

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

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.

INTRODUCTORY COMMENTS

The changes in population profile mean that many more children than before will have lifelong disabilities which will have a high financial cost for society. Many disabled children will require recurrent access to specialist services and access to structured earlier intervention. They will also, in increasing numbers, become dependent adults. Proposed changes in style of service delivery, improved choice for families, and extended services set high expectations for parents which will not be met when the child makes a transition into adulthood unless this review is linked to the adult services strand. It is also of extreme concern that this review is not explicitly coupled to the current debate on the future of special education. The message delivered most consistently by parents and carers of disabled children and over the greatest length of time is that they expect public services to be joined up, and predictable. The danger of addressing this element of the review to such a narrow set of circumstances could exacerbate current problems both in respect of transitions and the debate about choice, specialist and integrated services. A narrow focus also flies in the face of best practice throughout the country with regard to the inclusion of disabled children in community life.

It must also be pointed out that some of the disabilities mentioned, ASD being a good example, appear to be experiencing increases both in actual incidence and in numbers diagnosed as a result of improved access to diagnosis/assessment or new definitions. For some children the diagnosis or assessment leads to pressure for the creation of specialist services whereas the evidence indicates as good, or better outcomes are achieved through targeted or personalised universal services.

Slow progress in the development of the “Children Workforce” and the failure to grasp the full range of the workforce and plan on both a national and local basis for its future is also a recurrent theme in the evidence of barriers to progress.

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

The complex nature of this population requires an adequate pool of specialist agencies available in each local authority area and close joint working between such agencies. Some of the pathfinder Children's Trusts have concentrated on services for disabled children and there is emerging evidence of increased satisfaction, improved coordination and greater efficiency from this group. The impact of Section 31 Health Act Partnerships is also still to be fully evaluated or appreciated.

Early support programmes have been highly successful in bringing together services to not just assess but to develop joint intervention strategies with families. They do not eliminate the ongoing requirement for services, but create the climate in which needs are managed or met in child and family centred ways and with greater efficiency. However, where such services are not explicitly linked to outcomes, which set high expectations in respect of making a positive contribution or engaging in community life, specialist services have the potential to work against inclusion and integration.

Stockton-on-Tees has provided an example of delivering services in a localised/integrated way which reduces cross referrals between departments or agencies:

Some five years ago it was noted that the number of children being diagnosed within the authority was increasing at an almost exponential rate. Such referrals stemmed from CAMHS and were largely based on a one off clinic appointment for the family with a consultant Psychiatrist. Such a diagnosis then led to a one paragraph referral to other agencies for them to investigate and manage the other implications of the presenting difficulties. Such professionals then began to find amongst this cohort children who did not match the usual triad of impairment in all settings raising queries about the initial diagnosis.

Faced with this situation a fortnightly multi-agency clinic was established in order to secure;

- 1. in depth multi-agency assessments of children who were thought to be on the Autistic Spectrum*
- 2. an action plan (developed with the family) for co-ordinating the subsequent specialist support for the family and the youngster (this could range from securing specialised early years provision, arranging for families to attend relevant training, giving specific advice to the families and schools, etc.)*

The core composition of the team was a Consultant Psychiatrist or Paediatrician who acted as lead diagnostician, Specialist Educational Psychologist, Specialist teacher for ASD, Speech and Language Therapist. Relevant other professionals were also able to attend the clinic.

Prior to the family attending the clinic, a range of community (and or school) based assessments is undertaken in order to secure information as to how the youngster presents across a range of different settings. This information along with that compiled at the actual clinic is then analysed in order to determine a causality of the presenting problems.

The family is fully involved in both determining the diagnosis and also in the development of an individualised action plan which secures subsequent targeted interventions (irrespective of diagnosis).

Since the clinic was established the proportion of children referred to CAMHS/Paediatrics with a query regarding ASD who have been so diagnosed has reduced by 2/3rds.

However, more importantly children are being more accurately diagnosed and are receiving appropriate interventions.

Running parallel with the above arrange of training and awareness raising has been set up for families, schools and other professionals delivered by the team which is helping to secure more effective outcomes.

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

The biggest practical barrier identified is a shortage of specialist staff across the whole Children's Services spectrum. This ranges from a historical absence of psychiatrists trained to work with children with a learning disability to the current recruitment and retention problems for social workers and the anticipated difficulties in appointing Educational Psychologists as no newly qualified staff will be available for 3 years due to changes in their qualification requirements.

Despite significant progress having been made in the development and delivery of services to disabled children and their families the following problems still recur – and whilst some may be seen as the result of slow progress in local systems many are flow from poor resourcing:

- Lack of integration of service.
- Lack of key policy drivers for disabled children – NSF – they are not a priority in the health area.
- Lack of specific funding to develop services.
- Autonomy of schools – these children affect performance!
- Lack of information about what services are available for children and their families – particularly for children with more complex needs who would need more complex services.
- Co-ordination.
- Parents who “shouted the loudest” are the most likely to obtain services. Key workers are a good idea, but there is a need to empower young people and parents to take decisions.
- 80% of disabled children needed access to good quality mainstream services rather than specialist provision.
- One of the first things disabled children themselves talk about is social inclusion. Effective interventions to improve this included training staff and changing attitudes.
- School culture is important – without it disabled children could access the school but may not feel included.
- There are also issues around children not being able to take part in the life of the whole school.
- OFSTED inspectors need to look more at how inclusive schools are.
- Variation in provision of services across the country.
- Cost of disability and added difficulty for parents to access work means that disabled children are more likely to be poor. Poorer families are less likely to access services effectively.
- More help is needed for ethnic minority families.
- A significant minority of lone parents with a disabled child (which in some cases could be family breakdown due to lack of support for the family with a disabled child) may need extra help in accessing services and navigating the system on their own.

Levers that could be put in place to improve access to services across the country include:

- Minimum standards with greater accountability for the standards.
- Inclusion of disabled children in the performance management framework.
- Statutory requirements on Local Authorities to provide information on what services are available.
- Amending the Children Act to give disabled children an entitlement to services as long as resources were also provided.

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

The integrated services agenda is still at an early stage, and the lessons from Children's Trust pilots and Health Act Partnerships have yet to be fully appreciated. Integrated service delivery, when not underpinned by formal agreements is also vulnerable to pressures within the agencies responsible for commissioning and funding, and recent evidence of the impact on services to disabled children of PCT's well documented financial pressures is worrying.

There is a perception, based on activity, that children and young people are not a sufficient priority for the NHS and this results in significant variation of services.

At a child, rather than service level, the following have been identified as good practice:

The role of key workers is identified as a way to support greater service co-ordination.

- *They provide an important role in co-ordinating services, being most effective where their roles were clearly defined.*
- *There is insufficient availability of key workers in some areas of the country, partly because of funding. The time needed for key workers to provide an effective service was also sometimes underestimated.*

Creating effective co-ordination.

Suggested levers include:

- *Targets, particularly Public Service Agreements.*
- *Ring-fencing budgets, particularly to ensure that resources were directed to children's services across agencies.*
- *Ring-fencing budgets specifically for key workers.*
- *Pooled budgets across public services.*
- *Sustained funding streams, which could help build confidence amongst professionals to engage with disabled children and work with other agencies over the long term.*

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?

Generally speaking the national infrastructure seems to focus on crisis intervention rather than prevention. Early continued support could reduce the risk of family breakdown.

This is variable, and families struggle to find services that meet the needs of children with complex needs. In reality, families are asked for more money to care and support a disabled child in children's centres, etc. owing to perceived health and safety risks.

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

- Arrange a service building on universal services, supported where appropriate by direct payment, but there is a long way to go to move from funding being held in residential provision to a lower level.
- Short breaks and respite care are important to keep the family together.
- Help with sleep problems.
- Early identification also means better support and information being provided earlier for parents, empowering them and teaching them how to support their child.

Access to both mainstream and specialist services is very important for disabled children and their families' outcomes.

- Improving disabled children's emotional lives is important through positive activities and feeling part of the community, sport, access to youth clubs, etc.
- Education is identified as a key intervention to improve disabled children's life chances.
- Many disabled children are in residential placements and we need to address their needs also.
- Independent advocacy for looked after disabled children and young people is vital to help them stay safe, but more could be done to improve access to this service.
- Mainstream services needed to better understand that there is not necessarily high levels of risk involved in providing services for disabled young people, to help improve their accessibility for disabled children.
- Extended schools needed to do more to plan and provide for disabled children as their services expand.
- Listening to young people's needs was important – particularly for BME families.

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

Interventions targeted on preventing family breakdown and providing support to keeping children in their family and community rather than in specialist services should form the basis of future policy and consequent funding. This would have the benefit of both supporting the implementation of the Children Acts 1989 and 2004, and being cost-effective.

However, the needs of many disabled children are such that the services they require in their own right will inevitably cost what they cost. Procurement and commissioning efficiencies can help control costs, but only within relatively narrow parameters.

