

**National best practice in independent  
advocacy for parents with learning  
disabilities: a short scoping exercise**

CHANGE's report for the Office of the National  
Director for Learning Disabilities

July 2010

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 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**

 **www.changepeople.co.uk**



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 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**



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 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**



## 1. About CHANGE and this report

CHANGE is an organisation led by disabled people working for the human rights and full inclusion of all people with learning disabilities. CHANGE promotes a model of co-working, in which people with learning disabilities and people without learning disabilities work equally together on a project. CHANGE works in different areas that affect the daily lives of people with learning disabilities, including: employment, health and sexuality. CHANGE has a sound experience in working for the rights of parents with learning disabilities. CHANGE also has a unique expertise in delivering training and in making information accessible for people with learning disabilities, using pictures and easy words.

At CHANGE people with learning disabilities are employed and working with advocacy organizations across the country, supporting them to become more sustainable, sharing information about social enterprises, procurement and commissioning and training the people with learning disabilities to train other people with learning disabilities and professionals. We support advocacy organizations to think about and work towards employing more people with learning disabilities. We are setting up a network of advocacy organizations. Different advocacy organizations are skilled to deliver training in different areas, for example, parenting support, accessible information and employment. We have run a national network of parenting organizations of parents with learning disabilities and are training different groups of parents with learning disabilities to become trainers.

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**



In addition, we are currently doing a piece of work for Shared Lives around the support that is offered to parents with learning disabilities in Shared Lives schemes, identifying models of good practice. We also have links to what is happening nationally for parents with learning disabilities, and we completed a piece of research looking at pregnant mothers with learning disabilities experiences of maternity services in Leeds. We also have very comprehensive records of all the local authorities and PCTs that have bought our accessible parenting books. We feel that this insight into which areas parents are receiving accessible information on parenting is important, as receiving accessible information is part of human rights, good support and good practice.

Moreover, CHANGE is carrying out a project for the Equality and Human Rights Commission (EHRC) on hate crime and people with learning disabilities. We are focusing mainly on Leeds, and after an initial research, we are working on the creation of training materials by and for people with learning disabilities.

The Office of the National Director for Learning Disabilities commissioned CHANGE to do a piece of work into national best practice in independent advocacy for parents with learning disabilities. This work was commissioned in the context of this office's delivery plan, where it says that this office is committed to 'explore with other government departments, ways to further support or develop independent advocacy for parents with learning disabilities'.

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

Given the characteristics of this piece of work, the organisation proposed that this small piece of research should be developed by Ana Laura Aiello. Ana Laura is an international human rights lawyer. She also is an experienced consultant regarding disability and human rights. Ana Laura already worked as a researcher for CHANGE on the project into mothers with learning disabilities' experiences and on the hate crime project. She has conducted several projects for organisations like Amnesty International or Mental Disability Rights International<sup>1</sup>. In addition to her work, Ana Laura is currently undertaking part-time PhD research at the Centre for Disability Studies (University of Leeds).

The following report has been divided in two parts. The first part (point 2.) will revise the literature that informs the research. The second part (point 3.) will address the actual contributions of this document, or in other words, the new evidence provided by the research. Finally, point 4. provides conclusions and recommendations.

## 2. What we know already: the background

This part of the report will rapidly review the main literature around independent advocacy for parents with learning disabilities. The analysis will be guided by a human rights perspective and by the social model of disability.<sup>2</sup> Basically, the social

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<sup>1</sup> MDRI is a leading mental disability rights organisation based in the United States of America.

<sup>2</sup> On the social model of disability, the following references are of interest: Barnes C and Mercer G, *Disability*, Cambridge: Polity Press, 2003 and Priestley M, *Disability: A Life Course Approach*, Cambridge: Polity Press, 2003.



model of disability stresses that disability is produced by the society because the society does not provide adequate services or support for disabled persons.

## 2.1. Concept and types of advocacy

There is not an unique concept of advocacy. For example, the organisation Action for Advocacy defines advocacy in the following way:

**‘Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need.**

Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice<sup>3</sup>.  
[bold highlighted by Action for Advocacy]

As it can be seen from this definition, it is crucial that the advocate works towards making *the represented person’s voice* effectively heard.

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<sup>3</sup> <http://www.actionforadvocacy.org.uk/articleServlet?action=list&articletype=10> (last accessed on 28<sup>th</sup> June 2010).

The different types of advocacy will help an advocate to achieve the goal of making a voice heard, by different ways and with different purposes. As it happens with the concept of advocacy, the differentiation among types of advocacy is not uniform. For example, the aforementioned organisation Action for Advocacy distinguishes: citizen advocacy; short term, issue based or crisis advocacy; self advocacy; peer advocacy; bi-lingual advocacy; health advocacy; non-instructed advocacy; Independent Mental Capacity Advocacy (IMCA); and legal advocacy.<sup>4</sup>

## 2.2. When advocacy is 'independent'

In relation to advocacy, some of the organisations working in the field elaborated 'standards', 'principles' and/or 'values'.<sup>5</sup> For example, the organisation Action for Advocacy has created the following principles and standards: clarity of purpose, independence, putting people first, empowerment, equal opportunity, accessibility,

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<sup>4</sup> <http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=716&articletype=20> (last accessed on 28<sup>th</sup> June 2010). This website provides a definition for each type of advocacy.

<sup>5</sup> For example: Advocacy 2000, 'Principles and standards in Independent Advocacy organisations and groups', 2002; Action for Advocacy, 'Quality Standards for Advocacy Schemes – Based on the Advocacy Charter', 2006; The Scottish Independent Advocacy Alliance, 'Principles and Standards for Independent Advocacy', 2008; or Your Say Advocacy, 'Principles and Values' (<http://www.yoursay-advocacy.co.uk/principles.html> -last accessed on 5th July 2010).



accountability, supporting advocates, confidentiality and complaints.<sup>6</sup> This organisation maintains that its standards,

‘... are evidence based quality standards. They are an essential tool for developing and maintaining quality. They are the only nationally recognised generic quality standards specifically developed for the advocacy sector.’<sup>7</sup>

The scope of this document does not allow to address all of the ‘standards’, ‘principles’ and/or ‘values’ that have been elaborated in the field. Instead of this, and having into consideration that this research intends to find out about *independent* advocacy for parents with learning disabilities, this document will offer some considerations into the ‘standard’, ‘principle’ and/or ‘value’ represented by independence.

A number of considerations have been issued regarding the ‘independence’ of advocacy.

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<sup>6</sup> Action for Advocacy, ‘Quality Standards for Advocacy Schemes – Based on the Advocacy Charter’, 2006.

<sup>7</sup> <http://www.actionforadvocacy.org.uk/articleServlet?action=list&articletype=23> (last accessed on 5<sup>th</sup> July 2010).

The organisation Action for Advocacy explains that the essence of the independence standard's rationale is that:<sup>8</sup>

**'Advocates must not find themselves compromised by conflicts of interest** which prevent them from acting on behalf of service users. Advocacy schemes should take all practicable steps to avoid such conflicts of interest and will need to consider how they will "protect" advocates from external pressures' [bold highlighted by the researcher]

This document goes on by differentiating three types of independence: structural independence, operational independence and psychological independence. Structural independence is when a scheme is structurally independent (ie separate) from service provider organisations. The organisation clarifies that when there is structural independence, the standard of independence would be easier to achieve. At this point, the document establishes that,

'It is also important that schemes do not become too dependent on a single source of funding, and do not agree to funding criteria or performance measures which compromise their independence or integrity.'

When structural independence is not possible, operational independence should be pursued. According to Action for Advocacy,

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<sup>8</sup> The reference for this part of the research is the document issued by Action for Advocacy, 'Quality Standards for Advocacy Schemes – Based on the Advocacy Charter', 2006.

‘... this means that the service is not required to adhere to policies and procedures which could compromise its ability to provide independent support to service users. Operational independence is also reflected in line management arrangements, the culture and ethos of the scheme and local working protocols. It means that advocates are able to adopt advocacy principles in their work without compromise. One useful way of reflecting this independence is via a Code of Practice or engagement protocol for advocates.’

Finally, psychological independence is defined by this organisation in the following way,

‘... whatever relationships exist within and between advocacy schemes, individual advocates are expected and positively supported to act on behalf of and stay loyal to service users.’

The publication ‘Access to independent advocacy: an evidence review – Report for the Office for Disability Issues’ mentions a definition of independent advocacy which has been adapted from a definition provided by Age Concern Cheshire as well as definitions issued by the the National Forum for Independent Advocacy with Older People, the EHRC and The Scottish Executive (2000).<sup>9</sup> The definition adapted from the one provided by Age Concern Cheshire says that:

‘Independent advocacy involves a partnership between a concerned member of the community (advocate) and a person who may be feeling vulnerable, isolated or

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<sup>9</sup> Townsley R, Marriott A and Ward L, ‘Access to Independent Advocacy: An Evidence Review’, Office for Disability Issues, 2009, pp. 19-21.

disempowered. The advocate provides support, information and representation with the aim of empowering their advocacy partner and enabling them to express their needs and choices. If necessary, the advocate can represent their partner's wishes to another person or agency on their behalf. Disabled people, their organisations and many leading voluntary organisations welcome the use of advocacy and believe it is crucial to achieving the Government's vision of more choice and control for all disabled people.<sup>10</sup>

In summary, and after presenting the rest of definitions, this publication states that,

*'These definitions, with their separation of independent advocacy from other forms of service provision, independent governance, and pooled funding arrangements (such as pooled budgets), may be seen as the 'gold standard' for the provision of independent advocacy services. However, the reality of actual service provision in this sector is less clear than these definitions might suggest and, in practice, there is still confusion about what independent advocacy is and how this is interpreted by advocates and those they advocate for (their advocacy partner).'*<sup>11</sup> [italics highlighted by the researcher]

### **2.3. Independent advocacy for parents with learning disabilities and human rights**

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<sup>10</sup> Ibid p. 19.

<sup>11</sup> Ibid p. 21.



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**



When advocacy is offered for parents with learning disabilities, the preceding general considerations regarding advocacy are of application, but also a range of specific issues appear in the scenario. This part of the report intends to deal with these specific issues.

There is not a great deal of research on independent advocacy for parents with learning disabilities.<sup>12</sup>

According to Booth and Booth, in the case of parents with learning disabilities ‘the advocacy role is about making sure parents receive the support and services to

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<sup>12</sup> The following are examples of research conducted on this regarding: Booth and Booth, ‘Advocacy for Parents with Learning Difficulties’, Findings, Joseph Rowntree Foundation, 1998; Glasgow School of Social Work, ‘Parents with Learning Disabilities – The Lived Experience – A study for Equal Say, Glasgow’, 2008; Tarleton B, ‘Providing the right support for parents with a learning disability – Evaluating the work of the north east’s parents’ support service and the Walsall parents’ advocacy service’, 2006; Tarleton B, Ward L and Howarth J, ‘Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children’, 2006; Tarleton B, ‘Specialist advocacy services for parents with learning disabilities involved in child protection proceedings’, 2007 Blackwell Publishing Ltd, British Journal of Learning Disabilities, 36, 134–139; Townsley R, Marriott A and Ward L, ‘Access to Independent Advocacy: An Evidence Review’, Office for Disability Issues, 2009; Ward L and Tarleton B, Advocacy for Change: “The Final Tool in the Toolbox?” in *Parents with Intellectual Disabilities: Past, Present and Futures* Edited by Llewellyn G, Traustadóttir R, McConnell D, and Björg Sigurjónsdóttir H, Wiley-Blackwell, 2010.

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

which they are entitled'.<sup>13</sup> These authors have also made reference to the importance of an independent advocacy for this group of people by stating that 'parents must be assured that the project has no connection with the statutory services'.<sup>14</sup>

More specific issues which appear from a literature review<sup>15</sup> are:

- 'Advocacy organisations ... usually rely on grants from local authorities and charitable trusts for funding. This type of funding tends to be insecure and may restrict the activities of the organisations to a particular sector of the community, or type of case. The result is that these organisations are unlikely to be able to provide unlimited advice and advocacy for all parents who approach them';<sup>16</sup>

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<sup>13</sup> Booth and Booth, 'Advocacy for Parents with Learning Difficulties', Findings, Joseph Rowntree Foundation, 1998, p. 10.

<sup>14</sup> Ibid p. 10.

<sup>15</sup> Which can be considered relevant for the case of parents with learning disabilities.

<sup>16</sup> Lindley B and Richards M, Centre for Family Research – University of Cambridge, 'Protocol on Advice and Advocacy for Parents (Child Protection)', 2002, p. 12.

- 52 % of the advocacy schemes which answered a survey said that they do see people with a 'learning disability' as being a main client group for advocacy provision;<sup>17</sup>
- The involvement of independent advocates is critical for supporting parents with learning disabilities. However, 'the lack of independent advocates (paid or voluntary) can ... pose difficult role conflicts for professionals supporting parents with learning disabilities who are involved in child protection procedures ...';<sup>18</sup>
- 'The development of this much needed form of specialist advocacy [advocacy for parents with learning disabilities involved in child protection procedures] should be supported at a national level. There is an urgent need for the development of specific services... The development of this emerging area of advocacy should also be supported by national guidelines clarifying an advocate's role within child protection proceedings as well as they training and support they require in this emotionally draining area of work';<sup>19</sup>

<sup>17</sup> Clipson C and Lewington W, 'Advocating for Equality', SCOPE, 2003, p. 15. This was the highest percentage in the answers, being followed by 'mental health issues' (41 %), 'elderly' (28 %), 'physical impairments' (27 %), 'sensory impairments' (18 %), 'black and ethnic minority' (17 %), 'profound and multiple impairments' (11 %), and 'communication impairments' (10 %). This document clarified that 'percentages total more than 100 because respondents could choose more than one option'.

<sup>18</sup> Tarleton B, Ward L and Howarth J, 'Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children', 2006, pp. 90-91.

<sup>19</sup> Tarleton B, Norah Fry Research Centre, 'Specialist advocacy services for parents with learning disabilities involved in child protection proceedings', 2007 Blackwell Publishing Ltd, British Journal of Learning Disabilities, 36, p. 139.



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**

- ‘... where there are a complex interaction of issues involving parents with a learning disability perhaps the most effective model of advocacy would involve work with a professional advocate’,<sup>20</sup>
- ‘The evidence that exists shows that benefits of advocacy input for disabled parents in this situation [disabled parents whose children are subject to safeguarding procedures] include: increased and better quality involvement of parents throughout the child protection process, including increased understanding of the process by parents; increased knowledge and understanding among other professionals of the needs of disabled parents; better communication between parents and professionals; positive impact on empowerment and personal development of parents involved in child protection proceedings (in terms of an increased understanding of the reasons for loss of custody of their child, where this was an outcome).<sup>21</sup>

Another crucial issue is whether accessing an advocate constitutes a legal right or not. In the case of the United Kingdom, it has been defended that a right to access an advocate is *specifically* recognised only to people who are in certain situations.<sup>22</sup>

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<sup>20</sup> Glasgow School of Social Work, ‘Parents with Learning Disabilities – The Lived Experience – A study for Equal Say, Glasgow’, 2008, p. 43.

<sup>21</sup> Townsley R, Marriott A and Ward L, ‘Access to Independent Advocacy: An Evidence Review’, Office for Disability Issues, 2009, p. 133.

<sup>22</sup> <http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=715&articletype=20> ((last accessed on 28<sup>th</sup> June 2010).



In the case of parents with learning disabilities ‘there is no statutory provision for independent advocacy for parents with learning disabilities in the UK, even when their children are subject to safeguarding procedures’.<sup>23</sup> However, international law provides interesting resources for sustaining a right to access an advocate. In this way, it has been argued that international human rights law provides with sources for a right to advocacy through generic human rights norms and the Convention on the Rights of Persons with Disabilities.<sup>24</sup> Generic human rights norms offer dispositions connected to access to justice, socio-economic human rights and the human dignity principle. The United Nations Disability Convention offers dispositions connected to autonomy rights (ie: capacity) and participatory rights.<sup>25</sup> Arguably, also the United

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<sup>23</sup> Ward L and Tarleton B, Advocacy for Change: “The Final Tool in the Toolbox?” in *Parents with Intellectual Disabilities: Past, Present and Futures* Edited by Llewellyn G, Traustadóttir R, McConnell D, and Björg Sigurjónsdóttir H, Wiley-Blackwell, 2010, p. 231.

<sup>24</sup> Eilionóir Flynn (Centre for Disability Law and Policy), ‘Advocacy for people with disabilities – An innovative enforcement mechanism for human rights’, available at [http://webcache.googleusercontent.com/search?q=cache:QD\\_8oikbmAYJ:www.nuigalway.ie/cdlp/documents/publications/Flynn%2520CDLP%2520seminar%2520series%252002-10-09.ppt+&cd=1&hl=es&ct=clnk](http://webcache.googleusercontent.com/search?q=cache:QD_8oikbmAYJ:www.nuigalway.ie/cdlp/documents/publications/Flynn%2520CDLP%2520seminar%2520series%252002-10-09.ppt+&cd=1&hl=es&ct=clnk) (last accessed on 5<sup>th</sup> July 2010). The Convention on the Rights of Persons with Disabilities was adopted on 13 December 2006 at the United Nations Headquarters in New York (hereinafter, the United Nations Disability Convention).

<sup>25</sup> Eilionóir Flynn (Centre for Disability Law and Policy), ‘Advocacy for people with disabilities – An innovative enforcement mechanism for human rights’, available at [http://webcache.googleusercontent.com/search?q=cache:QD\\_8oikbmAYJ:www.nuigalway.ie/cdlp/documents/publications/Flynn%2520CDLP%2520seminar%2520series%252002-10-09.ppt+&cd=1&hl=es&ct=clnk](http://webcache.googleusercontent.com/search?q=cache:QD_8oikbmAYJ:www.nuigalway.ie/cdlp/documents/publications/Flynn%2520CDLP%2520seminar%2520series%252002-10-09.ppt+&cd=1&hl=es&ct=clnk) (last accessed on 5<sup>th</sup> July 2010).



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**



Nations Disability Convention offers more dispositions that could be used to base this right, such as articles 9 and 21. In this way, article 9 ('Accessibility') establishes that the State has 'to promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information'. Article 21 says that:

'States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice ...'

It is essential to take into account that the United Kingdom ratified the United Nations Disability Convention on 8 June 2009 and the provisions of this convention are mandatory for this country. This means that the United Kingdom must interpret the law integrating the United Nations Disability Convention's provisions. Therefore, the State has the obligation of exercising an interpretation towards a right to access an advocate for parents with learning disabilities. Moreover, this interpretation would comply with the postulates of the social model of disability as the State would be the one providing to the person with a learning disability with the right support, or in other words in this case, with the legal access to an independent advocate.

In addition to the consideration of the access to an advocate as a legal right, it must be said that this access has been contemplated in policy documents. Examples of these documents are the strategy 'Valuing People' and the strategy 'Improving the



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**



Life Chances of Disabled People'.<sup>26</sup> In addition, the essential 'Good Practice Guidance - Supporting Parents with Learning Disabilities'<sup>27</sup> establishes that one of the 5 points of good practice in working with parents with learning disabilities is the access to independent advocacy by these parents.<sup>28</sup>

### 3. What we know more after this report: the findings

#### 3.1. Methodology

The main goal with this scoping exercise has been to showcase what national best practice is, and what the benefits are, of independent advocacy for parents with learning disabilities.

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<sup>26</sup> <http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=715&articletype=20> ((last accessed on 28<sup>th</sup> June 2010). Both of the strategies mentioned can be found in the document Valuing People Now: A New Three-Year Strategy for people with learning disabilities: 'Making it happen for everyone' (available at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH\\_093377](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_093377) -last accessed on 5th July 2010), and in the document 'Improving the Life Chances of Disabled People' (available at <http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf> -last accessed on 5th July 2010).

<sup>27</sup> This publication can be obtained from CHANGE at <http://www.changepeople.co.uk/productDetails.php?id=1736&type=4> (last accessed on 2<sup>nd</sup> July 2010).

<sup>28</sup> Ibid p. 13.



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**

We intended to answer the following two subsidiary research questions,

- Where is independent advocacy for parents with learning disabilities working well?
- Why do we know that this independent advocacy is working properly?

To answer these questions, we interviewed people with learning disabilities as users of advocacy. The researcher explained the project to people with learning disabilities in an accessible way. We stressed that the personal data and the information given by people with learning disabilities was going to be anonymised in the final document. People with learning disabilities agreed to participate in the project.

In addition, an introductory letter and a questionnaire were sent mostly to advocacy organisations (see annex 1 and annex 2). At this point CHANGE would like to thank the Norah Fry Research Centre because they provided us with the questionnaire that they designed for their research 'Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children'.<sup>29</sup> The Norah Fry Research Centre's questionnaire provided useful insight and

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<sup>29</sup> Tarleton B, Ward L and Howarth J, 'Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children', 2006.



guidance at the moment of elaborating CHANGE's questionnaire. The questionnaire was sent by e-mail and by post to advocacy organisations<sup>30</sup> who work with parents with learning disabilities. In addition, the questionnaire has also been sent to advocacy organisations who for example do not work with parents with learning disabilities and do work with issues as mental health. We decided not to send the questionnaire only to organisations working with parents with learning disabilities because perhaps a good practice example in the mental health area, could be extrapolated to the area of work with parents with learning disabilities. The list offered by Action for Advocacy in their website<sup>31</sup> has been specially useful for selecting possible respondents. The questionnaire was sent to approximately 268 organisations. The number of organisations which replied to the questionnaire has been of 42. This number includes one organisation which replied twice to the questionnaire; however, as the researcher detected a discrepancy among the two replies, both of the replies have been included to the effects of calculating percentages. The last deadline advertised for filling in the questionnaire was 25<sup>th</sup> June and only the replies which arrived to CHANGE until 30<sup>th</sup> June were analysed. The rate of responses received has been of 15.67 %. This rate is near to the standard expected rate (around 20 %).<sup>32</sup> Regarding the organisations which did not reply to the questionnaire, CHANGE considers the possibility that some organisations do not identify themselves as providers of this kind of advocacy (when actually they could provide this advocacy). This last possibility could be connected with a lack of awareness among some organisations. Finally, the very short deadline

<sup>30</sup> And at least to one service.

<sup>31</sup> <http://www.actionforadvocacy.org.uk/> (last accessed on 1<sup>st</sup> July 2010).

<sup>32</sup> University of Leeds, Information System Services, 'Guide to the Design of Questionnaires, A general introduction to the design of questionnaires for survey research', 2001, p. 4.

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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for this research prevented the researcher of making a telephonic follow-up of the questionnaire.

We also conducted four visits to advocacy organisations. CHANGE's solid experience of working with parents with learning disabilities (and with respect to the issues that concern these parents) was fundamental when the researcher had to select the places to visit.

Finally, replies received to another questionnaire sent by CHANGE, in the context of a different but related project, were considered for answering the research questions of this research. CHANGE is working in partnership with the charity NAAPS on a project funded by the Baily Thomas Charitable Fund. This project intends to help Shared Lives Schemes learn from existing good practice in supporting parents with learning disabilities. In the context of this project, a survey was sent. Question 3a8 of the survey addressed the matter of advocacy. Respondents have been asked to rate the advocacy service in their respective area, with respect to its support for parents with a learning disability, from 0 (poor) to 5 (excellent). The answers received to the moment have also been considered for enriching CHANGE's piece of research for the Office of the National Director for Learning Disabilities.

The available time scale (40 working days) did not permit us to develop a global and in-depth study of the evidence, but allowed CHANGE to build a clear picture about some of the best national practice in the field. CHANGE's experience in working with parents with learning disabilities and advocacy issues clearly contributed to work

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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within a tight time scale. Our experience also indicated us that independent advocacy for parents with learning disabilities must be evaluated under two fundamental criteria: first, if the independent advocacy in question is aware of the issues that concern parents with learning disabilities, and second, if the independent advocacy is really independent (for example, independent from social services).

### 3.2. Profile of the participants

As it was advanced in the introductory letter (see annex 1) sent to the respondents of CHANGE's questionnaire for the Office of the National Director for Learning Disabilities, all sensitive or confidential data were going to be anonymised. It was advanced that personal data regarding parents with learning disabilities won't be included in this report. These same considerations apply to the cases of organisations visited by CHANGE and to the answers to the survey sent by CHANGE and NAAPS in the context of the Shared Lives Schemes' project. In summary, the information regarding the participant's name and address is not included in this document.

However, and in addition to the fact that 100 % of the respondents answered to question 3 of CHANGE's questionnaire for the Office of the National Director for Learning Disabilities stating that they do provide advocacy, it is possible to have an idea of the participants' profile differentiating according to different regions. Given the remit of the Office of the National Director for Learning Disabilities, the questionnaire was mostly sent to possible respondents located in England and Wales. However, a



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**



few replies from Scotland were received. In addition, one organisation located in Australia replied to the questionnaire. As examples of good or bad practice which are happening in other places could be extrapolated to the case of England and Wales, the answers from Scotland and Australia have been included. Replies to the survey sent by CHANGE and NAAPS in the context of the Shared Lives Schemes' project came from England and Wales. The organisations visited by CHANGE are included in the following tables (as all of them replied to our questionnaire) and the parents with learning disabilities interviewed were connected to some of these organisations.<sup>33</sup> In addition, the researcher interviewed one parent with a learning disability in Leeds. Taking all of this into account, the following tables show the respondents by region,

Table 1: respondents – England and Wales

Regions	Number of respondents
East Anglia	1
London	10
Midlands (East)	2
Midlands (West)	4
North (East)	9
North (West)	3

<sup>33</sup> And, therefore, they are also included in the tables.

South (East)	10
South (West)	5
Yorkshire and the Humber	3
Wales	2

Table 2: respondents – Scotland

Regions	Number of respondents
Glasgow	1
Orkney	1

Table 3: respondents – Australia

Regions	Number of respondents
Weston Greek Act	1

### 3.3. Building a model of good practice in advocating for parents with learning disabilities

Replies to the survey sent by CHANGE and NAAPS in the context of the Shared Lives Schemes' project prove that there is a different advocacy support for parents



with learning disabilities according to the geography. In other words, this means that there are more problems in advocating for parents with learning disabilities in some areas than in others. In fact the 10 questionnaires received to the moment have demonstrated that,

- 50% of the respondents rated the advocacy service in their respective area from 0 to 3 (respondents located in South East, North East and West Midlands);
- 20% of the respondents rated the advocacy service in their respective area from 4 to 5 (respondents located in London);
- 30% of the respondents did not answer the question.

Replies to the questionnaire sent by CHANGE in the context of the piece of research for the Office of the National Director for Learning Disabilities enriched the understanding of how advocacy is working in different geographical areas and highlighted a number of different issues. Also the interviews with parents with learning disabilities and the visits to organisations contributed to the identification of issues with respect to different regions. The main issues are presented following.

***a) Proper funding which allows to provide advocacy for all parents with learning disabilities***

A good independent advocacy for parents with learning disabilities requires of sufficient funding.

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**

 **www.changepeople.co.uk**

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This research showed that the lack of funding is a reality in this field, as 52.38 % of the respondents mentioned the issue of 'funding' or 'money' in their answers to question 18 of the questionnaire. Indeed some respondents mentioned the problem with funding as part of their answers to other questions. This means that the aforementioned 52.38 % could be higher. The following answer constitutes an example of the lack of funding for providing this advocacy:

'We do provide advocacy for parents with disabilities. However, in the past we have supported families through the child protection process this as [has] included going to core review meeting case conferences, solicitors and court. There is a real need for this type of advocacy because parents with disabilities really do get lost in the system. They certainly don't have a voice.

We are still working with a couple of families however, when they go to final hearing we won't be taking on any more cases. This is due to the lack of funding because of the time it takes with each family and the cost of mileage [mileage].

There is a real need for this service and we are very worried about the parents in ... who now won't be able to access our service. We are still receiving referrals from [from] social workers who really value our service, we have written and e-mailed the strategic manager in children's services and we haven't even had a reply.' (answer to question 9)



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**

Some respondents also raised the issue of restrictions imposed by funders. These restrictions do not allow an organisation to advocate for parents with learning disabilities, or allow only certain parents to access the advocacy:

- One respondent mentioned that his organisation do provide advocacy for parents with learning disabilities, but clarified that they provide this advocacy with 'limited numbers [of parents with learning disabilities] as agreed with funder' (answer to question 9);
- A respondent answered that his organisation does not provide advocacy for parents with learning disabilities 'due to the criteria being set by funders' (answer to question 10);
- A respondent answered that his organisation 'have to adhere to the criteria, whilst recognising that all parents, including those who may have a learning difficulty, rather than a disability, would benefit from support' (answer to question 17).

### ***b) Sufficient staff***

Clearly linked to the funding element, there is the element of staff. If an organisation does not count with sufficient staff,<sup>34</sup> it won't be able to provide an effective independent advocacy for parents with learning disabilities.

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<sup>34</sup> Usually, when an organisation does not count with sufficient staff, this is produced by a lack and/or limited funding.



Moreover, when it is the case of advocating for parents with learning disabilities, CHANGE was told that assigning an advocate per parent is the best way of doing this.<sup>35</sup> In addition, an important bibliographic reference established that 'eight families is the upper limit for a full-time advocate'.<sup>36</sup>

The organisation was also told that an advocate who works with parents with learning disabilities should have the choice of doing this kind of job or not.<sup>37</sup> This suggests that an advocate who is advocating for parents with learning disabilities by obligation instead of choice, in principle, would not be a good advocate.

This small piece of research demonstrated that lack of staff, or insufficient staff, has been a variable in the answers received to CHANGE's questionnaire. The evidence here is that the fact that 23.80 % of the respondents answered to question 18 by mentioning problems with staff (meaning the need of staff, or more staff, or full-time staff, or specialized staff) in order to provide an effective advocacy.

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<sup>35</sup> Interview with the Director of an advocacy organisation. This interview took place on 18<sup>th</sup> June 2010.

<sup>36</sup> Booth and Booth, 'Advocacy for Parents with Learning Difficulties', Findings, Joseph Rowntree Foundation, 1998, pp. 12.

<sup>37</sup> Interview with the Director of an advocacy organisation. This interview took place on 18<sup>th</sup> June 2010.



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**

**c) Trained staff**

Advocacy for parents with learning disabilities requires of staff who has the right skills. A knowledge of the issues that concern parents with learning disabilities, the learning of how to deal with the emotional implications that a case might produce in an advocate, or the skills regarding communication with a person with a learning disability, are some strong examples of the skills required in the area.

The acquisition of the rights skills is linked to an appropriate training. For example, it was advanced that CHANGE provides training. CHANGE hosts the initiative 'Parents training for CHANGE'. Parents with learning disabilities are employed at CHANGE to campaign, train and advise on best practice. The aim of this training is to make sure social services, health staff and legal teams support people with learning disabilities to have a positive experience as parents. By staff and parents with learning disabilities taking part in training together, everybody learns about: good ways of support, better communication, and better assessments. This training also explains what the 'Good Practice Guidance - Supporting Parents with Learning Disabilities' is.<sup>38</sup> The Parents Training for Change team have trained people with learning disabilities to set up local Parents Groups to train Social Workers, the group has presented at the Family Law Association National Day Conference, and the group

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<sup>38</sup> This publication can be obtained from CHANGE at <http://www.changepeople.co.uk/productDetails.php?id=1736&type=4> (last accessed on 2<sup>nd</sup> July 2010).



also trained Social Workers in Children's Services in West Yorkshire, Bristol, Norwich and North Somerset.<sup>39</sup>

This research showed that 50 % of the respondents answered to question 13 stating that they did not receive any training for dealing with parents with learning disabilities, that 47.61 % of the respondents said that they received training on this regarding, and that 2.38 % of the respondents did not answer the question.

There have been interesting points as a result of the additional comments that respondents provided to question 13, and from the answers to question 14:

- At least 4 respondents additionally commented to question 13 that they have their own training, or a solid experience in working on the issue, or research, or experience in parenting;
- 7.14 % of the respondents clarified that they undertook training specifically directed to the topic of parents with learning disabilities (answer to question 14);
- 4.76 % of the respondents indicated that they do provide training specifically directed to the topic of parents with learning disabilities (answer to question 14).

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<sup>39</sup> <http://www.changepeople.co.uk/training.php> (last accessed on 2<sup>nd</sup> July 2010). For more details about CHANGE's training, please contact Austin Bradshaw ([austin@change-people.co.uk](mailto:austin@change-people.co.uk)) who is the Training Coordinator.



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**

As the previous percentages show, although at a first view it seems that a high number of respondents received training for dealing with parents with learning disabilities, the additional comments to question 13 and the answers to question 14 demonstrate that a low percentage of respondents (approximately 11.9 %) received training for working with parents with learning disabilities or are providing training on the issue.

Finally, what seems clear from the answers is that the offer of valuable training for working with parents with learning disabilities is really low. Perhaps this is associated to a lack of awareness (and consequent interest) about the rights of parents with learning disabilities. As an advocate commented to CHANGE in an interview, for example her organisation is trying to put in place local training delivered by parents but the interested that they received has been low.<sup>40</sup>

#### ***d) Independence***

Questions 5, 6 and 7 of CHANGE's questionnaire dealt with the issue of independence.

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<sup>40</sup> Interview with an advocate who works for an advocacy organisation. This interview took place on 15<sup>th</sup> June 2010.

Question 5 asked how the advocacy is funded. Only 7.14 % of the respondents did *not* mention in their answers that they received funding from, for example, Social Services or the local authority.

Question 6 asked the respondents if the advocacy that they provide is independent from services and their staff. 97.61 % of the respondents answered 'yes', while 2.38 % of the respondents answered 'no'<sup>41</sup>.

Finally, question 7 found out about what the participants' understanding of 'independent advocacy' is. In this case, in general the answers provided by the respondents were on line with the considerations presented in point 2.2. of this small piece of work.

***e) Advocacy which covers all of the issues that concern parents with learning disabilities***

When the issues that concern parents with learning disabilities are being discussed, the most legitimated persons to speak about these issues are parents with learning disabilities themselves. Advocacy is about making a person's voice heard. Advocacy for parents with learning disabilities won't be possible if the parent's voice is not taken into account.

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<sup>41</sup> The respondent in this case pertains to a service which depends on the NHS.



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**

One of the parents with learning disabilities interviewed by CHANGE was very clear about some of the main issues that concern parents with learning disabilities:

*'Feeding, bathing, sleeping patterns, dressing, food, money... To look, how to look after the children... Every parent is different.'*<sup>42</sup>

This parent also addressed the issue of assessments.<sup>43</sup> According to this parent, these assessments should be:

*'At home; with less people doing it; focused on things that they [the parents] can do; [the] advocate should be in the assessment.'*<sup>44</sup>

Having an idea of the issues that concern parents with learning disabilities, it is time to analyse the information provided by the replies to CHANGE's questionnaire. The answers to question 12 are helpful at this point, as this question asked the advocacy organisations which are providing advocacy to parents with learning disabilities

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<sup>42</sup> Interview with Paul (this is a fictitious name) on 23<sup>rd</sup> June 2010.

<sup>43</sup> The assessment conducted by Social Services to evaluate if the parent with a learning disability is able to cope with a baby.

<sup>44</sup> Interview with Paul (this is a fictitious name) on 23<sup>rd</sup> June 2010.

about the main areas targeted by the advocacy offered.<sup>45</sup> The answers demonstrated that,

- 30.95 % of the respondents replied that they do provide advocacy for parents with learning disabilities regarding independent living;
- 40.47 % of the respondents replied that they do provide advocacy for parents with learning disabilities regarding the role as a parent with a learning disability;
- 80.95 % of the respondents replied that they do provide advocacy for parents with learning disabilities regarding these parents and children protection procedures;
- 26.19 % of the respondents replied that they do provide advocacy for parents with learning disabilities regarding another area;
- 9.52 % of the respondents did not reply to this question or considered it as non-applicable.<sup>46</sup>

#### ***f) Accessible information and communications***

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<sup>45</sup> The question asked the respondents to tick among four possibilities: 'advocacy regarding independent living', 'advocacy regarding the role as a parent with a learning disability', 'advocacy regarding parents with learning disabilities and children protection procedures', and/or 'another area'.

<sup>46</sup> These percentages sum to over 100 % because some respondents ticked more than one option.



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**



Advocacy is about voice and communication. Parents with learning disabilities have, in general, specific needs for communication. If the information provided to parents with learning disabilities is not accessible, the communications between the parent with a learning disability and the advocate won't be possible. The right to accessible information and communications is clearly established in the law. The United Nations Disability Convention establishes this right in its article 9:

'1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, **to information and communications**, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas ...' [bold highlighted by the researcher]

There is not a unique way of making information accessible to people with learning disabilities. CHANGE chose to work on this area by using easy words and pictures. Working with easy words means for us to write in short and simple sentences, without any hard words or jargon. Hard words are words that are not generally used in everyday conversation, as for example, the word 'participation'.<sup>47</sup> Jargon words are words that professionals often use to communicate with each other, as for example, the word 'misdemeanour' (a small crime that is not as serious as murder or

<sup>47</sup> How to make information accessible: a guide to producing easy read documents (CHANGE publication - <http://www.changepeople.co.uk/shop.php> -last accessed on 6<sup>th</sup> July 2010).



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



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rape).<sup>48</sup> In addition, CHANGE counts with specialized illustrators who work alongside people with learning disabilities and who produce a range of appropriate pictures. Combining easy words and pictures, CHANGE has produced a number of accessible publications regarding parents with learning disabilities. Some examples of them are: *My Pregnancy, My Choice*; *You and Your Baby 0-1*; and *You and Your Little Child 1-5*.<sup>49</sup> These publications are sold successfully and, for example, Scotland included in the Good Practice Guidance that CHANGE books are given to all parents with learning disabilities.

Question 15 of the questionnaire addressed the issue of accessibility. The answers received showed that 64.2 % of the respondents said that they do provide information which contains words and pictures, 16.66 % of the respondents said that they do provide information which contains *only* easy words, 4.76 % of the respondents said that they do provide information which *do not contain* not only easy words but also pictures, 11.90 % of the respondents did not answer the question, and 2.38 % of the respondents only answered the question by stating 'ensure that info is clear & easy to access & in an understandable format'. Additional comments that accompanied some of the answers (and therefore are included in the aforementioned percentages) have been the following ones:

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<sup>48</sup> Ibid.

<sup>49</sup> All of these publications can be obtained from CHANGE at <http://www.changepeople.co.uk/catalogue.php?type=3> (last accessed on 2<sup>nd</sup> July 2010).



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



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- [Making reference to pictures] ‘Yes – but not enough!!’ [respondent who said that provides information containing easy words and pictures];
- ‘But it is local authority duty under DDA to produce info in this accessible format ...’ [respondent who said that provides information containing easy words and pictures];
- [Making reference to pictures] ‘We use real life photos of parents’ [respondent who said that provides information containing easy words and pictures];
- [Making reference to easy words] ‘Some if available’ [respondent who said that provides information containing *only* easy words];
- ‘Pictures “would if necessary” [respondent who said that provides information containing *only* easy words]

### **g) Time, costs and outcomes**

A number of variables determine that advocacy for parents with learning disabilities will take a much longer time than advocacy which is not directed to them. Some examples of these variables are: people with learning disabilities’ communication needs or the chaotic characteristics of many parents with learning disabilities’ lives (as, for example, difficulties with money)<sup>50</sup>. If not properly addressed, all of these

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<sup>50</sup> It should be stressed that if people with learning disabilities have, in many cases, lives with chaotic characteristics, this is highly motivated by the lack of support available for people with learning disabilities.



variables can have a negative repercussion in the relationship between the parent with a learning disability and his or her advocate.

It is clear that advocacy for parents with learning disabilities will take much more time than advocacy which is not willing to address this group of people. However, it is really difficult to determine a standard duration time for the advocacy process in these cases. As this kind of advocacy takes more hours than an 'ordinary' advocacy, and also the number of hours can't be easily foreseen, this means that advocacy for parents with learning disabilities is considerably more expensive than the advocacy which is not directed to them.

Connected to the impossibility of advancing a duration time there is the difficulty of advancing the outcomes of this advocacy. As the director of a well known advocacy organisation expressed, 'measuring advocacy is almost impossible'.<sup>51</sup>

The previous difficulties of foreseeing time and outcomes for advocacy are intrinsically related to the problem of funding. Because more hours of advocacy, and a high level of uncertainty about how long it will take, makes the act of getting funders and funding really complicated.

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<sup>51</sup> Interview with the Director of an advocacy organisation. This interview took place on 18<sup>th</sup> June 2010.

Replies to question 17 demonstrated that, basically, a combination of available short term advocacy and late referrals from certain services makes it impossible to comply with the goal of a good advocacy provision. 28.57 % of the respondents to question 17 answered that they encounter problems regarding the time that they can offer for advocacy. However, more respondents mentioned problems on these specific issues in their answer to different questions, what means that in the reality the percentage is higher than the referred 28.57 %. Some answers have been the following and illustrate the state of affairs regarding advocacy and timing,

- ‘... We only have 18 hours a week funding & are finding it impossible to sustain given that we are a large rural county with lots of travel time involved. Currently this is sustained by overtime, unpaid.’ (answer to question 11);
- ‘... Waiting for “crisis” to develop rather than advocacy bought in earlier. Time constraints ... short term advocacy. No long term advocacy available.’ (answer to question 17);
- ‘Working with parents can be difficult for advocates as the cases tend to be very long and complicated and by their nature, can be emotionally draining on the advocate. Parents are expected to take in a lot of complicated information in a very short period of time – this doesn’t always give parents enough time to consider their options.’ (answer to question 17);
- ‘Timing of referrals can be an issue as these cases need to be dealt with quickly so referrals can come in too late sometimes and then it is hard to build a relationship with the parent in a short space of time. Ideally, we would like to get to know the parents before we attend court, case conferences etc with them.’ (answer to question 17);

- 'The situation does not allow enough time to be able to fully involve the person I am advocating ...' (answer to question 17);
- '... supporting parents fully & effectively is extremely time consuming, emergencies can arise on a weekly basis. Court proceedings can be up to 4 days in length – we do not have the time resources via the “standard” advocacy project ...' (answer to question 17);
- 'Sometimes referral to our service is made when Care Proceedings have already been instigated, or when it is close to the final hearing. It is often the case that parents are provided with reports a few minutes prior to child protection conferences taking place. This allows little time to read through the documentation with them, or to challenge content ...' (answer to question 17);
- 'Not given enough time at case conferences to read and explain reports to services users. This therefore puts the service user at a disadvantage in formulating any response or contributing to the case conference.' (answer to question 17)
- 'IN CHILD PROTECTION – sometimes not enough time for discussion with client to ensure they understand what is to be said at social work meetings – papers prepared too late by social workers (although this is less of a problem than previously)' (answer to question 17).

#### ***h) Links with other services and collaboration***

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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An interesting number of respondents mentioned that a good advocacy requires of good links and collaboration with other services (as, for example, Social Services). Many respondents mentioned that an important problem for advocacy is constituted by the attitudes of, specially, Adult Social Services and Children's Services. These services, according to the respondents, are characterized by a lack of coordination and by certain attitudes that influence the quality of the advocacy which can be finally offered. For example, it has been said in many cases that these services do not send reports required for meetings in advance, or in other words, that these services do not allow the advocate and the person with a learning disability to prepare a meeting properly (as they do not have the information with sufficient time in advance).

The views of a parent with a learning disability confirm some of the respondent's concerns. In an interview with April, she told the researcher the following thoughts about the work of, particularly, Social Services,<sup>52</sup>

*'Show to social workers ... how to work with people with learning disabilities [in her organisation, people with learning disabilities show to social workers how to work with people with learning disabilities]'*

*'Listen to people [they should listen to people], they do not listen [social workers], they are never patient, they are not quite good in a meeting'*

*'... longer time ... Time for thinking [parents with learning disabilities require of more time for thinking]'*

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<sup>52</sup> Interview with April (this is a fictitious name) on 15<sup>th</sup> June 2010.



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



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*'Don't use jargon words [Social Services should not use jargon words]'*

*'Explaining to people what they are doing first, official people ["official" people, in this case for example Social Services, in first place should explain to people with learning disabilities what they are doing]'*

In addition, the worker for an advocacy organisation interviewed by CHANGE, stressed that the reality that she regularly faces is that a considerable number of assessments to parents with learning disabilities are conducted by social workers without any experience on the issue.<sup>53</sup> Another worker for a different advocacy organisation, also interviewed by CHANGE, told us that in her area it is usual that when the case is related to a parent with a learning disability, this case is taken by a student rather than by a proper social worker.<sup>54</sup>

#### **4. Conclusions and recommendations**

This scoping exercise, although short, has confirmed many of the issues detected by previous research in the area. In addition, new evidence has been provided.

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<sup>53</sup> Interview with an advocate who works for an advocacy organisation. This interview took place on 24<sup>th</sup> June 2010.

<sup>54</sup> Interview with an advocate who works for an advocacy organisation. This interview took place on 29<sup>th</sup> June 2010.



Perhaps the most crucial contribution of this piece of work is the interpretation of a right to access an advocate for parents with learning disabilities, with basis on international law. This research demonstrated how specially the United Nations Disability Convention offers tools for sustaining a right of this kind. If parents with learning disabilities are legally entitled to access an advocate, all of the discourse in this area and all of the respective obligations will change. In other words, looking at the issue from a law perspective, it is not sufficient with a recognition of the access to an advocate in policy documents. The State and all of its components must then provide funding and other tools (for example, training) required by this kind of advocacy.

Having said this, the research demonstrated how the support offered by parents with learning disabilities in terms of advocacy, varies according to different regions.

In addition, this piece of work found major problems such as the following. Lack of funding and/or restrictions placed by funders were detected. Fundamental problems regarding staff of advocacy organisations, in relation to quantity, allocated time, and training, also appeared clearly. The lack of offer in specialized training for working with parents with learning disabilities was highlighted. After the research, the organisation has also serious concerns in relation to the accessibility of information and communications. Although parents with learning disabilities have a clear right to accessible information and communications, this work identified a number of problems with respect to the implementation of this right. In addition, this research

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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identified the big problem constituted by the time duration required by this type of advocacy.

CHANGE then would like to make a number of main recommendations. Although these recommendations are directed to different key stakeholders (and specially to advocacy organisations), the Office of the National Director for Learning Disabilities can make use of them to evaluate its next steps in the direction of good advocacy for parents with learning disabilities:

- Stakeholders should understand that the United Kingdom has the obligation of interpreting the law by using, for example, the provisions provided by the United Nations Disability Convention. Parents with learning disabilities have a right to access to an advocate if the interpretation of this possible right is enriched with the content of international law. Stakeholders should perform an interpretation of the law in this direction;
- Funding should be provided for advocacy for parents with learning disabilities. Funders should be aware about the danger of placing any kind of restriction on this area;
- Provided that they have funding, advocacy organisations should employ sufficient and skilled staff for working with parents with learning disabilities. Advocacy organisations should make sure that this staff can dedicate to this kind of advocacy the time that it requires while respecting a certain set of values;
- Stakeholders should pursue that adequate training for advocacy with respect to parents with learning disabilities is available (in terms, for example, of

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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costs). A national initiative at this point is lacking and therefore it should be put in practice. Specialized organisations as CHANGE can successfully contribute to this initiative and should be taken into account;

- Although the research demonstrates that the standard of independence is much more clear in the documents than in the practice, in order to achieve the highest possible standard, CHANGE considers that it would be useful to conduct a much more detailed study (with consequent time and funding). This study would permit to perform an indepth evaluation of, specially, the policy documents that are being followed by advocacy organisations;
- Advocacy organisations and services must provide, according to the law, accessible information and communications to parents with learning disabilities. Also in this case a national initiative seems necessary. This initiative could make a reality and coordinate the fact that accessible resources are mandatory given to parents with learning disabilities. As it was mentioned before, organisations like CHANGE should be considered to the effects of providing these materials.

We are aware that the preceding conclusions are not positive. We are also aware that our recommendations are not easy to put in practice. However, we are convinced that a radical change is necessary. Until this change does not happen, parents with learning disabilities' dignity and human rights won't be a part of these parent's *real* lives.

## 5. References

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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Advocacy 2000, 'Principles and standards in Independent Advocacy organisations and groups', 2002

Action for Advocacy, 'Quality Standards for Advocacy Schemes – Based on the Advocacy Charter', 2006

Barnes C and Mercer G, *Disability*, Cambridge: Polity Press, 2003

Booth and Booth, 'Advocacy for Parents with Learning Difficulties', Findings, Joseph Rowntree Foundation, 1998

CHANGE, 'How to make information accessible: a guide to producing easy read documents', available at <http://www.changepeople.co.uk/shop.php>

CHANGE, 'My Pregnancy, My Choice', available at <http://www.changepeople.co.uk/catalogue.php?type=3>

CHANGE, 'You and Your Baby 0-1', <http://www.changepeople.co.uk/catalogue.php?type=3>

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 **info@change-people.co.uk**  **www.changepeople.co.uk**

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CHANGE, 'You and Your Little Child 1-5', available at <http://www.changepeople.co.uk/catalogue.php?type=3>

Clipson C and Lewington W, 'Advocating for Equality', SCOPE, 2003

Flynn E (Centre for Disability Law and Policy), 'Advocacy for people with disabilities – An innovative enforcement mechanism for human rights', available at [http://webcache.googleusercontent.com/search?q=cache:QD\\_8oikbmAYJ:www.nuigalway.ie/cdlp/documents/publications/Flynn%2520CDLP%2520seminar%2520series%252002-10-09.ppt+&cd=1&hl=es&ct=clnk](http://webcache.googleusercontent.com/search?q=cache:QD_8oikbmAYJ:www.nuigalway.ie/cdlp/documents/publications/Flynn%2520CDLP%2520seminar%2520series%252002-10-09.ppt+&cd=1&hl=es&ct=clnk)

Glasgow School of Social Work, 'Parents with Learning Disabilities – The Lived Experience – A study for Equal Say, Glasgow', 2008

'Improving the Life Chances of Disabled People' (available at <http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>)

Lindley B and Richards M, Centre for Family Research – University of Cambridge, 'Protocol on Advice and Advocacy for Parents (Child Protection)', 2002

Tarleton B, 'Providing the right support for parents with a learning disability – Evaluating the work of the north east's parents' support service and the Walsall parents' advocacy service', 2006



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



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**info@change-people.co.uk**



**www.changepeople.co.uk**

Priestley M, *Disability: A Life Course Approach*, Cambridge: Polity Press, 2003

Tarleton B, Ward L and Howarth J, 'Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children', 2006

Tarleton B, 'Specialist advocacy services for parents with learning disabilities involved in child protection proceedings', 2007 Blackwell Publishing Ltd, *British Journal of Learning Disabilities*, 36, 134–139

The Scottish Independent Advocacy Alliance, 'Principles and Standards for Independent Advocacy', 2008

Townsley R, Marriott A and Ward L, 'Access to Independent Advocacy: An Evidence Review', Office for Disability Issues, 2009

University of Leeds, Information System Services, 'Guide to the Design of Questionnaires, A general introduction to the design of questionnaires for survey research', 2001

Valuing People Now: A New Three-Year Strategy for people with learning disabilities: 'Making it happen for everyone' (available at

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH\\_093377](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_093377))

Ward L and Tarleton B, Advocacy for Change: "The Final Tool in the Toolbox?" in *Parents with Intellectual Disabilities: Past, Present and Futures* Edited by Llewellyn G, Traustadóttir R, McConnell D, and Björg Sigurjónsdóttir H, Wiley-Blackwell, 2010

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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## ANNEX 1: INTRODUCTORY LETTER

CHANGE (a leading organisation fighting for the rights of people with learning disabilities) is developing a small piece of research. This research will be about **good practice in independent advocacy for parents with learning disabilities**. This project is funded by the Office of the National Director for Learning Disabilities.

We are interested in finding out what is working well, and what is working wrong, with advocacy. This will allow us to reach to conclusions and recommendations, regarding the best way of working with independent advocacy for parents with learning disabilities.

The main research methods employed for this project are interviews and questionnaires. The data collected for this research will be analysed and reported internally. All sensitive or confidential data will be anonymised.

Because of the work that your organisation develops, CHANGE is sending you a questionnaire. If you can complete this questionnaire and return it to CHANGE's offices **before 25th June**, we thank you very much in advanced. Please return it to:

Ana Laura Aiello



**CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS



**Tel:** 0113 388 0011



**Fax:** 0113 388 0012



**Minicom:** 0113 388 0013



**info@change-people.co.uk**



**www.changepeople.co.uk**

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CHANGE

Unit 41, Shine Harehills Road

Leeds LS8 5HS

Also you will find attached a reply paid envelope. Yours sincerely,

**Ana Laura Aiello - Independent Advocacy Project**

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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## ANNEX 2: QUESTIONNAIRE

### Good practice in independent advocacy for parents with learning disabilities

#### Survey

1. Can you please tell us the name of your organisation?

2. Can you please tell us the address of your organisation?

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

 **Fax:** 0113 388 0012

 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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**3. Does your organisation provide advocacy?**

yes  no

**4. If your organisation provides advocacy, can you please describe the service that you offer?**

**5. If your organisation provides advocacy, how this advocacy is funded? (For example, the advocacy is funded by a voluntary**

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

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organisation, individually per family, by Social Services, etc.).

**6. Is the advocacy that you offer independent from services<sup>55</sup> and their staff?**

yes  no

**7. What is your understanding of 'independent advocacy'?**

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<sup>55</sup> For example, health services.

**8. Can you please tell us about your role? (For example, if you are an advocate, if you are a paid worker or a volunteer, etc.).**

**9. Does your organisation provide advocacy for parents with learning disabilities?**

*Please note that for CHANGE, the case of a person who struggles to read, or to memorise, could be the case of a person with a learning disability.*

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

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yes  no

**10. If you answered 'no' the previous question, can you explain the main reasons that prevent your organisation of advocating for parents with learning disabilities?**

**11. If you provide advocacy for parents with learning disabilities, can you please tell us approximately to how many parents with learning disabilities you are providing advocacy?**

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

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**12. If you provide advocacy for parents with learning disabilities, can you list the main areas that you are working in?**

- Advocacy regarding independent living**
- Advocacy regarding the role as a parent with a learning disability**
- Advocacy regarding parents with learning disabilities and children protection procedures**
- Another area**

**13. If you provide advocacy for parents with learning disabilities, can you tell us if you received training for dealing with parents with learning disabilities?**

yes  no

**14. If you answered 'yes' to the previous question, can you tell us which kind of training you received?**

**15. If you provide advocacy for parents with learning disabilities, do you provide information which contains:<sup>56</sup>**

Easy words? (Writing in short, simple sentences without any hard words<sup>57</sup> or jargon<sup>58</sup>)

<sup>56</sup> Please tick any of the appropriate boxes.

Pictures?


**16. Please tell us about what have worked well with the advocacy that you provide (for example, tell us about things in general that you consider as good practice).**

*Please answer this question even if you are not providing advocacy to parents with learning disabilities.*

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<sup>57</sup> Hard words are words that are not generally used in everyday conversation. For example, 'participation'. Source: How to make information accessible: a guide to producing easy read documents (CHANGE publication - <http://www.changepeople.co.uk/shop.php>).

<sup>58</sup> Jargon words are words that professionals often use to communicate with each other. For example, 'misdemeanour' (a small crime that is not as serious as murder or rape). Source: How to make information accessible: a guide to producing easy read documents (CHANGE publication - <http://www.changepeople.co.uk/shop.php>).

**17. Please tell us about what have not worked with the advocacy that you provide (for example, tell us about any problems or obstacles that you find when you provide advocacy).**

*Please answer this question even if you are not providing advocacy to parents with learning disabilities.*

**18. Please tell us about what help or resources you would need to provide an effective advocacy.**

*Please answer this question even if you are not providing advocacy to parents with learning disabilities.*

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 **info@change-people.co.uk**  **www.changepeople.co.uk**



**Thanks for your time and for filling this questionnaire! Please  
return it before 25th June to,**

**Ana Laura Aiello**

**CHANGE**

**Unit 41, Shine, Harehills Road**

**Leeds LS8 5HS**

**You can find attached a reply paid envelope.**

 **CHANGE**, Unit 41, Shine, Harehills Road, Leeds, LS8 5HS

 **Tel:** 0113 388 0011

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 **Minicom:** 0113 388 0013

 **info@change-people.co.uk**  **www.changepeople.co.uk**

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