

Annex A – Covering Template for Responses

Please complete the attached cover sheet when sending evidence, indicating the set of questions to which a response is being provided and contact details of the person for any follow-up queries.

Contact details for respondent	
Name	
Job title	Lead Officer Joint Agency Services
Do you represent an organisation? (if so, name of organisation and type: e.g. voluntary, public body, private company).	Devon Children and Young People's Services Devon PCTs. Public body.
Postal address	County Hall Exeter EX2 4QG
Telephone	
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	Which area of the review are you responding to? (please mark X)
Prevention strand	
Review of disabled children	x
Strategy for youth services	
Review of high cost, high harm families	

Annex B2: Terms of reference for the Review of Disabled Children

Objective:

To improve outcomes and life chances of disabled children through the development of effective and accessible services for disabled children and their families.

The scope of the review will cover:

- services specifically for disabled children, including how specialist services for disabled children support access to universal services, specialist services provided in a universal setting and how universal services refer children to specialist services;
- childcare services, which are of particular importance in the early years for children's development and to support their parents;
- appropriate support for disabled children during the school years and in making the transition into adulthood;
- how expenditure by one service/department can avoid or reduce concurrent or later expenditure by another department.

The Government recognises that financial support and benefits have played an important role in reducing the risks of poverty and delivering economic wellbeing. This provides the foundation on which families, communities and government can work together to secure better outcomes for disabled children and their families. Although financial support and benefits will not be a focus, the review will consider the interrelationship between poverty and service delivery needs.

The review will consider the actions that can lead to better outcomes for those children already with a disability, including family support e.g. respite provision, rather than prevention and risk factors, which will be considered as part of the wider Children and Young People's Review.

The key questions the review will address include:

The changing profile of disabled children, for example, due to increases in complex disability and rise in Autistic Spectrum Disorders, profound and multiple learning disabilities and low birth-weight babies and the challenges this poses to services.

1. What progress has already been made in addressing the needs of disabled children and their families?

In Devon there are now strong multi-agency care pathways & support in place in much of county &/or for many needs across whole county. Provision of services are coordinated across agencies & with Voluntary and Community Services. Personalised services through a Fair Access to Carers Breaks project are being developed, and parents / carers & c&yp are becoming increasingly involved in planning & judging effectiveness of outcomes.

A range of preventative & specialist services & prompt access to full range of assessments & services & joint commissioning in place.

Joint Agency Teams for Children with special Needs are in place totally in 4 areas of Devon and in part in the further two localities. They provide fully integrated health, social care & some SEN functions, accessed through single referral & assessment process. Services are supported by well established protocols, integrated processes, business support, budgets & data management.

Numbers on Joint Agency Record (disability register) with access to JAT services increased from 550 in '03 to 1874 '06.

Expansion raises number of governance, managerial, structural & financing issues - now the subject of DCC-PCT Integration Project reporting detailed recommendations by late autumn. JATs operate in 4 PCTs of Devon with work to expand into others now being slightly restructured to coincide with NHS changes & Project timetable.

A JAT Manager typically manages a co-located team of health and social care staff consisting of local Care functions including OT and Social work including Children looked after and child protection, nursing including paediatric Children's nurses, Learning Disabilities nurses and Community Psychiatric nurses – providing assessment and direct nursing provision, integrated family support and enabling services including family based carers breaks and specialist residential support. Specialist therapy services are also co-located or aligned with the JATS including Child Development Centres, paediatric Physio and Speech and Language therapy. Early Years education functions are also integrated with aligned assessment and support functions alongside educational psychology. Also community consultant paediatricians and psychiatrists are aligned to the teams to provide a multi agency overview to children and young people referred to the services.

The issue of increased demand is illustrated by the increased numbers on the Joint Agency record and this is in part through better identification and representation of CYP with special needs. The demographic increase has not however been recognised by the resource allocation and teams find themselves overwhelmed with the demand for their keyworker assessment and ongoing support services. It is hoped that the lead professional framework will support ongoing keyworker roles, but a business case needs to be made regarding the additional numbers of CYP with clearly identified needs against the CIN category used in Devon.

2. What are the barriers currently restricting access to services and therefore effective intervention?

In Devon rurality is a factor and this is seen where the take up of Direct Payments by Parent Carers in rural Mid Devon now accounts for 50% of service provision, however resources are not pooled across all agencies effectively, partly due to restrictions on funding use, and also due to long term investment patterns in “bricks and mortar” support services and block

contract. The choice element puts additional financial demands on services which want to be more flexible but are restricted by patterns of investment and availability of pooled resources and co-ordination and integration with other agencies.

Devon is undergoing restructuring both in its Local Authority Children and Young Peoples Services and going from 6 PCTs to 1 PCT. In the long term this will support full integration of services for CYP but in the short term has proved to slow the ability of organisations to effectively engage in the integration of staff and resources.

Funding for extending advocacy and brokerage services has also been difficult to find and an advocacy contract run by a voluntary agency for CSN failed due to difficulties in attracting sufficient staff with the required skill in a rural area such as Devon. Additional resources to take in rural indices of deprivation need to be included in funding allocations especially for cyp with disabilities.

3. Are services sufficiently co-ordinated at local level to allow families to access sufficient support to meet their needs?

To a degree in Devon the Joint Agency teams have established a model of best practice but they are hampered by parts of agencies hiding behind issues of statutory service delivery – the biggest example is the alignment of education SEN services with the rest of health and social care. The Statutory assessment process puts high demands on agencies which could be achieved in more flexible and integrated ways but the framework of statutory assessment has not kept up with the changes in pooled resource and integrated assessments. A key challenge would be to review this process and incorporate this within a clearer agenda for children and young people with disabilities meeting the Children In Need criteria.

We are moving to newer integrated management structures but I feel clearer government guidelines along the lines used to prescribe the YOT model especially around SEN support would enable services locally to pool their processes and interventions to greater effect and to describe better more integrated lower levels of support and early intervention.

A Joint Equipment Service maximising efficiencies across all agencies while allowing local flexibility & individualised ordering has been established across Devon. In the 1st six months of operation the number of c&y with access to equipment increased from 365 to 451 within the same level of budget by improving circulation & recycling of equipment as well as procurement economies. Joint protocols give access to pooled funding for this service.

Direct Payment's for 16-17yrs, with around 50 in payment offers good practice example for vulnerable yp participation supported by Vol sector mentors

which we plan to further develop as part of our Youth Opportunities Fund developments.

3 special schools piloting Person Centred Transition Plans for c&yp with SLD, this national pilot uses trained facilitators & is linked to adult My Life My Plan process. So far 9 pupils with fully synchronised case planning with adult services. Pilot due to report in Oct 06. Further 4 facilitators due to be trained to allow expansion to cover all SLD c&yp and an integrated options project will manage the options for joint commissioning with all adult service directorates.

4. How does the system of support for disabled children and their families compare across the country and abroad? Are there lessons we can learn to improve outcomes?

In the work we have been looking into as part of the Fair Access to Carers breaks service we are aiming to arrive at a personalised package of support which is based upon child assessment – care and development levels and carers assessment . Families receive a banding which they can then request to “call off” using the JAT as enablers to services against a menu available or asking for Direct payments. When we looked at other models across the country the levels of financial support were governed by available resources and these were consistent with other local authorities. However when Parent carers asked about the levels of support offered they mostly were happy with the framework as it provided equity and transparency but also unanimously described the levels of available resources and access to organisations set up to support direct payments as still inadequate to meet needs.

Expansion of Direct Payments from 62 in 04/05 to 197 in 05/06, is linked to increased Parent Key Work from 0 to 32 over past 18 months & Community Key Workers (SENCOs, school nurses etc) from 52 to 110, supported by locally based DISC+ Information Officers, DP support workers & expanded enabling service . Now starting to drive personalised service delivery based on individual family needs/capacity. The engagement of a range of professionals as Community Key workers is also significantly adding to the flexibility and effectiveness of the workforce.

Each JAT has a part time Direct payments support co-ordinator and the county has a a full time Direct Payments advisor who provides part time support to children’s services.

Current Issues regarding the use of joint funding for Direct payments provision since NHS guidance regarding use of NHS finance has been misleading. This has challenged some of the agreed joint funding approaches .

Direct payments are flexible but they need to have resource to provide them without threatening retained resources to provide central support for those CYP and their families who are the most vulnerable. We also found that Parent Carers wanted more choice in provision and again in a rural environment it was difficult to pump prime market development to bring provider services into the area or to support their home grown elements. Full Fair Access to Carers breaks details are available on request.

5. What family support services i.e. key workers, short breaks, sibling support, behavioural management are currently available and how do these relate to other services?

As above. The keyworker service trialled over 5 years is now leading to the full implementation of the lead professional role. In Devon community Keyworkers support CYP with special needs and also Parent carers are also becoming Keyworkers for their own children. However organisations are struggling with this concept and Parent carers are being restricted from certain levels of representation which causes problems especially in education and equipment services.

The Family based carers Breaks service provides a high level of foster support directly for CYP with disabilities but again this project has struggled where CYP have extensive physical disabilities and the costs needed for adaptations in properties where the carers are not guaranteed to continue in the care role in the long term due to cost restrictions.

6. What are the most cost effective interventions in delivering better outcomes?

Early Intervention projects such as “Here’s Looking at You Baby” – an OT provision based in a number of Sure Start units which has identified young children at risk of attention and attachment issues and have then worked on a gross motor skills and activity programme aligned with early speech and language work. Transition into reception class levels have been raised in all cases.

Community Enabling services have reduced the demand for historic patterns of overnight care and are extending the opportunities for all CYP with special needs

Primary Mental health workers working in schools have also seen a decrease in the numbers of CYP referred to Tier 3 mental health services and have supported the alignment of behavioural support services into schools across the local authority services.

7. Are there interventions which, if made earlier, could reduce more costly interventions later? How can we identify the need to intervene earlier?

All areas of early identification and intervention have led to the pilot of the Access Pathways in 9 areas of Devon. We will have agreed the protocols and implementation arrangements for a Child Concern Pathway. The Pathway will be implemented using the Common Assessment Framework and will include separate pathways covering Autistic Spectrum, ADHD, acquired brain damage, substance misuse and severe emotional and behavioural needs. The pathway will be supported as part of the Budget Holding Lead professional project which will aim to support the pooling or alignment of early intervention budgets and resources including multi agency teams of staff co-ordinated and or collocates in the local areas.

Specific support for parents/carers accessing their benefits entitlements – a project has found an average so far of £ 3000 each for families - equipment – setting up a clear access programme to equipment including jointly funded protocols which stops the segregation of certain equipment from health social care and education – ie sleep systems, wheelchairs , augmentative communication equipment etc.

Personal Enabling at early stages in a child's life are seen as essential to support longer term needs ie the extension of portage services and access to 1-1 support for CYP with specific needs ie Deafblind intervenors from age 2.

Also a package of care support that is seen as long term costed out over a period of time to include critical transitions is also being asked for with longer term financial stability for services to agree such personalised packages.