

Transforming Short Breaks- County Report

1. Summary of Activity and progress

- 1 Locality groups have been convened and established in each of the five areas.
- 2 Attendance has been variable but parents have been represented at all meetings.
- 3 Terms of reference have been approved by county wide representative group incorporating feedback from all localities.
- 4 Each group meeting has undertaken;
 - a. Needs analysis
 - b. Gap analysis, on the basis of evidence of what is available.
- 5 Outputs of initial locality meetings have been drawn together at county level by representative group. This collation of activity has facilitated the definition of
 - a. set of priority needs
 - b. and commissioning principles.
- 6 In sum this activity is enabling the definition of a clear commissioning framework across the county.
- 7 All locality groups have a clear action agenda for the next stage. This involves the definition of specific service priorities in accordance with the commissioning framework.
- 7 Dates and invitations have been made for these next meetings, feedback has been sent out to all those attending and also to others who were unable to attend.

2. Activity, Outputs and Actions

TOR and Understanding of Role and Function

All groups have agreed draft terms of reference (attached Appendix 1) which clarify simple but clear emphasis on outcomes for children. This is underpinned by simple objectives; the key message emphasised to all groups was that the core functions take the activity and responsibility beyond participation; it is about planning and priorities with regards to service design and delivery.

The county steering group have approved the Terms of Reference these will be taken back to the locality meetings in September. Messages from the locality meetings from both parents and professionals around simplifying the aims and objectives were taken on board and are reflected in the revised document.

The groups were also briefed on:

- (a) Governance arrangements; (John Postlethwaite to look at following 7th August meeting)
- (b) Timeline of activity; (John Postlethwaite to look at following 7th August meeting)
- (c) The involvement of service users and parents in key aspects of the procurement process.

As agreed previously all Children's Centres provided a nominate lead in each locality. Obviously in some areas this equated to more than one organisation. It also emerged that those attending in this capacity were not entirely clear on their role. However it was agreed that it was important to have a consistent approach to this role across the county. Therefore briefings for those taking on responsibility for being a locality lead have been arranged for the 8th September at Keswick Children's Centre

3. Needs Analysis

Each locality group was requested to consider gaps in needs in relation to the five outcomes. Many groups found this challenging., reflected in a tendency to focus on service 'needs' rather than the simple needs of children and young people. However with help each group was able to produce a comprehensive child/young person focussed list. Groups were supported to articulate need directly in relation to the ECM five outcomes.

The headlines are summarised below, they appear to reflect both the need for acceptance and normalisation and the need for real choice in terms of affordable, accessible and local options.

- To have fun
- To be able to have friends
- To be accepted
- To belong to a peer group in the community.
- That these activities should be affordable.
- Transport

Additional Gaps:

Stay Safe

- Be protected from harm
- Safe space
- Supported to try new things and take measured risks
- Support to parents

Be Healthy

- Information about how to be healthy
- To be encouraged and praised
- Appropriate Physical activity
- Emotional support and help to deal with anxieties and fears
- Feel good about self confidence and self esteem
- Access to children's centre and health services
- To have individual needs met and understood including communication and behaviour
- Information about disabilities

Enjoy and achieve

- To have fun

- Equal access and support to a wide range of activities.
- To be able to have friends
- Belong to a peer group in community
- To be accepted
- Accessible information on the range of activities
- Choice
- Inclusive activities
- To be children and have age appropriate activities
- Stimulation
- Sensory opportunities
- Affordable options
- Celebrate achievement
- Transport
- Appropriate equipment
- Consistency

Positive Contribution

- To be listened to and valued and to be able to both give and be given feedback on ideas.

Achieve Economic Wellbeing

- Opportunities to contribute and share skills Learn skills to reach full potential
- To be Independent and have opportunity to learn life and social skills
- Info about full range of post school opportunities
- Information about rights
- Opportunities for volunteering and work placements for the disabled young person
- Help for parents to get jobs

Set alongside the strong messages regarding enjoy and achieve two other outcome areas carried strong messages for commissioners in terms of **Staying Safe** and also the need to **develop independence**.

It is evident that the locality groups will have to manage a number of challenges when translating these needs into priorities for services at the next stage of the process. This was recognised and began to be articulated at the county coordinating event for representatives of all locality meetings. In simple terms the locality groups have begun to recognise the challenge of balancing the need for normalisation, fun and acceptance with a desire to protect and keep safe.

4. Service Gaps

Groups were provided with overview of 'what is available' and 'what works' at a national level. In the knowledge of this they were then asked to consider what they believed to be the gaps in services.

Messages are summarised below but the overwhelming message from parents was the lack of choice and availability of overnight breaks; that the current provision is not

fit for purpose. Parents tell us (loudly) that in many cases they currently have to fight for a place in a service their child does not want to go ; that having secured a place it is not uncommon for the break to be cancelled at short notice due to an emergency placement.

Parents were not questioning the quality of the service rather its design and suitability for meeting most needs. Moreover, they began to suggest a number of interesting and creative (and not necessarily high cost) alternatives. The emphasis was on alternatives and real choice, not on more of the same.

The group in the West did continually emphasis the need for local residential facility.

Summary of service gaps:

- Trained/accessible workforce;
- Cross generational activities;
- Choice of fun / 'normal' activities;
- Family activities;
- Childminders and Child Minder Plus Service
- Youth Clubs for younger age groups.

Other Gaps from across the county

- Social and life skills training
- Disability awareness amongst mainstream providers
- Data and numbers of children with disabilities
- Information on sexual health
- Sports centres equipped for all activities
- More family support where criteria for disability service is not met
- Personal journal/passport where children attend lots of activities
- Appropriate residential placements for less complex needs
- Emergency placements and care

- Local residential facility in West
- Coordination of activities
- Transport inc wheelchair accessible
- Trained workforce including young staff and those who can administer **all** medication
- Key workers
- Specialist communicators
- Safe secure environments
- Dedicated staff to support school residential
- Service for those with most complex and challenging needs
- Cross generational activities
- One stop information on services and benefits
- Opportunities for positive risk taking
- Support at organised activities for carers
- Activities at weekends for carers and children
- Transition services
- Work experience and volunteering with appropriate support including buddy systems
- Provision for Siblings

5. Commissioning Principles

All those who attended the locality group were invited to a county wide forum to look at common themes and areas of cross over. This meeting took place in Penrith on July 15 and it produced a draft set of principles to underscore priority setting and service design as we move forward. The group also agreed that it would be essential to add the core principles which underscore the Comprehensive Area Assessment, judgements why apply to all services across the whole of the partnership. These have been added to list produced by the group. The complete set of commissioning principles is outlined below:

- (a) We build on existing strengths in the county.
- (b) We provide positive activities which promote independent living skills, including staying safe, risk taking behaviour and positive relationships.
- (c) We deliver services which are age appropriate and fun.
- (d) We will promote inclusion and independence – the right to a normal life.
- (e) We will deliver services which are sensitive and respectful.
- (f) We will deliver services which are sustainable, evidencing long term benefits at the same time as respecting the necessity to use resources wisely.
- (g) We will deliver services which target where improvement is most needed to tackle inequalities within and between communities.
- (h) We will deliver services that fully consider the needs of the most vulnerable.
- (i) We will deliver services which ensure a common approach to the use of resources across the whole of the local partnership and that are able to demonstrate good value for money.

6. Next Steps

The key step, which is planned for September, is for each locality group to translate this initial picture of needs, gaps and principles into a clear statement of intent in terms of a service specification required from April 1st 2010.

In order to facilitate informed discussion and clear outputs a commissioning framework will be produced prior to the meetings in September.

Key action and activity required to meet the overarching requirement of the AHDC strategy are summarised below:

- Planning group meeting in August to draw together commissioning framework taking into account outputs from meetings.
- Wider consultation with parents' forum on process and outputs from the locality meetings.
- Children's Trust Board and the Children's Health Trust Board approval/sign up
- Dates have been set for all locality groups early to mid September to undertake priority setting exercise on the basis of commissioning framework that is principles, needs, gaps, costs and outcomes.
- Commissioning /procurement processes clarified and agreed
- Timeline and deliverables
- Risks defined
- Communication strategy

7. Conclusion

What parents tell us is that what is available is NOT fit for purpose – not that it's not good quality but that for a significant number of children it's not what they want and doesn't meet their children's needs.

In very practical terms there is no continuity and poor choice.

Parents however did recognise the importance and need for specialist facilities for children and young people with more complex needs.

Crucially it was recognised across the county that there are a number of lower cost alternatives to overnight provision which are more likely to meet more needs for more children, young people and families. Aiming High is for additional services and all agree that families need alternatives to what is currently available.

Delivering these alternatives does present some real challenges. These challenges are not just about finite resources but also about balancing competing needs. This is most evident in terms of balancing the needs for normalisation, independence and fun on the one hand and a overarching desire of parents to keep their children safe and protected.

The challenge is offering variety and choice. This means providing options that better reflect need, which are affordable, sustainable and so encourage looking creatively at integration and the pooling of budgets.

Appendix 1 Terms of Reference

Aiming High for Disabled Children **Terms of Reference** **Short Breaks Stakeholder Groups**

Vision statement

Our shared vision is that disabled children and young people will be able to access more of the places and activities they want, both specialist and universal; will know about all the opportunities that exist; and will be supported to be as independent as possible. Every child and family will be listened to and will be respected as unique; and this will be reflected in their support plans.

Parents and siblings will also be supported to lead normal lives, including having the time and space to maintain other family relationships, to have fun, and to access opportunities themselves.

Aim

To improve outcomes for disabled children and young people through the provision of high quality short breaks.

Objectives

- 1 To develop a clear understanding of need and what is available at a local level
- 2 To use this information to establish and review local priorities for short breaks services.
- 3 To ensure that children, young people and parents/carers work alongside others to plan and review the design and delivery of short breaks in the local area.
- 4 To demonstrate that need is met by the delivery of a broad range of short breaks services in the locality.
- 5 To review the quality of services provided in relation to desired outcomes and changing needs.
- 6 To ensure effective links with the local planning group and county work streams.

Leadership

The Children's Centres have agreed to provide leadership to facilitate the group development. The group may want to consider the chairing of the meetings separately from this.

Membership

- Parents/carers
- Children's Services Disability Team
- Children's Centres
- Extended Services
- Local Specialist Schools
- Youth Services
- Sports Co-ordinators
- Connexions
- Health
- Other local provider services

These bodies will nominate a representative each to attend regularly to ensure continuity but they can be represented by deputies to ensure their agency's representation

- The Group may decide to delegate specific tasks to sub-groups.

How the Forum will work together

All members of the forum commit to improving outcomes for children and young people with a disability.

All members of the Forum are equal partners who have agreed to positively work together with respect for each other's contributions to benefit children and young people with a disability and their families.

All members of the Forum have the right to speak on any issues being discussed, and meetings will be organised to treat all members with respect.

All members of the group will respect confidentiality

Meeting frequency

The Group will meet at least monthly in the early stages of developing the stakeholder meetings, perhaps reducing in frequency as the project matures. Extraordinary meetings of the group may be called at the discretion of the Chair.