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Sharing information with disabled children in the early years

A summary of research carried out by
In The Picture project in 2006

Researched and written by **Penny Dickinson**

Time to get equal

scope

About cerebral palsy.
For disabled people achieving equality.

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www.childreninthepicture.org.uk

In The Picture promotes the
inclusion of disabled children
in early years' picture books



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Foreword

Information is vital to us all. Information for children, and particularly disabled children, is fundamental to improving the quality of their lives.

Sharing information with children under the age of six years can appear to be a daunting task to parents and the people working with families, but imagine how it must feel to have little or no idea about what is happening to you.

The In The Picture project has highlighted the Concise Oxford Dictionary definition of “in the picture” as “the state of being fully informed or noticed”. It aims to fulfil the “noticed” part of the definition with its campaign to increase the representation of disabled children in early years picture books. This foreword introduces the part of the project that is about being “fully informed”. It is about ways of communicating with young children to help them understand their condition and experiences from the very beginning.

This report demonstrates that the effective sharing of information can, and does, happen in all kinds of settings, but that we can do more sharing and learning from each other. It demonstrates, too, a lack of consistency with “pockets of good practice” and “postcode lotteries”. It is particularly impressive to see the inventive ways that both professionals and families have created bespoke resources. These can be very time-consuming to produce and show enormous commitment.

I hope you will find this report interesting and useful, and that it will inspire you to examine your practices around information provision and assist you in the development of strategies to address the already acknowledged need.



**Prof. Sir David Hall FRCPCH, FRCP, FRCP (Edin).
Patron, Scope**



Executive summary

In The Picture is part of Scope's Time to Get Equal campaign, which is aiming to change the way disabled people are perceived.

In The Picture is an innovative, three-year Big Lottery-funded project whose primary aim is to promote the inclusion of disabled children in early years picture books.

Another of the project's aims is to examine how organisations working with disabled children deliver information to them and their families; to identify good practice and build a range of materials to demonstrate ways in which disabled children can be put "in the picture" as well as their parents.

The primary focus of the project is disabled children aged under six.

This report summarises the findings of research carried out by the project team from March – August 2006.

Aims of the research

The aims of the research were:

- To capture information about the types of information available for disabled children and their parents
- To find out what parents and professionals feel is needed to improve the communication of information with disabled children
- To identify examples of good practice

The report is not a comprehensive survey of all that is available. Its primary aim was to uncover methods of information provision and dissemination that could be transferable across different early years settings.

Executive summary

Main findings

The main findings from the research were:

1. There is limited information available for parents and young disabled children.
2. Parents and professionals were unaware of what materials were available and of how to access them.
3. Good practice is not shared across settings despite the fact that most methods are transferable.
4. Story books, toys and games are the most used resources to convey information to this age group and are also viewed as the most effective by parents and professionals.
5. Inclusive cultures within organisations can assist in the sharing of information with young disabled children.
6. It can be difficult for organisations and parents to recognise that the processes they use are in fact methods of sharing information.

Recommendations

This report has shown that pockets of good practice in the provision and dissemination of information to disabled children in the early years do exist. Parents and professionals feel that more resources are necessary and that practice can be improved.

As a result of this survey recommendations by In The Picture include:

1. Organisations identify how they give information to children in the widest possible sense, for example through role play, photo sequences etc.
2. Information giving methods are conveyed openly to families so that they are clear about the techniques being used, and that information has been shared with their child.
3. A culture of inclusion is fostered in all early years settings.

Executive summary

4. A toolkit be produced to showcase good practice in sharing information with children and that resource be shared across early years settings.
5. Systems for sharing existing resources be identified and established for both parents and professionals.

Conclusion

The Government agenda places an emphasis on the rights of all children to have access to inclusive practices and information at a level they can understand and assimilate.

This report is by no means a comprehensive survey of all that is available; it offers a snapshot of the types of resources and begins to explore some of the issues faced by disabled children, their families and those working with them.

It became apparent that pockets of good practice do exist. Resources, often produced locally, meet the needs of very young children. This good practice is rarely shared, even locally.

Acknowledgements

The In The Picture project team would like to thank all parents and professionals who completed the initial survey.

We would like to thank the Big Lottery Fund for grant aid towards the cost of the In the Picture project.

Further thanks go to the early years settings and parents who offered more insight via follow-up interviews.

To obtain further copies of the In The Picture Report, please email inthepicture@scope.org.uk or visit www.childreninthepicture.org.uk

For more information on the work of Scope visit www.scope.org.uk

The report

This report focuses on the findings of research carried out by the **In The Picture** project between March and August 2006 into methods of sharing information with young disabled children.

It aims to reflect the provision of information, and methods of sharing that information, with disabled children from 0 – 6 years of age.

The report captures statistical data and demonstrates:

- What information is available
- What children, parents and professionals feel is needed
- Examples of good practice

The report does not demonstrate a complete and methodical mapping of practice in this area.

Its primary aim was to uncover methods that would be transferable to different settings.

Why the research was undertaken

This research is a follow-up to previously unpublished research, undertaken by Scope in the summer of 2003, and completed as part of some early work towards the In The Picture project.

The 2003 project surveyed 38 parents across England and Wales canvassing their opinions on information available for their children. It indicated a need for further investigation as over 60% of those responding did not feel “well supported” with information about how to explain to their child their condition and what was happening to them in relation to their condition.

The survey team had already noted the comments of Robinson and Stalker (1998) in their book **Growing Up With Disability**, (Chapter 8 – Quality of Life for Children and Young People with Serious Medical Conditions):

“Even young children may understand about their condition, although this may be less in very young children or less able children. They may visit hospital as day or in-patients. Other activities and interests may be curtailed. Modern medical policy is to involve patients in their own treatment. Some parents inform their children about their condition even if it is mutually painful. Children talk to fellow patients, overhear medical discussions and parental conversations, pick up leaflets intended for professionals or other adults or read their own clinical records.”

The chapter goes on to point out that *“children’s secret lives may hold extensive information about their condition, much of it potentially confused, deeply troubling and not shared.”*

By communicating directly with young disabled children and providing them with the appropriate information to meet their needs much of this confusion could be addressed. Children would also be encouraged to discuss their issues with their parents or the professionals working with them.

Why the research was undertaken

In September 2003 the Audit Commission published a report **Services for Disabled Children – a review of services for disabled children and their families**. The report states:

“And we found children being spoken to through their parents, rather than directly.”

Following on its heels, **The Department of Health’s National Service Framework for Children, Young People and Maternity Services** published in September 2004 states:

“Families of disabled children have contact with an average of 10 different professionals and over 20 visits per year to hospitals and clinics.”

This can make the first few years of life a perplexing and daunting experience for disabled children. As a result of these experiences, which inevitably focus on the negative impact of a child’s condition, many children begin to define themselves solely in terms of their condition, seeing themselves as “damaged goods”.

It is hoped that by conducting this research into the types of information available for young children and their families the In The Picture project can begin to redress the balance and encourage early years settings to produce more age-appropriate information.

In The Picture project

In The Picture is an innovative, three-year Big Lottery-funded project, which commenced in September 2005.

Aimed at the children's book world the project wants disabled children to be able to find themselves represented in early years books.

Disabled children often find themselves isolated from wider society as a result of their impairment. The project aims to overcome this isolation by putting disabled children "*in the picture*" in two important ways. These are with:

- **picture books**, to ensure disabled children are more visible in mainstream literature
- and
- **improved communication**, to give children the means to understand their condition and experiences

Picture books

There are currently some 770,000 disabled children in the UK who have virtually no role models in literature. The books we read as children have a profound effect on our attitudes, values and development. By identifying with the characters in these books we are able to learn a great deal about ourselves and how we interact with the wider world.

Research shows that children as young as three form prejudices against people who are visibly different. They are more likely to accept disability if they see images of disabled people at an early age.

Improved communication

Disabled children often grow up with a very confused understanding of why they differ from other children around them. Furthermore these children will be required to attend a whole host of appointments with various health professionals in a variety of strange and alien settings. These appointments will often be highly intrusive and intimidating.

To overcome this it is essential that disabled children are given the means to understand about their condition as well as understand what is happening to them at these appointments.

The research process

Methodology

The report is based on the findings of two main research methods:

1. A questionnaire
2. Follow-up interviews

Questionnaires

Two questionnaires were designed, one for professionals working with disabled children and the other for parents. (Appendix 1 and 2.)

The questionnaires were designed to capture data about the provision of information (particularly health information) for disabled children and their siblings.

As far as possible the questions were similar in both surveys. A comparison of the two responses could then be used to highlight any gaps in provision for families that health professionals working with them were not aware of.

Questionnaires were piloted with parents and professionals and their feedback was incorporated into the final documents.

Distribution – professionals and voluntary organisations

275 questionnaires were posted to a random sample of:

- Voluntary organisations
- Sure Start services
- Early Years Child Care Development Partnerships (EYDCP)
- Portage services
- Child Development Centres (CDC)

The research process

A few questionnaires were emailed to other interested parties.

Return rate for this group was 26.5% (relevant literature suggests that a response rate of 20 – 25% is good in this type of survey).

Distribution – parents

It is more difficult to quantify the number of surveys distributed to parents.

The team decided not to request too much personal information but to target those with disabled children in the early years. Using Scope's parent networks a random sample of questionnaires were distributed. We are aware that some services duplicated the questionnaire and forwarded it to their clients.

An article was placed in Scope's Early Years email newsletter asking for interested parties to contact the project.

We received 48 responses from families.

Demographics

The distribution of questionnaires and responses returned indicate a broad spread across England, Scotland and Wales.

Who responded?

Professionals – highest response rates for this group came from Child Development Centres and voluntary organisations, closely followed by Portage services and educational settings.

Parents – highest response rates came from parents of children aged 3 years and under. The oldest child whose parent replied was 13 and the youngest just 14 months.

The research process

Follow-up interviews

The questionnaire asked respondents to indicate if they were prepared to discuss their responses in more depth. Nearly three-quarters (73%) of parents and 50% of professionals answered “yes” to this question.

A number of personal visits were made to various settings to discuss responses. Follow-up interviews were also conducted by telephone and email.

A second pro forma was devised to capture the content of these interviews in a consistent way.

Arising from these interviews other contacts and resources were investigated and are captured within this report.

The research findings

A statistical analysis of responses to both questionnaires can be found in Appendix 3 (Professionals) and Appendix 4 (Parents).

The following section aims to capture the essence of responses to questions. It will also demonstrate where the views of parents and professionals vary significantly.

Ease of sharing information with children

According to the results of our research parents and professionals had certain similar perceptions as to how easy it is for parents to share information with their children.

- 70% of all parents find it hard to share information with their children and of that number 17% find it very hard.
- 63% of professionals responding thought that parents found it hard and of that number only 2.9% felt that it was very hard.

This would indicate that generally both sets of respondents agree that it is a hard task for parents but disagree on the degree of difficulty.

Only 7% of parents and 5.6% of professionals felt that sharing information with children was easy to do.

Use of resources

Parents were asked if they had ever used resources specifically designed for them as parents to use with their children – 60% had never used such resources.

This contrasts sharply with the number of professionals who indicated that they produced resources for parents to use with their children ie 68%.

The research findings

This could demonstrate that although it would appear that resources are being produced, parents are either unaware or unable to access them and could suggest a “postcode” lottery exists with pockets of good practice.

This point raises a number of issues that could, with further investigation and resources, be addressed:

- Methods for professionals to share and foster good practice
- Centralised systems for sharing good practice
- Methods of ensuring parents are aware of existing resources and have access to them

Information materials available

The questionnaire asked professionals about the resources they used; 56.2% of professionals responding to the survey said that they either produced or used information resources designed to give young disabled children information about their condition or experiences. However, only 36.6% of parents stated that they had used them.

Pockets of good practice do indeed exist. During the course of follow-up interviews we have seen many excellent examples of information produced for young children.

These have usually been produced by staff within the service specifically for children using that service. Methods would be transferable across many settings.

Fewer parents perceive themselves as accessing information than would be expected by the response from professionals.

It would appear from the follow-up interviews that some organisations do not overtly identify that it is information they are giving to children; and parents are not always aware that their children have been involved in a process of information giving – the messages can be subliminal.

The research findings

Sure Start – Bilsthorpe, Blidworth, Clipstone and Rainworth has developed a method of telling parents what the children had done during their time at the centre. Although in a letter format symbols were incorporated into the text thus reinforcing the inclusive methods used within the centre.

According to responses given by the professionals, information about therapies and the child's condition were the most produced resources by either themselves or other organisations. They also indicated that they frequently used information about their own service and sibling issues.

Finally, as one parent pointed out:

“Resources are not helpful if you don't know how to use them.”

This is a very salient point and professionals need to be aware that by merely supplying parents with information resources for their children they are not necessarily addressing the **child's** information needs.

Information materials and their effectiveness

Storybooks

How they are used

Nearly half (44%) of professionals said they use story books with children to help them understand their condition – this was the most popular method, closely followed by printed information eg leaflets.

Parents cited story books as their second most used method of sharing information with their children.

Some reasons given by professionals for using storybooks were:

- *“They tend to be shared with an adult.”*
- *“They don't focus directly on the disability.”*
- *“They facilitate discussion.”*

The research findings

There are many books available for children to explain their condition – few of these are story books. Many are factual and use photographs of other children with that condition (for example **Living with Cerebral Palsy**, Dr Paul Pimm, 1998).

Story books can be a more age-appropriate way to raise these issues, particularly with younger children.

The **Encephalitis Society** has produced a story book “Gilley the Giraffe”, which is aimed at children from 2 – 10 years of age and explains some of the things that could happen to a person when they have encephalitis and afterwards.

Children who have had encephalitis have been involved from the very beginning of this project. They have chosen the illustrator and been consulted on the content of the text – children often want different details to adults and can identify a more contemporary look.

Scope has produced a leaflet, “Celine’s New Splints”, which tells, in story format, the process of being fitted for a leg splint or ankle-foot orthosis (AFO).

The leaflet was designed in consultation with children and their parents who have gone through this process.



Scope leaflet –
Celine’s New Splints

The research findings

Effectiveness

Storybooks were rated as the most effective method by 26.8% of parents and 20.5% of professionals. Reasons given by parents included:

- *“We can talk to each other whilst reading and answer any questions that arise.”*
- *“Storybooks are easily accepted by children.”*
- *“He loves them!”*

Professionals felt that storybooks were effective because:

- *“Sharing experiences.”*
- *“They are visual and interesting.”*
- *“They can be tactile as well as visual.”*

A mini survey carried out by Scope in summer 2003 entitled “Visible Children in Focus” found that 75.7% of parents responding had not been able to find storybooks that contained images of disabled children. And 87.8% had not been able to find an image that their child could identify with. By identifying with characters in books young children learn about themselves and the world around them. The absence of images of disabled children reinforces the sense of isolation they often experience.

Scope’s **In The Picture** project aims to address this issue by encouraging the book world to recognise diversity.

Toys, games and play

How they are used

Interestingly parents cited toys and games as the most used form of sharing information with their child. Professionals stated that toys and games were their third most used resource.

The research findings

Reasons given included:

- *“Playing is the best way to get and keep my child’s attention.”*
- *“Play is less structured and more at the level my child can understand.”*
- *Toys and games make it easier to put the information across in their language.”*

Follow-up interviews indicate that this is a method often used in medical settings, in particular by hospital play therapists. Toys are used to show children how procedures work or what the outcome of a procedure will be.



Using Mickey Mouse to demonstrate blood tests

Kingston Hospital NHS Trust



A doll with a 'frog plaster'
Kingston Hospital
NHS Trust

Children often feel more comfortable expressing themselves through play.

At **Cool Kids**, an initiative for disabled children in Nottinghamshire, they use CK Bear, a teddy chosen by the children, to express their views about the services they access and their feelings. This means their thoughts can be shared on the website anonymously. The children using the service feel more comfortable using this method.

Many hospital play specialists and other professionals responding to the survey mention the use of puppets to help children explore their feelings.

Role play is also mentioned by professionals, ie giving children the opportunity to act out what is happening and how they feel.

Effectiveness

Both sets of respondents felt that the most effective methods of sharing information with children in the age group 0 – 6 years were toys and games and story books.

Toys and games rated the highest with parents, nearly 30% of them stating that they felt it was the most effective method of communicating with their child. Toys and games don't have to be specialist; children can use dolls, teddies and a host of other toys to role play and as one parent said:

“They are tactile and noisy!”

Professionals also rated play as an effective method with nearly 34% of them rating it as the most effective method.

- *“Toys and games are interactive and hands on.”*
- *“Games can be adapted to each individual child.”*

In many hospital settings, play specialists are used with children to help them understand what is happening and express how they are feeling.

“Through play children are able to effectively learn the sensory and concrete information they need to prepare for hospital procedures and treatment.” – National Association of Hospital Play Staff.

The research findings

Play specialists at many of the settings visited had created their own resources to use with children.

This includes **Great Ormond Street Hospital for Children**, where a play specialist has created a model for children to play with to explain why they need to be strapped in when having scans (see photograph). They have also created a model scanning machine for children to play with.



A model created by a play specialist
Great Ormond Street Hospital for Children
NHS Trust

Many early years settings have play areas for children attending the service. By introducing appropriate toys and games into these areas children's experiences can be made less frightening and they can express their feelings through play.



Hospital play area
Great Ormond Street Hospital
for Children NHS Trust

The research findings

Photographs

How they are used

With the advancement of digital photography and the ease of reproducing photographs this method of creating and sharing information with children is a rapidly growing area.

Our research indicated that photographs are widely used by professionals to convey information. This is demonstrated throughout the survey and is used in most settings from Portage schemes to therapy services. Over 50% of professionals who stated that they produced their own information for disabled children used photographs to convey their message.

Effectiveness

Photographs can make situations less “scary” for a child. It gives them an idea of what is likely to happen. This method of sharing information can be used across every setting from transition into school to having a medical procedure.

There are many examples of the use of photographs; during the course of this research they were particularly seen within medical settings. Photographic sequences are used to explain to a child the processes of ultra sound scanning, blood testing, visiting the outpatients department and many more.

The use of photographs is a method that could be transferred into most early years settings.

As care needs to be taken when using photographs of people and children (for example permissions must be obtained and using the photographs on a website can have a host of issues attached), organisations are developing methods to overcome these barriers. By photographing toys (eg dolls and cuddly toys) undergoing the procedure many of these issues can be avoided.

The research findings

Symbols and objects of reference

Symbols and objects of reference were the next highest used resource by professionals and parents.

There are many different symbols packages on the market. Some like Makaton and Bliss are well-known; others simply use pictures of everyday objects to convey messages to children.

The award-winning BBC TV series **Something Special** uses Makaton symbols and signs, as well as rhymes and songs, to help encourage communication and develop language in a fun and exciting way. Cool Kids has developed a website and comic for disabled children. Both use symbols.

Cool Kids meets monthly and is a group of children aged 5 – 13 years. The group form the editorial board for both resources and they decide the content and format of both the website and comic.

The group has recently subscribed to a “symbols package” and intend to include more articles with symbols where possible.

This initiative is “child-led” and demonstrates some excellent ideas around producing the information that children want in a format that they want.

The website address is: www.cool-kids.org.uk

Objects of reference is a term that describes the use of objects as a means of communication. Objects, just like words, signs and symbols, can be made to represent those things about which we all communicate: activities, events, people, ideas and so on. They can also be used to help children identify with their surroundings and what is happening to them.

The research findings

At **Great Ormond Street Hospital for Children** each ward is named after an animal for example “Starfish” and “Dinosaur”.

On Dinosaur Ward, pictures, models, toys and games all associated with dinosaurs are employed as objects of reference and act as a trigger to the child helping them place what’s happening to them. It can make the experience less frightening particularly for young children with limited cognitive development.



Dinosaur Ward – Great Ormond Street Hospital for Children

Great Ormond Street Hospital for Children NHS Trust

Parents also cited the use of pictures, symbols, photographs and facial expression drawings as an effective way to share information with their children.

The research findings

All children, and particularly those with autism, can find it difficult to say how they are feeling, but are able to point to the picture of the face that best fits their feelings. The scale below is one such method.

These can be easy to create and used with children of all abilities and in all early years settings.

Happy



OK



Worried



Sad



Using a series of faces can help a child to express their feelings

TV, DVD and video

Nearly one-fifth (19.5%) of parents nominated multimedia resources as being an effective method of sharing information with young children. Multimedia included television, DVDs and videos. As one parent said:

“Modern kids watch TV and these media can portray anything!”

Fewer professionals rated multimedia as an effective method – only 6.8%. One of these referred to multimedia resources as:

“Versatile and accessible.”

The research findings

During the course of this research we have not been able to find many multimedia resources for young children.

Parents referred to certain television programmes such as the CBBC programme Balamory, which has a character who uses a wheelchair. CBBC also has a website for this programme where children can play interactive games with this character:

www.bbc.co.uk/cbeebies/balamory/index.shtml

The CBBC programme **Tracy Beaker** was also mentioned by parents as it features a disabled child.

In March 1995 a conference entitled **Invisible Children** was held in London. The conference brought together 150 key image makers including those from the world of television, film and books. The conference found that:

“With a very few exceptions disabled characters and images are largely absent or when they do appear they are presented in a negative and stereotyped way.”

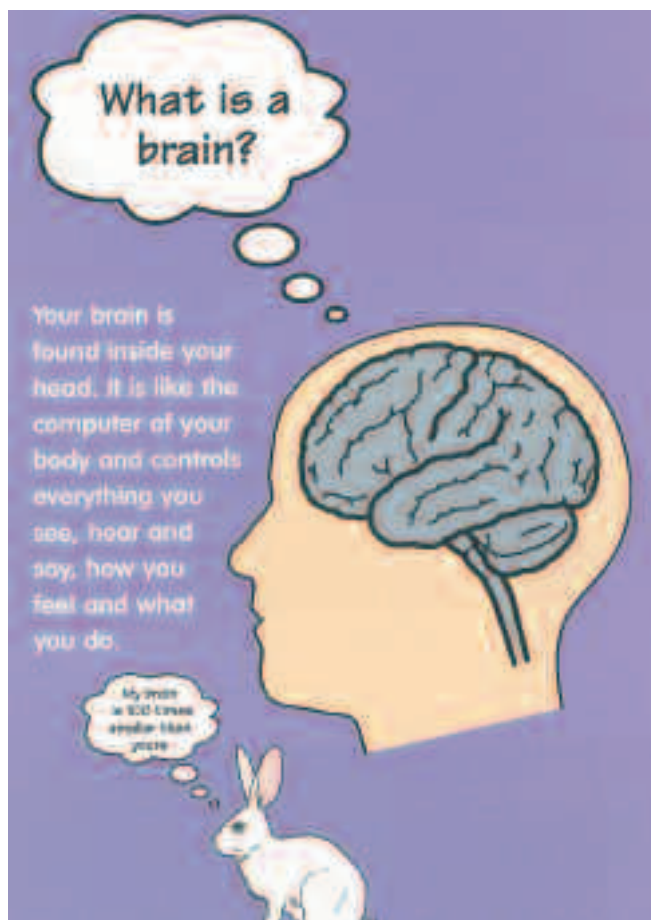
However, the August 2006 edition of Disability Now (DN) magazine had an Influence List of 25 people who have fought to make a difference to disabled people. Number 11 on the list, created by public nomination, was the actress Kim Tserkezie for the Penny Pocket role in the BBC’s Balamory. As DN says:

“What could be more influential for the future than toddlers thinking of Penny, a wheelchair user, as their favourite TV character?”

This could indicate that times have changed and we are moving towards a more inclusive world.

The research findings

The **Brain & Spine Foundation**, an organisation whose younger client group are mainly children with brain tumours and acquired brain injury, produces a DVD for their young clients; however it is aimed at an older age range than we were investigating. Some of the content and images would be useful to use with younger children but a parent would have to decide if it was suitable for their child.



An image from the Brain & Spine Foundation website (Headstrongkids.org)
The Brain & Spine Foundation

Websites

Further investigation of websites revealed that few are designed for young children to use without supervision. However there are resources available for children on websites, for example pictures to download and colour, that could help children understand some of the processes going on around them.

The research findings

The **Kids Zone of Alder Hey Children's Hospital** website has a selection of pictures to download and colour of "Who you might meet in hospital", each person gives an introduction to their job and what might happen to you in their department:

www.alderhey.com/RLCH/kids_zone.asp

In The Picture also has a children's area on the website with pictures to download and colour and a gallery for children to submit their pictures to: www.childreninthepicture.org.uk/childrensarea.htm

Parents and professionals feel that electronic resources (ie websites) are effective.

- *"Websites seem to grab and hold my child's attention."*
Parent
- *"Websites need to be kept simple and interactive."*
Professional

The Brain & Spine Foundation acknowledged the lack of information for children in their client group and launched a Children's Project in 2001. It developed, in consultation with children, a website and information pack on brain tumours. This website is now undergoing a major review; it will be re-designed and the content decided by children. The children being consulted range from 7 – 19 years of age. Cartoon characters will feature heavily but interestingly children felt that the 2001 design is now dated and have suggested a more modern look!

www.headstrongkids.org.uk

Interactive information technology (IT) programmes were seen as a good method of sharing information with children. As one professional described IT based resources:

"They are versatile and accessible – suit all ages."

The research findings

Bespoke

Some parents have gone to extraordinary lengths to create individualised materials for their children. These range from specific communication books to stories to help their child understand what is happening to them.



An example of a 'bespoke' book

This photograph (above) is of a tactile book made by the parent of one child, who has a visual impairment, to help her prepare for an operation. It was made with the full support of the medical team.

The picture book was made as interactive as possible and used memorable objects for the child. The parent reported that it moved from being a learning tool to a treasured possession after the operation.

Professionals too have designed and created unique resources to use with children – particularly toys and games. The research found that

The research findings

play specialists have been especially inventive and examples ranged from a model hand to insert a mock cannula (a small tube which can be inserted into the back of the hand) to models of x-ray and scanning machines and dolls that can be tube fed.

Other methods of communicating with children about their condition and experiences

Both parents and professionals indicated that the main method for sharing information with children, other than printed resources, was “talking to them”.

“Every child is different and I can talk to them at their own level.”

Talking to young children and facilitating them to express their worries, questions and feelings can be supplemented by all the methods listed above.

“It is important to support the family too and by talking to them all we can sort out all the child’s fears as well as giving information to the parents and siblings.”

Least effective methods of sharing information

Parents felt that printed leaflets were the least effective method of sharing information with their child. Professionals agreed citing printed information and websites as the least effective.

Follow-up interviews would indicate that this view is based on traditional printed materials. All parents interviewed felt that printed resources using photographs and stories, some of which are mentioned above, would be very useful for their child.

Professionals interviewed were keen to point out that they did not include too many words in their materials. They used the photographs and images to encourage conversation with the children rather than expecting them to read and absorb the information.

The research findings

Good practice

The questionnaire asked professionals which part of their service in terms of sharing information with young disabled children they were most proud of; 53.5% answered this question.

The answers reflected the cross sample of services surveyed; however nearly a third of the services which responded cited “partnership and joint working” as their best feature.

Joint working included multi-agency working as well as working in partnership with parents and children.

Consultation with parents and children is high on the Government agenda. This can be difficult for the age group our research was concentrating on; however soliciting views from young children is not impossible.

As the **Encephalitis Society** and the **Brain & Spine Foundation** have discovered, young children have opinions (which differ from their parents) on the style of and content of resources. They can contribute to their development and are able to say if they like the content of a story and if the information contained answers their questions.

Other areas that were cited included:

- Relationships with parents and children
- Approachability
- Flexibility
- Celebrating achievement
- Specialist staff
- Active involvement of children and parents
- Play facilities
- One-to-one contact
- An inclusive culture within the setting

The research findings

As part of their services, Sure Start, Bilsthorpe, Blidworth, Clipstone and Rainworth run crèches and groups for children aged from 0 – 4 years.

The nursery area demonstrates some excellent inclusive practices. All areas within the nursery are labelled with the Makaton symbol as well as words. Inclusive toys, books and games are available for the children to play with alongside mainstream resources.

Staff use Makaton signs with all the children, in every session, for example every time they say “please” and “thank you” the appropriate sign is used too.

In a perfect world...

The last question on the survey allowed parents and professionals to tell us how they would make sharing information with young disabled children and their siblings more effective if there were no boundaries.

Some 65% of parents and 39% of professionals responded to this part of the questionnaire.

Responses were many and varied, as would be expected given the diversity of the respondents; some replies are summarised below:

Parents' views

Storybooks were the top category for parents with 28.6% of them stating that more books would help in sharing information with their children.

Parents wanted more inclusive books for both their child and his/her siblings. One parent asked for:

“More stories about the people she sees and the treatments she receives.”

The research findings

Another stated that:

“Books, games etc. should be available in all schools.”

This reflected another area that parents feel could be improved, that of the school environment. Disability awareness in schools was mentioned by 10.7% of those responding.

An inclusive environment is key to “disability awareness” in all settings. Posters, murals, signage and so on can all reflect the diverse society we live in and include images that all children can relate to.

Many settings are keen to make their environment inclusive. They have pictures, posters, toys and murals demonstrating inclusive practices. Due to a lack of commercially available resources, settings have often had to create their own.



An example of a poster which can help make settings more inclusive

© Cath Smith

The latest agenda set by the Government encourages inclusion in schools. These responses would indicate that parents and children are finding that process more difficult than it needs to be.

The research findings

Research carried out in America (Diamond 1996) has shown that, by the age of three, children have already formed prejudices against people who are visibly different.

As a disability organisation **Scope** receives many enquiries from parents, teachers and children. One key topic is how to explain to a child and his or her peers why they are different. Some raise this in Scope's website forum. For instance in June 2006 four parents posted messages asking other parents how they had dealt with this issue and received mostly detailed responses about what to say rather than methods. Scope's helpline on average will receive four similar enquiries a month. This represents just one impairment and one method of communication. The fact that 770,000 children in the UK are disabled means the demand for this type of information for children must be very high indeed.

When the **Brain & Spine Foundation** asked children for their top issue to be addressed on the new website, the response was *"Information to share with their family and friends regarding their condition."*

The need for more toys, games and television offering inclusive play and viewing opportunities for children was the second highest item on parents' "wish lists".



Toy wheelchair and walking frame

The research findings

As referred to above, pockets of good practice are around; toys can now be bought from mainstream toy suppliers offering children the opportunity to reflect the diverse world we live in through play. Television and film are gradually including more disabled characters as part of the mainstream cast.

Professionals' views

By far the most popular item on the professionals' "wish list" was more time and resources, with 53% of those responding stating that this would improve their practices in sharing information with young disabled children and their siblings.

"There are too many barriers to producing information for children; we have to use Trust-approved photographers, and their image bank is very limited, or commission a medical photographer who has limited time. Illustrations are very expensive to commission. Time and resources are so limited."

Information professional

Many professionals who stated that time and resources were an issue also stated that in an ideal world they would make it a higher priority. This would indicate that they acknowledge the importance of providing information for children but the constraints of their jobs and settings they work in means that it has to *"take a back seat"*.

One professional wished for *"an audit of current resources"* and another for *"more coordination"*; this would indicate awareness that resources could be available but a lack of knowledge about where to find them.

More websites for children and multimedia resources were the secondary categories for professionals, with 25% stating that they would like more of these resources available.

Very young children are now able to access computers and most enjoy simple interaction with the characters on websites.

The research findings

Multimedia also includes video, DVDs and CD-ROMs. These media allow for an audio description, making them more inclusive for children with visual impairments. Most children will watch television from an early age – the average viewing time for children in the UK is three hours per day (**Children and Their Changing Media Environment**, Livingstone and Bovill, 2001). Children can watch videos with their peers and share the information they contain. However, they often view without adult supervision and opportunities to share information can be lost.

The need for more specialist staff and/or training for existing staff to work with disabled children was also a key issue highlighted by professionals. Staff trained in non-verbal communication were mentioned as was the opportunity to “consult with experts”. The need to “reduce professional barriers” is also mentioned in this section of the research.

It would appear from the results of the research that some professionals feel that they need further training to share information with children. Follow-up interviews could indicate this is not necessarily the case.

Conclusions

The National Service Framework for Children, Young People and Maternity Services is a ten-year programme that aims to stimulate long-term and sustained improvements in children's health by setting national standards for children's health and social care. The first of these standards requires services to:

*Give children, young people and their parents increased **information**, power and choice over the support and treatment they receive.*

The data collected from this research offers a snapshot of the types of information available for young disabled children and begins to explore some of the issues faced by children, parents and the professionals who work with them.

It is by no means a comprehensive survey of what is available; however, trends do begin to emerge that can be built upon to formulate recommendations.

- Limited information is available for parents and young disabled children.
- It is apparent that although information is out there; both professionals and parents lack awareness of where to locate resources.
- There is little if any sharing of resources and good practice. Information is created within one environment which could easily be adapted for use within others. However, no systems have been established to pool resources, even locally.
- Professionals and parents produce their own resources. using methods that could be transferred across many settings. They do this due to a perceived lack of anything else being available.
- Story books come out as the most used method of sharing information with this age group and yet there is an obvious lack of inclusion of disabled children in mainstream children's literature.

Conclusions

- Toys, games and story books were felt to be the most effective methods of sharing information with this age group by both parents and professionals.
- Time and resources would appear to be the main barrier for professionals when considering the production of information for children.
- The inclusive culture of an organisation can help when sharing information with young children. If children see themselves represented in artwork, toys or books within the environment their sense of isolation is immediately reduced.
- Not all organisations and parents recognise that the processes they use are in fact sharing information with children. These processes could be more overt.
- Consultation with children, regarding the development of information resources for them, takes place on an ad hoc basis.

Recommendations

This report has shown that pockets of good practice in the provision and dissemination of information to disabled children aged from 0 – 6 years do exist. Parents and professionals feel that more resources are necessary and that practice can be improved.

As a result of this research, In The Picture would recommend:

Information provision

- Early years settings develop information in consultation with parents and children to ensure the child's needs are met.
- A culture of inclusion is fostered in all early years settings to assist disabled children attending the service feel less isolated.
- Organisations identify how they give children information – even at the most subtle levels – and develop more overt communication with parents about this.

Sharing good practice

- Examples of good practice in information production for young disabled children be collated and a “toolkit” produced for professionals working with them.
- This resource be shared across all early years settings – most methods are transferable.
- Systems of sharing information resources between professionals be identified and established.
- Methods of allowing parents and children to access this information be identified and established.

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Appendices

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Response of Professional Organisations

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Response of Parents

Appendix 1

Questionnaire for Professional Organisations

Scope's In The Picture team is carrying out research into methods of sharing information with young disabled children. This brief questionnaire has been designed to establish the types of resources available to young disabled children in the early years (up to six years of age).

Please return to: Scope, Freepost RLYY-SXJG-ZCST, Suite 1, Winston House, Monckton Rd, Wakefield, WF2 7AX

OPTIONAL INFORMATION

It would help us to build up a profile of respondents if you are prepared to give the following information (delete as appropriate):

Is your organisation voluntary/statutory?

Does your organisation work directly with disabled children?

Yes/No

Do you involve children in your information development?

Yes/No

Q1 Do you/your organisation produce or use any resources that give information to disabled children in the early years designed to help them understand their experiences?

Yes (Go to question 2)

No (Go to question 4)

Q2 What form does it take?

	Produce own	Others resources
Printed (eg leaflets)	<input type="checkbox"/>	<input type="checkbox"/>
Toys and games	<input type="checkbox"/>	<input type="checkbox"/>
Multimedia (eg videos, DVDs, CD ROMs)	<input type="checkbox"/>	<input type="checkbox"/>
Story books	<input type="checkbox"/>	<input type="checkbox"/>
Electronic (eg websites)	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

If other, please give details.

.....
.....

Q3 What is the information about? Please tick all that apply.

- Their condition/impairment.....
- Your service.....
- What's happening to them
eg therapies
- Aids and adaptations.....
- Feelings
- Siblings
- Other

If other, please give details.

.....
.....

Q4 Information is not always conveyed using printed materials. How do you communicate with young disabled children using your service, about the services you offer? Please tick all that apply.

- Talking to them
- Signs and sensory
- Multi-sensory
- Play
- Drama.....
- Art work.....
- Multimedia
- Other

If other, please give details.

.....
.....

Q5 How easy do you feel most parents find it to convey information to their disabled child and/or his/her siblings, about your service and its place in their lives? Please tick the appropriate number on the scale below.

(1 = Hard, 10 = Easy)

1 2 3 4 5 6 7 8 9 10

Q6 Do you/your organisation produce or use other resources for parents to use with their children?

- Yes (Go to question 7)
- No (Go to question 8).....

Q7 If answered yes to question 6, what form does the resource take?

	Produce own	Others resources
Printed (eg leaflets)	<input type="checkbox"/>	<input type="checkbox"/>
Toys and games	<input type="checkbox"/>	<input type="checkbox"/>
Multimedia (eg videos, DVDs, CD ROMs)	<input type="checkbox"/>	<input type="checkbox"/>
Story books	<input type="checkbox"/>	<input type="checkbox"/>
Electronic (eg websites)	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

If other, please give details.

.....
.....

Q8 Which of the resources mentioned would you nominate as an effective way of giving information to young disabled children? Tick all that apply.

- Printed (eg leaflets)
- Toys and games
- Multimedia
(eg videos, DVDs, CD ROMs)
- Story books
- Electronic (eg websites)
- Other

Q8.1 Which is the most effective?

.....

Q8.2 Why?

.....
.....

Q9 Does your organisation have a child-focussed section on its website?

Yes.....

The website address is.....

.....

Not at the moment but one planned in the next two years

No.....

Organisation does not have a website

Q10 If you have answered yes to question 9, is your website accessible to children up to six years of age with supervision?

Yes.....

No.....

Q11 What part of your service, in terms of sharing information with disabled children, are you most proud of?

.....
.....
.....

Q12 If you could wave a magic wand how would you make the sharing of information with young disabled children and their siblings more effective? Continue on separate sheet if necessary.

.....
.....

Q13 Would you be able to discuss the issues raised in this questionnaire in more detail?

Yes.....

(See 'your details' section below)

No.....

(Please see 'update' information below)

Appendix 1

Your Details

Your name

Your job title.....

Organisation name

Address Line 1

Address Line 2

Town/City Postcode

Telephone number..... Fax number

Email address.....

Thank you for taking the time to complete this questionnaire.

For more information about the rest of the project please visit:

<http://www.childreninthepicture.org.uk>

We also produce a regular electronic **update** on the progress of In The Picture project. If you would like to receive this, please ensure that your email address is included above and tick

We would be happy to receive any sample products of your resources for young disabled children. Please enclose them with your questionnaire to: Scope, Freepost RLYY-SXJG-ZCST, Suite 1, Winston House, Monckton Rd, Wakefield, WF2 7AX.

Scope is a registered charity no. 208231 and a company limited by no. 520866 (England).

Registered office: 6 Market Road, London N7 9PW

Appendix 2

Questionnaire for Parents

Scope's In The Picture team is carrying out research into methods of sharing information with young disabled children. This brief questionnaire has been designed to establish the types of resources available to young disabled children in the early years (up to six years of age).

Please return to: Scope, Freepost RLYY-SXJG-ZCST, Suite 1, Winston House, Monckton Rd, Wakefield, WF2 7AX

OPTIONAL INFORMATION

It would help us to build up a profile of respondents if you are prepared to give the following information:

My child is years of age

My child is male/female

My child's disability is

Q1 Has your disabled child ever used information materials designed for them, to help them understand their experiences?

Yes (Go to question 2)

No (Go to question 3).....

Q2 If yes, what form does it take? Please tick all that apply.

- Printed (eg leaflets)
- Toys and games
- Multimedia
(eg videos,DVDs, CD ROMs)
- Story books
- Electronic (eg websites)
- Other

If other, please give details.

.....

Q3 Information is not always conveyed using printed materials. How do you communicate with your young disabled child about their life experiences? Please tick all that apply.

- Talking to them
- Signs and sensory.....
- Multi-sensory
- Play
- Drama.....
- Art work
- Multimedia
- Other

If other, please give details.

.....

Q4 How easy do you find it to convey information to your child and/or his/her siblings about what is happening to them? Please tick the appropriate number on the scale below. (1 = Hard, 10 = Easy)

- 1 2 3 4 5 6 7 8 9 10
-

Q5 Have you ever used any resources designed for you as a parent, to use with your child to help them understand their experiences?

- Yes (Go to question 6)
- No (Go to question 7).....

Q6 If answered yes to Q5, what form does it take? Please tick all that apply.

- Printed (eg leaflets)
- Toys and games
- Multimedia
(eg videos,DVDs, CD ROMs)
- Story books
- Electronic (eg websites)
- Other

If other, please give details.

.....

Q7 Which of the resources mentioned, would you nominate as an effective way of giving information to young disabled children? Tick all that apply.

- Printed (eg leaflets)
- Toys and games
- Multimedia
(eg videos, DVDs, CD ROMs)
- Story books
- Electronic (eg websites)
- Other

If other, please give details.

.....
.....

Q7.1 Which is the most effective?

.....

Q7.2 Please state why.

.....
.....
.....

Q8 Do you ever use websites designed to give information to disabled children about their condition or what is happening to them.

Yes No

Please give any website addresses that you have found particularly helpful.

.....
.....
.....

Q9 If you have answered yes to question 8, was the website accessible to children under 6 with supervision?

Yes.....
No.....

Q10 Is the information you/your child, use about any of the following? Tick all that apply.

- Your child's condition/impairment.....
- A service your child is using
- What's happening to your child.....
- Aids and adaptations.....
- Feelings.....
- Siblings.....
- Other

If other, please give details.

.....
.....

Q11 If you could wave a magic wand, how would you make the sharing of information with young disabled children and their siblings more effective? Continue on separate sheet if necessary.

.....
.....
.....
.....
.....
.....

Q12 Are you prepared to discuss the issues raised in this questionnaire in more detail?

Yes (Please see 'your details' section below)

No (Please see 'update' information below)

Your Details

Please give your contact details below (these will only be used by the project team)

Your name

Address Line 1

Address Line 2

Town/City Postcode

Telephone number..... Fax number

Email address.....

Thank you for taking the time to complete this questionnaire.

For more information about the rest of the project please visit:

<http://www.childreninthepicture.org.uk>

We also produce a regular electronic **update** on the progress of In The Picture project. If you would like to receive this, please ensure that your email address is included above and tick

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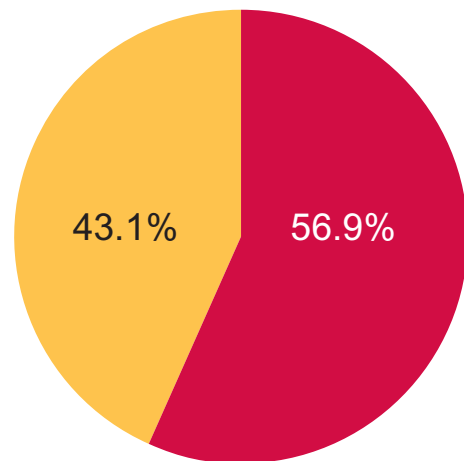
Appendix 3

Responses – Professional Organisations

Responses to question 1

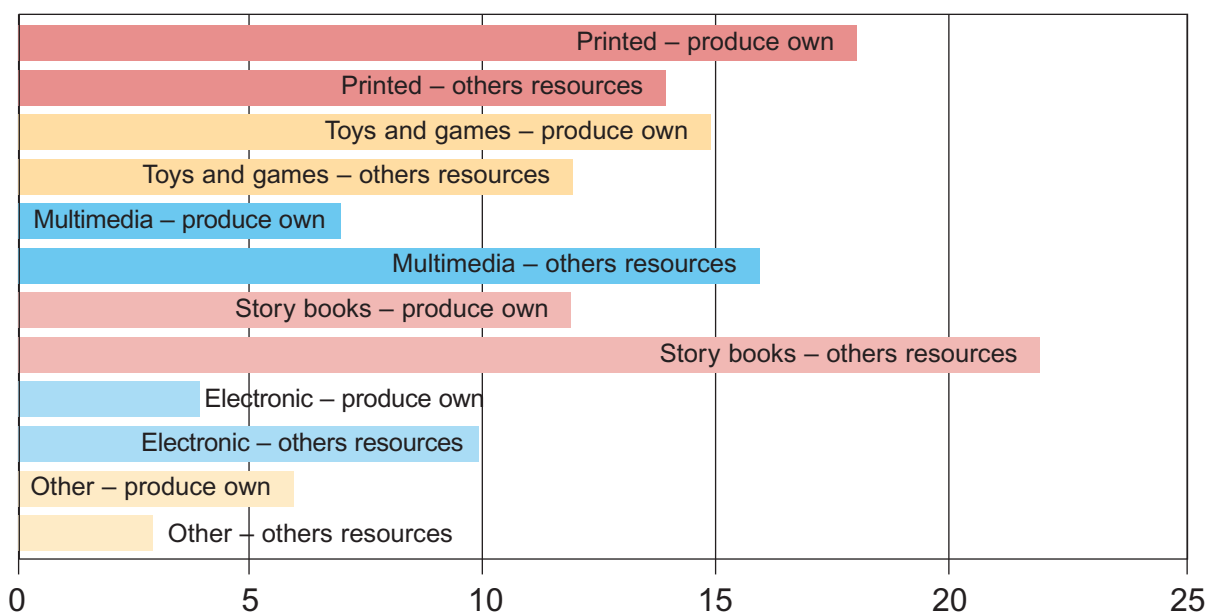
Do you/your organisation produce or use any resources that give information to disabled children in the early years designed to help them understand their experience?

- Yes (Go to question 2)
- No (Go to question 4)



Responses to question 2

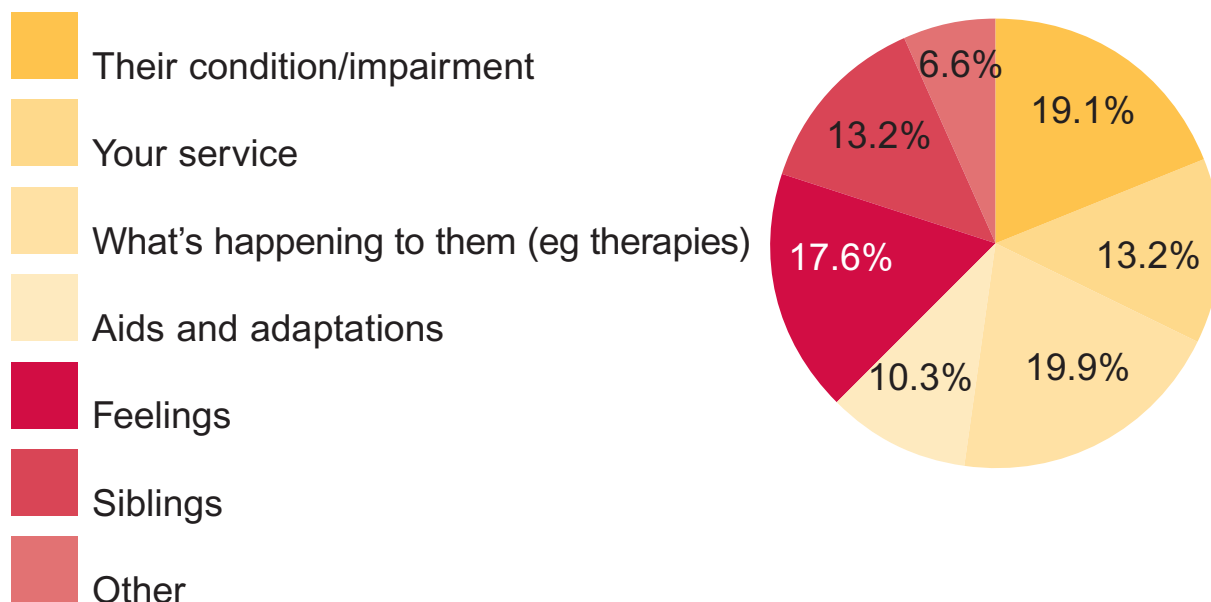
If yes, what form does it take?



Appendix 3

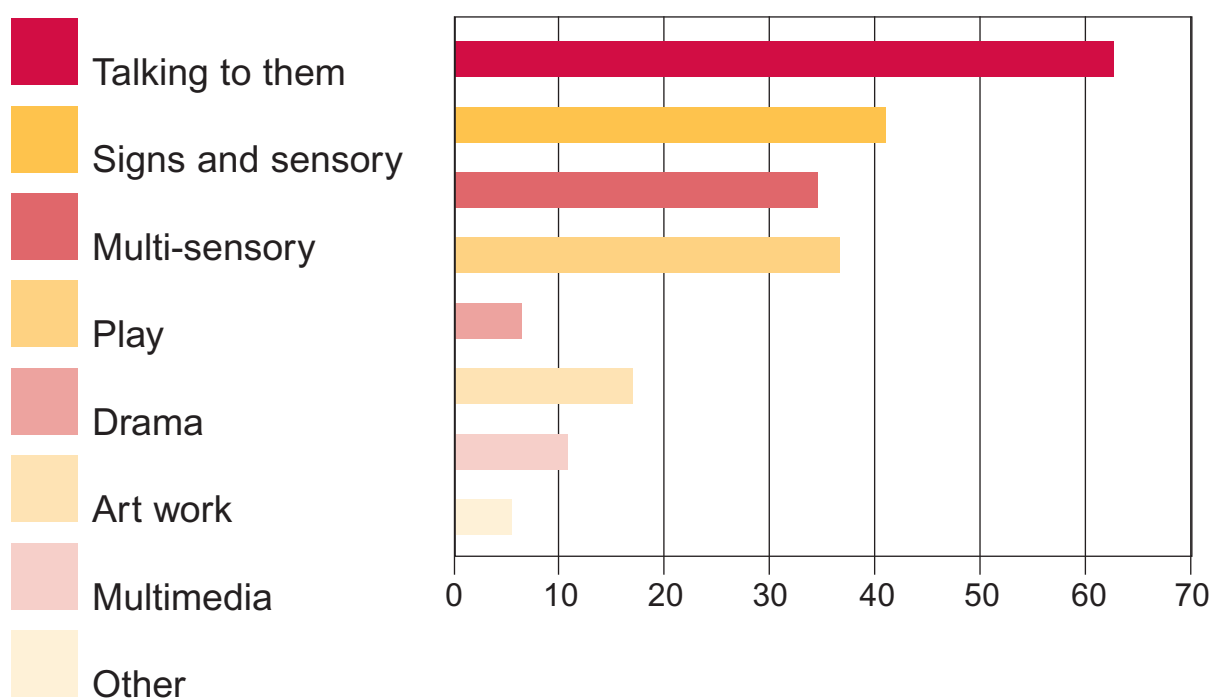
Responses to question 3

What is the information about? Please tick all that apply.



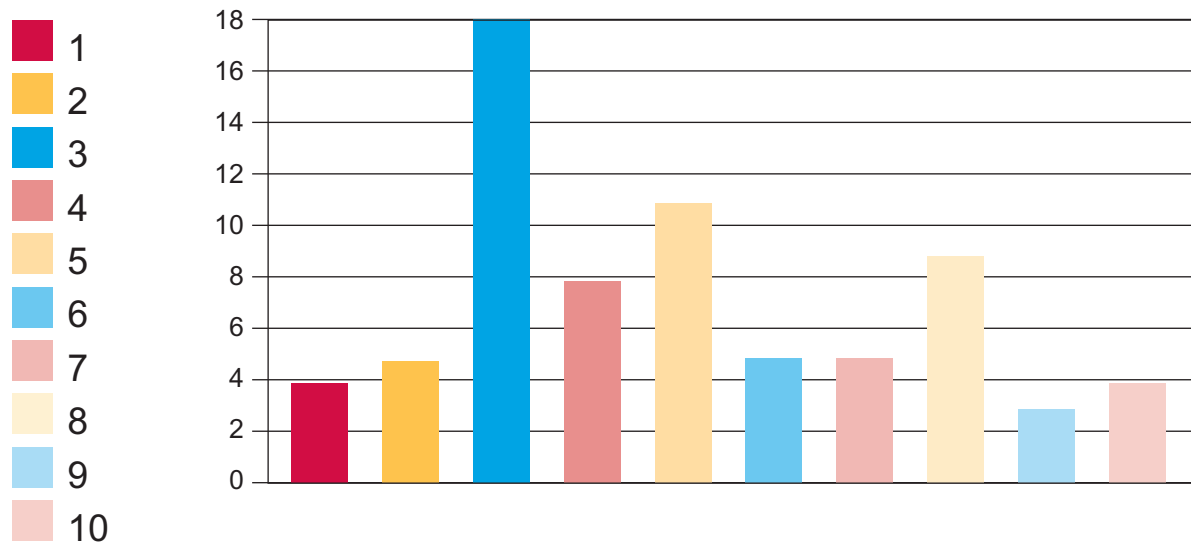
Responses to question 4

Information is not always conveyed using printed materials. How do you communicate with young disabled children using your service, about the services you offer? Please tick all that apply.



Responses to question 5

How easy do you feel most parents find it to convey information to their disabled child and/or his/her siblings, about your service and its place in their lives? Please tick the appropriate number on the scale below. 1 = Hard. 10 = Easy.



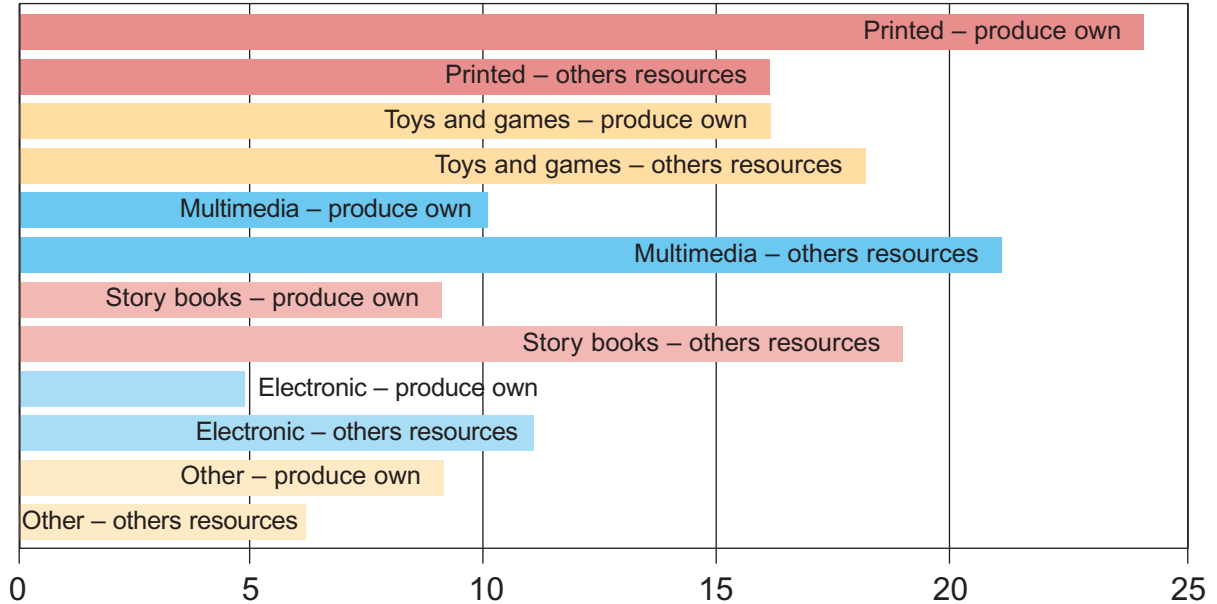
Responses to question 6

Do you/your organisation produce or use other resources for parents to use with their children?



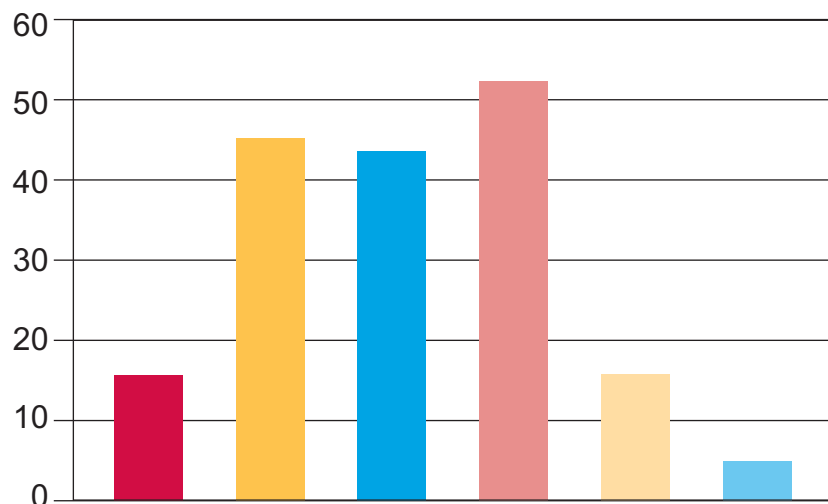
Responses to question 7

If answered yes to question 6, what form does it take?



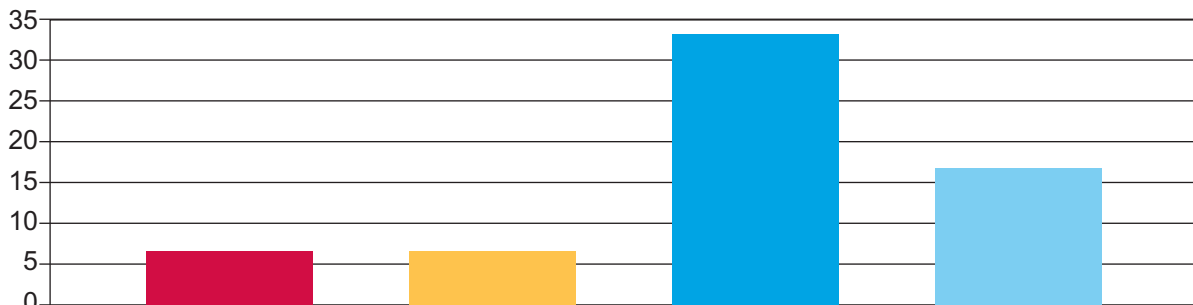
Responses to question 8

Which of the resources mentioned would you nominate as an effective way of giving information to young disabled children?



Responses to question 9

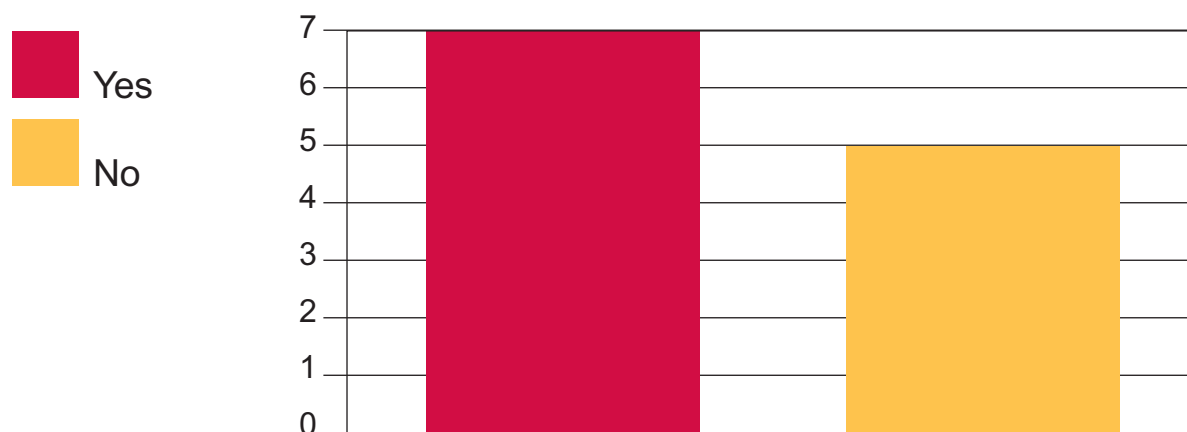
Does your organisation have a child-focussed section on its website?



- Yes. The website address is
- Not at the moment but one planned in the next two years
- No
- Organisation does not have a website

Responses to question 10

If you have answered yes to question 9, is your website accessible to children up to 6 years of age with supervision?






Appendix 3

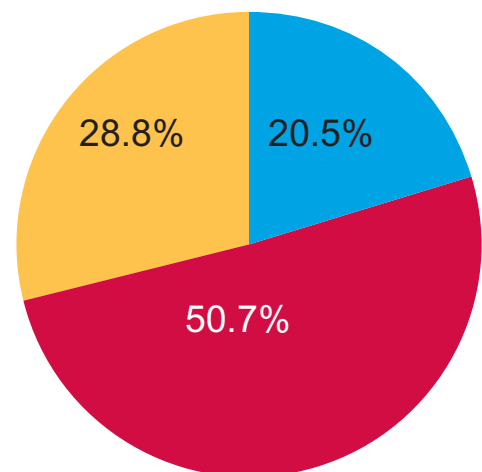
[Q11 What part of your service, in terms of sharing information with disabled children, are you most proud of?]

[Q12 If you could wave a magic wand how would you make the sharing of information with young disabled children and their siblings more effective? Continue on separate sheet if necessary.]

Responses to question 13

Would you be able to discuss the issues raised in this questionnaire in more detail?

-  No reply
-  Yes (See 'your details' section)
-  No (Please see 'update' information)

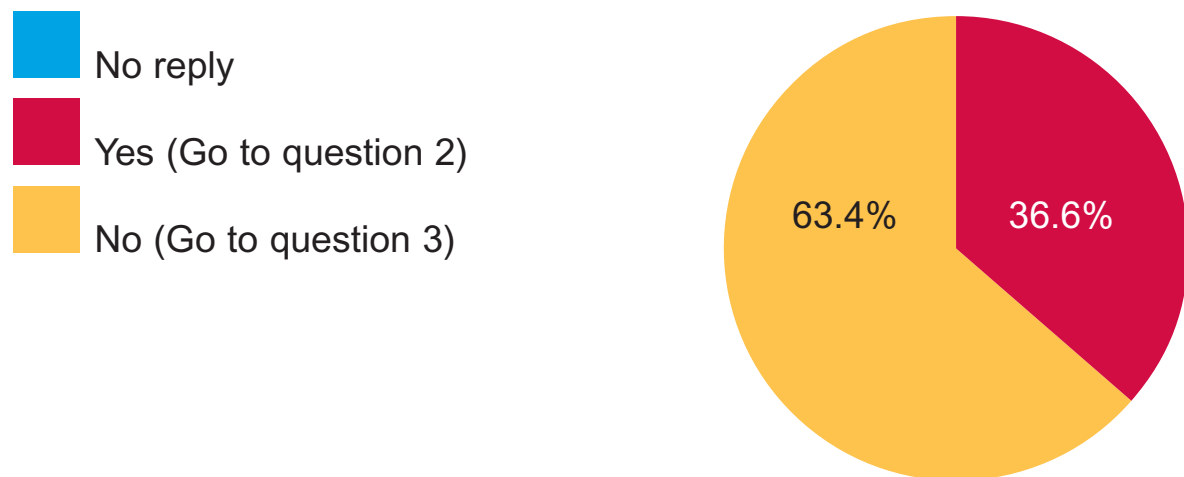


Appendix 4

Responses – Parents

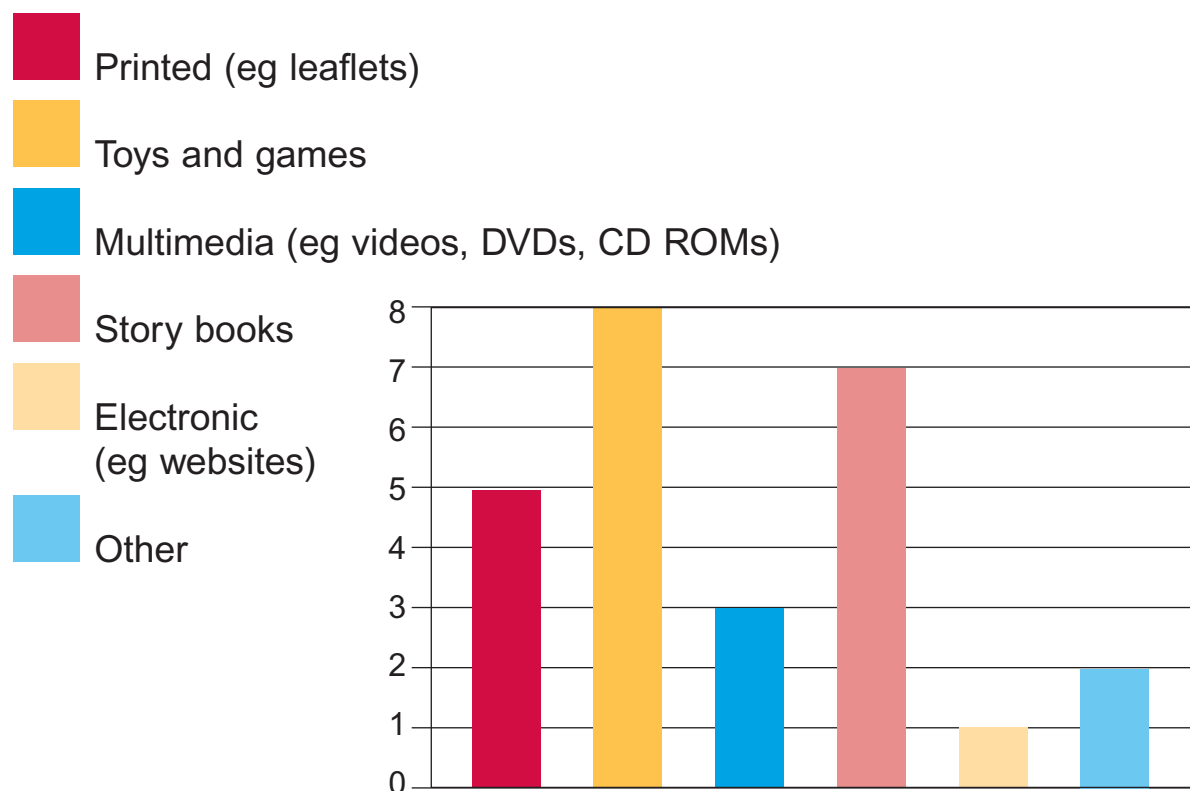
Responses to question 1

Has your disabled child ever used information materials designed for them, to help them understand their experiences?



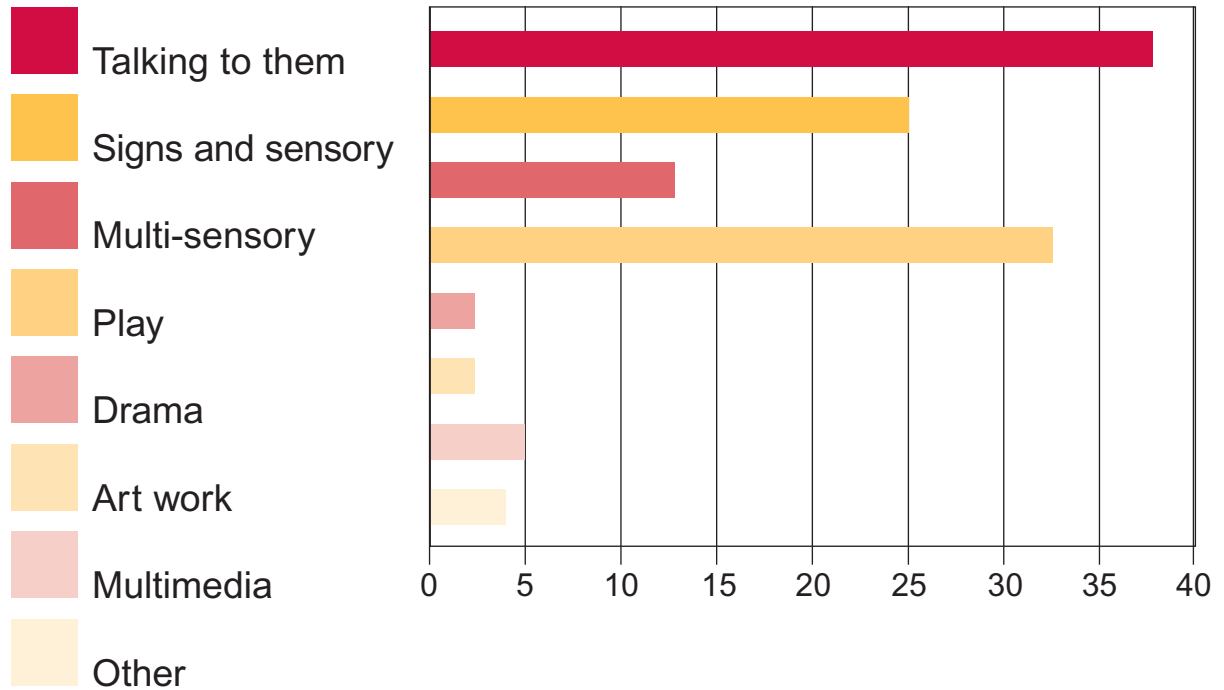
Responses to question 2

If yes, what form does it take? Please tick all that apply.



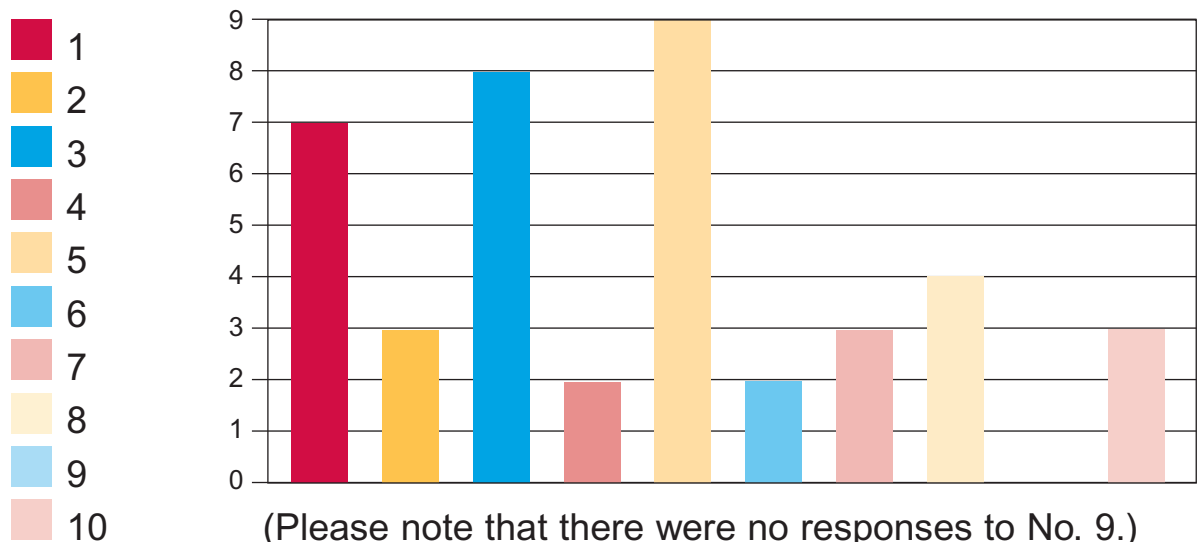
Responses to question 3

Information is not always conveyed using printed materials. How do you communicate with your young disabled child about their life experiences? Please tick all that apply.



Responses to question 4

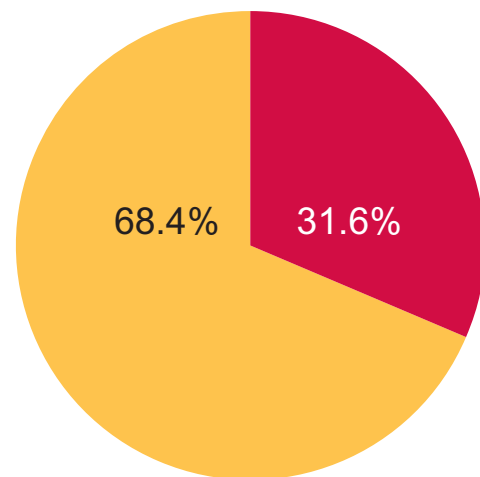
How easy do you find it to convey information to your child and/or his/her siblings, about what is happening to them? Please tick the appropriate number on the scale below. 1 = Hard. 10 = Easy.



Responses to question 5

Have you ever used any resources designed for you as a parent, to use with your child to help them with their experiences?

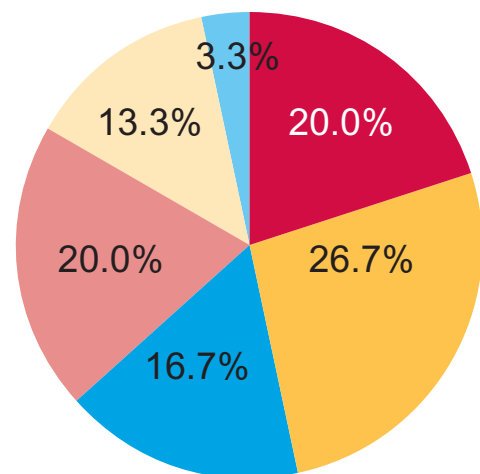
- Yes (Go to question 6)
- No (Go to question 7)



Responses to question 6

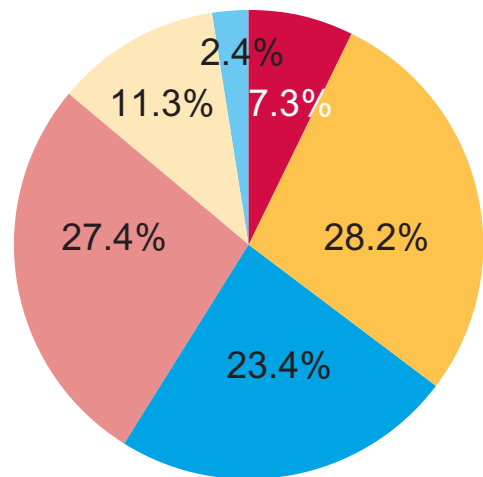
If answered yes to question 5, what form does it take? Please tick all that apply.

- Printed (eg leaflets)
- Toys and games
- Multimedia (eg videos, DVDs, CD ROMs)
- Story books
- Electronic (eg websites)
- Other



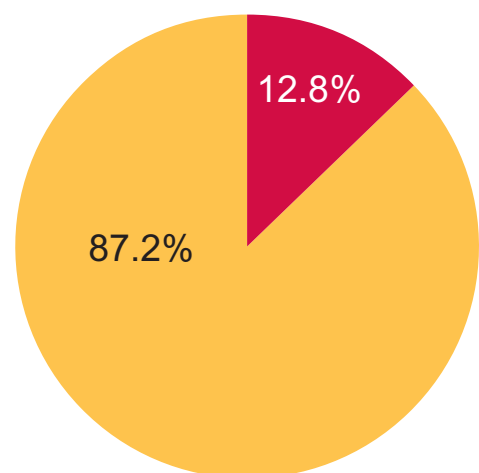
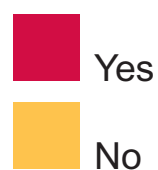
Responses to question 7

Which of the resources mentioned, would you nominate as an effective way of giving information to young disabled children? Tick all that apply.



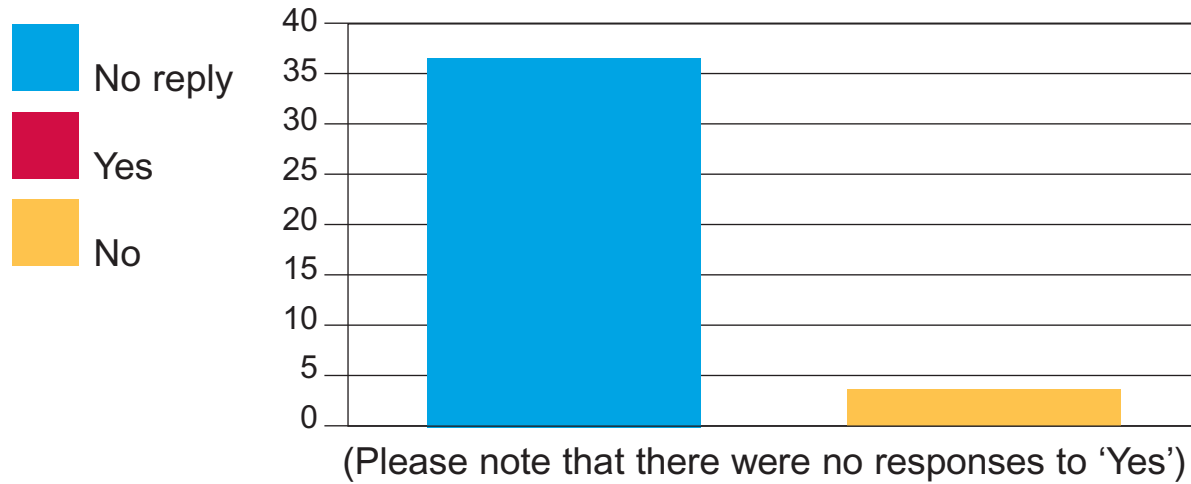
Responses to question 8

Do you ever use websites designed to give information to disabled children about their condition or what is happening to them?



Responses to question 9

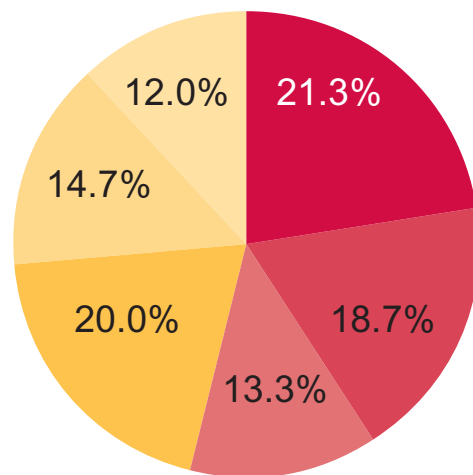
If you have answered yes to question 8, was the website accessible to children under 6 with supervision?



Responses to question 10

Is the information you/your child use, about any of the following?
Please tick all that apply.

- Your child's condition/impairment
- A service your child is using
- What's happening to your child
- Aids and adaptations
- Feelings
- Siblings
- Other



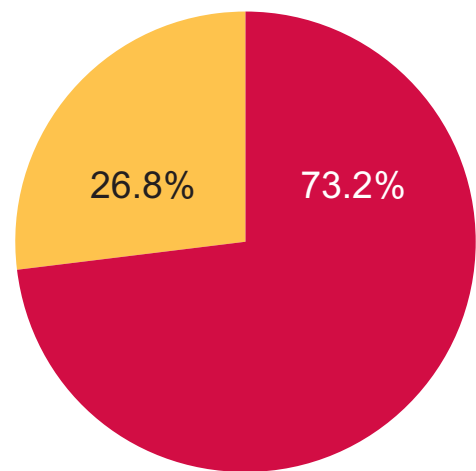
Appendix 4

[Q11 If you could wave a magic wand, how would you make the sharing of information with young disabled children and their siblings more effective? Continue on separate sheet if necessary.]

Responses to question 12

Are you prepared to discuss the issues raised in this questionnaire in more details?

- Yes (See 'your details' section)
- No (Please see 'update' information)



Click to Scope

You can support Scope's work in a number of ways by going to www.scope.org.uk/support

For information and advice on cerebral palsy, disability issues and Scope's services, visit www.scope.org.uk or contact **Scope Response** on **0800 800 3333**.

To obtain further copies of the **In The Picture Report**, please email inthepicture@scope.org.uk or visit www.childreninthepicture.org.uk

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Time to get equal



About cerebral palsy.
For disabled people achieving equality.