

Women Thinking Inclusive Communication (Women TIC)

Background and aims of project

Engender's Equality Counting project, funded by the UK Equality and Human Rights Commission (EHRC), is about promoting good practice in using the equalities duties and addressing issues such as the double discrimination faced by women with diverse communication support needs.

Women and men have an equal right to have their voices heard by policy/decision makers, for example in local authorities, health services or any other statutory service. The objective is to achieve public policy and practice that responds effectively and appropriately to their particular need.

This is true for all women and men including those with diverse communication support needs that are represented across age and interest groups. They may face barriers to expressing their views. It is vitally important that service providers understand how to support people to participate and put resources in place so they are on an equal footing in society. Groups working with equalities issues need to lead by example and understand the value and importance of inclusive communication and work to promote it across our organisations and through the work that we do.

The following is a case study describing the story of a group of women with a specific interest in diverse communication support needs who came together as a community-of-interest through 'Equality Counting'. The case study will outline the processes, expectations and outcomes *of* and *for* the group. It will also examine impacts of the project on some of the individual members.

Introduction to community of interest

The people who came together in this 'community-of-interest' (c-o-i) were a mix of women who had experienced strokes, women who had sustained head injuries and a group of women (and one man) who were caring for a partner who had had a stroke in the past two years.

People with diverse communication support needs, and their carers who often have to be a "voice for the voice-less", have had much to say about the ways in which health and professional care workers communicate with them. The development of inclusive communication is a complex process that includes, though goes well beyond, active listening. It will support people with and without language impairment to enrich communication practice, share power and celebrate the creativity and challenge of communication difference.

Women TIC

“Without a vision of how things should and ought to be, it is easy to lose your way and give up in the face of adversity and opposition . . .

We all need a world where impairment is valued and celebrated and all disabling barriers are eradicated. Such a world would be inclusionary for all.”

(Oliver and Barnes 1998)

In April 2010 Engender met with Communication Forum Scotland (CFS) to discuss the possibility of joining together the aims of the Civic Participation Network Project (a CFS project funded by the Scottish Government) and those of ‘Equality Counting’. That is to say, making it easier for people with diverse communication support needs to access training and capacity building events, thereby increasing voice and participation.

An email was sent through the CFS network and several groups and individuals came forward to note their interest in becoming involved in ‘Equality Counting’. The response was very positive and there was quite a wide geographical spread of interest from groups in Aberdeen, East Lothian and Inverness.

It quickly became very clear that the training programme as outlined in our ‘Equality Counting’ project plan was going to have to be tailored to the specific needs of this c-o-i. This provided an opportunity to demonstrate how the flexibility of the Participatory Research (PR) approach works very well across a diversity of groups.

Methodology

The onus is on service providers to face the challenges of enabling true participation of disabled people in decision-making processes, recognising that disabled people wish to participate in different ways. For ‘Equality Counting’ this had implications for the way in which we were able to introduce the PR methods and tools. For some people, particularly those with communication disabilities, the issue of time can be crucial to an inclusive communication environment and a slower tempo can be the only accessible pace to ensure understanding and allow participation. Access in meetings will require attention to their length and timing. Together with the groups in Aberdeen and in East Lothian 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 two consecutive days to start off then move to fortnightly sessions
- Finding appropriate and fully accessible venue (considering the diversity of communication support needs with the group)
- Checking timing with group as some members may be carers and work part-time

Very early in our discussions with the different groups, uncovering their issues and planning for how we could work together through 'Equality Counting' we recognised it was important for Engender, as an organisation committed to improving its inclusive communication, that we should consider our own practice.

Inclusive communication: putting communication support into practice

In June we organised a very interesting and practical one-day training session for Engender staff, interns/volunteers and associates/participatory researchers. The day was aimed at sharing ideas and resources.

Following a trainee's journey, exploring barriers and solutions we looked at:

- the diversity of communication support needs, which go wider than those related to sensory impairment
- basic good practice in inclusive communication
- adapting training activities to meet the diversity of need.

Issues

Women TIC members in Aberdeen raised specific concerns over funding cuts – loss of taxi-cards, concessionary bus passes and dial-a-bus services. They were keen to do some work on these issues and felt this would move them on in actually having a chance to influence change.

Transport issues were also a big problem for the women in East Lothian, who were members of a Headway (the brain injury association) group. Their issues were very similar to those experienced by the Aberdeen women and greatly affected their ability to participate in activities, training and support groups etc. The limited local bus service gave priority to school children if there were any difficulties i.e there was no back up if the bus broke down.

The women felt that there should be equal priority given to people with disabilities needing to travel to centres and activities in order to get out of the house and join together with other people. The dial-a-bus service, while not having been cut altogether was not very satisfactory since it had to be booked approximately two weeks in advance and no standing orders for transport were allowed. This, alongside the fact that taxi cards were only accepted by certain taxi firms and not all drivers were trained in 'transferring' clients in wheelchairs, severely restricted the independent movement of the women and their ability to have a social life.

Some group members identified the stigma they face through sometimes having 'invisible' disabilities (for example, as a result of brain injury) and they reported also that there was very little help for them as carers caring for their adult children.

“My son was in the car accident with me and he still depends heavily on me even though he is a young man now... he has slipped through the crack between children and adult services. I need help to help him but it is just not available...”

Processes

The establishment of shared goals between the women across the different geographical areas was not particularly difficult since the issues and priorities for action were depressingly similar (as above). The main challenge was in supporting the women to organise as a research team and put their participatory research skills into action.

Instead of following the route taken by the Women Thinking Trans Issues the Women TIC chose instead to participate in focused peer discussions on their chosen issues and to make important links with to the shortfalls and pitfalls in service provision as highlighted by the Women Thinking Disability c-o-i.

In working with Women TIC we were mindful of six key communication support principles:

1. Recognise that every community or group may include people with communication support needs
2. Find out what support is required
3. Match the way you communicate to the ways people understand
4. Respond sensitively to all the ways an individual uses to express themselves
5. Give people the opportunity to communicate to the best of their abilities: environment, timing, methods of communication, support from carer and/or support worker, positive communication style, budget
6. Keep trying.¹

Continued resources are required to bring the different geographically placed groups together as a c-o-i and Engender would urge that there is a need to develop creative and effective ways to enable this.

Carers – a voice for the voice-less

At the beginning of June we were invited to meet with a group of carers through NHS Highland in Inverness. Members of this group (4 women and 1 man) each have a partner who has had a stroke or strokes in the last two years resulting in severely impaired communication. There were very many gendered issues uncovered here including the need to seek power of attorney and/or guardianship in order to take financial decisions for the family, negotiating the legal, health and care systems. Issues around disempowerment linked to caring responsibilities and voice-less-ness (ironically whilst attempting to advocate for a literally voice-less partner)

¹ Talk for Scotland Toolkit www.communicationforumscotland.org.uk

Expectations

In terms of Engender's expectations of 'Equality Counting' as a project, it was our aim to 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. We knew that as an organisation we wanted to examine our own practices and anticipated that this would be a very interesting 'learning curve' for us.

The carer's group was keen to participate in 'Equality Counting' and to consider not only their own issues but to highlight that information should be a right, not something that has to be searched for by people who are in vulnerable situations such as experienced by relatives of stroke patients.

"We have to battle just to get basic needs met and systems are not adequate for our (self and partner) situation... help should be given and not have to be searched for..."

Some of the women voiced that they had not been adequately prepared for coping with the range of situations that arose following the discharge of their partner home from hospital. Their expectations in terms of receiving appropriate support and useful information from medical and social services at the point when they most needed it had effectively been shattered.

"It has been said that there are worse things than death..."

Outcomes

Across the 'Equality Counting' project we were looking to effect change for women who suffer inequality and disadvantage, supporting them to have greater choice, control and empowerment over their own lives in relation to accessing public services.

The Chest, Heart & Stroke Scotland (CHSS) Aberdeen South, Service-Users Involvement Group had piloted the Civic Participation Training (CFS). This was very successful and led to several changes with members joining local committees and feeling much more empowered to participate in meetings, influencing how minutes are taken, which venues are used and what ground rules the groups have (which contribute to effective communication). One member was asked to join the Scottish Intercollegiate Guidelines Network (SIGN) Committee participating in developing guidelines for services for stroke rehabilitation.

The Aberdeen group had hoped that the time was right to join the 'Equality Counting' project to keep up the momentum, to work on issues and actually have a chance to influence change. However, the Aberdeen City CHSS Service-User groups underwent a process of restructuring following staffing changes and this precluded further participation in 'Equality Counting'.

Engender has plans for future work with CHSS in Edinburgh and the Scottish Borders to carry forward the aims and objectives of 'Equality Counting' with Women TIC 2011. We will aim to pick up with the Aberdeen women again at this time.

The Inverness carers have continued to work with our Participatory Researcher to explore their communications needs across a range of life circumstances:

- With health and other support staff and agencies
- With friends and relatives as they find they are the interface between their partner and others in the immediate friendship/family circle
- With their partner, especially with regard to accurately imparting their partner's needs and views on medical and financial decisions

This exploration covers:

- Working with a group where there is a 'shadow' group present, as members include what they believe their partners would say/feel
- What 'good' communication would be like
- What problems 'bad'/inadequate communication causes for them and their partner

The carers' outcomes were outlined as their community based indicators:

- Training/ Guidelines for NHS staff on 'What is Good Communication' between patients/carers and service providers
- Procedure for patient assessment (evidence no need for multiple assessments)

The Scottish Government has already expressed a commitment to these outcomes in its Better Health Better Care: Action Plan (2007).

"I want us to move to a more mutual NHS where partners have a real involvement, representation and a voice that is heard." (Nicola Sturgeon MSP)

The benefits are for all and Engender recognises that working with a diverse range of groups will improve our own capacity to serve women in Scotland. Our policy work will be grounded in the real experiences of women managing the consequences of their multiple/intersecting identities.

"Someone was interested in where we were coming from"

Impacts on individuals

Group members have been involved (depending on time and energy constraints around their carer roles) in a range of meetings and discussion sessions on issues around Equalities and Human Rights. One woman was keen to have further discussion on the matter of female residents, in care homes, receiving intimate care from male care assistants and whether residents were offered a choice of female or male carers (unlikely).

Meetings have been held with the Highland Council Director of Social Work. NHS Highland will now handle the budget for care of elderly.

"I managed to go to a meeting with Managers... it was daunting but I did it!"

"We got positive reactions and encouragement"

Members have also attended a care home meeting with NHS managers where key points discussed included:

1. People in private homes are not deemed a priority
2. Equipment in the home is an issue as some relatives wanted to know if the family bought specialist items for their relative whether staff would use it?
3. Identifying a formal contract with residents that set out their rights
4. There is an annual review with the resident, carer, care home and social worker

Members will examine the care home brochures to check what details they contain about a contract (point 3).

"People who have had a stroke are discriminated against because many of those providing intimate care have not had specialist stroke training. Some very good staff are aware of this lack and have even offered to pay for their own training."

Following an incident involving a senior staff member at a care home, which distressed group member(s), a meeting was convened with relatives.

Key points:

- Suggestions to improve communication were offered by relatives including the development of a communication sheet for staff to fill in. This should be read by the carer and the relatives and should be signed.
- It was asserted that some care staff fail to persist in taking the time to understand what the resident is saying or otherwise attempting to communicate to them
- It is not clear to relatives what rights the resident has or are being denied in that situation
- Relatives are concerned that if they complain then this may affect the treatment /experience of the resident in the care home

Outcome of this discussion

The group will find out what the complain protocols are and familiarise themselves with the carer home's complaints procedure.

Conclusion

“We knew we were united”

Work on ‘Equality Counting’ with Women TIC has proved a challenging but very exciting opportunity for Engender and one which we are keen to progress. The pace of work with this community is one of the biggest challenges in terms of working within the timeframe of a funded project but such investment is vitally important if we are to eradicate disabling barriers and truly value an inclusive society.

We have forged positive links with CHSS and together hope to be able to organise and facilitate workshops and training embodying the aims and objectives of ‘Equality Counting’.

“This has stimulated me to keep on fighting!”

Further Reading

McVicker, S., Parr, S & Pound, C., Duchan, J. (2009). The Communication Partner Scheme: A project to develop long term, low cost access to conversation for people living with aphasia. *Aphasiology*, 23, 1, 52-71.

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Thompson, N. (1998) *Promoting Equality: Challenging discrimination and oppression*

Websites

http://www.chss.org.uk/voices_scotland/stroke_voices/

<http://www.chss.org.uk/forums/>

<http://www.headway.org.uk/Regions/Scotland.aspx>