to housing, education, employment, support services and quality of life.
- Monitor the extent to which adolescents are inappropriately placed on child or adult wards and develop a strategy to reduce, and ultimately end, this practice.
- Build on models such as the Teenage Cancer Trust Unit at the Beatson and ensure adolescents are properly catered for within the new children's hospitals in Edinburgh and Glasgow.
- Consider development of a specialist nurse role for children and teenagers living with disability or long term conditions.

Transitions

"I have an older brother, who was basically one year above me at school, and he was allowed to do everything and I felt it wasn't fair that I'm not allowed.

So, I started to neglect my diabetes. Basically I started to wonder well, if they're not going to listen to me then I'm not going to do as I'm told either. So I started missing out on my insulin injections and basically doing everything I shouldn't be doing."

Shazia – 'Seen and not Heard' Digital Story

- There has been a lot of discussion about transitions and the issues are well known. However people's **experiences remain poor**.
- Transitions can be a time of **stress and uncertainty**. This can undermine a young person's physical and mental health and wellbeing.
- Improving the process of transition is only one part of the picture. Many young people have **little 'to transition to'**, for example limited housing and employment options and reduced health and social care services. Linked to this is the need to **evaluate the impact** of transition planning in terms of the **outcomes** for young people.
- For young people with higher-level support needs **arranging the services they need to live independently can be extremely complex**. This includes the process of obtaining funding for personal assistants, finding suitable accommodation and arranging support to access education or employment.
- **Peer support** has a particularly important role to play during transitions. Children, young people and families should be given opportunities to meet others who have already been through transitions.

Transitions

Health services

“They have to get the balance right when you’re a teenager. I’m not an adult so I don’t want them using big words I dinnae understand and I’m not a kid so I don’t want them to dumb down and patronise me.”

‘In their own words’ Asthma UK Scotland Report 2008

“Why don’t doctors and nurses inform you of all the choices available to control your diabetes?”

‘Getting our act together’ Diabetes UK Scotland Report 2007

- The **difference in ethos between child and adult services** can be difficult for young people to deal with, especially if transition is not gradual. Adult services tend to offer less pastoral care and expect people to cope more independently.
- There is a **lack of consistency about the age at which transition to adulthood should happen**. The move from paediatric to adult health services should take place at the most appropriate time for each individual young person.
- There is a lack of **age appropriate health services** and settings for teenagers. This can result in adolescents being in children’s wards or alongside much older people (often at a far progressed stage of illness). There is also a lack of training for staff in adult services about dealing effectively with young people.

“Before I had it myself I did think arthritis was an older person’s thing. But being in a ward with people that are much older and really ill was, I think really quite terrifying.”

Arthritis Care in Scotland: Joint Potential DVD

- There can be a lack of engagement in transition processes (for example joint planning meetings) from **adult services**. This may be due to staff in adult settings not being able to allocate time to participate in transition planning.

Transitions

- There is **variation between conditions and geographical areas**. Some transitional services have been developed but provision is patchy.

“About six months ago when I was sixteen I was asked if I wanted to go to transitional care and I said at the moment I’m happy so I stayed but then I was asked again and I said “I’m getting older now” so I’ll move.

I don’t know if that’s the usual to be asked but I think that’s pretty good because it gave me a choice and a bit more confidence to make the change.”

‘In their own words’ Asthma UK Scotland Report 2008

Education

“I wasn’t getting enough support [at college]... A few simple things never happened...

This is my argument, that if a child goes to a local school the school just cannae say ‘right ta ta go and find another school’, they’re no allowed to do that. They’ve got to go through the council and the council have got to find another school... but... the colleges aren’t funded the way schools are. If a college can’t support you that’s tough luck.”

Andrew – ‘Seen and not Heard’ Digital Story

- **Information is not always passed on** effectively from primary to secondary school. Where it is passed on it is not always given sufficient attention.
- There is **not enough information** for children, young people and parents about the support available to help them through transitions.

Transitions

- **Higher and Further Education** providers do not always meet their requirements under the Disability Discrimination Act (DDA). It is often complex and difficult for young people to arrange all the support necessary to enable them to leave home and go to college or university.

Employment

- Young people who are disabled or live with long term conditions face greater **barriers** to employment and may experience **more limited options**.

“Is it good to say you have diabetes?”

‘Getting our act together’ Diabetes UK Scotland Report 2007

'Seen and not Heard' Conference

Conference

Event Panel Discussion

The panel at the 'Seen and not Heard' conference comprised:

- Jane-Claire Judson, Director, Diabetes UK (Scotland)
- Karen Martin, Project Officer, Action for Sick Children
- Professor Jurgen Schwarze, Chair, Child Life and Health, University of Edinburgh
- Will Scott, Head of Long Term Conditions Unit, Scottish Government
- Alan Haughey, National Development Officer, School to Post-School Transitions, Scottish Government
- Colin Young, Young People's Information and Advocacy Worker, Special Needs Information Point

Key points from panel discussion

Participation of children and young people

- Children and young people themselves must be at the heart of this agenda. While this conference was not a 'child or young person friendly' format the films enabled their voices to be heard.
- At an individual level involvement and empowerment of children and young people needs to be improved. In medical consultations health professionals need to speak directly to the child or young person and ask: what are their expectations? What outcomes do they want? What help or support do they need?
- Good practice should be built upon. For example there are NHS Quality Improvement Scotland (QIS) asthma standards which have been effective in improving the extent to which children and young people are involved in managing their own condition.
- There is a need to skill up children, young people and parents so they can participate and be involved effectively.

Making a holistic support a reality

- Some children and young people are being seen by some services but not by others. For example a child may be receiving the health services he/she needs but not be getting support with other issues such as poverty, bullying or family breakdown.
- There are around 70,000 disabled children and young people in Scotland – how do we ensure they all get access to the support they need? There needs to be an improvement in how well long term conditions and disability are picked up within other groups, for example looked-after children and young people.
- Services must move away from working with labels and focus on meeting the range of needs of each child and young person. LTCAS and its members have a key role to play in defining the long term conditions agenda more broadly than health or medical issues.
- All services – health, social work, education and voluntary sector – are working towards the same goal of person-centredness.
- A range of important policy exists – particularly Getting it Right for Every Child and the Education (Additional Support for Learning) (Scotland) Act – but there seem to be significant barriers to implementing it.

Equality

- There is a risk that some children and young people will fall through the net. In particular those whose parents are less articulate are less likely to have their needs identified or met.
- The Education (Additional Support for Learning) (Scotland) Act places a duty on education authorities to identify pupils with additional support needs. This is positive but the definition of 'additional support needs' may require further clarification.

Tackling negative attitudes

- There is a need to change how society thinks about disability and long term conditions. There are not enough positive messages in the media, in schools and from the medical professions.

Conference

'Seen and not Heard' Conference – Minister for Children and Early Years

The Minister for Children and Early Years, Adam Ingram MSP, addressed the 'Seen and Not Heard' conference in November 2009.

The Minister started by acknowledging that issues affecting children and young people with long term conditions have not been given the attention they deserve. He reaffirmed that the Long Term Conditions National Action Plan applies to all ages and that it reflects a holistic view of people's needs.

The Minister made reference to a new national intranet being developed for teachers. He highlighted the opportunities this would provide for sharing information and good practice. He also outlined a range of existing policy that should support children and young people living with long term conditions including: Guidance on Administration of Medicines in Schools; Schools (Health Promotion and Nutrition) Act 2007; and the Education (Additional Support for Learning) (Scotland) Act 2004.

The Minister recognised that children and young people living with long term conditions are more likely to experience mental health problems. He referred to the focus on health and wellbeing within the Curriculum for Excellence as well as the Scottish Government priority (set out in Towards a Mentally Flourishing Scotland and the Early Years Framework) of improving mental health and wellbeing of children and young people. The Scottish Government's Mental Health Department is currently considering ways to make a mental health link person available to every school.

On transitions the Minister highlighted a range of activity. This included guidance on hospital services produced in May 2009 which includes provision for key workers. He also drew attention to two projects funded through the Self Management Fund for Scotland (run by Asthma UK Scotland and PAMIS) that focus on transition.

The Minister concluded by talking about the Getting it Right for Every Child programme. This is about improving early, effective intervention and developing all children's services so they put the child at the centre of a "one team approach".

Conference



Conclusion and Thanks

It is clear that living with a long term condition has a significant impact on many aspects of a child or young person's life. This is an area that has received too little attention in the past. While there have been important developments in policy relating to children – most notably the Education (Additional Support for Learning) (Scotland) Act 2004 and Getting it Right for Every Child – and to long term conditions, there has been little linkage between the two agendas.

The 'Seen and not Heard' conference was invaluable in bringing together people from across national government, health, education and the voluntary sector. We need to build on this cross-sectoral approach that recognises that children and young people's lives do not operate in neat silos.

There was a strong feeling amongst participants at the 'Seen and not Heard' event that policy already exists to address many of the issues raised. However there are serious questions about how effectively and consistently this is implemented. It is clear from the voices of children and young people that their experiences frequently do not match the aspirations of policy makers. In particular we must monitor how well Getting it Right for Every Child and the Long Term Conditions Action Plan are being implemented for children and young people living with long term conditions.

There is also a need to examine the impact of any cuts in public spending on children and young people who are disabled or live with long term conditions.

This report contains many recommendations that do not require legislation or significant resources but which would make a big difference. A key issue that runs throughout all the themes is the need to raise awareness about long term conditions and tackle negative attitudes. Schools offer a key opportunity to embed an ethos of disability awareness and self management throughout Scottish society.

In summing up the 'Seen and not Heard' conference, the chair – Professor Nick Watson – pointed to progress that has been made in Scotland, particularly in relation to inclusive education. He acknowledged that improvements in some areas have given rise to new challenges and stressed the need to maintain focus on this agenda. Professor Watson also underlined that it was not possible

Conclusion and Thanks

to cover all themes in a one-day conference. He highlighted the need to explore other significant issues, particularly those relating to poverty and disability/long term conditions.

LTCAS' vision is for a Scotland where all people with long term conditions enjoy full and positive lives. We will continue to work with members, children's sector organisations, children and young people, the Scottish Government and others to try to achieve this vision for children and young people.

Thanks to...

Everyone who has been involved in this work so far, including:

The LTCAS children and young people's working group

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Diabetes UK Scotland
Dystonia Society
Epilepsy Connections
Epilepsy West Lothian
Enquire
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LTCAS

LONG-TERM CONDITIONS
ALLIANCE SCOTLAND
people not patients

March 2010

For more information

LTCAS
Venlaw Building
349 Bath Street
Glasgow
G2 4AA

Email: info@lucas.org.uk
Tel: 0141 404 0231
www.lucas.org.uk

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