Introduction:

This article summarises some key themes, policy and practice from the workshops on “Promoting emotional resilience in children and young people with learning disabilities and neurodevelopmental conditions”. I was heartened by the interest, experience, question and comments from the enthusiastic participants. The workshop aimed to use the presentation slides and discussion to enable participants to learn/explore:

- the increase in learning difficulties/disabilities which may go unrecognised
- why this area matters to all of us
- how interventions (eg adapted FRIENDS for Life) can be delivered which
  o enhance multi-agency collaboration
  o offer cost-effective interventions
  o illustrate “proportionate universalism” in action (Chief Medical Officer’s annual report, 2013)
- how Community Child Health roles could/should influence relevant systemic levers for children, young people, their families and communities within universal, targeted and specialist services.

Why does promoting wellbeing & emotional resilience in children and young people with learning disabilities and neurodevelopmental conditions matter to all of us?

Compelling reasons include that although they have higher rates of emotional, behavioural and mental health problems than ‘typically’ developing children and young people, research shows they have less access to services and support (Foundation for People with Learning Disabilities, 2002; Emerson and Hatton, 2007); numbers of children and young people with Complex Learning Difficulties and Disabilities are increasing (Carpenter et al., 2011; Blackburn et al., 2010; DCFS, 2010) with increased low birth weight babies, Foetal Alcohol Spectrum Disorder etc. http://complexld.ssatrust.org.uk ). In addition, higher rates of learning difficulties/disabilities/neurodevelopmental conditions/communication difficulties are found in “vulnerable” populations (e.g. LAC, emotional, behavioural and mental health populations (Emerson and Hatton, 2007) and in the Criminal Justice System (Talbot 2007, DH and Bradley 2009a, 2009b, Bryan 2012) whereas these learning difficulties/disabilities/ neurodevelopmental conditions/communication difficulties frequently go unrecognised in schools, mental health, care, criminal justice settings (Simonoff et al., 2006, Emerson and Baines 2010; Talbot 2007). Within children and young people with Autistic Spectrum Conditions, approximately 70% have a non-verbal IQ below 70, 50% have a non-verbal IQ below 50 and only 5% have an IQ above 100 (Turk 2012). Where children and young people have severe learning disabilities up to 50% will have an Autistic
Spectrum Condition. Finally, we need to remember that equality and diversity is a responsibility we all have, attending to equality and diversity is important to reduce health inequalities and ensuring services are accessible across diverse abilities and needs and across the range of socio-economic, culture, age, gender, religion etc is a legal requirement (Equality Act 2010). It is useful to utilise proportionate universalism...... where

“.... to reduce the steepness of the social gradient in health, actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage”. (Chief Medical Officer Annual Report, 2013, quoting Marmot: Fair Society, Healthy Lives, 2010).

Contextual issues are key factors in promoting emotional well-being and resilience for children and young people with learning disabilities and neurodevelopmental conditions and include factors relating to the child, their family, community as well as access to services and the perceptions of society around disability. Protective and risk factors can be identified across domains in contextual models such as the familiar Assessment Framework (Fig 1) or Bronfennbrenner’s ecological systems model (Fig 2) to contribute to planning.

So what can we do?

A number of examples of potentially cost-effective interventions are summarised or signposted. These impact on a range of levels -individual children and young people with learning disabilities and neurodevelopmental conditions, their families, schools and communities, they enhance multi-agency collaboration and illustrate “proportionate universalism” in action. I use the terms “potentially cost-effective interventions” as the current evidence-base can, at best, be described as thin. This is partly due to methodological issues such as within-group heterogeneity potentially being larger than between-group changes on measures pre and post interventions, or challenges finding measures that are valid and appropriate. A further factor has been exclusion criteria which exclude children and young people with learning disabilities and neurodevelopmental conditions from general studies whilst there are major challenges accessing research funds for studies specifically for
children and young people with learning disabilities and neurodevelopmental conditions. The recent NIHR themed research calls for applied research with children with long term conditions should facilitate some relevant studies. In addition, Heyvaert et al. (2012) in their meta-analysis, draw on earlier work of Horner et al. (2005) and highlight the value, appropriateness and features of Single Case Methodology with children and young people with disabilities. Hence, collecting systematic clinical information before and after interventions using Single Case designs can be robust and contribute to the evidence-base.

One method of effective service delivery is for health and education colleagues to collaborate in school-based groups to develop emotional management skills. Rossiter et al, (2011) describe a 10 week group with pupils with severe learning disabilities drawing on adapted Cognitive Behaviour Therapy and developing sensory stories. Adapting manualised evidence-based interventions used with typically developing children to be accessible for children and young people with learning disabilities and neurodevelopmental conditions offers promise. An adaptation project for FRIENDS for Life school-based groups for promoting resilience, emotional coping skills and treating anxiety demonstrates how it can be made accessible for children with severe learning disabilities. FRIENDS for Life uses a Cognitive Behaviour Therapy framework and incorporates attachment, mindfulness and healthy behaviours to develop social and emotional coping skills through fun graded activities including some parent sessions. There are FRIENDS for Life programmes for 4-6 years (Fun FRIENDS), 8-10 years, 12+ years and an adult resilience programme (Strong not Tough) for parents and teachers. See http://www.learningdisabilities.org.uk/content/assets/pdf/publications/friends-for-life-guide.pdf for details of the adaptation. Funding for a systematic feasibility study is being sought.

Adaptations which worked included much simplified materials with high visual, low verbal content, use of “symbol systems”(Wiget) and Makaton signing, use of multi-media to make the sessions more meaningful (more puppets, props for role play, photos), repetition, repetition, repetition is crucial. Our FRIENDS for Life – LD adaptation project showed that time is needed (lots!!) for planning, de-briefing, creating resources (next time round, less work!), relaxation exercises were very successful and different children enjoyed/benefitted from different types of relaxation (milkshake breathing, pizza massage, robots/monkeys), slower pace and flexibility is needed to adapt during the session, redo, repeat. Other findings were that children and young people with learning disabilities could engage with, and enjoy, the adapted FRIENDS activities and develop their
emotional vocabulary, relaxation skills, some red and green thinking, social and emotional problem solving, different people liked and didn’t like different activities, types of relaxation and role plays, it is crucial to include people who know the children and young people really well such as teachers, teaching and speech and language therapy assistants and that more parental/carer involvement is needed.

Relational or attachment based interventions such as Video Interaction Guidance (Kennedy et al., 2010) and Intensive Interaction (Nind and Hewitt, 2006) have shown some positive outcomes in case studies. The Solihull Approach (2006) integrates reciprocity, containment and behavioural management in their model of supporting parents to better support their children. Parenting Groups for parents of children and young people with learning disabilities and neurodevelopmental conditions may draw on relational and resilience theories eg the “Insiders Guide” groups (Britton and Aumann, 2013) looks at parental experience, the joys and sorrows, and has parents as co-facilitators, utilising a Resilient Therapy framework (Hart and Blinkcow 2010, Aumann and Hart, 2011) or more developmental and learning theories eg Stepping Stones from Triple P (Plant and Sanders, 2007). Most share goals and some process elements to develop stronger, more attuned relationships between parents and children, develop parental confidence and utilise learning/social learning theories.

As communication is so fundamental for social and emotional development, use of appropriate communication approaches is crucial. Guidance, evidence and resources are well summarised in Goldbart and Caton (2010) and include use of objects of reference, Makaton, Communication in Print/Widget, Photosymbols, Communication Passports, Picture Exchange Communication System (PECS), Social Stories and Comic Strip Conversations. Challenging behaviours can reflect communicative intent (I want …. / I don’t want…; I feel…….) and teaching alternative, appropriate ways of communicating or ensuring an effective communication environment is in place to meet individual communication needs can be key elements in Positive Behaviour Support Plans.
More community/social engagement interventions such as Circles of Support can develop relationships, opportunities, skills and self-esteem (see http://www.learningdisabilities.org.uk/help-information/information-for-teachers/transition-to-adulthood/building-circles-of-support/ for information). Similar approaches may be important for maintaining/developing emotional resilience of parents, families and carers which will be important for maintaining/developing emotional resilience in children and young people with learning disabilities and neurodevelopmental conditions.

Finally, to improve emotional resilience in children and young people with learning disabilities and neurodevelopmental conditions, there needs to be action to reduce health inequalities, implement proportionate universalism and create change in broader systemic issues within communities, services and society so children and families experience more valued, safer fulfilled lives (MENCAP 2007, found significantly more children with disabilities had been bullied than non-disabled peers). Possible foci for such interventions are mapped below.

![Emotional resilience for CYP-LD & NDC: health inequalities, proportionate universalism and broader systemic issues (community, services, society)](image)

What next?

I hope readers will think about the “BACCH starfish” given by David Baum, as described in the 2013 BACCH News-ASM special by BACCH Chair, Gabrielle Laing, reminding us “that services for children in the UK need us all”. So, to make a difference to the emotional resilience of children and young
people with learning disabilities and neurodevelopmental conditions, what will you do now? What will be your starfish? ……

- Find out who’s doing this kind of work in your patch, build stronger partnerships, get a project going?
- Link with Health and Wellbeing Board – equality and diversity issues?
- Follow up references?
- Have training? Give training? Lobby for training?

References & websites (a full list is available with the workshop slides on the BAACCH ASM website)


Dunn Buron K  2006 When my worries get too big. APC: Kansas.


