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The **aim** of this workshop was to consider how better partnership working between professionals and family carers can improve local support for children with learning disabilities whose behaviours challenge.

The **objectives** were to:

- Understand the support and services that should be in place locally for children with learning disabilities whose behaviours challenge.
- Consider how families and professionals can work together to plan and develop better local services.

Outcome

- Brought two key action points to the plenary Action Planning session

Background

In order to meet the needs of children effectively we need to see clear local pathways which are:

- Child and family centred (based on the needs of children and young people, rather than driven by the provision currently available)
- Lifelong; linked to transition and adult pathways and consistent across childhood (rather than dropping away at key points)
- Preventative (using evidence and data about the local population to put in place effective community support and services at the right times)
- Multi-agency (with co-operation across education, health, social care and other services; avoiding the assumption that any one service provider (e.g. a special school) can provide all the support required.)
- Developed in partnership with families (not as a token gesture but as part of the strategic development work)

Families offer a wealth of experience and can offer practical examples about how to make the system work better. Developing a pathway in partnership with families from the outset is key, but it should not be underestimated as a task. This workshop will consider how professionals and families can work in partnership to improve local services.

Workshop discussion

The presentations set out the key issues around working in partnership with families to develop local pathways for children and young people with severe learning disabilities and behaviour described as challenging.

It was noted that the Transforming Care agenda and the NHSE Service Model had been initially developed with a more adult focus and the specific needs to children and young people had been neglected. NDTi and CBF have worked with NHSE to develop a Children's Pathway and it is being launched soon. It is important to see this as part of a wider

preventative agenda, building up community support to stop children and young people entering inpatient provision.

What needs to happen: The ‘must do’s highlighted the need to develop effective joint commissioning across education, health and social care to improve the outcomes for this group and their families. These outcomes include a promoting inclusion and a meaningful life, participation and effective family support. These outcomes can only be achieved through reasonably adjusted healthcare, better access to appropriate housing and integrated, multi-disciplinary support in the community. Ensuring the participation of children and young people and their families is vital to ensuring the success of this process and it clearly highlighted in Section 19 of the Children and Families Act 2014. But although the principles and duties are clearly laid out in statute and policy the biggest challenge is *how to deliver* this at a local level. Although it is relevant for all age groups it is particularly urgent around the transition group.

Discussion

It was noted that education were not represented at the conference and this is a significant omission and reflects the difficulty of engagement with them at both a national and a local level. This is a real obstacle to developing a joined up approach.

There was substantial discussion about how to make co-production with families a reality. It was suggested that there is a need to clarify what we mean by ‘co production’ and how it relates to improved outcomes for the child/ young person and their families. There was a strong feeling that there needs to be proper investment to support the development of meaningful and effective co-production with families, which needs to be recognised as a key element in a successful local preventative strategy. The successful Gloucester model of investment in supporting families to have a voice in strategic and operational issues was highlighted as a success, alongside their commitment to peer support and training for families. However, it was pointed out that the squeeze on local budgets had the potential to have an impact on the work in Gloucester that would be a retrograde step. There was a discussion about the role of creative investment and the need to make the case to Public Health around a preventative approach. Though, it was noted that we needed to provide more robust evidence to support the claim.

There was also a discussion about the importance of the role of joint training and inter-professional work and engagement with families around developing both a shared understanding around language and about outcomes.

Actions

Two key priority actions to feed back to the CB-NSG, LD Professional Senate and other stakeholders.

Action	Who	When
Provide practical support to families to know what good looks like and how to challenge. <u>Involve families at all levels including:</u>	1. All services and commissioners	1. Discuss at next management meeting (CBF)
	2. CB-NSG to share	2. January 2017 (link

<ul style="list-style-type: none"> - Parents training professionals - Parents involved in recruitment - Parents part of multi-disciplinary discussions from start - National Network of Parent Carer Forums (NNPCF) representation on LD Professional Senate 	<p>good practice examples</p> <p>3. LD Senate to consider professional training/family involvement</p>	<p>w/ Julie Higgins re: Hope 100)</p> <p>3. Next LD Professional Senate meeting</p>
<p>Explore and promote innovative funding models so financial resources are directed to the right place. Make the case to Public Health that this is a preventative programme (like stopping smoking); invest in early intervention to save (and improve outcomes). Don't cut what little is there.</p>	<p>Partnership project across DH, DfE, NHSE, ADCS, HEE etc.</p> <ul style="list-style-type: none"> - Modelling the joint commissioning and pooled budgets we want to see locally 	<p>CB-NSG to feed back to all organisations listed by NOV 2016</p> <p>CB-NSG to feed this point into the Lenehan Review of Children's Services by Nov 2016</p> <p>Request joint response by next CB-NSG for more substantial discussion.</p>

Further information/guidance/ background reading

See www.pavingtheway.works for the findings from the Department of Health funded Early Intervention Project, delivered in partnership between CBF and the Council for Disabled Children.

See diagram below of the Joint Commissioning Cycle, taken from Department for Education & Department of Health (2015) *Special educational needs and disability code of practice: 0 to 25 years* (p.41)

