

# pathways to **success**

**Good practice guide for children's services in  
the development of services for disabled children**

Evidence from the pathfinder children's trusts

Helen Wheatley



# pathways to **success**

**Good practice guide for children's services in  
the development of services for disabled children**

Evidence from the pathfinder children's trusts

Helen Wheatley

**Council for  
Disabled  
Children**

department for  
**education and skills**

**DH** Department  
of Health

ISBN-10: 1-904787-82-7

ISBN-13: 978-1-904787-82-2

© The Council for Disabled Children 2006

Designed by Susan Clarke for Expression, IP23 8HH

### **Disclaimer**

This handbook is intended as guidance only and should not be treated as an authoritative interpretation of the law.

The forms, protocols and other documents included in the handbook are developed by local authorities, trusts and other providers and are intended to illustrate the main text. The content does not necessarily reflect the views of the DfES or Council for Disabled Children.

### **Photocopying**

The forms in this book can be photocopied and adapted for local services and settings.

### **About the Council for Disabled Children (CDC)**

The Council for Disabled Children operates under the aegis of the National Children's Bureau. The Council for Disabled Children provides a national forum for the discussion and development of a wide range of policy and practice issues relating to service provision and support for disabled children and young people and those with special educational needs.

Our membership is drawn from a wide range of professional, voluntary and statutory organisations, including parent representatives and representatives of disabled people. This ensures we have a good balance of interests and expertise.

Our broad based membership and extensive network of contacts gives us a unique overview of current issues. It also helps us promote collaborative and partnership working among organisations, and develop quality support for disabled children and their families.

For more information on CDC please see our website at [www.ncb.org.uk/cdc](http://www.ncb.org.uk/cdc)

Council for Disabled Children  
8 Wakley Street  
London  
EC1V 7QE  
020 7843 1900

## **Acknowledgements**

This guide was written by Helen Wheatley, Principal Officer at the Council for Disabled Children. It would not have been possible without help and support from a wide range of sources. The Council for Disabled Children would particularly like to thank:

- the Department for Education and Skills, and Department of Health for funding this work,
- the national children's trust and emerging practice team based at the DfES for their co-operation and support,
- Contact a Family who worked with us on gathering the views of parents and carers. Pauline Shelley and Liz Ranger led this work.

We would also like to thank the parents and staff we have worked with in the pathfinder children's trust areas. It has been a great education and inspiration to learn from their experiences:

- Richard Vickers, Children's Trust Manager, East Riding of Yorkshire
- Kathy Rist, Regional Development Officer, Contact a Family
- Chris Bush, Service Manager, Disabled Children's Developments, Leicester Federation, Leicester City
- Dorothy Duffy, Integration Manager, Ealing Children's Trust
- Toby Price, Manager, Sutton Trust for Children and Young People
- Patrick Mallon, Children's Trust Co-ordinator, Darlington
- Andy Roberts, Children's Trust Manager, Newcastle
- Khalida Khan, Integrated Service Manager, Children with Disabilities, Tower Hamlets
- Alison Webster, Children's Trust Manager, Gateshead
- Robin Miller, Service Manager for Disabled Children, Sandwell
- Elisabeth Mannion and Jacqueline Winstanley, Bolton children's trust
- Julian Easton and Kay Woods, Hammersmith and Fulham children's trust
- Lou Williams, Programme Manager, Redbridge children's trust
- Susan Twemlow, Development Manager, Nottinghamshire children's trust
- Lindsay Richardson, Joint Commissioning Manager, Children and Young People, Telford and Wrekin

# Contents

**Introduction** 4

**Development of children's trusts** 6

**Key work areas** 8

- 1 Strategic planning** 8
- 2 Commissioning services, pooling budgets** 14
- 3 Joint working and co-location** 19
- 4 Assessment process and information sharing** 28
- 5 Keyworking and lead professionals** 32
- 6 Developing capacity for change** 36
- 7 Transition to adulthood** 38
- 8 Evaluation** 41
- 9 Participation of disabled children and young people** 43
- 10 Participation of parents and carers in children's trusts** 46

**The future** 51

**Appendices**

- 1 *Resources* 53
- 2 *Extract from London Borough of Tower Hamlets job description for the post of Disabled Children Integrated Services Manager* 57
- 3 *The quest: for improved services in transition to adulthood in Leicester* 59
- 4 *Parents' participation in children's trusts: key elements of success* 62

# Introduction

---

*'People's expectations of social care are changing. In future, people will expect social care services that enable them to live independently, that give them choices, that are of high quality, and that leave them in control. For children, social care services must support them and their families to make the most of their educational and life chances.'*<sup>1</sup>

The development of the children's trust model for delivery of local services is at the heart of legislation and policy regarding all children and young people. Alongside the Every Child Matters agenda the development of the pathfinder children's trust's work has been at the forefront in taking forward the duties set out in the Children Act 2004.

35 pathfinder children's trusts were announced in 2003. Their brief was to improve partnership working and try out ways of doing this which suited local needs. Each children's trust had a specific area which they identified as a focus for the development of an effective model. A third of the children's trusts had identified disabled children's<sup>2</sup> services as their priority areas of work. A primary reason for this was the realisation that to effectively develop high quality, responsive and flexible services for disabled children, greater levels of cross agency and multi-agency working are required. If this can be achieved successfully for disabled children then the development of subsequent services for other groups would benefit greatly from this learning.

The pathfinder children's trusts generated huge amounts of interest and the learning from these models is invaluable in highlighting good practice in multi-agency working. The children's trusts developed their own styles in approaching what can be seen as 'well established' challenges for disabled children's services, for example the lack of communication and co-ordination across agencies when working with disabled children and their families.

The Council for Disabled Children (CDC) received funding from the Department for Education and Skills (DfES) and the Department of Health (DH) to carry out a piece of work with the pathfinder children's trusts looking at how to more effectively meet the needs of disabled children and their families using the new service structures. We worked with the national children's trust and emerging practice team based at the DfES. This team set up a number of events for the children's trusts, provided regional support and developed the good practice and information sharing areas on the Every Child Matters website at [www.everychildmatters.gov.uk/childrenstrusts/](http://www.everychildmatters.gov.uk/childrenstrusts/)

1 *The state of social care in England 2004/05*, Commission for Social Care Inspection (CSCI), December 2005.

2 To make reading easier we use the term 'children' throughout this document to mean children and young people.

The CDC project ran from April 2004 to March 2006 and set out to work alongside the pathfinder children's trusts in developing new ways of working and to capture the learning from their work. Also, to work with Contact a Family (CaF) to contact parents and carers and look at what real difference the children's trusts can make to the lives of disabled children and their families. The work covered a number of areas which are reported on in the following chapters.

Throughout the project, CDC and CaF staff were constantly impressed by the commitment of children, young people, families and professionals involved in making the children's trust models work. All felt that the Every Child Matters agenda and the formulation of children's trusts to carry it out was a hugely positive step and a great opportunity to improve support for disabled children, young people and their families.

Beyond the pathfinder children's trusts there are many other authorities developing excellent work in this area. Whilst this work is invaluable and provides a significant contribution in the field, this report will focus solely on the pathfinder children's trusts to ensure we learn as much as possible from their experiences.

# Development of children's trusts

---

*'By 2008, local authorities are required to have in place arrangements that produce integrated working at all levels, from planning through to delivery, with a focus on improving outcomes. Local authorities may choose not to call this a 'children's trust', but the important point is that the way of working is in place and committed to.'*<sup>3</sup>

The setting up of a children's trust of some kind is integral to the success of local authorities meeting national and local targets and improving services. Throughout the life of the work, the environment in which the pathfinder children's trusts worked was very fast paced as national, regional and local government structures, health, and other agencies all underwent change to some degree and will continue to do so for some time to come. For the children's trusts this wider series of change set the context for their work in making sense of new structures and systems locally and in meeting regional and national targets.

*Every child matters: change for children* further sets the context for the development of these new ways of working:

*'The government's aim is for every child, whatever their background or their circumstances, to have the support they need to reach these five outcomes:*

- *be healthy,*
- *stay safe,*
- *enjoy and achieve,*
- *make a positive contribution,*
- *achieve economic well-being.*

*This means that the organisations involved with providing services to children – from hospitals and schools, to police and voluntary groups – will be teaming up in new ways, sharing information and working together, to protect children and young people from harm and help them achieve what they want in life.'*<sup>4</sup>

Although the Every Child Matters (ECM) range of documents has little specific information about developing services in response to the needs of disabled children and their families, the 'five outcomes' provide a firm foundation to build on in the development of new ways of working and planning to improve services and support for disabled children, young people and their families.

Along with the main guidance, the concept of children's trusts is an integral part of a number of recent main policy initiatives which affect the lives of disabled children. This includes:

<sup>3</sup> Every Child Matters, [www.everychildmatters.gov.uk/aims/childrenstrusts/faq/](http://www.everychildmatters.gov.uk/aims/childrenstrusts/faq/)

<sup>4</sup> [www.everychildmatters.gov.uk/aims/](http://www.everychildmatters.gov.uk/aims/)



- *Improving life chances of disabled people*, 2004, Prime Minister's Strategy Unit, Cabinet Office,
- *Health White Paper: our health, our care, our say: a new direction for community services*, 2006, Department of Health,
- *Independence, well-being and choice: our vision for the future of social care for adults in England*, 2005, Department of Health,
- *National Service Framework for Children, Young People and Maternity Services*, 2004, Department of Health (DH) and Department for Education and Skills (DfES),
- *Youth matters*, Youth Green Paper, 2005, DfES,
- *Education and Inspections Bill*, 2006, DfES,
- *Extended schools: providing opportunities and services for all*, 2002, DfES,
- *Children's centres practice guidance*, 2005, DfES,
- *Childcare Bill*, 2006, DfES.

Information on these and other related legislation and guidance is in Appendix 1.

In summer 2003, the government awarded 35 local authorities pathfinder children's trust status. These original 35 authorities are listed below:

Barnsley	Essex	Redbridge*
Bexley	Gateshead*	Sandwell*
Blackburn and Darwen	Greenwich	Sheffield
Bolton*	Hammersmith and Fulham*	Solihull
Brighton and Hove*		South Tyneside
Calderdale	Hampshire	Sutton*
Cambridgeshire	Hertfordshire	Telford and Wrekin*
Croydon	Leicester City*	Tower Hamlets*
Darlington*	Newcastle*	Trafford
Devon*	North Lincolnshire	West Sussex
Ealing*	Nottinghamshire*	Wokingham
East Riding of Yorkshire	Portsmouth	City of York

At the beginning of the project CDC held an open day for all 35 of the pathfinder children's trusts to look at their work with disabled children and young people and how this could develop. The day was well attended and led to the development of the Pathfinder Managers Disabled Children's Services Group. The purpose, content and actions of the group were developed and decided upon by the trust managers. The group holds meetings which are used to share information and learning, and to focus on a specific issue which the children's trusts are working on. To date, these have included; co-location of teams, participation of families in the children's trusts and the new Disability Discrimination Act (DDA) 2005 duties.

The range of issues covered at these meetings and the information placed on the Every Child Matters website gives some idea of the size of the task the pathfinder children's trusts took on. The next section explores some of these areas in detail.

\* Members of the Pathfinder Managers Disabled Children's Services Group.

# Key work areas

---

At the start of the CDC project, we asked the children's trusts to identify key work areas they would be concentrating on including areas they were particularly concerned about. From this, we identified a number of common threads running through the work the children's trusts embarked upon.

Priorities for the pathfinder children's trusts included:

- agreeing shared aims and objectives within the strategic planning framework and across agencies,
- agreement of workstreams across agencies,
- developing an effective communication strategy,
- pooling budgets,
- making the children's trust a priority in wider authority/council business,
- co-location of mixed staff teams,
- joint training for staff groups,
- linking in with the development of extended schools/services,
- transition to adulthood for disabled young people,
- participation of parents and young people.

From these priorities came a number of workstreams. The following sections give an overview and examples of how a number of the children's trusts worked on specific areas to improve services and support for disabled children and their families.

---

## 1 Strategic planning

### Background

At the start of the work, children's trusts were invited by government to use a number of models, some commissioning, some offering direct services and some using a mix of the two. As the work developed, and further guidance became available, the children's trusts began to focus on a commissioning role working within the local government structure to be accountable for the development of flexible and responsive children's services.

Each pathfinder children's trust developed a model best suited to meet local needs. So, for example, Nottinghamshire, a large county with huge geographic spread and diverse population has developed a strategic partnership with participation from all seven Primary Care Trusts (PCTs), education, culture and community and social services,

Connexions the Voluntary sector and the healthcare trust responsible for mental health and learning disability services. Subsequent development has embraced the Local Strategic Partnerships and colleagues from District Councils. Their model was based from the start on the commissioning of services jointly and reaching agreements on operational working at a strategic level. In contrast, Darlington, a unitary authority with a small geographic area and relatively stable population, proposed a children's trust development based on services being delivered from a single resource base for all families across the area, with the children's trust looking to bring in grants to support specific pieces of work rather than acting as a purely commissioning body.

## Legislation and guidance

The children's trust arrangements have their foundations in the **Children Act 2004**. Although the Act does not set out a specific duty for local authorities to develop a children's trust, there is an expectation that authorities will use the duty to co-operate and the imperatives on pooling budgets set out in the Act and develop a children's trust to administer the process. The new integrated inspection processes also concentrate on joint working and partnership arrangements which are at the heart of children's trust frameworks.

The lead member and director of children's services share accountability and leadership of local children's trust arrangements. To reinforce this, broader governance and accountability arrangements are made with partner agencies. This works to ensure all partners get a voice in the development process and clear, locally agreed guidance is in place. The duty to co-operate sets out within the Act a duty for all 'children's services authorities' to promote co-operation with particular partners to improve the well being of local children and young people. These partners are under a reciprocal arrangement to co-operate too.

These key partners are:

- the district council in two tier authorities,
- the police authority,
- probation board,
- the youth offending team,
- Strategic Health Authority and Primary Care Trust,
- agencies providing services under Section 114 of the LSA, 2000, eg Connexions partnerships,
- Learning and Skills Council.

In addition, there is a requirement to include other agencies in these arrangements, which work locally and have an impact on services to children. For example, voluntary and community organisations, schools, GP surgeries and Job Centre Plus.<sup>5</sup> Areas also need to agree how disabled children and their parents are

<sup>5</sup> Statutory guidance on inter-agency co-operation to improve the well-being of children, children's trusts, 2005, DfES.

involved in governance arrangements.

The children and young people's strategic partnership (CYPSP) should ensure that chief executives of partner organisations are involved in developing strategy. Most areas set up children's trust boards led by the director of children's social services or education (superseded by the director of children's services as these posts develop).

The Children Act 2004 also brought in the requirement for local authorities to develop children's and young people's plans. This plan must set out how local authorities and partner agencies, like health services are going to support local children. Authorities are required to gather the views of children and young people to inform this plan. Although authorities awarded 'three stars' in the council ratings<sup>6</sup> are not required to produce a plan, it is widely recognised good practice to do so in any case. This can make a real difference in keeping the needs of disabled children on local agendas.

Alongside the Children Act 2004, many other pieces of legislation and guidance refer to the development of children's trust arrangements as being important at a strategic level. The **Choosing Health White Paper, 2004**, for example, highlights children's trusts, along with children's centres and extended schools as key mechanisms in promoting and improving the health of all children and young people.

The Office of the Deputy Prime Minister (ODPM) brought in the development of **Local Area Agreements** (LAA). The LAA is a statement covering a three year period which sets out the formal agreements across partner agencies. Children and young people is one of the service areas identified as a priority for inclusion in the LAAs. The formal agreements and subsequent work is expected to reinforce joint working and use available funding streams to best meet local needs. All top tier council areas are expected to have an LAA in place by 2007.

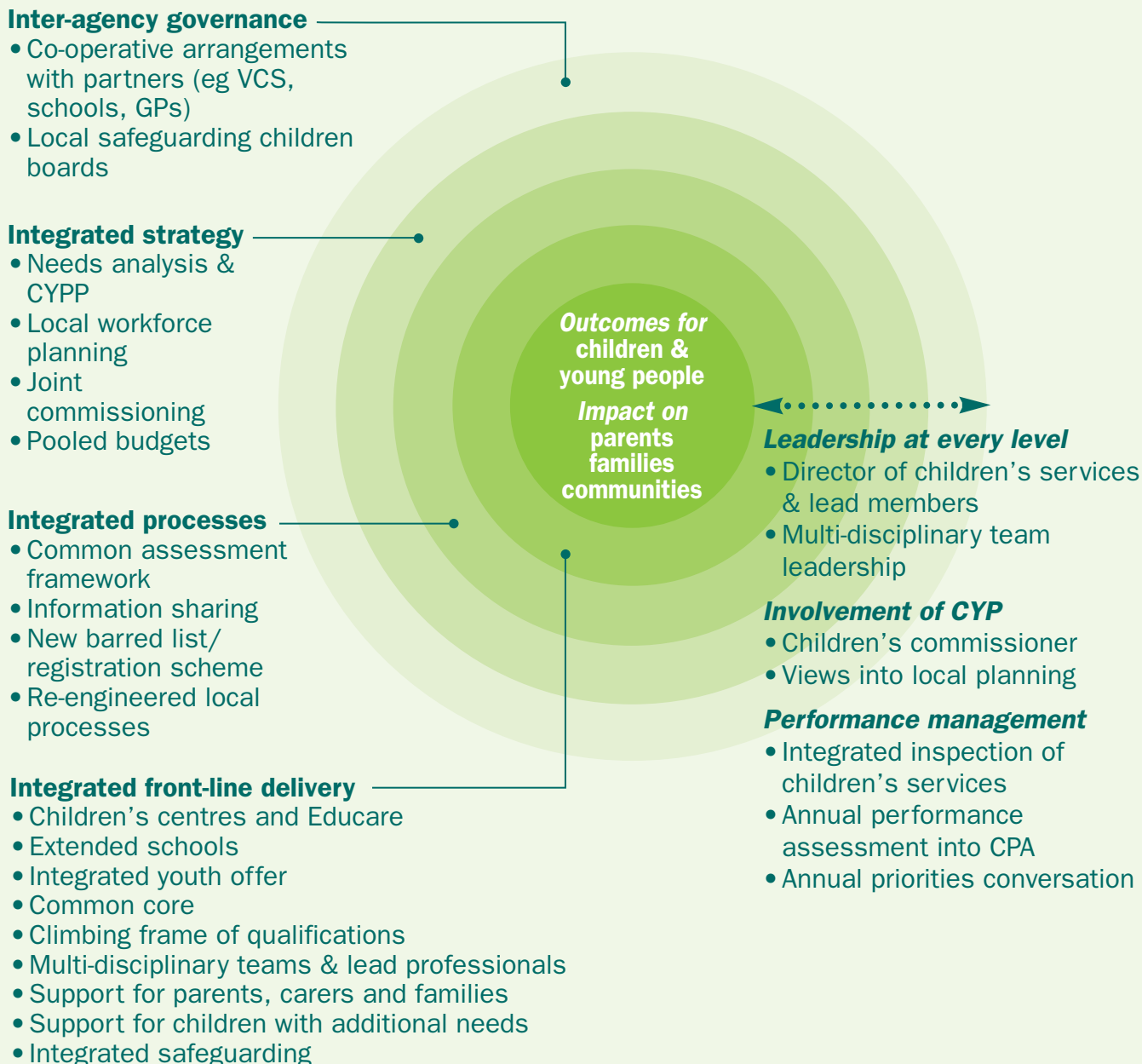
A number of the local authorities which were pilot areas for the development of LAAs have identified, like the pathfinder children's trusts, that implementing far reaching strategic change takes a considerable amount of time and effort. However welcome the change may be, trying to deliver results in a short timescale doesn't really work and is rarely sustainable.

The diagram below is taken from the DfES information for developing children's trust arrangements. Further details are available from the ECM website, [www.everychildmatters.gov.uk/childrenstrusts/aims](http://www.everychildmatters.gov.uk/childrenstrusts/aims)

The diagram illustrates the layers of management and governance expected to be in place to ensure the children's trust can operate effectively.

The layers of the diagram represent the different levels of work needed to set up and operate an effective trust model. The three

6 Commission for Social Care Inspection, [www.csci.org.uk/council\\_performance/](http://www.csci.org.uk/council_performance/)



areas running through them all are; leadership; involvement of children and young people and performance management, to measure effectiveness. These areas are the mainstay of the process.

Appendix 1 contains further information on legislation and guidance.

## Good practice

### Newcastle

Started the process of change by working with operational managers to agree shared principles and a vision of 'joined up' services for disabled children. This was used as a basis for bringing together strategic managers and parents to gain a consensus on the strategy the trust would use and agree the priorities. The Operational Managers Group then identified ways to achieve the key priorities for

each service. This was achieved using day conferences, meetings and the convening of the children's trust board to discuss and negotiate the strategic outcome.

During this period trust staff talked to and involved all agencies in building relationships based on trust. This is essential to taking forward this kind of change and it builds the foundations for addressing sharing funds and pooling budgets at the next stage. Newcastle are developing a system so that all funds allocated and charged through the trust will have an audit trail back to parents so it is clear how decisions are reached and why.

As the strategy developed, a communication strategy was worked out to ensure all staff and service users were aware of the changes and how they might be affected. The trust realised it was crucial to extend this message to all support services; for example estates management, administration support in each agency and schools staff. Doing this meant that as workstreams developed, like co-locating teams, people were aware of the strategy and could respond appropriately.

The trust originally set out a 10 year strategy of work which moved incrementally toward the inclusion of all children's services in the trust. This has been superseded by a plan to bring this forward and include all children's services sooner. To this end, work on disabled children's services has now been handed over to mainstream strategic and operational managers and the trust work is focusing on looked after children and those with challenging behaviour.

Newcastle now has in place a management partnership with input from all services which looks at planning and taking children with disabilities workstreams forward. On the same level as this partnership is a parents' forum, which members of the management partnership attend to share information and gather views.

### **Nottinghamshire**

The county covers a large geographic area which includes both market towns closely associated with the declining textiles industry, rural areas and a number of isolated former mining villages which face particular issues around unemployment and poverty. The county has seven Primary Care Trusts operating across its boundaries. At the outset of planning what the pathfinder trust could reasonably do, a decision was made to prioritise the needs of children with complex needs and disability. An early task for the children's trust board was to agree a set of priorities which all partners could sign up to and commit time and resources to addressing. This was a challenge as each service set different priorities and finding common ground across these proved to be challenging.

Work was guided by four key issues identified by parents as areas where attention was needed if the children's trust was to make a difference to the experience of local families. They were:

- provision of timely information to enable informed decision making,

- working arrangements that would reduce the number of times a family needed to re-tell their story,
- more co-ordination of services to reduce the impact on family life,
- the identification of a named person who would be their guide through services.

## Key elements of success

There are a number of common elements to success which the pathfinder children's trusts have used.

- boards, groups and sub-groups all need clear aims and agreed terms of reference,
- rationale for membership and consistency of those attending,
- clear knowledge of others roles and responsibilities,
- develop a framework with work plans attached so all can keep referring back to what has been agreed,
- look beyond health, education and social services and develop strategies to include further partners like the police, Connexions services and local leisure services to plan wider reaching, effective change,
- need to recognise all services priorities and agree on one or two that everyone can commit to. To achieve this the children's trust board in Bolton took the approach of having themed groups, agreed by all partners. These groups looked at a particular area of need and planned for improvements. The first area they looked at was short breaks, followed by transition.

Having a dedicated post of trust manager is essential to achieving the aims of the children's trust. The manager is key in working with others in bringing services together, negotiating new ways of working and identifying aims and priorities that everyone feels they can sign up to. Also, to keep up momentum and focus everyone on attaining the joint vision.

It is important throughout the development of children's trust arrangements for leaders to take a step back and check out how strong the joint vision is across all partner agencies. Building up relationships and trust across services has to come before anything else.

## Conclusion

The creation of children's trusts arrangements has presented authorities with a huge challenge. Even in areas with a good history of partnership working across services, it takes time – years – to get the foundations right. Change is required across all partner agencies at strategic and operational levels. This requires a strong strategy, a real commitment from all agencies and the inclusion of service users from the outset. This is a real challenge as this work is part of the much wider restructure of local government and the health service.

## 2 Commissioning services, pooling budgets

### Background

Once authorities have brought together partner agencies and agreed a list of priorities to address, work starts on practical arrangements for the joint commissioning of services. This was not new to the pathfinder children's trusts as many areas across the country have for some time used joint commissioning of services at some level. The purpose of doing so as a children's trust was to build on good practice to date, bring more services under a joint commissioning strategy and begin the process of pooling budgets to create a more effective use of funds.

The majority of children's trusts, when planning commissioning strategies for disabled children's services, defined a specific group of disabled children to concentrate on. The most common criteria used was that the child had support from two or more key agencies. This essentially means most areas concentrated on those disabled children who have the most complex needs. A smaller number of areas, like Darlington and East Riding of Yorkshire, used the broader definitions of the Children Act 1989 or the Disability Discrimination Act 1995.

The role of commissioning through children's trusts has developed alongside extended schools and extended services which are also beginning to develop a role in the commissioning of services. Children's trusts and their partners in extended services are beginning to address how to work together to make services accessible and inclusive for disabled children. The forthcoming Education Act (currently Education and Inspections Bill 2006) will have an impact on how this work is taken forward in the future. For information and updates on the progress of the Bill visit [www.dfes.gov.uk/publications/educationandinspectionsbill/](http://www.dfes.gov.uk/publications/educationandinspectionsbill/)

### Legislation and guidance

The Children Act 2004 contains powers to pool budgets which authorities are beginning to explore. However, Section 31 of the Health Act 1999 provides the main legislation on the pooling of budgets. Many of the children's trusts have struggled alongside health colleagues to find ways to achieve pooled budgets. As the work of the children's trusts has leapt ahead of government guidance in identifying realistic and effective methods to share funds. The full, formal pooling of budgets is not possible under much of the existing legislation and guidance. DfES are currently working with a number of children's trusts to find ways to address these anomalies.

Alongside these developments is the use of practice based commissioning. The use of this in the health service is growing and will have an impact on local agreements made with children's trusts.



*'Where PCTs have pre-existing agreements, such as those with an Independent Sector Treatment Centre or a Foundation Trust, or where partnership arrangements exist such as the integration of children's services, Children's Trusts or Section 31 agreements, these should be reflected in the decisions taken by practices.'*<sup>7</sup>

Commissioning takes place on a number of different levels, for example; GP practice level for holding budgets, managing demand and patient choice. It can also apply at the borough/trust level for commissioning public health services, developing partnerships, developing Local Area Agreements or for joint commissioning.

## Good practice

### London Borough of Tower Hamlets

Have developed a joint commissioning panel which is operating a pooled budget system between education and social services. Agreement has been reached and plans are in place for the Child and Adolescent Mental Health Service (CAMHS) and health services to follow on. The children's trust commissions CAMHS at the moment. Relations between services are good and people are willing to work together. The excerpt below is from the Joint Commissioning Protocol, reproduced with the kind permission of Tower Hamlets Children's Trust.

*In order to consider joint funded placements, a Joint Commissioning Panel has been established comprising senior officers from Education, Social Services and Health. The Drug Action Team may attend occasional panels where relevant.*

*The Panel aims to meet every month or more frequently if necessary. The venue, chairing and clerking of the Panel is shared between the three agencies.*

*The panel will consider submissions from any of the three agencies. However, wherever possible, the Panel would prefer to consider joint applications.*

*The agenda will be published a week before the meeting. If a child's case is new to an agency which will consider funding at the panel, advance copies of the relevant papers should be made available to the representative of that agency.*

*Once a case has been considered by the panel, an outcome sheet will be produced by whoever is taking minutes that day, which should be distributed to interested parties the next working day. Minutes are taken by the panel administrator. It is the responsibility of each Agency to inform members of their services of decisions made.*

*The Panel will consider a joint funded placement when three or more of the following conditions exist:*

<sup>7</sup> Paragraph 13, *Making practice based commissioning a reality – Technical Guidance*, 2005, Department of Health, [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

- *a child has a statement of special educational needs,*
- *a child needs to be formally accommodated to have his or her social needs met,*
- *a child suffers from severe mental health, addictive behaviour or other complex medical conditions which require specialist intervention, treatment or care. These needs have been clearly identified by a senior clinician,*
- *a child requires specialist educational provision which is not available in a day school,*
- *a child requires a consistent, structured and predictable provision for 24 hours a day,*
- *a child is at risk of neglect or abuse or their development would be impaired if they remained at home,*
- *emotional factors within a family interfere significantly with the child's development,*
- *a child's needs could only be met at home with unacceptable consequences for family life or the well being of others.*

*In line with the principles of the panel consideration should first be given to educational and other provisions available within the community. This should include the range of Social Services placements and community health options.*

### **Leicester City**

The children's trust in Leicester is generic, but is carrying out a major piece of work on disabled children's services, inclusion and transition. As part of this work, decision making and planning processes have been reviewed to enable planning to begin earlier in the year to accommodate a wider range of disabled children and young people in local play schemes. In future, early years, social care and youth services will all have services commissioned together to give continuity to families and disabled children and young people and provide a better spread in provision. Alongside this, a key achievement in Leicester has been the development of a shared and integrated disabled children's action programme. This action plan, informed by integration and inclusion policy approved by the Children's Trust Board has a range of shared goals. Progress on the action plan is reported to the Integrated Disabled Children's Programme Board, as well as the local health Children's Model of Care Board and is seen as the lead programme for the implementation of NSF standard 8.

### **London Borough of Sutton**

Have developed a joint commissioning panel which meets fortnightly. The panel criteria has been agreed across all services. It operates by agreeing a level of response, eg one or multi-agency response. Any other agencies the panel thinks should be involved are contacted and a review arranged. The common assessment framework is used so that children with lower level needs can be referred to the panel from other services, speech and language therapists for example. This

enables them to access low level services without getting caught in the bottleneck of the assessment process.

Representatives from health services attend. The panel are currently trying to resolve with health finance staff difficulties in pooling budgets. Health staff attending the panel has really improved joint working and access to all budgets. The introduction of continuing care criteria gave a good illustration of which services were over/under funding and this has had positive effect. The panel is supported by 2 admin staff who provide general support to the co-located site. These posts are funded from small contributions from all budgets.

### **Brighton and Hove**

Have developed a service redesign and commissioning strategy based on:

*'How the Children's Trust Partnership should respond to the impact of disability – the barriers which children with special needs, their siblings and parents have to deal with and which prevent them from achieving their potential and leading ordinary lives.'*<sup>8</sup>

A service redesign core group were appointed to review services, put together a report and make recommendations to the children's trust board. The process included consultation with parents.

The new service model they developed recommended the children's trust should:

- adopt an integrated care pathway for child development services,
- establish an integrated child development service co-located in a new child development centre,
- set three high level outcomes to prioritise what services are provided and commissioned by the Children's Trust, ie empowering parents, providing timely interventions which meet the therapeutic needs of individual children, and supporting families to look after their children,
- implement a workforce development strategy that will build on good practice to drive forward changes to the organisational culture and structure of specialist and mainstream services to promote inclusion and equality for children and young people with special needs,
- address commissioning, infrastructure and governance issues.

The children's trust are now taking this work forward.

### **Key elements of success**

Many children's trusts have made considerable progress on budget sharing and agreeing joint funding. The formal process of pooling budgets however throws up a number of challenges, not least the incompatibility of various related regulations and guidance. It is important within services that agreement can be reached on who pays for what. For example acute trusts receive funding from Primary Care Trusts (PCTs). It is very hard to move money out of this system so

<sup>8</sup> Reproduced with kind permission of Brighton and Hove Children's Trust Board.

working with children's trust arrangements on commissioning in this way (eg budget sharing) can be difficult. This is often compounded by the fact that local authorities and PCTs still have to deliver things beyond the reach of the children's trust so the focus on disabled children needs to be promoted to make sure it remains a priority.

The skills of the children's trust manager and other staff are often the lynchpin for making commissioning work. This is a crucial ingredient but must be backed up with formal agreements to safeguard against lack of clarity if staff move on or teams change. Service Level/Partnership Agreements can help with this process.

Agreements formulated by the children's trusts have developed over time and many have started off with informal arrangements, building up to having formal documents in place which are reviewed within agreed timescales. They cover things like:

- which services from each agency will be included in children's trust arrangements,
- named staff responsible in each agency for being part of the commissioning process,
- working with training departments to develop joint training programmes,
- data collection and sharing arrangements across agencies.

A framework to support the children's trusts has been produced by the DfES. *Joint planning and commissioning framework for children, young people and maternity services; processes for joint planning and commissioning*, DfES 2006, [www.everychildmatters.gov.uk/strategy/planningandcommissioning](http://www.everychildmatters.gov.uk/strategy/planningandcommissioning)

Having a series of agreements in place can help keep everyone focused as more people become involved in the process of developing a children's trust. Further information from: [www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/](http://www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/) and [www.integratedcarenetwork.gov.uk/](http://www.integratedcarenetwork.gov.uk/)

## Conclusion

Joint commissioning is now successfully underway across the majority of children's trusts focusing on services and support for disabled children. Many areas are planning the next stage of work and building on their early successes to expand the groups of children covered and the services involved.

Many of the children's trusts found the most effective way to begin the process of joint commissioning and pooling budgets was to try out flexible, informal aligning of budgets, looking at individual cases and sharing budget information before formalising the process and developing pooled budgets. This is an area where children's trusts are running somewhat ahead of strategic thinking and national policy. Most children's trusts are still in negotiation to look at how to meet

all the legal requirements in place and successfully pool funds across agencies. It is anticipated that more guidance/adjustments to requirements will be needed to resolve some of these issues.

## 3 Joint working and co-location

*'Shared expertise is the driver of change.'*<sup>9</sup>

### Background

The joining up of teams and co-locating diverse professional groups has been one of the main challenges for the pathfinder children's trusts, but also an area where significant progress has been made, and service users and professionals are reaping the benefits of the changes.

At the outset, children's trusts reported that each service had only a rough idea of what others can offer. This can lead to tension in planning co-location and misplaced requests for services. For example; requests for a community nurse or social worker from other agencies can be inappropriate or vague. In areas where joint teams have been developed a marked improvement can be seen in appropriate referrals, increased trust and constructive joint working.

As well as evidence direct from the children's trust areas, the following is an extract from the University of East Anglia (UEA) national evaluation of children's trust arrangements first phase report:

*'Of those schools that were involved with children's trusts, a number of positive impacts were reported: on children's wellbeing, information sharing protocols, identification of children at risk or in difficulty, and sometimes direct impact case management, levels of temporary and permanent exclusion and overall attendance.'*<sup>10</sup>

The report goes on to state that there are still issues in engaging schools in the children's trust process. However, where schools were involved in multi-agency working on their sites, their experiences were very positive.

### Legislation

As listed in previous sections, the Children Act 2004 is the mainstay of legislation, guiding the development of children's trust arrangements. This includes a duty for agencies to co-operate with each other in developing strategies and services (see page 9).

The current development of the Children's Workforce Strategy will have a significant impact on the future of joint teams and cross-agency working, including with extended schools and children's centres. For more information on the children's workforce strategy see [www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)

<sup>9</sup> 15/15, *National Evaluation of children's trust arrangements*, University of East Anglia (UEA), September 2005.

<sup>10</sup> 4/15, *National evaluation of children's trust arrangements*, University of East Anglia (UEA), September 2005.

## Good practice

### **Sandwell**

The Children and Young People's Strategic Partnership facilitated the development of an integrated, co-located service to support children and young people with a disability up to the age of 25. Staff from the Council, Primary Care Trusts, Sandwell & West Birmingham Hospital Trust, Sandwell Mental Health Care Social Care Trust and Connexions are based within the service. All staff remain employed by their host organisations and a manager has been appointed through Sandwell council to manage the service. A management framework has been developed to clarify management and professional lead responsibilities and has been agreed formally by unions. The building will host the child development centre, out-patient clinics and a parent carer information and resource room.

Teams within the service include:

- an integrated early years service incorporating the Child Development Centre, pre-school SEN team and area Senco,
- children with disabilities social work team,
- counselling service,
- register service,
- sensory support teachers,
- community nursing and psychology,
- transition team incorporating Connexions PAs, youth co-ordinator and social workers to support young people from 13 to 25 years old,
- joint business support team.

### **London Borough of Ealing**

The children's trust in Ealing hopes to co-locate up to 160 staff by the end of 2006 to provide a one stop shop for integrated disabilities services. Staff and parents have been involved in the process since initial planning stages. Certain staff groups were keen to maintain peer support in their professional areas so smaller teams, like speech and language therapists and educational psychology services will move as whole services together. This will also mean teams are ready to move into the wider trust as this develops beyond disabled children's services. A comprehensive communications strategy is underway to keep staff informed, with regular meetings, joint training events and joint team planning days. Parents have also been encouraged to take part in trust activities and a series of events have been held to hear their views.

A Section 10 partnership agreement is being drafted to ensure both financial and governance arrangements are in place to sustain the programme long term.

### **Newcastle**

Faced a real challenge in identifying a suitable building large enough for the children's trust to develop. The children's trust board looked at a number of options but have been unable to find anything all agencies could sign up to. As a starting point, social workers and nurses will be co-located in a local hospital. In the longer term, the children's trust are working with local schools on the planning for new school buildings which will hopefully accommodate the children's trust. This will ensure the co-located site

meets the needs of those working there and using it. This will also meet some of the schools targets in becoming more community focused, sustainable resources.

### **London Borough of Sutton**

Has taken steps to move toward fully integrated services. Staff groups and parents were consulted from the planning stage of work. Staff were clear that they did not want full teams to transfer into the new service. As a result of this, the main co-located site – in a primary school – has 25 staff working from it. As well as these permanent staff, there are a number of ‘hot desks’ for visiting staff like portage workers and therapists.

The school released four classrooms for use by the children’s trust. This worked well as the school roll was falling so they formally deregistered a reception class to accommodate the children’s trust. The aim is to operate this space as a one stop shop for families and the staff team is built around this. The centre is now used for panel meetings, parents’ groups, etc.

Alongside the development of this main site, further co-location has been:

- the trust manager is located at the local Primary Care Trust (PCT) headquarters. This has proved invaluable for senior managers who now know more about each other’s roles,
- a transition social worker and adult care manager are based in the local Connexions offices.

### **Telford and Wrekin**

Have set up joint disability equality training which is available for all staff across agencies and will be a mandatory part of induction training. The new children and young people portfolio now has one, joint training department, brought together from health and social care.

### **Bolton**

Developed a young adults multi-agency team. The integrated management agreement was important in making it work, as was the post of a dedicated team manager. Staff also have access to clinical supervision from managers within their professions to monitor good practice and ensure that all staff have appropriate professional development opportunities. All staff have quarterly three-way supervision sessions with the team leader and their clinical/professional supervisor. This amount of supervision is seen as essential for building an ethos to improve the service for disabled young people. Staff have faced issues like having to learn about different pieces of legislation and guidance which would normally be covered by a different agency or colleague, for example the Children Act 1989 and the Community Care Act 1990. This means staff are developing a far broader knowledge of legislation and guidance than they have had previously.

11. ECM multi-agency working fact sheet, July 2005, [www.everychildmatters.gov.uk/multiagencyworking](http://www.everychildmatters.gov.uk/multiagencyworking)

## **Key elements of success**

The Every Child Matters (ECM) fact sheet<sup>11</sup> states that there is no single, correct way to develop multi-agency working. It goes on to identify three

key models: multi-agency panel, multi-agency team and an integrated service. Their key features are listed below.

### **Multi-agency panel**

(See page 15 for case studies.)

- practitioners remain employed by their home agency,
- they meet as a panel or network on a regular basis to discuss children with additional needs who would benefit from multi-agency input,
- in some panels, casework is carried out by panel members. Other panels take a more strategic role, employing key workers to lead on case work.

### **Multi-agency team**

- a more formal configuration than a panel, with practitioners seconded or recruited into the team,
- team has a leader and works to a common purpose and common goals,
- practitioners may maintain links with their home agencies through supervision and training,
- scope to engage in work with universal services and at a range of levels – not just with individual children and young people, but also small group, family and whole school work.

### **Integrated service**

- a range of separate services share a common location, and work together in a collaborative way,
- a visible service hub for the community,
- has management structure that facilitates integrated working,
- commitment by partner providers to fund/facilitate integrated service delivery,
- usually delivered from school/early years setting.

The children's trusts have taken up the challenge of implementing some kind of multi-agency approach with gusto and many have taken elements of each of these three models to work with.

The co-location of staff and development of joint working is a complex process which brings together many diverse areas of work. There are a number of barriers to this which the children's trusts have worked on including:

- suitable buildings,
- commitment from all agencies,
- sustainability,
- staff terms and conditions,
- realistic timescales.

Using work from the London SEN<sup>12</sup> Regional Partnership<sup>13</sup> as a starting point, we have built on this and used the experiences from the pathfinder children's trusts to compile the checklists below which cover the fundamental elements which need to be in place to achieve a successful transfer to joint working and co-located services.

<sup>12</sup> Now known as the Regional Partnership.

<sup>13</sup> *Integrating children's services: checklist*, London SEN Regional Partnership, 2004. [www.londonsen.org.uk/Documents/Integrating\\_services\\_chklist.pdf](http://www.londonsen.org.uk/Documents/Integrating_services_chklist.pdf)



## Checklist on integrating services

### Preparation work

<b>Action</b>	<b>Notes</b>
Gather evidence that shows services would benefit from being integrated. For example: best value review, parents' forum, complaints review, annual performance assessment.	To provide credible evidence, agencies must first work together to gain an accurate picture of the population they are providing services for. This can be very complex as information is held and accounted for differently in each service. Developing a working group to formulate an agreed reporting system – using the Integrated Children's System as a base – could be a useful way to build on any existing information sharing arrangements. This is particularly important in locating the local population of disabled children as there will be a significant number who are not receiving any services and may not have a statement of Special Educational Needs.
Set the data out as potential outcomes for disabled children, young people and their families.	For example: <ul style="list-style-type: none"><li>• shared data = single assessments,</li><li>• faster response,</li><li>• appointments more co-ordinated,</li><li>• families called upon less to act as negotiator between services.</li></ul>
Identify all the key stakeholders, eg Connexions, voluntary agencies, and schools.	Important to remember a range of services will need to be aware of ideas and be included in planning.
Decide which services from these will be integrated.	In many of the children's trust areas there are a range of agencies not fully integrated into the work of the children's trust but who are involved in work when needed, for example, housing services. It is important to keep these agencies up to date with progress so they are ready to be involved more fully when needed.
Work with the elected members to ensure they share and support the vision.	This can be crucial to the success of the project in pulling together support from all services. Some of the children's trusts found a change in members following election periods was seriously disruptive to the change process. Having clear agreements and pathways in place can help lessen the effect of this.

*continues*

<b>Action</b>	<b>Notes</b>
Assess the local change agenda to identify how the new service will impact on/be impacted on by cross agency working. For example; children's health services which sit outside the remit of the integrated children's service.	Need to make sure the children's trust board is linked in to the Children's and Young People's Strategic Planning Partnership (CYPSP) and is taken into consideration when wider development plans are decided.
Can services reasonably be reshaped using existing resources?	Reviewing priorities for each agency and where the common ground is will provide an indicator of what may be available. Where a short fall is likely, some children's trusts set up working groups to apply for external funding, eg from independent trust funds, to develop specific pieces of work and gather evidence to illustrate local need and how it can be effectively met.
Contact other services who have been through this process to learn from their experience.	Adult social services or CAMHS services could be good starting points. Regional Partnerships and Regional Government Offices will be able to offer information on services undergoing similar change across a wider area.
Secure senior level commitment	Presenting the case for change and the specific benefits to each agency can help secure commitment from senior staff.
Research the management skills and capacity that will be needed.	Again, use learning from local services who have been through this process to help identify the right skills needed. An audit of the skills within the project management group will be useful to identify project management and other relevant experience.

## **Managing integration**

<b>Action</b>	<b>Notes</b>
Draw up with key stakeholders the principles that will underpin the integrated service.	This list will need to reflect the priorities of each service, take into account the different approaches of universal and targeted services, eligibility criteria, agree a definition of disability and which groups will be included.
Agree with each agency who will be involved in the process and what level they can operate at.	It is important to have staff who can make decisions and have a clear brief involved in the planning process. Having the same named staff attending meetings, also gives a clear line of communication and makes it easier to keep each stakeholder involved in the process.

<b>Action</b>	<b>Notes</b>
Map out the key priorities for each agency involved	Meeting individual targets is a driver for each agency and will need to be addressed as early as possible in the process. Each priority will need to be understood by others and the new service will need to have key priorities set and agreed by all agencies.
Use risk and opportunity management tools to help identify common goals for agencies to work toward.	Many of the children's trusts reported this stage as being crucial to moving the change agenda forward. This often takes much more time than anticipated and is a process that needs revisiting often to ensure all agencies are still in agreement and committed. Common goals identified include: <ul style="list-style-type: none"> <li>• giving individuals more of a say over services and their own support,</li> <li>• more flexibility and autonomy for front line services,</li> <li>• reducing paperwork (eg common assessment and IT system access).</li> </ul>
Developing a culture of participation	Involvement of parents and disabled children is essential – so is the involvement of staff at all levels. Need to have a good communication strategy in place, opportunities to comment on plans, have sub-groups to research areas for change and inform the main agenda.
Plan how disabled children and young people will contribute to this process.	Contributions from those children and young people already using services is invaluable. Arranging for their contribution to the planning process needs careful consideration. Some children's trusts commissioned external organisations to conduct surveys with disabled children in their area to gather initial views on what they would like to see from redesigned services. Other children's trusts consulted local established groups of disabled children, not necessarily service users, for their views.
Plan how families with disabled children will contribute to this process.	Many children's trusts approached existing parents' groups and, in some areas, supported them to further develop their role in local planning initiatives. Parent Partnership Services are also used as a conduit for contacting parents to be involved in this process.
Finding a building which meets needs of all staff groups and that families are able to access easily.	Many children's trusts struggled to find buildings in suitable locations which would be able to accommodate the children's trust, some have moved

*continues*

Action	Notes
Funding a building	<p>into schools and hospitals. If a new build or refurbishment is likely, it is worth planning in time for:</p> <ul style="list-style-type: none"> <li>• the consultation process with service users and staff,</li> <li>• planning and explaining the brief to the architect.</li> </ul> <p>Time needs to be built in to check plans regularly throughout the process.</p>
Staff at all levels need to understand the benefits and the process of change.	<p>Administration staff and other support staff from across the agencies will need to know how changes will affect their roles and new teams they may work with/new language and systems they may need to learn.</p> <p>Front line staff need to understand how their skills and professional development will be maintained.</p> <p>Senior staff and team managers will need to understand how the changes will benefit their teams and make their work more effective. The disruption of the change process has to be worth it.</p>
Staff training	<p>Training departments need to be involved in children's trust development early so they can assess the needs of groups likely to be co-located and working together in new ways at strategic and operational levels. Training departments have long lead in's for developing new courses so get them involved as soon as possible.</p> <p>Change management with staff groups is essential. For some, the move from the service they work in and strongly identify with, for example, a school, health setting, or a Connexions service is very difficult. People need support to make the change into a multi-agency team.</p> <p>New staff teams need shared experiences and understanding of each others roles to make the team work, build trust and mutual respect and understanding. For example:</p> <ul style="list-style-type: none"> <li>• practicing joint working, understanding roles and responsibilities of other staff groups,</li> </ul>

<b>Action</b>	<b>Notes</b>
Contractual issues for staff	<ul style="list-style-type: none"> <li>• joint basic training opportunities,</li> <li>• managers spending planning days together.</li> </ul> <p>Teams who are not directly involved but who work with the multi-agency team must also be kept up to date and know how they can communicate and work with the new team in future.</p> <p>Concerns about redundancy, changing roles and responsibilities, loss of professional peer support and skills development are of real concern. Many of the children's trusts addressed concerns through meetings with staff, involving unions and working with human resources teams to develop a strategy acceptable to staff from across agencies.</p> <p>To resolve some of the issues children's trusts have tried out a range of solutions like staff working across the year rather than just in term time and having more control over their hours. Offering more part time working, sharing roles across the team. Also, seconding staff part time from their home agency – with clear agreements in place, agencies working together on new staff job descriptions, and using cross agency interview panels.</p>
Keeping up momentum – it takes a long time to get foundations in place.	To hold the entire process together an effective children's trust manager needs to be in place.

## Conclusion

Getting to a point where services are fully integrated marks a milestone on a long journey. It starts a new phase of work which in itself can present many challenges. The pathfinder children's trusts found that some of the most common challenges were actually finding a suitable site for a co-located service, allaying staff concerns about how the change will affect their lifestyle and work, and building in enough time to make the changes needed to make sure the move toward integrated services is successful.

Service integration is a long term, complex project. It involves major structural and cultural change for organisations and the individuals within them. However, parents and professionals report multi-agency teams do bring real improvements, to understanding of roles, better joint working and an improved response to requests from families.

## 4 Assessment process and information sharing

### Background

As the pathfinder children's trusts developed, the new models for capturing, collating and sharing information were also being tested. The Integrated Children's System (ICS) and Common Assessment Framework (CAF) form the bedrock of change for delivering faster, more appropriate referral and recording processes to disabled children. The children's trusts worked to develop systems which would be more responsive to the needs of families. Many of the children's trusts were also pilot sites for the Common Assessment Framework (CAF). This led to workstreams looking at the potential of using the CAF as a simple information gathering tool and to identify any specialist assessments which may be needed.

### Legislation and guidance

#### **The Common Assessment Framework (CAF) for Children and Young People**

The development of the CAF is still underway, with local areas finding ways to use this standardised tool most effectively to meet local need. The system is designed to gather information from families, to more quickly identify children with additional needs. For most disabled children, the CAF works as an initial process, leading to more specialist assessments as needed. For example; access to speech and language therapy services.

For more information, [www.everychildmatters.gov.uk/delivering-services/caf/](http://www.everychildmatters.gov.uk/delivering-services/caf/)

#### **Integrated Children's System (ICS)**

The ICS aims to promote better outcomes for children in need. Since January 2006, local authorities in England should have the computer software in place to support the ICS for all new referrals. Children's social care services are at the hub of implementing the system and working with it. A number of authorities acted as pilots for the ICS and identified a number of strategies which are needed to involve all agencies effectively and make the system work:

- interagency steering groups,
- interagency briefing and training sessions,
- using specialist staff to act as champions for their agency,
- focusing on opportunities to share information electronically.

For more information: [www.everychildmatters.gov.uk/socialcare/ics](http://www.everychildmatters.gov.uk/socialcare/ics)

## Good practice

### London Borough of Tower Hamlets

All services have agreed to use the same definition of disability to improve access to services and continuity for families. Reaching agreement on the definition was time consuming and involved key agencies coming together over many months to reach a consensus. The thought and planning in producing the definition is an important process for staff to experience to have an investment in the end product. As well as providing clarity across services, this common definition will help in developing the Disabled Children's Register and broaden understanding across a range of wider agencies about who this is for. The extract below is reproduced with kind permission of Tower Hamlets children's trust.

*For Tower Hamlets it is proposed that the definition of disability for the services provided links to the following legislation, guidance and regulations:*

- Children Act 1989
- Disability Discrimination Act 1995
- Human Rights Act 1998
- SEN Code of Practice
- National Service Framework
- Improving the Life Chances of Disabled People

*A clear distinction needs to be made between disability, impairment and ill-health. Impairments are long-term characteristics of an individual that affect their functioning and/or appearance. Ill health is the short term or long term consequence of disease or sickness. Many people who have an impairment or ill health would not consider themselves to be disabled.*

*As the basis for future development the definition will be:*

*The service will address the needs of any disabled child who permanently or temporarily:*

- is experiencing significant developmental or acquired impairments or delays, in one or more areas of cognitive development, sensory or physical development, communications development, social, behavioural or emotional development, or;*
- has a condition which has a high probability of resulting in developmental delay or deteriorating functional ability, and;*
- whose ability to achieve their potential is impaired due to a wide range of barriers facing them.*

*'Potential' relates to the five outcomes of the Children Act 2004.*

*Services are now reviewing their eligibility criteria with reference to the new definition.*

### Gateshead

Has developed work around issues of assessment and information management, bringing together a range of agencies to look at

common assessment requirements and joint information strands. Gateshead started using their 'signs of wellbeing' assessment with disabled children in March 2005. Signs of wellbeing is a simple assessment tool based on solution focussed practice and thinking. It supports practitioners to engage with families and jointly plan next steps. For disabled children the completed assessment is used as a referral tool into a single point of access and is looked at by a multi-agency group with wide representation across health, social care, education, family support, early years and the voluntary sector. The group also nominates a key worker identified to work with the family and other practitioners involved to co-ordinate services.

### **Newcastle**

The Framework for Multi-agency Environments (FAME) is a government (ODPM) initiative launched in 2003 to support local areas to share information effectively across agencies. Newcastle City Council, through the pathfinder children's trust worked on a pilot project to test the FAME system in developing a single assessment process for disabled children:

*'Previously children with disabilities or complex health needs received as many as 18 different assessments. The assessments were not co-ordinated and could be simultaneous or sequential. Each assessor asked similar questions resulting in the parents and carers having to repeat 'their story'. The parent or carer almost became the co-ordinator of the various services. This was complex, time consuming and frustrating for parents and carers already experiencing high levels of stress.'*<sup>14</sup>

The system was developed by staff and parents, installed and education, social services and health agencies signed up to use it. However, because of the variety of existing systems across the agencies a good deal of work was needed on technical support to enable the existing electronic systems themselves to communicate. Also, differing priorities across services and the impending introduction to the NHS of a whole new electronic management and information system NPFIT (National Programme for Information Technology) meant the project included many challenges.

Staff from all services were trained in using the system and parents were involved in planning how it would be designed, where the information would be stored, who would be able to see it and how it would be used. This approach helped allay fears about the safety of on-line information and issues about confidentiality. The role in the early stages of parents was crucial to the success of the project.

Like the wider elements needed to successfully bring multi-agency teams together, plan change and integrate services, the issues identified during the process are the same:

- time,
- understanding of each other's roles,
- training,

<sup>14</sup> FAME case study booklet, October 2004. [www.fame-uk.org](http://www.fame-uk.org)



- meaningful involvement of service users, parents and carers.

The system, Link-IT was adopted for local use after the pilot and brings together referral, assessment and planning information for individual children. Link-IT identifies a lead professional for each child so that work is co-ordinated by the professionals. It draws information from and to the education and social services electronic systems. It is portable using tablets and allows single assessments by staff from several agencies.

For more information visit [www.fame-uk.org](http://www.fame-uk.org)

### **Hammersmith and Fulham**

Have mapped out pathways for each agency and developed a generic pathway starting at birth for children with complex needs. The pathways are used by a multi-agency team which agrees a multi-disciplinary assessment pathway with parents involved. This team forms the framework of support for the family and will meet together at key transition points to review support.

## **Key elements of success**

Services in children's trusts are applying the common assessment framework as their initial assessment tool. In most cases, this means that it simply acts as an information gathering exercise for families with disabled children as a further, more specialised assessment is inevitably required. With this in mind, it is important to get the most out of the initial contact for both the families and agencies involved.

As part of the quality protects initiative in 2002, a working group in the Trent, Eastern and West Midlands regions produced a guide to carrying out effective multi-agency assessments, this in turn was based on work by Jenny Morris.<sup>15</sup> An excerpt from their report, reproduced below, outlining the basic principles of multi-agency assessments for disabled children and young people, offers a solid foundation to mutually agreed aims in a multi-agency assessment:

*There should be one mutually acceptable model of assessment owned by all subscribing agencies, including both assessor and providers and young people and their families. Para 1.50*

*The model must recognise that the concept of disability is created by society and that this concept may not necessarily represent an individual's needs. Para 1.19*

*The model must recognise assessment as a process, not as an event. Para 1.51*

*The process of assessment must reflect a positive approach to partnership between all parties involved. Para 1.44*

*The parties to assessment and subsequent reviews must include all relevant statutory agencies, the independent and voluntary sector and young people, their carers and families. Para 1.22*

<sup>15</sup> *Think multi-agency: a practice based framework for multi-agency planning and assessments for disabled children and their families.* Quality Protects, Trent, Eastern and West Midlands Region, 2002.

*The process of assessment must be clear and easily understood by all parties involved. Para 1.24*

*The outcomes of the assessment must be understandable, measurable and relevant to the young persons needs and must be subject to review. Para 1.54*

*The young persons views must be ascertained and heard and documented within the assessment. They must be integral to the plan. Para 1.34-35*

*The assessment must recognise the young person as, above all, an individual and that each person, whether they be a child, young person or an adult, experiences their own environment and situation individually. Para 1.43*

The numbers shown at the end of each statement refer to the corresponding paragraph in the *Framework for the Assessment of Children in Need and their Families*, Department of Health, 2000, which supports the principles it relates to. Many of these are also cross referenced in the SEN Code of Practice.

## Conclusion

In spite of the progress the children's trusts have made, the effective assessment of need for disabled children and their families continues to be an area requiring further work. The use of restrictive eligibility criteria for many social care services is a reality which no improvement to the assessment process itself will change.

Developing a systematic approach to gathering and keeping information across key agencies will lead to a better, more co-ordinated response, it gives families more control as they can access records when they want and have a degree of control over who sees which information. The new systems will also hopefully improve things like: clashing hospital appointments, reasonable notice of SEN reviews and planning meetings, and more transparency in how services are allocated.

## 5 Key working and lead professionals

*'Whatever the title of the role, the critical point is that children, young people and their parents or carers have access to one practitioner who acts as a single point of contact for them, who supports them in making choices about the help that they need, who ensures that they receive the right help at the right time, delivered by the most appropriate practitioners, and who makes sure that professional duplication and inconsistency are avoided.'*<sup>16</sup>

<sup>16</sup> Page 34, *Lead professional guidance for children with additional needs*, DFES, 2005.

## Background

Historically, parents of disabled children have been called upon to negotiate across a range of services to get appointments, follow up actions, find out when meetings are planned, etc. The opportunity of having a key worker to take on a supporting role is an extremely welcome initiative. The planning and implementation of key worker systems is now commonplace. The pathfinder children's trusts have developed this work primarily in early years settings, with some areas looking to extend cover to the transition to adulthood. Alongside this is the development of the role of a lead professional, also potentially a welcome support to families.

There remains some level of confusion around the roles of a lead professional and that of a key worker, and how they differ.

Key working, in the context of supporting families with disabled children, is usually used to refer to a person acting as a single point of contact for a family, who has an advocacy and support role. They usually work with families who have children with complex needs, and work with them over an extended period of time. The role is likely to be much more involved than that of lead professional.

The role of lead professional is to work primarily with families who have some identified need but do not meet the eligibility criteria for specialist services and support. The lead professional guidance describes the primary functions as including:

- *act as a single point of contact that children, young people and families can trust, and who is able to support them in making choices and in navigating their way through the system,*
- *ensure that children and families get appropriate interventions when needed, which are well planned, regularly reviewed and effectively delivered,*
- *reduce overlap and inconsistency from other practitioners,*
- *ensuring that the child, young person and their family remain central to any decisions made about them,*
- *ensuring that where children, young people and their families may require more specialist services, the lead professional continues to support them while any more specialist assessments are carried out.*<sup>17</sup>

The lead professional role is being piloted alongside the common assessment framework in a number of authorities in 2005/06. There is a formal evaluation of this trial planned. The Lead Professional Guidance is also due to be revised in 2006. For updated information on this see [www.everychildmatters.gov.uk/](http://www.everychildmatters.gov.uk/)

<sup>17</sup> [www.everychildmatters.gov.uk/deliveringservices/leadprofessional/](http://www.everychildmatters.gov.uk/deliveringservices/leadprofessional/)

## Legislation and guidance

The role of lead professional is identified in the Children Act 2004 as a key element in making sure frontline services can provide integrated delivery for families. The DfES produced Lead Professional Guidance for children with additional needs in 2005. The guidance lists criteria for effective management and accountability frameworks to support the delivery of the lead professional role. It also looks at the difference in the role of lead professional and key worker for disabled children.

An update of this guidance is expected to be available in summer 2006. More details are available from [www.everychildmatters.gov.uk/deliveringservices/leadprofessional/](http://www.everychildmatters.gov.uk/deliveringservices/leadprofessional/)

*The National Service Framework (NSF) for Children, Young People and Maternity Services, 2004* includes recommendations on families having access to a key worker type role, as does the early years guidance *Together from the start* (DH and DfES, 2003).

For more information: [www.dh.gov/policyguidance/healthandsocialcaretopics/childrensservices](http://www.dh.gov/policyguidance/healthandsocialcaretopics/childrensservices)

## Good practice

### Gateshead

A lead professional scheme is underway with 40 families taking part. The lead professionals are working with families which include children with complex needs and covers a wide age group.

Support for the lead professionals includes regular briefings and a support pack. The lead professionals taking part are from across the board and include social workers (from the children with disabilities team), community nurses and health visitors. One of the main challenges so far is making sure staff feel supported, and reassuring managers that staff taking part will not be overloaded.

### Darlington

Have developed a key worker service for 0 to 5 year olds which will eventually be rolled out to support the 0 to 19 age group. The service is underpinned by the following values, reproduced with kind permission from Darlington Children's Trust:

- *key working should empower and enable families to meet their own needs as far as possible,*
- *the key worker for a family will change over time as the family's needs change. This should always be done in partnership with the family and the family can also request a change of key worker or approach another key worker in specific circumstances,*
- *negotiation should take place with families about the support they need,*

- *key workers should aim to co-ordinate services and cannot nor should not do everything for the family,*
- *there should be a child and family centred approach to key working,*
- *for a key working system to be effective there needs to be openness, honesty and sharing of information between families and professionals,*
- *it is crucial that all involved with a family recognise the importance of respecting their wishes about what information they want shared and with which other professionals,*
- *recognition that times of transition for families of disabled children are often stressful.*

### **Ealing**

Has been piloting a keyworker service using designated and non-designated key workers. Full evaluation will be available in June 2006. Early feedback has been very positive and they are looking to secure long term funding to rollout the programme.

### **Key elements for success**

The children's trusts found, in developing these roles to support families, that identifying children with specific needs, beginning work with a small group of families, and working with a specific age group gave time to build an effective service. This gives staff time to plan the role and take on the tasks associated with it.

Some areas are employing key workers as a dedicated post, whilst most are using existing staff from across a range of agencies and building in the new role to their existing one. The children's trusts identified that the status of key workers needed to be promoted across other staff groups and agencies to make sure they had the authority to negotiate on a families behalf.

Involving families in choosing a key worker is essential to the success of the work, some children's trusts have families involved on interview panels. This has to be managed so they are not asked to interview staff who could potentially take on this kind of role for their family in future.

The Care Coordination Network UK produced a set of standards for key workers in 2004. This includes both organisational and practice levels. The organisational level standards include:

- *multi-agency commitment at a strategic and practice level;*
- *multi-agency management group including families and, at the minimum, representatives from education, health, social services, and the voluntary sector, if a stakeholder in the area. This group needs to include senior managers with the power to commit resources. The group should establish formal links with other agencies, including housing, leisure and benefits, to enable the key worker service to access services from these agencies to meet families' needs;*

- *an agreed referral system and specific guidelines for eligibility for the key worker service;*
- *a joint policy for information sharing between agencies;*
- *a multi-agency protocol for joint assessment, drawing up an inter-agency care plan and review of the needs of the disabled child and their family;*
- *a communication strategy. All professionals working at all levels of the organisations involved – managers and practitioners – as well as parents and children and young people need to be kept fully informed and, where appropriate, involved in the planning and development of the key worker service;*
- *a key worker manager to manage the service on a day to day basis and to report to the multi-agency management group;*
- *ongoing resources to run the service including the provision of administrative support, induction and ongoing training and supervision for key workers;*
- *identifying the cultural needs of the local population, including minority ethnic groups, and ensuring that the service provides for these needs;*
- *monitoring, reviewing and evaluating the service.*

The full list of standards can be found at [www.ccnuk.org.uk/](http://www.ccnuk.org.uk/)

## Conclusion

The support families can potentially receive from having a named person they can contact who will support them and act as a conduit to their access to services is of huge value to families with disabled children.

This role, whether provided by a key worker or a lead professional, can really make a difference to the quality of life families enjoy, and add to staff's personal development. The children's trust areas are part of a wider move to try and make this a reality for all families. Information from families and staff so far is that this does make a real difference. The next challenge for services is to establish the roles and extend out to meet the needs of a wider set of disabled children and their families.

## 6 Developing capacity for change

*'The membership of the children's trust board needs to comprise chief executives and directors at sufficiently high level in their organisations to be able to make decisions and to ensure that decisions made at board level are implemented. The nature of children's trust arrangements requires the participating organisations to make decisions that will affect their own organisations strategic plans, budget plans, management*

structures, staffing and recruitment, resources and financial management. If the organisation's representative is not authorised to make these decisions then the progress of the children's trust is severely impaired.<sup>18</sup>

## Background

The majority of pathfinder children's trusts have operated with one or two dedicated posts, many of which were funded to March 2006. Although much was achieved in this period, the question of capacity at both strategic and operational levels was a real concern for children's trusts and looks set to remain a challenge for the existing and developing children's trusts around the country.

In this context, the role of children's trust manager or co-ordinator becomes a crucial element in the success of developing an effective children's trust. One of the most important lessons from the pathfinder children's trusts is about the importance of having an identified lead to move the work forward, liaise with all services, build trust across agencies and, as one manager put it, act as an honest broker.

Taking on a role like this requires a range of experience which in itself can present a challenge. It is very unusual for an individual to have a working knowledge of all three key services which constitute the core of the children's trust (health, education and social services). Most people have expertise in one, good knowledge of a second and some knowledge of the third. To develop an effective children's trust and ensure it delivers the best options for service users, the manager needs to develop skills in understanding all services.

## Good practice

### Hammersmith and Fulham

The children's trust manager arranged to shadow peers from other key agencies for a number of days, and to attend key meetings with them within their services. This led to a much better understanding of their roles, established a working relationship early on and gave those in other services a much clearer understanding of what the children's trust was about and trying to achieve. This also gave the manager an insight into the different language and criteria services use and led to the formulation of a multi-agency pathway for disabled children with complex needs.

### Leicester City

Planning to develop a post for an interagency pathways planning officer to develop a disabled children's pathway. The post will be based with the disabled children's team. An interagency project planning group has been established which will commission the work. The focus will be on clear generic pathways rather than detailed condition based pathways.

<sup>18</sup> 11/15, *National evaluation of children's trust arrangements*, September 2005, University of East Anglia (UEA).

## Key elements of success

The induction process is essential and acts as a dual exercise in broadening knowledge of other services and promoting the role of the children's trust across agencies. A complex set of skills is needed to meet this challenge and many of the children's trusts developed job descriptions to reflect this. Attached at Appendix 2 is an extract from the job description of the disabled children integrated services manager in Tower Hamlets.

## Conclusion

Having someone in place in a dedicated post to establish the children's trust is essential to its success. This role is key in implementing effective children's trust arrangements against a backdrop of fast paced change at local, regional and national government level. There is a need for someone who can focus on local issues and set this in the context of wider change.

# 7 Transition to adulthood

## Background

The transition to adulthood for disabled young people continues to be one of the most challenging times for securing the support needed to make their experience positive and successful. At the outset of their work, a number of the pathfinder children's trusts had identified this as an area they were keen to improve. The first steps for the children's trusts was to get agreement from across services on who was responsible for offering which support to disabled young people. As in other areas of work this often proved to be the most difficult and time consuming part of the process. A number of children's trusts have made significant progress in setting up a transition service which improves the experience of disabled young people and their families.

## Legislation and guidance

Over the past five years, the increasing concern about the lack of support for disabled young people moving into adult life has led to a significant amount of legislation and guidance which sets duties and standards on transition. Listed below are the main documents. More detailed information is available from [www.transitioninfonynetwork.org.uk](http://www.transitioninfonynetwork.org.uk)

- *Improving life chances of disabled people*, 2004, Prime Minister's Strategy Unit, Cabinet Office.
- *Independence, well-being and choice: our vision for the future of social care for adults in England*, 2005, Department of Health



- *National Service Framework for Children, Young People and Maternity Services*, 2004, Department of Health (DH) and Department for Education and Skills (DfES).
- *Youth Matters*, 2005, Youth green paper, DfES.
- Education and Inspections Bill 2006, DfES.
- The Learning and Skills Act 2000, DfES.
- *Valuing people: a new strategy for learning disability for the 21st century*, 2001, DH.
- *Removing barriers to achievement; the government's strategy for SEN*, 2004, DfES.

## Good practice

### **Sandwell**

Have developed a joint transition team. This is being managed by a team manager from the Connexions service. It already has Connexions personal advisors (PAs) and a youth co-ordinator as part of the team. The PAs support young people within the special schools and out-of-borough colleges and provide advice and guidance to PAs in mainstream settings. The youth co-ordinator is responsible for helping young people to identify suitable mainstream and specialist resources, directly managing 4 Youth service provisions and supporting mainstream resources with meeting needs of young people with a disability. Funding has been agreed to incrementally increase social work posts within the team with a view to having these staff also working with young people from 13 to 25 years old. The team have introduced a multi-agency transition pathway that will be piloted in special and mainstream schools and developed an interactive cd-rom to capture the views of young people.

### **Bolton**

Have a young adults team that works with disabled young people in transition.

The development of a young adults team came about through a service redesign and needed only a small amount of investment of resources to achieve. Resources for the team come from both the adults and children's teams. The team aims to be person centred in its focus and is committed to supporting disabled young people to participate in the local community.

The transition team members include:

- team leader,
- 3.5 social workers (from disabled children team and learning disabilities team),
- 2 part time community nurses,
- 1 occupational therapist (vacant),
- 1 BME development worker,
- 1 Connexions personal advisor.

The service was introduced using an incremental approach – rather than taking on all cases of young people aged 18 to 24 they took on certain groups of young people. This approach means that partnership with other services is particularly important.

The workers in the young adults team work with young people from age 16 to the time that they exit the service which could be up to the age of 24. This provides consistency for the young people at a time when other professionals who are involved in their lives are changing.

The team has met with parents to discuss the changes and what they mean for young people and their families. Parent representatives were on the task force that worked on the development of the team and are now on the steering group of the young adults team.

### **Leicester City**

Have a jointly commissioned transitions development officer shared between LSC/LDPB/Disabled Children's Programme Board for the children's trust/children's strategic partnership. Appendix 3 gives an account of the process.

## **Key elements of success**

Transition to adulthood is an area that has certainly benefited from the bringing together of teams and the beginnings of shared budgets. This makes the information flow to young people, and the transfer to new services a less disjointed experience.

There is a wealth of information on good practice in transition. The Transition Information Network (TIN), a consortium of agencies working in this field, can provide information and signposting to these resources. For further details visit [www.transitioninfonetwork.org.uk](http://www.transitioninfonetwork.org.uk)

The government have commissioned the Council for Disabled Children and Skill to work with them on producing a Transition Guide for children's services. The Council for Disabled Children are also producing a partner document which maps good practice in transition from across the country. Both will be published in summer 2006.

## **Conclusion**

The transition to adulthood should be a time of celebration for all young people. For those with disabilities this is often not the case. Within the children's trusts, most success has been brought about through the forming of multi-agency teams, in particular working with adult social services and health professionals to formulate ways of making the provision of support effective during the transfer of responsibility.

## 8 Evaluation

### Background

Measuring the effectiveness of the pathfinder children's trust models and sharing learning is a work in progress. This guide is part of that process. More formally, the University of East Anglia (UEA) is carrying out a national evaluation of the pathfinder children's trusts. Reports produced to date are available from [www.everychildmatters.gov.uk/strategy/childrenstrustpathfinders/nationalevaluation/](http://www.everychildmatters.gov.uk/strategy/childrenstrustpathfinders/nationalevaluation/)

The evaluation has been commissioned by the Department of Health and Department for Education and Skills.

Beyond this, a number of the children's trusts have developed local mechanisms for measuring effectiveness. There is an enhanced role for Regional Partnerships and Regional Government Offices in supporting this part of the agenda. The pathfinder children's trusts had support available through the national team who were tasked to support them in learning and networking. Some regions came together to meet and share experiences throughout the time they were pathfinders. These meetings were seen as valuable. A broader network meeting, bringing together the children's trusts focusing on disabled children services nationally, was convened by CDC with similar results. It is hoped that a similar network, incorporating a wider set of authorities taking on children's trust status will be developed later in 2006.

### Legislation

Key levers for change for the children's trusts are set out in the statutory requirements of the Children Act 2004. Although there is no duty to create a children's trust, the following imperatives are in place:

- the duty for agencies to co-operate in the delivery of services,
- the production of a children and young people's plan (CYPP), although 'three star' authorities are not required to produce a CYPP, many do as a matter of good practice and planning,
- leadership and accountability through the roles of the director of children's services, the lead member, and, in the case of transition to adult services, the director of adult services,
- the integrated inspection framework including the joint area reviews,
- funding streams accessed by reaching particular targets.

Annual performance assessments (APA) are the result of the Every Child Matters requirements to move toward integrated inspection to rationalise planning, accountability and performance management.

The APAs look at services locally to see how they are working together to improve outcomes.

Joint area reviews (JARs) started in September 2005. A number of the pathfinder children's trusts have undergone a JAR and some were tested as pilot sites earlier in 2005. JARs are intended to inspect cross agency provision. They replace separate inspections of education and social care services. The reviews are expected to take place at the same time as the corporate assessment of councils for the comprehensive performance assessment, to align the processes and make them complimentary.

## Good practice

### East Riding of Yorkshire

The new team created by the pathfinder children's trust has developed a direct payment scheme for disabled children and those with life limiting illness. The scheme has recently been evaluated to look at the impact on the lives of disabled children and their families. The report demonstrated an 'overwhelmingly positive' impact on family life, with (amongst other things) children enabled to make new friends and develop their confidence.

### North East Region

A group of pathfinder children's trusts in the North East took part in a series of peer reviews. This work was supported by their regional co-ordinator. Each children's trust worked with one other to evaluate their work and learn from their experience. All of those taking part, including York, Darlington, Newcastle and Gateshead, valued the experience highly and found the learning excellent.

### Telford and Wrekin

Have commissioned a piece of work to identify the specific needs of families with disabled children from black and minority ethnic communities and work at how to effectively offer services and support.

## Key elements for success

*'In planning changes authorities will want to balance the pace of reform against the need to maintain ongoing services. Every local area has a different starting point and different circumstances, so there cannot be a single model for managing the necessary changes. Each area needs to determine its own route.'*

From [www.everychildmatters.gov.uk/strategy/planningandcommissioning](http://www.everychildmatters.gov.uk/strategy/planningandcommissioning)

### SEN Regional Partnerships<sup>19</sup> benchmarking initiative

All 11 regions have been collecting data for some years now. This includes basic statistics on the number of children with statements in mainstream schools, funding information; information on pupils out of authority placements; parent partnership services and sensory impairment services. This data is used to support regional and local priorities.

<sup>19</sup> Now renamed Regional Partnerships.

In the south west SEN Regional Partnership, parent partnership services used benchmarking data to create a set of standards for SEN provision, which builds on the minimum standards in the SEN code of practice.

### **National child health and maternity service mapping**

This is an annual collection of data covering the child health provision across England. Information is collected about services within health and at the interface between health, education and social care. The data aims to support the development of child health services locally and nationally by providing information that will support the implementation of child policy.

For more information: National Health Service Mapping Project, [www.childhealthmapping.org.uk](http://www.childhealthmapping.org.uk)

## **Conclusion**

Effective ways of measuring the impact of change are key to sustainable, responsive services. For the pathfinder children's trusts this meant employing a range of tools and adapting them as the new service structure took shape. The participation of children and families in the evaluation process has been a success in children's trust areas and led to a much more responsive range of support. The formal inspection process is in the midst of change, with bodies merging and the advent of the Joint Area Review. It will be crucial for inspectors to have a clear understanding of the needs of disabled children and their families and to learn how the new systems and multi-agency teams can deliver this most effectively.

# **9**

## **Participation of disabled children and young people**

*'The views and aspirations of the people who use services are not yet at the heart of commissioning services for individuals. Councils need to pay more attention to what people say about the qualities that are important to them in services.'*<sup>20</sup>

### **Background**

Children and young people are affected by decisions made on all levels and in particular, disabled children and young people are hugely affected by service planning and commissioning strategies. The involvement of disabled children in the pathfinder children's trusts proved to be a real challenge. Many children's trust areas which had a focus on disabled children's services managed to achieve some progress but remained concerned at the lack of involvement of disabled children in service planning and improvement.

<sup>20</sup> *The state of social care in England 2004-05*, a summary, page 21, CSCI, December 2005.

As the children's trusts continue to develop, the role of disabled children and young people will increase as their involvement is very much on agendas – the capacity and expertise to support them is still being put in place.

As part of the CDC project, we worked with the National Children's Bureau Research Team (as part of the National Evaluation Project at UEA) on looking at the role disabled children and young people have in the development of the trusts. The UEA first phase report concluded that:

*'The enthusiasm of professionals' commitment to consulting young people and parents matches their aspiration to place children and families at the centre of service reorganisation.'*<sup>21</sup>

## Legislation

There is a wealth of legislation which enshrines the right for the voice of children and young people to be heard. Below are listed some of the key documents:

- The Children Act 1989 requires that whenever a court considers any question with respect to the welfare of a child, it must have regard in particular to the ascertainable wishes and feelings of the child concerned (considered in the light of the child's age and understanding);
- The Children Act 2004 promotes the participation of children and young people in both service planning and local community activity. It also creates the post of Children's Commissioner for England. The Commissioner's role is to promote awareness of the views and interests of children in England;
- The Disability Discrimination Act 2005 requires public authorities to have due regard to the need to promote positive attitudes towards disabled people and to encourage participation by disabled people in public life;
- National Health Service and Health Care Professions Act 2002 created patients' forums for each NHS Trust and Primary Care Trust. The forum monitors services and seeks the views of patients to make recommendations;
- The National Service Framework, 2004 includes specific statements on participation. The *SEN Code of Practice*, 2001 and Education Act 2002 also uphold the principles of participation.

## Good practice

### Calderdale

Working with the Calderdale Parent and Carers Council, the children's trust is funding a young disabled people's forum which meets regularly and runs a range of activities as well as operating as a forum. This work is supported by an Inclusion Worker.

<sup>21</sup> 9/15, *National evaluation of children's trust arrangements*, September 2005, University of East Anglia (UEA).

### **London Borough of Ealing**

Commissioned a specialist agency to work with young people with complex communication needs to make sure their views were included in children's trust planning. Developing a DVD with Children with Disabilities for circulation to all Ealing schools

### **Sandwell**

Have developed a range of opportunities for young people with a disability to develop advocacy skills and influence the planning and running of services. These include:

- Funding a youth worker at People First self-advocacy group. In addition to developing self advocacy skills they will undertake two formal consultations during each year.
  - Setting up a mixed young people's committee to represent young people with a disability across the borough and also nominate representatives to attend the youth cabinet.
  - A youth committee within the local independent living centre.
- Work in 2006/7 will focus on joining up the work of these groups to strengthen the voice of young people with a disability.

### **Newcastle**

Have worked with their human resources team to develop ways of involving disabled children and their parents and carers in the selection process for posts like social workers/managers. There are plans from the trust to utilise the skills of nursery nurses, play staff and others who have experience of working with disabled children to train other staff in supporting disabled children to take part. The team are currently drawing up good practice guidance based on their experience of this work. The guidance will look at issues like ensuring young people interviewing staff are not then allocated the same staff as a social worker.

## **Key elements of success**

Many mechanisms for young people's involvement exclude disabled children, mainly unintentionally. Local youth parliaments or forums are a common way for children's views to be heard by their local authority. Disabled children and young people cite the following reasons for not attending this kind of board:

- feeling those elected do not represent them,
- lack of transport to and from the meetings,
- discuss things that don't interest them,
- no one senior takes the group seriously,
- no supporter to help in group, for example, with communication,
- no easy read/accessible information available.<sup>22</sup>

There is a wealth of information available on participation of children and young people. For further information visit [www.participationworks.org.uk](http://www.participationworks.org.uk)

<sup>22</sup> Views from young people working with youth services, 2005, CDC

## Conclusion

Disabled children and young people should be at the heart of the children's trusts. They are a group who use services and strive to be included in communities. They have a right to have a say and participate in the improvement of services and support so they can fulfil their potential and live life to the full – like all children and young people.

# 10

## Participation of parents and carers in children's trusts

### Background

As part of the CDC project, we worked with Contact a Family to bring together families and professionals in pathfinder children's trust areas to look at a range of subjects, from how they found out about the pathfinder children's trust, to how many parents of disabled children are actively involved in the planning and operational aspects of their local children's trust.

Some of the pathfinder children's trusts worked effectively with local parent carer representative groups. However, parents and disabled children's representation on children's trust boards and in planning groups remains the exception rather than the rule. Many of the children's trusts found it difficult to persuade colleagues of the importance of including service users in the strategic process. In this section we include parents' views on progress of the children's trusts. A short good practice guide on parent participation is attached at Appendix 4.

### Legislation

A broad range of legislation and guidance requires the participation of service users. For a comprehensive list see the CDC and Contact a Family publication *Parent participation: improving services for disabled children*, details in the Resources section.

The impending duties on public bodies and the duty to promote equality, which the new Disability Discrimination Act 2005 will bring to local authorities, and through them to children's trusts and their partner agencies will begin to have an impact on planning late in 2006 when areas are expected to draw up disability equality schemes – including information on how disabled people and their representatives are included in decision making. This underpins existing guidance and legislation with similar messages. For more information on these duties see [www.drc-gb.org](http://www.drc-gb.org)



## Parents' views about children's trusts

During the project, we brought groups of parents together to ask for their views on the levels of development in children's trusts and the participation of families with disabled children. Meetings were held in seven of the pathfinder children's trust areas. These meetings took place at the beginning and end of the project. Below is a summary of parents' views on their local pathfinder trust.

In every area where meetings were held parents thought the pathfinder children's trust was a great idea and were cautiously optimistic about the possibilities they could create for more responsive and less wasteful services. However, many parents still don't know what children's trust arrangements mean for services they may use. General findings were:

- Parents are very keen to participate constructively but all say that they need more parents to join them and that they should be more diverse in background and range of disabilities (of their children).
- Parents identified the need for support and training for them to participate fully and be effective at forums and in working groups.
- Parents have commented on the inconsistency of professionals' attitudes to participation across a local authority area. This may be because the participation aspect of the work is managed by one particular service. Where parents had an established forum and a support worker this did not come up as an issue to the same degree.
- Many of the pathfinder children's trusts have employed participation development workers to support parents and act as a link to the children's trust. The workers are highly regarded by parents especially when the workers are employed independently by voluntary agencies, although the funding may come from the children's trust. Parents felt this role was essential to sustain and develop parents' participation.
- Parents respect and give credit to professionals who genuinely engage with them and such professionals give them hope and encourage them to participate.
- Parents are very aware of tokenism and are quick to disengage when they are faced with situations where they are devalued. For example not paying expenses, poor timing of meetings and use of jargon.
- All parents are concerned about parents who are left out of the information loop, have no say and are marginalised through poverty, language or caring responsibilities.
- Parents say that visible action and evidence of their influence is vital to maintain their participation. They accept that change will take time but they need evidence of progress.

## London Borough of Sutton

*'Having parents on the board is brilliant.'*

*'Parent reps are involved with different specialist groups. The effects of this are profound. It reaches the parts that other messages don't.'*

*parents from Sutton*

In Sutton, parents have been involved since an initial consultation exercise in 2001. This fed into the joint strategy which later became the foundation for Sutton's application for pathfinder children's trust status.

A parents' forum meets regularly giving parents an opportunity to discuss service provision and decide what they would like to raise at children's trust board level.

The children's trust is unique in having six parent representatives sitting on the children's trust board. This gives parents parity with the statutory and voluntary sectors which also have six representatives each. This model has increased the direct communication between parents and senior decision makers within each of the main services. Officers from other agencies also attend regularly to report to the board and hear directly from parents.

Parent representatives also sit on the children's trust sub-groups for a wide variety of relevant services. This enables them to have a voice at other levels and to work directly with a wider range of professionals.

The children's trust funds a Contact a Family worker who organises the election and training of the parent representatives and facilitates the running of the parents' forum.

As a result of this level of participation by parents, there have been some significant changes in service provision. These include the promotion of a key worker service for parent carers, the development of an inclusive summer youth scheme and a project to develop information and support resources for parent carers and the professionals who work alongside them.

## Devon

*'[As a result of the Trust] ... professionals are now much more willing to listen to parents' voices and acknowledge that parents are the ones that know their children best. Just because they are talking to parents it doesn't mean it is going to cost them money. Once they understand this point they really get to grips with it.'*

*member of a parents' forum, Devon*

As a rural authority with a population spread over a wide geographical area and relatively infrequent travel links, parent participation poses particular challenges.

The children's trust has responded by providing 60 hours of participation support per week via paid workers. This is divided between the six locality forums, which each feed into the county forum. This feeds directly to the children's trust board.

The locality forums ensure that parents around the county can get involved and give their views without having to travel long distances. There are now three paid forum support workers in post, each with responsibility for two locality forums and joint responsibility for the county forum.

Another recent development has been parents' representation on the children's trust board which has increased from one parent to two.

### **Darlington**

*'Parents of disabled children in Darlington now have an effective voice; contributing and changing the delivery and relevance of Children's Services. The benefits of an open access policy to the Board of the children's trust allows a full contribution to decision making especially within the agenda of 'Every Child Matters''*

*Parents' forum member, Darlington*

The parents' forum has developed dramatically over the last 12 months. Parents who are involved are very positive and feel that the forum is accomplishing positive changes for disabled children and their families.

The forum meets every two months, rotating between two daytime meetings and one evening meeting. It has a core of approximately 20 parents who attend every meeting, plus others who attend when they can. There are 80 parents registered.

Meetings have a regular agenda of feedback from the parent representatives about the progress made on the board, an update from an invited professional, networking time and coffee during which parents can write down questions they would like to ask, followed by a question and answer session with the professional.

Currently meetings are taking each of the Every Child Matters outcomes in turn and addressing these. Future meetings will then look at the skills which parents need as a result of having a disabled child.

The forum has two representatives who attend the children's trust board. They have negotiated a regular slot at the children's trust board meetings which they use to raise parents' issues. They have regular business meetings where they decide which issues will be taken forward to the next children's trust board meeting. The process is transparent: minutes of these meetings are available to view on the Darlington Association on Disability website: [www.darlingtondisability.org](http://www.darlingtondisability.org)

The Forum is aware that they need to communicate with other parents in Darlington who they are not currently in touch with. They would like to:

- train new parents to take over the representative role when the current parents step down,
- increase their representation of families who have children with a range of disabilities,
- know more about what different parents need, for example those from black and minority ethnic backgrounds.

The parents' forum is funded by the children's trust. This covers their speaker and personal expenses, venue costs, publicity and the support worker employed by Darlington Association on Disability.

### **Key elements of success**

A short guide to good practice in parent participation is attached at Appendix 4.

### **Conclusion**

In areas where families are at the centre of planning, services and support are more responsive to need. Families' confidence increases and professionals have a much better understanding of how services and support can be provided most efficiently and effectively. This is a major culture change and one the pathfinder children's trusts have made a significant contribution to.

# The future

---

The aims of developing local children's trust arrangements have been well received in most areas. Certainly, the pathfinder children's trusts involved in the CDC project have huge commitment from staff and families alike.

There is real evidence of change in children's trust areas which has led to an improvement in services and support. The pathfinder children's trusts have begun to tackle some of the more complex and challenging issues facing all children's services today; they have developed effective communication strategies, brokered joint agreements across services, brought multi-agency teams together and used this work to improve services in areas like transition and family support.

Their approach has been flexible to accommodate local needs. In many cases, with agencies beginning to work together informally, building up trust and developing formal agreements over an extended period of time.

This has in some large part been possible due to the commitment and professionalism of the managers appointed and the ability to rely on good, motivated staff teams. The value of which must not be underestimated.

The pathfinder children's trusts have been operating now for over two years. They have achieved a lot, but there is still much to do. Bringing about structural and cultural change in a series of complex organisations takes commitment, consistency and a considerable amount of time to ensure the change is effective and sustainable. The National Children's Trust and Emerging Practice Team is changing structure and specific support for new and developing children's trusts will primarily be from their regional Government Office through the new post of Director of Children and Learners. Alongside this, it is important to consider the use of peer support groups and some sort of focus for children's trusts to contact and share information and learning. The pathfinder children's trusts found the opportunities to do this invaluable.

As the role of children's trusts continues to develop, it is becoming evident that other initiatives also developing are not always interlinking with the children's trust agenda and in some instances are duplicating or going in a different direction. For example the development of a separate information database within the NHS, the wider functions of the developing extended schools/services

and children's centres and the reorganisation of local government support networks.

In the move toward further integrated services, it is essential to make sure all services, mainstream and targeted are included in changes. For the Every Child Matters agenda to really make a difference, mainstream services need to be central to the development of the children's trusts with groups of children who are most vulnerable, including disabled children, at the heart of service support.

# Appendices

---

## Appendix 1 Resources

Many resources are set out in the relevant sections of the guide. Below is a summary of this information.

### ***Legislation and guidance***

#### **Children Act 1989**

[www.crae.org.uk](http://www.crae.org.uk) [www.opsi.gov.uk/acts/acts1989/](http://www.opsi.gov.uk/acts/acts1989/)

#### **Children Act 2004**

DfES, [www.dfes.gov.uk/publications/childrenactreport/](http://www.dfes.gov.uk/publications/childrenactreport/)

#### **Improving life chances of disabled people, 2004**

Prime Minister's Strategy Unit, Cabinet Office,  
[www.strategy.gov.uk/work\\_areas/disability/](http://www.strategy.gov.uk/work_areas/disability/)

#### **Health Act 1999**

Department of Health, [www.dh.gov.uk/PolicyAndGuidance](http://www.dh.gov.uk/PolicyAndGuidance)

#### **Health White Paper: Our health, our care, our say: a new direction for community services, 2006**

Department of Health, [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/)

#### **Independence, well-being and choice: our vision for the future of social care for adults in England, 2005**

Department of Health, [www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare)

#### **National Service Framework for Children, Young People and Maternity Services, 2004**

Department of Health (DH) and Department for Education and Skills, (DfES), [www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/)

#### **Youth matters, 2005**

Youth Green Paper, DfES, [www.dfes.gov.uk/publications/youth/](http://www.dfes.gov.uk/publications/youth/)

#### **Disability Discrimination Act 2005**

[www.drc-gb.org](http://www.drc-gb.org)

#### **Extended schools: providing opportunities and services for all, 2002**

DfES [www.teachernet.gov.uk](http://www.teachernet.gov.uk)

### **Children's centres practice guidance, 2005**

Sure Start, DfES, [www.surestart.gov.uk/](http://www.surestart.gov.uk/)

### **Childcare Bill 2006**

At the time of writing this bill was before parliament.

[www.publications.parliament.uk/](http://www.publications.parliament.uk/)

### **Education and Inspections Bill 2006**

[www.dfes.gov.uk/publications/educationandinspectionsbill/](http://www.dfes.gov.uk/publications/educationandinspectionsbill/)

### **Learning and Skills Act 2000**

DfES, [www.opsi.gov.uk/acts/acts2000/](http://www.opsi.gov.uk/acts/acts2000/)

### **Valuing people: a new strategy for learning disability for the 21st century, 2001**

DH, [www.valuingpeople.gov.uk/](http://www.valuingpeople.gov.uk/)

### **Removing barriers to achievement: the government's strategy for SEN, 2004**

[www.teachernet.gov.uk/wholeschool/sen/senstrategy/](http://www.teachernet.gov.uk/wholeschool/sen/senstrategy/)

### **Every child matters: change for children**

DfES, [www.everychildmatters.gov.uk/](http://www.everychildmatters.gov.uk/)

### **Health Planning Framework 2005/06 to 2007/08**

A framework for all NHS organisations to use in planning, commissioning and delivering services. Cites importance of NSF especially for disabled children as has significant effect on health services. Stresses organisations' performance will be assessed not just against national targets but increasingly on whether they are delivering high quality standards across a range of areas, including NSFs and Nice guidance.

[www.dh.gov.uk/policyandguidance](http://www.dh.gov.uk/policyandguidance)

## ***Publications***

### **Multi-agency working toolkits**

[www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/teamtoolkit/](http://www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/teamtoolkit/)

### **Performance management discussion paper**

[www.integratedcarenetwork.gov.uk/resource\\_view.php?resid=26](http://www.integratedcarenetwork.gov.uk/resource_view.php?resid=26)

### **Good practice in commissioning for community care**

An e-book is being developed. This resource will offer a wide range of perspectives on the role, responsibilities and activities and potential benefits of commissioning in promoting effective investment in social enablement for vulnerable adults.

Institute of Public Care, tel 01225 484088, <http://ipc.brookes.ac.uk>

### **Standards for key workers, 2004**

Care Coordination Network UK, [www.ccuk.org.uk/](http://www.ccuk.org.uk/)



### **Lead professional guidance for children with additional needs**

Will be updated in summer 2006.

DfES, [www.everychildmatters.gov.uk/deliveringservices/leadprofessional/](http://www.everychildmatters.gov.uk/deliveringservices/leadprofessional/)

### **ECM multi-agency working fact sheet, July 2005**

There is also a web-based resource available to support managers and practitioners in starting multi-agency working.

[www.everychildmatters.gov.uk/multiagencyworking](http://www.everychildmatters.gov.uk/multiagencyworking)

### **Think multi-agency: a practice based framework for multi-agency planning and assessments for disabled children and their families**

Trent, Eastern and West Midlands Region, 2002,

[www.dfes.gov.uk/qualityprotects/info/publications/](http://www.dfes.gov.uk/qualityprotects/info/publications/)

### **Life out of school, report**

Thomas Coram Research Unit, [www.ioe.ac.uk/tcru](http://www.ioe.ac.uk/tcru)

### **The state of social care in England 2004/05**

Commission for Social Care Inspection, enquiries tel 0845 015 0120,

[www.csci.org.uk](http://www.csci.org.uk)

### **Children's trusts and Sure Start: improving outcomes for disabled children**

[www.everychildmatters.gov.uk/resources-and-practice/](http://www.everychildmatters.gov.uk/resources-and-practice/)

### **Building a culture of participation, research report, DfES/0826/2003**

Kirby et al, 2003, [www.dfes.gov.uk](http://www.dfes.gov.uk)

### **aMAZE**

Supports and provides information to parents of children and young people with special needs, mainly in the areas of education, health, benefits and social services, and leisure

Community Base, Brighton, tel 01273 772289,

[info@amazebrighton.org.uk](mailto:info@amazebrighton.org.uk)

### **Ten policy briefings**

Email subscription service offering policy briefings on key legislation and guidance covering range of areas including children in public care, education and children's services.

Tel 020 7554 2810, email [info@ten.info](mailto:info@ten.info), [www.ten.info](http://www.ten.info)

### **Freedoms and flexibilities negotiated in pilot local area agreements**

Centre for Local Economic Strategies, [www.cles.org.uk](http://www.cles.org.uk)

### **Integrating children's services: a checklist**

London Regional Partnership, tel 020 7217 3231, [www.londonsen.org.uk](http://www.londonsen.org.uk)

**Children’s workforce strategy: building a world class workforce for children, young people and families**

The government’s response to the consultation.

2006, DfES, [www.everychildmatters.gov.uk/deliveringservices/workforcereform/childrensworkforcestrategy/](http://www.everychildmatters.gov.uk/deliveringservices/workforcereform/childrensworkforcestrategy/)

**National evaluation of children’s trusts: realising children’s trust arrangements, a summary**

University of East Anglia (UEA) and National Children’s Bureau (NCB), September 2005

[www.everychildmatters.gov.uk/strategy/childrenstrustpathfinders/nationalevaluation/](http://www.everychildmatters.gov.uk/strategy/childrenstrustpathfinders/nationalevaluation/)

**Framework for multi-agency environments (FAME)**

Office of the Deputy Prime Minister project. Part of the national strategy for e-government.

[www.fame-uk.org](http://www.fame-uk.org)

**Practice based commissioning**

Website containing comprehensive information.

[www.practicebasedcommissioning.info/](http://www.practicebasedcommissioning.info/)

**Practice based commissioning: promoting clinical engagement, 2004, reprinted 2005**

Department of Health, [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

**Making practice based commissioning a reality: technical guidance, 2005**

Department of Health, [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

**Joint planning and commissioning framework for children, young people and maternity services; processes for joint planning and commissioning, 2006**

DfES, [www.everychildmatters.gov.uk/strategy/planningandcommissioning](http://www.everychildmatters.gov.uk/strategy/planningandcommissioning)

**A process evaluation of the negotiation of pilot local area agreements**

[www.odpm.gov.uk/index.asp?id=1137779](http://www.odpm.gov.uk/index.asp?id=1137779)

**Learning from trailblazer experience of information sharing indexes**

Explains how local authority Information Sharing and Assessment (ISA) trailblazers have influenced the development of the information sharing index project managed by the DfES.

[www.everychildmatters.gov.uk/resources-and-practice/RS00009/](http://www.everychildmatters.gov.uk/resources-and-practice/RS00009/)

**Participation of children and young people**

[www.participationworks.org.uk](http://www.participationworks.org.uk)

### **Parent participation: improving services for disabled children**

A professionals' guide/A parents' guide  
CaF and CDC, 2004. Available from Contact a Family,  
[www.cafamily.org.uk](http://www.cafamily.org.uk), tel 0808 808 3555

### **Parent participation: improving services for disabled children in health settings**

Contact a Family, 2005  
Available from [www.cafamily.org.uk](http://www.cafamily.org.uk), tel 0808 808 3555

## ***Organisations***

### **Care Services Improvement Partnership (CSIP)**

Integrated Care Network (part of CSIP)  
[www.icn.csip.org.uk](http://www.icn.csip.org.uk)

### **Developing Community Hospitals (part of CSIP)**

Information and toolkits.  
[www.developingcommunityhospitals.org.uk](http://www.developingcommunityhospitals.org.uk)

### **Regional Partnerships (formerly the SEN Regional Partnerships)**

The regional partnerships help local authorities and other providers of services to work together, sharing ideas, experience and expertise, with the aim of improving the quality of, and access to, services and provision; and promoting inclusive practice.  
[www.teachernet.gov.uk/sen](http://www.teachernet.gov.uk/sen)

### **Transition Information Network**

Information signposts on the transition to adulthood.  
[www.transitioninfonetwork.org.uk](http://www.transitioninfonetwork.org.uk)

## **Appendix 2    Extract from London Borough of Tower Hamlets job description for the post of Disabled Children Integrated Services Manager**

**Responsible to** Head of Children's Services

**Accountable to** Director of Health Partnerships [Tower Hamlets PCT],  
Head of Access and Inclusion

**Responsible for incorporated services** Child Development Team,  
Community Children's Nursing Team, disabled children's services in  
Social Services, incorporated commissioning

**Developing links with associated and related services** SEN, EPS,  
Inclusive Education Team, Connexions, CAMHS, schools, early years  
provision

## **Main purpose of the job**

To improve outcomes for disabled children in Tower Hamlets.

To work as part of the children's services to ensure the development, implementation and monitoring of:

- The integration of operational services from health, education and social services for disabled children in Tower Hamlets.
- The implementation of common referral, assessment, care planning and reviewing processes for disabled children.
- To strategically and operationally manage the incorporated elements of the Integrated Service.
- To lead the integrated elements of the Integrated Service.
- To implement the Section 31 pooled budget arrangements.
- To be responsible for clinical governance and professional standards within the service.
- To support the development of inclusive provision for disabled children.
- To liaise with the agencies to ensure compliance with all statutory requirements.

## **Duties and responsibilities**

- To establish an Integrated Service for Disabled Children in line with the aspirations of the children, families and carers and the local authority and PCT.
- To develop and implement agreed procedures and protocols for the integrated service ensuring that service provision is child centred, effective and improves outcomes for children
- To establish within the Integrated Service for Disabled Children effective information sharing, referral, assessment, care planning and review processes in line with agreed approaches.
- To participate in any children's trust pathfinder or other work-stream groups required to establish the service.
- To advise the Children's Trust Pathfinder Management Group on the effectiveness of the integration of disabled children's services assisting them to identify any areas that need development or intervention.
- To work with the Children's Trust Manager to monitor performance of the Integrated Service against the agreed quality expectations.
- To work closely and build relationships with all partners to ensure effective collaboration and coherence in relation Disabled Children's Services.
- Through agreed delegation to monitor, control and plan the operational budget for the Integrated Service for Disabled Children and contribute to the overall financial process of the pooled budget arrangements.
- To ensure that management responsibilities are carried out in line with agreed policies and procedures.

## **Person specification**

### ***Knowledge***

- Understanding of work with disabled children in health, education, social services and the voluntary sector.
- Understanding of the primary and secondary legislation, regulation and guidance in relation to services to disabled children.
- Understanding of the interface between different sectors working with disabled children.
- Understanding of the role of children's trusts in the development of Integrated Children's Services.
- Understanding of the development and management of projects.
- Knowledge and understanding of child development.

### ***Experience***

- Experience of working with children and young people.
- Experience of working with one of the partners agencies in the field of disabled children's services.
- Experience of working within a multi-agency context.
- Experience of managing improvement in disabled children's services.
- Experience of change management.

### ***Skills***

- Ability to write clear reports for a variety of purposes and audiences.
- Ability to plan and prioritise work even when under pressure.
- IT literate and willing to undertake further training as required.

### ***Aptitude***

- High level of communication skills in group and individual settings, with adults and children.
- Ability to demonstrate positive multi-agency working.

### ***Personal style and behaviour***

- Commitment to regularly and actively contributing to developing own and team's practice.
- Manages levels of stress in an appropriate manner, which ensures that standards of work are maintained and deadlines are met.
- Effective communicator with staff, service users and other professionals.

## **Appendix 3    **The quest: for improved services in transition to adulthood in Leicester****

### **Introduction**

This article considers the problem of developing inter-agency transition pathways for disabled and special needs young people. It reviews the nature of the problem and the requirements of parent/carers and young people. The writer looks at the process that has led to an agreed inter-agency pathway in Leicester. Finally the essay examines some of the future work that is needed.

## **The mountain – the problem**

Transition to adulthood has always been a large mountain, covered in cloud and high winds. (Some would say a good deal of hot air as well!). The mountain, when viewed from different sides leads to various different, appreciations of the geography. This can lead to different routes to the summit. Typically we discovered that education, further education colleges, health and social care all had a different appreciation of the topography.

The key issue to resolve such differences was that parent/carers and young disabled adults all made it absolutely clear that we had to climb the mountain – roped together. The aim, therefore, was to agree a pathway up the mountain, to reduce complaints and unnecessary disputes – we had to trust and rely on each other.

## **Base camp**

Having agreed to climb the pinnacle some key elements of the leadership were assembled. The Connexions Senior Manager for Learning Disabilities and Disabilities, the LD Head of Service in Social Services and the Service Manager for Disabled Children agreed to lead the developments.

A series of early (rather than easy) wins were identified. These were smaller, but challenging peaks. The idea was that by working together we would develop mutual trust and confidence as well as a team approach: all would recognise the same initiatives and achievements. Examples of these foothills are: regular transition information events (14 to date), transitions information packs that are issued each year, and commitment to a programme of information sharing.

## **The foothills**

We have been surveying this mountain for four years; it is a major climb rather than a ramble. There have been many preparatory milestones. These have included: scoping meetings, focus groups, stakeholder events, parent/carers consultation, and young people consultation.

## **Camp 2**

The above activities led to two major stakeholder events. The significance of these was that they combined professionals, parent/carers and young people's interests together. It was crucial that half of the people at the events were consumers of the service. It was also significant that they approached the meeting in a professional manner.

At these events outline presentations were given about the commitment to work together and to produce an agreed policy for transition. The consultation for the policy led to hundreds of colleagues expressing views on the relevant issues.

## **Camp 3**

We were then able to produce a working policy document that is called the 'Journey for life'. This was adopted informally to practice our approach towards the summit. After about 18 months of informal officer

usage, the revised document was presented to the Leicester Federation (children and young people's trust); the Learning Disabilities Partnership Board; the Connexions service and the Special Educational Needs Management Team.

After this achievement we needed to wait for more oxygen.

#### **Camp 4**

More oxygen was delivered in the form of the local children's trust with high-level interagency policy support. The Leicester Federation is a generic trust. However their commitment is to prioritise our disabled children's inclusion policy (January 2004) and agreed a further commitment to implement an interagency pathway for transition.

This commitment was supported by the LDPB with an assurance to establish an interagency Transitions Task Group. It was at this gathering that the need for a Sherpa was identified.

As a result a post was developed for an interagency pathway professional. The Learning and Skills Council fund the post on a time limited basis. The Sherpa is roped to the transitions champion; the LD head of service and is managed on a day-to-day basis by the lead Service Manager for Disabled Children. The work programme meets the agreed shared agenda.

#### **The summit?**

As part of our Children's Trust programme of work, we have now achieved a set of agreed interagency transition procedures for both Education and Social Care. These are each supported by the relevant departmental manuals and, for the first time, complement each other.

A new interagency pathway has also been agreed. This is an inclusive pathway for securing further education provision for all young people with learning difficulties and disabilities. Social Care Management Team and the LDPB Task Group have adopted it. Also the pathway has been approved by the Connexions service as a key practice standard for all Personal Advisers. Both key partnership bodies are currently accepting the procedure and pathway and there is a commitment to implement interagency training on each aspect of this work.

#### **New horizon ...**

We are now completing an interagency protocol that will offer strategic and operational support for a range of services. This protocol is built on the success of this transitions work. It sets out to expand the partnerships and good practice identified in transition into other areas of practice.

As a result our commitment to interagency training will be programmed with shared outcomes that relate to the ECM outcomes and the Valuing People principles. It will support a new brokerage role identified for Personal Advisers, reduce gaps and duplication and, ultimately, revise and simplify the new pathway.

## Conclusion

We have climbed the mountain! It is clear that we have made a start. We are gratified that so many agencies believe that they have achieved a shared success. Despite this our future work will ensure that we implement the pathway over the next few months and review its effectiveness in a year.

## Parent/carers and young people have been involved in developing this service. They will be involved in the training and future improvements.

We have already identified the next challenging summit ...

*Christopher Bush*

*Service Manager, Disabled Children's Developments, Leicester Federation*

Leicester's *Pathway and procedures and transition guide* are available via email from the Council for Disabled Children from Lucia Winters at [lwinters@ncb.org.uk](mailto:lwinters@ncb.org.uk)

Comments and information about the developments in Leicester are available from Christopher Bush at [christopher.bush@leicester.gov.uk](mailto:christopher.bush@leicester.gov.uk)

## Appendix 4 Parents' participation in children's trusts: key elements of success

There are a number of reasons why children's trusts need parents to participate in service and strategic planning. As well as helping to create services better designed to meet the needs of users, being involved empowers parents and helps them to feel they have some control over their own and their child's lives, which can lead to lower levels of stress for families and better use of services.

Below is a short guide to good practice taken from the parent participation guide.<sup>24</sup>

### What is participation?

The 'ladder'<sup>25</sup> model of participation illustrates well how working with parents can be developed. Before deciding which level to work at, it is helpful to think about the capacity of the service and the purpose of the exercise. The three rungs are outlined below. It is likely that eventually all three approaches will be used together to keep parents informed, ensure they are satisfied and enable them to be involved in new developments.

24 *Parent participation: improving services for disabled children: A professionals' guide/A parents' guide*, CaF and CDC, 2004.

25 Wilcox, David, 1994 *The guide to effective participation*, Joseph Rowntree Foundation.



<b>Rungs of ladder</b>	<b>Typical process</b>	<b>Typical methods</b>	<b>The message from the resource holder</b>
Information	Presentation and promotion	Leaflets, newsletters, displays	This is what we are going to do
Consultation	Communication and feedback	Surveys, meetings	Here are our opinions, what do you think?
Participation	Partnership building	Working groups/ forums	We want to make decisions together

### **Participation in children's trust arrangements**

A number of the pathfinder children's trust areas have built on existing good practice to develop a range of ways for parents to be involved on equal terms in planning.

Any existing parents' forums or councils can give information on local activity and how parents are currently involved in local authority work. If there is no such forum in your area, the children's trust could think about supporting the development of one with the support of the local parent partnership service.

Inviting parents to planning meetings, the children's trust board or other trust related activity is a positive step. Involving parents who are part of a group means they have support and back up from other parents and they are there to represent a range of views. It's a good idea therefore to seek parents who are active in a local parent led multi disability group or forum as members who can undertake to be a conduit of information. Remember that such voluntary groups and forums cannot absorb the tasks of communication with, and supporting, parent representatives without resources. Members of such groups are likely to be volunteers with many other responsibilities for example looking after children or working so the more notice and practical support you can offer, the more likely it is that they can provide members willing to be part of working groups.

#### **Example checklist:**

##### **Parents as members of the children's trust board**

When invited on to a children's trust board, parents need to make a decision about whether this is a good use of their time. For example, how effective will their contribution be? The following checklist can help parents and professionals think about the issues:

##### **Children's trust board membership**

- Who is on the board: their names, titles and organisations?
- Who chairs the board, what is their background, how are they chosen?
- How are members selected – are they representatives of organisations or there due to personal interest?

### **Remit and power**

- What is the role, purpose and terms of reference of the board?
- Who is the board accountable to?
- How does the board link with other groups; like the children and young peoples' strategic partnership, the council members, the learning disability partnership board? It may be useful to have a chart to show how the groups connect up.
- How is information from the board disseminated to other groups?
- What has the board achieved to date?

### **Ways of working**

- Who sets the agenda; is there a specific slot for parents?
- When, where and how often does the board meet?
- Is there an expectation that members will also sit on sub-groups as part of their role on the main children's trust board?
- Does the board use plain language?
- How do people address each other, eg Mr/Ms or first names?
- What is confidential and what can be shared outside of the meetings?
- Supporting team working, eg holding team building days, training and social events; would support be available for parents to attend such events, eg childcare?
- What is the induction process, eg pre-meeting the chair before attending the board to brief parent members on the way the board works?
- Who sends out papers, how long before meetings are they available, will parents get them the same time as professionals?

### **Parent representation on the children's trust board**

- How are parent members chosen?
- How many parent members are there?
- How long would they be expected to be a member for?
- What is their role, eg an individual voice or representing a wide body of parental views?
- Are expenses paid?
- Will interpreters be provided if needed?
- Will access arrangements be made if needed?
- What practical support is available, eg provision of stationery?

The parent participation guide<sup>26</sup> gives more detailed accounts of good practice and ideas.

Inviting parents to sit on the children's trust board and be involved in any sub-groups, task and finish groups, etc, sends a positive message about the local authority and the commitment of the children's trust to getting services and support right. Developing parent participation can be time consuming. However, in the long run it is likely to save both parents' and professionals' time as parents will have access to more responsive services which better meet their needs – and improve the life chances of disabled children and young people.

<sup>26</sup> *Parent participation: improving services for disabled children: A professionals' guide/ A parents' guide*, CaF and CDC, 2004.



**The development of the children's trust model for delivery of local services is at the heart of key legislation and policy regarding all children and young people. Alongside the 'Every child matters' agenda the development of the trust's work has been at the forefront in taking forward the duties set out in the Children Act 2004. The pathfinder children's trusts were announced in summer 2003 and ran until March 2006 when their pathfinder status ended. Each area developed their own styles in approaching what can be seen as 'well established' challenges for disabled children's services, for example the lack of communication and co-ordination across agencies when working with disabled children and their families.**

**This guide looks at the development and learning from these trusts and how support and services can be improved. It will be of use to staff responsible for the commissioning and delivery of services to disabled children and their families across health, education, social care and the voluntary sector.**

**Some of the areas covered in *Pathways to success*:**

- **legislation and guidance affecting children's trust arrangements**
- **strategic planning**
- **commissioning services**
- **developing multi-agency services**
- **integrated working**
- **participation of parents**
- **assessment processes**

*Produced and distributed by*  
The Council for Disabled Children  
8 Wakley Street  
London  
EC1V 7QE  
Tel 020 7843 1900  
Email [cdc@ncb.org.uk](mailto:cdc@ncb.org.uk)  
Web [www.ncb.org.uk/cdc](http://www.ncb.org.uk/cdc)

*March 2006*

**Council for  
Disabled  
Children**

department for  
**education and skills**

 **Department  
of Health**

  
**national  
children's  
bureau**