Evaluation of CHANGE resources to support the information needs of parents with learning disabilities with professionals

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ACKNOWLEDGEMENTS

EXECUTIVE SUMMARY

- The aim of this evaluation was to establish the views and experiences of different professional groups in terms of their awareness and/or use of the CHANGE resources. A separate evaluation exploring the views of parents with learning disabilities in relation to what extent the CHANGE resources are a high quality resource are easy get hold of, read, use and understand was also completed (and is reported separately).

- The overall objectives of both of these evaluations were to find out:

  o What issues help or prevent practitioners from getting and using the resources?
  o How easy the books are for parents with learning disabilities to get hold of, read, use and understand?
  o If the resources are suitable for use by parents and health professionals, for example, their tone, how they are written, how they look and the information they contain?
  o If the resources have any gaps in information or messages and what should be included to fill the gaps?
  o What recommendations can be made so that in the future parents who need them can get them and use them?

- The methodology for this evaluation was:
  o 11 interviews with strategic informants representing different professional groups in health, social work and the voluntary sector from across Scotland
  o 9 focus groups with 62 practitioners representing midwives, health visitors, school nursing, LD adult teams, Early Intervention (children & family) teams and others from across Scotland.
  o A small number of follow up interviews with participants from the focus groups to clarify emerging issues/services provided.

Key findings include:

- Awareness of the CHANGE resources was low among practitioners and this means that they are not being widely distributed to parents with a learning disability.
- Levels of awareness and use were significantly influenced by wider barriers to providing support to parents with learning disabilities.
- Factors which prevented practitioners from getting the CHANGE resources include:
  o Confusion about cost implications to purchasing the CHANGE resources.
  o A lack of information on the internet about the CHANGE resources availability and use in Scotland.
  o The resources were not always perceived as relevant to practitioners – partly due to work with parents with a learning disability often being a small part of their case load.

- o Difficulties getting the resources from NHS Health Scotland and a lack of clarity on the number of resources organisations are allowed to order.

- Factors which have helped raise awareness of the resources include:
  - o Promotion through conferences and networks – particularly for raising awareness among some NHS teams.
  - o Word of mouth between practitioners and different teams of professionals.

- Approaches used by practitioners to find out about new resources include Google searches, e-mails that are sent out from managers to wider teams, information accessed through intranet sites and/or e-bulletins (mainly within NHS).

- Overall, practitioners were more aware of the pregnancy and the 0 to 1 years resource than the resource for 1 to 5 years.

- There was debate on which professional groups should take the lead on distributing the CHANGE resources and who the resources should be provided to i.e. parents with a learning disability diagnosis or not? Wider groups who may benefit such as those with low levels of literacy, English as 2nd language etc?

- Among those who were aware of and use the CHANGE resources there were mixed views on their suitability for parents with learning disabilities. Points of discussion included:
  - o Majority of practitioners being very positive about the easy read format and pictures and particularly liking the lever arch files as felt to be easier to navigate (than the book format)
  - o Some concerns about incorrect and outdated information, lack of breastfeeding images and over reliance on bottle feeding information
  - o Concerns around some images and pictures being insensitive and potentially being misconstrued – particularly if the individual has literacy issues.

- Factors which encourage practitioners to use and distribute the resources were the positive reaction from parents who have received them and awareness that the resources had been developed in partnership with people with learning disabilities.

- There were mixed views on the best way to use the resources including whether they should be held by the practitioner and referred to in work with a parent or distributed in their entirety to parents. Key discussion points included:
  - o The size of the resources and them potentially being daunting to parents if given out.
  - o Importance of the resources being used alongside wider (practical) support to parents.

- o Potential of aligning the resources to Ready Steady Baby! And Ready Steady Toddler!

- A key benefit of the CHANGE resources was felt to be their potential to be a central point of information which provides consistent and standardised messages to parents with learning disabilities.

- A number of recommendations are provided on the future promotion, distribution and use of the CHANGE resources. There are outlined below.

Recommendation 1: There should be a more consistent and co-ordinated approach to the promotion and distribution of the CHANGE resources. Consideration should be given to the following:

- how the CHANGE resources could be promoted in a way that makes them relevant to a wide range of practitioners many of whom will only work with parents with a learning disability on an infrequent basis;
- the potential of using a staged approach to the promotion of the CHANGE resources i.e. prioritising professional groups i.e. universal health services, specialist learning disability staff, specialist early intervention staff etc and their associated networks and conferences;
- being more proactive in the promotion and awareness raising of the resources i.e. attendance at local level meetings.

Recommendation 2: Better use should be made of existing processes through which practitioners are made aware of new resources. This includes:

- search engine optimisation to ensure that the NHS Health Scotland website has a higher prominence when people search the internet for the CHANGE resources or resources for parents with learning disabilities in Scotland;
- having information on the CHANGE website which indicates they are available free in Scotland with a link to NHS Health Scotland site;
- using intranet sites of organisations to promote the availability and use of the CHANGE resources in Scotland;
- engaging managers and heads of service within social work and the NHS to utilise internal cascade systems of resource distribution.

Recommendation 3: Specific work is required to raise awareness of the 1 to 5 years resource and to ensure that the most appropriate practitioners are made aware of it. Focus should be placed on raising awareness among health visitors, family centres and nurseries.

Recommendation 4: There should be a clear process for ordering the CHANGE resources and guidance on how many resources can be ordered for free from NHS Health Scotland.

Recommendation 5: Adaptations should be made to the CHANGE resources to correct any inaccurate information or pictures and to ensure that they are in line with

Scottish and national policy on breast feeding/bottle feeding imagery and information whilst still meeting the needs of parents with learning disabilities.

Recommendation 6: The 0 to 1 resource should be redesigned into the clip arch lever style in line with the pregnancy and 1 to 5 years resources.

Recommendation 7: All promotion materials about the CHANGE resources should highlight that they are an alternative for parents with learning disabilities to the Ready Steady Baby! and Ready Steady Toddler! resources that are available to all parents.

Recommendation 8: Guidance should be provided to practitioners on who should distribute the resources, the best way for the resources to be used and who the resources should be targeted at. This should be in keeping with the guidance from UNICEF on the promotion of breastfeeding and specific allowances for parents with learning disabilities, the Scottish Consortium for Learning Disabilities (SCLD) guidance and the findings from the parents' evaluation of the CHANGE resources.

Recommendation 9: All midwives and health visitors should be made aware of the CHANGE resources and their responsibilities to distribute them where a parent has a learning disability. In addition, a wider range of professional groups including Early Intervention teams (Children & Families), LD Adult teams, family centres, nurseries and advocacy organisations should be provided with promotional information about the CHANGE resources with detail on where and how parents – whom they may be working with – can access free copies of the resource.

Recommendation 10: All promotion of the CHANGE resources should include personal testimonies of parents who have used them and clearly indicate that parents with learning disabilities have been involved in their creation.

Recommendation 11: Any future development of resources should consider practitioners positive views on the use of DVDs and video clips.

Recommendation 12: Having the CHANGE resource is not enough. Practitioners and managers need to have a better understanding of learning disabilities if parents are to be adequately supported. There also needs to be greater clarity on the responsibilities of different professional groups providing pan support to parents with a learning disability. This will require training, partnership working and the development of joint protocols.

INTRODUCTION

1.1 WHAT ARE THE 'CHANGE RESOURCES'?

NHS Health Scotland provides parents with resources to help them with becoming a parent and taking care of their child. These are called Ready Steady Baby! and Ready Steady Toddler! These books require good literacy skills and are not felt to be accessible for people with learning disabilities.

The 'CHANGE resources' are available for practitioners to give to pregnant women or parents, who have learning disabilities. They were developed alongside people with learning disabilities and use simple pictures and language to give information and help on pregnancy, and caring for babies and children.

There are 3 'CHANGE' resources:

1. 'My Pregnancy My Choice' is a ring binder folder about all aspects of pregnancy, giving birth and having a new baby. It has 436 pages split into sections.

2. 'You and Your Baby 0 to 1 years' is a yellow book about caring for a baby, feeding a baby and support for parents in the first year of a babies life. It has 371 pages split into sections.

3. 'You and Your Little Child 1 to 5 years' is a ring binder folder about caring for a child 1 to 5 years old (toddler). It has 503 pages split into sections.

NHS Health Scotland recommends that the resources are given to pregnant woman or parents of a baby or toddler in Scotland (ideally with support) by the most appropriate professional as an alternative to Ready Steady Baby! and Ready Steady Toddler!. This could be a midwife, health visitor (or public health nurse) or another person – such as their key worker from a learning disability team.

They are meant to be used along with advice from health professionals. They have been written to meet the needs of pregnant women or parents with learning disabilities.

1.2 EVALUATION AIM AND OBJECTIVES

The aim of this evaluation was to explore to what extent the CHANGE resources are a high quality resource which parents with learning disabilities can easily get hold of, read, use and understand.

The objectives of the evaluation were to find out:

- What issues help or prevent practitioners from getting and using the resources?
- How easy the books are for parents with learning disabilities to get hold of, read, use and understand?

- If the resources are suitable for use by parents and health professionals, for example, their tone, how they are written, how they look and the information they contain?
- If the resources have any gaps in information or messages and what should be included to fill the gaps?
- What recommendations can be made so that in the future parents who need them can get them and use them?

Create Consultancy Ltd was commissioned to carry out one strand of the evaluation to establish the views and experiences of different professional groups in terms of their awareness and/or use of the resources. Running parallel to this process, People First (Scotland) were commissioned to carry out an evaluation of the CHANGE resources through the direct engagement of parents with learning disabilities.

This report should be read together with the report by People First.

1.3 WHY IS THIS IMPORTANT?

People with learning disabilities are full and equal citizens. This means that they have the same rights as everyone else. This includes the right to be parents.

They also have the same responsibilities as everyone else. Sometimes they need extra support to fulfil those responsibilities. Being a parent is a huge responsibility and it is normal for all parents to need help and support with this.

People with learning disabilities need help to find out where they can get support and what their responsibilities are as parents. If they do not know what their responsibilities are, they should not be judged on whether they have met them. Clear information on what to do and how to do it is therefore very important for parents with learning disabilities.

This research project will help NHS Health Scotland to find out
- if the books they provide for parents with learning disabilities are getting to the people who need them and meeting their needs
- what practitioners think about the resources
- whether and how the resources are being used or not being used.

This research is important because it will help to make sure that parents with learning disabilities are supported to learn about pregnancy and parenting and where they can get help when they need it.

RESEARCH METHODS

This evaluation was overseen by a project steering group that had representation from NHS Health Scotland.

The methodology agreed for this project was to conduct approximately 10-11 strategic informant interviews to include representation from rural and urban areas of Scotland with the following:

- Health visitor team leader
- Manager of learning disability agency and/or support service
- Head of Midwifery
- Head of Public Health Nursing
- Manager of Learning Disabilities Adult Team
- Learning Disabilities Advocacy Agency
- Manager of Children and Families teams
- Head of Psychological services (linked to LD adult teams)

This was to be followed with approximately 9 focus groups representing practitioners from health (midwives, health visitors etc), learning disability specialists (LD Adult teams, advocacy workers etc) and other practitioners who are non-learning disability specialists (Children and Families teams, social care staff etc).   The focus group were to be split into those that were aware of the CHANGE resources and those that were not, if possible.

The final aspect to the methodology was to conduct interviews (approx. 20) with practitioners who had seen the CHANGE resources (either follow up from focus groups or those unable to attend focus groups) and others who had a specific remit for working with different inequality groups such as minority ethnic communities, people with physical disabilities etc.

2.1   PROCESS FOR RECRUITMENT

Strategic informants were engaged using a number of methods including using information available on public websites, NHS Health Scotland contacts etc.

The identified individuals were sent information about the evaluation by e-mail and this was followed up (at least twice) with a phone call.   In many instances the person whom was initially identified provided the name of another colleague whom they felt to be more appropriate. This meant than in many instances 7 or 8 phone calls were required to identify and speak with the appropriate person.

The engagement process for the focus groups involved the identification of practitioners through contacts provided by the strategic informant interviews and NHS Health Scotland and public information available on health board and council websites. Initially it had been hoped that contact could be made with practitioners

who had ordered the resource from NHS Health Scotland and/or those who were part of the Early Years Network supported by NHS Health Scotland. It was felt that this would enable the groups to be split into practitioners that had used the resources and those that had not. In practice these processes were not as successful as was hoped for the identification of potential focus group participants. This was partly due to the limited numbers of CHANGE resources that had been ordered and also because a number of practitioners did not provide consent when asked by NHS Health Scotland if they could be contacted as part of this evaluation.

2.1.1 Strategic Informants

14 telephone interviews were carried out with strategic informants in different locations across Scotland, including urban and rural areas. Table A provides a breakdown of the different professional groups and geographic areas included in this strand.

Table A: Breakdown of Strategic Informant interviews	
	Geographic area
Learning Disability agency	National agency
Learning Disability support services	Dumfries and Galloway
Supervisor of midwives	National agency
Head of Midwifery	Greater Glasgow & Clyde
Pregnancy and new born screening co-ordinator	Lothian
Lead nurse (health visitor)	Forth Valley
Project manager – children's services	Fife
Head of LD Adult team	Borders Glasgow City Aberdeenshire
Consultant Clinical Psychologist	Greater Glasgow & Clyde
Speech & Language Therapist	Greater Glasgow & Clyde
Social work manager – Children & Families	Aberdeenshire
Learning Disability development officer – children's team	Highland council

An interview schedule (Appendix 1) was developed to support the telephone interviews. The purpose of the interviews was to better plan the sampling strategy for the focus groups and to get a clearer picture of what support services are available to parents with learning disabilities in each area and how practitioners normally hear about and access resources.

2.1.2 Practitioner Groups

9 focus groups were conducted with 62 practitioners covering the following geographic areas:

- Glasgow
- Clyde
- Dundee
- Lothian
- Inverness
- Borders
- Ayrshire
- National group

The professions represented within the focus groups were:

- advocacy workers
- midwives
- health visitors
- school nurses
- social workers (LD Adult teams)
- social workers (Early Intervention - Children and Family teams)
- specialist nurses & midwives (Early Intervention - Children and Family teams)
- family support workers, nursery staff (Early Intervention - Children and Family teams)
- literacy workers

The focus groups often included a mix of practitioners in terms of their professional role and their awareness of the CHANGE resources i.e. those that were aware of the resources and those that weren't.

A discussion guide (Appendix 2) was developed to support the facilitation of the focus groups. The overall purpose was to gain an insight into the experiences and opinions of the CHANGE resources across a range of professional groups as well as wider issues relating to resource use and distribution and barriers/facilitators to working with parents and soon to be parents with a learning disability.

A number of follow up interviews were carried out after the focus groups with participants. This was to explore in more detail and/or to seek clarity on issues that had arisen in the focus groups.

2.2   LIMITATIONS OF METHODOLOGY

There were a number of challenges faced when conducting this research.

Although, previous experience had indicated that the identification process can be time consuming it was felt that overall there were more pronounced difficulties in the identification and engagement of strategic informants for this evaluation.   It was felt that this may be reflective of the practitioners involved not having a specific remit for parents with learning disabilities and perhaps not feeling that the evaluation was directly relevant or related to their work.

The process of carrying out the focus groups was significantly disrupted due to adverse weather conditions in December 2010 which restricted (& stopped) travel around Scotland. This meant that with the exception of one focus group which ran in November, 2010 all of the focus groups had to be rescheduled for January/February 2011.

Unfortunately two focus groups (one in Grampian and another in Argyll and Bute) were unable to be arranged within the new timescales due to staff absence and the new date of an existing meeting (which we were linking into) falling into March.

As the evaluation was carried out less emphasis was placed on the interviews following the focus groups. This was partly due to the quality of the information received from the strategic informant interviews and the focus groups and also the realisation that few practitioners (excluding those who took part in the focus groups) with a specific remit for inequalities were aware of the CHANGE resources.

2.3   ANALYSIS AND DATA MANAGEMENT

The data generated through this research falls into two main categories opinion based data and factual data. The analysis of these categories required different approaches.

Opinion based data

Most of the data generated through this evaluation consisted of opinions given by the participants (in interviews and focus groups). The majority of interview and focus groups were recorded electronically and transcribed.   In a small number of interviews participants did not want the interviews electronically recorded therefore detailed notes were taken and immediately typed up.

Transcripts were analysed to identify both cross-cutting themes and any new points or issues raised using the computer package NVivo as a supportive tool.

The themes identified formed the outline of the results section of this report.

Factual Data

Some of the information provided by the participants was based on factual data. This included, for example, concrete information (rather than opinions) on current provision for parents and soon to be parents with a learning disability; what services were available locally to parents with learning disabilities and what the services provided. The accuracy of this information was dependant on participants' knowledge.

2.4   RESEARCH ETHICS

Prior to carrying out this evaluation clarity was sought by NHS Health Scotland from the West of Scotland Research Ethics Service as to whether formal ethical approval was required. The advice received from the service was that ethical approval was not required based on the following:

- The project is an opinion survey seeking the views of NHS staff on a service delivery
- It is not intended to assess or pass judgement on professional competency
- Recruitment is invitational and the transcripts from face to face interviews will be irreversibly anonymised so that the respondent's identify is fully protected.
- It is not possible to identify the individual from any direct quotation used in the reporting of the project

RESULTS

Throughout the interviews and focus groups significant issues were raised about the wider challenges to support parents who have a learning disability. In this results section emphasis is placed on the awareness/use/experience of the CHANGE resources in recognition of the overall aim and objectives of the evaluation. However, due to the significant impact these wider issues have on the awareness and use of the CHANGE resources it is important to summarise them prior to exploring specific issues relating to the CHANGE resources.

The results section is laid out in the following way:

Section 3.1: Support for parents with a learning disability
Summarises the support mechanisms participants identified as being available to parents with a learning disability.

Section 3.2: Barriers to supporting parents with a learning disability
Outlines the wider issues that impact on the support provided to parents with learning disabilities

Section 3.3: Process for resource distribution and awareness raising
Highlights how practitioners currently find out about and are made aware of resources

Section 3.4: Awareness of CHANGE resources
Summarises the differing levels of awareness and use of the CHANGE resources

Section 3.5: Who should distribute the resources?
Summarises discussion on whose role it is to distribute the resources and potential barriers and facilitators to distribution by different professional groups

Section 3.6: Who should the CHANGE resources be used with?
Summarises discussion on which groups of people the CHANGE resources are appropriate to use with

Section 3.7: How best to use the CHANGE resources
Summarises discussion on how the CHANGE resources are currently being used with parents

Section 3.8: Views on the CHANGE resources
Summarises the views of participants on the content, layout and tone of the CHANGE resources

Section 3.9: Way forward
Participant suggestions on the best way to take forward the promotion and use of the CHANGE resources and development of wider resources to support work with parents who have a learning disability

3.1 SUPPORT FOR PARENTS WITH A LEARNING DISABILITY

Within the interviews a large number of organisations and professional groups were identified as having a role in the support of parents with a learning disability in pregnancy and the early years of their child's life (0 to 5). All of the interview participants commented that the sheer number of people involved in the provision of support, and the different specialisms that they have, makes the process of raising the awareness of the CHANGE resources difficult.

Interview participants identified the following services and professional groups as having an important role in the support of parents with a learning disability:

Universal Services i.e. midwives, doctors and health visitors

It was recognised that staff providing universal services often have no specific training for working with parents with a learning disability. It was felt that in many instances where a learning disability is identified i.e. learning disability has been formally diagnosis, the midwife or health visitor would work alongside the parents identified 'key worker' from a LD Adult team or call upon the expertise of a 'specialist' nurse, if available, in their local area. It was acknowledged that the availability of 'specialist nurses' to support midwifery and health visitors varied across health board areas. In addition, some areas have specialist nursing staff with specific expertise in learning disabilities and others have staff that have a wider remit to support work with vulnerable parents.

It was raised that the above picture may be less clear where a learning disability is suspected but has not been formally diagnosed. In this instance the action taken by the midwife or health visitor will vary depending on their relationship with other teams and local referral systems and processes as well as their own abilities to identify and recognise that a learning disability could exist. Potential options available include:

- referral to Children and Family services (potentially due to child protection concerns)
- referral to LD Adult team – specifically support to access a cognitive assessment
- informal support from specialist nurses or others who have expertise in learning disability

Learning Disability Adult teams i.e. social workers, speech and language therapists, physiotherapists, psychologists, psychiatrists etc.

The LD Adult teams provide ongoing support to adults to help them manage day to day tasks. The extent to which support is provided will depend on whether a person has a formal diagnosis or not.

Generally practitioners within these teams will not have specialist training or expertise relating to pregnancy or child care in the early years. However, as per the principles outlined in Getting it Right for Every Child they do have a role in supporting all children.

The teams also provide advice to other practitioners working with people with a learning disability and carry out cognitive assessments as part of the process of formally diagnosing a learning disability.

Early Intervention (Children & Families) teams i.e. social workers, family support workers, specialist health visitors and midwives etc.

Generally these services work with parents with a range of vulnerabilities i.e. aren't specific to learning disability and are linked into the Children & Families social work team as well as specialist NHS staff i.e. health visitors, midwives etc. Different members of the team will work with the parent to develop their parenting skills and will carry out parenting assessments. These services often provide support to parents over a limited time and whilst their child is relatively young i.e. until child is age 1 or 3. Examples of these services include the New Beginnings team (Tayside) and Parent and Child Together Teams (PACT) (GGC).

Although the ideal is for these teams to provide early intervention support, many are involved with families due to child protection concerns. This can mean that there is some reluctance (from a parent) to discuss the potential of having a learning disability and/or to access an assessment due to fears that a diagnosis will be used as evidence against their parenting capabilities.

Often staff within these teams will not have specialist knowledge or training in learning disability.

Family Centres
Family centres are linked into the support offered by Children and Families social work teams. They provide ongoing specialist input to identified vulnerable families up to the age of 5.

Voluntary organisations/Advocacy organisations
There are a number of voluntary organisations who provide services to people with a learning disability. This can include services that specialise in learning disability and services that provide parenting and early years support. The provision through voluntary organisations differs from area to area.

There are a number of advocacy organisations that specialise in working with people with learning disabilities (& difficulties). Some of these organisations will have specific projects for parents with a learning disability. Examples include Equal Say and People First.

3.2 BARRIERS TO SUPPORTING PARENTS WITH A LEARNING DISABILITY

Throughout the interviews and focus groups a number of issues arose which relate to wider issues that impact on the support provided to parents with a learning disability. The issues raised are important as they provide the context within which the distribution and use of the CHANGE resources are placed.

It was raised that if learning disability adult teams are already involved in the life of a person (who becomes pregnant) then they will be generally be well supported. However, if the learning disability is only identified (or suspected) at the pregnancy stage (or later) accessing support can be more difficult.

This is due to potential issues with universal health care staff – who have no formal training in learning disabilities – being able to identify that a person may have a learning disability and the level of support provided by services being dependent on the criteria that they use to allow people to access support. This criteria is likely to be different from service to service.

> 'What was key to me was probably a lot of midwives aren't aware or maybe don't recognise if someone has a learning difficulty.'
> **Interview participant, health (midwifery)**

> 'How much of a learning disability do you need to have?...Generally LD services have a higher threshold than other social work services and social work services have a higher threshold than universal services.' **Interview participant, social work (LD adult team)**

There was agreement among participants that cognitive assessments are very helpful in providing practitioners with knowledge about how a person learns, retains and acts upon information. However, it was raised that the processes for getting an assessment carried out differs across the country. Some participants reported problems and long delays in getting a cognitive assessment carried out.

> 'One of the things we need to know is have they got a learning disability? Do we need an assessment to tell us if they've got a learning disability and what their learning style is so that you can try and marry how we work on it?….but we have a major problem getting assessments.' **Interview participant, social work (Children & Families)**

> 'They [assessments] tell you whether someone can take on information and retain it and whether they can act on it and that is very useful… but if the person didn't attend SEN there isn't any assessment….LD team say if they didn't go to special school we can't get involved, which I suppose is resource driven as well.'
> **Focus group participant, Glasgow B**

In addition to problems getting assessments carried out there was also some concern about when LD Adult teams get involved. It was raised by participants who are in LD Adult teams that they often feel that referrals come to them too late. This linked into wider issues around communication and partnership working between agencies and social work departments. In particular there being a lack of agreed protocol around whether LD Adult teams should take the lead for and fund the support provided to an individual or whether it should be Children and Family teams. Some participants made reference to the development of joint protocols in their local area, however it was felt that these had yet to be fully implemented.

'We find that cases are referred to learning disability adult teams far too late in the process so generally when decisions have already been made to remove children and this results in limited opportunities for our teams to work and help support parents.' **Interview participant, health (Clinical Psychologist)**

'One of the big issues of course is who pays for support. First of all who assesses? What they are assessing and who pays? Should it be children and families or should it be adult learning disability teams? When budgets are tight of course it's a game of ping pong.' **Interview participant, voluntary organisation**

Some of the participants from LD Adult teams also raised concerns about cognitive assessments being used to make decisions about a person's parenting capabilities. It was felt that this links into societies understanding of what a learning disability is and what the implications of having a learning disability are. It was felt that a wider barrier to all work with parents with a learning disability was wider attitudinal issues such as learning disability being seen automatically as a risk factor for parenting.

'Where we have been arguing is where it's just a normal run of the mill pregnancy – no additional complications – the learning disability team have a role in supporting people and skilling them up. Really it shouldn't be flagged up immediately to children and families. That's the problem because learning disability within children and families is just automatically regarded as a risk factor and a vulnerability and some of our parents object to that.' **Interview participant, health (Clinical Psychologist)**

'Generally maternity just want learning disability teams to assess that the person isn't fit to be a parent.' **Interview participant, social work (LD adult team)**

It was felt that barriers caused by attitudinal issues are strongly linked to the lack of training provided to non learning disability specialists who have a role in supporting people with learning disabilities. Another issue raised by participants was that some staff lack confidence about being able to identify if a person has a learning disability and in knowing the best way to work with them. There were also some issues about staff not wanting to raise it for fear of offending the person they are working with. This was linked into parents also being reluctant to get that label, particularly if they are being assessed by social work as part of a child protection concern.

'I think if you talk to midwives generally they would say "we are not trained to diagnose who has a learning disability and who hasn't".' **Interview participant, voluntary organisation**

'The stigma is that if someone gets labelled whilst they are getting assessed by a social worker as having a learning disability they won't get to keep their child.' **Focus group participant, Glasgow B**

It was suggested that in order to make the CHANGE resources more widely and appropriately used it would be important to raise understanding more generally in society about learning disabilities and to provide training to a wide range of practitioners.

> 'It would be helpful if the profile of this [learning disability generally] was raised nationally and I think that is something that needs to be done.' **Interview participant, health (nursing)**

> 'Training for people working with this particular client group…if you don't then handing people information doesn't change things.' **Interview participant, health (Clinical Psychologist)**

3.3   PROCESS FOR RESOURCE DISTRIBUTION/AWARENESS

Through the interviews and focus groups it was apparent that practitioners are made aware of new resources in a range of different ways. The most commonly referred to were attendance at local and national networks and conferences and e-mails distributed through senior management i.e. team managers being informed and then circulating information around area teams.

Among participants who worked within the NHS reference was made to health promotion libraries, the NHS net website and newsletters – sometimes from health promotion teams - being good sources of information.   It was felt that there aren't similar types of systems in Councils for informing social work staff.

> 'A lot of health promotion teams send alerts when new resources come in through the e-mail system' **Focus group participant, Ayrshire**

> 'We find out about things through Early Years Conferences or there's the X Health Network, but information through social work is not very useful.' **Focus group participant, Borders**

> 'Network ran by Scottish Consortium for Learning Disabilities is a useful source of information in terms of what is available to parents.' **Focus group participant, Glasgow A**

A number of participants from a range of backgrounds (health and social work) highlighted that when information about resources is sent around staff this doesn't necessarily mean that staff are then aware of – or use – that resource. This was felt to be due to the relevance of a resource to the case load of the practitioner at any given time. This was felt to be an issue for resources, such as CHANGE, that are very specific to a particular issue or client group. This was linked into the view that working with parents who have a learning disability is not a common occurrence. Within LD Adult teams and Early Intervention teams (Children & Families) parents with a learning disability make up a small amount of their caseload and for universal health services i.e. midwives, health visitors, GP's etc this is less again. Therefore when teams are informed about resources that are specific to supporting parents with a learning disability it might not seem relevant to their work.

> 'It's really difficult because there are so many resources out there and so many different things and unless someone is interested at the time when we are circulating an e-mail.' **Interview participant, social work (LD adult team)**

> 'We don't have huge numbers of parents with learning disabilities.' **Interview participant, social work (Children & Families)**

Linked to the above was the approach that many participants made reference to in terms of how they find out about existing resources. This was by carrying out Google searches when they need support with a particular issue relevant to their case load.   The problem with this approach for the CHANGE resources is that it is

the CHANGE website that is found – rather than NHS Health Scotland - and many practitioners dismiss the resources as they think there are cost implications to them i.e. they don't realise that they are free in Scotland via NHS Health Scotland.

> 'What's happened in the past is that we've been presented with a problem, or a parenting issue and we've gone and looked up a tool possibly to help us work with that parent…we Googled it and we've bought it rather than access it through health.' **Focus Group participant, Borders**

> 'I've looked at the CHANGE resources and one of the comments I would make is they are very expensive and we don't have a budget for something like that.' **Interview participant, social work (LD adult team)**

3.4 AWARENESS OF CHANGE RESOURCES

Across the interview and focus groups there was mixed awareness about the CHANGE resources. Of the fourteen interviewees six participants were not previously aware of the CHANGE resources and in eight of the nine focus groups there were participants who were not aware of them at all or not aware of at least one of the resources.   In addition, within the focus groups, the participants made reference to wider colleagues who had informed them that they were not aware of the CHANGE resources.

> 'We are the people who support vulnerable groups and we don't know about this... It makes you wonder what else is out there.' **Focus group participant, Glasgow B**

> 'I would have expected that a resource like this would have been brought to our attention, though I know we have to go out and find things ourselves.' **Focus group participant, Clyde**

> 'I phoned round all the Health Visitors and it was a bit of a mixed bag, some had them and were aware of them and others weren't.' **Focus group participant, Borders**

Of the participants that had previously seen the CHANGE resources the majority had greater awareness of the 0 to 1 years resource (the yellow book) and significantly less were aware of the 1 to 5 years resource.   The majority of participants indicated that they had stumbled across the resources through attendance at network meetings or conferences rather than any planned distribution process in their local areas or through team managers.   The only exception to this was representatives from three local areas – East Ayrshire, Lothian and Inverness – who discussed a more co-ordinated approach to distribution. However, even within these areas there was recognition that awareness at practitioner level was patchy.

> 'In East Ayrshire we purchased these resources for our advocacy colleagues…we made sure the learning disability team and advocacy

all had them so it was a resource that was common across agencies'. **Focus group participant, Ayrshire**

'The My Pregnancy, My Choice and the yellow one [zero to one years] we have copies in our office and all the midwifery areas in each CHP should at least have one or both of these resources.' **Focus group participants, Inverness**

Among the participants that were aware of the CHANGE resources some indicated that they had found it difficult to access the resources. In addition there was a view that the resources were only available in limited numbers. This made practitioners reluctant to give out the resources to parents; instead they used them as a professional resource.

'It's quite a convoluted process to access them…felt like a James Bond exercise!' **Focus group participant, Glasgow A**

'I think they gave us the six but is was kind of, if you spoke to the right person you got six but it wasn't something that they said oh there's these….so the four CHP's got a copy but we don't think that they are being used.' **Focus group participant, Inverness**

3.5   WHO SHOULD DISTRIBUTE THE RESOURCES?

Within the focus groups participants were asked their views on whether particular professional groups should take the lead for distributing the CHANGE resources. The discussion that followed focused on the pros and cons of different professional groups taking the lead e.g. midwives and health visitors in universal provision or LD Adult teams or Early Intervention teams (Children & Families) in specialist provision.

It was recognised that universal health services work with all expectant parents and therefore would ideally distribute the resource in situations where a parent had a learning disability. In particular it was felt that midwives should be distributing the pregnancy resource because they are the 'first point of call' and that health visitors should distribute the 0 to 1 resource.

'It needs to be set up in the same way as Ready Steady Baby! That's got mostly pregnancy and some stuff about early days with your baby. Because that's the kind of thing you would like to cover in pregnancy, parent's education and things like that.' **Focus group participant, Clyde**

'First thought is that the health visitor would be ideally based but it depends on the relationship.' **Focus group participant, Glasgow A**

However, it was felt by some participants that although this may be the ideal there are a number of barriers to universal health services giving out the resources. This included the large demands placed on health professionals – particularly midwives and health visitors – to already give out a large number of resources to expectant

and new parents. This currently includes Ready Steady Baby!, Ready Steady Toddler!, screening leaflets and local initiatives within health board areas i.e. tooth brushing programmes etc.

It was also identified that universal health services do not have the time required to work through a resource of this type with a parent who has a learning disability thus there is a danger that the resource would get distributed but would be of no benefit to the parent.

> 'Health visitors give all that out [RSB, RST, dental info etc] so they are getting an awful lot of stuff and it's whether or not the Health Visitors are having the time to actually go through it, some are and some aren't. It's very patchy.' **Focus group participant, Borders**

Within a smaller number of the focus groups, participants raised the issue of mainstream staff within universal health services potentially not having the expertise or confidence to engage with parents who have a learning disability. The points raised by participants' link to the wider barriers identified to working with parents with a learning disability.

> 'With learning disability I feel out of my depth so would want to do a joint consultation with the learning disability team.' **Focus group participant, Lothian**

It was also felt within the focus groups that specialist teams have an important role to play in the distribution of the CHANGE resources. This included LD Adult teams and Early Intervention teams (Children & Families).

A key benefit from these specialist teams taking more of a lead role was felt to be them having the time to work through resources with a parent and being able to ensure that they fully understand the information that they are being provided. However, there was disagreement over whether it should be LD adult teams or Early Intervention teams (Children and Families) that should take the lead. The issues that arose were reflective of the wider barriers to providing support to parents with a learning disability.   A key consideration here was the difficulty with no one agency having all of the expertise, for example although LD Adult teams have the learning disability expertise they do not have the child care knowledge and for the Early Intervention teams (Children and Families) the reverse of this is true.

> 'It would be the family support workers within the child care teams that would be responsible for doing it because we are responsible for the adult with learning disabilities but they are responsible for the child so we would see it as their job.' **Focus group participant, National group**

> 'I would like to see the learning disability teams take more ownership of stuff like this'. 'Yes, it needs to be a key worker that's got responsibility to take the person through and develop their parenting skills.' **Focus group participant, Borders**

The potential drawback of specialist teams taking a lead role in distributing the CHANGE resources was that many parents who have mild or moderate learning disabilities may not qualify for specialist support – in particular might not meet the criteria for support from LD Adult teams. In addition, Early Intervention teams (Children and Families) tend to offer support for a short period of time or until a specific age i.e. child is 1 or 3.   This final point raised issues about the distribution of the resource aimed at parents of 1 to 5 year olds.

It was recognised by all participants that there are considerably more support structures and professional groups involved in early years i.e. pregnancy and until 1 year than the older age ranges. Due to this there was less clarity or suggestions on who should distribute the 1 to 5 years resource. The suggestions given were that there is an important role here for family centres and nursery organisations. However, it was felt that at the moment staff within these settings would be even less aware of the CHANGE resources than in other settings.

> 'Ante-natal and Post-natal there often is a lot of services in place and it's not until that child hits about the age of two, that's when they are referred to the Family Support Service because mum can't cope, child's tantruming, they don't know what to do.' **Focus group participant, Dundee**

Irrespective of the differences of opinion on which professional group should take the lead for distributing the resources it was felt to be critical that more staff are aware of the CHANGES resources.   This was felt to be particularly important in terms of the potential benefits that could arise from having one central point that standardises information provided to parents with a learning disability.   It was also raised by a number of participants that who distributes the resource is less important than how the resource is used to help parents with a learning disability.

> 'I think the big issue for me is not where they get the materials; it's how to use it properly.' **Focus group participant, Borders**

> 'I think it would depend on the work that you are doing with the individual parents. Although the health visitor may be responsible for providing them, sections of it could be done by other professionals from another team.' **Focus group participant, Ayrshire**

> 'It would be the case of them [different professionals] working together to make sure they use the same information and the thing is that's what the idea of the information trail is - that we standardise information that's given to women because we don't want practices just to be plucking resources'. **Focus group participant, Inverness**

3.6   WHO SHOULD CHANGE RESOURCES BE USED WITH?

Focus group participants were asked for their opinions on which groups of people the CHANGE resources would be appropriate to use with.   A key issue that emerged in the discussion was whether the CHANGE resources should be given to people with a learning disability diagnosis or to a wider group.

It was identified in each of the focus groups that the CHANGE resources could be useful to use with lots of people.   Specific groups of parents mentioned included those with a learning disability (and learning difficulty), parents who are low functioning (due to lack of education, mental health issues, drug use etc), those who have English as a 2nd language, young parents etc.

It was felt that potentially this might be a more useful way to approach the use of the CHANGE resources as it would take away any concerns relating to staff feeling like in order to use the resources they need to be 'experts' in learning disability or be able to diagnose a learning disability . Instead the resources would simply be for those who may benefit from them.

> 'I sometimes think even if you are in doubt, a resource like that could
> be really good anyway, whether you have a learning disability or a
> learning difficulty. Even for a lot of younger parents, because it is
> quite straight forward. There are lots of pictures that back it up and
> it's easy just to dip in and out of.' **Focus group participant,
> Ayrshire**

> 'There's a lot of women who have not been diagnosed with a
> learning disability who would find [the resources] helpful. If I was a
> pregnant mum I'd be quite happy to flick through that.' **Focus group
> participant, Clyde**

This linked into wider discussion around taking an individualist approach to the needs of all parents and not assuming that even those with a learning disability would always benefit from the CHANGE resources.

> 'I think it comes down to what individual needs are and that's why,
> you know, it's very suitable for some folk but some folk may feel that
> the resources that we give them already are adequate.' **Focus
> group participant, Dundee**

It was interesting to note that across the focus groups participants indicated that overall they wouldn't be worried about offending people by asking if they might want the resources - even if a learning disability had not been diagnosed.   This was largely due to the relationships they had established. However, conversely, a smaller number of participants felt that because the resources say that they are for people with learning disabilities they wouldn't leave them lying about to read and they might be cautious about using them with people with literacy issues in case they felt patronised.

'I think a lot of it comes down to the relationship you have with the individual person, and knowing when you can say 'this would help', so it really comes down to the person you are working with.' **Focus group participant, Ayrshire**

'It's almost a shame that it actually says this is for women with learning disabilities because you couldn't just leave that lying somewhere for somebody to have a flick through.' **Focus group participant, Clyde**

'There is obviously a blurring there [between learning disability and literacy skills]. I would say that wouldn't suit people with low literacy skills. It is too simplistic I think it would come over as patronising.' **Focus group participant, Lothian**

Other issues raised as potential challenges to providing the CHANGE resources to a wider group of individuals was the potential of swamping people with information – particularly in light of all the other information received in pregnancy and early years, the budget implications to the NHS if the resources were given out more widely and an awareness by some that there are other resources that exist that have been produced to more specifically meet the needs of other equality groups.

'Presumably they should be given the whole lot of information [each of the resources]. That would be a huge cost to NHS Health Scotland. You really want to make sure you are getting it to the right people. So I would keep it for specific diagnosis I think at the moment.' **Interview, national**

'A language barrier could be overcome by giving them a resource that already exists in their own language, rather than giving them something that's not in their language.' **Focus group participant, Vale of Leven**

3.7   HOW BEST TO USE CHANGE RESOURCES

Participants in the focus groups were asked their opinion on how best to use the CHANGE resources and/or how they currently use the CHANGE resources with parents with a learning disability.   This raised many differences of opinion about whether the resources should be given out to individual parents or used as a toolkit for practitioners and referred to during joint work.

In each of the focus groups there was debate and discussion on the best way to use the CHANGE resources. Overall the consensus was that the most common way they are being used and the preferred way to use them was for practitioners to keep hold of them and refer to them during work to support a parent but not actually to give them out as a whole for parents to keep.   There were many reasons given for this preference.

It was felt that because of the size of each of the resources it may be daunting to provide them to a person with a learning disability.

> 'If going into a family with that big pack some of them might run for the hills.' **Focus group participant, Glasgow B**

> 'Presenting the whole book and telling them to keep it might be a bit daunting.' **Focus group participant, Glasgow A**

> 'I wouldn't give it out as [they] might not look at it. Instead it would be more information to pile on top of the other information they had been given.' **Focus group participant, Lothian**

This also linked to the strong feeling by participants across the focus groups that the CHANGE resources should be used alongside wider support being provided to parents. Due to this requirement many participants felt that using the resources in sections would be the preferred approach. It was felt that this would enable practitioners to leave parents with information that covered the issues they had worked on during a session. For the practitioners that had already used the CHANGE resource they had tended to provide women with photocopies of individual sections.

> 'Feel that it would be better broken down and given to women in stages. So if you were dealing with early pregnancy issues for example, that's all you would give them.' **Focus group participant, Clyde**

> 'I would work through the book with the mum but I wouldn't leave it with her and not necessarily every section, just the parts that I felt were relevant.' **Focus group participant, Borders**

The above linked into views about the need for information given to parents with a learning disability being tailored and relevant to their needs and learning style. It was felt that using the resources in sections enables practitioners to focus on the issues where the parents require support and doesn't assume that they need support for all parenting duties. It was also raised that currently the CHANGE resources require relatively good levels of literacy which parents don't always have.

> 'It depends on the level of the learning disability. If someone just had comprehension issues but they were able to read you might just give it away with them….but it very much depends on the level of their needs.' **Focus group participant, Clyde**

Participants in a minority of the focus groups indicated that they were giving out the resources to women to keep (in some instances only the 0 to 1 years book). In one focus group this practice had been implemented only after a lot of discussion and debate within the team on the best way to use them

> 'That was a question for us because they're quite large books and what we were initially concerned about was will it overwhelm them,

will it just appear daunting to a service user? We initially started actually taking segments and photocopying them and asking the adult what are you worried about, what would you like to know about and then leaving them the relevant section. But to be perfectly honest because they are so well divided, it's a binder, they can take bits out if they need to so we're leaving them the whole book. If need be, we will help [them] to find the relevant section and go through it.' **Focus group participant, Dundee**

Among those that felt that they might provide the resources for parents to keep there were felt to be a number of barriers to doing this. This included the perception that the resources are very expensive therefore limited in numbers and the lack of guidance provided to practitioners on how to use the resources.

'I think there is a communication issue about whether or not it's a resource to teams or whether it's a resource that all parents are getting because we're not giving out the material like that to parents.'

'I've never ever left the folder with a mum. I didn't know I was allowed to do that. I thought it was too expensive'.
Focus group participants, Borders

'I didn't realise that these were actually intended for being given to clients to take away with them. My concern is there is no guidelines or anything with them…I don't think it actually takes into consideration the different ways in which people do learn so I don't think they're actually stand alone resources.' **Focus group participant, Inverness**

Irrespective of whether the resources are provided for parents to take away or used in sections by practitioners there was agreement that it would be useful for the resources to be available in all clinics and centres that provide support at the antenatal stage and in early years.

'I think it would be beneficial for the midwives to have, certainly My Pregnancy, My Choice and You and Your Baby at the GP clinics because obviously the women are seen by their midwives at their GP surgeries.' **Focus group participant, Dundee**

3.8   VIEWS ON THE CHANGE RESOURCES

Within the focus groups all participants were shown the CHANGE resources so that even those who hadn't previously seen the resources could provide feedback on the content and style of the resources. Across the discussion there were mixed feelings about different aspects of the resources.

A number of participants felt that overall the resources are good because they are eye catching, use easy words and are simple to understand. Specific comments were made about the word bank being particularly helpful.

'The language used is very clear and concise and easy to understand.' **Focus group participant, Glasgow B**

'I like the fact that it's got easy words because I think that sometimes we get caught up in our jargon, the big words, and sometimes you think how can I say this to make it easier? It gives you a few suggestions. **Focus group participant, Ayrshire**

A minority of participants disagreed about the resources being eye catching and commented on them being a bit bland.   This was with specific reference to the 0 to 1 resource.

'I would maybe say that it's a wee bit bland, if it was a bit more colourful it would maybe grab their attention a bit more but I mean there's plenty of pictures. So that would be the only thing that I would say was a down side.' **Focus group participant, Borders**

There was preference across all participants for the resources that are presented in a binder rather than the book i.e. the pregnancy and 1 to 5 years resources rather than the 0 to 1 'yellow book'. This was because they were felt to be easier to use in sections and easier for parents to navigate through

'Ring bound ones are better, feels more manageable and the colour coding makes it easier to find sections' **Focus group participant, Glasgow A**

'Having them in a binder rather than a book is better…so they can be split up?...yes.' **Focus group participant [& researcher], national group**

'Overall the clip arch resources are better as easier to photocopy and use the parts that are relevant.' **Focus group participant, Lothian**

There were a number of issues raised about the content of the resources, both positive and negative. In particular, practitioners in two focus groups were more negative than positive about them. Key issues raised were:

Size of Resource
Practitioners from the majority of focus groups commented upon the size of the resources being a barrier. This was related to the resources being daunting to parents and also impractical for practitioners to carry about. However, some practitioners felt that after looking at the resources in more detail and using them they recognised why they were so large.

'Initially I thought it was huge. I said if we could just half that folder, but looking at the pictures and the text, you know, it does need to be at that size, because actually even some of the pages they've got quite a bit crammed onto them. There's a lot of information on one

or two pages so I've probably pulled back on that and thought, no,
just leave it at that size.' **Focus group participant, Dundee**

Inaccurate & Outdated Information

In two focus groups it was raised that some of the information contained within the resources is outdated and inaccurate. One group in particular were aware that amendments were being made to the CHANGE resources and had reservations about practitioners being able to access them before the amendments had been carried out.

'I know our infant co-ordinator was really concerned about the feeding parts of it....I think they are generally very good but the worry is that some information is inaccurate.' **Focus group participant, Ayrshire**

'Some of the information is quite outdated....It's odd because there's stuff about Health Start and Health Start replaced the milk tokens...but they've got stuff about milk tokens and Health Start so that's odd.' **Focus group participant, Inverness**

Pictures and Imagery

In two focus groups practitioners raised issues about the pictures and imagery used to depict medical procedures (not accurate), breastfeeding (not enough) and sensitive issues. In two other focus groups issues were raised about the pictorial representation of parents with a learning disability. Practitioners in one focus group indicated that this was so concerning that they would not use or promote the CHANGE resources.

'I know a couple of the professionals I spoke to about the pictures, there were some that they felt maybe a wee bit uncomfortable with, but that was more because of the sensitive nature of them, like the stillbirth pictures, but how do you depict that in a picture?' **Focus group participant, Ayrshire**

'Well I've had e-mails from other people saying they felt the pictures were quite condescending to people with learning disabilities. Why aren't they just normal pictures of normal people? To me that looks like somebody who might have some kind of, you know, the belly's hanging out...' **Focus group participant, Inverness**

'I don't know if parents have an issue with this or not but there is a tendency to cartoon everything for parents with a learning disability a little bit.' **Focus group participant, Borders**

However, other participants were very positive about the pictures and felt that they made the resources very appropriate to use with parents who have a learning disability.

> 'The pictures are great, they are easy for people to understand, and I think the fact that they are colourful helps, because it catches the attention.' **Focus group participant, Ayrshire**

Although there were felt to be weaknesses to the content of the resources it was interesting to note that in one of the focus groups, where the greatest reservations about the content had been expressed, participants indicated that they still used the resources in recognition that people with learning disabilities had devised them and that in their experience of using them with parents, the parents liked them. They had overcome issues around inaccurate information by not giving out sections they felt were particularly confusing or misleading.

Within six of the focus groups some participants indicated that they had used the resources with parents. Overall the feedback and reaction of parents had been positive. In addition participants felt that any resources that help them to put across information in a more simple way are welcome.

> 'Parents have been quite positive about it and have seen the value in it [one parent said] 'that would be really good if I could have that because with that I could sit down and look at it on my own and I wouldn't need support' for her that was quite freeing.' **Focus group participant, Glasgow A**

> 'A client that we are working with at the moment she's been quite excited by it, having her own book and, you know, it's obviously easier for her to understand. In fact I think she's kind of raced ahead, going through it. She wanted to go through the whole book rather than sort of do it in stages and I assume that once she's had her baby, without giving her too much, she'll move onto the other resources as well.' **Focus group participant, Dundee**

However there were some cautionary points raised about ensuring that parents don't feel patronised by the CHANGE resources – particularly if they were managing well with the Ready Steady Baby! resources. This linked into wider discussion on the importance of tailoring information and support to the individuals' needs and abilities and understanding their learning style and process time.

> 'Staff are struggling to help people to take on information so any materials to help us to do that would be welcome.' **Focus group participant, Glasgow B**

> 'It's a teaching tool, because sometimes the visual aids are really really beneficial and other times they've caused parents with learning disabilities being offended by it….You've always got to gauge the person you're working with, and it's always around their needs and abilities.' **Focus group participant, Borders**

3.9 WAY FORWARD

Across the interviews and focus groups the most prominent suggestion to ensure that future parents who need the CHANGE resources can use them was better promotion of the resources among local teams and a wider range of professional groups being made aware of them.

It was felt that a more concerted and co-ordinated effort was required to raise awareness. However, due to some of the barriers discussed earlier it was felt that it might not be enough to send out information letting practitioners know that they exist. Instead it was felt that it might be better to go out to local areas to engage local teams and let them know how the resources are relevant to their practice.

> 'Its not enough just to send out the resources they need to attend these meetings and provide an exploration around the resources, like who they are for, how best to use them.' **Focus group participant, Lothian**

Another practitioner felt that it would be beneficial to more closely align the resources to Ready Steady Baby! and Ready Steady Toddler! so that health professionals (particularly midwives and health visitors) see them very much as an alternative option to these resources.

> 'I am wondering whether there would be a reason for making that more in line with Ready Steady Baby!?' **Focus group participant, Lothian**

Within a number of focus groups it was also raised that it would be beneficial to have more guidance on the resources which would include where to access the resources, how many you can get and the best way to use them.

> 'I think you would need to have background training be that within the parenting side of things, disabilities, literacy issues etc. So there's a fair bit of guidance actually needed with them rather than them just being a resource off the shelf. It's like giving me a Haines manual and saying right go and build a car.' **Focus group participant, Inverness**

The final suggestion provided by participants was the provision of a DVD or supporting video clips.

> 'For some of the parents with a learning disability actually seeing it modelled is more useful than seeing it on paper so to actually have a DVD of someone changing a nappy or breastfeeding in the different stages. So you could watch it, you could do it with them along side and that's easier.' **Focus group participant, Borders**

'Video clips to go along with it would really help particularly around managing a child's behaviour. We need to be very consistent with this. It is difficult for any parent to recognise when they are being less consistent.' **Focus group participant, Glasgow A**

DISCUSSION

Levels of awareness and use of the CHANGE resources are significantly influenced by wider barriers to providing support to parents with learning disabilities. This includes issues such as

- the number of agencies and professional groups involved
- difficulties around long-term support for parents with a learning disability
- difficulties getting cognitive assessments carried out
- a lack of appropriate support if there is no formal diagnosis
- attitudes and assumptions made by staff about learning disabilities
- a lack of knowledge about what having a learning disability means i.e. impact it will have on how a person processes information, and what having a learning disability doesn't mean i.e. does not automatically mean the person will experience parenting problems or difficulties.

These wider issues should be taken into account when reading the following discussion.

4.1 WHAT HELPS OR PREVENTS PRACTITIONERS FROM GETTING THE CHANGE RESOURCES?

The CHANGE resources are not widely available for parents with a learning disability. This is because of the mixed awareness of the CHANGE resources and varying levels of use among practitioners that provide support to these parents. There were a number of reasons for this lack of awareness, not least the wide range of organisations and professional groups that could potentially be involved in the delivery of support to parents with a learning disability. Other factors which were felt to prevent practitioners from getting the CHANGE resources were:

- Confusion about any cost implication to purchasing the CHANGE resources.
- A lack of information on the internet about the CHANGE resources availability and use in Scotland.

In addition to the above, the results from this evaluation would indicate that at present there is greater awareness of the CHANGE resources among NHS staff and learning disability teams. The reasons for this were not clear but could be due to NHS Health Scotland having closer links to other parts of the NHS. What it means is that some key professional groups were not aware of them. This includes some Early Intervention teams (Children & Families) and a wider range of staff that could have a role in the distribution of the 1 to 5 years resource such as nurseries etc.

Overall there was less awareness among participants of the 1 to 5 years resource than the others; in addition there were fewer practitioners from organisations that could have a role in the distribution of these resources

involved in this evaluation. This is partly due to the challenges that were experienced when conducting the fieldwork (which prevented a focus group taking part in a family centre) but is perhaps also reflective of a lack of engagement generally with nursery staff and family centres about the CHANGE resource. This is concerning due to the important role they could have in the promotion and distribution of the 1 to 5 years resource.

The majority of participants in this evaluation had become aware of the CHANGE resources (particularly the pregnancy and 0 to 1 years resources) through attendance at conferences and information sharing networks – particularly the NHS Health Scotland Early Years Network and the Scottish Consortium for Learning Disability Parenting Network. This would indicate that the awareness raising and promotion of the CHANGE resources through this route has been a partial success.

Among the practitioners who were aware of the resources it was apparent that there were a number of barriers to them then accessing and getting the resources. Key issues include:

- The resources not always feeling relevant to practitioners – partly due to work with parents with a learning disability often being a small part of their case load.
- Difficulties getting the resources from NHS Health Scotland and a lack of clarity on the number of resources organisations are allowed to order.

A wider and potentially more difficult barrier to overcome was a lack of clarity on whose role it is to distribute the resources.

The discussion on distribution links into wider issues relating to the role of different professional groups (& teams) in the life of a parent with a learning disability. Although universal health services have contact with all parents and expertise on early years they lack time, and potentially the confidence, to work in depth with a parent with a learning disability. Although the LD Adult team have the expertise on learning disabilities they only support those who have a diagnosis and their focus is to provide wider support to the adult which is not felt to include specific support on parenting duties. Finally the Early Intervention teams (Children & Families) have expertise around parenting but not learning disabilities and don't work with all parents as they have a higher threshold for working with individuals in terms of vulnerability than universal health services. In some instances they were also involved due to child protection concerns which could make a parent anxious about being identified as having a learning disability.

It was evident that the issues surrounding the provision of support to parents with learning disabilities are complex and require high levels of partnership working which, participants in this evaluation feel don't always exist.

4.2 WHAT HELPS OR PREVENTS PRACTITIONERS FROM USING THE CHANGE RESOURCES?

This evaluation found mixed views among participants about the CHANGE resources with some being very positive about them and others feeling that there were a number of issues that required to be resolved before they would feel comfortable using them. These include:

- Incorrect and outdated information
- Concerns around a lack of breastfeeding images and over reliance on bottle feeding information
- Concerns around some images and pictures being insensitive and potentially being misconstrued – particularly if the individual has literacy issues.
- Concerns about the pictures potentially being condescending towards people with learning disabilities.

It should be noted that the above issues were raised by a minority of participants; however for these participants these concerns hindered their use of the CHANGE resources.   In addition, there was some indication that these concerns were more likely among NHS staff providing universal services i.e. midwives and health visitors - than staff (NHS and social work) from LD Adult teams or Children and Families teams. However, this was not found across the board, therefore it is not possible to make any strong conclusions about this.

In every focus group participants felt that the format of the resources i.e. ring binder rather than a book made them more useable for parents and practitioners. .

Although there were some examples of teams providing parents with the CHANGE resources directly, it was evident that few practitioners were using the resources in the way that NHS Health Scotland recommends i.e. providing parents who have a learning disability with them to keep. Participants in all of the focus groups felt very strongly that it was important that the resources were used alongside ongoing support to a parent with learning disabilities. The majority also felt that using these resources (amongst others) to reinforce the work they do with a parent was a good way to do this. It was felt that practitioners use the resource in sections because this enabled them to tailor the information to individual needs and learning styles. This was felt to reflect best practice for working with people with learning disabilities.

Whilst taking the above into account it is unclear whether the current approach of using the resources in sections was linked to concerns around the availability and potential cost of the resources. It is possible that if local areas and practitioners were given clarity on the number of resources available to them and that there are no cost implication they may be more likely to provide them direct to parents.

An additional issue that was raised was who the resources should be used with. This discussion encompassed whether they should be for people with a learning disability diagnosis or those with a learning difficulty and also whether they should be used with others who may benefit. Overall it would seem that there was a case for providing the CHANGE resources to individuals with a learning difficulty but not a formal diagnosis. Individuals within this group may be well placed to use the resources with the support of family and friends and may also be receiving less formal support from services. Potentially this means that the CHANGE resources could be very useful for them.

In terms of providing the CHANGE resources to parents from other equality groups generally participants felt that they could be beneficial however some issues arose about the appropriateness of the CHANGE resources in terms of being too simplistic and potentially patronising (particularly for people who have literacy issues). Other barriers included the potential cost of doing this. It was interesting to note that although previous comments were made about some of the imagery in the resources no participants identified the inclusion of bottle feeding imagery and information as being a barrier to providing the resources to people who do not have a learning disability. It was evident that participants were not aware that the CHANGE resources should not be given to parents – other than those with a learning disability – due to the inclusion of formula feeding information. Due to the unique needs of parents with learning disabilities NHS Health Scotland have sought agreement from UNICEF that boards can use these resources with this target audience and still meet the requirements for baby friendly accreditation.

There was also a suggestion that it would be helpful to more clearly align the CHANGE pregnancy resource and the 0 to 1 years resource with the national resources Ready Steady Baby! and Ready Steady Toddler! It was felt that this would help practitioners to see the CHANGE resources as a viable alternative to these resources and help to promote the CHANGE resources as being a central point of information which all practitioners working with parents with a learning disability should use. It was felt that this is important to ensure that the messages given to parents who have a learning disability are consistent and standardised.

It was evident that an important factor that impacted on practitioner's use of the CHANGE resources was the positive reaction they receive from parents when they do use them. This was clearly a powerful motivator for practitioners to use the resources – for some it meant continuing to use the resources even when they had reservations and concerns about the content.

Overall it was felt by participants in this evaluation that it would be beneficial if guidance was provided to practitioners on the best way to use the CHANGE resources. However, it was also evident that the use of the CHANGE resources are interlinked with wider issues relating to the support provided to parents with a learning disability. These are larger issues that fall out with the remit of this evaluation but could have a significant impact on the use of the CHANGE resources.

CONCLUSIONS AND RECOMMENDATIONS

This evaluation found that awareness of the CHANGE resources is low among practitioners and this means that they are not being widely distributed to parents with a learning disability.

The results indicate that attendance at conferences and networks is currently the main information route for practitioners to find out about the CHANGE resources and to date this has meant that staff within the NHS are more likely to know about them. The findings also indicate that there are a wide range of barriers that impact on the promotion, distribution and use of the CHANGE resources.

Recommendation 1: There should be a more consistent and co-ordinated approach to the promotion and distribution of the CHANGE resources. Consideration should be given to the following:

- how the CHANGE resources could be promoted in a way that makes them relevant to a wide range of practitioners many of whom will only work with parents with a learning disability on an infrequent basis;
- the potential of using a staged approach to the promotion of the CHANGE resources i.e. prioritising professional groups i.e. universal health services, specialist learning disability staff, specialist early intervention staff etc and their associated networks and conferences;
- being more proactive in the promotion and awareness raising of the resources i.e. attendance at local level meetings.

Recommendation 2: Better use should be made of existing processes through which practitioners are made aware of new resources. This includes:

- search engine optimisation to ensure that the NHS Health Scotland website has a higher prominence when people search the internet for the CHANGE resources or resources for parents with learning disabilities in Scotland;
- having information on the CHANGE website which indicates they are available free in Scotland with a link to NHS Health Scotland site;
- using intranet sites of organisations to promote the availability and use of the CHANGE resources in Scotland;
- engaging managers and heads of service within social work and the NHS to utilise internal cascade systems of resource distribution.

Recommendation 3: Specific work is required to raise awareness of the 1 to 5 years resource and to ensure that the most appropriate practitioners are made aware of it. Focus should be placed on raising awareness among health visitors, family centres and nurseries.

It can be concluded from this evaluation that, in some instances, even when practitioners are aware of the resources there continues to be barriers to them being used. It is apparent that this is partly due to misinformation about cost and availability of the resources and also difficulties in ordering the resources from Health Scotland.

Recommendation 4: There should be a clear process for ordering the CHANGE resources and guidance on how many resources can be ordered for free from NHS Health Scotland.

The evidence suggests that there are additional barriers to using the CHANGE resources due to personal views about the tone and content of the resources, and concerns about how impractical they are (due to size) to carry and distribute, and in the case of the 0 to 1 resource, navigate through. It is felt that some of the practical solutions provided by participants on ways to overcome these barriers should be taken into account by NHS Health Scotland and CHANGE.

Recommendation 5: Adaptations should be made to the CHANGE resources to correct any inaccurate information or pictures and to ensure that they are in line with Scottish and national policy on breast feeding/bottle feeding imagery and information whilst still meeting the needs of parents with learning disabilities.

Recommendation 6: The 0 to 1 resource should be redesigned into the clip arch lever style in line with the pregnancy and 1 to 5 years resources.

Recommendation 7: All promotion materials about the CHANGE resources should highlight that they are an alternative for parents with learning disabilities to the Ready Steady Baby! and Ready Steady Toddler! resources that are available to all parents.

The findings indicate that parents with learning disabilities should not only receive the CHANGE resources but wider practical support to help develop their parenting skills. The findings also suggest that at the moment practitioners are not using the resources as intended i.e. giving them out for parents to keep, and lack clarity on any restrictions in terms of who the resources should be provided to. It would be helpful for NHS Health Scotland to provide clarity on what best practice is in relation to the provision of information to parents with a learning disability.

Recommendation 8: Guidance should be provided to practitioners on who should distribute the resources, the best way for the resources to be used and who the resources should be targeted at. This should be in keeping with the guidance from UNICEF on the promotion of breastfeeding and specific allowances for parents with learning disabilities, the Scottish Consortium for Learning Disabilities (SCLD) guidance and the findings from the parents' evaluation of the CHANGE resources.

There was some indication that due to their role in providing support during pregnancy and in early years midwives and health visitors have a key responsibility in providing the CHANGE resources (as they currently do for RSB and RST). However, due to the wide range of professional groups that provide ongoing support to a parent with a learning disability there is also a need for this wider group to be aware that the CHANGE resources exist and in some instances provide them to parents themselves.

Recommendation 9: All midwives and health visitors should be made aware of the CHANGE resources and their responsibilities to distribute them where a parent has a learning disability. In addition, a wider range of professional groups including Early Intervention teams (Children & Families), LD Adult teams, family centres, nurseries and advocacy organisations should be provided with promotional information about the CHANGE resources with detail on where and how parents – whom they may be working with – can access free copies of the resource.

The findings show that an important facilitator to practitioners using the resources is the reaction they get from parents about them. Due to this it is felt it would be beneficial to inform all practitioners (including those that have not yet used the resources) about the views of parents towards them.

Recommendation 10: All promotion of the CHANGE resources should include personal testimonies of parents who have used them and clearly indicate that parents with learning disabilities have been involved in their creation.

Finally it is clear that in addition to the provision of accessible written information (as per the CHANGE resources) participants felt that it would be beneficial for there to be a DVD developed to further support parents with learning disabilities to develop their parenting skills.

Recommendation 11: Any future development of resources should consider practitioners positive views on the use of DVDs and video clips.

As highlighted throughout this report, the provision of support to parents with a learning disability is a complex area within which there are a number of barriers and challenges. Each of these has an impact on the distribution of the CHANGE resources. Due to this it is felt important to include a more far reaching recommendation than those that are specific to the CHANGE resources. It is recognised that this recommendation will require action from a number of stakeholders both nationally and at the local level.

Recommendation 12: Having the CHANGE resource is not enough. Practitioners and managers need to have a better understanding of learning disabilities if parents are to be adequately supported. There also needs to be greater clarity on the responsibilities of different professional groups providing pan support to parents with a learning disability. This will require training, partnership working and the development of joint protocols.

APPENDICES

APPENDIX 1

Evaluation of CHANGE resources: Strategic Informants Interview Guide

Support Provided

- What is your understanding of who the key professionals are that work with parents/soon to be parents with learning disabilities?

- How is support provided by [professional group]? How does this link into other support structures? i.e. adult LD teams, children and family services, health visiting, midwifery etc. Does this differ across areas?

- How is [professional group] organised? What are the structures teams/ networks in which they work?

Resource Distribution

- What are the ways that [professional group] would be made aware of the existence of resources (CHANGE or similar)?

- Is there a system for resource distribution, if so, what is it? If not what are the barriers to accessing and using these resources? What suggestions do you have for overcoming these barriers?

- Are there any particular individuals with whom you would suggest we speak/might be willing to take part in a focus group?

APPENDIX 2

Evaluation of CHANGE resources: Focus Group Discussion Guide

Thank you for agreeing to take part in a focus group as part of the evaluation of the CHANGE resource. This evaluation is being carried out by Create Consultancy Ltd on behalf of NHS Health Scotland. This guide provides you with information on what the focus group will involve and the areas of interest we will explore.

- The focus group will take no longer than 1 hour. You do not have to have used or seen the CHANGES resources prior to taking part.

- The researcher will take notes during the focus groups and will also record the discussion. This recording will only be heard by the research team within Create Consultancy Ltd who will also transcribe it. The anonymised transcription will be used to explore key themes and issues emerging across the evaluation.

- The views given by all participants who take part in the evaluation will be incorporated into a final report that will be presented to NHS Health Scotland and may be available publicly via their website.

- All information in the final report will be anonymised with no names of individuals and/or local clinic or service names.

1. **General Questions about Resource Use and Access**

   1.1. How do you (and/or colleagues) generally find out about and access resources (like CHANGE)?
   1.2. Are you aware of the CHANGE resources? How did you find out about them? Do you use any other resources specific to parents/soon to be parents with learning disabilities?
   1.3. How easy is it/would it be for you (and/or colleagues) to decide who to use these resources with?
   1.4. Who are you/would you use them with? Are there any additional equality issues that affect its use with those individuals?
   1.5. What helps/prevents you (and/or colleagues) using resources for parents with learning disabilities generally?
   1.6. What support can you access in working with parents with learning disabilities? E.g. advocates, specialist help? Have you used it/why/why not?
   1.7. How confident do you think you (and/or colleagues) would feel about using the CHANGE resources? E.g. confidence in the topic area, in working with parents with learning disabilities generally?

2. **Specific Questions about the CHANGE Resources**

   2.1. Initial impressions and how you use or might use the resources with patients/service users.
   2.2. How well do they meet the needs of parents with learning disabilities?
   2.3. Overall impression including strengths and weaknesses of resource, gaps in information provided etc.