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c/o Durham SENDIASS

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Making Changes Together XIX Conference Report

Ramside Hall Hotel & Golf Club, Carrville,
Durham

Wednesday 15 November 2017
(Evening Session)
Thursday 16 November 2017

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The Conferences

To encourage as many parent/carers as possible to attend the nineteenth Making Changes Together Conference, a shortened evening event was held prior to the main full day conference. This gave parents who were unable to attend the full day event, especially working parents, the opportunity to gather important information about what is happening locally and nationally for children with disabilities and their families.

Parent/carer questions and comments from both the evening and day conferences are captured within this report.

Welcome and Introductions

Marsha Dolan – evening

Lileen Cuthbertson – daytime

Making Changes Together Steering Group current and previous members.

Lileen had been asked to return to open and welcome everyone to the daytime conference. This year, she was dressed in full football kit to highlight the challenges parent/carers face when the government keep changing the goal posts but to emphasise how they are always prepared and ready for any future changes thrown at them.

The Durham Model and Making Changes Together – The Story So Far

Elaine Chandler, Durham SENDIASS - evening

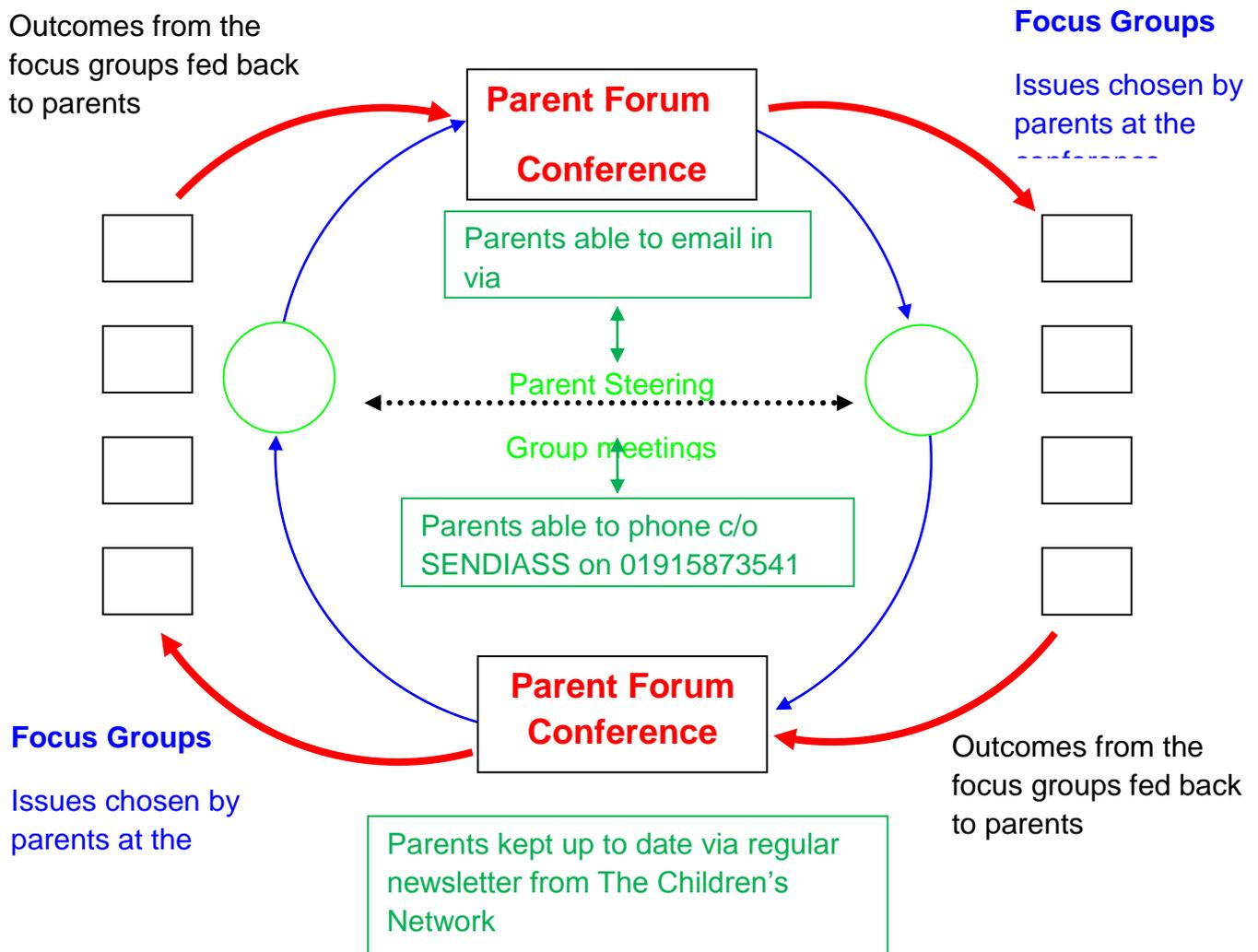
Marsha Dolan - daytime

Elaine has been involved since the beginning of Making Changes Together in 2007 and Marsha since the second conference held in May 2008.

The forum started through the Aiming High Programme, when the Labour government at the time provided funding to Local Authorities to spend on services for families with disabled children but stipulated that parent/carers HAD to be involved in the spend; this was the start of the Short Breaks agenda.

Making Changes Together was formed and over the years, the steering group has developed and become a very efficient, effective group of parent/carers who are mutually supportive and work closely with Durham County Council to continue to develop and improve local services.

The Durham Model illustrates how Making Changes Together continues to work:



Conference History

October 2007 - Every disabled Child Matters Conference – County Hall

Parents and professionals got together to discuss possibility of Working together. A steering group of parents, a professional and Contact a Family arranged first by parents for parents conference.

May 2008 - Making Changes Together I – Seaham Hall

Worked out the Durham Model. Chose the initial Focus Groups, Lead Professional, Information, Transport and Early Years.

October 2008 - Making Changes Together II – Beamish Hall

Updated progress. Chose three more focus groups – Short Breaks, Transition and Therapies - Durham Model 2. Parents signed the Every Disabled Child Matters charter alongside Durham Council members. Email: info@mctdurham.co.uk

April 2009 - Making Changes Together III – Redworth Hall

Reported back on progress. Looked at new initiatives such as Confident Schools/Confident Parents, The Lamb Inquiry and Durham's Disability Strategy.

November 2009 - Making Changes Together IV – Ramside Hall

Celebrated having admin support – Ann! Beginning of big changes in strategic planning, attitude and recognition of value of parents and professionals working closely together. Process really becoming grounded and fundamental to developing services. Website started. Durham Model 3. Website: www.mctdurham.co.uk

May 2010 - Making changes Together V – Beamish Hall

Went through history of process. Updated focus group achievements. Looked at Accessibility Strategy.

November 2010 - Making Changes Together VI – Hardwick Hall

Making Changes Together, the Story so Far. Focus Group Feedback. Wishes for the future. Short Breaks Update. Education Update. Lead Professional.

May 2011 - Making Changes Together VII – XCEL Centre

Update / revisit EDCM. Disability awareness: challenges and opportunities. The Green Paper: Support and Aspiration. Children and Young People's Plan and Over 14's Transitions Update.

November 2011 - Making Changes Together VIII – Durham Town Hall

Update on focus groups. Transition Protocol Launch. Where are we going? Information Days – Disability Awareness Week. Links to Education through Communities of Learning. Celebrating what we have achieved!

October 2012 – Making Changes Together IX – Ramside Hall Hotel

History of MCT and achievements to date. Update on Children and Adults Services Merger. Children and Families Bill. Focus Group update. One Point. Looked at Welfare Reform. Presentation from the eXtreme Group.

May 2013 – Making Changes Together X – Ramside Hall Hotel

Making Changes Together (the last six months). Short Breaks update. Introduction to Hartlepool Borough Council SEND Pathfinder. Looked at the changes to Public Health and Care. Focus Group update. Presentation by the Cheesy Waffles Group.

November 2013 – Making Changes Together XI – Ramside Hall Hotel

Short Breaks Consultation. An overview of the SEND reforms. Feedback from Durham County Council Transport Survey. A Young Persons view by Michael. 'Your child's life plan' a table exercise to identify where services that are needed do not exist.

May 2014 – Making Changes Together XII – Ramside Hall Hotel

Welcome and Introduction to Making Changes Together. Social Care and Health (new structure and implications for families). Durham's Short Breaks Programme. Presentation on the Wiki Pilot Scheme and video of Shanes Wiki Page. Looked at Durham's Local Offer www.countydurhamfamilies.info

November 2014 – Making Changes Together XIII – Ramside Hall Hotel

Updates from: - SEND Reforms, Short Breaks, Wiki Pilot Scheme, Children's Therapy Services, Social Care and Health.

May 2015 – Making Changes Together XIV – Ramside Hall Hotel

Presentation of the Care Act 2014. Transitions update. Introduction to the Innovations Programme. Core Assets. Update from CAMHS. SEND Reforms. Presentation from Welfare Rights. Investing in Children.

November 2015 – Making Changes Together XV - Ramside Hall Hotel

Welcome and Introductions. Short Breaks update. SEND Strategy. Looked at the Independent Evaluations of SEND Reforms. Transitions update. Presentation from the Cheesy Waffles Group. Local Area Inspection. Welfare Rights update.

May 2016 – Making Changes Together XVI – Ramside Hall Hotel

Welcome and Introductions to Making Changes Together. Updates from Short Breaks, Welfare Rights, Investing in Children and Transport. An overview from CAMHS. A review of Durham's Local Offer. Presentation about the SEND Local Area Inspection.

November 2016 – Making Changes Together XVII – Ramside Hall Hotel

Welcome to MCT Conference XVII (17). An introduction and overview of Durham Housing Solutions. Updates from Healthwatch, CAMHS, Short Breaks, Preparing for Adulthood and Transport. Presentation from Paul Shadforth - Identifying the Durham SEND population and meeting their needs. Presentation from Bridge Young Carers. Information from Christopher Nash about the Young Persons Event 2017.

May 2017 – Making Changes Together XVIII – Ramside Hall Hotel

Welcome and introductions to MCT Conference XVIII (18). Durham Constabulary gave information and a presentation around Hate Crime and Safe Places. Presentations were also given about Preparing for Adulthood, Healthwatch, SEND Toolkit, Complex Communication Needs including Autism and Short Breaks. Irwin Mitchell came along to talk about legal issues and the conference was finished off with MCT's Question Time.

Each conference has reflected the changes and developments throughout the years and how these changes affect families in County Durham.

What next?

There are still many developments and changes to local services taking place. Steering group members' children are getting older so moving forward some will leave and replacements will be needed. All those in attendance at the conference were encouraged to sign up and get involved with Making Changes Together.

Children's Rights and Advocacy in County Durham

Steve Percival, Service Manager for North East Region, National Youth Advocacy Service (NYAS)

NYAS is a social-legal not for profit organisation providing independent advocacy for children and young people aged 0-25 in 11 Local Authority areas in the North East (not in Northumberland)

This is a free, confidential and independent service for children and young people. NYAS is commissioned by Local Authorities but contractually obliged to act independently from them – their primary aim is to give children and young people a voice.

What is advocacy?

It's about getting something STOPPED, STARTED or CHANGED.

Advocacy:

- should always enable the young person to self-advocate wherever possible.
- is about empowering children and young people
- makes sure that their rights are respected and their views and wishes are heard at all times.
- is about representing the views, wishes and needs of children and young people to decision-makers, and helping them to navigate the system.
- uses s17 and s22 Children Act 1989 and Article 12 of the United Nations Convention on the Rights of the Child.

In the North East there is large team of people who are very skilled in communication and use a variety of methods (e.g. Makaton, BSL, technology) and also non-instructed advocacy for those with profound disabilities to give children and young people a voice.

The service works alongside parent/carers and other professionals working with the child or young person.

Children and young people do not use the service if they are happy, they use it if they are unhappy with something and they need to see their voice is being heard and that action is being taken resulting in positive changes.

What does the advocacy service provides?

NYAS provide **independent** and confidential:

- Information
- Signposting
- Advocacy
- Representation
- Support
- Legal services

Core Principles

Advocacy services should be:

- Independent
- Child-led
- Confidential
- Accessible

These principles are set out under The United Nations Convention on the Rights of the Child (UNCRC)

Adults have to act in the best interests of children. Article 12 of UNCRC states that when adults are making decisions, they must do so listening to children and young people's thoughts and wishes and act with these in mind. This is a powerful thing for children and young people to understand; that they will be heard and listened to.

What can an advocate do?

- Talk things over with young people and help them to sort things out by themselves
- Attend meetings with/for young people; write letters with them or on their behalf
- Visit with professionals etc. on a young person's behalf if they don't want to go themselves
- Provide information or signposting to other professionals or services.
- Support a young person with a formal representation.

NYAS can stand behind children and support them if they are happy to talk for themselves (moral support), they can stand by their side and speak with them or they can stand in front and represent them (after taking instruction from them) if this is what a child or young person wants. An advocate sitting around the table at a meeting powerfully changes the dynamic.

Who can receive support from an advocate?

- All Looked After children and young people
- Children and young people in foster care or residential children's homes
- Children and young people at home subject to care orders
- Children and young people in 'out of county' placements
- Children and young people who access short break care
- Care Leavers eligible under the Leaving Care Act
- Children and young people who wish to make a complaint, whether or not they are a Looked After Child
- All Children in Need
- Children who wish for support with transitions, or to appeal their Education, Health and Social Care Plan at Tribunal
- Children and young people subject to Initial or Review Child Protection Conferences

In other Local Authorities this list would be a lot shorter. In County Durham, they extend this service to more and more children and young people.

NYAS get very few referrals from children and young people who have additional needs and disabilities which is one of the reasons for NYAS being present at this conference to raise awareness that the service is available for them to use.

Advocacy and "Best Interests"

- The advocate acts only upon the young person's express permission and instructions, even when these may not meet the advocate's view of the child or young person's best interests.
- Where there is conflict between the child or young person's wishes and those of others, advocates give precedence to those of the child.
- Advocates provide children and young people with all relevant information and support them in interpreting and understanding that information so that they can make well-informed decisions.

Adults make decisions on behalf of children and young people all the time. Professionals do too but when they do, they have to have listened to the views of the child or young person.

A Statutory Right

The Children Act 2004 required “a culture of listening to children and taking account of their wishes and feelings, both in individual decisions and the development of services”.

The SEND Code of Practice 2014

- ‘The provision of information, advice and support should help to promote independence and self-advocacy for children, young people and parents.’ (p32)
- Local authorities must provide independent advocacy for young people undergoing transition assessments, provided certain conditions are met (under section 67 of the Care Act 2015).’ (p33)
- ‘Establish protocols and mechanisms for referring parents and young people to disagreement resolution and, where necessary, provide advocacy support to help them take part.’ (p251)
- ‘Young people with learning difficulties, in particular, may need advocacy support when taking part in mediation.’ (p257)

<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

s67 The Care Act 2015

The relevant provisions are:

- carrying out a needs assessment
- carrying out a carer's assessment
- preparing a care and support plan
- preparing a support plan
- revising a care and support plan
- revising a support plan
- carrying out a child's needs assessment
- carrying out a child's carer's assessment
- carrying out a young carer's assessment

In a way, the history of the Making Changes Together parent forum reflects this statutory right. County Durham are very open with NYAS and the services they provide in acting as a voice for local children and young people.

NYAS has around 160 open cases across the county but very few involve children and young people with SEN and additional needs.

The National Picture

“A common phrase I hear from families when seeking to resolve a complaint about special educational needs provision is that it feels like a constant battle. It should not have to be this way.”

Special Educational Needs: preparing for the future - Focus report: learning lessons from complaints, Dr Jane Martin, Local Government Ombudsman, 2014.

<http://www.lgo.org.uk/news/2014/mar/ombudsman-calls-fair-treatment-children-sen/>

Local Government Ombudsman (2017): “Families struggling with new special educational needs system when councils get it wrong.”

- Many plans are not being completed on time, with less than 60% of new EHC plans issued within the 20 week timescale in 2016
- LGO investigators have upheld nearly 80% of those it has received. This is far in excess of the Ombudsman’s average of 53%
- Issues include: the significant delay in the process; failing to involve parents and young people properly in the decision-making process; not gathering sufficient evidence to inform decisions; a lack of proper forward planning when young people move between key educational stages.

<http://www.lgo.org.uk/information-centre/news/2017/oct/a-disproportionate-burden-families-struggling-with-new-special-educational-needs-system-when-councils-get-it-wrong>

So in 2014 and again in 2017 the same picture emerges of families facing struggles and battles.

An Open Service

- Advocates provide an ‘open’ service – making sure that no information they have or action they take is hidden from the child or young person.
- Advocates ensure that the views and wishes of children and young people are heard, understood and recorded in all decision-making that affects them.

Referring Young People for Advocacy

Contact Steve Percival to discuss a referral: 07899 790 689

Call: 0808 808 1001

Email: help@nyas.net

Professional referrals: <https://www.nyas.net/referral-form/>

Discussions took place at the conference as for the majority of both parent/carers and professionals in the room, this was the first time they had heard about NYAS and the fact that this service is available for children and young people with SEN and additional needs.

NYAS acknowledge this and by presenting at the conference, they are hoping to redress this and ensure more families know that they can access the service. Young people can refer to a service themselves; if a family member makes a referral they will be asked straight away if they have the consent. Also, if a young person lacks capacity, they can still access the service through a family member.

Positive feedback of the service was provided by professionals at the conference who had used the service in the past with regards to Looked after Children.

Parents' Charter and Engagement Strategy

Danielle Martin - SEND Engagement Worker, Durham County Council

As demonstrated through the Making Changes Together forum, parent voice and involvement is vitally important in County Durham. Danielle's task is to write an engagement strategy which will act as a how to guide and cover every aspect of a family's journey (e.g. health, education, social care, one point hubs, transport, short breaks).

To help Danielle ensure that parents' views and thoughts are reflected in this strategy, on tables, parent/carers were asked to write down some thoughts on their experiences of communication and involvement in County Durham.

Alongside the strategy will run a parents' charter about how Durham County Council will communicate with parent/carers.

Parent/carers' voices and views will make a difference so everyone was encouraged to contribute.

The council wants everyone to have a chance to have a say so parent/carers were also advised that if they wanted to give further information they could contact Danielle directly.

Danielle Martin

SEND Engagement Worker

danielle.martin@durham.gov.uk

Direct Line: 03000 264 437

Mobile: 07786027049

North East Autism Society Services and Early Years Support

Kerrie Highcock, Family Development Manager

Many parent/carers may be familiar with some of the services NEAS provide but the aim of this presentation was to share information about all of the services available for families and children and young people.

NEAS History

- formed by parents in 1980
- no appropriate provision
- changed name in 2010 to reflect the wider geographical area
- now one of the main providers of autism specific services in the North East

NEAS now employs around 700 staff. They receive funding from Local Authorities but also rely on fundraising as a registered charity.

Vision

To be the number one provider of autism services within the North East, where individuals are inspired and supported to realise their maximum potential

Central services run from the NEAS head office based at Chester-Le-Street, County Durham.

Children's' Services

Education

- Provides Education for ages 4 – 19
- Newton Aycliffe and Thornhill Park (Sunderland)

Residential Services

- Residential homes (4)
- Residential unit at centre for Autism
- Short break Service based at Centre for Autism

Adult Services – Social and Vocational

- New Warlands Farm (Durham)
- Workshops (Sunderland)
- Emsworth (Sunderland)

Programmes consist of a range of vocational and social activities including:

- woodwork
- textiles
- IT
- horticulture
- leisure
- accessing the Community

Adult Services – Educational

Thornbeck College

- curriculum based
- accredited learning
- quality assured
- functional skills
- supported internships

Adult Services

Residential Care (15 homes)

NEAS offer a number of small, family style homes

Each house is home for between three and six residents and most are situated within Sunderland. They are currently building a 15th residential home at their site at Newton Aycliffe.

Supported Living (11)

NEAS have a number of supported living services to enable individuals to live in their own home rather than living in residential accommodation or living with their family. These span across the North East from Durham to Newcastle and include adult short breaks lodges at New Warlands Farm

Offsite Curriculum

For some children and young people, four walls learning is not going to work so NEAS take them out into the community and approach education differently to meet the needs of individuals who have complex needs.

Family Support Services

The aim is to provide support when families need it

- outreach support
- holiday clubs
- youth group (Sunderland)

This is a commissioned service usually through a social worker where a child or young person has had an assessment and then funded to access this service.

Discussions at the conference took place from families who are unable to access a social worker so therefore would be unable to access these support services. Families were encouraged to go back through their child's school to ask for their needs to be reassessed and were advised to contact Durham SENDIASS for support if required.

Family Development Services

Aim: to Provide support to families living with autism across the breadth of the North East
Services include:

- toddler Groups (Sunderland/Aycliffe/Stanley)
- family Support Groups (Gateshead)
- family Workshops (as and when)
- one-to-one support in the family home
- Enquiries
- North East Autism Society family networking group on Facebook
- Weekly question and answer sessions on Facebook live

Managed by Kerrie Highcock (kerrie.highcock@ne-as.org.uk)

These services are free for families. Groups include play-based curriculums for the children and offer parents an opportunity to come together with others who have children with ASD. A new Family Support Group is being established in the Chester-Le-Street area.

Family workshops are dependent on funding so parents are encouraged to give their views on what is needed in their local area to help NEAS apply for funding so that these can be developed to meet local need.

Employment Futures

The Employment Futures programme exists to help remove barriers to meaningful employment for adults with autism and other disabilities. The service has been designed to support both the individual and the employer.

It comprises three elements:

- coaching
- assessment
- training

Only 15% of adults with ASD are in paid employment. This is unacceptable when there are so many individuals with amazing skills who are not being supported to find meaningful employment. This programme works with individuals to get them into paid and meaningful employment.

External Work

Supporting the Autism friendly campaign and putting together a directory of places that are working towards being Autism friendly. This is about changing cultures, helping to dispel myths and making progress in changing services' views and attitudes.

Examples include

- Theatres - putting on relaxed performances
- Job Centres – offering training for workers to help with people with ASD going in for job interviews
- Prisons – working with individuals who often have undiagnosed ASD
- GP surgeries – making small changes e.g. in waiting areas

On tables, parents were asked to write down ideas of what NEAS services they would like to see in the areas they live in and identify gaps that could be filled.

All information gathered will help NEAS to develop future services across the County Durham area.

Post 16 Transport

Sheila Parmerley, Strategic Manager for School Places and Admissions, Durham County Council

Part of Sheila's responsibility is assessing home to school transport; to ensure all young people are placed in the right place and to promote access and inclusion.

It is acknowledged that home to school transport is an area of concern nationally, not just in County Durham. Families have a constant worry about transport changes and whether their child or young person will get the transport they require to meet their needs.

The government now realise this and have agreed to a review of the home to school transport legislation (as this hasn't been undertaken for a number of years). Each Local Authority has a home to school transport policy and the Department of Education provides guidance on the development of these policies but everyone is aware of the difficulties and the impact these can have on families with disabled children.

All councils review their own policies, being mindful of updated guidance and ensuring that statutory requirements are fulfilled.

Challenges

There are continual changes happening that have an impact on transport provision; e.g. SEND Reforms, Increasing in Participation, Equality Act. These area all good initiatives and it is understood that families feel home to school transport can be a stumbling block when thinking about the opportunities available to their child or young person.

The council does not want parents to be upset and angry about transport issues; they want to offer support to help your children thrive and develop and work together with families to look at solutions to issues faced, for example in accessing alternative funding (e.g. some bursaries for those aged 16-19 or Access to Work funding). Funding can come from different sources to provide a young person with the transport they need on a day to day basis.

In previous times, every family who had a child or young person who could not travel independently was given free transport. Since that time however, financial assessments have now been required and there is a balance between promoting access and equality alongside running a home to school transport policy.

The team at the council looks at each individual case as one blanket policy cannot be applied to every child or young person with SEND.

In traditional times, post 16 young people carried on at school or went to college however now there are changing learning patterns which can involve half days, work placements and different locations. Education provision needs to be tailored to meet the individual needs of a child or young person and transport has to meet these needs to.

Children with complex needs may take longer to reach their goals so they may attend education provision for a longer period of time than other students so the council needs to have discussions with families to see how long they will need transport to help them with their developments.

As education is provided in lots of different ways, it is important that transport issues are addressed in a very practical sense and for the local authority to work with each individual family to mutually get the right outcome for that individual child or young person.

Durham County Council must apply their transport policies to adapt and meet the changing needs. They are hoping that in future, families will feel these adaptations have worked for them in supporting their child or young person to thrive and develop.

Developments

A North East regional group has been established so teams from other Local Authority areas can share best practice and their ideas of what works in each area.

In Sunderland and Gateshead they ask families for £650 each year (if a child went to mainstream, this the amount they would have to pay). If families make this contribution then the council meets the extra costs for the SEN.

Because of County Durham's geographical area and diverse mix, this solution would not be possible but this could act as a suggestion of moving forward with how to achieve aims in this area.

The transport team at Durham County Council are also working with the Direct Payments team to look at how Personal Travel Budgets may help and provide solutions that are more cost effective. Some families might get support with mileage costs in these cases.

It is all about moving forward with looking at more suitable arrangements for individual families.

Durham are bit further behind with a really robust independent travel programme and this is something that is also being addressed and the council are looking at the many different models that exist across the country.

The council have just commissioned some organisations to work on a pilot Independent Travel scheme with a group of 10-12 students. A pilot is being undertaken so that lessons can be learnt moving forward to develop a service that is most helpful to children and young people across the county.

Questions

Q - What happens for those young people whose specialist post 16 provision is provided in a different local authority area?

A -Issues such as this are discussed at the regional group and local authorities talk to each other to meet needs

Q – Springboard (post 16 training provider across County Durham) works closely with DurhamWorks so includes lots of young people with SEN. They can currently offer travel between centres but because of reductions this offer may not always be available. Would the local authority be able to provide transport if a young person's training course was being held at a different centre?

A – Durham County council would want dialogue with families to find out what happens on a day to day basis so that they can come up with creative solutions to meet individual families' needs. Sometimes it is just some days that arrangements need to be put in place

Q – Do escorts and transport providers receive training and what do they receive?

A – Yes training is provided and specific training is offered to meet the needs of individual children

Comments

For children who are in year 11 and know where they are going from September 2018, the policy says apply as soon as you know where your child is going and has a confirmed place, don't leave it late and come and talk to us early yet some parents have received information that they cannot apply yet and that it is too early to do so

A parent in attendance at the conference praised the service as said that transport had helped their daughter to get back into school after a long period out.

For children who have severe ASD; why is there no continuity from one academic year to the next. Sometimes families have not known until 5.00pm the previous evening which taxi firm and which escort will be coming to collect their child the next day. This causes severe stress on families and means they have no relaxation over the summer holidays because of the disruption this causes.

Constantly having different taxi companies and different escorts increases children and young people's anxiety. Parent/carers always tell their children "don't go with strangers" yet when they open the door on the first day of term, they are expected to send their children to school with someone they have not met before.

Parent/carers were encouraged to contact the transport department at Durham County Council and say that they need a visit from the transport provider during the summer to familiarise a child or young person with the service.

Training for drivers and escorts should include compassion and empathy.

Some parents advised that they had reported significant numbers of incidents to the transport department but nothing has previously been taken on board to address these issues.

Parents were therefore encouraged to write down their concerns and issues and these were sent through to Sheila following the conference.

The following is a summary of these questions and the responses:

Issues that were raised and what has been done:

Concerns from a grandparent and other parents that they were informed very late about the school transport arrangements for their grandson/children and this causes anxiety over the 6 week summer holiday. The council has spoken to the grandmother and sent her the information that she requires. The council explained that transport can only be arranged for Post 16 students once they have been offered a place at a school sixth form or college. The council will aim to inform parents much earlier about transport arrangements and will ask operators to make contact with the families as soon as possible to discuss arrangements.

A pilot programme of Independent Travel Training (ITT) has been organised by the council. One parent asked when this will be rolled out to other children. The council phoned the parent to explain that the pilot will run from February – August 2018. After that the council will use the outcomes of the pilot to hopefully move forward with a full programme of ITT across the council in 2019.

One parent had experienced many problems on school transport as a result of her son's behaviour and had appealed. The council had considered the case very carefully and has offered appropriate transport for the boy to travel to school. The council will continue to respond to any concerns that the parent has to see how best the issues raised can be resolved.

One parent highlighted concerns about a particular operator that had transported her child to school. This was followed up by the council and transport was changed. In addition, the council is still following up a further request from the family.

This was the first time a representative from the transport department was in attendance at one of the Making Changes Together conferences and illustrates how the council wants to work together with families to provide solutions to ensure that every child or young person gets the service they require to allow them to continue to access education and training post 16.

Investing in Children

eXtreme Group – Who are we

Chris Affleck handed over to eXtreme group members Ethan, Jaide and Emma

- Hi we are Ethan, Jaide, and Emma and we are members of the eXtreme Group
- We are young people who all live in County Durham.
- We all have a disability and we are all individuals.
- We all have ideas about things that could make our lives better.
- We talk about things that are important to us and it's all linked to having a disability.

Ethan and Jaide

What have we done?

- We have reviewed the Local Offer and Youth Offer
- We ran Agenda Days™ for the Preparing for Adulthood agenda about further education and transitions
- Given feedback about the Short Breaks Service
- Supported the Autism Review
- Supported the High Needs Review
- Helped plan and deliver the 1st Young Peoples Future Event
- Developed the Children and Young People's SEND Promise for County Durham

What are we doing now?

High Needs Review

A person called Pat came from the National Development Team for Inclusion service came to one of the eXtreme group meetings. She wanted to know more about the SEND promise. She also wanted to know what we thought of education in our area.

Children and Young People's SEND Promise for County Durham

We got asked to do a charter for the Durham Area which all services within county Durham had to agree on. We asked people with SEND needs what they expect from services within County Durham. We did this by holding Agenda Days™ where young people can have their views without adults being there. We decided to call it a promise, not a charter.

The Promise has been agreed by the SEND Strategy & Accountability Group, the Children and Families Partnership and soon the Health and Wellbeing Board. Copies of the Promise were available in conference packs.

Young People's Future Event

This event was held in May 2017 at New College Durham. People liked the fact that there was a quiet room to go to for people who have autism and CAMHS were available to chat to. County Durham Sports were there to offer a wide arrange sporting activities and the sports were offered at different times. We also loved the entertainment that was offered but people said that the event went on for too long. This meant that they were not able to enjoy it as much as we would have liked them to.

Next time we would like to invite Project Choices to talk about NHS internships this helps young people who are transitioning from college into a job is made easier.

I feel we need to invite NUS Extra because it gives discount on everyday brands and shops. To help children and young people who may be struggling financially.

The Girl Guide and scout association is close to my heart because they helped me through tough times. They are like my second home and I want other young people to benefit from this wonderful association. I also think there are not a lot of people with SEND needs who know about it and I want to change this.

Emma

- I am the newest member of the eXtreme Group
- I found out about the event from Cheesy Waffles
- The best thing about the first Young People's Future Event was getting lots of information
- I found out a lot and this is where I met SENDIASS and Investing in Children
- I joined the eXtreme Group because Chris Nash suggested it to me and it's been really good
- At the next event I hope to achieve a greater understanding of what my future might be
- I want Dark Matter café to come as they didn't turn up last time

To help the group plan the next event please can you ask any young people with SEND to complete their online survey or get in touch with Investing in Children.

<https://www.surveymonkey.co.uk/r/95QVCDZ>

Young people thanked Chris as without him; the group wouldn't be in existence.

Website: www.investinginchildren.net

Tel: 0191 3746113

Email: info@investinginchildren.net

Short Breaks

Mark Smith, Strategic Commissioning Manager for Durham County Council

There are potential changes on the horizon in County Durham with regards to the short breaks offer and these presentations are to raise awareness of these and to advise how parents can become more involved.

Examples and benefits of Short Breaks for parent/carers were highlighted by parents at the conference:

“My son has made friends, enjoyed activities and is choosing which short break activities he wants to go to which is a real positive difference”

“Without short breaks, my son’s social skills would go down, they give us time with our other children. My son is now 15 and sees us, his parents, as the enemy and he doesn’t want to go out with us; with short breaks he is able to access the things other teenagers do and he is really enjoying it”

A **SHORT BREAK** is something that a child/young person can access which provides ‘parent/carers’ with a break from their caring role.

A short break can range from a couple of hours taking part in a local activity with friends to holiday schemes or specialist over-night hospice care.

The type, length and cost of a short break can vary to meet the needs of each family. Legislation uses the term “disabled children” Durham County Council have to ensure parent/carers can access a short break but in doing so, the Council also wants to ensure the child or young person enjoys a positive activity. The offer balances both requirements.

Short Break Opportunities



Commissioned Short Breaks



Some parents won't have the confidence in a general provider to provide the support for their child. Durham County Council commissions a number of providers, funded with colleagues from Clinical Commissioning Groups, to ensure there is a good offer of breaks across County Durham in different geographical areas and to give a good spread of options to parents.

Some providers are better than others at meeting the needs of children and young people with disabilities

Durham's Local Offer includes information on short break services available to families across County Durham:

<http://www.countydurhamfamilies.info/kb5/durham/fsd/localoffer.page?localofferchannel=0>

Some children have particular complex needs and need support across all aspects of their lives so to provide families with a short break – without any compromise to their safety, health and wellbeing – takes a lot of work and is very expensive. These are assessed short breaks.

Assessed short breaks are for those parent/carers who are in receipt of children's services (based on the complexity of the child's needs sometimes due to life limiting conditions, which takes a lot of assessment and understanding) to ensure their needs are being met. Some families really struggle to cope, for example a parent/carer might fall ill so a short break service is vital to enable them to manage, Durham County Council can offer support in these circumstances too.

Short breaks are always under review as the Council are always looking at new ways to respond to children and young people and family's needs and looking at improvements that can be made.

If you haven't got a social worker; there are short break providers in place where parents can self-refer so they do not need a referral from a social worker or an assessment of need.

Future Short Break Services

Budget

As part of Durham County Council's requirement to save £250 million by 2020, they propose to save £68,000 from the total £3 million short breaks budget. To achieve this saving, they propose to make changes to the community-based short breaks service.

Access to services

Currently, certain children automatically access community-based short breaks or can attend multiple events in their communities, to give their parent/carer a break. However, there are children who can't automatically access these services, or attend sessions with other providers, which mean their parents/carers do not receive a break.

What are we proposing?

Durham County Council are looking to offer a community-based short breaks service that is fairer by targeting those parents/carers who need a break most, while still delivering on the required savings target, and they want parent/carers to work with them to achieve this.

Currently over 90% of the short breaks budget is used to offer breaks to those families who are assessed as having the most complex needs. This is a statutory requirement and will be unaffected by the proposed savings programme.

Durham County Council are taking these proposals very seriously. It is important to acknowledge that since Aiming High, there has been a significant amount of money allocated to short breaks for families with disabled children. Previously, budgets have been provided for positive activities (e.g. special school's breakfast and after school clubs). Durham now needs to ask parents their views on the kind of services are most important to them

It is about how Durham uses the reduced money available to offer the best services to local families.

If the national picture changes then there may be further reductions but at this stage, no one knows what this could look like.

Consultation

The Making Changes Together steering group has worked alongside the Local Authority to ensure money is spent more wisely and given to providers who provide the best possible short break services across County Durham.

In order to achieve the saving, the council proposes to make changes to the service and it is hoped that these changes will be designed in the spirit of co-production, working with local families and service users.

How will this be done?

Durham County Council would like to re-design and re-shape these services together. Parents are invited to give feedback about when, where and how community-based short breaks are provided and the consultation is also reviewing the maximum hourly rate charged by some providers for short breaks.

Please tell the Council.....

- How much does it currently cost for short breaks?
- When would short breaks be beneficial for you?
- What types of activities would be best to meet your needs?
- What types of venues are best for you?
- Should there be short breaks for all the family?
- How should these community short breaks be prioritised?
- How much are you willing to pay? (Some providers currently ask for payments from parents others don't)

Current Existing Short Break Services this affects

- Durham Area Disability Leisure Group (DADLG)
- Integrating Children
- Sports Works
- MAIN
- Gateway North East

Special Schools

- Villa Real
- The Oaks
- Evergreen
- Trinity
- Walworth

Next Steps

Everyone in attendance was asked to take part in this consultation as these are your services.

You can complete the consultation online at:

<http://www.durham.gov.uk/article/17231/Consultation-on-short-breaks-for-parents-carers-of-children-with-special-educational-needs-and-or-disabilities>

- Complete paper-based survey
- Consultation will close on 4th December 2017
- Notification of new service model - January 2018
- Introduce new Short Break Offer - April 2018

Focus groups are being held with Lindsey Dunn from Durham County Council and parent/carers to get your views on this issue and on the future short breaks that should be in place in County Durham.

There is also a piece of work ongoing gathering children and young people's views about Short Breaks.

Comments

Is there scope within the budget to look at crossovers with Universal Services? For example where young people are given the right services they are not then complex needs – major concerns are that Durham's high cost spending will increase because short breaks are pulled and children and young people's needs are then not met from current short breaks.

Parents have said they would be willing to pay and contribute but some providers charge £7.00 an hour and not every parent can afford this amount for their children. Especially as within the special needs community there are a number of single parents or where only one parent can work because of caring responsibilities; this needs to be taken into account, the nature of children and young people with disabilities and the higher costs involved in bringing them up.

Communication is key.

School used to offer holiday clubs but they no longer run these and they have been put out to another provider in a different area so then you also get transport costs on top of paying for the actual activity for your child.

All parent views and consultation responses will be used in moving forward with the development of future Short Break services in County Durham.

Annual Health Checks

Evening - Kim Lowther, Children's Nurse working with CCGs as Quality and Development Manager and also Designated Clinical Officer for SEND

Daytime – Alice Jamieson, RNLD Health Facilitation Nurse Learning Disability Adult Team

Annual Health Checks for people with a recognised Learning Disability over the age of 14

What is it?

- Set up in 2008/9 to monitor health needs under NHS Direct Enhanced Service
- Comprehensive health check offered by GP practices
- Offered to any person with a Learning Disability over the age of 14

As an opt-in service, 80% of GP practices are currently signed up to deliver these checks but only 44% of people with a Learning Disability are accessing them.

If parents' GPs says that they do not offer these checks, they are encouraged to ask where they are offered in their local area and raise this as a concern with their current GP.

Why is it important?

- Earlier detection of unmet, unrecognised and potentially treatable health needs.
- Improves the rate of secondary care referrals in a timely manner.
- Improves communication
- Ensures the right service and specialities are involved to meet the identified need

How do you get an Annual Health Check?

- Make sure you or the person you are supporting is on the Learning Disability Register
- If you are not on the register then the GP does not have this written on their system
- Being on the register means that the GP can make reasonable adjustments

If applicable, parents are encouraged to tell their GP that your child has a Learning Disability and ask them to add them to the Learning Disability Register which activates the annual health check invite.

Reasonable Adjustments

- These are things that the GP should try and do to make your health appointment go well
- It should be person centred and take into account what works for you
- You can ask for these adjustments when making your appointment

What can be offered

- Some GPs offer telephone reminders or text messages that you have an appointment
- Double appointment so this is not rushed and there is time to process information and ask questions
- Quieter time of the day when the surgery is not as busy
- Easy read information leaflets on the health needs you are talking about
- Pre-visits to the GP surgery before health appointment to meet the nurse/receptionist/familiarise with the environment
- Having someone support you in the appointment

Summary Care Record with Additional Information

- We all have a Summary Care Record. It is basic information that GPs can access so they care for you better
- You can now ask your GP to add extra information that will help them care for you better. This record can be seen by doctors caring for you if you went in to hospital
- Consent/best interest

This additional information flag can hold up to ten items. If the person does not have capacity to have additional information on their care record, this can be done in a best interest decision with the GP and parent/carer and recorded as such.

Examples of extra information can include

- Reason why someone is on a medication.(this will help with medication reviews, putting a context around it)
- Significant medical history(past and present)
- Information about the management of any long term conditions
- Ways you prefer to communicate
- End of Life care information
- Immunisations

What you should expect from an Annual Health Check

- There is standardised guidelines for all GPs offering health checks
- You should be invited for an Annual Health check via letter from your GP
- The appointment should be 30 minutes long
- The health check should be person centred and tailored to the individual
- Health Action Plan

Support

- Health Facilitation Teams working with individuals aged 18+
 - County Durham Green Lane Council Offices, Green Lane, Spennymoor DL16 6JQ Tel: 03000269992
 - Darlington, Hundens Lane, Darlington DL1 1DT Tel: 01325 522050

Resources and Research

Mencap Be Healthy, Be Happy, Don't Miss Out video

<https://youtu.be/7gANZupyBHM>

Our stories

<https://youtu.be/z8407Uzys3E>

Links for easy read resources

<http://www.easyhealth.org.uk/>

App for Autism and info on autism;

[http://www.easyhealth.org.uk/listing/autism-\(leaflets\)](http://www.easyhealth.org.uk/listing/autism-(leaflets))

'Health is everybody's responsibility' - a video made by the Misfits theatre company about going for an annual health check.

<https://youtu.be/p4T9QrUchTU>

The views of carers of adults with Intellectual Disabilities on Annual Health Checks

<https://www.basw.co.uk/resource/?id=6035>

'Being Disabled in Britain', a journey less equal

<https://www.equalityhumanrights.com/en/publication-download/being-disabled-britain-journey-less-equal>

The NDTI; Better health for people with learning disabilities

https://www.ndti.org.uk/uploads/files/RH_Health_Checks_Guide.pdf

Questions and Comments

Parents at the conference asked why those with Autistic Spectrum Disorders are excluded from these annual health checks.

Unfortunately, as they could not be included on the Learning Disability Register, they would not qualify for these but there are alternative services offered including similar health checks undertaken by some GPs and telephone apps that can be used when people are visiting their GP to make accessing these services easier.

Hospital passports are also available for any children, not just those with a Learning Disability. Blank copies of these were distributed at the conference. They are very helpful for families to complete and give to GPs and other healthcare professionals as they offer comprehensive information about a child or young person. Parents can ask professionals to scan them so their records are always available when their child accesses a health service.

Nationally Annual Health Checks are offered to those aged 14 and upwards but it is worth speaking to your GP about offering the same kind of checks to those who are under 14 too.

SEND Local Authority Update

Kevin Burns - Education Development Partner SEND Support and Improvement, Durham County Council

Local Area Highlights

Work Force Development - Multi Agency Training an Introduction to SEND

- over 700 colleagues from Education, Health and Care agencies have attended an 'Introduction to SEND' training session since Spring 2017 delivered by DCC Education, SENDIASS and other partners
- Online Training – 'SEND in County Durham' has been made freely available on the Local Offer. This training is mandatory for all Durham County Council Children's Services Staff – over 1500 people have now completed this training.

High Needs Review

- a young person with High Needs is considered as any Child/Young Person who requires additional resource beyond schools typical budget to help them to learn and progress
- National Development Team for Inclusion (NDTi) have been invited to become Durham's critical friend in reviewing High Needs Provision
- several lines of enquiry are underway including Local Offer gap analysis, school adaptation, parent and child choice and engagement

Surveys were available in conference packs and parents were asked to complete these to gather views on these issues.

School Support and Challenge

- all schools to be engaged in appreciative enquiry about the impact of their SEND provision
- revised Enhanced Mainstream Provision (EMP) quality assurance framework
- revised Special School quality assurance

Next Steps

- High Needs Review Publication – published January 2018
- High Needs Review Action Plan – published March 2018
- Autism Review Action Plan – published Dec 2018
- Continuation of WorkForce Development Programme
- Development of Independent Transport Training offer
- Improving SEND provision at all levels throughout County Durham

How Durham County Council spends money has not yet been decided, these decisions will be made once the survey and consultation is over. An amount of £1.2-£1.4 million is available to be spent over 3 years but there are limits to what this can be spent on.

Parent views are vital as Durham County Council needs to hear where things are going right and where things are going wrong so everyone was encouraged to feed into this work.

Pathways

Paul Graydon – Countywide Pathways Manager

Pathway Care Hubs

Care and Support Pathways are specialist care hubs delivering lively and enriching therapeutic and multi-sensory activities.

They focus on opportunities for people, no matter how complex the support required. They are for young people aged 16+ and operate on a 5 day service 52 weeks a year.

Opportunities are bespoke around the individual working in a very person centred approach.

Premises with County Durham

- Durham Pathways
- Peterlee Pathways
- Stanley Pathways
- Newton Aycliffe Pathways
- Spennymoor Pathways

Durham and Peterlee are purpose built; Stanley, Newton Aycliffe and Spennymoor are based within local leisure centres.

They offer a wide range of activities and therapies including:

- Rebound therapy
- Hydrotherapy
- Posture care
- Positional changes
- Music therapy
- Magic carpet – communication tools
- Visual, auditory and tactile stimulation
- Specially adapted sports and games
- Interactive music and drama events
- Preparing for adulthood, domestic skills and cookery sessions

Pathways and Education

They work with a number of community education providers to offer individuals who access these services the opportunity to continue in further education

Everyone has their own individual package of therapies and activities, so there is no typical day at a Pathways hub.

There is also specialist support by speech and language professionals, occupational therapists and physiotherapists through external agencies working alongside Pathways. This multi-agency approach with external agencies coming in on a weekly basis helps to maintain people's health and wellbeing.

Communications

Pathways use a number of social communication platforms to promote their services within County Durham.

They are keen to engage with parent/carers and hold regular forums for individuals to highlight what works well, to help identify gaps and improve things where they are not working so well. This is to ensure services are constantly developed and improved to meet local need.

Pathways have gone through significant changes but they are now focussed on being a person centred service that benefits County Durham. A recent proud moment has been with Durham County Council recommissioning the service. They are determined to make this a first class service for individuals. There are places available so if any parent/carers know of young people who could benefit, they are encouraged to contact Pathways.

Pathways Durham Care Hub - **03000 264 850**

Closing Remarks

Marsha thanked everyone for attending and contributing to the conference.

All attendees were encouraged to complete their evaluation sheets to help improve future events.

A summary of evaluation comments is attached as Appendix One.

Appendix One – Summary of Evaluation Comments

A summary of the evaluation comments received from attendees follows:

Something I have learned from today

- Most parent/carers said services they had found out about for the first time, all those who delivered presentations were mentioned but particularly the National Youth Advocacy Services that were available within County Durham

“That there is a lot of good support out there but that it is sometimes tricky to track down”

Something I’ve felt/experienced today

- Most parents were happy with how useful the conference had been in sharing information
- There was some frustration at not knowing about the existence of some of the services before the conference, particularly for those families who have faced struggles when they could have been helped by the involvement of these services in their lives
- A number of people focussed here on the eXtreme group and how amazing the young people were who presented at the conference

“Always very informative with services and support available to us as parent/carers plus nice to talk to people going through the same issues”

Something I’ll take away from today

- The majority of parents mentioned the vast amount of information they had received during the conference and that they would be following up and contacting many of the services that had presented to find out more about accessing these
- Others said they would be taking the fact that there is support available away along with the positive experience of being together with others and offering each other mutual support
- Parents also appreciated having the opportunity to give their views and feed in to the number of consultations that are taking place

“That my opinions have been asked for a lot today and that the professionals have taken them away with them”

Something that was not so good about today

- A number of parents were very disappointed to hear about potential cuts to Short Break funding and services
- Others mentioned the difficulties of living with uncertainty but with the hope that their views and concerns would be listened to
- Parents felt that some presentations could have been shorter which would have helped others who had to rush through theirs