



## Section one: The Background to the Project

You can tell someone in authority or a parent, but you are not often taken seriously or believed ... It's hard to get people to listen ... it's hard to make a complaint about someone you know - they might take it out on you ... I know where the forms are but not what to do with them ... It can be embarrassing to complain ... It is hard to complain about people because it might get them into trouble ... It is important to know who to talk to, if you don't it is very difficult to complain ... You need to be able to trust someone ... Some people are too nervous to make a complaint ... Staff can get angry and get people into trouble ... Sometimes there is no point in complaining because nothing gets done about it ... There's a fear of getting into trouble, worry about being labelled a nuisance or making things worse ... Sometimes people can say you have challenging behaviour if you disagree or complain because people are not taught how to complain the right way ... Sometimes a complaint is made and nothing is done about it; people aren't being listened to.

**Comments made by people with learning disabilities in evidence to the Joint Commission on Human Rights 2008<sup>1</sup>**

People with learning disabilities face many barriers in being able to complain about the services they receive. **'A life like any other' (2008)<sup>2</sup>** says that many do not complain because the complaints system is confusing and difficult to understand; some people do not have the confidence to complain and people with complex needs can't complain because people don't know how to communicate with them.

People with profound and multiple learning disabilities and other complex communication needs face all of these barriers and more. The scandals of **Cornwall (2006)<sup>3</sup>**, **Sutton and Merton (2007)<sup>4</sup>** and **Death by Indifference (2007)<sup>5</sup>** are sad reminders of the potential for abuse and neglect and infringement of human rights that can result when people's voices go unheard.

Nationally there is a drive to improve access to complaints procedures in both health and social care through **'Making Experiences Count' (Department of Health 2007)<sup>6</sup>**. However, people with profound and multiple learning disabilities and other complex communication needs are not going to be greatly helped simply by the production of an integrated complaints procedure or an 'accessible' complaints leaflet, however well designed.



In the light of these concerns the **Hearing from the Seldom Heard project** (2008-9), funded by the Department of Health, aims to look at how we might begin to overcome these barriers and create listening cultures within organisations to hear from those who are seldom heard. The planned outcome of the project is the creation of a freely available resource pack, to be shared widely, containing good practice recommendations, resources and links to examples of innovative work.

This project will produce an accessible guidance and complaints pack for wide use amongst services ... the primary aim is to enable people with learning disabilities, including those who do not use words to communicate, to have their voices heard when complaining about poor services they may be receiving; thereby preventing bad and potentially abusive practice across a variety of settings .. the project will work with people with a range of learning disabilities and those in services to develop an accessible complaints pack ... we will build on some of the person centred work which has been done by speech and language therapists and advocacy groups in this area – the accompanying guidance will provide practical help in adopting the pack and give ways in which the materials can be used

**Section 64 stage 2 application by BILD October 2007**

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<sup>1</sup> **A life like any other? Human Rights of Adults with learning disabilities** Seventh report of session 2007-8 volume 2 Oral and written evidence, House of Lords House of Commons Joint committee on Human Rights March 2008

<sup>2</sup> **A life like any other? Human Rights of Adults with learning disabilities** Seventh report of session 2007-8 volume 1 Report and formal minutes, House of Lords House of Commons Joint committee on Human Rights March 2008

<sup>3</sup> **Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust** Commission for Social Care Inspection (July 2006)

<sup>4</sup> **Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust** Healthcare Commission (January 2007)

<sup>5</sup> **Death by Indifference; following up the Treat Me Right! Report** Mencap (March 2007)

<sup>6</sup> **Making Experiences Count - A new approach to responding to complaints A document for information and comment** Department of Health (June 2007)