

# SW Every Deaf Child Matters

## South West Every Deaf Child Matters Conference 2014

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All Ages, All Stages and the Spectrum of Need  
8 July 2014

# Conference Report

## Executive Summary

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The fourth South West Every Deaf Child Matters conference – *All Ages, All Stages and the Spectrum of Need* – focused on the changing rights and entitlements of deaf children and young people and the responsibilities of commissioners and service providers to realise the best possible outcomes across education, health and social care.

**Keynote speaker, Liz Sayce OBE, Chief Executive of Disability Rights UK**, reminded delegates of the basic rights of and protections for deaf children and young people under the **UN Convention on the Rights of Persons with Disabilities** and the **Equality Act 2010**. As discussed in a break-out discussion led by **Catriona Filmer, NDCS Manager of Education Appeals Advisers**, the Equality Act's reasonable adjustment duty is potentially important for protecting and ensuring deaf children's access and participation in education, particularly for those children who don't have the benefit of specified SEN support through a statement / EHCP.

**The Children and Families Act 2014** and the new **SEND Code of Practice**<sup>1</sup> have introduced further duties and responsibilities for LAs, schools and other organisations. In a break-out session looking at early years support, **Andrea Scrivens, NDCS Education Policy Officer**, pointed to the importance attached in the Act to early action and the statutory framework set out for all children aged 0 to 5 years in the **Early Years Foundation Stage (EYFS)**. Communication and language, and personal, social and emotional development are among the prime areas of development identified in the EYFS early learning goals. The discussion also underlined the importance of the new duty for LAs to publish a **Local Offer** setting out information about provision for all children with SEN or who are disabled. **Amber Burton, SEN Strategic Officer at Devon County Council**, outlined key features of the Local Offer to the full conference. LAs must keep their education, training and social care provision under review, they must demonstrate how any changes will improve provision, and they must publish comments and their responses on their Local Offer.

The potential for the new frameworks of rights and responsibilities has still to be tested in practice. **Anne Porter, Department for Education SEND Adviser**, stressed that the Children and Families Act is designed to bring about a clear culture shift towards achieving positive outcomes and involving children and young people and their parents more directly in decision-making. The experiences described by a **panel of parents of children with little or no aided hearing**, depicted a system of education and family support that has often bypassed their children's basic needs for language, communication and social development. Parents stressed the need for statutorily funded and easily accessible BSL tuition and provision up to a much higher level than 'family sign' / Level 1. Another parent talked about how she and her family had used Cued Speech as well as BSL to enable her son to access natural spoken English at home, but she had felt completely alone and unsupported by her local authority in her efforts to ensure her son's access to language and communication when he was young.

The need for a culture shift was further underlined by our **panel of young people** who explained how they and their parents have often not been listened to in the past and how they have faced substantial obstacles to participation, communication and language, often having to wait or fight for essential support at critical stages in their education. They also told of their experiences of bullying. Liz Sayce emphasised that schools and LAs have a responsibility to address disability-related bullying, and a break-out discussion of deaf children's emotional and social wellbeing, led by **Dr**

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<sup>1</sup> Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations who work with and support children and young people special educational needs and disabilities. Department for Education and Department of Health, July 2014. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

**Maria Gascon-Ramos and Dr Hilary Sutherland from National Deaf Child and Adolescent Mental Health Service (NDCAMHS)**, highlighted the need for better resourcing to improve schools' awareness of and action to address the problem and to support victims directly.

Liz Sayce also stressed that the barriers that young deaf people face in moving from education into careers need to be given much more attention. She lamented the growing pressures to restrict **Access to Work** and **Disabled Students' Allowance (DSA)**, and the fact that the Children and Families Act doesn't extend to helping disabled young people into work, or to helping them overcome barriers to progression once in employment.

Lack of knowledge and expertise of deaf children's needs within universal services and lack of capacity in specialist services was a recurrent theme in discussions throughout the day. **Jayne Carroll, Head of Virgin Care Devon Integrated Children's Services**, emphasised the joint commitment to prevention, inclusion and effective safeguarding across children's services. Comments from delegates focused on the need for children's social care and other services to pay special attention to deaf children and young people as a particularly vulnerable group whose needs are often poorly understood. **Adam Beckman, Past President of the British Academy of Audiology and Head of Audiology Services at Plymouth Hospitals NHS Trust** presented on the new Department of Health (DoH)/NHS-led project to create a networks-based National System for Children and Young People with Hearing Impairment, which is intended to deliver joined-up and high-quality provision across all relevant services to ensure that children with Permanent Conductive Hearing Impairment (PCHI) should have language and communication skills at the key developmental stages comparable to their hearing peers. The National System project is intended to cover *all* deaf children and young people, regardless of their type or level of hearing impairment, and *all* paediatric hearing services across health, education and social care.

On the theme of parents' participation, **Charlie Martin from Optix Solutions** and **Sarah Collinson, SW Regional Director of the NDCS**, reported on the South West Deaf Children Matter Facebook group ([www.facebook.com/groups/swedcm](http://www.facebook.com/groups/swedcm)), set up at last year's conference and now with over 200 members. They outlined how the group could be developed further in the future, such as by providing a Local Offer discussion platform. Charlie also talked about the very fast pace of new digital technologies that might benefit deaf children and young people and their families.

## Conference Report

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The fourth South West Every Deaf Child Matters conference – *All Ages, All Stages and the Spectrum of Need* – was held in Exeter on 8th July 2014, bringing together over 100 delegates from education, health and social care services, along with commissioners, parents and a panel of young deaf people. The event was sponsored by a number of companies and organisations:

- GNResound
- NHS England
- Phonak
- Exeter Royal Academy for Deaf Education
- Starkey Laboratories
- The National Deaf Children's Society
- PC Werth
- Oticon
- Lightspeed Technologies.

As in previous years, the conference provided a unique opportunity to examine some of the most current and important developments affecting deaf children and young people and their families, both in the South West region and nationally. The value of the conference was reflected in the evaluation feedback which indicated that **98% of delegates would attend the conference again and 96% would recommend it to a colleague.**

This year's conference focused on the changing rights and entitlements of deaf children and young people and the responsibilities of commissioners and service providers to realise the best possible outcomes across education, health and social care.

**Keynote speaker, Liz Sayce OBE, Chief Executive of Disability Rights UK**, reminded delegates of the basic rights of deaf children and young people under the **UN Convention on the Rights of Persons with Disabilities**, ratified by the UK in 2009, and emphasised that local commissioning and provision of education and other key services need to be in line with this important international legal commitment. Under the UN Convention, the goal should be full inclusion for deaf and other disabled children and young people, with all able to access and participate equally in education, cultural life, recreational activities and sport, and to benefit from effective support for their academic and social development.

She explained that the legal framework supporting deaf children's rights is further strengthened by the **Equality Act 2010**. The EA 2010 prohibits public sector organisations from discriminating on grounds of disability and promotes and protects disabled people's access to and participation in education and other key public services by imposing duties on providers (including schools and local authorities) to make 'reasonable adjustments' to avoid disabled people experiencing any substantial disadvantage compared to non-disabled people. The reasonable adjustments duty includes providing auxiliary aids and services such as radio aids or communication support, if this is deemed reasonable and effective for overcoming any substantial disadvantage.

The importance of the Equality Act was further explored in a break-out discussion led by **Catriona Filmer, NDCS Manager of Education Appeals Advisers**. There are no hard-and-fast rules about what adjustments are reasonable, so this is for education providers and local authorities to consider based on the circumstances of each case. So far there is very little case law to guide these assessments. Nevertheless, the reasonable adjustment duty is potentially very important for protecting and ensuring deaf children's access and participation in education, particularly for those

children who don't have the benefit of specified SEN support through a statement / EHCP or direct support from a specialist education service. Many children with a mild, moderate, unilateral or conductive hearing loss receive minimal SEN support at present, and according to latest surveys by the Consortium for Research into Deaf Education (CRIDE), only 17% of deaf children and young people currently have a statement.

The plenary and break-out discussions also highlighted the duty under the Equality Act for all schools and colleges to write, implement and review **Accessibility Plans** outlining steps taken to make the physical environment accessible and ensure disabled pupils' full participation. LAs must also prepare an accessibility strategy for all maintained schools that they are responsible for. Many delegates were previously unaware of the importance of accessibility plans and their potential to address the needs of deaf and hearing impaired pupils. The Equality Act also allows schools and other public sector providers to take positive steps to help deaf and other disabled pupils to overcome any disadvantages related to their disability and promote their participation.

**The Children and Families Act 2014** and the new **SEND Code of Practice**<sup>2</sup> have introduced further duties and responsibilities for local authorities, schools and other organisations involved in supporting deaf children and young people.

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**All children are entitled to an education that enables them to:**

- **achieve the best possible educational and other outcomes, and**
- **become confident young children with a growing ability to communicate their own views and ready to make the transition into compulsory education.**

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**SEND Code of Practice, para. 5.1**

Liz Sayce emphasised the duty for all education providers to use their 'best endeavours' to ensure high quality provision for deaf and other children with SEN and high quality teaching that is differentiated and personalised to meet individual needs. A second break-out discussion looking at early years support, led by **Andrea Scrivens, NDCS Education Policy Officer** further underlined the importance of new duties and accountability for LAs and education providers under the Children and Families Act. These include the duty for LAs to publish a **Local Offer** setting out information about provision for all children with SEN or who are disabled. **Amber Burton, SEN Strategic Officer at Devon County Council**, outlined key features of the Local Offer to the full conference. LAs must keep their education, training and social care provision under review, and when considering any reorganisation of SEN provision, they must make it clear how any alternative arrangements being proposed will lead to improvements in the standard, quality and/or range of educational support for children with SEN. Local authorities are also required to publish comments

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<sup>2</sup> Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations who work with and support children and young people special educational needs and disabilities. Department for Education and Department of Health, July 2014. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

on their Local Offer and their responses, and these in turn must inform their ongoing review of provision and help to identify gaps.

The need for early action is emphasised as critical to the future progress and outcomes needed to help a child prepare for adult life. Settings must also work in partnership with parents to establish the support that a young child needs, and should adopt a graduated approach: assess, plan, do and review. The new SEND code of practice stresses the need for early action and re-emphasises the importance of the statutory framework set out for all children aged 0 to 5 years in the **Early Years Foundation Stage (EYFS)**. Communication and language, and personal, social and emotional development are among the prime areas of development identified in the EYFS early learning goals.

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**The level of progress children should be expected to have attained by the end of the EYFS is defined by the early learning goals [including:]**

- **Listening and attention: children listen attentively in a range of situations. They listen to stories, accurately anticipating key events and respond to what they hear with relevant comments, questions or actions. They give their attention to what others say and respond appropriately, while engaged in another activity.**
- **Understanding: children follow instructions involving several ideas or actions. They answer ‘how’ and ‘why’ questions about their experiences and in response to stories or events.**
- **Speaking: children express themselves effectively, showing awareness of listeners’ needs. They use past, present and future forms accurately when talking about events that have happened or are to happen in the future. They develop their own narratives and explanations by connecting ideas or events.**

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**Early Years and Foundation Stage statutory guidance**

The potential for these new frameworks of rights and responsibilities around SEN and disability to deliver positive outcomes for deaf children and young people has still to be tested in practice. **Anne Porter, Department for Education SEND Adviser**, stressed that the Children and Families Act is designed to bring about a clear culture shift towards much more direct involvement of children and young people and their parents in decision-making and on a clearer focus and commitment to achieving individual positive outcomes. The experiences described by a **panel of parents of children with little or no aided hearing** depicted a system of education and family support that has largely bypassed their children’s basic needs for language, communication and social development. One parent reported that she had spent at least £11,000 herself to pay for British Sign Language (BSL) tuition for her family to reach the fluency in sign that they needed to communicate with her deaf child and support his language development. Parents stressed the need for statutorily funded and easily accessible BSL tuition and provision up to a much higher level than ‘family sign’

or Level 1, and they agreed that this needs to be accessible for the whole family, not just the one primary carer, otherwise the child's right to family life and other rights would be compromised. Another parent talked about how she and her family had used Cued Speech as well as BSL to enable to access natural spoken English at home despite having no aided hearing. This, she said, has made a huge positive difference to his language, literacy and social inclusion over the years, but she had felt completely alone and unsupported by her local authority in her efforts to ensure her son's access to language and communication when he was young. Conference highlighted more than ever this year that listening to parents with children across the whole spectrum of deafness is a universal learning point to all those supporting deaf children, and one that reflects well the SEN reform focus on involving parents in decision making and removing barriers to learning.

The need for a culture shift with the new SEN system was further underlined by input from our **panel of young people**, who explained how they and their parents have often not been listened to in the past and how they have faced substantial obstacles to participation, communication and language, often having to wait or fight for essential support at critical stages in their education.<sup>3</sup> Matt recounted that he waited for eight weeks when he started university for any note-taking support, and that he couldn't understand why the university hadn't arranged anything in advance. Another young person, John, was given a Communication Support Worker (CSW) who only had Level 1 BSL when he was 11 years old; it was only when he was later supported by a CSW with Level 4 BSL that he started to progress educationally and began to catch up with his hearing peers. Will talked about the dedication of his parents and his communication support worker over the years to ensure that he experienced a rich language environment and had full and equal access to everything at school, but when he was asked about the one thing that he would change, he replied that "when I get to 16 and starting sixth form, I don't want my parents to have to fight again for the support that I need."

Liz Sayce emphasised that these experiences illustrate how important it is for education providers to take an active approach to inequality rather than wait for cases of disadvantage to surface, as responding only after problems have arisen puts the responsibility wrongly on the shoulders of the young people and parents.

Some of the young people also told of their experiences of bullying which affected their confidence levels in the past. Liz Sayce emphasised in response that schools and local authorities have a responsibility to address disability-related bullying, and effective action against bullying of deaf children and young people is supported by the UN Convention of Rights of Persons with Disabilities, the Equality Act 2010 and the Children and Families Act 2014. Participants in a break-out session looking at support for the emotional and social wellbeing of deaf children, led by **Dr Maria Gascon-Ramos and Dr Hilary Sutherland from National Deaf Child and Adolescent Mental Health Service (NDCAMHS)**, highlighted the need for better resourcing to improve schools' awareness of and action to address the problem and to support victims directly. This session also underlined a shared concern that the social and emotional needs of moderately deaf children are not being met sufficiently.

Liz stressed that the barriers that young deaf people face in moving from education into careers need to be given much more attention. She lamented the growing pressures to restrict **Access to Work** and **Disabled Students' Allowance** (DSA), and the fact that the Children and Families Act doesn't extend to helping disabled young people into work, given the huge barriers that many face when transitioning from education into employment, and the barriers to progression that many experience once in employment. Many employers lack understanding of how to make it a

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<sup>3</sup> 72% of delegates completing the evaluation rated this session as Very Good, highlighting the importance of creating opportunities for the 'voice' of young people to have influence and be listened to. When asked what they would do proactively as a result of the conference, comments included: "to seek the views of young people and families more and involve them in service/provision development."



successful environment for themselves and young deaf employees. Matt from the panel of young people said that he was really pleased to have found a temporary job while back from university for the summer; he had managed to overcome his anxieties about communication with customers and other staff, but found that “customers can be rude when I don’t catch what they say. What we need is for everybody to understand what we go through.”

**“Access to Work and DSA are investments in people’s potential – not costs to be contained and controlled.” Liz Sayce**

While recognition of the rights and responsibilities education, health and social care support is essential, so too is the quality and effectiveness of the services that deaf children and young people depend on to help them achieve positive outcomes. Lack of knowledge and expertise of deaf children’s needs within universal services and lack of capacity in specialist services was a recurrent theme in discussions throughout the day. **Jayne Carroll, Head of Virgin Care Devon Integrated Children’s Services**, emphasised the joint commitment to prevention, inclusion and effective safeguarding across children’s services. Jayne’s point highlights the importance of effective leadership and management to ensure deaf children are neither overlooked, under-valued or under-commissioned simply due to low numbers. Comments from delegates focused on the need for children’s social care and other services to pay special attention to deaf children and young people as a particularly vulnerable group whose needs are often poorly understood, and who have a range of needs that can require very specialist professional support. The lack of children’s social workers with specialist knowledge of deafness and its implications for children and young people was highlighted as a key concern.

**Adam Beckman, Past President of the British Academy of Audiology and Head of Audiology Services at Plymouth Hospitals NHS Trust** presented on the new DoH/NHS-led project to create a networks-based National System for Children and Young People with Hearing Impairment. This project has originated from the reorganisation of health commissioning and services across the NHS and a requirement from the DoH and NHS England for a service specification to support future specialist commissioning of children’s hearing services.

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**Children with PCHI should have language and communication skills at the key developmental stages comparable to their hearing peers.**

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**Draft National System for Children’s Hearing Services, 2014**

Although still in its infancy, the system has very broad and long-term aspirations that cut across all relevant areas of health, education and social care provision for hearing impaired children and young people, aiming ‘to enable children and young people to fulfil their social, emotional, communicative and educational potential, by maximising their use of auditory sensory information’, while also acknowledging the importance of non-speech environmental sound awareness and the



needs of sign language users. A central objective is that children with PCHI should have language and communication skills at the key developmental stages comparable to their hearing peers. The National System project is intended to cover *all* deaf children and young people, regardless of their type or level of hearing impairment, and *all* paediatric hearing services across health, education and social care. The overall vision is one of tight regional or sub-regional networks that link services within and across sectors, striving to integrate their support and drive up standards with annual reporting to local stakeholders on key performance measures.

Mirroring many of the new responsibilities introduced for service providers by the Children and Families Act, some of the key objectives of the National System focus on the importance of ensuring high quality services, partnership with children and young people and their families, the need to explain the full range of support available, the importance of focusing on outcomes, and accountability to children and families as well as commissioners. Adam explained that a number of pre-existing networks in the South West will be crucial to the progression of the National System project in the region. These include the sub-regional paediatric audiology interest groups and ABR peer review groups, numerous CHSWGs and the two Strategic CHSWGs in the region.

On the theme of parents' participation, **Charlie Martin from Optix Solutions** and **Sarah Collinson, SW Regional Director of the NDCS**, reported back on the South West Deaf Children Matter Facebook group ([www.facebook.com/groups/swedcm](http://www.facebook.com/groups/swedcm)), which was set up during last year's conference and now has over 200 members and the membership continues to grow. The membership includes both parents and professionals, and members have been using the group to keep each other informed of new developments or important policies or documents, publicising local events, seeking or giving advice on problems, sharing research findings, encouraging members to participate in consultations, and seeking feedback for ideas for future projects or events. Sarah outlined how the group could be developed further in the future, such as by providing a Local Offer discussion platform, crowdsourcing opinions on key policies or issues affecting deaf children and young people, reviewing websites, and other resources.

Charlie demonstrated the very fast pace of new developments in digital technologies that might benefit deaf children and young people and their families, including 'apps' that can support various aspects of learning and communication. The huge diversity of apps now available means that it is important that people try them and share their experiences to help inform others about their usefulness and suitability. Charlie offered a technology zone at lunchtime to answer delegates' questions and demonstrate a range of apps that are particularly suited or relevant to deaf children and young people.

## **Delegate Voice & Feedback**

In the final session, delegates were invited to discuss the main issues from the day and highlight areas that they feel demand further attention. Networking and updating information and knowledge was mentioned the most by delegates when asked about the value of the conference to them. Also commonly mentioned was the information on the national picture and relevant legislation.

In the conference evaluation, many delegates mentioned their improved understanding of particular topics, including the Equality Act 2010, the SEN Code of Practice, Education Health and Care Plans, Access to Work, and apps. Others mentioned that they particularly valued the contacts they made on the day and the young people's input. Delegates' comments included:

- *Opportunity to meet other professionals working in similar situations. Free exchange of views and ideas.*

- *Becoming an established annual event to hear about developments across the spectrum and to network*
- *Opportunity to reflect on issues affecting deaf CYP, to network and share experiences and ideas.*
- *Opportunity to hear the ideals but also to discuss with colleagues and CYP and families, how to make it work in practice*
- *That despite the difficulties persuading decision makers of the importance of services for deaf children and young people, those of us who work with or for deaf children and their families understand the importance of working together*
- *The focus on outcomes for young people*
- *Increased and renewed motivation*
- *The chance to address issues specific to deaf children and young people outside of the routines of the day-to-day job*

## Conference Organisation

SWEDCM Steering Group includes Dr Sarah Collinson, NDCS SW Regional Director, Louise Cole Director Heart of Deafness/Groupworks, Rosie Denham Director BSL Sign-Up and Angela Deckett NDCS.

We are supported by a Virtual Reference Group by Brian Lamb (OBE) SEN Consultant, Adam Beckman, Jim Edwards CEO Signature, Brian Kokoruwe Director Deafinite Equality and Lindsey Rousseau NatSIP Facilitator, to help us ensure the best possible sector knowledge is fed into the conference design. Registration and finance services were provided by South West Forum.

For 2015 we will again be approaching a range of sector specialist to ensure this learning event is the best value for money. We are delighted that Brian Lamb OBE has agreed to be our expert Chair once again.

## Sponsorship & Exhibition Space – Expanding Reach

This year's conference exhibition space was significantly larger and populated with a wider range of organisations and sponsors. Evaluation responses and direct feedback on the day indicated that the exhibition space was greatly valued by delegates and sponsors alike, providing a great opportunity to network and share innovations. We are keen to widen the representation of organisations and companies involved in supporting deaf children and young people in any area.

This year we have expanded the reach of the conference via our social media platforms, with delegates and sponsors using our hashtag #swedcm14 to share the key messages. Phonak kindly filmed the speakers and these were shared to a national network of over 3000 professionals. Our twitter feed was active with a record retweet accessed by over 500 people.

## Participation and Planning – Partnership in Action!

- It is important that we are able to evidence the impact of the conference and its role in helping to implement culture and practice improvements and on the achievement of outcomes for deaf children, young people and their families. **Please let us know about the difference this year's conference had on you and your organisation.** What actions did you take away? What did you share with your teams and networks?

- Please feel free to **share the report** with the session presentation link, and ensure that as many commissioners, professionals and parents as possible are able to access the information and learning from the conference.
- The **SWEDCM Facebook Group** is a dynamic social media forum to share and seek information and exchange views or to keep an eye on sector developments and regional events. Please send us a request to join via: [www.facebook.com/groups/swedcm](http://www.facebook.com/groups/swedcm)
- **SWEDCM 2015: emerging themes...** As the conference itself highlighted there is no room for complacency and there is much to do to improve. This includes ensuring that the conference itself is on a pathway of continuous improvement. The evaluation feedback to the 2014 conference indicated that next year, delegates would like to see specific case study examples against which to benchmark and improve practice and outcomes, alongside an update 'one year on' of implementation of the SEND reforms and a review of the SEN Code of Practice. Delegates would also like to see an even more dynamic sponsors' and exhibitors' space and to have more time to focus in-depth on the challenges that face the sector and what can be done to improve outcomes for deaf children. **Your input counts** and shapes the conference, so please share your views.

#### Contact Details for the SWEDCM Steering Group are:

**Sarah Collinson:** [sarah.collinson@ndcs.org.uk](mailto:sarah.collinson@ndcs.org.uk)  
**Louise Cole:** [louise.cole@heartofdeafness.org.uk](mailto:louise.cole@heartofdeafness.org.uk)  
**Angela Deckett:** [angela.deckett@ndcs.org.uk](mailto:angela.deckett@ndcs.org.uk)  
**Rosie Denham / Conference Administration:** [swedcm@gmail.com](mailto:swedcm@gmail.com)

#### Thanks and Acknowledgements

The Steering Group (Sarah Collinson, Louise Cole, Angela Deckett and Rosie Denham) are grateful to all those who attended the conference as delegates, to our speakers and panellists, young people and parents, to South West Forum for their administrative support, to the Rougement Hotel, to the Conference Chair Brian Lamb, to the Advisory Panel, to Deafinite Interpreters and AI Communications and all our sponsors and exhibitors. Our thanks to all of you who contributed to making this year's conference a great success.

#### And finally...

### Save the Date!

## SW Every Deaf Child Matters 2015

**Tuesday 7 July, Exeter**

- Please hold **Tuesday 7<sup>th</sup> July 2015** in your diary for next year's conference to be held at the Rougemount Hotel in Exeter. Remember to identify the cost in your training budget. There will again be an early bird delegate rate and we will again commit to keep delegate fees highly competitive to ensure cost effectiveness and affordability.
- The Steering Group will endeavour to ensure the full costs of the conference can be achieved through a 'crowd sponsorship funded approach'. Please contact us if you would like to sponsor SWEDCM 2015 or have ideas about additional **sponsors and exhibitors**.