

# Finding the Right Help



Anna Marriott

Beth Tarleton

December 2008

## Section 1

---

### Introduction

Research, and the experiences of parents with learning difficulties, has shown that they are committed to their children and concerned with safeguarding their welfare. The data suggest parents with learning difficulties can be capable of coping with a parenting role, especially when provided with good, ongoing emotional and practical support (Cleaver & Nicholson, 2007; Morris, 2007). Recently, research in this field has moved on from documenting the removal rates of children from their parents with learning difficulties and identifying the barriers faced by these parents, and now has a more positive and proactive focus. This is reflected in studies such as *What works for parents with learning disabilities?* (McGaw & Newman, 2005) and *Finding the Right Support* (Tarleton et al, 2006). Similarly this shift in attitude is exhibited in policy, such as *Valuing People*, (DH, 2001) which acknowledged that parents with learning difficulties can be good parents with appropriate support. This White Paper recognised the need for services to work with parents with learning difficulties and included a commitment that these parents and their children would benefit from all general initiatives aimed at supporting families. The more recent consultative document *Valuing People Now* (DH, 2008) again emphasises that mainstream services must address the needs of these parents and states “parents with learning disabilities must have access to the same level of information and advice that is intended for all parents” (page 79). Along with the *Good practice guidance on working with parents with a learning disability* (Morris, 2007) such documents are now framed within a Human Rights context. There appears to be a growing recognition that under such legislation as the *Human Rights Act* (1998) people with learning difficulties do have the right to enjoy consenting sexual relationships and to be supported as parents. These rights need to be balanced with the rights of children to live in a safe and supportive home.

The right to a family was an issue highlighted in a recent study funded by the National Institute of Health Research Service Delivery and Organisation Programme in which “relationships and parenting” was one of the six themes prioritised for future research (Williams et al, in press). More specifically, there are still research gaps around society’s attitudes towards parenting by people with learning difficulties, in terms of social workers, parents, teachers, judges, managers and midwives. It is imperative to establish how the approach of such professionals affects the quality of support provided and how to provide better long-term support to parents with learning difficulties.

*Working together to help safeguard children* (HM Government, 2006) acknowledged the challenges of parenting and that most parents need support and advice at times. Moreover it stipulated that requesting help should not be viewed as a failure to parent adequately but rather as demonstrating responsible parenting. This principle should surely extend to parents with learning difficulties. However there is evidence that when parents with learning difficulties ask for help this is seen as indicative of their inability to cope with the demands of parenting (Baum and Burns, 2007). Previous research has shown that parents with learning difficulties need support with many everyday tasks after birth:

- explaining things to their children
- managing their children's behaviour
- helping their children with homework
- ensuring the safety and welfare of their children
- understanding what professionals say
- helping with transport
- managing finances and paperwork
- practical tasks around the home
- coping with bullying or harassment (Tarleton et al, 2006)

This list highlights the need for the support to be ongoing, as issues such as managing the child's behaviour and ensuring their safety will clearly change as the child ages. Therefore a parent may have learnt how to safeguard a young child, but as they become more independent there will be new challenges for parents to address around the personal safety and development of their child.

Research has shown that for support to be effective it needs to be both long-term and flexible (Young and Hawkins, 2006; O'Hara and Martin, 2003; Guinea, 2001). Other research has identified more specifically the type of support needed. For example, women with learning difficulties tend to receive very little antenatal support (James, 2004; Wates, 2003). Traditionally, antenatal classes are considered to provide an opportunity for parents to receive information and advice around labour and birth as well as to begin to prepare for life with a new-born baby and the vast majority of pregnant women will attend these. Many women also report that antenatal classes provide an important opportunity for social networking and support. Similarly there is a multitude of book titles and magazines aimed at helping expectant mothers cope with pregnancy and prepare for motherhood. However as such resources and classes are often not accessible or inclusive for parents with learning difficulties they are often unable to benefit from such information. Ironically this group of parents who may need extra support and information often end up being the parents who receive the least.

Evidence supports the effectiveness of practical support for parents with learning difficulties but in order for this to be directed appropriately there is a need for mainstream services to be better at identifying these parents (Ward, 2007). There have been screening tools developed to assist professionals with this but there is a debate that the continuing emphasis on cognitive assessments is misguided. Historically services for people with learning difficulties have been driven by the medical model in which people with a disability are defined by their medical condition; this has led to IQ scores determining if a person is eligible for services. Clearly such a model of practice requires cut-off levels and therefore traditionally if an individual has a score of above 70 they would be deemed ineligible for support. Individual performance on such cognitive assessments will always fluctuate and be affected by a variety of factors so if cut-off scores are used it is likely there will be vulnerable parents who may not meet strict learning difficulty criteria, but who may still be in need of some extra support and should be included in service provision. The guidance for Fair Access to Care recognises that even if an adult is not eligible

for services because of their IQ if they have parenting responsibility that they cannot fulfil they should be provided with support (Department of Health, 2002). Furthermore as there is no evidence of a relationship between parenting ability and IQ this model may be an inappropriate basis for determining level of need (Booth and Booth, 2005).

It is vital that parents with learning difficulties are not judged by higher standards than other parents and discriminated against within the system. Parents, with and without learning difficulties, will never be perfect; professionals, family members and the parents themselves should not strive towards such unobtainable goals but should focus on the concept of being 'good enough' parents and the necessary support to achieve this (Tarleton et al, 2006). Crucially there continues to be an unmet need for accessible information and advice around the everyday parenting tasks. This is true despite the fact that providing accessible information is a legal requirement under the Disability Discrimination Act (HM Government, 2005). Additionally it is part of public authorities' Disability Equality Duty to ensure that parents with learning difficulties have the same access to family advice and support services.

The failure of many services to provide adequate support and information, compounded with the negative and judgemental attitudes many parents with learning difficulties have experienced need to be acknowledged. There is a widespread presumption of inability to parent from professionals and parents often feel they are expected to fail and are scare of having their children taken into care. It is imperative that services wishing to engage with parents with learning difficulties are aware of the historical context and the ways in which these parents have been treated. Studies providing the narratives of parents with learning difficulties have provided insight into their perspectives:

*They judge you too quickly – that's what hurts the most*  
Tarleton et al (2006)

*They're asking questions and you've got to think what you say before you answer because half the time they twist it, to say something what they want to say and not what you said*  
Booth & Booth (2005)

Such experiences may impact on the willingness of parents with learning difficulties to work with professionals and may account for the often adversarial relationship between parents and professionals.

It is clear from the existing research that parents with learning difficulties are at a high risk of having their children removed against their wishes but equally it is apparent there are many potential areas for intervention which could have a great impact on the necessity for this. Unfortunately, instead of receiving appropriate support, parents with learning difficulties will frequently face child protection proceedings. There are high rates (40 to 60%) of child removal from parents with learning difficulties (Booth *et al*, 2005; Elvish *et al*, 2006). Clearly, it is paramount to ensure the welfare and safety of the children of parents with learning difficulties, but there is some consensus that stricter criteria may be used when judging this group of parents, as compared with other groups. A review of the literature found that some of the concerns for children of parents with learning difficulties include the fear that the

children will suffer developmental delay and also that there is a high risk of abuse and neglect (James, 2004). However, these perceived risks may not be backed up by evidence. "Equating parental learning disability with wilful neglect and abusive parenting is *not* supported by research" (Cleaver & Nicholson, 2007, page 14).

Once child protection proceedings have begun, parents with learning difficulties will be disadvantaged by their impairments in terms of understanding the rules of evidence and procedures (Tarleton *et al*, 2006). Analysis of court records has shown that they were disproportionately represented in care proceedings, with one in every six children at Family Court having at least one parent with a learning difficulty (Booth *et al*, 2005). Data showed that 47% of these cases were as a result of misguided parenting as opposed to actual abuse and that the vast majority of cases were brought due to neglect. It was found that many professionals focused on the parent's learning difficulty as a specific risk factor for neglect rather than objective evidence. Data from the files analysed suggested these parents had been offered little or no support, as it was assumed this would be ineffective but the authors concluded this contradicts findings from international research and is indicative of discriminatory treatment of parents with learning difficulties. The lack of support and accessible information available to parents with learning difficulties are factors which compound any difficulties parents may be having in looking after their children and similarly will be to their detriment in court proceedings. For example, it is generally considered to be in the best interests of the children for proceedings to move quickly but this can disadvantage parents with learning difficulties as there may be no acknowledgement that these parents may need a longer time period to exhibit changes in their parenting following professional input (Booth *et al*, 2006).

The views and experiences of parents with learning difficulties going through care proceedings have been explored in qualitative studies by researchers (Booth and Booth, 2004; 2005; Baum and Burns, 2007). These studies identified common themes including a failure in support, even when specifically requested. Furthermore, inappropriate assessments and lack of advocacy have been highlighted as areas which need addressing.

The lack of existing accessible resources and support services for parents with learning difficulties, along with recent high-profile reports such as *Valuing People Now*, underline the importance of organisations such as the NSPCC addressing this issue. Such parents are a vulnerable group and arguably may be in need of additional support and advice and yet consistently they are unable to access most of the information that parents without learning difficulties generally receive. Although the research evidence demonstrates that parents with learning difficulties can benefit from appropriate support, fear of removal of their children can act as a deterrent to seeking support from social services (Wates, 2003). Consequently organisations such as the NSPCC must also seek to be viewed as approachable by these parents as well as having accessible resources and information that will be of use to them.

## **Methodology**

Norah Fry Research Centre (NFRC) has a strong commitment to inclusive research which enables the voices of people with learning difficulties to be heard. The inclusion of people with learning difficulties in the research process should increase the relevance and usability of the work. Therefore researchers at NFRC worked in

partnership with CHANGE, the leading organisation of people with learning difficulties working on issues with parents. An important aspect of the research methodology was the consultation process with the Parents2Parents group in Walsall.

There were three objectives of this research:

1. To identify and review existing materials aimed at people with learning difficulties to support them in both their parenting role and that of safeguarding their own and other children
2. To provide guidance in relation to ways in which the NSPCC can get its messages across to parents with learning difficulties
3. To provide guidance on ways of making it easier for parents with learning difficulties to seek help

### **Locating easy information relevant to parents for difficulties:**

This study employed multiple methods in an attempt to retrieve as many resources as possible. These included:

- Searching of academic databases (Web of Science, Social Care Online) and then retrieval of relevant academic articles and a follow up of relevant references and any resources cited
- General internet searching including searching via google search engine using relevant search terms and searching via websites of specific organisations, such as the Ann Craft Trust
- Contacting experts in the field with whom we have previously collaborated
- Contacting specialist research groups (IASSID Special Interest Research Group)
- Emailing all members of the *Working Together With Parents Network*
- Emailing via Choice Forum
- Hand search of specialist libraries

### **Evaluation of resources retrieved:**

Establishing criteria by which to gauge the quality and potential use of the resources was a crucial stage of this project. As professional researchers we were aware of information that needed recording such as the format of the resource, price and availability. We had two separate meetings with researchers from CHANGE (including parents with learning difficulties) and with the Parents2Parents Walsall group which is comprised of parents with learning difficulties. We used these findings to develop the checklist of other aspects of the retrieved resources that needed assessing such as usability and attractiveness. The work with them led to the development of a form to summarise information about and to comment upon various aspects of each resource (see Appendix A)

### **Consultation processes:**

A series of consultation exercises was used to address aims 2 and 3 of this project:

- Meeting with the NSPCC

- This session was attended by 4 representatives from the NSPCC, 2 researchers from NFRC, 2 members of the CHANGE team, 5 parents with learning difficulties from Parents2Parents and the Family Mentoring Co-ordinator of the Walsall Parents Advocacy project.
- Consultation with key colleagues nationally
- Possible ways in which the NSPCC can work with parents with learning difficulties were also explored with key partners in the Working Together with Parents Network. This provided the opportunity to consult with members of the National Learning Disability Taskforce and other experts in the field.
- Consultation with other organisations
- An easy read summary of the findings from the initial consultations was sent to WTWPN members and 13 parents groups for their feedback, which has been incorporated in this report.

## **Findings**

### **Scope of the search**

Previous research has demonstrated that there is a paucity of resources designed for parents with learning difficulties and therefore the search was extended beyond the U.K. Obviously there are limits to the extent to which information produced in another country will be useful, however when resources are scarce then all existing resources must be utilised. It was agreed that excluding all resources and research from abroad would limit this review; international collaboration can only serve to benefit researchers, service providers and parents with learning difficulties themselves. When funding is restricted it would be frustrating to see researchers across the world reinventing the wheel.

The concept of safeguarding children is not simple to define as it extends to many areas in life. It can be argued that safeguarding of children begins prior to conception as there are lifestyle factors to consider when planning a pregnancy that can affect the subsequent health of a baby. Clearly during pregnancy there are many ways in which parents can already be safeguarding their children and these will include their own psychological preparation for birth and life with a new-born baby. Most expectant parents choose to arm themselves with information in the belief that such knowledge and preparation will stand them in good stead subsequently. Furthermore a child can be physically safe and healthy but there still be issues to consider such as emotional development.

Therefore, in order to maximise the potential benefits of this review stage the parameters of the search were broadened as much as possible. This not only included lateral thinking around the concept of safeguarding children and what facets of life this extends to, it also meant retrieving resources from as many sources as possible. As there is a paucity of accessible information the search was not limited to information designed directly for parents with learning difficulties but resources for professionals to use in their work supporting parents with learning difficulties were also included. Similarly, resources which were not specifically designed for parents with learning difficulties were also considered in the review, e.g. information aimed at adults with low literacy.

## **What makes good information?**

Previous research projects at NFRC on obtaining accessible information (*Information for All*, Rodgers et al, 2004; *The Road Ahead*, Tarleton, 2004) have provided guidelines about the production of easy to understand information in general. The *Information For All* (Rodgers et al, 2004) guidelines summarise good practice in producing easy information for people with learning difficulties. This guidance provided the baseline for this research. We wanted to consult with parents with learning difficulties around provision of easy information specifically for them. The consultation with CHANGE and Parents2Parents highlighted important aspects of easy information and validated the findings of the previous research, confirming that parents with learning difficulties have the same information needs as other parents. Any comments made that differed to the *Information For All* (Rodgers et al, 2004) guidelines have been noted below. For example the Parents2Parents group liked the laminated, wipeable format of one resource for practical use around the house whereas *Information For All* (Rodgers et al, 2004) recommends the use of matt paper to avoid glare. This is indicative of the type of decision to be taken in relation to each specific resource.

The Parents2Parents group have produced some general guidelines about easy information for parents with learning difficulties on which there was complete consensus (Parents2Parents, 2008). However it was clear from the consultation exercises that some answers to the question “what makes good information?” are subjective. Therefore there were specific issues that individuals disagreed on. For example, some people prefer the use of photos whilst others think that simple drawings are more effective. Where possible a consensus was reached but on some issues reference is made to the differing opinions and guidance included on each. This highlights some of the challenges in developing accessible information. Despite uncovering a range of opinions the consultation exercise provided clear guidance in relation to a number of key aspects in the development of easy information:

- General issues
- Design and layout
- Pictures
- Words
- Format

### **General issues**

- Resources should be produced in response to a demonstrated need
- Information must be up to date
- Information must be accurate
- It should look and sound good
- It should be produced in consultation with people with learning difficulties and targeted at a specific audience
- All the information should be checked with people with learning difficulties as well as with professionals to ensure the information is accessible, accurate and



correct (This could not be verified for the majority of the resources retrieved in this search)

## **Design and layout**

- Should look inviting
- Should be easy to pick up and use
- The layout should be clear and no pages crowded with words or pictures
- Black print on cream or yellow paper is considered to be the easiest format to read. However, this may vary for individuals and therefore the resource should be good enough quality so it can be photocopied onto different coloured paper for people who have problems with reading. For instance some individuals with dyslexia can benefit from specific colours of paper
- Pictures and photos should be used to explain the text
- Large, sans serif font should be used (existing guidelines recommend a minimum size 14 (info for all ref) although CHANGE recommend a minimum of size 16)
- Line spacing should be at least 1.5

## **Pictures**

- Pictures must relate well to the text
- One picture should be used to relate to each important point. There should be consultation of people with learning difficulties to ensure the picture accurately reflects the text
- The pictures must be developed specifically; the same picture should not be used several times to illustrate different points
- Pictures should not contain extra, unnecessary information. Too many details can be confusing
- Pictures should be up to date
- Symbols should be avoided
- Some people prefer photos as they are more life-like whilst others prefer line drawings as they are clear and simple. There is no reason why a mix can't be used
- Some people liked the use of cartoons whilst others felt they have childish connotations
- Some people prefer colour pictures as they are brighter and the colour can help with detail, whilst others think that black and white pictures are clearer
- Pictures should be at the side of the text. *Information For All* (Rodgers et al, 2004) suggested the left hand side in order to give priority to the pictures for non-readers. Our consultations suggested placement side does not matter

## **Words**

- Jargon and acronyms should be avoided

- Vocabulary should be as simple as possible and any difficult words should be explained
- The level of writing should be matched to the needs of the audience
- Each sentence should only express one idea
- Sentences should be as short as possible. *Information For All* (Rodgers et al, 2004) recommends 15 words or less

### **Format considerations**

- Obviously cost is a major issue in determining the type of format to be used when producing a resource. This is crucial as it is important that these resources are genuinely available to parents with learning difficulties and ideally this would be without charge
- Ideally written resources should also be available on an audio CD which can be used in conjunction with the written text and pictures. There could be a sound that denotes when to turn a page. This resource could then used by people who cannot read and also by blind people
- Websites should use audio as well to help people navigate their way even if they have low literacy skills. Some people cannot use, or do not have access to computers, so this should not be the only format a resource is available in
- Websites should have a mixture of pictures and text but the words should be simple and not use any jargon. There should be somewhere to click so the words are read out loud. Websites could have video clips on that people and click to watch. Animation should be used
- Websites could also have information sheets to print off. These should use pictures. It was suggested that this could be in the form of a cartoon strip with each picture representing each step of a task.
- DVDs and videos are good as you can use subtitles easily and this can be useful for people with a hearing impairment
- DVDs/videos should not last more than thirty minutes. If they need to be longer then they should be broken down into smaller sections. It is easier to navigate your way around different sections on a DVD than on a video.
- DVDs/videos can be a better format for teaching tasks. For example film of how to bath or feed a baby might be easier to follow than separate pictures breaking the task down
- Role play could be used on DVDs/videos to show both good and bad ways of completing a task. DVDs/videos should not use actors but they should use people with learning difficulties
- Ideally DVDs/videos would have someone signing alongside, but this is expensive
- DVD can be a good tool to get a message across and to have it to show at conferences so parents do not have to stand up in public and tell a personal and difficult story

- Not everybody has access to a DVD/video player so this should be a consideration
- Books shouldn't be too long as this is off-putting. A series of booklets that can be kept in a folder may be preferable
- Laminated pages are good as they can be kept clean and are practical to use. However *Information For All* (Rodgers et al, 2004) recommends the use of matt paper
- Each individual resource must be looked at and the appropriate format chosen for the group of people it is aimed at
- Ideally all resources would be available in a variety of formats so individuals can choose the most appropriate for their own needs. This would have major financial implications for the development of any resource

The *Information For All* (Rodgers et al, 2004) guidelines also provide some further related recommendations:

### **Design and layout**

- Printed clearly – no italics or underlining
- Should be printed on matt paper

### **Pictures**

- They must be good quality; lines must be bold enough to be seen clearly
- Avoid metaphors as these can be hard to understand, e.g. a light-bulb to represent a new idea

### **Words**

- Repeat the same words instead of using different terms for the same concept
- Avoid metaphors
- Sentences should be written in a positive way
- Do not split words over lines
- Do not let sentences run over to the next page
- Numbers should be written in figures
- Clear headings should be used
- Writing in the form using “I”, “we” and “you” is more friendly and makes it seem relevant to the individual
- It is acceptable to start sentences with “and” or “but”

### **Resources retrieved**

In total 30 resources were retrieved through the search strategy employed. These are all detailed in Tables 1 and 2 in Appendix B. Some of the resources had multiple parts but as denoted in the tables, these are still referred to as a single resource.

The majority of the resources retrieved were aimed at professionals directly or for them to use when working with parents with learning difficulties. There was a paucity of information developed specifically to be given to parents with learning difficulties.

These resources were reviewed in accordance to the criteria developed with CHANGE and Parents2Parents (see Appendix A for form). Although it was deemed important that resources are developed in conjunction with parents with learning difficulties this was not a criteria noted as it was not possible to determine this for the majority of the resources. There were other resources identified that did not meet the criteria of this study yet it was felt they could be a useful source of wider reading and therefore a list of these is included in Appendix C.

## **How good was the existing information?**

### **Topics covered**

The full range of the topics covered by the resources retrieved is shown in Tables 1 and 2 in Appendix B. In summary, there were several resources that addressed sexual health<sup>5</sup>, preparing for pregnancy<sup>4,10</sup>, pregnancy care<sup>6,10</sup>, labour and birth<sup>6,10</sup>. There were also a number of resources that focussed on parenting a new born baby<sup>7,9,10</sup> and covered topics such as feeding, sleeping, bathing, development and behaviour. Similarly there are detailed resources about looking after children up to the age of 5 addressing the same types of topics<sup>8</sup>. There was a lack of information about such topics for older children. Only one resource<sup>15</sup> dealt with child development up until the age of 18.

A lot of the resources retrieved in this search were on the subject of accident prevention, first aid and general safety<sup>1,2,3,12a,13d,14</sup>. The majority of this information seemed to be relevant to younger children although some aspects would be ongoing.

There was some information specifically targeting the emotional needs of children<sup>18</sup> and how a parent can be an active part of the local community<sup>16</sup>. There were a couple of booklets that addressed the rights that parents with learning difficulties have and the support they can expect, especially when a family is going through Child Protection proceedings<sup>26,27</sup>.

Other resources retrieved were not necessarily aimed at parents with learning difficulties specifically but dealt with relevant topics such as looking after your teeth and medication<sup>28,29</sup>.

Resources targeting professionals directly addressed the identification of parents with learning difficulties<sup>24</sup>, ways of assessing these parents<sup>25</sup> and ways in which to support them<sup>22,23</sup>.

### **Usability**

It can be difficult for people to navigate their way through the larger resources; people need to be able to find the applicable section if they are going to continue to use a resource as a reference tool. Various strategies have been employed to facilitate this. *Building Foundations: A Curriculum Guide for Supported Parenting*<sup>23</sup> uses tabs on the right hand side to assist with moving between the 14 sections.

Other resources such as *Healthy Start for me and my Baby*<sup>10</sup> and *The UPS*<sup>17</sup> use different colour sections to relate to the separate topics. The participant scrapbook which is part of the *Me and my Community*<sup>16</sup> training pack is ring-bound which means it opens flat making it much easier for the mothers to work in it. CHANGES's *You and your little Child*<sup>8</sup> is an excellent example of a usable resource despite its length. At over 500 pages it is necessary that an individual can find the section they need easily. They have enabled this by using a combination of colour coded sections and a tab system to separate the sections. Furthermore the ring-binding ensures the book stays open at the desired page and permits the book to be separated and the sections to be used individually. Each of the 7 sections has its own contents. This is an improvement on the earlier *You and your Baby*<sup>7</sup> resource from CHANGE which is also long and the Parents2Parents group felt that the length limited the usability and that it would be easier to use if clearly separated into sections.

Some of the resources use puzzles and quizzes in order to aid engagement with the resource<sup>10,30</sup> although these may only be suitable for those with higher literacy levels.

It can be useful when the resource uses ticks and crosses to help indicate if the picture is showing something that you should/should not be doing. Some of the resources use happy/sad faces<sup>1-3</sup> or ticks/crosses<sup>12a,12c</sup>, in their pictures to make the resources easier to use for parents with learning difficulties. Similarly the *Surestart* leaflet<sup>11</sup> uses a traffic light system to denote the different states a baby can be in: green for go; amber for caution; red for stop. Such methods can make it easier to understand and use a resource. *The UPS*<sup>17</sup> uses pictorial symbols by each item so it can be noted if this skill is: no concern; rarely a concern; sometimes a concern; a big concern. This provides a simple method to identify areas in which training and skill development are needed.

The *Skills Cards*<sup>12a-d</sup> are an example of a practical, easy to use resource as they are covered in a plastic film which makes them durable and also allows them to be written on. Similarly *You and your little child*<sup>8</sup> contains wipeable recipe cards and also star charts which can be used. Such innovative ideas can help to ensure that the parents actually use the resource and get direct benefits from it.

## **Attractiveness**

The attractiveness of the individual resources related to features such as spacing and the use of pictures and colour. Generally the resources reviewed used colour and pictures well to ensure attractiveness. *The UPS*<sup>17</sup> was one resource where the focus was on the pictures rather than the text and the majority of these were large, colourful photographs. One resource was designed with space on the coloured front cover of the booklets for the parents to personalise<sup>14</sup>.

## **Font size**

*Information For All* (Rodgers et al, 2004) guidance recommends that font should be of a sans serif style and of a minimum of size 14 (info for all ref) although CHANGE prefer a minimum of size 16. The vast majority of resources aimed directly at parents with learning difficulties did meet this criterion. Some occasionally used smaller font in pictures or in summaries. Electronic worksheets on CD-ROMs did not always use large font but this could easily be altered before printing the worksheets. There was one resource<sup>15</sup> designed for professionals to work through with the parent which

provides leaflets to look at together and the print was often only size 9 font, which many parents would find too small.

### **Pictures used (type, amount, appropriateness)**

All the resources retrieved that were aimed directly at parents with learning difficulties had some pictures in. Some of these seemed to use occasional pictures to brighten up the resource rather than using the pictures to illustrate the point being made in the written text. Some of resources also used pictures which contain a lot of words within them, which is not ideal as the pictures are generally to aid those with low literacy skills. There were resources which did not include any pictures but these were aimed at professionals.

There were examples of resources that used detailed, specifically commissioned pictures to relate to each section of text<sup>7,8,9,12,13</sup>. Although in these resources the pictures still do not provide as much information as the text does, they are functional pictures which do add to the value and usability of the resource.

As mentioned in the usability section, the use of ticks and crosses can help to make the pictures clearer. Examples of this include the Skills cards<sup>12a,12c</sup> and the CHANGE resources<sup>7,8</sup>. There were three leaflets produced by the Child Accident Prevention Trust<sup>1-3</sup> which were aimed at adults with low literacy. In these, for every point made in each leaflet there was a picture of a sad face by a picture showing how children get hurt and a happy face by the picture showing the safe way to do something. If pictures are not used carefully then they can increase confusion. For example we found one instance<sup>28</sup> where one page lists the different types of medications (e.g. tablets, capsules, liquid etc.) and there are pictures but these are not in the correct order and do not all relate to the items listed.

### **Easy read**

The resources designed to be used directly with parents with learning difficulties were generally written in an accessible way. Sentences were usually kept short and made a single point in line with the guidance from *Information For All* (Rodgers et al, 2004) which recommends a maximum of 15 words per sentence. There were some occasions where the sentences were longer than ideal, e.g. 38 words<sup>27</sup>. Some of the subjects dealt with require a degree of jargon or technical terms; the *Court and your Child*<sup>27</sup> book used legal terminology at times but if this was necessary the term was clearly explained. Another good example is the *Healthy Start for me and my Baby*<sup>10</sup> resource which used simple language, short sentences and also explained any more difficult words. *The Health and Wellness Program: A Parenting Curriculum for Families at Risk*<sup>14</sup> is designed for service providers working with vulnerable parents. The CD-ROM contains 18 booklets to be printed off for use. Some of the language in these booklets is unnecessarily complicated (e.g. tangible, anticipate) but one of the booklets is a dictionary of words relating to health and safety. This could be a useful addition to some other resources; the dictionary spells the word out phonetically and gives an example of how the word is used in context. This increases the usability of the other booklets.

The *Skills Cards*<sup>12</sup> were the only resource reviewed which specified the reading ability necessary to use the cards. They have been designed so that a parent who has a reading age of 9 or above should be able to follow the written instructions. Guidance such as this could be useful when professionals are gauging if a resource

will be of use to an individual. The consultation process in this study raised the issue of involving speech therapists in the making of easy information as 90% people with learning difficulties have a communication impairment and materials must be provided at the appropriate level for that individual (personal communication from Speech and Language Therapist from the Working Together with Parents Network).

In total 4 resources were included in the review which were produced by mainstream organisations, as opposed to Learning Disability organisations<sup>1,2,3,11</sup>. The series of leaflets developed by the Child Accident Prevention Trust used minimal text, simple vocabulary and short sentences<sup>1,2,3</sup>. The Surestart leaflet<sup>11</sup> was also written using simple language so it was deemed to be fairly accessible but this is limited by the fact there are some quite long sections of text within it.

Eight of the resources were from the U.S.A.<sup>14,18,20,21,22,23,24</sup> or Canada<sup>9</sup>, and there are issues here of different terminology such as the use of “diaper” instead of “nappy” and also alternative spellings. Such factors need to be considered by professionals when they are deciding upon the appropriateness of a resource for an individual. It is worth noting that the *Nurturing Parenting Easy Reader Handbook*<sup>18</sup> is also available in Spanish and Arabic. This was the only example of a resource available in more than one language.

Consultation on this project and existing guidance has identified the need to keep concepts “concrete” as abstract ideas can be difficult to grasp. Generally the resources reviewed were good at this although the *Nurturing Parenting Easy Reader Handbook*<sup>18</sup> did use some metaphors that may be difficult for parents to understand.

## **Format**

The vast majority of resources retrieved in this search were in a written format. This included books and leaflets. Some of these were accompanied by a CD-ROM or a DVD, however CHANGE is the only organisation that has produced a resource that was available either in a written format or on an audio tape<sup>7,8</sup>. No DVDs/videos aimed directly at parents with learning difficulties were identified although there were some video/DVD resources aimed at professionals<sup>21,24</sup>.

There were 2 resource packs retrieved in the search<sup>15,16</sup>. The *Family Matters Toolkit*<sup>15</sup>, was still in development and included A3 laminated worksheets to use with the parent to explore significant events in their lives and to establish their personal goals and the type of support they would find helpful. The pack also includes a set of developmental booklets which cover children from the age of 1-18 and they address topics such as: stimulation; safety; basic care; communication; emotional warmth; education; health and safety. Additionally there is an “abuse tool” which includes a booklet and sets of cards to use when working through this topic. There are also leaflets on communication, housing, budgeting, healthy lifestyles and advocacy. The other training programme retrieved (*Me and My Community*<sup>16</sup>) was developed in Australia and was based upon research and practice from Sheffield. This resource has three books:

1. Key readings (for professionals)
2. Participant scrapbook
3. Facilitator’s guide

The programme is designed to last for approximately three months and aims to assist mothers with learning difficulties to identify their own learning needs and aspirations, and to help them create learning opportunities and connect with resources available in their local communities. It is a flexible programme and it combines group-work with individual advocacy and support.

The only assessment resource retrieved is the Parent Assessment Manual (2.0)<sup>25</sup> which is a pack comprising: instruction book, CD-ROM, parent booklet and a set of cartoons. This is essentially a PC software CD-ROM application which includes clinical assessment forms, worksheets, graphical parent summary and profiles. There are 94 worksheets to be used by professionals during clinical assessments, which can also be printed if necessary. Error checking is automatically undertaken for all the inputted data. The assessor is required to make judgements about whether a parent's ability is good/adequate/poor in relation to different tasks. A wide range of skills are assessed and these relate to children at all different ages. Guidelines and example answers are provided to aid these judgements. The PAM aims to generate a clear, visual family profile of functioning that targets parenting support needs as well as child protection issues.

BILD have produced a series of skills cards<sup>12</sup> (currently unavailable) which are a series of A4 laminated cards. They are durable and can be written on with a washable pen making them very practical for use and it allows individualised information to be recorded on them. They can be stuck to walls and if relevant they can be used in the bathroom or kitchen as they will not be damaged if they get wet. The Parents2Parents group likes this format and thought that being able to write on the sheets was an excellent way to personalise the resource.

### **Overall length**

There was huge variation in the length of the different resources. Obviously if resources are following other recommendations such as using plenty of pictures, spacing information out appropriately and using large font then the length of the resource will increase. The Parents2Parents group stipulated they did not think that books for parents with learning difficulties should be too long as this can be off-putting. Therefore consideration needs to be given to the balance of these factors when designing a resource. The shortest resource reviewed was *Looking After Your Teeth*<sup>29</sup> at 8 pages whereas the *You and Your Little Child*<sup>8</sup> book is over 500 pages, however it is a comprehensive resource and deals with a large range of topics. It is also in clearly marked sections and is in a ring-binder so it is possible to use a small number of pages at one time if the overall length is overwhelming for an individual.

### **Summary of accessibility of resources retrieved**

Overall there was a good variety of topics covered in varying levels of detail but primarily the focus was on younger children. It was evident that most of the resources retrieved have clearly been developed with reference to the needs of the people they are targeting, even if there are still ways in which they can be improved. There was not a great variety in the format type; the vast majority are still written. Even though there was good use of pictures to support the written text, this may not be the best medium for educating parents with learning difficulties. Despite the fact that most resources were in a written format there were some innovative ideas used



in their development, such as the laminated skills cards, wipe-clean recipe sheets, star charts and other ways of personalising the resources. There was also good use of fun activities in order to engage the parents, including the use of games and puzzles. The Circles Family Toolkit<sup>15</sup> had some inventive ways of working with parents to ascertain their goals. It is important though to ensure that the use of fun activities to aid the work does not result in the resource appearing childish. There is a need for clear spacing, large font and the inclusion of pictures, all of which will make the resource longer. When any resource is being developed there needs to be some consideration given the balance between length and usability as parents have reported that it can be off-putting if a resource is too long.

We searched websites and also contacted relevant mainstream organisations such as The Royal Society for the Prevention of Accidents to ascertain if they have easy-read material. The only mainstream organisation we identified that produced a resource specifically aimed at people with low literacy skills was the Child Accident Prevention Trust<sup>1,2,3</sup>. However professionals did make recommendations of some mainstream materials that might be useful as they were written fairly simply. These were the SureStart leaflet<sup>11</sup> and the Department of Health *Skills For Life Programme*<sup>30</sup>.

This review demonstrated that many of the resources from abroad would also be useful for parents in the U.K. although some changes would need to be made. For example, resources from the U.S.A. use terminology that many people in the U.K. would find unacceptable such as “mental retardation”. Furthermore many of these resources give information such as a phone number to be called in an emergency and again this would be inaccurate for people in another country.

It is crucial that any resources that are produced will need to be regularly revised as many provide contact information which may change. It was clear in some of the resources that there were details which would need updating for the information to be of use to parents now.

### **Information required by parents with learning difficulties**

Information about having and looking after a small baby was regarded as vitally important by the Parents2Parents group and a book on this topic had been produced by the parents experts at CHANGE. This information relating to babies and young children should include:

- Bathing a baby
- Feeding a baby; breast/bottle/weaning
- Changing a baby
- Holding a baby safely
- Playing with a baby/child – safe touching
- Basic first aid relating to a young baby, e.g. choking
- Safe behaviour around a baby and hazards– no smoking etc. locked cupboards, no access to medicines/razors etc. socket covers, stair gate

- Suitable clothing and how often to change. Suntan lotion etc. What do you need to take with you when you go out?

The two most relevant resources, *You and Your Baby*<sup>7</sup> and the Skills for Life Cards/Booklets<sup>12,13</sup> covered the above topics and other pertinent information in detail. These resources are well thought out, detailed and developed through consultation with both parents and professionals. The skills cards<sup>12</sup> are also laminated for use around the home and to enable parents to record details such as how many scoops of baby milk they need to use. These leaflets<sup>13</sup> and skills<sup>12</sup> cards are currently out of print but would be useful resources to parents if they were updated and re-issued.

In addition, the Parent2Parents group and the parent information experts at CHANGE stressed that a wide range of information on every aspect of childrearing should be available to parents. This information should clearly relate to the different stages of childhood. This information should include:

- Discipline and behaviour
- Communication
- Gaining independence whilst maintaining safety, e.g. safe places to play. What age can children do what?
- Who is it ok to leave your children with and at what age?
- Road safety
- Looking after them when ill
- Hygiene, cleanliness and nits
- Bedtime advice all the way through
- How to cook and a good diet
- How to use the computer safely
- Advice on stranger danger
- Activities for growing children/teenagers. How do you encourage more exercise and less television?
- Bullying and how to protect your child from exclusion
- Adolescent mood swings and how to handle these
- Emotional issues
- Sex education: sexual health and contraception
- Drug use
- Peer pressures
- Eating disorders
- How to support your child in their relationships
- How to handle development – tantrums, discipline etc. Boundaries etc.

Specifically in relation to school

- Choosing and attending nursery/school – which school or nursery is best
- What do they need to take? Change of clothes at nursery etc.
- Information to help them understand school processes and systems
- How to monitor and support their child's progress at school
- How to provide support with their child's homework when they develop beyond the parent's academic ability
- Exam stress

It was also recognised that letters from school should be sent home in an accessible format.

*You and Your Little Child*<sup>8</sup> covers the majority of issues including child protection for parents of children from 1-5 years of age. However, there is very little easy information relevant to children above the age of 5. Some resources touch briefly on issues relating to older children such as the *Nurturing Parenting Easy Reader Handbook*<sup>18</sup> which gives examples of how to confront problems with adolescents in a constructive, respectful manner rather than simply being critical. However the only resource to clearly target children at different ages is the Circles Family toolkit<sup>15</sup>. This toolkit for professionals to use with disabled parents provides detailed developmental booklets on the different stages of childhood 1-3, 3-5, 5-10, 10-13 and 13- 18. Parents with learning difficulties may need support to access this information because although the activities and booklets have vibrant illustrations and the text is written quite simply, there is a lot of information presented in rather small dense text.

Section 2 provides a discussion of the ways in which existing NSPCC resources could be adapted for parents with learning difficulties.

## References

---

- Baum, S. and Baums, J. (2007). Mothers with learning disabilities: Experiences and meanings of losing custody of their children. *Learning Disability Review*, 12(3), 3-14
- Booth, W. and Booth, T. (2004). A family at risk: multiple perspectives on parenting and child protection. *British Journal of Learning Disabilities*, 32(1), March 2004, pp.9-15
- Booth, T. and Booth, W. (2005). Parents with learning difficulties in the child protection system: experiences and perspectives. *Journal of Intellectual Disabilities*, 9(2), 109-129
- Booth, T., Booth, W. & McConnell, D. (2005). The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 7-17
- Booth, T., McConnell, D. and Booth, W. (2006). Temporal discrimination and parents with learning difficulties in the child protection system. *British Journal of Social Work*, 36(6), 997-1015
- CHANGE (2007). *Supporting parents with learning disabilities – Good Practice Guidance* (easy read version)  
<http://valuingpeople.gov.uk/dynamic/valuingpeople2.jsp>
- Cleaver, H. & Nicholson, D. (2007). *Parental Learning disability and Children's Needs*. London: Jessica Kingsley
- Department of Health (2001). *Valuing people: a new strategy for learning disability in the 21<sup>st</sup> century: a White Paper*. London, The Stationery Office.
- Department of Health (2002). *Fair Access to Care Services: Practice Guidance*. London: Department of Health.
- Department of Health (2007). *Valuing People Now: From Progress to transformation*. London: Department of Health.
- Disability Discrimination Act (2005). London: The Stationery Office.
- Elvish, J., Hames, A., English, S. & Wills, C. (2006). Parents with learning disabilities: an audit of referrals made to a learning disability team. *Learning Disability Review*, 11(2), 26-33
- Guinea, S.M. (2001). Parents with a learning disability and their views on support received: a preliminary study. *Journal of Learning Disabilities*, 5(1), 43-56
- HM Government (2006) *Working Together to Safeguard Children: A Guide to Inter-agency Working to Safeguard and Promote the Welfare of Children*. London: The Stationary Office
- James, H. (2004). Promoting effective working with parents with learning disabilities. *Child Abuse Review*, 13(1), 31-41

- Llewellyn, G., McConnell, D. & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse and Neglect*, 27, 235-151
- McGaw, S. & Newman, T. (2005). *What works for parents with learning disabilities?* Ilford: Barnardo's.
- Morgan, P. & Goff, A. (2004). *Learning Curves. The assessment of parents with a learning disability: a manual for practitioners*. Norwich: Norfolk Area Child Protection Committee
- Morris, J. (2007). *Good practice guidance on working with parents with a learning disability*. London, Department of Health/Department for Education and Skills
- O'Hara, J. & Martin, H. (2003). Parents with learning disabilities: a study of gender and cultural perspectives in East London. *British Journal of Learning Disabilities*, 31(1), 18-24
- Rodgers, J., Townsley, R., Folkes, L., Tarleton, B., Mears, C., Levy, G., Waite, L., Namaganda, S., Jones, J. and Thurman, S. (2004) *Information for All: evidence based guidance on producing accessible information for people with learning disabilities*. Available: [www.easyinfo.org.uk/dynamic/easyinfo7.jsp](http://www.easyinfo.org.uk/dynamic/easyinfo7.jsp) [28th November 2008].
- Tarleton, B. (2004) *The Road Ahead – Information for young people with learning difficulties, their families and supporters at transition*. London: Social Care Institute for Excellence. Available: [www.scie.org.uk/publications/tra](http://www.scie.org.uk/publications/tra) [28th November 2008]
- Tarleton, B., Ward, L. & Howarth, J. (2006). *Finding the right support. A review of issues and positive practice in supporting parents with learning difficulties and their children*. London: Baring Foundation
- The Stationary Office (2003). *Every Child Matters*. London: The Stationary Office [www.everychildmatters.gov.uk/aims/](http://www.everychildmatters.gov.uk/aims/) [28th November 2008].
- Ward, L. (2007). Supporting parents with learning disabilities and their children. *Community Care Inform*
- Wates, M. (2003). *It shouldn't be down to luck: results of a DPN consultation with disabled parents on access to information and services to support parenting; summary*, Disabled Parents Network.
- Williams, V., Marriott, A. and Townsley, R. (in press) *Shaping our future: a scoping and consultation exercise to establish research priorities in learning disabilities for the next ten years* (Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation)
- Young, S. & T. Hawkins (2006). Special parenting and the combined skills model. *Journal of Applied Research in Intellectual Disabilities*, 19(4), 346-355

## Appendix B

### Resources

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p><b>1. I'm only a baby but...</b> A baby introduces the accidents that babies are most likely to be hurt in during the first few months of life and explains what parents need to do to keep their baby safe. They use pictures of a sad face to show how babies can get hurt and a happy face to show the things that keep them safe.</p>	<p>Falls Fire Burns Getting into trouble Car safety</p>	Leaflet	Practitioners working with parents	<p>From the Child Accident Prevention Trust: <a href="http://www.capt.org.uk">www.capt.org.uk</a> Free downloadable sample copy. £35 for 50 leaflets</p>
<p><b>2. Now I can crawl, I can...</b> This picture-based guide looks through a baby's eyes at the changing hazards they may face in the home and car now they can crawl or stand. Simple precautions a parent should take are set out using accessible language and pictures.</p>	<p>Falls Fire Burns Getting into trouble Car safety</p>	Leaflet	Practitioners working with parents	<p>From the Child Accident Prevention Trust: <a href="http://www.capt.org.uk">www.capt.org.uk</a> Free downloadable sample copy. £35 for 50 leaflets</p>
<p><b>3. It's fun to go out but...</b> This picture-based guide is written from the point of view of children and gives advice on keeping them safe as pedestrians or in the car.</p>	<p>Out and about: running into the road crossing the road out in the dark Riding in the car: strapping us in</p>	Leaflet	Practitioners working with parents	<p>From the Child Accident Prevention Trust: <a href="http://www.capt.org.uk">www.capt.org.uk</a> Free downloadable sample copy. £35 for 50 leaflets</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p><b>4. Planning a baby</b>  This book acknowledges that planning a baby is a big decision but it starts at this point. It then covers in detail:  How to prepare for getting pregnant – this includes information on stopping contraception; rubella; inherited conditions; sexual health; medicines; smoking; diet; folic acid; what the male needs to do  How you get pregnant – this section gives a simple but fairly detailed description of: ovulation; fertilisation; after fertilisation  How you can have a better chance of getting pregnant – information on: how to find out when you are ovulating; other factors that affect the chance of conceiving; where to go for advice.</p>	<p>getting us out  How to prepare for getting pregnant  How you get pregnant  How you can have a better chance of getting pregnant</p>	<p>Book or audio tape</p>	<p>Parents with learning difficulties</p>	<p>From CHANGE: <a href="http://www.changepeople.co.uk">www.changepeople.co.uk</a>  £4 (inc P&amp;P) for book  £3 (inc P&amp;P) for audio tape</p>
<p><b>5. Sex</b>  This book provides explicit information about the topics it covers. It briefly describes physical changes during pregnancy and then gives advice about hygiene, periods and smear tests. Some of the language used is</p>	<p>Puberty  Hygiene  Periods  Smear tests  Sex, oral sex and masturbation  Safe sexual health</p>	<p>Book</p>	<p>People with learning difficulties</p>	<p>From BILD: <a href="http://www.bild.org.uk">www.bild.org.uk</a>  £8 (plus 10% P&amp;P)  ISBN: 1-873791-47-X</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>quite complicated, although most difficult words are explained. There are also detailed, explicit pictures accompanying the text. It emphasises that heterosexual and homosexual sex is ok as long as both people want to have sex. It talks about masturbation, sex and oral sex. It lists sexually transmitted diseases and advises men to use a condom and gives further information about where to get these and how to use them. It then deals with sexual abuse and rape. Finally it explains how men and women should examine their bodies regularly to stay healthy. There are also contact phone numbers for relevant organisations.</p>	<p>Condoms Sexual abuse Staying healthy Useful telephone numbers</p>			
<p><b>6. Pregnancy and childbirth</b> This book provides quite detailed information to pregnant women about what to expect from pregnancy and the birth. It gives advice on keeping healthy during pregnancy, covering topics such as smoking, medication and diet. It describes some of the ways that being pregnant may make you feel – physically and emotionally. It describes things that will happen during pregnancy such as antenatal</p>	<p>Keeping healthy How you may feel While you are pregnant Having your baby in hospital When your baby is born The birth After the birth Going home</p>	<p>Book</p>	<p>People with learning difficulties</p>	<p>From BILD: <a href="http://www.bild.org.uk">www.bild.org.uk</a> £8 (plus 10% P&amp;P) ISBN: 1-902519-88-4</p>



Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>classes and scans. It focuses on having a baby in hospital and suggests a list of things that might be needed. It then gives advice on what to expect during labour and the birth and about going home from the hospital.</p>				
<p><b>7. You and your baby (0-1)</b>  This is a large book that covers many topics in detail. It gives practical and detailed advice on topics such as handling, feeding and bathing your baby. It also provides reassurance to parents and advice on what to expect. Information is given relating to developmental stages and there is practical information relating to people and organisations that can provide further advice or support. The end of the book contains a "word bank" and there is also a list of useful contacts.</p>	<p>New babies  Loving your baby  Feeding  Growing  Keeping your baby safe and well  You, your family and your friends  People who help  Useful resources</p>	<p>Book or audio tape.  CD-ROM available of the picture bank used in the book for others to use when developing information.</p>	<p>Parents with learning difficulties</p>	<p>From CHANGE:  <a href="http://www.changepeople.co.uk">www.changepeople.co.uk</a>  £36 (inc P&amp;P) for book  £7 (inc P&amp;P) for audio tape    CD-ROM picture bank from £200 (dependent upon number of users)</p>
<p><b>8. You and your little child (1-5)</b>  This is a large book that covers many topics in detail. It is a ring-bound book, so the individually colour-coded chapters can be separated. Throughout there are detailed pictures that relate well to the text. The topics</p>	<p>Parenting skills  Routines  Play and learn  Food  Safety  Health  Abuse</p>	<p>Book.  CD-ROM available of the picture bank used in the book for others to use</p>	<p>Parents with learning difficulties</p>	<p>From CHANGE:  <a href="http://www.changepeople.co.uk">www.changepeople.co.uk</a>  £38 (plus £8.50 P&amp;P) for book    CD-ROM picture bank from £325 (dependent upon number of users)</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>are dealt with comprehensively and the book gives advice on simple behavioural modification techniques, such as "Time out" and includes wipeable star charts. There are suggestions for indoor and outdoor activities. The "Food" section includes advice on encouraging children to eat well and then there are eight wipeable recipes. The end of the book contains a "word bank" and there is also a list of useful contacts.</p>		<p>when developing information.</p>		
<p><b>9. Step by Step Child Care: A Manual for Parents and Child-Care Providers</b>  This resource can be used to assess the child care skills of parents in order to determine training needs. Over the next few visits the parents are encouraged to use the self-instructional training. If performance does not improve then more intensive training should be provided. There are a number of checklists which detail the steps needed to carry out particular skills. These are scored in accordance to the level of prompt needed: no prompt; verbal prompt; modelled prompt; physical prompt.</p>	<p>Newborn Care  Feeding  Diapering  Bathing  Cribs and Bedtime  Safety and First Aid prevention treatment  Miscellaneous (e.g. teething, toilet training, cleanliness)  Additional Information</p>	<p>Book</p>	<p>For professionals to use when assessing and training parents with learning difficulties</p>	<p>Available from Maurice Feldman:  Dr Maurice Feldman,  Director, Centre for Applied Disability Studies  Dept. of Child and Youth Studies  Brock University  500 Glenridge Ave.  St. Catharines, Ontario,  Canada L2S 3A1  Tel (905) 688-5550, ext. 3785  Fax (905) 641-2509  Email: mfeldman@brocku.ca</p> <p>Cost \$70 (U.S. dollars) including P&amp;P</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>The checklist can be converted into a percentage score and it is recommended that skills should be performed at a minimum of 80% correct. There are step-by-step black and white line drawings that are accompanied by some text to reflect the different stages for the skills.</p>				
<p><b>10. Healthy start for me and my baby</b>  This book forms part of the <i>Healthy Start for me and my baby</i> programme run by midwives and other pregnancy care workers. There is an individual booklet to be used by pregnant women with learning difficulties, in consultation with their health practitioners, at home and/or clinic. It was developed to promote informed choice and participation in health care, and facilitate more effective consultations between pregnant women with learning difficulties and their health care providers. The book covers the different stages of pregnancy and what to expect and combines this with advice around exercise, healthy eating etc. It is an interactive book with space to write in</p>	<p>Changes in you and your baby  Pregnancy care  Caring for you and your baby  Things that can make you and your baby sick  Labour and birth  Going home  My pregnancy visits  Emergency information</p>	<p>Book and blank audio tape</p>	<p>Parents with learning difficulties</p>	<p>From Australian Supported Parenting Consortium  <a href="http://www.healthystart.net.au">www.healthystart.net.au</a>  Ordering process is being finalised. Please see website for latest details.</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>answers and to complete exercises and record changes etc. There are also checklists for various aspects, such as suggestions of what you might need to take to hospital. Each chapter ends with suggested questions for midwife in relation to that topic area and a related word search puzzle. The chapters are in individual colour coded sections and the resource is easy to use as well as being bright and colourful.</p> <p>Some references are specific to Australia and would need to be changed for use in the U.K.</p>				
<p><b>11. Understanding your baby</b>  This is not a resource designed for parents with learning difficulties. It gives useful tips for how parents can interact with their baby and for activities to try. It uses a traffic light system to explain the different "states" a baby can be in and what this means:  Green for go – the baby wants to interact  Amber for caution – the baby is likely to need a change from what is happening</p>	<p>Social behaviour  Understanding baby's communication  Different baby states  Rousing and soothing  Crying babies  How to help your baby sleep</p>	<p>Booklet</p>	<p>This is a mainstream resource aimed at families with new babies.</p>	<p>All parents in Leeds receive one and it is being used a part of the Family Nurse Partnership Project (a national DH project in 10 areas). It is hoped it will be more widely available soon.</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>Red for stop – the baby is distressed Overall, for a resource not aimed at people with learning difficulties, it is very useable. Colour photos brighten it up and there is also good use of different coloured backgrounds (reflecting the traffic light coding) throughout the booklet. It is written in simple language and generally the sentences are quite short so it is fairly accessible. Larger font and bigger spacing would make it more accessible to people with learning difficulties.</p>				
<p><b>12. I want to be a good parent (Skills cards)</b> <b>Children need to be safe</b> <b>Clean, healthy and warm</b> <b>Healthy food</b> <b>What is love?</b> These are sets of A4 skills cards. Each card provides pictorial instruction on a basic parenting skill alongside simple written instructions. The cards are designed to provide prompts to enable parents to follow sequences and subtasks of a specific skill. Overall this resource provides detailed information relating to a wide range of areas in an accessible way. The cards</p>	<p>Titles in the series: Children need to be safe Clean, healthy and warm Healthy food What is love?  See each individual resource for topic areas.</p>	<p>Plastic covered, durable A4 cards, which can be written on using a washable pen. This allows individualised notes to be made and means they are made to be used around the house, e.g.</p>	<p>For professionals to use when working with parents with learning difficulties</p>	<p>These were produced by BILD. Currently unavailable.</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>have been designed so that a parent who has a reading age of 9 years or above should be able to follow the written instructions.</p>		<p>they will not get damaged if they get wet.</p>		
<p><b>12a. I want to be a good parent: children need to be safe</b>  Many of the cards use ticks and crosses to indicate good and bad practice. They cover in detail many aspects of each topic area and provide advice on how to react to accidents as well as giving further information about accident prevention. These have a key with symbols relating to children of different ages: 0-2 years; 2-5 years; 5+ years and then these symbols are used to show which age groups each specific card relates to.</p>	<p>Fire  Burns/scalds  Electric shocks  Choking  Falls  Poisons  Sharp objects  Drowning  Safety in the home  Safety outside the home  Road safety  Stranger danger  Abuse/neglect  Preventing accidents</p>	<p>As above</p>	<p>As above</p>	<p>As above</p>
<p><b>12b. I want to be a good parent: clean, healthy and warm</b>  The cards break down activities, such as washing boys' bottoms, into simple steps and also provide a visual checklist of what equipment you need for the activity. Although they provide a high level of detail, this is done in an accessible way. There is a checklist</p>	<p>Clean bodies  Clean home  Healthy  Warm home  Warm in winter  Cool in summer</p>	<p>As above</p>	<p>As above</p>	<p>As above  ISBN: 1-902519-42-6</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
provided for developmental checks and vaccinations. Each card in this set has written at the top what age child it relates to.				
<p><b>12c. I want to be a good parent: healthy food</b></p> <p>This set of cards covers many areas around a healthy diet. The information is clearly broken down into a large number of simple steps. There is also space on the cards for the parents to write down figures relating to making up formula, e.g. ratio of scoops to water. This ensures this is of practical help in an ongoing way. The cards clearly state (using words, pictures and ticks/crosses) what food children have at what ages.</p>	<p>Food groups Cooking methods Getting ready – pregnancy Feeding Weaning Eating Meal times Medicine Food storage</p>	As above	As above	As above ISBN: 1092519-12-4
<p><b>12d. I want to be a good parent: what is love</b></p> <p>These cards give advice to parents about preparing for the birth and what support you may need. They give information around developmental stages and what to expect at specific ages and what sort of stimulation is suitable. The top of each card states what age group the information is</p>	<p>Getting ready for baby Responding to baby Being available Providing stimulation Supporting and teaching Encouraging independence</p>	As above	As above	As above ISBN: 1-902519-43-4

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>applicable to. An accessible, detailed resource addressing the emotional development and needs of children.</p>				
<p><b>13. I want to be a good parent (booklets)</b>  <b>What's it like to be a parent?</b>  <b>Children need healthy food</b>  <b>Children need to be clean, healthy and warm</b>  <b>Children need to be safe</b>  <b>Children need love</b>  This series of booklets provides information about the different areas and some include exercises to informally assess the parents' knowledge of these areas, e.g. pictures where you need to spot the dangers.  Detailed and colourful pictures are used to illustrate the written text.</p>	<p>Titles in the series:  What's it like to be a parent?  Children need healthy food  Children need to be clean, healthy and warm  Children need to be safe  Children need love</p>	<p>Booklet  Some of these booklets are ring-bound at the top and can be hung up on the wall.</p>	<p>For professionals to use when working with parents with learning difficulties</p>	<p>These were produced by BILD.  Currently unavailable.</p>
<p><b>13a. I want to be a good parent: What's it like to be a parent?</b>  This introductory booklet provides an overview to the series, which cover areas central to children's needs.</p>	<p>What's it like to be a parent?  Children's needs  Children need healthy food  Children need to be</p>	<p>Booklet</p>	<p>As above</p>	<p>As above  ISBN: 1-873791-36-4</p>



Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
	clean, healthy and warm Children need to be safe Children need to learn Children need love Children need to learn right from wrong How parents cope			
<b>13b. I want to be a good parent: Children need healthy food</b> There is fairly detailed information about breast and bottle feeding and the weaning. Ticks and crosses are used with pictures and text to show which foods to try and which food to avoid at the different ages.	0-3 months – breast or bottle feeding Weaning Foods for 4 months old Foods for 6-8 months Foods for 9-12 months Foods for 12 months- 2 years Foods for children 2 years and over	Booklet	As above	As above ISBN: 1-873791-41-0
<b>13c. I want to be a good parent: Children need to be clean, healthy and warm</b> This booklet explains why it is important to keep children and their homes clean and addresses the issues to be aware of.	Clean, healthy bodies Health check-ups Clothes Clean and warm house	Booklet	As above	As above ISBN: 1-873791-46-4
<b>13d. I want to be a good parent:</b>	Burns, scalds, fires	Booklet	As above	As above

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p><b>Children need to be safe</b> This offers advice on accident prevention and how to make the home a safer place. There is also some information about responding to an emergency. There are recommendations for further resources.</p>	<p>Kitchens/bathrooms Choking, falls, cuts, poisons Fire, electricity, gas Roads and cars Accidents and emergencies</p>			<p>ISBN: 1-873791-51-8</p>
<p><b>13e. I want to be a good parent: Children need love</b> This booklet looks at the relationship between children's happiness and their behaviour. It discusses how parents can make their children feel loved.</p>	<p>Children need love Love and teaching Teaching right from wrong Understanding behaviour Managing behaviour</p>	<p>Booklet</p>	<p>As above</p>	<p>As above</p>
<p><b>14. The Health and Wellness Program: A Parenting Curriculum for Families at Risk</b> The programme is designed to run over approximately 30 sessions. It covers topics such as identifying illness and symptoms and how to respond to these appropriately, e.g. when to call the doctor, giving medication. There is also a lot about general safety, hazards in the home and how to prevent accidents. All topics are covered very thoroughly.</p>	<p>The program consists of 4 components: Fundamental knowledge and skills for parents Understanding child development Health education: infant and child health care and well-being Home safety</p>	<p>Book and CD-ROM The CD-ROM contains 18 booklets to be printed off for use</p>	<p>This resource is designed to enable professionals to deliver a validated, structured programme to be used when working with families at risk.</p>	<p>Brookes Publishers Link<sup>a</sup> ISBN: 1-55766-817-5 Cost: \$69.95 plus P&amp;P</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>There are booklets on the CD-ROM to be used within the programme and instructor manuals including quizzes assessing knowledge of child development and safety to use. The book offers clear guidance as to which resources are needed for each session and there are worksheets and other resources to leave with the family each week. There are also assessments to be used such as reading recognition scales in the first session.</p>				
<p>a: <a href="http://www.brookespublishing.com/store/books/tymchuk-8175/index.htm">http://www.brookespublishing.com/store/books/tymchuk-8175/index.htm</a></p>				
<p><b>15. Family Matters: Circles Network Toolkit</b>  This training resource has many different features. There are 10 A3 laminated sheets which people can write or draw on to fill in personal information. These are to be used by the professional as the first stage in engaging with an individual. They address such topics as “who am I?” and “my gifts” as well as a weekly and a daily planner.  They are colourful and accessible and</p>	<p>Parent’s background  Abuse  Advocacy  Budgeting  Housing  Healthy lifestyles  Communication  Developmental  booklets: 1-3 years; 3-5 years; 5-10 years; 10-13 years; 13-18 years</p>	<p>Training pack, including activity sheets, booklets and picture cards</p>	<p>For professionals to use when working directly with parents with learning difficulties</p>	<p>This resource is produced by Circles Network.  It is not currently available but will be available from: <a href="http://www.circlesnetwork.org.uk">www.circlesnetwork.org.uk</a>  No details available yet about cost.</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>could be a relaxed and effective way of the professional developing a relationship. They help professionals to explore significant events in people's lives and to get a sense of what is important to the individual, what their goals are and what type of support they would find helpful.</p> <p>The developmental booklets cover children from the age of 1-18 and they address topics such as: stimulation; safety; basic care; communication; emotional warmth; education; health and safety. There is a huge amount of useful information in these for parents. Overall the leaflets include a lot of useful information but the way they are presented may make much of this inaccessible.</p> <p>There is an abuse tool consisting of a leaflet, stranger cards and feelings cards.</p> <p>The leaflet talks about abuse, neglect and bullying and how to avoid these and how to look for warning signs.</p> <p>The Communication booklet addresses areas in parents' lives in which they may feel they need support and how to get this.</p>				

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>There is a pack of “people cards” to use, with pictures on the front and a description on the back, e.g. social worker/judge</p>				
<p><b>16. Australian Supported Learning Programme (ASLP): Me and my community</b>  The aim of the ASLP is to assist mothers with learning difficulties to identify their own learning needs and aspirations, and to help them create learning opportunities and connect with resources available in their local communities. It is designed to be a flexible programme and it combines group-work with individual advocacy and support. There are weekly mothers' group sessions within the facilitators' organisation and individual sessions between facilitator and mother. The programme is based around individual and group goals which are set at the beginning. Typically one weekly session per module would be advised – there are 10 modules. There are 10 group-work sessions which includes 3 outings; these should last about 2 hours 45 minutes.</p>	<p>Places I know and love  Different kinds of places in my community  Places for children and families  Outing (to a family-friendly place)  Doing things for me in the community  Outing (to a place for “me in my community”)  Helping out and being active in the community  Outing (to a place to help out and be active in the community)  Friends and significant others  Review – bringing it all together</p>	<p>Three books come as part of this programme:  Key readings (for professionals)  Participant scrapbook  Facilitator’s guide</p>	<p>Service providers working alongside mothers with learning difficulties</p>	<p>Australian Supported Parenting Consortium  <a href="http://www.healthystart.net.au">www.healthystart.net.au</a>  Ordering process is being finalised. Please see website for latest details.</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>The facilitator's guide includes advice around setting up the group and issues to consider as well as giving advice on how to facilitate the group. The information for each module suggests ice-breakers and other activities along with time durations for each section.</p> <p>The sessions aim to leave the mother feeling confident about using the community and with good information about appropriate places to go with her child. The book includes goal setting forms and evaluation forms for each session.</p>				
<p><b>17. The UPS – understanding and planning support with parents with learning difficulties.</b></p> <p>This set of visual aids is designed to support conversation to help practitioners to work collaboratively with parents with learning difficulties. It aims to identify parental needs to help support to be planned around these. The UPS includes a self-instructional practitioner's guide, a hard copy of visual aids and a resource CD. The sections are clearly colour-coded and within each section</p>	<p>Caring and protecting Nurturing – helping my child grow Socialising – belonging and participating Things that affect parenting</p>	<p>Ring-bound book and resource CD</p>	<p>For professionals to use when working with parents with learning difficulties</p>	<p>Produced by NSW Family Services Inc with The University of Sydney</p> <p><a href="http://www.nswfamilyservices.asn.au">www.nswfamilyservices.asn.au</a></p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>there are a number of items which are represented through coloured photographs, e.g. giving medicine. Each item is graded on a four point scale: No concern; rarely a concern; sometimes a concern; a big concern. There is an additional section of communication cards to be used to facilitate the work. These provide visual metaphors for emotions and thoughts.</p>				
<p><b>18. Nurturing Parenting - Easy Reader Handbook</b>  This book focuses on parenting skills and strategies for babies and young children. The Nurturing Parenting Programs are designed for the treatment and prevention of child abuse and neglect and are targeted at families deemed to have a high-risk of abuse or neglect. The philosophy focuses on emotional development, empathy and the development of self-worth in children.  It covers a variety of topics and offers practical advice but primarily emphasises the emotional aspects. The book encourages parents to try suggested “nurturing” activities at</p>	<p>Nurturing as a philosophy  Childhood growth and development  Discipline with dignity  Empathy  Managing feelings  Communication  Self-worth and empowerment  Making good choices and keeping kids safe  Nurturing routines</p>	<p>Book</p>	<p>For professionals to use when working with families with learning difficulties</p>	<p>Produced by Family Development Resources:  <a href="http://www.nurturingparenting.com">www.nurturingparenting.com</a>  \$26 (inc shipping to the U.K.)</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>different developmental stages and to record these. It acknowledges that parents also need to look after their own needs in order to be good parents and it offers advice on how to cope with stress.</p> <p>It is aimed at parents with an elementary school reading level and is available in Spanish and Arabic.</p>				
<p><b>19. Mother Knows Best</b></p> <p>This booklet includes both the experiences of parents themselves and the results of an academic study. It aims to show how people with learning difficulties can succeed as parents if they are given the support they need. The first section is written in an accessible format and aimed at people with learning difficulties. The majority of the booklet discusses the issues involved from the perspective of professionals who could be providing support. It reports on one specific study undertaken by the authors and also reviews other research and policies. Two personal stories are used to illustrate peoples' experiences. This resource is thorough and thought-provoking and focuses</p>	<p>The survival guide to parenting</p> <p>Personal stories</p> <p>The past – historical context</p> <p>The present – the law</p> <p>Review of the research</p> <p>The future – discussion of services/support available</p> <p>Supporting parents with learning difficulties</p> <p>Contact list</p>	<p>Booklet</p>	<p>Parents and professionals</p>	<p>Produced by Values Into Action. Available to order from:</p> <p><a href="http://www.viauk.org">www.viauk.org</a></p> <p>Cost: £10 plus £1.50 for P&amp;P</p>



Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>more on good practice and attitudes rather than practical advice about giving support.</p>				
<p><b>20. Supporting Families When Parents Have Intellectual Disabilities</b>  This resource advocates an <i>integrated service delivery system</i> as in this model one agency takes the lead and works with the entire family in a variety of ways. The booklet gives advice about what type of support parents need and how this can be provided. There are some sheets included which could be used with parents, e.g. checklists of the day's jobs.  There are suggestions for suitable, and cheap, activities to do together and an accessible version of this list with pictures.  It contains handouts from training modules and training scenarios and there are links to website which have further information about assessments for example. Any contact information is local to Dakota, U.S.A. so the resource would need some adapting.</p>	<p>The impact of beliefs and attitudes – facts and myths  Parenting with Intellectual Disabilities – styles; needs and barriers  Providing support to families – successful support; when children are removed;  integrated service delivery; beyond traditional support  Getting started – organising support; training providers; training parents  Resources – assessments; strategies; web resources</p>	<p>Book</p>	<p>Designed as a guide for providers who wish to support parents with learning disabilities.</p>	<p>Produced by the North Dakota Center For persons with Disabilities  Downloadable from link<sup>b</sup></p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<a href="http://165.234.216.166/prod/pub/pdf/Supporting_Families_w_ID_Manual.pdf">b:http://165.234.216.166/prod/pub/pdf/Supporting_Families_w_ID_Manual.pdf</a>				
<p><b>21. Designing support groups for parents with intellectual disabilities</b></p> <p>This book and accompanying dvd are designed to assist with setting up a support group for parents with learning disabilities. One of the objectives of this group is for the members to assist with the tasks involved in running the group and they give suggestions of how the group activities can be used as a chance to help attendees develop practical skills. There are descriptions of activities to use within the group and suggestions for ways in which members can increase their social skills and confidence. There is advice for professionals on how to facilitate group discussions and how to handle sensitive topics.</p> <p>A playgroup is provided alongside to enable parents with young children who do not have childcare to attend. The book has discussion questions for professionals which relate to the accompanying DVD. There are checklists of issues that would need to</p>	<p>Rationale and benefits of a support group  Concrete organisational ideas  Details for success  Video clips of the group  Discussion questions  Descriptions of other groups  Worksheet to help design a support group</p>	<p>Book and DVD  NB: DVD may not play on all U.K. machines</p>	<p>This is a tool for any individual or organisation that wants to form a group for parents with learning disabilities.</p>	<p>Produced by Through The Looking Glass:  <a href="http://www.lookingglass.org">www.lookingglass.org</a>  \$100 plus \$7 or \$13 for shipping</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
be addressed in order to establish a group like this.				
<p><b>22. Strategies and adaptations in working with parents with intellectual disabilities</b></p> <p>This guide provides information and concrete ideas for working successfully with parents with learning disabilities. It offers advice for how professionals should engage with such parents. It gives practical suggestions for how to build the relationship and emphasises the need for treating parents with respect. There are suggestions for who to include in providing wider support and how to do this. There are suggested phrases to use to ensure you are not making the parent feel inadequate or patronised. There is information on how to observe when a parent may need additional help with gaining parenting skills and advice on how to tailor interventions so they are appropriate.</p>	<p>Behavioural indicators of a learning disability</p> <p>Common personal issues</p> <p>Fundamental elements of intervention</p> <p>Adaptive approaches and the use of self</p> <p>Adaptive strategies that maximise learning</p> <p>Taking care of yourself</p>	Booklet	Professionals	<p>Produced by Through the Looking Glass.</p> <p>Available via: <a href="http://www.lookingglass.org">www.lookingglass.org</a></p> <p>Came free with “Designing support groups for parents with intellectual disabilities” resource but can be ordered for \$15 plus \$7/\$13 for shipping</p>
<p><b>23. Building Foundations: A Curriculum Guide for Supported Parenting</b></p> <p>Part 1 explores the attitude and</p>	<p><b>Part 1:</b></p> <p>Guiding principles</p> <p>Best practices</p> <p>The Growing Together</p>	Book	Professionals who are supporting parents with	<p>Produced by the Kennedy Krieger Institute. Available via email: <a href="mailto:irwin@kennedykrieger.org">irwin@kennedykrieger.org</a></p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>approach needed to work with this group of parents whilst Part 2 provides practical advice on effective methods of teaching.</p> <p>The main section is Part 3 and this is broken down into a range of topic areas. Each topic area then follows the same format and covers:</p> <p>What a parent needs to know about the topic</p> <p>Why do parents need to know about this topic</p> <p>Suggested activities/ways to work with the parent in relation to this topic</p> <p>Most sections then use a brief vignette as an example of working with a parent to overcome a problem in this area.</p> <p>Although this would be a very useful resource for professionals, it still requires initiative and further work. For example, it suggests activities or charts/videos that would be useful to use but the book does not come accompanied by such resources so a professional would need to create these or use/adapt existing resources. There are lots of links to useful/relevant websites.</p>	<p>Program</p> <p>Creating a framework</p> <p>Self-advocacy</p> <p><b>Part 2:</b></p> <p>Instructional strategies</p> <p><b>Part 3:</b></p> <p>Child development</p> <p>Nutrition</p> <p>Health</p> <p>Safety</p> <p>Transportation</p> <p>Childcare</p> <p>Education</p> <p>Money management</p> <p>Time and household management</p> <p>Housing</p>		<p>cognitive limitations</p>	<p>\$69.95 plus \$9.50 for shipping</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>This resource has a lot of useful information but seems to be aimed at guiding and stimulating further ideas, rather than aiming to be a comprehensive training pack. This resource is divided into 14 sections and there are tabs at the right-hand side to mark these and help you move around the sections.</p>				
<p><b>24. Working with parents who have cognitive limitations</b>  This DVD has three separate programmes on it aimed at teachers, nurses and service providers. Each programme highlights signs that may indicate to professionals that they are working with a parent with cognitive limitations.</p> <p>1) Aimed at teachers (25 minutes long). It suggests that teachers must try to get parents involved in school activities and support the parents' efforts to provide a home environment that helps learning. There are suggestions on how to communicate effectively and how to provide accessible information for the parents. They also give advice on how to structure meetings with</p>	<p>Recognising when parents have a learning disability  Effective communication with parents  Developing a respectful working relationship with parents  Maximising appropriate and beneficial conditions for the children</p>	<p>DVD</p>	<p>Service providers, teachers or health professionals who may be working with parents with borderline learning disabilities.</p>	<p>This resource is produced by Iris Media and is available from:  <a href="http://www.lookiris.com">www.lookiris.com</a>  Cost is \$85</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>parents and emphasise the need to create a respectful relationship in which the parent feels empowered.</p> <p>2) Aimed at nurses (27 minutes). It uses a fictitious example of the potential problems when health professionals do not make allowances for peoples' cognitive limitations. Health professionals need to ensure that parents understand medical advice and how to give medication. Main advice:</p> <ul style="list-style-type: none"> <li>• Keep instructions simple</li> <li>• Keep it concrete</li> <li>• Keep it respectful</li> </ul> <p>They emphasise that children whose parents have cognitive limitations can resemble children who are being neglected but that they are not and that it often linked with poverty.</p> <p>3) Aimed at social service providers (27 minutes). Raises awareness that some cases of apparent neglect are due to issues around cognitive limitations. It addresses setting up a circle of support and to establish important routines. Recommends spending more time with these parents to develop trust. It gives</p>				

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>advice on how to do this and how to communicate honestly and effectively. It emphasises that service providers mustn't expect change too quickly and that it is important to follow up.</p> <p>There are also links to online resources, printable posters, and a printable visual prescription form is also included in the viewer's guide. As this is an American resource it does use the term "mental retardation".</p>				
<p><b>25. Parent Assessment Manual 2.0</b></p> <p>Essentially PAMS 2.0 is a PC Software CD-ROM application which includes Clinical Assessment Forms, Worksheets, Graphical Parent Summary and profiles.</p> <p>PAMS 2.0 consists of 94 worksheets to be used by professionals during clinical assessments.</p> <p>The PAMS 2.0 software will perform error checking on all data input into the worksheets to maintain integrity. All 94 worksheets can be printed if needed.</p> <p>The assessor is required to make judgements about whether a parent's ability is good/adequate/poor in</p>	<p>Feeding Healthcare: general; hygiene; warmth Parental responsiveness Stimulation: visual; motor; language Guidance and control Responsibility and independence Household routines Time telling Telephone skills Travel skills Budgeting Shopping Cooking</p>	<p>Training pack: instruction book, CD- ROM, parent booklet and a set of cartoons</p>	<p>Service providers working with parents</p>	<p>From Pill Creek Publishing: <a href="http://www.pillcreekpublishing.com">www.pillcreekpublishing.com</a> £255 plus £8.50 P&amp;P ISBN: 978-0-9556729-0-3</p>

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>relation to different tasks. Guidelines and example answers are provided to aid this judgement. After assessment the PAMS should provide a clear, visual family profile of functioning that targets parenting support needs as well as child protection issues. A wide range of skills are assessed and these relate to children at all different ages.</p>	<p>Washing Hygiene: kitchen/living room; bedroom; bathroom General safety Safety: kitchen/living room; bedroom; bathroom; outside the home; abuse Parent healthcare: mental; physical Relationships and support Environment and community</p>			
<p><b>26. Supporting parents with learning disabilities – good practice guidance, easy read version</b> This easy read version of the guidance designed for service providers means that parents with learning disabilities can refer to this to find out what type of support they are entitled to and should be getting. It talks about equal access to services and also about the need for accessible information and advocacy. This document clearly states the rights</p>	<p>Supporting parents with learning disabilities Good practice to keep their children safe and to get fair treatment for the whole family Where to get more information</p>	<p>Booklet</p>	<p>This easy read version is designed for parents with learning difficulties.</p>	<p>Produced by the Department of Health and Department of Education. Free to download from Valuing People website <a href="http://www.valuingpeople.gov.uk">www.valuingpeople.gov.uk</a> Direct link<sup>c</sup></p>



Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p>that parents have e.g. they should be invited to meetings about their children</p> <p>Each section of text has a picture relating to it and the vocabulary and sentences are kept simple.</p>				
<p>c: <a href="http://valuingpeople.gov.uk/dynamic/valuingpeople115.jsp?highlight=parents">http://valuingpeople.gov.uk/dynamic/valuingpeople115.jsp?highlight=parents</a></p>				
<p><b>27. The court and your child</b></p> <p>This booklet aims to prepare parents for the processes they will go through once social workers have got involved and if they are facing court proceedings. It offers practical advice and covers many stages with explanations of what could happen at each.</p> <p>There are pictures relating to each section of text. They use the same character drawings consistently and have a key at the beginning so the role of the characters in the pictures are clear. Many of the pictures use text.</p> <p>They have kept the text fairly simple. They have had to use legal terminology at points but explain this when they do.</p>	<p>The role of social workers and social services</p> <p>Child Protection Conferences</p> <p>Role of solicitor</p> <p>What to expect in court</p> <p>Care Orders</p> <p>Supervision orders</p> <p>Foster carers and supervised contact</p> <p>Appeals</p> <p>Adoption</p>	<p>Booklet</p>	<p>Parents with learning difficulties</p>	<p>Produced by Wake Smith</p> <p>Available to down load for free<sup>d</sup></p>
<p>d: <a href="http://www.family-justice-council.org.uk/docs/Public_Law_booklet(1).pdf">http://www.family-justice-council.org.uk/docs/Public_Law_booklet(1).pdf</a>  <a href="http://www.bristol.ac.uk/norahfry/right-support/download/socialworkers.pdf">http://www.bristol.ac.uk/norahfry/right-support/download/socialworkers.pdf</a></p>				

Title and description	Topics covered	What format is it in?	Who is it aimed at?	How do you obtain it?
<p><b>28. Using medicine safely</b>  This booklet is about taking medication. All the messages (such as “read the label” and information about side effects) would apply to administering medication to children. Therefore this could be a useful resource for parents with learning difficulties. The language is quite simple and sentences are fairly short.</p>	Prescriptions Keeping medicines safely Instructions Side effects Antibiotics	Book	People with learning difficulties	From BILD: <a href="http://www.bild.org.uk">www.bild.org.uk</a> £8 (plus 10% P&P) ISBN: 1-873791-04-6
<p><b>29. Looking after your teeth</b>  This booklet is about looking after your own teeth but would also be relevant in terms of looking after your children’s teeth. Therefore this could still be a useful resource for parents with learning difficulties. It is a short and basic resource though so parents might need more detail in regard to brushing teeth for example.</p>	Brushing your teeth Dentist visits Problems with your teeth	Book	People with learning difficulties	From BILD: <a href="http://www.bild.org.uk">www.bild.org.uk</a> £8 (plus 10% P&P) ISBN: 1-873791-37-2

### **30. Skills For Life Programme**

This programme is a national strategy launched in 2001 aimed at improving adult literacy and numeracy skills. It is not a programme specifically designed for adults with learning difficulties but it could still be a useful set of resources it targets adults with poor literacy, language or numeracy skills. Each module is accompanied by a curriculum coverage chart for the teacher.

The modules are designed to help adults with their skills in relation to their workplace. However there are sections of each of the modules included in this review that are relevant to parents at home. Therefore these are resources that could be used with parents with learning difficulties with some adaptation. The booklets contain advice for the professional on how to work through the provided exercises and to make the information relevant to the individual.

Most of each booklet is information and guidance for professionals but there are also pages are to be used directly with the people being trained. There are quizzes to assess the knowledge that has just been taught and these are alternated with less educational, but related, puzzles. Some of the quizzes have an audio version available.

The booklets use coloured drawings and photos, with lots of pictures on the pages designed for the people being trained. They are useful drawings and relate well to the text but many of the drawings use text within them (in speech bubbles for example) so this is not a resource suitable for people with very low literacy skills. There are four relevant streams: Early years; Family Health; Focus on parenting; Growing child

These resources are designed to be used by teachers coming from vocational, professional and community education backgrounds and also by teachers from specialist literacy, language and numeracy backgrounds.

They are produced by the Department for Education and Skills and are available to download free of charge at:

<http://rwp.qia.oxi.net/embeddedlearning/search.dfm>

<p><b>30a. Skills For Life Programme</b>  <b>Early years Module 2: health and safety</b>  Some aspects of this module are directly relevant, such as how to take and interpret a child's temperature. Other sections are aimed at being in a workplace, such as security. However with adaptation these could also be useful for parents at home.</p>	<p>Taking notes during training  Reading instructions that include graphics  Reading product labels  Following security and fire procedures  Making emergency phone calls  Reporting accidents and incidents both verbally and in writing  Temperature  Involving children in safety matters</p>
<p><b>30b. Skills For Life Programme</b>  <b>Family Health Module 1: Getting in touch</b>  The majority of this module contains information that would be extremely useful for parents with learning difficulties and this module could be used with minimal adaptation. There are audio role plays to accompany this module.</p>	<p>Communicating with health services  Accessing information  Time – making and keeping appointments  Handling forms</p>
<p><b>30c. Skills For Life Programme</b>  <b>Family Health Module 2: Healthy eating</b>  These contain detailed information on topics such as choosing a range of healthy food and what is a helping of fruit/vegetables. There are tables for recording information, such as how many helpings of fruit/vegetables you eat each day. A lot of this booklet would be directly relevant to parents with learning difficulties, such as the advice on planning cheap, healthy meals and lunch-boxes and the recipe suggestions.</p>	<p>Choosing food  Preparing food  Breastfeeding and weaning  Food shopping  Kitchen safety and hygiene</p>
<p><b>30d. Skills For Life Programme</b>  <b>Family Health Module 3: Looking after yourself</b>  The contact information provided in this module relates to mainstream organisations so information about support services specifically for parents with learning difficulties would be a useful addition to this booklet. This module focuses on the mother but a mother's emotional and physical well-being will impact on her parental ability.</p>	<p>How new mothers may be feeling  Where to go for help  Health issues for women</p>
<p><b>30e. Skills For Life Programme</b>  <b>Family Health Module 4: Early childcare</b>  This booklet contains places to record developmental milestones and advises on</p>	<p>Child development and growth  Play  Medication  Safety issues around the home</p>

<p>monitoring height and weight etc. There is also information and resources for activities to do with children. The information relating to medication, reading labels and safety in the home could all be used with minimal adaptation with parents with learning difficulties.</p>	
<p><b>30f. Skills For Life Programme Family Life- the growing child Module 1: 0-3</b> This module contains lots of information on the topics listed and includes activity suggestions along with suggestions of number and action rhymes suitable for children.</p>	<p>The Child: recording milestones; being active; interests; a sense of being; sleeping patterns; hygiene Family Time: being together; travelling; playing together; celebrating together; party food; party games Family Literacy: speaking and listening; sharing books; learning through play</p>
<p><b>30g. Skills For Life Programme Family Life- the growing child Module 2: 3-5</b> Alongside suggestions for fun activities with children of this age there are practical suggestions for developing routines and managing difficult behaviour. This module has lots of practical information about supporting a child's development.</p>	<p>The Child: recording milestones; being active; interests; a sense of being; sleeping patterns; hygiene Family Time: being together; travelling; playing together; celebrating together; party food; party games Family Literacy: speaking and listening; sharing books; learning through play</p>
<p><b>30h. Skills For Life Programme Family Life- the growing child Module 3: 5+</b> This module addresses issues raised by a child starting at school. There is also a lot of information about appropriate food, games and activities for children of this age.</p>	<p>The Child: recording milestones; being active; interests; a sense of being; sleeping patterns; hygiene Family Time: being together; travelling; playing together; celebrating together; party food; party games Family Literacy: speaking and listening; sharing books; learning through play</p>
<p><b>30i. Skills For Life Programme Family Life- focus on parenting Module 4: The family</b> This module covers many different aspects of family life, with an acknowledgement of different culture and traditions. There is information about celebrations, discipline and safety.</p>	<p>Being together My family is changing Dealing with emotions Family Safety</p>

<p><b>30j. Skills For Life Programme</b>  <b>Family Life- focus on parenting Module 5: The community</b>  Some of this module may not be relevant to parents with learning difficulties but there is advice on integrating children into school and social groups that could be helpful.</p>	<p>Taking part  Getting help  Citizenship</p>
<p><b>30k. Skills For Life Programme</b>  <b>Family Life- focus on parenting Module 6: Family finance</b>  Some of the information in this module may need adapting to be relevant to the individual, e.g. the section on benefits. However, given the high rates of poverty for adults with learning difficulties, this could be a very relevant module, although it may need some adaptation.</p>	<p>Entitlements  Responsibilities  Budgeting  Money-saving tips</p>

## Appendix C

---

### Depo-Provera

Frances Affleck, CHANGE

This accessible book explains the contraceptive injection Depo-Provera. It tells you what Depo-Provera is, how it works and what the side effects are.

Book £4 (inc P&P); audio tape £3 (inc P&P)

Available from [www.changepeople.co.uk](http://www.changepeople.co.uk)

### Everything you wanted to know about safer sex but were afraid to ask

People First

This is an accessible guide covering sexual rights, sexual health and contraception. It is also available on tape. Price: £15

<http://www.peoplefirstltd.com/shop-guides.php>

### Living Safer Sexual Lives

#### 260 ring-bound resource plus video/dvd

A training resource pack for people with learning disabilities and those who support them

This easily accessible training aims to support people with learning disabilities, their families and friends, service providers and staff to learn about values, attitudes, safety and rights in relation to sexuality and relationships.

Available from Pavilion, <http://www.pavpub.com/pavpub/home/index.asp>

£97.50 plus 10% for P&P

ISBN: 978-1-84196-115-6

### Sex and the 3 Rs

Michelle McCarthy and David Thompson

A frank training resource, with clear line drawings to inform adults with learning disabilities about their rights and responsibilities and possible risks of their sexual lives.

Available from Pavilion, <http://www.pavpub.com/pavpub/home/index.asp>

£95 plus 10% for P&P

ISBN: 978-1-84196-223-8

### Sex and Staff Training

Michelle McCarthy & David Thompson

A training manual for staff working with people with learning difficulties

Ringbound materials including guidelines for running sex education programmes (78pp), photocopiable handouts and exercise materials (64pp).

Topics: - Introduction to staff training - Introducing sexuality - Masturbation - General sexuality - Sexual abuse - HIV and safer sex work - Resources and training organisations.

Available from Pavilion, <http://www.pavpub.com/pavpub/home/index.asp>

£32.50 plus 10% for P&P

ISBN: 1-871080-34-7

## **Taking the Initiative**

Supporting the sexual rights of disabled people This report is designed to provide an overview of sexuality and personal relationship issues facing disabled people and of positive service initiatives designed to address them. *Taking the Initiative* sets out to review these issues and to identify priorities for research and service development. It describes the legacy of segregated schooling, patronising attitudes and institutional provision, for individuals and for services.

Handbook (122pp)

Available from Pavilion, <http://www.pavpub.com/pavpub/home/index.asp>

£3.75 plus 10% for P&P

ISBN: 978-1-84196-005-0

## **ACTing to Support Parents with Learning Disabilities**

Pamela Cooke, Ann Craft Trust

Project report

£8.50 (inc P&P)

[www.anncrafttrust.org/](http://www.anncrafttrust.org/)

## **Sexual Health and Relationships: A review of resources for people with learning disabilities**

Editors: Kat Hasler, Rachael Yates and Jackie Anderson

Available to download:

<http://www.healthscotland.com/uploads/documents/ResourceReview.pdf>

**These resources are no longer available to buy but they may still be accessible via specialist libraries:**

## **Sex in context: strategies and safeguards relating to the sexuality of children and adults with profound and multiple impairments,**

Part 1 with handbook

This three-part training pack is designed to redress this balance and help staff in services develop approaches, strategies and safeguards in this area. The handbook is designed to facilitate a review of service policies and the development of practice guidelines.

A separate ringbinder provides information and exercises for staff (Part I) and service users (Part II).

JRT/pavilion

## **Reach Out Training Pack**

Personal relationships, sexuality and needs of African and Asian decent learning disabled women

Razia Aziz & Aqeelah Alam, Family Planning Association

ISBN: 1-899194-14-2