

# Women Thinking Disability

## Background and aims of project

'Equality Counting' at Engender was funded by the UK Equality and Human Rights Commission (EHRC) to promote the effective implementation of the equalities duties by establishing opportunities for dialogue between public service providers and women using their services.

The social model of disability understands people to be disabled by attitudes and barriers in our social environment. The solution to the problem is focussed on recognising this discrimination and the role that society plays in disabling its citizens. The task then is to remove barriers and secure support for disabled people to participate equally.

The following is a case study describing the story of a group of disabled women and women with disabled children who came together as a community-of-interest (c-o-i) through 'Equality Counting'. This case study along with the Oakland's story will outline group processes, expectations, impacts and outcomes.

## Introduction to community of interest

Disabled people are frequently literally invisible in our society. There is almost a parallel society for people with disabilities with different schools, play facilities, transport, toilets, health services, not to mention the very many public spaces that cannot be accessed by people with mobility difficulties for example.

Our economic system and our values mirror one another so people who face discrimination are devalued in monetary terms, both in their ability to earn money and in their access to services that are paid for from tax revenues because they are seen as a 'cost' or a 'burden' to the system. Presently disabled people are twice as likely to live in poverty as non-disabled people.

The Women Thinking Disability c-o-i (a group of mothers and grandmothers linked to **Oaklands School**, Edinburgh) initially came together in December 2009 around the issue of proposed education cuts.

By chance one of the mothers was attending an Engender training session on *Gender Budgeting and using the Gender Duty* and in one of the discussion slots she spoke about the proposed cuts. We suggested that the woman should 'ask the question' in relation to equality impact assessment and encouraged her and the other mothers to keep asking the question. This was the beginning of our working relationship with the Oaklands parents (see Oaklands case study).

Having been made aware of the difficulties faced by this group of women we were particularly keen to tap into other campaigning issues around transition from children's services to adult services.

The women were keen to use participatory research methods to look into the pressure they have experienced from Social Work and other professionals towards certain benefits which do not take full account of individual family circumstances.

In March 2010 we entered into discussions with agencies including the Families Advice and Information Resource (FAIR), and 'Contact a Family' to offer Participatory Research Training to local campaigning groups in order to cascade the strategies through to the benefit of families with disabled children.

In June we organised an Involvement Workshop session for female disabled volunteers at Capability Scotland. One of the participants at this session later attended our 'Equality Counting' Workshop on Opportunities in Equalities Legislation and instigated the creation of a second c-o-i under the Women Thinking Disability umbrella.

### Opportunities in Equalities Legislation Workshop

On the 31 July we held an interactive workshop with input from each of the three 'Equality Counting' c-o-is as a way of bringing them together to share experiences and learning. We used Power point presentations combined with handouts and question and answer time to explore opportunities in equalities legislation, focusing on the Equality Act (2010).

Together we discussed the importance of making equality count and how we were organising and participating in the project to this end. We discussed:

- Public sector duties
- Resources and spending decisions
- Service design
- Public scrutiny and challenge
- Budget analysis

We had a presentation by one of the Oaklands women and we had arranged for Glasgow Disability Alliance to show their 'Rights to Reality' DVD and have input to the discussion on the day.

### Women Thinking Disability

One of the most exciting outcomes from the July workshop was that a young disabled woman asked if we could come and work with a group in Perth who were interested in becoming involved in 'Equality Counting' to address a number of issues around access to services.

Over the next few months our Participatory Researcher worked with the group to introduce PR methods and identify which issues the group wanted to research. They looked in particular at the new Equality Act focusing on the implications for disabled people and their carers; how the changes affect public services, banks, colleges and transport. They wanted to explore how the new law could be used to tackle the issues important to them as a community. Proposed funding cuts were and continue to be a huge issue for this c-o-i with the potential to impact on all areas of the women's lives including access to education, independent living and health care.

### Methodology

The 'Equality Counting' project outline states that *"women will be trained to design and carry out PR then supported to apply these acquired skills, knowledge and confidence to design a PR project around their disadvantage in accessing appropriate public services due to their gender or gendered inequality"*.

For this c-o-i, as with the Women TIC group, access to training sessions and meetings required attention to their length and timing. Following discussion with the women, together we decided that basic requirements would include:

- Arranging short sessions (2-3hrs) with plenty of comfort breaks – issues with concentration, need to move around etc.
- Considering having one day training sessions to begin the process then move to shorter fortnightly meetings
- Ensuring an appropriate and fully accessible venue
- Checking timing with group as some members may have a number of different health appointments etc.

Two full day training sessions on PR methods, using equalities legislation, 'getting to work on our priority issues' and reflective analysis were organised.

Further meetings took place to follow progress and ensure that the group members were adequately supported to deal with responses to their enquiries, analyse survey data and devise strategies for action as appropriate.

### The Women Thinking Disability (Perth) group

The group identified an issue with **Bank services** which appeared to be unable to provide access to the full range of their services for disabled customers. The women conducted a PR exercise surveying fellow residents at Upper Springlands care home to gather information from a sample of bank customers.

They looked at some of the major banks' websites to research their policies for disabled customers and also drafted a standard letter to be sent to the Head Offices of some of the major High Street banks asking about their policy on supporting customers with complex disabilities.

At the time of writing this case study, none of the banks had responded to the letter so the group members are now going to pursue the matter on an individual basis with their own banks.

Several of the women had encountered difficulties in accessing **Education**. The group were keen to explore how the Equality Act might be used to address such issues. One problem was a lack of course information made available in clear and understandable format. The problem was exacerbated by a lack of support and guidance from colleges prior to disabled students enrolling on courses.

Two group members wrote to the Additional Support Coordinator at their college to request a copy of their Personal Learning and Support Plans. They are now awaiting reviews.

Another issue of concern to the group was access to **Health Care**. Group members have to pay for physiotherapy services as this is a service available on the NHS only for conditions which are deemed “curable”. If individuals want to access physiotherapy to offer short-term relief, or for long-term management of conditions then it has to be paid for. The group contacted the EHRC to enquire about this situation, in particular whether or not it constituted indirect discrimination.

A Caseworker with the EHRC responded to clarify provision under the Equality Act. The group decided to pursue the issue with NHS Tayside. They will ask whether NHS Tayside have considered making adjustments to their restrictions to physiotherapy for people with some or all disabilities and what steps they have taken to meet their Disability Equality Duty.

### Processes

In using PR approaches with this c-o-i it was vitally important to hold to strong communication support principles alongside recognised good practice in community engagement.

- Involving the women from the start of the process  
This encouraged working in partnership, meaning that participants did not feel decisions had already been made without them.
- Working at a pace that suited both Engender and the women  
We knew how important it was to allow enough time for group members to consider the issues properly and it was important to us that they were able to do so.
- Providing information that was clear, timely and accessible  
If we didn't allow the women enough time to take in the information, we would effectively have excluded them from the participation process.
- Providing a range of ways to participate

Not everyone necessarily wanted to get involved at the same level or in the same way at different stages of the process.

By providing a range of participation methods we were able to increase the opportunities for women to get involved in a way that suited them.

- Providing support to increase the opportunity for involvement  
As well as support with communication, some participants required help with transport to meetings, or required support to build confidence and capacity.

- Providing participants with feedback and outcomes from all sessions

### Expectations

From the outset we had to consider Engender's expectations of 'Equality Counting' as a project. Beyond enabling communities of women to address their issues of concern it was our hope and expectation that increased participatory research and support work with a diverse range of communities-of-interest would improve our capacity to serve women in Scotland by grounding our policy work in the real experiences of women managing the consequences of their multiple/ intersecting identities.

Ailie, the young woman who had initially expressed an interest in working on 'Equality Counting' continued to play a central role in galvanizing the group. She has been an inspiration to us all during her participation in the project.

*"I want to kick some ass!"*

We are delighted that Ailie has become an Engender member.

## **Oaklands Parents' Council**

*It is important to state at the outset that the Oaklands Parents' Council is not a women's group and there are of course fathers and other male family members involved and supportive of all actions to protect and maintain the excellent service provided by the School.*

*As quite a typical statistic, approximately one third of the Oaklands' parents are lone-mothers.*

*This case study is written from the perspective of the work undertaken by the women who have been in communication with Engender during the lifetime of the Equality Counting project. The women have included us in Parent Council meetings and school events and they have attended a session we organised for them on, 'Understanding Tools and Levers for Change.' They have given us access to all the emails and letters that they have sent on behalf of the Parents Council. The information within this case study is taken directly from communications between these women and the local authority and all other actions taken, including organising meetings, contacting the press, establishing the Facebook group and making presentations to the Council.*

## Introduction

On **03 Dec 2009** Engender held a workshop on *Understanding Gender Budgeting and holding public bodies to account on their responsibilities under the Gender Equality Duty* (and other equalities legislation). During the group discussions one of the women raise the issue of proposed education cuts of 2.5% across all schools in Edinburgh. A flyer alerting parents of this proposal had been sent home in the children's schoolbags and a Parent Council Meeting was taking place that evening to discuss the threat.

It transpired that the proposal was that special schools (including Oaklands) were to face the same cuts as mainstream schools. The parents were concerned about the disproportionate effect that budgetary cuts would have on Oaklands School and did not feel that due consideration had been given to this.

The Director of Engender recommended that in the first instance the parents ask whether an Equality Impact Assessment (EIA) had been undertaken.

## Getting organised

In the run up to the City of Edinburgh Council Revenue Meeting on **16 Dec 2009** (open to all Parent Council Chairs) the Oaklands mothers (and grandmothers) galvanised and wrote to the First Minister and to all the MSPs that sit on the Cross party groups for disability and learning disability.

On **12 Dec 2009** one of the women wrote, on behalf of the Parents' Council, to all local Councillors to invite them to come and meet the children, parents and staff of Oaklands School on 25 January 2010.

*"As you know, the council will be meeting in February to decide on budgets and among the proposals being put forward for consideration are cuts in funding for special schools. Before you make a decision on this, we feel that it is important to fully understand the needs of children who attend Oaklands need and what the impact of reducing the level of support that they receive may be".*

Only two Councillors actually came along on the day.

The Finance Convenor declined to visit because he said, *"It is not appropriate for me to be involved with the individual items that may come up in the budget."*

## Asking the question

On **16 Dec** at the Council Revenue Meeting the woman who had attended our training on 03 Dec asked whether Children and Families had conducted an equality impact assessment on the budget proposal to reduce the number of learning assistants in special schools.

She was told by the Children and Families Resources Manager that yes it had and that no school would be disproportionately affected.

Two days later, on **18 Dec**, the Resources Manager emailed her to say that this in fact was not correct. *“I am told we have in fact only conducted an equalities relevance assessment and not an equalities impact assessment as I thought. The proposal is highly relevant and an assessment will be required.*

*My sincere apologies for inadvertently misleading you. I will ensure the error is noted in the minutes of the meeting which should be available next week”.*

**20 Dec** the woman responded to the Resources Manager, thanking him for clarifying the position regarding an equality impact assessment on the proposal to reduce the number of learning assistants in special schools. She stated that she was pleased that a full assessment would be being carried out and stressed the importance of considering the varying degrees of disability of the children that attend special schools.

*“They are not a uniform group that can be considered as a whole. We would particularly ask you to consider the most profoundly disabled children with the highest level of support needs that attend Oaklands School. We would sincerely hope that an impact assessment will involve gaining a full understanding of what is involved in ensuring that these children are able to live high quality lives. The level of their dependence on adult support cannot be underestimated and assessing impact cannot be meaningful without involving those that are experts in the care of these children”.*

#### Asking the question again

On **21 Jan 2010** the women followed up a phone call with an email to the Principal Officer Equalities at CEC requesting confirmation of how the EIA would be undertaken given the lack of time with the Budget Meeting set for 11 February.

They received an email response from the Principal Officer, Equalities on **26 Jan** which said, *“I can confirm that staff are carrying out an Equalities Relevance Assessment of those areas of budget savings that are of concern to you.*

*In terms of the reduction in out-of-authority placements, it was agreed that this is of significance. However, as a managed and consensual process with alternative arrangements in place within the Throughcare and Aftercare Service, it was concluded that any negative impact would not be substantial.*

*In terms of the review of Special School Services, a meeting is to take place with Special School Head Teachers early next week which will, amongst other things clarify whether or not a full equality impact assessment is required”.*

This was confusing information since it had earlier been stated that an equalities relevance assessment had been undertaken and “While accepting that budget reductions will be difficult to manage for all schools we do not believe that any school will be disproportionately affected”.

**The women requested a definitive answer on this point.**

### The Open Day

Meantime the ‘Open Day’ for Councillors to meet with parents, children and staff took place on 25 Jan with only two local Councillors attending.

Despite apologies, with varying degrees of support and/or understanding, coming from 16 other Councillors only one suggested that he would like to make another time to visit. (This was immediately followed up by one of the women who arranged to meet the Councillor at the school on 03 February).

The following day an email letter from Oaklands Parents’ Council, expressing their concerns, was sent out to all Councillors. There were many responses to this letter, once again with varying levels of support and understanding and demonstrating clearly that party lines were being drawn over the budget.

An article appeared in the Evening News on **28 Jan**, focusing on one mother’s situation and appearing under the headline, ‘Care school cuts could cost lives’.

The parents established a Face book group ‘Save Oaklands School from Budget Cuts’ which gained tremendous support with more than 340 people signing up within a week.

The women kept up their dialogue with individual Councillors and requested a deputation at the 11 Feb Council Meeting when the budget was to be decided.

### Eleventh hour ‘reprieve’

On **10 Feb** an email came through from the Convenor of Education which said, *“I understand that the Parent Council intended to come to the Budget Meeting tomorrow as a deputation. I thought it might be useful to tell you that the only cut to the Special Schools Budget is the reduction of absence cover from 5 to 4 days, which is the same as in primary schools. So thankfully there is minimal impact on the DSM of Special Schools this year. As an Administration we have been very keen to prioritise education and young people services in this Budget and a number of pressures have been covered centrally.*

*As tomorrow’s meeting has attracted a large number of deputations, it may be that you would wish to consider whether you and your colleagues still wish to attend”.*

The women decided to go ahead and make a shorter version of their planned presentation. There was still clearly a deal of confusion on the part of individual Councillors as to whether or not an EIA had been carried out.

### What have we learned from this?

First and foremost there was a complete lack of transparency in the processes of the decision-makers communicating with the people who were going to be most affected by the decisions taken.

There was a lack of accountability from the decision-makers in their handling of the EIA question.

There appeared to be a lack of appropriate understanding of the requirements of the Disability Duty and other legislation including the Additional Support for Learning Act, under which all of the children at Oaklands have coordinated support plans that are legal documents outlining how their educational needs will be met (thus requiring adequate resources for implementation).

### What next?

The parents have mountains to climb on a daily basis in their dealings with all sorts of services in relation to their children's additional support needs. They have limited time and energy for engaging with projects such as ours which aims to put policy into practice and to ground equalities legislation and practice in people's lived experiences.

Engender will continue to work with the women using participatory research methods to help keep them in dialogue with the local authority on these issues. The women will explore ways in which to paint a picture of life with a child with profound additional support needs and how to promote greater understanding of the issues and the impacts that the decisions taken have on the lives of whole families. They will also gain knowledge on the legislative tools and levers for change which we already have in Scotland and to which our public bodies must be accountable.