Kent’s local offer for supporting children & young people with disabilities who display challenging behaviour & their families

Making a difference locally
Friday 4th October 2013
Martin Cunnington & Dr Nick Gore
“The provision of integrated services around the needs of patients occurs when the right values and behaviours are allowed to prevail and there is a will to do something different. We need to move beyond arguing for integration to making it happen.”

Professor Steve Field, NHS Future Forum
Bringing initiatives together

We can view the needs of a child and family through different lenses or we can work on themes that unite us.

Education

Improved outcomes for children, young people and families

NHS

Social Care
Common themes

• Whole system change linked to personalisation.
• Joint commissioning.
• Integrated services and integrated assessment and planning.
• Personal budgets.
• Improved information, transparency and accountability.
• Workforce training and development.
• Improved data and key performance indicators.
Co-production

SE7 definition of co-production

“Co-production happens when all team members together agree outcomes, co-produce recommendations, plans, actions and materials as a collective. It is an approach which builds upon meaningful participation and assumes effective consultation and information sharing…Parent carers are not just there to illustrate the experience of service users, but rather to take responsibility to help shape future experiences and be an active part of delivering the solutions”.

The local offer

• Local offer aligned to the new joint commissioning duty.
• Web based tool that creates a snap shot in time.
• Opportunity to innovate.
• Organic process that changes over time.
• Improved information, transparency and accountability
Where did we start from?

Parents’ perspective

• Families told that they do not meet the criteria – no alternatives offered.
• If families do meet the criteria the interventions center on medication.
• Families are in crises.
• Siblings are being assaulted.
• Homes are being destroyed.
• “Every aspect of family life is slowly destroyed”
• Children are removed from the family.
Who has been involved?

- Family Carers
- OTs
- Clinical Psy
- Head teachers
- Tizard Centre
- CBF
- SALTs
- Social Workers
- Ed Psy
- SEN leads unit
- KMCS
- GP clinical lead for CCG
- Special teachers
Where did we start from?

What next?

What next?

What next?

What next?

Child & Family

What next?
Kent local offer for disabled CYP who display challenging behaviour and their families

• Shared aims, objectives and outcomes
• New integrated pathway, which includes a multi-agency intensive support team.
• Joint approaches to assessment, intervention and review
• Joint approaches to early intervention and prevention
• Promotion of family and community resilience.
• Key working functions
• Joint approaches to workforce training and development
• Co-location of staff
• New multi-agency professional network.
Common definition

- Children and young people who have a learning disability and / or autism
- Children and young people who have Asperger’s Syndrome

- Those who display or who are at risk of displaying behavior that challenges
Core principles for integrated working

- No decision about me, without me.
- Tell my story once.
- Parent carers / young people and professionals both have active roles to play in the assessment of need, identification and implementation of the shared goals.
- Shared goals that a team around a child / family can work on.
- Shared understanding of key working functions.
Core principles for integrated working

- Clear and accessible information that is available to parent carers and young people early in the process.
- Shared values.
- Open and transparent process.
- Joint workforce training and development, with parent carers empowered to deliver key aspects of the training programme jointly with professionals.
- The training offered to professionals linked to a particular child / young person should also be delivered to the parent carers.
Whole system approaches to meeting current & future demand

Outcomes
- COMMISSIONED
  For children & families
- Specialist
- Targeted
- Universal

Delivered by an integrated WORKFORCE
- Specialist Workforce
- Wider Workforce

Training and Development

Leadership & Management
Kent multi-agency commissioning framework for CYP with SLCN

- **Universal**: All children benefiting from good language environments as part of early development.
- **Targeted**: Children with significant primary SLCN requiring targeted and / or specialist support in addition to universal.
- **Specialist**: Children with severe, complex & long term SLCN requiring specialist support in addition to targeted and universal provision.
My involvement in the project:

Born, raised and worked in Kent!

3 year fellowship focusing on early intervention in challenging behaviour at Tizard Centre

Developing new intervention approaches and working with others to try and strengthen service delivery and practice.
PBS framework

• Initial presentation to all stakeholders in January this year providing an overview of PBS and the evidence base

• Support for a series of further workshops and meetings to help develop a shared understanding of how PBS might usefully inform development of a county wide system of support

• Drafting of service specifications and recommendations for inclusion in the final proposal
Why PBS?

Evidence base suggests the most effective means of structuring support to people who display behaviour that challenges

In the UK however, this generally is **not** reflected in how the NHS, social services or educational services support children and young people who have learning disabilities

PBS, by definition places considerable emphasis on organisational change and there are now a range of examples in the literature that have described a tiered approach to delivery of PBS

The values, principles and procedures of PBS fit with what families are asking for—this was clear following the first meeting in January.
Universal level supports

• **Reduce the risk of challenging behaviour developing and escalating for the broad population** of CYP with learning and developmental disabilities.

• This should include children who have a borderline diagnosis or for whom a confirmed diagnosis of learning /developmental disability has not been fully established.

• **Proactively meet the additional needs** of CYP with learning / developmental disabilities and their families, many of which are established risk factors for the later development of challenging behaviour.
Universal level supports

1. Early identification and diagnosis of disabilities (and identification of children with additional risk factors for development of challenging behaviour)
2. Early and on-going support for communication development and skill acquisition
3. Smooth access to physical health services
4. Prevention of community and social isolation for children and families
5. Emotional / mental health support for family carers
6. Culture change initiatives regarding proactive support for children with learning / developmental disabilities across settings
7. Enhanced co-ordination of support services, collection and use of outcome data
Targeted Level Supports

- CYP with recognised learning / developmental disabilities who have begun to display challenging behaviour and/or display challenging behaviour of low severity/frequency.

- Reduce the escalation and impact of challenging behaviour, at a relatively early stage. In addition targeted supports should be provided to those children who have been identified as having increased risk factors for later development of challenging behaviour.

- Supports at this level should include:
  1. Use of Positive Behaviour Support via CAMHS services and schools
  2. Provision of evidence-based parenting programmes
  3. Access to specialist short-breaks provisions that can accommodate the needs of children who display challenging behaviours
Specialist Supports

• These supports should be provided to the smaller subset of children with Learning / developmental disabilities who display high rates and severe forms of challenging behaviour.

• These children are at high risk of family and placement breakdown which may historically have resulted in costly out of area placements.

• Supports at this level should focus on development of an Intensive Supports Service (see below).
Intensive Supports Team

Core Team
- Highly Specialist Clinical Psychologist x 2
- Highly Specialist Speech and Language Therapist
- Behaviour Specialist
- Tizard Centre

Re-Aligned Professionals
- Social Worker Time
- Social Work Assistant Time
- Psychiatrist Time
- Educational Psychologist/Specialist Teacher Time

1) Prevention of Out of Area Placements Children and Young People with Disabilities who Display Challenging Behaviour
   - 10-12 Cases at any one time (absence of other complexities such as CP issues)
   - Intensive model of support based on PBS model and short break provision

2) Supporting Children and Young People with Disabilities who Display Challenging Behaviour in out of area placements to return to Kent
   - 2-3 cases at any one time
   - Intensive model of Support

3) Supporting the development of allied services and other stakeholders in targeted and universal tiers of strategy
   - Delivery of training events
   - Consultations to professionals and family carer groups
   - Guidance and support on specific strands of early intervention

Data Driven Approach

*Clear outcome and cost benefit data to support development of best practice*
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