

# Evaluation with expectant and new parents with children from pregnancy to age 5 years of CHANGE resources to support parents with learning disabilities

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- Equal Say, Glasgow
- Sighthill Children and Families Centre, Edinburgh

## **Terminology**

Many people who have the label 'learning disability' have said that they prefer to be called 'people with learning difficulties'. This is the term used by People First (Scotland).

The term 'people with learning difficulties' is used in this report to mean people who have a real and lifelong difficulty in learning things. It is used in the same way as the term 'people with learning disabilities' is used in legislation, policy and research.

Whichever term is used it should not be taken to imply that people cannot learn. It is particularly important that professionals do not jump to this assumption when working with parents with learning difficulties.

## Executive Summary

### Background

There are growing numbers of parents with learning difficulties in the UK (Tarleton *et al*, 2006). Exact numbers are not known, but in recent years research reports and policy documents have drawn attention to the issues faced by this group and begun to address some of the discrimination experienced.

Research has highlighted the importance of parents with learning difficulties having an equal opportunity to acquire adequate childcare skills and to learn appropriate parenting behaviour (Booth T. and Booth W., 1994). Easy to understand information on all aspects of parenting, the right sort of ongoing, flexible support, joint working and independent advocacy, have been shown to be important factors in helping families where a parent has learning difficulties to stay together (Tarleton *et al*, 2006).

The *Scottish good practice guidelines for supporting parents with learning disabilities* (SCLD, 2009) specify accessible information and communication as key features of good practice when working with parents with learning difficulties.

The Joint Committee on Human Rights has highlighted that the way parents with learning difficulties have been treated, including a lack of accessible information, may amount to a breach of article 8 of the European Convention on Human Rights, the 'Right to respect for private and family life' (Joint Committee on Human Rights, 2008).

The Disability Equality Duty, and the new Public Sector Equality Duty under the Equality Act 2010, place a duty on public bodies to give due regard to advancing equality of opportunity by taking steps to meet the needs of people with disabilities where these are different from the needs of others.

Further information about the research, policy and legal background can be found in the *Scottish good practice guidelines* (SCLD, 2009, Appendix B).

NHS Health Scotland decided to make the CHANGE resources available to parents with learning difficulties free of charge, as an easy read alternative to *Ready Steady Baby!* and *Ready Steady Toddler!*

*My Pregnancy My Choice* and *You and Your Baby 0–1* first became available in April 2009 and *You and Your Little Child 1–5* became available in April 2010. Anecdotal evidence raised concerns that these resources were not reaching parents. NHS Health Scotland decided therefore to commission an evaluation of the resources and their distribution.

People First (Scotland) was commissioned to carry out one strand of the evaluation to establish the views and experiences of parents with learning difficulties. This report should be read together with the report of the other strand

of the evaluation, which sought to establish the views and experiences of professionals.

### **Aims and objectives**

The key aim of this evaluation was to establish the extent to which the CHANGE resources are a high quality accessible resource for parents with learning difficulties.

The key objectives were:

- To establish the extent to which materials are perceived to be accessible, inclusive, representative and acknowledging diversity.
- To determine the perceived tone and format of materials' presentation and whether this is felt to be appropriate for use by parents.
- To highlight additional messages that should be included, or information gaps.
- To determine if the content of the materials is felt to be appropriate for use by parents.
- To develop recommendations to ensure these resources are accessible locally to the parents who require them.

### **Method**

A Project Steering Group oversaw the evaluation. The evaluation adopted a user-led approach with parents with learning difficulties acting as co-researchers as well as sitting on the Project Steering Group.

A qualitative methodology was adopted which comprised in-depth interviews and a focus group. The criterion for inclusion was that parents with learning difficulties must have a child under five who had lived with them at least some of the time since August 2009. An easy read leaflet was widely circulated inviting parents to take part in the evaluation. Consent was obtained using an easy read form, which was explained to all parents.

Semi-structured individual interviews were held with eleven parents and an additional seven parents attended a focus group.

### **Summary of main or key results**

The majority of parents had never seen the CHANGE resources.

Only five parents had received a copy of the resources - two had received them at the right time and two had received them through mainstream services. Two parents had received one resource but not the follow on resource when the child

grew older. Two parents talked about confusion and delay in getting the resources.

All parents were extremely positive about the resources and wanted their own copy to use at home.

Most parents commented on how inaccessible they had found *Ready Steady Baby!* and, for those who had received it, *Ready Steady Toddler!*

Parents liked the pictures, layout, large print, short sentences and paragraphs, and easy words in the CHANGE resources.

Parents suggested including additional information and a range of improvements to make the resources more accessible, including a DVD to accompany each resource. A resource about looking after children aged over five would be useful.

Parents had a variety of support needs in using the resources. A significant number said that they would find the resources easy to use on their own, but the number saying that they would like support to be offered was also significant. Several parents mentioned informal supports as being important. Only one parent had had support from a professional to go through the resource.

Parents thought that all professionals who had contact with parents with learning difficulties should have a copy of the resources and know how to access them.

In terms of how the resources should be given out, parents thought that:

- *My Pregnancy My Choice* should be given out by midwives early on in the pregnancy – maybe at the time of the first scan.
- *You and Your Baby* should be given out by midwives well before the baby is born.
- *You and your Little Child* should be given out by health visitors.
- Where there is an equivalent mainstream resource parents should be offered a choice between the CHANGE resource and the NHS Health Scotland resource. Parents may be reluctant to identify themselves as having learning difficulties and will be unlikely to ask for help.

## **Conclusions & Recommendations**

Parents with learning difficulties are not routinely accessing the CHANGE resources as intended by NHS Health Scotland. They are therefore not getting equal access to information about looking after their children.

The evidence points to a lack of awareness of the resources amongst professionals and a lack of a clear procedure for distributing them – a full discussion of these issues can be found in the other strand of the evaluation.

**Recommendation 1:** NHS Health Scotland should engage in a series of awareness raising activities designed to ensure that all relevant professionals are aware of the resources, the benefits to parents of using them and the rights of parents to accessible information.

**Recommendation 2:** There should be a lead professional in each area who oversees the provision of information and support for parents with learning difficulties.

The CHANGE resources met the information needs of parents with learning difficulties better than *Ready Steady Baby!* and *Ready Steady Toddler!*

The resources were not as accessible to parents who did not read well. Various improvements to the resources would increase accessibility.

**Recommendation 3:** NHS Health Scotland should explore with CHANGE adding colour-coded sections to *You and Your Baby* and making the index easier to find and use.

**Recommendation 4:** NHS Health Scotland should explore with CHANGE the possibility of developing a DVD to accompany each of the resources.

Gaps in the information provided should be filled by the provision of additional information.

**Recommendation 5:** NHS Health Scotland should explore with CHANGE adding information to *You and Your Little Child* about parenting children with behaviour difficulties.

**Recommendation 6:** NHS Health Scotland should explore with CHANGE adding information to *You and Your Baby* and *You and Your Little Child* about having people coming into your home to provide support and the best ways of managing this.

**Recommendation 7:** NHS Health Scotland should raise with CHANGE the gap in information for parents of children over five years of age.

All professionals working in this area should have a good understanding of the possible need for support to use the resources and the complex issues around parents with learning difficulties asking for help. Support should be routinely offered. The importance of informal supports should not be overlooked.

**Recommendation 8:** NHS Health Scotland should explore how to provide awareness raising and capacity building with midwives, health visitors and other professionals on the needs of parents with learning difficulties and on how to use the resources with parents including input by parents with learning difficulties.

All parents should be offered a choice between the mainstream resources and the CHANGE resources where possible. This would overcome the potential barriers around identification of learning difficulties and stigma. Parents would be

unlikely to ask for the resources themselves. For a further discussion of these issues see the report from the other strand of the evaluation.

As the CHANGE resources do not correspond exactly with the two mainstream NHS Health Scotland resources, there needs to be a separate process for distributing *You and Your Baby*. This needs to be approached with sensitivity.

**Recommendation 9:** All parents should be offered *My Pregnancy My Choice* as an alternative to *Ready Steady Baby!* by midwives at the booking appointment.

**Recommendation 10:** Midwives, in agreement with the parent, should record who accessed *My Pregnancy My Choice* to allow for a flag to be raised signifying who to distribute *You and Your Baby* to.

**Recommendation 11:** *You and Your Baby* should be offered to parents at twenty-eight week check.

**Recommendation 12:** All parents should be offered *You and Your Little Child* as an alternative to *Ready Steady Toddler!*

To fully meet the information needs of parents with learning difficulties all professionals working with this group should be aware of these resources and should have copies to hand.

**Recommendation 13:** A copy of each relevant resource should be provided to all social work teams, nurseries, children and families centres, advocacy projects, GP surgeries, community learning disability teams, teams of midwives and health visitors, and support agencies.

# 1. Introduction

## 1.1. Background

There are growing numbers of parents with learning difficulties in UK (Tarleton *et al*, 2006). Exact numbers are not known, but in recent years research reports and policy documents have drawn attention to the issues faced by this group and begun to address some of the discrimination experienced.

Some of the first research into this area to gain publicity in the UK was carried out by Tim and Wendy Booth from Sheffield University in early 1990s and drew attention to the disproportionate numbers of parents with learning difficulties in the child protection system (Booth T. and Booth W., 1994). This study highlighted the importance of parents having an equal opportunity to acquire adequate childcare skills and to learn appropriate parenting behaviour.

More recently the *Finding the Right Support* research identified the provision of easy to understand information on all aspects of parenting together with the right sort of ongoing, flexible support, joint working and independent advocacy to be important factors for families where a parent has learning difficulties being given an equal chance to stay together (Tarleton *et al*, 2006).

Following on from the *Finding the Right Support* research, the Westminster Government published *Good Practice Guidance on working with parents with learning disabilities* (Department of Health, Department for Education and Skills, 2007). This guidance, however, only covered England and Wales and in 2009 the Scottish Parenting Network, a group of parents and professionals concerned about the issues for parents with learning difficulties, published a Scottish version (SCLD, 2009). This guidance, like it's Westminster counterpart, identifies the provision of accessible information and communication as a key feature of good practice when working with parents with learning difficulties.

Providing accessible information to parents with learning difficulties is more than just good practice, however. In 2008 the House of Lords and House of Commons Joint Committee on Human Rights published the report of their investigation into the human rights of adults with learning difficulties titled *A life Like Any Other?* (Joint Committee on Human Rights, 2008). They devoted a chapter to *Parenting and Family Life* (Chapter 6) and highlighted potential breaches of article 8 of the European Convention of Human Rights, the 'Right to respect for private and family life', in the way that parents with learning difficulties were treated. Amongst other issues they pointed to evidence showing the lack of accessible information available to people with learning difficulties who had or who were about to have a baby.

This report also drew attention to the Disability Equality Duty 2006 under the Disability Discrimination Act. This places a positive duty on public bodies to pay 'due regard' to the promotion of equality of opportunity for disabled people, to the elimination of discrimination and of harassment, to the encouragement of

participation by disabled people in public life and to take steps to meet the information and other needs of people with disabilities, even if this requires more favourable treatment.

The new Public Sector Equality Duty under the Equality Act 2010 will replace the Disability Equality Duty on 6th April 2011. This provides a similar duty on public bodies to give due regard to advancing equality of opportunity by taking steps to meet the needs of people from protected groups where these are different from the needs of others.

All of these research reports and policy documents, however, are clear that providing parents with learning difficulties with accessible information is only one aspect of the right sort of support. The information needs to be provided within a wider context of ongoing, flexible support that meets the needs of this group of parents and their children. This evaluation should therefore be read in this context.

Further information about the research, policy and legal background can be found in the Scottish Good Practice Guidelines (SCLD, 2009, Appendix B)

People First (Scotland) is the national independent self-advocacy organisation of people with learning difficulties. The People First East Parents' group has been running since November 2006. It is a group run by and for parents with learning difficulties and currently has fourteen members. Group members support each other and campaign for better support for parents with learning difficulties.

A representative from the group sits on the Scottish-wide Parenting Network and has been very involved in producing the *Scottish Good Practice Guidelines on Working with Parents with Learning Disabilities* (SCLD, 2009). The group has run training for social work students, Parentline Call-takers, workers at Children First and other professionals. They have run workshops at conferences including NHS Health Scotland early years conferences on health inequalities. People First (Scotland) has a new parents' group in the West of Scotland.

It was largely as a result of letters from the Parents' Group and contact with other members of the Parenting Network that NHS Health Scotland decided to make the CHANGE resources available to parents with learning difficulties free of charge as an easy read alternative to *Ready Steady Baby!* and *Ready Steady Toddler!*

*My Pregnancy My Choice* and *You and Your Baby* first became available in April 2009 and *You and Your Little Child* became available in April 2010.

Anecdotal evidence again from the People First Parents' Group and the Scottish Parenting Network raised concerns that these resources were not reaching parents. NHS Health Scotland decided therefore to commission an evaluation into the resources.

People First (Scotland) was commissioned to carry out one strand of the evaluation to establish the views and experiences of parents with learning difficulties. This report should be read together with the report of the other strand of the evaluation which sought to establish the views and experiences of professionals.

## **1.2. Aims and objectives**

The key aim of this evaluation was to establish the extent to which the CHANGE resources are a high quality accessible resource for parents with learning disabilities.

The key objectives which the evaluation sought to address were:

- To establish the extent to which materials are perceived to be accessible, inclusive, representative and acknowledging diversity.
- To determine the perceived tone and format of materials' presentation and whether this is felt to be appropriate for use by parents
- To highlight additional messages that should be included or information gaps.
- To determine if the content of the materials is felt to be appropriate for use by parents
- To develop recommendations to ensure these resources are accessible locally to the parents who require them.

## **1.3. Key themes**

- Whether parents are getting the resources.
- What parents think of the quality of the resources.
- How to ensure parents can access the resources.

## **2. Method**

### **2.1. Methodology**

#### 2.1.1. Steering group

The evaluation was overseen by the Project Steering Group. The group was made up of representatives from NHS Health Scotland and the research contractors for this piece of work (People First (Scotland) and Create Consultancy) also attended the meetings. The group met four times during the project.

#### 2.1.2. Making contact

Previous work and research in this area has shown that parents with learning difficulties are a particularly hard group of people to reach: many parents have a negative view of social work and professional services in general and are reluctant to make contact; others are struggling to cope and negotiate their way through complex child protection procedures with minimal support and lack the time or energy to attend further meetings.

The researchers made contact with parents by email, phone and letter through:

- Advocacy projects
- Community learning disability teams
- Children and families and learning disability social work teams
- Children and families centres
- Health visitors
- Midwives
- Support providers and other local voluntary sector agencies
- Surestart and Homestart
- Scottish Parenting Network
- Contacts from NHS Health Scotland
- People First (Scotland) parents' groups

An easy read leaflet about the evaluation was circulated (see Appendix 1: Information leaflet). In addition to explaining the purpose and nature of the evaluation the leaflet also stated that:

- Any travel costs incurred by parents would be covered.

- Each parent would receive a payment to thank them for their time.
- Refreshments would be provided.
- Parents would receive a copy of each of the relevant CHANGE resources that they were entitled to.

Contact details for the researchers were clearly displayed on the leaflet. Contact with all those who responded to the initial mail out was followed up and the best place and time to meet with each parent was determined.

Whilst the initial aim was to recruit a minimum of ten parents, a total of eighteen parents participated in the evaluation.

#### 2.1.3. Criteria for inclusion

The criteria for inclusion in the evaluation were that parents must have learning difficulties, and must have a child under five who had lived with them at least some of the time since August 2009.

Including parents whose children had been permanently removed could have given a false result because of the ethical dilemma of providing information to parents who were very unlikely to regain care of their children.

#### 2.1.4. User-led approach

People First (Scotland) is an organisation run by people with learning difficulties. People with learning difficulties therefore played a full part both in designing and carrying out the interviews. People First also supported a parent with a learning difficulty to sit on the project steering group to advise the other strand of the evaluation.

The advantages of this approach were not only that people with direct experience of the issues were best placed to determine what questions to ask and the best ways of approaching parents with learning difficulties, but also that parents were more likely to trust and open up to people whom they know have had similar experiences to their own.

A small pool of parents with learning difficulties from the People First parents' groups in the East and West of Scotland acted as co-researchers. This group included both mothers and fathers so the researchers could achieve a gender match with the interviewees where useful. Within this pool were people who have cared for their children despite considerable challenges. Through their involvement with the parents' groups all co-researchers had input and taken part in discussions around the legal and policy background. All had also acted as trainers, co-led workshops and responded to consultations by a range of services.

The co-researchers were given training before beginning the evaluation and were provided with on going support and training, especially in the areas of

confidentiality and on People First (Scotland)'s policies on Protecting Vulnerable Adults and Child Protection.

Whilst three parents took part in the initial training session, one of these was unfortunately not able to take part in the evaluation itself for personal reasons.

#### 2.1.5. Methods

Qualitative information was obtained from parents using a very flexible approach involving a mixture of focus groups and one to one interviews as appropriate for each person. In both the focus group and the one-to-one interviews a semi-structured interview format was used. This allowed for flexibility in approach and the possibility of exploring certain issues in more depth as appropriate. Interview schedules were agreed in advance with the Steering Group.

The focus of the interviews was:

- Ease of access in obtaining the resources – including whether parents received them, how long it took and whether professionals were aware of them.
- Accessibility of the resources generally – including how easy the information was to understand, whether parents could find the information they wanted, use of pictures, etc.
- What parents considered the best ways of accessing the resources.

All interviews were conducted by a National Development Worker at People First (Scotland) together with parents with learning difficulties from the parents' groups as described above.

#### 2.1.6. Consent

Consent was obtained from each participant through the use of a short, easy read consent form, which was agreed with the Steering Group (see Appendix 2: Consent form). Before beginning each interview the form was explained to each parent to make sure that they fully understood what they were taking part in and how the information they gave would be used.

## 2.2. Procedure for data collection

### 2.2.1. Individual interviews

Individual interviews took place with eleven parents. Parents were asked where they would like the interview to take place.

Area	Mother/ Father	Age of Child/ pregnant	Place of interview	Had they received resource?
Glasgow	Mother	23 months	Home	Yes
Glasgow	Mother	8yr,3yr,1yr	Community centre cafe	No
Edinburgh	Mother	4yr, 2yr	People First (Scotland)	No
Edinburgh	Mother	6yr, 5yr, 3yr, 2yr, 5 months	People First (Scotland)	Yes
Dundee	Mother	4yr, 3yr, 2yr	St. Andrews Family Project	No
Dundee	Mother	3yr	St. Andrews Family Project	No
Dundee	Mother	2yr, 10 months	St. Andrews Family Project	No
Dundee	Mother	12 weeks	Home	Yes
Falkirk	Mother	17 months	Advocacy Into Action	Yes
Bo'ness	Mother	9 months	Advocacy Into Action	No
Alloa	Mother	14yr, 5yr, 6 weeks	Advocacy Into Action	No

**Table 1:** Participants in individual interviews

### 2.2.2. Focus group

One focus group took place in Edinburgh at the People First (Scotland) office and was attended by seven parents.

Area	Mother/ Father	Age of Child/ pregnant	Had they received resource?
Edinburgh	Mother	5yr, 6 weeks	No
Edinburgh	Mother	5yr, pregnant	No
Kinross	Mother	1yr	No
Kinross	Father	1yr	No
West Lothian	Mother	9yr,7yr, 4yr, 2yr, 3 months	No
West Lothian	Father	3 months	No
Midlothian	Mother	1yr	Yes

**Table 2:** Participants in focus group

Whilst the original intention had been to also hold a focus group in Glasgow, the two Glasgow parents indicated that they preferred individual interviews in their own local areas.

Parents' ages ranged between seventeen and over forty, and they were from a mixture of urban and rural backgrounds. All parents interviewed were from a white UK ethnic origin. Whilst contact was made with one parent from a South Asian background, unfortunately an interview with this parent did not take place because of the timescale.

Due to the ages of the children in their care all parents interviewed were eligible to have received at least one of the CHANGE resources.

### 2.2.3. Recording.

Whilst the initial plan was to digitally record all interviews and then transcribe them, none of the parents interviewed in the early stages of the evaluation were happy for the interviews to be recorded. In the interests of enabling parents to feel totally at ease this plan was therefore abandoned and written notes of the interviews used instead. Participants' responses were anonymised and kept confidential.

### 2.2.4. Data analysis and report writing.

Key themes were then extracted using a process of clustering and counting and then examined across all the interviews in relation to the original aims and objectives. Coding was then used to analyse which themes were mentioned across all interviews. The researchers also used observer impressions in interpreting the data gathered.

The National Development worker took the lead in clustering, counting and coding the raw data, and then presented this information for discussion with the co-researchers with learning difficulties to develop joint analyses.

The National Development Worker then took the lead in writing the evaluation report based on the analyses agreed by all researchers. The report was agreed with the co-researchers who also played a key role in giving feedback on the easy read version.

### **2.3. Problems and solutions**

The project encountered some problems in making contact with parents. In two local authority areas, despite initial enthusiasm by managers in supporting the project and rigorous follow-up by the researchers, staff working on the ground either reported that they were not currently working with any parents with learning difficulties or did not return calls.

The snow in the weeks before Christmas affected the timescale of the evaluation when several planned meetings with parents had to be postponed. All of these were subsequently re-arranged however.

As anticipated, not all the planned interviews with parents took place and two parents did not attend arranged meetings. Whilst both interviews were re-scheduled one of the parents did not turn up. Time constraints prevented a further interview date being offered.

The researchers were unable to meet with one parent from Caithness who was keen to take part in the evaluation because of the time and expense involved for only one interview (it would have meant an overnight stay). An offer was made to travel to the area if there were more parents who wanted to participate.

The other main problem was the overwhelming number of emails and phone calls received from professionals requesting copies of the CHANGE resources in response to the initial email giving information about the evaluation that the researchers sent round the NHS Health Scotland early years contact list. Responding to these requests was time consuming!

### 3. Results

#### 3.1. Getting the books

Only five out of the eighteen parents interviewed had received copies of one or other of the CHANGE resources. Three parents had a copy of *You and Your Baby* and two parents had received *You and Your Little Child*.

One of these parents had not however gone on to receive *You and Your Little Child* when her daughter had turned one, and another had only received *You and Your Baby*, despite also having children aged between one to five.

Only two out of these five parents had received the relevant resource at around the time when they first needed it. Both had received a copy of *You and Your Baby* about the time that their children were born – one two weeks before the birth, and one just after.

One parent only got a copy of *You and Your Little Child* when her daughter was nearly two years old.

Two other parents who had received the resources talked about a considerable amount of confusion and delay in getting the books. One parent told us:

[*advocate*] phoned up my health visitor and she said she couldn't get a copy, so she went to the library or something and got one from there.'

Another, where the advocacy project had tried to help her get a copy through her health visitor said:

'It took months and months. My daughter was nine months when I got it!'

Three out of these five had obtained the resources through advocacy projects, one from a social worker, and one from a health visitor.

In addition to the five who had received a copy, one parent was waiting for a copy of *You and Your Little Child* from her advocacy project and another had seen a copy of the resources at the advocacy project, but had not been given a copy.

None of the parents interviewed had seen or received copies of *My Pregnancy My Choice*. This included the parent who was currently pregnant and more than half of the total number of parents who would have been pregnant since April 2009 when this resource was made available.

All of the parents had contact with a range of professionals. In addition to midwives, all had health visitors, all but two had had contact with social workers at some point, and the majority had been to children and families centres. Ten

parents had been in contact with advocacy projects. As stated by one parent, however, in most cases these professionals had not mentioned the CHANGE resources:

‘My health visitor didn’t mention these books at all. She was coming out to my house every week, and if she wasn’t coming out I was going to the baby clinic.’

One parent commented, ‘that’s pathetic, that’s utterly pathetic – that’s shocking!’ when she heard that she should have received a copy of this book free of charge.

In contrast all of the parents said they had been given *Ready Steady Baby!* and had mixed views about this. Three of the parents with children aged one to five said they hadn’t seen *Ready Steady Toddler!* a few others weren’t sure.

In terms of other easy read information, one parent said that she had an easy read cook book from her child’s nursery and that someone came round once a week to help her with that.

### **3.2. What parents thought of the books**

#### 3.2.1. What are your first thoughts about the books?

All parents were very positive about the books. Comments included:

‘Very interesting.’

‘A lot of good information.’

‘I found it quite useful.’

‘It’s a good book.’

‘Aye, that’s a lot better.’ [compared to *Ready Steady Baby!*]

‘I thought it was easy to read – I’m half way through it.’

‘I’d recommend it to any parent out there.’

One parent who had received a copy of *You and Your Little Child* commented that:

‘It is good for people who can’t read or write or for people who need writing in bigger print. It gives you all the things to do with your children that you’d never think to do.’

Several parents commented that it would have been really helpful to get these resources when they had their first child. Comments, for example, included:

‘It’s what I needed ages ago. I should have had it when X was born.’

'If I'd had this book when I was nineteen when I had my first I would have been sorted.'

All parents wanted their own copy of the resources and seemed very pleased when they were given one. One parent emphasised that parents with learning difficulties, like all parents, wanted to do the best they could for their children, and the importance of resources to help with this:

'You're looking to the future so your bairn can have a better life and get a good education and get a good job.'

These comments were in direct contrast to parents' views on *Ready Steady Baby!* and *Ready Steady Toddler!* for those who had seen it, which ranged from not being able to understand any of it, to the four parents who could read reasonably well and had found them 'OK'.

These four parents, however, all still said that they would have found the CHANGE resources more useful and found them much easier to understand in that they:

- tell you and show you
- they are well spaced out and use bigger writing
- and you don't have so much information to take in all at the same time.

One mother commented that she had struggled with *Ready Steady Toddler!* because what they were saying and what she was doing were so different.

One parent said that *Ready Steady Baby!* had made her think she was stupid:

'If you didn't have a clue about certain stuff you look at the book and think – what?'

Three parents said that they had to get someone to read it to them. One mother, for example said she had found it:

'A bit hard. I have to get my man to help me read that.'

The majority of parents in the focus group had been very frustrated by *Ready Steady Baby!* and *Ready Steady Toddler!* Comments included:

'I just put mine in the pile.'

'I got stuck, I couldn't read it. I had to put it away until my Dad came in.'

### 3.2.2. What's good about the CHANGE books?

When asked what was good about the books, the most common responses focussed on the following three areas:

- **Pictures:** Generally the parents found the pictures helpful and said that they made the books easier to understand. Several parents said the pictures were useful both for those who couldn't read and those who could. The parents in the focus group all agreed that 'the pictures tell you everything'.
- **Lay out:** Several parents said that the way the books were laid out made them easy to understand. They liked the way the information was broken up into smaller chunks, that there wasn't too much information and it was well spaced out – 'not all squashed together'. Several parents preferred the books that used more than one colour. They said this made it easier, more interesting and exciting to read, and made it stand out more.
- **Writing:** Parents liked the fact that the writing was big and bold, there wasn't too much writing and the books didn't use big words. One parent said she liked that there were no big sentences or paragraphs.

Other comments included:

'It helped me learn some stuff that I didn't have a clue about.'

'Recipes.'

'What was good about it was how it told you how to look after your wean and what to do.'

'How to keep them away from people who might abuse them.'

'It tells you how to look after your children.'

'It's just what you're needing to get.'

'Anyone'd be able to understand that. It goes into detail on everything.'

'The pictures are clear, the words are clear. It's got everything – not just bits here and there – it's got everything altogether.'

### 3.2.3. What's not so good?

Only a few parents could think of anything that wasn't so good about the books.

A couple of people commented that *You and Your Baby* would be better if the index was clearer, if the different sections were colour coded and if it had more colour in generally. As one parent said 'it would probably get more peoples attention that way'.

A couple of parents who didn't read much or at all said they found the books a bit hard.

When asked directly if they thought the books were too big and heavy all parents said that they weren't. One parent said she preferred it to be big as it had all the information in one place. Another said she would prefer one book to two books.

### 3.2.4. Could you find your way around easily?

Parents gave mixed responses to this question.

Quite a few parents said that the colour coding in *You and Your Little Child* made it easy for them to find their way around the book. One parent, for example, commented that it was:

‘Good that there’s different colours – they’ve been labelled out so you don’t have to read it all to find the right bit.’

Another commented that the index in *You and Your Little Child* was nice and clear.

One of the parents who couldn’t read said she found it hard to find her way around *You and Your Little Child* just by the colours and the pictures. She pointed out that some of the colours used to indicate the different sections were quite similar.

Parents found *You and Your Little Child* easier to find their way around than *You and Your Baby*. One parent said that she just had to skim through the latter as she didn’t find the index easy to use. She thought colour coding the different sections would help.

Other comments included:

‘If I get stuck there’s always someone who could help me.’

‘Obviously it’ll take a bit of thinking – but you get there.’

### 3.2.5. Is there anything that isn’t there but you think should be?

Two parents said that information on dealing with children with behavioural difficulties would be really useful. Both of these parents had children who had been diagnosed with ADHD.

Another parent commented that something on getting support and having people coming into your home would be good.

Most parents simply answered ‘no’ – they thought that the resources contained all the information they would need.

### 3.2.6. What do you think of the pictures?

Most parents were very positive about the pictures. A good number of parents particularly liked the ticks and crosses. One parent, for example, said she found them:

‘Really good ’cos it’s showing you what to do and what not to do.’

Similarly parents in the focus group said that they liked the way

'It shows you what way to do stuff and what way not to do stuff 'cos it's got crosses.'

Parents generally thought the pictures were bold and clear and that it was obvious what they were trying to tell you.

Two parents said they didn't like the pictures about abuse. One said that whilst these pictures were good and clear:

'What if the bairn picks it up and sees it? The pictures are alright until it gets to that part and I think that's a bit too full on for the bairn.'

The other parent said she found that section 'a bit hard'.

### 3.2.7. Do the pictures show a good mix of people?

All parents agreed that the pictures did show a good mixture of different people. A couple of parents commented that it was good to see pictures of people from different backgrounds including pictures of South Asian people.

### 3.2.8. Do you think the book would be easy to use on your own?

Parents gave a mixture of views about how easy the resources would be to use on their own.

Whilst half of the parents said they thought they would find the books easy to use on their own, two of these also recognised the value of support to go through some parts to ensure they had understood, or to go over sections that they found more difficult. One of these parents said there might be some words she didn't understand, and another said she sometimes needed to go over things more than once.

Eight parents, including the four parents who didn't read much or at all, indicated that they would like support to use the resources. Three out of this eight identified their health visitor as the best person to provide this support.

One parent in the focus group said that she would like her health visitor to offer support to go through the resources:

'I would like my health visitor to ask if I needed support to go through it – to say "I'll come round for maybe half an hour one day and go through that!" '

The woman who was pregnant said that midwives should provide help to go through *My Pregnancy My Choice*.

Three parents also identified informal supports such as their parents and partners as being important sources of help. One of these parents said that she had looked through a section of the book with her partner the previous evening.

Another parent who had received a copy of *You and Your Baby* said she hadn't found it easy and if she didn't understand something she just had to ask her Mum or social worker.

Another was confident that there would be someone around who could help:

'If I got stuck there's always someone who could help me.'

### 3.2.9. Did you get any support to use the book?

Only one of the parents had received support from a professional to use the book. She said that her social worker had showed her certain pages that he thought she would need help with, like bathing and sterilising. She commented that:

'It was helpful, especially with the sterilising – I didn't have a clue!'

The parent who had received the book from her health visitor said that she had just left the book with her and hadn't supported her to go through it. She had, however got support from her partner.

The other three parents who had received the resources had found them easy to use on their own without support.

### 3.2.10. Anything else that you think would improve the book?

Responses to this question fell into two themes:

- **Colour and colour coding:** These comments related mostly to *You and Your Baby* – see sections 3.2.3 and 3.2.4 above.
- **DVD:** Several parents, including those taking part in the focus group, thought that it would be really useful to have a DVD that came with each book with the information on. The parents who didn't read well were particularly keen on this idea. Parents in the focus group explained that if you still did not understand the pictures in the book you could then put on the DVD and understand them.

One parent said she would like the books to have more writing and less pictures.

## 3.3. Making sure parents get the resources

All of the parents thought that all the professionals who worked with parents with learning difficulties should know about these books, have copies that they can show to parents and be able to help parents to get their own copies.

This included social workers, children and families centres, nurseries, mother and toddler groups, advocacy projects, midwives, health visitors, GPs, support agencies, psychologists, speech and language therapists, and community nurses. Parents felt very strongly that even if all of the above did not have copies

of the books they should know about them and know where parents can get them from.

Several parents said they would like to be able to talk through some of the information in the books with workers at their child's nursery or children and families centre. One parent, for example, said:

'They should have one of them there, so you can go in and say to nursery "Can I have a wee peek at that book?" '

One parent explained that it would be useful for GPs to have a copy so that if their child had one of the illnesses in the book their GP could use the book to explain it to them in an easy way. A few parents suggested having the books out on a table in GP's surgeries so that parents could take a look.

There were mixed views about whether the books should be in libraries or not. Those parents who could read felt this would be useful, but several others said they didn't use libraries at all. One parent, for example, said:

'Not everyone has got a library card. If they can't read why would they go to a library?'

A couple of parents thought that having copies of the books would also raise awareness about the needs of parents with learning difficulties amongst social workers and others, in that:

'if they've got one of these to look at they might understand'.

One parent also suggested that they would be useful for use in schools.

In terms of how they should get the resources, all parents agreed that, where possible, they should be given out at the same time and in the same way as the mainstream resources and that parents should be offered a choice between the two.

All parents agreed that *My Pregnancy My Choice* should be given out by midwives at some point early on in the pregnancy and several parents suggested that the first scan would be a good time.

All parents thought that *You and Your Baby* should be given out by midwives well before the baby is born.

It was very important to parents that they were offered the books rather than be expected to ask for them. The reasons for this were that parents were scared to identify themselves as having learning difficulties in case this led to their children being removed – as one parent said:

'Some people might not like to tell you that they've got a learning difficulty'.

Several parents also said that they wouldn't ask for help, as illustrated by the following two comments:

'A lot of people don't want to come out and show their feelings. Some people don't want to ask for help'

'If I hadn't been given it I don't think I would have asked. I'm really shy especially at asking for help.'

Whilst most parents said they would take the CHANGE resource if given a choice between the two books, a few said they would like to have both.

All parents thought that *You and Your Little Child* should be given out by health visitors. Most spoke positively of their health visitor and thought that they would know if they had a learning difficulty. One parent suggested keeping a record of those parents who took a copy of *My Pregnancy My Choice* so professionals knew who would want a copy of the other resources.

A couple of parents suggested leaflets and posters to let parents know about the books, but the majority thought these would not be very useful, especially for those who could not read. One parent was very clear that leaflets in *Ready Steady Baby!* would not work since most parents with learning difficulties would not open the book in the first place (see 3.2.1 above), and those that did see the leaflets would not ask for the books anyway. One parent suggested using the internet to let parents know about the books, whilst again others were not so keen.

#### **3.4. Anything else?**

Several parents said that a book about looking after children aged over five was important. One parent, for example said:

'You need to know how they get on at school and other things.'

One parent said that an accessible CD about breastfeeding would be useful.

One other parent suggested having the pages in the resources laminated to make them last longer.

Parents in the focus group expressed a concern that NHS Health Scotland might stop providing the resources:

'What if they turn round and say "we don't have any left"?''

#### **3.5. Summary of findings**

The majority of parents had neither been given the CHANGE resources nor seen them before. The resources, therefore, did not appear to be easily available.

Of the five parents who had received the resources, only two had had them at the right time. Some parents had received one book, but not the next.

Only two parents had received the resources through mainstream services, despite all parents being in contact with a wide range of professionals.

Two parents talked about a considerable amount of confusion and delay in accessing the resources.

All parents were extremely positive about the resources. This was true of both the group of five parents who had received one of the resources prior to meeting with us, and the parents who were looking at the resources for the first time. All parents said they wanted their own copy to use at home.

Most parents commented on how inaccessible they had found *Ready Steady Baby!* and, for those who had received it, *Ready Steady Toddler!*

Parents said that they liked the pictures, the layout and the large print, short sentences and paragraphs, and easy words in the resources.

Most parents could not think of anything that was not so good about the resources.

Whilst most parents said they found the resources easy to find their way around, a significant number said they would find *You and Your Baby* easier if the different sections were colour coded.

A couple of parents said that they would like the resources to contain information on children with behavioural difficulties. Both these parents had children who had been diagnosed with ADHD.

Parents suggested that information about having professionals coming into the home and how to manage support would also be useful.

Most parents were very positive about the pictures and thought they showed a good mixture of different people. A couple of parents did not like the pictures about abuse.

Parents had mixed views on how easy the resources would be to use on their own. Whilst half of the parents said they would find them easy to use on their own, two of these also said they would value some support. Eight parents, including four who did not read much or at all, said they would like support to use the resources. Three of these parents identified health visitors as the best people to provide this support. The woman who was pregnant wanted support from her midwife to go through *My Pregnancy My Choice*. Several parents mentioned informal supports such as their parents or partner as being an important source of help.

Only one of the five parents who had received one of the resources had had support from a professional to go through it. Another had received support from her partner. The other three had managed on their own.

Parents thought that it would be useful to have a DVD to accompany the resources and that this would be particularly useful for those who did not read. A number of parents also said that a book about looking after children aged over five would be really useful.

Parents thought that all professionals who had contact with parents with learning difficulties should be aware of the resources, know how parents can get them, and have a copy themselves.

In terms of how the resources should be given out parents thought that:

- *My Pregnancy My Choice* should be given out by midwives early on in the pregnancy – maybe at the time of the first scan.
- *You and Your Baby* should be given out by midwives well before the baby is born.
- *You and your Little Child* should be given out by health visitors.
- Where there is an equivalent mainstream resource parents should be offered a choice between the CHANGE resource and the NHS Health Scotland resource rather than be expected to ask for the CHANGE resource. Parents may be reluctant to identify themselves as having learning difficulties and will be unlikely to ask for help.

## 4. Discussion

It is important to note that this evaluation only looks at the views and experiences of a small number of parents with learning difficulties. It does not provide evidence of how many parents across Scotland have received these resources. It was also not possible to include any parents from Black and Minority Ethnic groups in the sample. The findings therefore do not cover any additional issues of language, unequal access to services and discrimination that these parents may encounter.

### 4.1. Getting the resources

The findings clearly indicate that parents with learning difficulties are not accessing the resources easily through mainstream services. They are not getting equal access, compared to non-disabled parents, to information in a format that they can understand about looking after their children.

All of the parents were in contact with a range of professionals. All of them had also received a copy of *Ready Steady Baby!* There was therefore no indication of a lack of suitable opportunities for distributing the CHANGE resources.

As very few of the parents had been shown or told about the resources by professionals it is possible that the professionals themselves were not aware of them or did not have easy access to them. The number of professionals contacting the researchers requesting copies of the resources in response to information sent out about the evaluation also suggests that awareness of the resources and how to access them was not widespread. Information about the views and experiences of professionals can be obtained from the other strand of the evaluation.

Whilst advocacy projects on the whole seemed to be more aware of the resources than other services, this awareness was not universal. Five of the parents had regular contact with advocacy projects but had not heard of the resources. Two others had only heard about or obtained the resources very recently through their advocates, when their children had already passed the age at which the resources should have been provided. The finding that more parents accessed the resources through advocacy than through mainstream services is in itself worrying, since parents generally only contact advocacy projects when they are in crisis. The resources are therefore not reaching parents at the optimum time.

The confusion that a couple of the parents experienced, even when supported by advocates to try and obtain the resources, suggests a lack of clarity amongst professionals as to who should be distributing them. There was no evidence of a clear procedure for distribution. Where two parents had received the resources through mainstream services this appeared to have been due to individual workers (one health visitor and one social worker) rather than an area-wide

policy or procedure, since other parents from the same local authority and health board areas had neither received nor seen the resources.

Several of the parents spoke about being nervous of identifying themselves as having learning difficulties. Whilst parents were not asked directly whether professionals knew that they had learning difficulties, the evaluation leaflet clearly stated that having a learning difficulty was a criterion for inclusion. As eight out of the eighteen parents had heard about the evaluation through professionals other than advocacy workers, the professionals had clearly identified them as parents with learning difficulties. Only one of these eight had received a copy of the relevant resource. This therefore suggests that their lack of access to the resources was not caused by professionals' failure to identify learning difficulties. It is not known whether identification of learning difficulties was an issue with any of the other parents. For further discussion of the issues around identification of learning difficulties see the report from the other strand of the evaluation.

It has been suggested that professionals are concerned that handing out these resources to parents may overload them with information, and that they preferred to go through the information together with the parents. None of the parents, however, had been shown the resources by a professional but not been given a copy to take home. There was therefore no evidence to support this idea.

It has also been suggested that professionals may not be keen to give out the resources to parents if they do not think they will have care of their children in the long term. At least half of the parents, however, were not currently going through the child protection system, and social work was supporting at least two of those who were to retain or regain care. It would therefore seem that this was not the reason in the majority of cases for parents not getting the resources.

#### **4.2. Quality of the books – what parents thought of them**

As stated above parents were all very positive about the resources and wanted their own copy.

The wide range of views of the parents about whether or not they would need or want support to use the resources highlights that it is important for professionals not to make assumptions. Individual parents will need different levels and types of support. The resources do rely on parents being able to read and are not so accessible to parents who do not have this skill.

A significant number of parents who did read reasonably well, however, also identified that they would value support to go through the resources: it can be helpful to go over things more than once, to get help with hard words, and to make sure that they really understood the information.

Providing the right support to this group is a challenge for professionals in that it is clear from the findings that parents with learning difficulties are unlikely to ask for help or to volunteer information about their learning difficulties. This appears

to be due to a number of reasons including being afraid of having their children removed, being embarrassed at not being able to read or write very well, and being thought of as not being able to cope.

There needs to be a procedure, therefore, whereby those providing the resources and supporting parents routinely offer support to understand the information and to put it into practice. Professionals need to be aware that parents with learning difficulties may be reluctant to ask for help. Information by itself will also not necessarily be enough and does not replace good person-centred support.

Three parents identified health visitors as the best people to provide support with *You and Your Baby* and *You and Your Little Child*. The parent who was pregnant thought midwives would be best placed to support people with *My Pregnancy My Choice*. The most important factor, however, would seem to be not so much who provides the support, but that parents do receive the support and information they need and that there is a clear procedure for making sure this happens.

Several parents mentioned informal supports such as parents or partners as an important source of help in using the resources, and this highlights the importance of parents having their own copy. If the professional kept the resource, parents might not be able to draw on this support.

A DVD to accompany the resources would make them accessible to a wider group of parents, including those who do not read well.

The majority of parents requested that all books were colour coded. Colour clearly helped parents to find their way around the resources and would again make the books accessible to a wider audience.

The concerns raised about the pictures of abuse may indicate a need for support to develop greater confidence to talk about keeping children safe or to address possible issues in the parents' own past.

The two parents of children with behavioural difficulties flagged up some interesting issues. Services need to remember that parents with learning difficulties will be struggling with the same range of issues as all other parents, but with the additional challenge of not being able to access information in formats that they can understand. Accessible information is therefore needed on all childcare issues.

Similarly the request from a number of parents for a book about looking after children aged over five highlights the need of parents with learning difficulties for different information as children's needs change. It is important to remember that the usual sources of information open to parents may not be accessible to them.

Parenting with support is not always easy to manage and can carry some stigma. An openness to professionals coming into your home to provide support can be a crucial step towards families being able to stay together. A number of parents

talked about difficulties they had with this process. Including information in the resources about what happens when supporters come into your home and how to manage this could help parents to be more open to support.

These resources are large and heavy and it is interesting that none of the parents said that they thought this would be a problem when asked directly. They were all hungry for information about looking after their children and said that they would rather have one large book with everything in it than two smaller books, or one smaller book without enough information.

### **4.3. Making sure parents get the resources**

For any information resource to reach a group of people three things need to be in place:

- there needs to be a clear procedure for distributing the resource,
- all professionals working with that group need to be aware of the resource and to have a positive attitude towards it,
- and professionals need a good understanding of the needs of the target group.

#### **4.3.1. Procedure**

Parents were very clear that any process that relied on them asking for the resources was unlikely to work for the reasons identified in 4.2 above. They all wanted to be offered a choice that would then enable them to pick the CHANGE resources without stigma as an alternative to, or together with, the mainstream version where there was an equivalent resource.

For *My Pregnancy My Choice* this would involve midwives offering the resource at the same time as they gave out *Ready Steady Baby!* This resource is currently distributed at the booking appointment. Giving this choice to all parents would avoid any potential difficulties about parents being correctly identified as having a learning difficulty or having a formal diagnosis.

The two resources however do not cover the same areas: *My Pregnancy My Choice* focuses on pregnancy and *Ready Steady Baby!* covers both pregnancy and care of a baby up to one year old.

Parents with learning difficulties would then, therefore, need to be offered *You and Your Baby* before the baby is born to provide them with the equivalent information about looking after a baby. Midwives would need some way of identifying which parents might benefit from this second resource as they would not be giving out a mainstream equivalent at the same time. Keeping a record of those parents who took a copy of *My Pregnancy My Choice* would be a useful approach. This would need to be done in a sensitive way with an awareness of

the fact that parents may be reluctant for professionals to know that they have a learning difficulty.

*You and Your Little Child* could be offered by Health Visitors when they give out *Ready Steady Toddler!* As not everyone who was interviewed had received *Ready Steady Toddler!* it would seem that the procedure for distributing this needs further attention.

#### 4.3.2. Awareness and availability

The findings of the evaluation suggest a lack of awareness of the resources amongst professionals (as discussed in 4.1 above).

This is somewhat surprising as information about the resources had been circulated by NHS Health Scotland to all early years professionals, using the same email list as was used to send out information about this evaluation.

Possible explanations include:

- Lack of clarity about who is taking the lead in providing support to parents with learning difficulties.
- Lack of interest in the issues for parents with learning difficulties by mainstream early years professionals.
- Discrimination against parents with learning difficulties.

The interest demonstrated in the evaluation, however, suggests that there is a high level of interest in this subject amongst the professionals involved. For a full discussion of the views and experiences of professionals please see the other strand of the evaluation.

Parents were clear that all professionals working with parents with learning difficulties needed to know about the resources. They thought that all social work teams, nurseries, children and families centres, advocacy projects, GP surgeries, community learning disability teams, teams of midwives and health visitors and support agencies should have copies so that parents could ask to look at them there and professionals could offer support to go through them. This would ensure consistency of support, raise awareness of the resources amongst these professionals and would mean that they could make use of the resources when working with parents.

Interestingly parents were also aware that seeing the resources could in itself help to change attitudes, in that it would raise awareness of the needs of parents with learning difficulties. A social worker who had a copy of these resources in her/his office, for example, might be less likely to write an inaccessible letter to a parent with a learning difficulty.

#### 4.3.3. A good understanding of the needs of parents with learning difficulties

The finding that parents are not getting equal access to information about looking after their children would suggest that there may be a lack of understanding amongst professionals about the needs of this group. It would seem that there is a possible need for training for early years professionals on the needs of parents with learning difficulties, including training by parents with learning difficulties, to raise awareness and increase understanding in this area of work. Further discussion of these issues can be found in the other strand of the evaluation.

## 5. Conclusions and Recommendations

These conclusions and recommendations should be read together with those from the other strand of the evaluation.

The key aim of the evaluation was to establish the extent to which the CHANGE resources are a high quality accessible resource for parents with learning disabilities.

Within this aim three themes were explored:

- Whether parents were getting the resources.
- What parents thought of the quality of the resources.
- How to ensure parents can access the resources.

### 5.1. Getting the resources

Despite the limitations of this evaluation, it provides clear evidence that parents with learning difficulties are not routinely accessing the CHANGE resources as intended by NHS Health Scotland. They are therefore not getting equal access to information about looking after their children.

Whilst the evidence points to a lack of awareness of the resources amongst professionals and a lack of a clear procedure for distributing them, a full discussion of these issues can be found in the other strand of the evaluation.

**Recommendation 1:** NHS Health Scotland should engage in a series of awareness raising activities designed to ensure that all relevant professionals are aware of the resources, the benefits to parents of using them and the rights of parents to accessible information.

**Recommendation 2:** There should be a lead professional in each area who oversees the provision of information and support for parents with learning difficulties.

### 5.2. What parents thought of the resources

The evidence shows that parents found these resources to be beneficial and were keen to have their own copies. The CHANGE resources met the information needs of parents with learning difficulties better than *Ready Steady Baby!* and *Ready Steady Toddler!* Parents liked the pictures, the layout and the style of writing and these all helped to make the information accessible to them.

The resources were not so accessible, however, to parents who did not read well. Colour coding the different sections in *You and Your Baby* and improving the index would make it more accessible to a wider group of parents. A DVD to

accompany each of the resources would be really useful for parents who struggle with the written word.

**Recommendation 3:** NHS Health Scotland should explore with CHANGE adding colour-coded sections to *You and Your Baby* and making the index easier to find and use.

**Recommendation 4:** NHS Health Scotland should explore with CHANGE the possibility of developing a DVD to accompany each of the resources.

The resources do not currently provide information about parenting children with behaviour difficulties and parenting children over the age of five. Parents identified these as gaps in the resources and would find it beneficial for this information to be included. Information about people coming into your home to provide support and how to manage this would also be valuable.

**Recommendation 5:** NHS Health Scotland should explore with CHANGE adding information to *You and Your Little Child* about parenting children with behaviour difficulties.

**Recommendation 6:** NHS Health Scotland should explore with CHANGE adding information to *You and Your Baby* and *You and Your Little Child* about people coming into your home to provide support and the best ways of managing this.

**Recommendation 7:** NHS Health Scotland should raise with CHANGE the gap in information for parents of children over five years of age.

Accessible information does not replace good, person-centred support. The parents interviewed had a diverse range of support needs and mixed views on how easy the resources would be to use on their own. Whereas a significant number identified a need for support to go through the resources, only one parent had received such support from a professional. Parents were also clear that for a range of reasons they were unlikely to request support, so it would need to be offered by professionals.

All professionals need to have a good understanding of these complex issues if they are going to be able to provide effective, flexible and individualised support and it is recommended that these issues are addressed through training including input by parents with learning difficulties. The importance of informal supports should not be overlooked.

**Recommendation 8:** NHS Health Scotland should explore how to provide awareness raising and capacity building with midwives, health visitors and other professionals on the needs of parents with learning difficulties and on how to use the resources with parents, including input by parents with learning difficulties.

### 5.3. How to ensure parents access the resources

The findings show that parents wanted to be offered a choice between the mainstream and CHANGE resources where possible. Parents were clear that even if they knew about the resources they would be unlikely to ask for them themselves. Offering all parents a choice would be a positive way of overcoming the potential barriers thrown up by the complex issues around identification of learning difficulties and stigma. For a full discussion of the issues around identification of learning difficulties see the report from the other strand of the evaluation.

As the three CHANGE resources do not correspond exactly with the two mainstream NHS Health Scotland resources there needs to be a separate process for identifying who would benefit from *You and Your Baby* and for distributing this resource. This needs to be approached with sensitivity.

Given the difficulties in distributing *Ready Steady Toddler!* to parents generally and the lack of other sources of accessible information for parents with learning difficulties, awareness of the resources by all professionals working in this field should act as an additional check.

**Recommendation 9:** All parents should be offered *My Pregnancy My Choice* as an alternative to *Ready Steady Baby!* by midwives at the booking appointment.

**Recommendation 10:** Midwives, in agreement with the parent, should record who accessed *My Pregnancy My Choice* to allow for a flag to be raised signifying who to distribute *You and Your Baby* to.

**Recommendation 11:** *You and Your Baby* should be offered to parents at the twenty-eight week check.

**Recommendation 12:** All parents should be offered *You and Your Little Child* as an alternative to *Ready Steady Toddler!*

To fully meet the information needs of parents with learning difficulties all professionals working with this group need to be aware of these resources and to have a copy to hand. This would ensure consistency of support and raise awareness of the resources and the information needs of parents with learning difficulties amongst professionals.

**Recommendation 13:** A copy of each relevant resource should be provided to all social work teams, nurseries, children and families centres, advocacy projects, GP surgeries, community learning disability teams, teams of midwives and health visitors, and support agencies.

## 6. References

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Tarleton B., Ward L. and Howarth J. (2006). *Finding the Right Support: A review of issues and positive practice in supporting parents with learning difficulties and their children*. Norah Fry Research Centre, University of Bristol.

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## **Appendices**

## Appendix 1: Information leaflet



**NHS Health Scotland  
And  
People First (Scotland)**

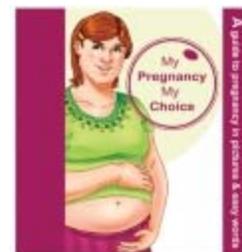
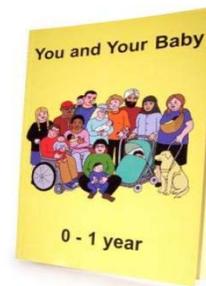


**Research about CHANGE books about being pregnant and looking after your baby and child.**

### **Who will do the research?**

**People First (Scotland)** is an independent self-advocacy organisation of people with learning difficulties. People First is run by the members all of whom have learning difficulties. We have many members who are parents. We help parents stand up for their rights and to get their voices heard. We have two parents' groups – one in Edinburgh and one in Glasgow.





## What is the research?

- NHS Health Scotland is giving out free easy read books to people with learning difficulties who are pregnant and who have babies and young children.
- They want to know if you've heard of these books
- They want to find out if parents are getting the books
- They want to find out what's good about the books and what could be better



## Who do we want to talk to?

We want to talk to parents with learning difficulties who are pregnant or have a **child under 5**. It's fine if you also have older children.



Your child under 5 must have lived with you for some of the time since **August 2009**.

August 2009

1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

## What happens next?

- If you are happy to talk to us please call us and we will arrange a meeting at a time and place that suits you best.
- If you live in **Edinburgh** or **Glasgow** we will invite you to a 'focus group' with other parents to talk about the books.
- All meetings will be in **October** and **November**
- If you don't have a copy of the relevant book we will leave one with you.
- It won't cost you anything. We will pay your **travel costs** and give you a **payment** to thank you for taking part.
- There will be drinks and nice biscuits!



## Who will talk to you?

The researchers will be parents with learning difficulties from People First and **Jane Lewis**, a national worker at People First.



## What happens to what you tell us?

We will use the information to write a report for NHS Health Scotland. The report will say what needs to happen to make sure that parents with learning difficulties get these books. It will also say what could make the books better.



No-one will know that the information is about you as your name and details will not be in the report.



## How to contact us

Phone Jane Lewis on **0131 478 7707** or **07801138265**

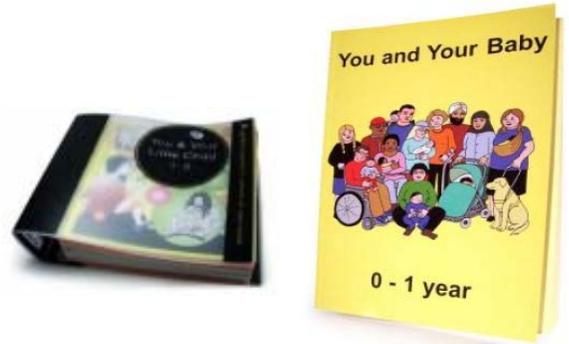


Email: **[jane.lewisp1st@btconnect.com](mailto:jane.lewisp1st@btconnect.com)**



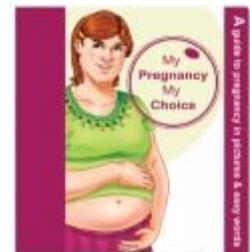
## Appendix 2: Consent form

### Consent



I **agree** to take part in the evaluation of the **CHANGE** books.

I am happy to tell the researchers what I think of the books.



I understand that the information will be used to write a report for NHS Health Scotland.



I understand that all the information will be kept anonymous. This means that no-one will know my name or address or know that I have given the information.



I understand that the information will be kept safely on the computer for 7 years. This is in case anyone wants to check that the report is telling the truth.



Only the researchers will see the information.

I understand that if the researchers have serious concerns about my safety or the safety of my children they will need to tell someone about this. I understand that no-one would do this without talking to me first.



I understand that I can **stop the interview** with the researchers at any time.



Are you happy for the interview to be recorded?

Yes

No



Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## **Appendix 3: Interview schedule: individual interviews**

### **1. Introductions**

1. Names and who we are
2. Background to what we are doing and why
3. Consent form
4. Check OK with recording interview
5. Can you please tell us your name and the ages of your children? (Check children living with parent at least some of the time since August 2009)

(Start recording)

### **2. Getting the books**

Show books

Explain they are meant to be given out free of charge to parents with learning difficulties as alternatives to *Ready Steady Baby!* and *Ready Steady Toddler!*

(1) Have you seen or heard about any of these books before?

NO:

If you didn't get these books did you get any other easy read information?

**Go to section 4**

YES:

(2) Who showed you/told you about it/them?

(Prompts: midwife, health visitor, social worker, advocate, children and family centre, GP, community nurse, psychologist)

When?

Where?

Did they say you could get your own copy?

(Check for each relevant book)

NO:

(3) Did they help you to read some of the sections in the book?

(Check for each relevant book)

**Go to section 3** (or 4 if more appropriate).

YES:

(4) Did you want your own copy?

NO:

(5) Could you tell us why not?

(Check for each relevant book)

YES:

(6) Please tell us what happened when you tried to get one.

Who did you ask?

Did anyone help you?

Did you manage to get one?

NO:

(7) Do you know why not?

What were you told?

Who told you this?

YES:

(8) Who gave it to you?

How did you get it – what did you have to do?

When did you get it?

How long did it take?

How old was your child when you got it?

If it took a long time, do you know why?

Would you say it was easy to get hold of?

(If parent is eligible for more than one book check if the process was different for each book)

**3. About the books (for those who have a copy or have spent time working through the books)**

(Show them the relevant book/s to remind them.)

- (1) What did you think of the book/s?
- (2) Did you use it?
- (3) What was good about it?
- (4) What was not so good?

- (5) Was there anything you thought should have been in the book/s that wasn't there?
- (6) Could you find your way to the right section in the book?
- (7) How easy was it to use on your own?
- (8) What did you think of the pictures?
- (9) Do you think the pictures show a good mixture of different people?
- (10) Is there anything else that you think would improve the book?
- (11) Did you get any support to use the book?

NO:

- (12) What support would you have liked? Who from?

YES:

- (13) How good was this support?
- (14) What was good about it?
- (15) What was not so good about it?
- (16) Was it the right sort of support?
- (17) Who supported you?

(Check for each relevant book)

#### **4. About the books (for those who haven't seen them before)**

(Show them the relevant book/s)

Could you have a look at the book/s now?

(Give support if needed)

- (1) What are your first thoughts about the book/s?
  - (2) What do you think is good about it/them?
  - (3) What do you think is not so good?
  - (4) Do you think you could find your way around the book/s easily?
  - (5) On a first look is there anything that you think should be in the book/s but isn't there?
- (6) What do you think of the pictures?
- (7) Do you think the pictures show a good mixture of different people?

(Check for each relevant book)

#### **5. How to make sure parents get the books (for everyone)**

- (1) What do you think would be the best way of parents hearing about and getting their own copy of these books easily?
  - (2) What professionals have you had contact with? (Prompts if needed)
  - (3) Who do you think should tell parents about the books and give them a copy?
- (Prompts: midwife, health visitor, GP, social worker, advocacy worker, community nurse, psychologist, children and families centre, library)
- (4) Do you think this should be different person for the different books?
    - My Pregnancy My Choice
    - You and Your Baby
    - You and Your Little Child

(5) Where do you think parents should get the books from?

(6) Do you think this should be different for the different books?

- My Pregnancy My Choice
- You and Your Baby
- You and Your Little Child

(7) When should they get the books?

(8) Do you think this should be different for the different books?

- My Pregnancy My Choice
- You and Your Baby
- You and Your Little Child

**6. Anything else to add?**

- Thank you.
- Remind them what will happen to the information.
- Leave contact details in case they want to add anything.
- Leave copy of relevant book if they don't already have one.
- Give money
- Sort travel expenses

## **Appendix 4: Interview schedule: focus group**

### **1. Introductions**

1. Names and who we are
2. Background to what we are doing and why
3. Consent form
4. Check OK with recording interview
5. Can you please tell us your name and the ages of your children? (Check children living with parent at least some of the time since August 2009)
6. Suggestions for how to be together in the group

(Start recording)

### **2 Getting the books**

Show books

Explain they are meant to be given out free of charge to parents with learning difficulties as alternatives to *Ready Steady Baby!* and *Ready Steady Toddler!*

(1) How many of you have seen these books before?

*Discussion*

Where did you see them?

When? What age were your children? How many months pregnant were you?

Who showed you them?

Did they say you could get your own copy?

(2) Who has their own copy?

*Discussion*

How easy was it to get a copy?

What worked what didn't work?

Who gave it to you?

How long did it take?

Did anything make it difficult?

What could have helped?

(3) Did anyone try to get a copy but not manage to get one?

*Discussion*

What happened?

What were you told?

Who did you ask?

Did anyone help you?

What would have made it easier to get one?

(4) If you didn't get these books did you get any other easy read information?

**3 About the books**

(Give those who haven't seen the books before a few minutes to have a quick look through them – with support if needed.)

(1) What do you think of it/them? (particularly those who have had a copy)

(2) What 's good and what's not so good about the books?

(3) Is there anything that you think should be there but isn't?

(4) Can you find your way to the right section easily?

(5) How easy were they to use on your own?

(6) Did you get any support to use the books?

(7) How good was this support|?

(8) What do you think of the pictures?

(10) Do you think the pictures show a good mixture of different people?

(11) Is there anything else that you think would improve the book/s?

(Check whether those who haven't seen the books before agree or have anything else to add.)

#### **4 How to make sure parents get the books**

(1) What do you think would be the best way of parents hearing about and getting their own copy of these books easily?

(2) What professionals have you had contact with? (Prompts if needed)

(3) Who do you think should tell parents about the books and give them a copy?

(Prompts: midwife, health visitor, GP, social worker, advocacy worker, community nurse, psychologist, children and families centre, library)

(4) Do you think this should be different person for the different books?

- My Pregnancy My Choice
- You and Your Baby
- You and Your Little Child

(5) Where do you think parents should get the books from?

(6) Do you think this should be different for the different books?

- My Pregnancy My Choice
- You and Your Baby
- You and Your Little Child

(7) When should they get the books?

(8) Do you think this should be different for the different books?

- My Pregnancy My Choice
- You and Your Baby
- You and Your Little Child

## **5 Anything else to add?**

- Thank you.
- Remind them what will happen to the information.
- Leave contact details in case they want to add anything.
- Leave copy of relevant book if they don't already have one.
- Give money and expenses