Monitoring and Implementing the UN Convention on the Rights of Persons with Disabilities in the UK:

Role of Government, Statutory and Civil Society Organisations

Report

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INTRODUCTION

On the 9th February 2009 a roundtable was held at the University of Bristol to discuss the UN Convention on the Rights of Persons with Disabilities. The aim of the roundtable was to consider the implications of monitoring and implementation, to identify the role of the different sectors in undertaking these tasks and to explore what resources would be needed to undertake them effectively.

The reasons for holding the roundtable were:

- The UN Convention is an important step forward in confirming the rights of people with disabilities in the UK and internationally. A report by the House of Lords and House of Commons Joint Committee on Human Rights commented that the UN Convention

  ‘offers an opportunity to achieve a paradigm shift in the way disabled people are perceived and treated across the world, from objects of charity and welfare to equal human beings with the full set of rights that confers’

Given the importance of the Convention both nationally and internationally it was vital that there were opportunities for those who are concerned with its future implementation and monitoring to explore how this might best be done.

- While the Convention was at the time of the event not yet ratified in the UK it was expected that this would happen in spring 2009. Therefore it seemed opportune to have a roundtable which would allow for some discussion of how and by whom the Convention would be implemented and monitored following ratification.

- Given the importance of the Convention to the lives of disabled people and the commitment within the Convention to their involvement in its

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2 Subsequently (13 May) the Government has announced that it intends deposit its instrument of ratification with the UN on 8 June 2009.
implementation and monitoring, a roundtable of key players and stakeholders seemed an important step in considering its future development.

- Previous research on the Optional Protocol to the UN Convention Against Torture undertaken at the University of Bristol revealed a need to be clear about the processes involved in implementing and monitoring international treaties such as the UN Convention and the resources required.  

- While the Convention provides a clear statement of rights on paper, there is a need to ensure that its articles and provisions can be translated into actions which support the rights of disabled people.

For these reasons Professor Rachel Murray (Law) and Professor Kelley Johnson (Norah Fry Research Centre) developed a proposal for a roundtable which would focus on Articles 33 of the Convention which states:

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

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3 For more information on the project and its outcomes see: [http://www.bris.ac.uk/law/research/centres-themes/opcat/index.html](http://www.bris.ac.uk/law/research/centres-themes/opcat/index.html).
Funding was sought and gained from the Department of Work and Pensions for a one day roundtable.

The day was organised with panels of speakers from Government, the Equality and Human Rights Commissions and representatives from organisations of and for disabled people. Each panel session was followed by a group discussion which aimed to explore key questions arising from a consideration of Article 33. Almost half the participants represented organisations of and for disabled people indicating widespread interest from civil society organisations in how the Convention would be implemented and monitored in the UK (see Appendix III for a list of participants).

This document aims to

- Provide a summary of the key note speakers’ addresses.
- Identify key themes which arose during group discussions and plenary sessions at the roundtable.
- Suggest some proposed actions arising from the roundtable discussions.
KEY NOTE ADDRESSES.

There were two sessions during the day where a panel of key note speakers delivered presentations. The morning session focussed on the nature of the UN Convention on the Rights of Persons with Disabilities (CRPD) and the afternoon session was more concerned with the roles of Government, the Equality and Human Rights Commissions and civil society.

Morning Key Note Addresses.

Professor Rachel Murray, School of Law, University of Bristol.
Professor Murray welcomed the participants. In explaining the reasons for having this event, Prof Murray outlined the research project she was heading in the Law School which looked at the provisions of the Optional Protocol to the UN Convention Against Torture (OPCAT), an instrument that requires states parties to set up national bodies to visit places of deprivation of liberty. It also sets up an international body, the Subcommittee for Prevention of Torture (SPT). The research project had examined the reasons behind government’s choices for these national bodies and how they become effective. These aspects were of interest also in the light of the provisions of the CRPD as Article 33 of the Convention, the focus of the roundtable, required states parties to designate a focal point, national institution and involve Non Governmental Organisations (NGOs). Professor Murray indicated that a number of questions relevant to the new UN Convention had arisen from the work on OPCAT. These were:

1. Do obligations to monitor and implement the UN Convention mean ‘business as usual’ for national bodies or does the Convention require something new from the government, National Human Rights Institutions (NHRIs) or NGOs? Under the OPCAT, there has been a tendency to designate as national preventive mechanisms (NPMs) already existing institutions, adding the ‘OPCAT tasks’ to the existing workload of the organisations. Can this be
considered as sufficient to meet the obligations under the OPCAT? The answer so far appears to be ‘no’. Is this similar in the case of the CRPD?

2. Coordination: Under OPCAT it has emerged that there is, in practice, a need for cooperation and coordination between the various bodies, namely, NPMs, NGOs and government. In case of the CRPD- how can this coordination take place? What does it involve? Should this be ‘light touch’, namely coordination of activities? Or should it involve more, for example, ensuring the consistency of approaches and standards?

3. Respective responsibilities: In practice, it is not easy to separate monitoring tasks from implementation, leading to questions about which organisation or body has responsibility for certain tasks.

4. Role of the civil society: The involvement of civil society is crucial for the success of the instrument and the system that it puts in place. The research on OPCAT has shown that the involvement of civil society varies between countries and contexts, but generally such involvement has been crucial in lending the legitimacy to the process of implementation.

5. System: the CRPD puts in place a system or framework which does not and should not emphasise one particular body. Different organisations need to work together. The CRPD stresses the need for input from civil society, particularly disabled people. How will these organisations work together effectively?

Professor Kelley Johnson, Norah Fry Research Centre University of Bristol.

Professor Johnson introduced the CRPD from the perspective of people who were working with disabled people. The Norah Fry Research Centre (NFRC) has undertaken research with disabled people for 21 years. She noted that the Convention has been very much welcomed by organisations of and for disabled people. She went on to highlight a number of issues:
1. The continuing need for change: Prof Johnson noted that huge changes had taken place in the lives of many disabled people over the past twenty to thirty years. There had been an increasing emphasis on inclusion and a more recent personalisation agenda which had given more choice and power to disabled people to manage and control their lives. However there were still huge problems. For example recent research by NFRC, which included a national consultation with people with learning disabilities, revealed the following concerns: lack of employment opportunities and control of money, lack of choice in housing, poverty, discrimination and lack of access to good health services, loneliness and lack of relationships and the need for ‘good’ personal support workers. She noted that this consultation reflected many of the issues addressed in the provisions of the Convention, such as discrimination, lack of inclusion in the community, lack of choice, and the need to remove social barriers.

The Convention presented a positive step forwards in its affirmation of the rights of disabled people.

2. The Convention as a tool for advancing positive change: Professor Johnson noted that the CRPD was an important step in recognising the rights of disabled people as members of society. She noted that the ratification may bring practical benefits to disabled people. However while the words in this Convention, as well as in other international instruments may be well intentioned, there was sometimes a gap between words and actions. It was important to ensure that the Convention did not remain ‘elegant words’ on paper but was translated into action. The current roundtable was one step towards achieving this.

Mr Tony Aston: Guide Dogs

Mr Aston focussed on the strengths and weaknesses of the Convention in his presentation. He first of all noted that language is very important and highlighted that most of the obligations in the CRPD were expressed in rather soft terms,
such as ‘promote’, ‘take all appropriate measures’ etc but more concrete obligations were rare through the text. This ‘soft language’ allowed governments a lot of room for manoeuvre.

He examined the issue of ‘progressive implementation’ of some rights as envisaged in the CRPD. While acknowledging that full realisation of many rights may require time, this formulation should not be used as an excuse to delay or prevent work on the realisation of these rights.

Mr Aston dealt also with the issue of reservations and noted that these were allowed under the provisions of the Convention if they did not defeat the object and purpose of the instrument. It appeared the UK government was considering entering four reservations to the CRPD and this implied a certain reluctance on the part of the civil servants to the Convention and its provisions. The commitment of the government to ratify the Optional Protocol to the CRPD was however noted as a positive step.

In evaluating the content of the Convention, Mr Aston noted that the instrument would have had more deficiencies if it were not for the involvement of organisations of and for disabled people which had worked hard to influence the work of the Ad Hoc Working Group over the five years of drafting. He noted that the Convention represented an excellent campaigning tool, but as with any tool, it would be of no help if it remained on the shelf. So he questioned how this tool could be utilised and highlighted three strategies that disabled people would need to develop:

1. To understand what disabled people and others want from the Convention. Different rights in the CRPD may mean different things to different groups of disabled people; some may be more important to some groups than to others;

2. To identify who disabled people want to represent their cause. Article 4 of the CRPD obliged governments to work with organisations representing persons with disabilities, but who were these? He suggested that these should be
democratically elected, know the specifics about disability and have persons with disabilities in them. They should not be generic disability organisations, rather organisations representing people with specific impairments.

3. There was a need for disability organisations to ‘get our act together’. A good example was how disability organisations worked together to influence the work of the Ad Hoc Working Group through a common front which was presented despite some disagreements within the group. The same should be possible at the UK level- the various organisations needed to agree and to be able to present the government with a common front. If disability organisations were unable to agree, it may provide a loop-hole for the government not to work effectively.

4. Implementation: it was important that there be discussions with government about implementation. There should be a gap analysis undertaken on what the Convention required and what already existed in the country. There should then be an implementation plan based on this analysis with concrete milestones against which performance/progress could be measured. Monitoring should be carried out by a truly independent organisation, which should not be a government body nor receive substantial funding from it. Government should provide sufficient resources for the implementation plan. Results of the progress in implementation should be put in the public domain to provide the possibility for re-evaluation and, if need be, reassessment of the analysis and implementation plan. Implementation may take many years, but disabled people needed to be part of the process.

Mr Mark Harrison: Norfolk Coalition of Disabled People.

Mr Mark Harrison started his presentation by characterising the CRPD as a developmental Convention and noted that many parallels could be drawn between the process that happened around the CRPD at the international level.
Mr Harrison described the work of his organisation, the Norfolk Coalition of Disabled People, its composition and means of operation. He noted that the biggest challenge when discussing the implementation of the CRPD in the UK was the fear that this would be ‘business as usual’.

He commented that there was a need for a huge paradigm shift which could be achieved through the work of activists and other persons with disabilities. Persons with disabilities, if compared to other ‘disadvantaged groups’, were the only ones defined by biology. The need for allies in government and for bold civil service action was highlighted.

He noted that the possible government reservations to the CRPD indicated that there is a willingness to ‘keep business as usual’ as opposed to embracing changes in the existing practices at government and civil service level.

The need for truly representative bodies by disabled people was noted, ones which would be properly funded and which could have an effective voice. This unfortunately was not the case now as disability has been turned into a huge business which was driven by commercial market interests and charities which were there for their own interest and did not involve disabled people.

He noted that Article 33 of the CRPD was very clear: persons with disabilities and organisations representing them must be involved. These must not be charities which did not actually involve persons with disabilities or who had not fought for the Convention; these he described as parasitic.

He also noted there was a colonialist approach at the international level which claimed to represent disabled people but actually did not involve those they claimed to represent.
He emphasized that disabled people do not want special treatment; rather they wanted to be full members of the society and to be able to get on with their lives normally. However, much is invested in the ‘special needs’ ideas which precluded this happening. The problem rested with vested interests and the fact that government listened more to these interests than to disabled people.

Mr Harrison argued that this constituted a breach not only of the CRPD but also of other international instruments, like the Convention on the Rights of the Child. There was a need for bodies that truly represented people with disabilities and a need to ensure that these bodies were properly resourced.

**Afternoon key note addresses**

The afternoon of the roundtable focused on the role of Government, the Equality and Human Rights Commissions and organisations of and for people with disabilities. A summary of three of the addresses is given. The fourth (Peter Beresford) was not presented but is available in *Appendix IV*.

**Mr Richard Timm: Department of Work and Pensions**

Mr Timm ran through what Article 33 of the CRPD required from government. A focal point within Government had to be designated, and he anticipated that this would be the ODI. However, ODI would need to agree suitable arrangements with the Devolved Administrations and the good contacts with them and with Departments which had been established through the on-going work towards ratification needed to continue.

Turning to the issue of a coordinating mechanism within Government, he said that there was a question about the extent to which the ODI fulfilled these requirements already and whether or not there was a need for a new mechanism. He noted that ODI had a cross-Government remit to ensure the delivery of equality for disabled people by 2025. He cautioned against duplication and noted that there were coordination and monitoring mechanisms already in place in
respect of a number of initiatives. The question that needed to be addressed was - was this enough to fulfil the requirements of the CRPD.? There was, therefore, a need to:

- Identify what coordination mechanisms were already there, whether they could absorb the Convention and if not, determine what was missing.

- Designate independent elements of the “monitoring framework”- the four Commissions would be designated. However, the independent element could not be the entirety of the framework. There was a need, for example, to involve Departments and the Devolved Administrations.

- Involve civil society – The Convention required disabled people and their organisations to be involved in monitoring implementation - it was important to ensure this.

Mr Timm went on to identify three roles for government within the “framework”:

1. Promotion: There was a need to embed and mainstream a human rights culture in policy making across Whitehall and the Devolved Administrations. This would be a challenge. It was also important to ensure that this understanding of disabled people’s human rights reached policy makers and practitioners at local levels, and regulatory bodies that influenced delivery on the ground. There was also a need to raise awareness of the Convention across society and to ensure that disabled people, including people in ‘hard to reach’ groups, understood their rights.

2. Protecting the Convention: “Protection” of the Convention could not be seen in isolation, both implementation and promotion contributed to protection. Enforcement mechanisms, such as those in the Disability Discrimination Act would also, albeit indirectly, protect the Convention. The Optional Protocol,
which the Government had recently announced its intention to sign\textsuperscript{4}, was also a mechanism for protecting the Convention.

3. Monitoring: Article 31 required Government to collect and disseminate statistics and data. The Government already held, and published, a substantial amount of data which was relevant to the Convention. However Government was reviewing data it collected and considering whether this would meet its needs in terms of policy development and monitoring the Convention.

He also noted that statistics and data were very relevant to the reporting provisions in the Convention. Reporting was a key element of the monitoring process. He anticipated that production of the UK report would be coordinated by ODI. Departments and the Devolved Administrations would need to contribute to the report. However, the exercise could not be conducted solely within Government. The Commissions and disabled people would need to be involved in the process (and would also be able to submit their own reports). This was an important issue and he posed the question: how would disabled people and their organisations wish to be involved? One suggestion, arising from Equality 2025 discussions, was that a forum of Disabled People’s Organisations should be established. Would this be a good idea? How might it work in practice?

Mr Timm concluded by sketching in three main challenges in relation to the Convention:

1. Delineation: For example, between the focal point and coordination roles; and between the Commissions. There was a need for interplay between these entities, but also a need for their independence from each other, so how would these organisations work with each other?

\textsuperscript{4} The UK subsequently signed the Optional Protocol on 26 February 2009
2. Coordination - what level of coordination would be necessary between the various elements of the monitoring framework, and between the “framework” and disabled people and their organisations?

3. Collaboration - there was clearly a need to work together on a number of issues – for example, awareness raising.

Mr Neil Crowther: Equality and Human Rights Commission

Mr Crowther started his presentation with an examination of what was required by Article 33 of the CRPD and first of all examined the independent mechanism and requirement that the Paris Principles should be taken into account.

He noted that while there had not yet been an official designation by the UK government, there was widespread agreement that the four Human Rights Commissions would fulfil this role. While the Paris Principles were important and should be taken into account, the mere fact that an institution was not accredited by the ICC Subcommittee on Accreditation should not be an obstacle to designation. The Northern Ireland Equality Commission was not accredited, but would be part of the mechanism. He also pointed to other entities such as the Children’s Commissioner and Care Commissions which could become part of the independent mechanism in future. The initial designation by the government should not be considered as a ‘done deal’: other entities could be brought aboard later. In other words, the current list should not be exhaustive.

He went on to highlight tasks of the government prior to ratification and noted the importance of involving people with disabilities as per Article 4 of the CRPD so as to find ways of how to make the Convention most effective.

Turning to the issue of a focal point, Mr Crowther noted a particular need to give attention to how the CRPD would work with the devolved administrations. He also noted the need to minimise the use of reservations and interpretative declarations as far as possible.
Turning to the issue of promotion of the Convention, Mr Crowther argued that this not only entail the information duty, but also a need to encourage other institutions to act. In his opinion government had a strategic role to ensure that disability issues were on the agendas of other institutions and in their overall policies. There was therefore a need to embed the Convention in wider strategies and the need to mainstream disability issues into wider issues, including those with which the Commissions were involved.

In terms of monitoring, he highlighted the need for proper data collection and analysis. In terms of protection, he spoke about the whole set of legal powers that could be used. States needed to ensure a whole range of rights and domestic avenues of redress would have to cope in cases of breach. He questioned how they would cope. He asked how the Optional Protocol would be used and wondered if it would give any extra powers to the four Commissions.

Mr Crowther also emphasized the need to celebrate the achievements of the Convention and of the ODI- the number of reservations has shrunk considerably due to its efforts and the government has promised to sign up to the Optional Protocol.

The real task however remained, namely implementation, for which the organisations representing people with disabilities must come together to make the rights real and effective.

Ms Rachel Hurst: Disability Awareness in Action.
Ms Hurst started her presentation by noting that the CRPD would not have happened if it were not for the efforts and struggle of disabled people. She sketched in the historical background to the Convention and its negotiations and the struggles that had to be overcome to get the process moving.
She noted that Articles 4 and 33 of the CRPD were about including disabled people through their organisations, which must be independent. In relation to this issue she emphasized the need to understand the difference between organisations that genuinely represent people with disabilities and those which ‘add-on’ disability issues to their agendas for various other reasons. She strongly stressed the view that disabled people must be listened to.

Ms Hurst then turned to the question of what was a representative organisation and what it meant. She noted that such organisations must be democratic organisations, with considerable membership of disabled people, must be independent and not service-provider organisations.

She noted the importance of documenting what was available in relation to rights and people with disabilities, and what ought to be available, and the need to keep the latter as the aim to strive towards. She emphasised that human rights must be at the core of government and until that happened, the Convention would not be implemented fully.

She characterised the ODI as only one section in a large government department with no real resources. She thought this raised questions about the degree of the government’s commitment to mainstream human rights of persons with disabilities. She argued for the need to have a Minister for Disability and an Office for Disability Issues which would be replicated at the local level, as well as fully resourced and funded organisations representative of persons with disabilities.

**Professor Peter Beresford: Brunel University**

Professor Murray noted that there is a DVD presentation from Professor Beresford who has been unable to attend. Due to time pressures this was not able to be played. However it was noted that all participants had a copy of the paper prior the roundtable. For a copy of this paper see Appendix IV.
Ms Rowan Jade: Equality 2025

As an extra item on the agenda, Ms Jade gave a brief summary of the work of the Equality 2025\(^5\) and explained the remit of this Advisory Body.

\(^5\) Equality 2025 is a network of disabled people which advises the Westminster Government on how to achieve disability equality. It is an Advisory Non Departmental Public Body and was set up in December 2006 in response to the Government report *Improving the Life Chances of Disabled People*. 
KEY THEMES EMERGING FROM THE DISCUSSIONS

The discussions in working groups were wide ranging and there was considerable overlap in the issues raised across the groups. For that reason we have identified the key themes arising from the discussion, as taken from notes and recordings of the groups. We have tried to ensure that all views expressed are represented in the report.

1. Views about the Convention.

The groups generally looked favourably on the wording of the Convention. Issues were raised about what the words might mean when translated into practice.

1.1 The Convention was seen by some as offering the potential for a paradigm shift from policing discrimination to a more positive rights/duties perspective. For this to happen, however, there needed to be clarity and a united voice from disabled people to inform the process.

1.2 There was some discussion about the nature of monitoring of the UN Convention in the UK. There was a necessity to produce a report within two years of the Convention coming into force in the UK and thereafter every four years to a treaty monitoring committee at the UN which had already been formed and consisted of disability experts. The ODI would coordinate the preparation of the UK’s reports. The Commissions and disabled people needed to be able to input into that report (and also to submit their own reports).

1.3 It was anticipated that the ODI would be designated as the focal point within Government for implementation of the Convention. The EHRC’s remit was confined to Great Britain and it would be the “monitoring commission” in England and Wales. In Scotland the EHRC and the Scottish Human Rights Commission would be the “monitoring commissions”. In Northern Ireland the “monitoring commission” role though would be exercised jointly by the

1.4 Concerns were raised about how other legislation was implemented in practice, such as what did the articles of the European Convention on Human Rights as incorporated by the Human Rights Act actually mean in practice? What did they mean for people being detained in hospital against their will? There was a need to ensure that the CRPD could be used effectively in practice.

2. Placing the Convention in Context
2.1 There was recognition in two groups that there had been a lot of groundwork already done in relation to rights and disabled people. Some noted that ‘we are not starting from scratch.’ It was seen as important to recognise what could be built upon.

2.2 The issue of whether implementing the Convention simply meant ‘business as usual’ was discussed in some detail by one group. It was commented that since 2005 many changes have taken place and while not all of these had produced effects on the ground, the changes were coming- the Independent Living Strategy was given as an example.

2.3 It was acknowledged the 2025 Equality Commitment Plan had been run separately from the CRPD implementation and that there was a need to bring the two together.

2.4 Evidence to Parliament’s Joint Committee on Human Rights of adults with learning disabilities (A Life Like Any Other 6th March 2008) was shocking re widespread disregard of human rights. (The recently published Valuing People Now referred to in the next sentence takes account of the JCHR’s report). On the positive side, 2009 ‘Valuing People Now’ discusses rights whereas the previous version hardly mentioned them. Some change did seem to be occurring in terms of policies and actions.
2.5 One group asked how the Convention was different or similar to the Disability Equality Duty, where the latter did provide for positive duties which may help in the understanding/implementation of the CRPD.

2.6 Some asked whether it was possible to learn lessons from the other human rights treaties and conventions such as the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

3. Placing the Convention within the broader human rights context
Many stressed the need to look at the Convention in the human rights context, including drawing upon the experiences relating to other human rights treaties and making links with mainstream human rights organisations.

3.1 There must be a human rights approach to disability. There needed to be a social as opposed to a medical/biological approach and to involve a range of disability organisations and cross-impairment groups. Links needed to be made with other human rights organisations and the promotion of the Convention needed to be combined with the wider issues around human rights.

3.2 Were there lessons to be learned from other groups/countries in relation to other human rights conventions? Reference was made to Gerard Quinn’s paper – which had been circulated to delegates in advance of the round table. Would other instruments give a better idea of people could be drawn into the process?

3.3 The ‘Improving Life Chances of Disabled People’ report was noted as a potential vehicle to increase the human rights capacity of organisations of disabled people. It had the potential to create local independent organisations for disabled people.

3.4 The CRPD also presented an opportunity for a broader discussion on human rights in the UK.
3.5 There was some discussion in one group about whether or not disability organisations should form wider alliances and coalitions with other groups who wanted to promote a human rights agenda. No real consensus was reached.

3.6 The issue of human rights organisations was also discussed and some participants noted that outside England (London) there were no real human rights organisations operating in other areas of the country. Moreover, most of the ‘general’ human rights organizations did not have disability issues as their prime focus. Some participants felt that with the CRPD some had now become interested in disability issues, but they had not been the driving force behind the Convention and thus appeared to be taking on disability issues for other reasons than the true interests of disabled people.

4. Involvement and Participation by People with Disabilities
This issue was of particular importance to all three groups involved in the discussions. There was consensus on the importance of disabled people being actively and effectively involved in the implementation and monitoring of the Convention. However there was a recognition that this was difficult to put into practice. In particular the diversity of the organisations representing disabled people was raised.

The nature of involvement
4.1 It was seen as important to take history into account and to remember where disabled people were coming from in the future development of the Convention. A strong view was expressed in two groups that it was important not to lose sight of Article 4 of the Convention\(^6\) and that there was

\(^6\) Article 4 sets out general obligations on States Parties including the obligation in 4.3:
"In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."
a need to build on the role that disabled people had played in drawing up the Convention.

4.2 The importance of attaining some kind of united or co-ordinated voice among groups representing disabled people was discussed. The danger of multiple groups arguing between themselves was noted. It was acknowledged that there was no problem with the existence of various impairment groups, but that they all should be able to speak with a united voice when this was needed. This, however, was difficult and there was a need to explore the differences between various disability organisations.

4.3 A view was expressed by some participants that very few organizations would be concerned with the whole of the Convention but would wish to focus on parts of it and how it related to real life. This was seen as a better strategy than thinking about involvement in a monolithic Convention.

4.4 One group felt there was a duty on the Equality and Human Rights Commissions and Government to involve disabled people in the processes about the Convention and that so far these efforts had been patchy. Their involvement was important as ‘the average non-disabled person has no concept of disability and doesn’t care about it.’ It was felt strongly in one group that the ODI and Equality and Human Rights Commissions could not do all the work alone.

4.5 A number of questions were raised about the kind of involvement organizations representing disabled people might have in the implementation and monitoring of the Convention. It was agreed that there were different agendas in which organizations could become involved. Deciding where to become involved was a complex task for these organizations. Involvement was needed around different themes in the Convention for example, health, legal issues, etc. One group commented that it was possible to use the Convention to further and support existing work/arguments e.g. using Article 19 to support existing work around
deinstitutionalization. However there was also a need for involvement in the ‘top level’ processes.

4.6 It was felt that some movement towards bridging the divide between disabled people and public authorities was needed.

4.7 The importance of viewing rights from a social perspective rather than a medical one was stressed and this had implications for how groups representing people with disabilities were organised and involved in the Convention.

4.8 In one group it was stated that the EHRC was going to commission research on good practice on how active involvement might work successfully.

4.9 The experience in Northern Ireland had been that each geographical area consulted with the different organizations separately and these organizations felt that they had to keep going through things again and again. There was no collective gathering of information.

**Action by people with disabilities**

4.10 One group expressed the view that that historically, change in this country fundamentally happened at the grass-roots level.

4.11 The Parliamentary Joint Committee on Human Rights and other similar mechanisms were seen to be important points of leverage in getting change to happen.

4.12 There was a clear statement in one group that organizations of disabled people and individuals needed to know the processes involved in providing evidence to the Equality and Human Rights Commissions and other bodies. An EHRC representative commented that the Commission was going to produce information on how people had effectively used the law.

4.13 A number of different tools were seen as important if the Convention was to be effectively implemented. These ranged from taking test cases to court
on breaches of legislation relevant to Articles in the Convention, to the importance of working at a grass roots level.

**Representativeness of organisations.**

4.14 Concern was expressed that only some groups or organisations were consulted by Government and that these did not always represent disabled people. For example in the Deaf world it was often only RNID which was consulted. The need for discussions among organizations of and for disabled people about what representation meant was stressed.

4.15 Representation was seen as crucial to implementation. People needed to be asked who they want to represent them rather than the groups saying who they want to represent. It was seen as important to come at this issue from a grass-roots level.

4.16 In one group there was discussion of the need for a sophisticated discussion and response about what is a representative organization.

4.17 One group discussed the role of Equality 2025 and whether it was an appropriate representative. Some people commented that it had no real constituency – but it was acknowledged that it was possibly influential. Equality 2025 was an Advisory Non Departmental Public Body sponsored by ODI. Its primary role was described as a conduit between disabled people and government in a safe, confidential context/framework. It could hold consultations with disabled people and it was their voices that were fed in.

4.18 A lot of people who were defined as disabled (e.g. older adults or those with mental health problems) did not identify as disabled. This created problems when trying to find unity between groups of disabled people and also clarifying to whom the rights in the Convention applied.

4.19 Disabled people were not a homogenous group and concern was expressed at the idea of one overarching organisation representing all disabled people:
how would all the different stakeholders come together; and who would
decide their roles and responsibilities? Should it be impairment-specific or
cross-disability? As long as there were factions within the disability
movement it was not going to be possible to find a common platform and
understanding.

4.20 A view was expressed by one group that the truly representative
organizations of disabled people were not resourced by government.

4.21 One group raised the issue of international organizations of disabled people
and thought it was important to explore who these were for different groups
of disabled people. It was thought that such organizations might have a role
to play in working with national organizations.

4.22 Many felt, however, that there was not one solution to this issue and
different groups may need to be drawn on for different issues. It was
important that thought be given by organizations representing disabled
people to identify in which organizations particular interests and expertise
might lie.

4.23 Jane Campbell’s lecture⁷, ‘Fighting for a slice or for a bigger cake’ was
mentioned as it referred to dominant voices from disabled people in the UK
and those that were not routinely heard. EHRC had to deal with equality in
terms of the group and the individual, but it was asked ‘who is the group?’

4.24 Although it was important to obtain the view of the “man in the street” it was
also essential that involvement should include experts and disabled people
with particular interests and expertise.

4.25 Concern was expressed that not all disabled people were members of
organizations of and for disabled people. In relation to the CRPD, these
people may therefore not be heard by Government or the monitoring
organizations. They may have very different views to those involved directly.

⁷ http://www.leeds.ac.uk/disability-studies/archiveuk/Campbell/Fighting%20for%20a%20slice%20of%20the%20cake%20FINAL%20FINAL%2029%2004%2008.pdf
It was a challenge to make contact with these people particularly if they did not consider themselves to be disabled. There were some suggestions that websites and other forms of new media, e.g. Facebook or Twitter, could be used to engaging with them, particularly with younger people. Other disabled people would find it difficult to have a voice, for example, people with dementia.

4.26 One group strongly emphasised that disabled people were 'less in the public eye' than other citizens. They were reliant upon public services and this may make it more difficult for them to voice their opinions and concerns. Therefore it was seen as important that all discussions around disability issues were headed by the slogan 'nothing about us without us' (i.e.- no decisions regarding disabled people to be taken without them being consulted).

Responsibility to Act.

4.27 In one group the issue of who was expected to act was raised. In comparison with other countries, where there was a stronger emphasis on citizens bringing about change, Within the UK there was an expectation that this was the responsibility of Government.

4.28 Some asked how the government and other organizations could help to educate disabled people to understand their own rights.

4.29 From experiences in Northern Ireland one group recognised the difficulties involved in consulting on each issue with everyone.

5. Leadership.

All groups noted the importance of leadership among groups of and for people with disabilities.

5.1 Article 4 needed to be kept in mind when considering Article 33. Article 4 had expectations of 'leadership'.

25
5.2 Government rather than the Equality and Human Rights Commissions must take the lead in the implementation and monitoring of the CRPD and this must be the responsibility of all ministries. ODI was incapable of carrying out the implementation on its own. Work must be carried out across all government departments.

5.3 However, promotion of the Convention was seen as an integral part of implementation. Questions were asked about who should lead this. Doubts were expressed about the capacity of Government to do so and it was strongly felt that the promotion of the Convention should be led by organization(s) of and for disabled people rather than by government. Funding should be available for this to happen.

5.4 One group noted that Equality 2025 was in theory well placed to provide leadership by people with disabilities. However there was a lack of clarity and some distrust about how Equality 2025 was seen within Government.

5.5 One group felt that leadership included a need for bold people in the civil service to follow things through and for a body which would have power to impose real sanctions in case of non-compliance. However, if an individual post were to be created it would need institutional backing and the idea of someone equivalent to the Children’s Commissioner, as independent of government, being appointed was discussed.

5.6 The intention to designate ODI as the focal point in Government, was generally noted but some participants commented that as it was part of government its independence would be called into question. The view was expressed in one group that the ODI lacked status in Government hierarchies as it was a sub-section of another department. To be able to provide successful leadership and to implement the Convention successfully there should be representation of the issues within the Cabinet Office.
6. Coordination

6.1 Co-ordination was seen as essential by one group (and voiced also as a concern by others) for implementation. Government and disabled people’s organizations needed to work together if the Convention was to be successfully implemented.

6.2 Some people expressed the view that currently there was a lack of co-ordination about who was driving the implementation process forward and what the roles and responsibilities of different organizations were.

6.3 Concern was expressed by some participants that the disability field was split and factionalized but there was a need to have a common platform to drive change forward.

6.4 There needed to be clarification of the status and roles of the following organisations in relation to the Convention, taking into account issues relating to devolution:

- ODI
- Equality 2025
- Equality and Human Rights Commissions

7. Implementation and role of government

7.1 Implementation was seen as having a number of components including establishing a baseline of rights, a gap analysis and drawing up a framework for implementation.

7.2 If the Convention were to be successfully implemented it needed to be effective across all government departments and public bodies. One government representative commented that ODI had worked to get all departments to reflect on the Convention in an attempt to get it more mainstreamed.
7.3 The linking the Convention provisions to the Disability Equality Duty and other national legislation, for example, was seen to be important.

7.4 Many felt that equality must be prioritized across all government departments, public bodies and in Cabinet. There needed to be a single Equality Bill\(^8\) with no ‘watering down’.

7.5 The issue of progressive implementation was discussed at some length by one group. It was acknowledged that provisions for progressive implementation were extensive and the group considered that these were strengths of the instrument. For example the requirement that ‘maximum resources’ should be devoted to implementation allowed for considerable scope to debate the issue with the government if the state was not doing what it ought to do.

7.6 The importance of Article 4.1d\(^9\) in the Convention was stressed in terms of the need to ensure that public authorities and institutions acted in accordance with the Convention.

7.7 A view was expressed in one group that the ODI/government wanted disabled people to be actively, not passively, involved in matters relating to implementation of the Convention. This meant that organizations representing disabled people needed to make decisions about the issues in which they wanted to be involved.

\(^8\) The Equality Bill was introduced into Parliament on 24 April 2009

\(^9\) Article 4.1. “States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

\(\ldots\)d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
7.8 A view was expressed in one group that a deeper, cultural change was needed in the way government worked. There was resistance among participants to the creation of lots of new groups/bodies. Rather the focus should be on embedding all the principles in Local Authorities and in policy making, for example, within Government. All local and national bodies should be considering human rights aspects in all their work. This was seen as the only way to mainstream the Convention.

7.9 It was emphasised in all groups (though sometimes in different ways) that disability issues must be placed at the top of the agendas of all institutions and government departments.

7.10 It was argued that there was a need to work with the existing system, taking examples and best practices from other countries and contexts, to see how those can be applied in the UK context in a practical and meaningful way.

7.11 One group expressed the view that government provided funding only to service providers and that this was very problematic because it resulted in disabled people’s organisations having no resources to engage in awareness raising campaigns, lobbying, coordinating activities, etc. It was noted that service providers were driven by the commercialised market which required them to provide more services to the public. Organisations representative of people with disabilities should not be equated with service providers, however it appears that this was the current trend.

8. The Role of the Equality and Human Rights Commissions

8.1 One participant commented that the EHRC was committed to real involvement by disabled people and groups in the development of its work in respect of the Convention.

8.2 An EHRC representative commented that it was drawing up guidelines on involvement which would be published later in 2009.
8.3 A view was expressed in one group that there needed to be a memorandum of understanding between the ODI and the EHRC and the devolved administration and Northern Irish Commissions to clarify their separate roles. This was felt to be important because lines of responsibility between implementation and monitoring could be blurred and the two sectors needed to work together.

8.4 It was noted that in Northern Ireland the two Commissions worked closely together with NGOs in the field in awareness raising campaigns. The most recent exercise involved a series of events similar to this roundtable which were financed by the NGOs (it was noted that ideally these would be financed by government, but since finances were not available, NGOs had taken a pragmatic approach and provided finances themselves).

8.5 The Scottish Human Rights Commission explained how it had started to work with human rights activists across the country as well as with professionals (medical and legal, for example) so they would become activists in the community and hold local authorities to account. Activities like these were noted by the participants as important in giving people tools to defend their own rights.

9. Getting the Convention Known.
Across all three groups the importance of the Convention becoming known was seen as an important issue. However, the following concerns and ideas were raised in discussion:

9.1 One group in particular felt that the Convention would not make any difference to the lives of disabled people until there was a common understanding and recognition of the importance of their rights and of the effects of institutional disablism.

9.2 Translating the CRPD into understandable language and escaping the use of jargon was seen to be particularly important in order to raise awareness
of the instrument among disabled people. Disabled people were often not aware of their rights and it was crucial to the effectiveness of the Convention that they should know their rights and be able to use them.

9.3 The example of Northern Ireland was discussed in relation to training of disabled people as human rights activists. This training had been around what human rights were and what they meant to disabled people. They had been provided with training around the Convention and this had brought people together in a network. They were then working with government departments and policy makers. It was asked if this human rights training could translate to other parts of the UK, especially if done at the local level.

9.4 The importance of educational campaigns that would make the Convention available and known by others not actively involved in the disability movement was stressed.

9.5 Some suggested involving young people through means that were more familiar to them, like Facebook and UTube.

9.6 Some people commented that there was overall lack of knowledge about international human rights instruments, such as CEDAW and in order to avoid the CRPD following ‘the same path’, there was a need to simplify the text, make it accessible to persons with disabilities and carry out educational campaigns.

9.7 Concern was expressed at the lack of knowledge in the general public and public authorities of other rights legislation, for example, the Human Rights Act and the Disability Discrimination Act. It was felt that it would be helpful to have education and publicity which addressed these Acts and how the Convention related to them.

9.8 There was also a particular need for training teachers and social workers in relation to disability and also in relation to the Convention.

9.9 Front line workers were seen as needing support and to be freed up from bureaucratic responses/frameworks so that they could embrace a human
rights approach. For example, for many people with learning disabilities, their support worker may be one of the most important people in their life so they (ie support workers) needed to know and understand about human rights.

9.10 Lastly, many stressed the opportunities to celebrate the Convention and what it meant. This applied particularly to ratification. A suggestion was made for a year-long celebration which would promote the Convention and educate people about it.

10. The Need for a Gap Analysis
The need for a gap analysis which would identify ‘gaps’ in current legislation in relation to the Convention was raised and discussed in all three groups and was strongly advocated. Some felt that this should be carried out by organisations of and for disabled people.

10.1 There is a need to compare the text of the CRPD with the existing UK legislation to identify what was available under the domestic legislation as required by the instrument and what was not.

10.2 It was emphasized that existing legislation was rather advanced in the UK but the problem was often with poor implementation, barriers that existed in society or public opinion. The Convention provided an opportunity to bridge this gap.

10.3 In undertaking these gap analyses and research it was felt to be important that they be a ‘bottom up process’ which engaged disabled people. Some people commented that there was a gap in properly resourced and funded organisations which were representative of people with disabilities and which would be expected to have a role in a gap analysis.

10.4 Concern was expressed by some people that previous exercises such as gap analyses and maps for implementation of rights had been undertaken
but had led to little change. It was seen as important that for the CRPD to be effective change needed to happen on the ground.

11. Resources
11.1 A strong view was expressed by some participants that it was important that adequate government resources be made available to facilitate successful implementation and monitoring of the Convention.

11.2 Promoting the Convention would cost money. In Northern Ireland no additional resources (and no dedicated expertise in relation to disability) had been allocated.

11.3 Resources were needed to bring together disability organizations – to create a common platform which could inform implementation and monitoring. However, concern was also expressed that such organizations may find it difficult to be independent in their views if they were receiving money directly from Government. It was suggested that it would be better if this funding was channelled through another organisation, such as the EHRC, as this would create more “distance” between organizations and government.

12. Devolution.
12.1 There was considerable discussion on how the CRPD would work across the UK. As for any gap analysis and who should carry out this task, the EHRC indicated that it intends to do this, that a strategy will be put in place and that the relevant stakeholders would be consulted on it.

12.2 The Scottish Human Rights Commission noted that it intended to undertake a mapping exercise on the realisation of all human rights for all people and that the proper way of doing this also required that the views of people with disabilities were reflected in it. The end of this exercise would be in 2010, in time for the UK’s Universal Periodic Review at the UN.
12.3 The importance of ensuring that Northern Ireland was included in all discussions was stressed in one group.

12.4 While the ODI has the whole of the UK as its remit, its powers in relation to devolved administrations were unclear. In practice, however, contacts between Westminster and devolved administrations were good which facilitated work on the ground.

13. Reservations
A discussion of possible Government reservations to the Convention was not included in the planning for the roundtable. However there were some strong views expressed in the discussions:

13.1 Concern was expressed that the proposed reservations could be contravening the Convention itself. Members of one group felt that the reservations being considered by Government revealed that disability rights were low on the government’s agenda.

13.2 It was noted that the scope of reservations as stated in the Convention were limited and could not be used as a way ‘to avoid’ the requirement of utilizing ‘maximum available resources’.

13.3 The issue of the interpretative declaration was also examined by one group and the difference on legal opinion on this matter was noted.

13.4 The question was raised in one group: How could implementation be discussed when there were these reservations?

14. Research
14.1 The issue of research was discussed in one group which noted that research projects were given to top research companies which did not involve people with disabilities. The consequence of this was that their conclusions were not truly reflective of the views of people with disabilities.
The need for a small advisory group composed of people with disabilities was stressed if research was to be carried out on the CRPD.

14.2 The issue of data was also raised in this context: some participants felt that there was no proper data on people with disabilities as that which had been collected was not as representative and reflective as it needed to be.

14.3 Such data needed to be qualitative as well as quantitative.
CONCLUSION AND RECOMMENDATIONS

A large number of issues were raised at the roundtable. While these were not put in the form of recommendations it does seem important to pull together some of the important issues and suggestions that were made in terms of possible future action. We do this tentatively and hope that the participants in the roundtable will use them as points for discussion and further action.

Promotion and awareness raising.

Promotion of the CPRD with organisations of and for disabled people, Government, civil service and the broader society were seen as very important:

- The ratification of the Convention and the signing of its Optional Protocol were seen as opportunities to both celebrate the Convention and to increase awareness about it. These occurrences should therefore be accompanied by both publicity and educational campaigns.

- It was strongly felt that the promotion of the Convention should be led by organisation(s) of and for disabled people rather than by Government.

- Funding should be made available for this to happen.

- There should be an intensive, funded campaign to educate disabled people and others in the community about human rights and the Convention.

- The Convention should be made available in accessible and easy to read versions.

- Training in human rights and in advocating for them should be available to disabled people.

- Education and training about human rights and the Convention should be provided to personnel in all government departments and to those who work with disabled people.
Relationship with the broader human rights field

Action needs to be taken to examine the CPRD in relation to other national human rights legislation and international treaties:

- To examine what can be learned from such legislation and treaties that may assist in the implementation and monitoring of the Convention.

- The involvement of wider human rights organisations with disability issues has been sporadic and it appears that some have been engaging with these only now with the CRPD.

- To identify commonalities and possible differences between the CPRD and other treaties and legislation which may be important in implementation and monitoring of the Convention.

Engagement with people with disabilities

It is essential in the view of participants that bodies undertaking implementation and monitoring of the Convention ensure that there is REAL involvement by disabled people in the processes. This involvement was seen to be essential at all stages. In order to move towards this the following steps would be needed:

- A recognition by relevant government bodies and the Equality and Human Rights Commissions that organisations representing disabled people were diverse.

- Resourced opportunities, distanced from government, for organisations of and for disabled people to come together to explore both their diversity and where they have common ground.

- A discussion on the issue of what representativeness means. Resourced opportunities for such organisations to come together to discuss how they might represent their constituents. This included discussions about focusing on particular areas of concern or interest, working with other human rights organisations, deciding who is best placed to represent particular interest groups.
• The EHRC should publish its paper on active involvement as an aid to discussion.

• Training on how best to approach and use the EHRC in making their views known should be provided by the EHRC to organizations of and for disabled people.

• New technologies like Facebook and UTube should be actively used to reach out to disabled people who may not be linked with existing organisations. This was felt to be particularly important in relation to young people.

• Government provision should be made for regular meetings of organisations representing disabled people so that they can monitor the effectiveness of implementation of the Convention in relation to their constituents.

• Organisations of and for disabled people should make use of the bodies such as the House of Lords House of Commons Joint Committee on Human Rights and other relevant bodies to make their views known.

Clarifying the roles of the respective bodies
There needs to be clarification of the status and roles of the ODI, Equality 2025 and the Equality and Human Rights Commissions in relation to the Convention, taking into account issues relating to devolution. To this end:

• A memorandum of understanding should be drawn up by the ODI and Equality and Human Rights Commissions in consultation with disabled people to reduce the possibility of blurring of boundaries and responsibilities between ODI and the Equality and Human Rights Commissions.

• Trying to ensure that issues were mirrored across all government departments so that it is not only the Disability Officer who knows about disability issues, but it is fed across the departments; On this aspect a useful point of entry was noted as the duty of Secretary of States to report on equality every December.
• Equality 2025 and its role in wider issues need to be clarified.

• Importance of independence of the commissions from Government and the need for such independence in implementing/monitoring the Convention.

With respect to government in particular:

• The Office on Disability Issues be based at the Prime Minister’s office; properly staffed and resourced by people with disabilities. This should be properly resourced by disabled people to obtain their authentic voice;

• The need for transparent ways of engaging disabled people by Government;

• The training of activists across the country and across professions was noted as important;

• The need to support organisations of people with disabilities. The current push to be a service provider and not an activist was noted as negative in relation to its impact on involvement in work of the Convention.

Gap analysis and research

• A gap analysis which identifies gaps between the Articles of the Convention and current UK laws and practices should be undertaken as a matter of urgency. The gap analysis should establish benchmarks by which progress can be monitored.

• Research which would assist the implementation and monitoring of the Convention was needed. Such research should be led by and involve disabled people at all stages.

Follow up

• One group expressed the need for regular meetings of organizations of and for disabled people on a regular basis, for example annually. It was thought that such meetings, which would not be expensive, would provide a forum for
looking at what the successes and set-backs were in relation to the Convention.

- A further roundtable should be held in the next twelve months to note progress on implementation and to develop an independent framework of organisations representing disabled people within which they can act in relation to the Convention.
APPENDIX I: AGENDA

9.30 Registration

10.00 Opening and welcome

10.10 Placing the UN Convention in a UK Context

Paper: Introducing the Convention

Professor Kelley Johnson (Norah Fry Research Centre, University of Bristol)

Professor Rachel Murray (School of Law, University of Bristol)

De-Mystifying the Convention: the aims and content of the Convention, looking at some of the concepts underpinning the Convention: e.g. progressive achievement, what is required by Article 33, responsibilities of government, what is required by the monitoring framework.

Tony Aston (EBU Commission on the Rights of Blind and Partially Sighted People)

Mark Harrison (Norfolk Coalition of Disabled People)

Expectations of the Convention: Perspectives from disabled people and their organisations. Starting points for discussion

11.00 BREAK

11.10 Working groups: Two working groups can then take these issues and examine them in more depth, e.g.:

What exactly is required by Article 33?

What does implementation mean? What does it mean to promote, protect and to monitor?

What steps need to be taken to translate the words of the Convention into direct positive effects on people’s lives?
Is this ‘business as usual’ or is something else required by the Convention?

12.20 Feedback and recommendations from working groups

1.00 L U N C H

2.00 The role of the respective organisations

Papers:

Richard Timm (Office of Disability Issues)

The role of government

Neil Crowther (Equality and Human Rights Commission)

The role of the human rights commissions

Rachel Hurst (Disability Awareness in Action) & Peter Beresford (Open Services Project)

The role of civil society

2.45 B R E A K

2.55 Working Groups: Questions to be discussed may include:

What were the respective roles of government, the human rights commissions and civil society?

How will these bodies work together?

Does the implementation and monitoring of the Convention have any resource issues for existing bodies?

What coordination should there be?

What issues of independence are raised?

How can people with disabilities have a consistent voice in the progress of the UN Convention?

3.45 Feedback from groups and recommendations

4.00 Closure
APPENDIX II: LIST OF QUESTIONS FOR THE WORKING GROUPS

Group A
1. What exactly is required by Article 33?
2. What does implementation mean?
3. What does it mean to promote, protect and to monitor?
4. What do you see as the important factors which will help or inhibit these processes?
5. What are the respective roles of government, the human rights commissions and civil society?
6. How can people with disabilities have a consistent voice in the progress of the UN Convention?

Group B
1. What steps need to be taken to translate the words of the Convention into direct positive effects on people’s lives?
2. Is this ‘business as usual’ or is something else required by the Convention?
3. How will government, the human rights commissions and civil society work together?
4. What coordination should there be across different sectors in order to support the processes of implementation, monitoring and protection?
5. How can people with disabilities have a consistent voice in the progress of the UN Convention?
**Group C**

1. What do you see are the main differences and similarities between implementation and monitoring?

2. What strategies would you want to see in place that would support implementation and monitoring?

3. What issues of independence are raised by the roles of these three groups?

4. What strategies, if any, do you think might resolve these?

5. Does the implementation and monitoring of the Convention have any resource issues for existing bodies or for those who may become involved in the process?

6. How can people with disabilities have a consistent voice in the progress of the UN Convention?
APPENDIX III: LIST OF PARTICIPANTS

Group A

Chair: Linda Ward, Norah Fry Research Centre
Notetaker: David Abbott, Norah Fry Research Centre

Susan Archibald Archibald Foundation
Tony Aston Guide Dogs
Ines Bulic European Coalition for Community Living
Neil Crowther Equality and Human Rights Commission
Steven Emery Centre for Deaf Studies
John Evans Disability Consultant
Rowen Jade Equality 2025
Lisa King Equality Commission, Northern Ireland
Denise McGill Northern Ireland Human Rights Commission
Barbara McIntosh Foundation for People with Learning Disabilities
Camilla Parker Just Equality
Sue Green Office of Disability Issues

Group B

Chair: Rachel Murray, School of Law
Notetaker: Elina Steinerte, School of Law

Wendy Ashton Disability Wales
Mark Harrison Norfolk Coalition of Disabled People
Sophie Heitz Leonard Cheshire Disability
Paddy Ladd Centre for Deaf Studies
Ruth Scott Scope
Grainne Teggart Centre on Human Rights for People with Learning Disabilities
Richard Timm  Dept for Work and Pensions
Lynn Welsh  Equality and Human Rights Commission
Duncan Wilson  Scottish Human Rights Commission
Patricia Carey  OFMDFM NI

Group C

Chair: Kelley Johnson, Norah Fry Research Centre
Notetaker: Anna Marriott, Norah Fry Research Centre

Alison Bryan  British Deaf Association
Bronagh Byrne  Centre on Human Rights for People with Disabilities
David Congdon  Mencap
Marije Davidson  RNID
Nigel Dotchin  Department for Transport
Pauline Heslop  Norah Fry Research Centre
Rachel Hurst  Disability Awareness in Action
Joan Langan  School for Policy Studies
Diane Mulligan  Equality and Human Rights Commission
Mike Smith  National Centre for Independent Living
Hello. First can I say how sorry I am that I can’t be with you today. My day job has had to come first and today I am working with our professional social work students on professional practice in relation to end of life care, where as we will all be aware, important issues relating to human rights are increasingly being highlighted in public and political discussion.

It may be helpful if briefly I tell you about myself, so you can get a clearer understanding of why I have the take I do on the issues under discussion today. As well as working at Brunel University, involved in the professional education of social work students and directing a University research centre, the Centre for Citizen Participation, I am a long term user of mental health services and chair of Shaping Our Lives, an independent national user controlled organisation and network. Please google us: Shaping Our Lives or check out our website: www.shapingourlives.org.uk.

The work we do is funded by government and independent charitable trusts. We are made up of and work across a wider range of groups of social care service users, including older people, people with learning difficulties, people with drug and alcohol problems, people living with HIV/AIDS, disabled people, mental health service users, people with life limiting illnesses and conditions who use palliative care or hospice services and others. We work with local, national and international organizations to increase the say and involvement that health and social care service users can have in the support they received and over their own lives and to improve the quality of support and services that they receive. We seek to work in accessible ways to enable the effective involvement of a diverse range of disabled people. For us access is an equality issue. This and our commitment to include people and address difference in terms of ethnicity, age, gender, sexuality, impairment, belief, culture, class and so on, is reflected in the composition of our management group and our national user group. These
concerns regarding diversity also inform my approach to today’s seminar and its focus.

I want to highlight how key a task securing the rights of disabled people still is. We know that these rights are far from secure in our society at large. But I need to add, from the evidence that is emerging from a large scale national project we are currently completing how far from secure those rights also are in the services that are meant to support, liberate and safeguard, disabled people. Routinely we have been finding such services, state and independent services, failing to secure disabled people’s rights and indeed putting them at risk and overruling them. This includes their right to freedom of movement, from discrimination, from abuse, to live independently, to access to information, to privacy, to material wellbeing, to respect for family and home life, to have relationships, be parents, to live alongside non-disabled people if they wish, to have the right to access to decent employment, rather than being forced off benefits to inappropriate employment, to participation, to the right to life.

We also know that big organisations, particularly charitable organisations, that claim to speak on disabled people’s behalf and present themselves as fighting for their rights, also often don’t respect them. Most recently this has become public with Leonard Cheshire Disability, where the Information Commissioner has required them to make available to a residential service user a series of emails from senior managers which abuse and slander him.

That’s why in my comments I have to stress the crucial importance of ensuring the full and equal involvement of disabled people and their own organisations in the operation, monitoring and working of the UN Convention on the rights of disabled people - if it is to have meaning and positive impact. We all know the difficulty of making paper rights real, for all. We know that there is in the UK a wide suspicion of paper rights and human rights approaches as people see them used to safeguard the privacy and power of powerful groups and individuals and
people who abuse the rights of others, rather than having sufficient broad-based democratic relevance.

So I want to stress the crucial need for the involvement of disabled people and their organisations at all stages, at all levels and at all opportunities in this development and process. This is far easier to say than achieve. It will require proper resourcing. We must fight for that.

This involvement must as I earlier indicated be diverse, across the many different groupings of disabled people, addressing diversity in terms of gender, ethnicity, sexuality, age and so forth. It must work to include disabled people who face especial barriers; people with complex and multiple impairments, who are institutionalised, refugees and asylum seekers, who communicate differently, are in the penal system, homeless and so on. This can be done, but again requires proactive and outreach approaches. To make this real, issues of access need to be prioritised and understood broadly in terms of physical/environmental access and also communication and cultural access. They need to recognise and act upon this principle that access is a key equality issue.

We also need to recognise that some particular issues may apply to particular groups of disabled people. For example, mental health service users have long argued, including in relation to the UN Convention that some of the so-called treatments they receive, like electro-convulsive therapy and brain surgery constitute inhuman or degrading treatment. The UN Convention sets out the right to Freedom from torture or cruel, inhuman or degrading treatment or punishment. Governments have determinedly sought to have such ‘treatments’ excluded from this category and indeed have in numerous cases, including the government in England, been extending provisions for compulsory so-called treatment. This needs to be kept under the closest scrutiny. Similar issues are likely to arise if governments are susceptible to the current clamour
from lobby groups for ‘assisted suicide’ and euthanasia, including for people with impairments, rather than life-limiting illnesses and conditions.

It is key that disabled people and the organisations they control must be at the heart of taking forward the UK Convention. Only in this way will the issues that are particular concerns for them get the attention that they demand. For example, hate crime against disabled people is only now being recognized as an issue – because of the efforts of disabled people. Disabled people’s involvement is vital if the issues they identify as key are to be included. They will need resources and support to take on this task at local, regional, national and international levels, to reach out proactively to the diversity of disabled people and to engage with governments and policymakers over these rights issues. They will need to be resourced to do so, particularly they will need to be resourced to be able to link up at an international level, which is crucial but where there are particular barriers.

The Convention will set up a Committee on the Rights of Persons with Disabilities which will consist at the time of entry into force of the present Convention, of 12 experts with more subsequently to be added. It is crucial that expertise by experience as disabled people figures strongly in this membership. We know from experience that if it doesn’t, the value of such a body and such a development is likely to be qualified. More than this there need to be structures, such as an ongoing disabled people’s reference or steering group to ensure that the Convention is properly monitored and acted upon. This needs to be properly funded, preferably independently

All these proposals may be seen as pie in the sky. A great wish list, but unattainable. But having achieved the Convention, what use will it be unless it is consistent with the watchword of the international disabled people’s movement, ‘Nothing About Us Without Us’. These aims for effective say and diverse
involvement need to be seen as an ongoing part of the struggle to realise the Convention. Thank you.