



## **Principles for working with parents of disabled children: meetings and reviews**

# Principles and promises for working with parents of disabled children: meetings and reviews

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# Principles and promises for working with parents of disabled children: meetings and reviews

## Introduction

The involvement of parents of disabled children and young people is a theme running through all recent government legislation, as well as the inspection framework for children's services. We have produced this pack to help professionals working with disabled children, young people and their families translate legislative and policy guidance into practice.

## About the pack

We asked parents and professionals about the essential qualities needed to support parents of disabled children and young people at reviews. They told us that the main qualities professionals need for successful partnership working are:

Being human

Being positive

Being available and open

Listening

Being flexible to need

Seeing the child in the context of the whole family and their local community

Understanding family dynamics

Not giving false expectations

Knowing the child/young person

Journeying alongside the parents

Being non-judgemental

Showing empathy

We took these qualities and shaped them into principles that are equally applicable to education, health, social care and the voluntary sector. While the pack was made to support meetings and reviews, the principles are applicable to other areas of work. We translated the eight guiding principles for professionals into promises to parents.

To support their implementation we include a good practice guidance section relating to each principle. We give examples of how some organizations and

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local authorities are putting the principles into practice. We hope these will inspire others to develop their own ways of working supporting the principles.

This pack sits alongside the participation pack 'involving children and young people in meetings and reviews' published by the partnership in 2006.

# Principles and promises for working with parents of disabled children: meetings and reviews

## Principles for working with parents of disabled children: meetings and reviews

- 1. Every family is different, and we should treat them as individual.** We should prioritise the time needed to build trust with individual families.
- 2. Parents understand that they are the experts on their child and we should acknowledge their huge emotional investment.** We strive to work in a non judgemental way, doing all we can to extend empathy. We recognise that listening to parents' needs and expectations can be an empowering experience for them and us. We acknowledge the importance of taking into account the needs of the whole family.
- 3. Parents are given genuine choices about opportunities and services available to their family.** We have a duty to meet parents' right to appropriate local and national information given clearly in a suitable way, at the right time. We consider our role as sign posters to be a critical component of supporting parents to prepare for (rather than having to react to) events and transitions.
- 4. Meetings should be planned well in advance and take into consideration parents' commitments.**
- 5. Parents understand the purposes and processes of the meetings and reviews involving their child.** We can support this by providing impartial and accessible information beforehand, not giving false expectations, explaining the 'what and why' of the meeting, outlining who has been invited and inviting people parents want to be there.
- 6. Parents and their son or daughter should be supported to prepare for the meeting.** Materials reflecting their family life and the views of their child should be central. Parents should be asked if they would like a supporter of their choice to accompany them to any meetings.
- 7. Meetings should focus on the outcomes parents and their families want.** All meetings and reviews should start with positive statements about the child and his/her family.
- 8. Parents should be clear about what happens after the meeting and what comes next for them and their child.** All meetings should produce action plans with clear actions, timescales and responsibilities. Ideas and possibilities for the future should be introduced well in advance. Parents should be given regular updates on actions agreed at meetings.

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## **Promises to parents of disabled children: meetings and reviews**

1. Your views are essential. You are the expert on your child and your family so it is important we know and understand what you think and how you feel.
2. You are central to any meeting about your child. We will ask you how we can make meetings a positive experience for you.
3. Before the meeting we will agree with you what will be discussed. We will ask you how you would like the meeting to be run and who you would like to be there. We shall ask you what you want to get out of the meeting, and take responsibility for making this happen.
4. All the way through, we will provide clear and accurate information at the right time and in an appropriate way.
5. We will ask you about ways your child might be included – either directly or by providing pictures, quotes, for example. If you wish we will support you to produce materials that give a clear picture of your child.
6. If you wish, we will help you present your views and those of your child.
7. At the end of the meeting we will go through the notes taken, and ask if everyone present agrees with them. We will also have agreed on an action plan and who is responsible for carrying each action out.
8. We will be clear about what happens next and will keep you updated on progress after the meeting.

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## Good practice one: building trust

Every family is different, and we should treat them as individual. We should prioritise the time needed to **build trust** with individual families.

Disabled children, young people and their families are often not accepted as the individuals they are, but are given labels and categories that can make it difficult for them to be accepted, and can prevent healthy interactions with others. Sometimes life can be hard for disabled young people and their families because not everyone understands we are all as important as each other.

Disabled young people and their families usually have to work with a large number of professionals. Parents have to live with and manage all these relationships. Because professionals provide the gateway to services, they hold a position of power over parents. In order to access the resources they need to live ordinary lives, families have to share intimate details about their lives and relationships with each professional they come into contact with.

Parents tell us they find it very helpful when professionals take a flexible approach, adapting their ways of working to meet their unique needs.

## Examples

### **Barnsley and Sheffield**

Living and Learning (Mencap NOW) is a two year pilot in Yorkshire and Humberside, supported by the national Learning and Skills Council. The project focuses on developing alternatives to out-of-area residential placements for young disabled people with severe and complex impairments when they come to the end of their statutory education. Families are asked to complete a self assessment questionnaire about their son or daughter's support needs. From this the young person and their family are told how much their budget is likely to be. Professionals then support the young person and their family to plan how they will spend this funding. Individually appropriate learning and living packages will be designed for each young person.

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## **Big Plan, Sheffield Children and Young People's Department**

The transition team commissioned ibk initiatives to help them deliver their 'Big Plan' project. The project brought families together to think about and plan for how they would like to live when their son or daughter leaves school. Professionals were supported to think 'outside the box' to find innovative ways of meeting the individual needs of each young person and their family.

In addition to holding workshops with parents, project workers worked with the young people to produce individual profiles of what they wanted to do when they left school. Parents were invited to a celebration evening where the young people presented their hopes and aspirations.

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## **Good practice two: parents are experts on their child**

Parents understand that they are the experts on their child and we should acknowledge their huge emotional investment. We strive to work in a non - judgemental way, doing all we can to extend empathy. We recognise that listening to parents' needs and expectations can be an empowering experience for them and us. We acknowledge the importance of taking into account the needs of the whole family.

It is important to remember that most parents of disabled young people do what they believe is best for their son or daughter. This is no different from the majority of parents. There will inevitably be times when professionals do not understand or agree with the aspirations and needs of families. Working in a non-judgemental way helps parents feel good about their parenting skills and can, over time, help increase confidence and a positive attitude. Being listened to is an empowering experience that can support parents move forward and take on new ideas and ways of working.

It is very difficult for parents when professionals – all of whom are supporting them – argue with each other in meetings. Although debate and dialogue is

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welcome, points of tension between professionals are best dealt with outside of the meeting.

It is important to remember that parents are frequently looking after more than one child, and it is easy for professionals to overlook the needs of non-disabled brothers and sisters.

When I was little I was teased about my little brother being seen as 'different'. I had no friends that could understand the pain it gave me as everyone thought I was too little to understand. But I still remember.

Sister, aged 14

Meetings should be individualised to meet the needs of the whole family.

## Examples

### **Calderdale Parent and Carers Council**

CPCC is parent led organization which aims to empower parents. In addition to working with families on individual concerns, the council listens to the views of families and takes collective issues forward to create strategic change. In order to appeal to a wide range of families, CPCC hold a range of get togethers from social events to focus groups. Workers from the council plan with families to work towards their shared goal.

CPCC encourages families to plan for the future and start early with their Leap Ahead course for families of under 5's where parents learn about person centred thinking and how to develop and use a 'one page profile'.

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### **Rotherham Parent Partnership Service**

Rotherham Parent Partnership Service have set up a parents e-forum in order to inform, consult and involve parents and carers in shaping local services for children with special educational needs.

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## Good practice three: genuine choices

Parents are given **genuine choices** about opportunities and services available to their family. We have a duty to meet parents' right to appropriate local and national information given clearly in a suitable way, at the right time. We consider our role as sign posters to be a critical component of supporting parents to prepare for (rather than having to react to) events and transitions.

Professionals should understand the context they are working in and make themselves aware of local initiatives. Parents should be given information, in a manner that is meaningful to them, about available resources and how they can access them. They should be supported and encouraged to take a full part in making decisions, and influencing the outcomes of any review about their son or daughter. Professionals should tell parents they too have rights, and how they can get everything they are entitled to.

Parents need access to information if they are to make informed choices and take part in the decision making process. Parents should be made aware before the meeting of **all** the possible options available to their son or daughter – not just those commonly recommended. The different options open to young people and their families should be made available to them prior to the review meeting so that they have time to consider any decisions that might be made.

## Examples

**Talbot Special School, Sheffield** produces a regular Transition Newsletter for parents. The newsletter gives information about best practice across the country as well as details of local initiatives and events.

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### **Moving On, North Yorkshire**

**Moving On** is an annual event at which adult support/service providers are invited to talk about the service they offer to young people and their families. This includes social support providers, local colleges, Connexions, local employers and job centre. The event also offers the opportunity for young people and their families to gather information and ask questions.

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## **North East Lincolnshire**

### **Directory of information for people with learning difficulties -**

[www.123go.org.uk](http://www.123go.org.uk) is an easy to browse, accessible local web - site designed and created for anyone requiring information about local and national services / opportunities for people with a learning disability. There is a section on transition.

Information on transition is also available on a DVD made by young people – No Limits. For a copy of the DVD contact: Transition Service, Molsen Centre, Kent Street, Grimsby, North East Lincs, DN32 7DJ. Tel: 01472 325306  
[angie.kershaw@nelincs.gov.uk](mailto:angie.kershaw@nelincs.gov.uk).

## **East Riding of Yorkshire**

FISH, the East Riding Families Information Service, has a transition section which parents and carers can access on line. FISH also produce the IMPACT newsletter for parents – this too includes a Transition Page.

[www.fish.eastriding.gov.uk](http://www.fish.eastriding.gov.uk)

## **Good practice four: taking parents commitments into consideration**

Meetings should be planned well in advance and take into consideration parents' commitments.

Parents of disabled young people have a range of commitments that inevitably vary from one family to another but might include looking after other children, working, supporting elderly relatives, everyday household tasks and responsibilities connected with family life. Meetings of crucial importance to the family are often held at times suiting professionals rather than parents. Organisations should consider offering families the possibility of a date and time that would suit both parents.

Families often find that one parent, usually the mother, takes the main responsibility for attending meetings and appointments. This can have an impact on relationships within the family. Dates and times offering the possibility of suiting both parents should be offered.

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Parents should be asked who they would like at the meeting and what support they need e.g. interpreter, advocate.

### Examples

#### **Calderdale**

In order to reduce the pressure on families, statement support and reviewing officers offer home visits.

[yvonne.howarth@calderdale.gov.uk](mailto:yvonne.howarth@calderdale.gov.uk).

### **Good practice five: understanding what the review is about**

Parents understand the purposes and processes of the meetings and reviews involving their child. We can support this by providing impartial and accessible information beforehand, not giving false expectations, explaining the 'what and why' of the meeting, outlining who has been invited and inviting people parents want to be there.

In order to avoid false expectations, it is essential parents have a clear understanding of what the review is about, who will be there, and how it will run. Parents and professionals should understand the meeting is about the young person and their family and the kind of lives they want to live. The purpose of a review is **not** to fit young people into services.

Parents should be asked who they would like to be at the meeting, how they would like it to be run, and should be made aware they are welcome to bring a friend or advocate with them. Parents should be asked who they would like to chair/facilitate the meeting.

Invitations to meetings should include a clear description of the purpose and objectives of the meeting. The aims and objectives of the meeting should focus on outcomes. Information about the agenda of the meeting should be circulated at least two weeks beforehand. Language should be kept simple throughout the meeting and in all paperwork.

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## Examples

### **Calderdale Parent and Carers Council**

In addition to hosting information sessions about the transition process, CPCC also holds a rolling programme of training sessions for family members. Topics covered include 'getting the best out of meetings' and 'negotiation skills'.

[liz.wilson@parentcouncil.myzen.co.uk](mailto:liz.wilson@parentcouncil.myzen.co.uk)

## **Good practice six: family centred**

Parents and their son or daughter should be supported to prepare for the meeting. Materials reflecting their family life and the views of their child should be central.

Parents and young people should be offered support to prepare for their review. This needs to take place separately so that there is a clear distinction between the needs and expectations of the young person and their parents.

Participation at reviews should be in a way that is meaningful to the young person and their family, and they should all have access to appropriate systems or methods of communication. Young people should be offered the opportunity to have someone they know well and trust at their review. This allows parents to attend fully to the process and content.

Parents should be offered the possibility of splitting a meeting into different parts, with different people attending as appropriate.

All papers circulated before the meeting should include the views of parents and the young person. If evidence is to be viewed in video/DVD form, then this needs to be shown at the beginning of the meeting so that it can be taken into consideration. The views of the young person and their parents should not be taken into account as an afterthought, when a decision has already been made.

Parents should be given choice about where the review is to be held – perhaps in an impartial building, or at home. All reviews should be held in a welcoming environment.

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## Examples

### **Calderdale: Person Centred Transition Reviews**

All Y9 pupils in mainstream schools who have a Statement of SEN are given a person centred transition review.

There is regular monitoring of the Transition/Action Plan to ensure progression and development. This will ensure every young person with a Statement of SEN leaves school with a clearly defined route into their chosen career which will be recorded in a written format.

Additional funding was allocated to Statement Support & Review Service budgets for the development of booklets and documentation to support the person centred approach, and to provide additional facilitator training within Calderdale to increase capacity.

[yvonne.howarth@calderdale.gov.uk](mailto:yvonne.howarth@calderdale.gov.uk).

### **Transition Pathway, Sheffield**

Developed and piloted with families, the pathway planning booklet is now being used with families across the city. Families are supported to fill the booklet in, and one school is supporting students explore the areas covered in the booklet during PSHCE lessons.

[Niki.marshall@sheffield.gov.uk](mailto:Niki.marshall@sheffield.gov.uk)

### **Person Centred Reviews**

The following local authorities have taken part in the Person Centred Review Training delivered by Valuing People Support Team:

Calderdale	NE Lincs	Kirklees	North Yorkshire
East Yorkshire	Bradford		

For information about free person centred review training taking place in June/July 2008 please contact [Karen.Roberts@dh.gsi.gov.uk](mailto:Karen.Roberts@dh.gsi.gov.uk)

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## **Calderdale Parent and Carers Council**

CPCC supports families to prepare for reviews through training and information sessions. They have a range of materials and resources that families can use with their child to prepare for meetings and reviews. Workers provide a listening ear for families from an independent perspective. CPCC promotes the view that it is never too early to start planning, and the dream is always worth reaching for.

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## **Good practice seven: focus on outcomes**

Meetings should focus on the outcomes parents and their families want. All meetings and reviews should start with positive statements about the young person and his/her family.

Parents tell us they want reviews to be a positive experience. All reviews should centre on the young person and their family, and should start with positives about the young person.

Parents also tell us they want meetings to lead to positive outcomes. They do not appreciate being told that things take a long time to change, and there is a shortage of opportunities. Their child has only one life, one chance to grow from being a child to an adult.

## **Examples**

### **Big Plan, Sheffield Children and Young People's Department**

Positive outcomes chosen by young people and their families are central to the success of the Big Plan. The final stage of the project consists of follow up interviews with young people in the winter of 2008, several months after they have left school, to see if they are actually doing what they planned to do. The information they give will be fed back into the planning process for future school leavers.

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## **North East Lincolnshire - Positive transition framework**

Six young people were 'tracked' throughout their transition as a way of evaluating and providing feedback on the impact and outcomes of the process. All six recorded information and captured images of their aims and aspirations. They were helped to prepare for their meetings and provided feedback about their experience.

Leaflets on transition and the transition planning process for young people and parents were produced. Joint training with health, Children and Adult Services and linked agencies was delivered.

Two jointly funded Transition Workers working across Children's and Adult Services were recruited. They co-ordinate, assist and support the person centred transition planning process for young people and parents along with schools, Connexions and health and social care services.

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## **Good practice eight: clear action plans**

Parents should be clear about what happens after the meeting and what comes next for them and their child. All meetings should produce action plans with clear actions, timescales and responsibilities. Ideas and possibilities for the future should be introduced well in advance. Parents should be given regular updates on actions agreed at meetings.

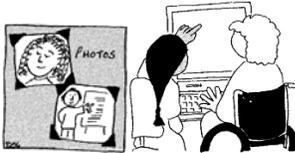
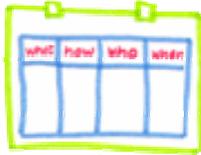
Parents should leave the meeting feeling clear about what has been agreed and who has taken responsibility to do what. Professionals should take great care about how they impart information about future possibilities – a positive or negative tone can make all the difference.

One person should be appointed to check on the progress being made with the whole action plan.

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## Examples

Bolling Special School, Bradford

What?	How?	who will help me?	When?
Reading - I would like to be able to read more words	 <p>Photos, words, computer</p>	School and Janet	Now
Staying safe	 <p>talking with people I know really well</p>	Everyone	Now
Learning to do things on my own, like tidying my bedroom	 <p>Charts to remind me</p>	School, home and Janet	Now
I would like to go to college and have work	 <p>visits from school. Work experience next year.</p>	Anne, Margaret, Susan	From September

[pippa@ibkinitiatives.com](mailto:pippa@ibkinitiatives.com)

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## Appendix One

### Let Our Children Be

*As this collection developed, a list of themes emerged – being, difference, humanity, labels, power, rights, love, hope, courage, journeying, dreaming, belonging. Each of these themes is woven throughout the collection as a whole. As a list they prompted the following piece, which we have written for people who work with our families in particular.*

Please allow our children to be. To be just as they are.  
Being is essential; it is about identity, about existence.  
Being is the essence of ourselves.  
Our children have the right to be.

Please welcome difference. Difference teaches us about ourselves and each other.  
Do not allow your fear of our children to spoil the opportunities they offer and the gifts they bring.

Please acknowledge our children's humanity. Do not treat them as less than human.

Please try to accept that our children are ordinary children.  
We are not interested in your labels for them.

Please try to accept that we do what we believe is best for our children. This is no different from the majority of parents.  
When we do not share your perceptions of our children, understand we recognise the labels you give to us, also.

Please recognise your power. Think very carefully about the messages you give when you talk to us about our children and their futures.

Please recognise that we are very tired of our children being treated as the property of professionals.  
Do not tell us to be patient. Our children are children now.  
If their time is wasted they do not get it back. Understand our anger if you tell us you know what is best for them.

Please understand that we love our children very much.

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This may be difficult for you, since you perceive them as defective.

Please recognise we are on a journey.

We are travelling towards a point in the future where all children are of equal value.

Please understand that we are absolutely serious when we talk to you of the need for change.

We will not accept present discrimination.

When we say all children must be included, we mean all children.

All does mean all.

Pippa Murray  
Jill Penman

(From Let Our Children Be: a collection of stories [ibk initiatives, Sheffield] 2007)

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## Resources

### **The Essential Family Guide: how to help your family member be in control (Caroline Tomlinson)**

This resource guide was written by a family member for families who have a relative who needs support in order to have a good life. It offers suggestions about how family members can help their son or daughter get a better life. It offers help in making choices about the support they receive.

[admin@in-control.org.uk](mailto:admin@in-control.org.uk)

### **Keys to Citizenship (Simon Duffy)**

This has lots of information and detail about being in control, making decisions, support, money, benefits and housing. It is available online at [www.in-control.org.uk/shop](http://www.in-control.org.uk/shop)

### **Let Our Children Be – a collection of stories (compiled by Pippa Murray and Jill Penman)**

A collection of stories about the lives of disabled children, young people and their families. Written by disabled children and their families.

Available from [info@ibkinitiatives.com](mailto:info@ibkinitiatives.com)

## Organisations

**ibk initiatives** is a research, consultancy and training agency whose aims are to promote the inclusion of disabled children, disabled young people and their families in their local communities, and to challenge a disabling world that denies their right to an ordinary existence.

[www.ibkinitiatives.com](http://www.ibkinitiatives.com)

**Calderdale Parent and Carers Council** is made up of parents working together to create change so all children and young people can learn, make friends, have a voice and be part of ordinary school and community life. The council works with families of children and young people who have special educational /additional needs, are disabled, have emotional and behavioural difficulties or are experiencing difficulties fitting with school or community life for any reason.

[www.parents-and-carers.org.uk](http://www.parents-and-carers.org.uk)

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## **Policy and legislation**

### **Every Parent Matters, DfES (2007)**

Every Parent Matters sets out the role of parents in improving their child's life chances and educational attainment and the role of government in supporting them to achieve this. It brings together ways in which the government is promoting the development of services for parents, as well as their involvement in shaping services for themselves and their children. It also highlights practice where public services are already working with parents in innovative ways, particularly with those parents that are most disadvantaged and for whom services have often been inaccessible.

### **Every Child Matters (2004)**

Every Child Matters' emphasizes the need for parents to have access to high quality advice and support.

### **National Service Framework (2004)**

Standard 8 of the National Service Framework for Children, Young people and maternity services which focuses on disabled children and young people and those with complex health needs has the active involvement of youth people and their families in all decisions affecting them and in shaping local services is part of the vision of Standard 8. One of the markers of good practice is that disabled children, young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support.

### **Improving the Life Chances of Disabled People, Prime Minister's Strategy Unit (2005)**

Improving Life Chances identifies four key areas as the most important determinants of disabled people's life chances:

- Empowered citizens with choice and control over how additional needs are met
- Support for families with young disabled people
- Smooth transition into all aspects of adulthood, and
- Improved employability

Improving the Life Chances of Disabled People, p. 53

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

A Green Paper setting out proposals for the future of social care based on giving individuals greater choice and control over ways in which their needs are met. The vision for the future of social care rests upon people who need services having more control over their lives, more choices about how they live, a say about the services they use and the way they are developed. One of the key proposals to deliver this vision includes the wider use of direct payments and individual budgets.

**Valuing People: a new strategy for learning disability (DH, 2001)** is the government's plan for making the lives of people with learning disabilities and their families better. It is based on people having:

- their rights as citizens
- inclusion in local communities
- choice in daily life
- real chances to be independent

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