Mothers of children with learning disabilities belong to a marginalized group of women, not only in our society but also in feminist research where their voices are seldom heard. This is particularly true for Irish mothers who face a greater challenge than many of their peers in other European countries. The Irish Constitution, influenced by a strong Catholic ethos, limits the choices Irish women can make, in particular those women who have children with special needs.

This paper discusses findings from a qualitative study of mothers with children with Autistic Spectrum Disorders, Down syndrome and/or Attention Deficit Hyperactivity Disorder (ADHD) in Ireland. Firstly, I will give a brief historical introduction to existing disability policies in Ireland and give examples of the power struggle between mothers and the Irish State. Secondly, I discuss my preliminary research findings of my participants’ lived experience of mothering a child with special needs. Finally, I will argue that the feminist movement has ignored this group of women in our society who, as active agents for their children, are fighting a very lonely battle and need a structured feminist forum for emancipation.

The Irish Free State, or the Republic of Ireland, was established in 1922, politically independent of its former colonial master, Great Britain. The new independent state was a poor agricultural country, cut off from the wealthier, industrial northeast part of the country, which remained British. Ireland’s new government was cash starved and socially conservative with ideologies rooted in traditional Catholic values (Powell, 1992). The role of the woman in the family was enshrined in the 1937 Irish Constitution.

1. In particular, the State recognises that by her life within the home, woman gives to the State a support without which the common good cannot be achieved.
2. The State shall, therefore, endeavour to ensure that all mothers shall not be obliged by economic necessity to engage in labour to the neglect of their duties at home. (Article 41)

This anti-feminist wording is still affecting the lives of women in today’s Irish society, where the vast majority (88.4 percent) are Roman Catholics (Cullen, 2003). Irish women’s choices are far more limited in comparison to many of their peers in other European countries.

*This study is supported by grants from the Irish Research Council for the Humanities and Social Sciences and the National Disability Authority.
Legislation on, for example, contraceptives (illegal until 1979), divorce (illegal until 1997) and abortion (still illegal after several referenda) limit the rights and the freedom of women in Ireland. Economically Ireland has prospered during the last decade and an increased number of women have entered the labour market. Today’s figures show that 46 percent of Irish women participate in the labour force in comparison to 30 percent in 1985 (CSO, 2002). Nevertheless, it still remains very difficult for women to combine a career and a family, as there is no state funded childcare system in Ireland and private childcare places are very costly. The educational system assists in “caring” for children, aged 4 and up, for those women who are able to work during school hours, and although it is difficult most women with able-bodied children can participate in the labour force. For mothers of children with disabilities, however, this is not the case. Firstly, the right to an education cannot be taken for granted and secondly, it is difficult to find mainstream services that will cater for the needs of a child with a learning disability.

Among grossly under-developed social policies in Ireland are policies for people with disabilities. In 2003, the European Year of the Disabled, there is still no disability legislation based on rights in Ireland. Despite nearly half a century of debating among politicians and campaigning by the disability movement, consecutive Irish Governments have not introduced a law protecting the rights of people with special needs. In 2002, the Government made two attempts to introduce legislation, but both bills had to be withdrawn due to large protests from various disability organisations. An independent social policy analyst and policy advisor in Dublin has described the bills to “appear to be out of step with other international developments in disability rights” (Pillinger, 2002:2). The Irish Government has also come under strong criticism from the United Nations over housing around 1200 people with learning disabilities in mental institutions (Shanahan, 2002).

Annie Ryan, a retired teacher and a mother of a now grown-up son with autism, experienced the Irish State’s neglect of providing services for people like her son. It prompted her to write the book *Walls of Silence*, (1999). It is a document about “Ireland’s Policy Towards People with a Mental Disability” and it is disturbing reading. The State could not provide any service for Annie Ryan’s son, and as a teenager he was admitted into a mental institution. Annie Ryan blames the Irish political system and constitution for not protecting the helpless and for having abandoned the idea of specific legislation for the “mentally handicapped” between 1953 and 1957. The Irish State’s unwillingness to take responsibility for children with disabilities was closely linked to the Catholic ethos. According to the Catholic Church a child with special needs was either “a cross to carry”, a burden to the family, or “a special gift from God”. Both these statements made it very difficult for the mother to do something about her situation and ask for help, as this was “God’s will” and she just had to accept it.

The Irish Government’s attempt to legislate for people with disabilities came in the wake of two landmark cases taken by two mothers on behalf of their sons, against the Department of Education. In 1993 the High Court ruled in favour of Marie O’Donoghue, who had taken action on behalf of her seven-year-old son Paul whom, according to the State, was not entitled to an education due to his severe learning disability. The judge ruled that according to Article 42 in the Irish constitution, the State has an obligation to provide a free education for all its citizens, including those with special needs. The State, in fear of the implications, appealed this decision to the Supreme Court, but five years later, in 1997, the Government was forced “into a humiliating climb down that will cost it millions of pounds.” (“State is defeated”, 1997).

Three years later, Kathy Sinnott, mother of Jamie, 23 years old and autistic, fought and won another battle in the High Court. The case established that the State had breached its constitutional obligation to provide Jamie with an appropriate education, and furthermore, that this education should be provided regardless of a person’s age. Yet again, the State appealed the High Court’s decision, and this time, in July 2001, the Supreme Court overturned the High Court ruling. The Supreme Court’s seven judges agreed that Jamie had not received the education he had been entitled to, but that this entitlement ends at the age of 18 (O’Toole, 2001). For Kathy Sinnott’s son it was too late, but in the aftermath of her case, it
is estimated that there are almost 200 legal actions being taken by parents with children with special needs throughout Ireland (McGlinchey, 2001).

Kathy Sinnott, a mother of nine, did not cease her campaigning. In the general election in May of 2002, she ran as a candidate for a seat in the Irish parliament and was only defeated by six votes by a veteran politician.

Annie Ryan, Marie O’Donoghue and Kathy Sinnott are all mothers of children with learning disabilities who have made headlines like “Mother power wins over a deaf state” (Carolan, 2000). Their personal struggles have become political, as they have entered the public arena. As Ireland hosted the Special Olympics in June 2003, both Annie Ryan and Kathy Sinnott were among high public profiles protesting against the Government’s hypocrisy of enjoying the PR of hosting an international community of people with learning disabilities while at the same time cutting back on services for its own people (Haughey, 2003).

Jane Ribbens describes women like Ryan and Sinnott as “active social agents rather than passive dependents within male social structures” (Ribbens, 1994:205-206). Ryan, O’Donoghue and Sinnott initially fought their own battle as individuals and are now forefront campaigners in the disability movement. The majority of Irish mothers with children with special needs, however, never make it to the court or appear in the news. Their extra ordinary mothering goes on unnoticed as they try to get on with their lives. The aim of my research is to give a voice to these mothers.

Methodology/Unearthing Irish Maternal Voices

My research is an ethnographic study with 18 participants from various parts of the country and from various socio-economic backgrounds: single/married, middle class/working class, urban/rural etc. They are mothers of children with Autistic Spectrum Disorder, Attention Deficit Hyperactivity Disorder and/or Down syndrome. To limit the study I decided to focus on children born between 1992 and 1994 and as it happened the majority of the children in my study are boys.

There is an abundance of research on parents’ coping mechanisms and their adaptation to having a child with a disability. The research, often undertaken by psychiatrists or psychologists, is mainly of quantitative character using tools such as personality tests and questionnaires (Rydebrandt, 1991, Fitzgerald, 1999, McGlinchey, 2001). The mother’s relationship with her child is measured statistically according to how stressed and/or depressed she is. And yes, every mother in my study agrees that having a child with special needs increases both levels of stress and depression. The stories are sad and many tears have been shed during the course of the interviews. However, while most research ends here, there is much more valuable data to be collected from the narratives of mothers with children with learning disabilities.

Being a mother of a son with autism and ADHD (Attention Deficit Hyperactivity Disorder), I have lived in this “world” for many years and I know the experience of mothering a child with special needs. This personal experience has been of great help to me in establishing a research-relationship with my participants. The majority of my participants were recruited through a research-letter, published in various organizations’ newsletters such as Down Syndrome Ireland and Aspire (the organization for Asperger’s syndrome – High Functioning Autism). Remaining mothers were contacted through personal involvement in organizations such as the Irish Autism Alliance and the ADHD support group. During Spring and Summer of 2002 I met my mothers for the first time, for semi-structured, in-depth interviews, all tape-recorded. I transcribed all interviews word for word, and sent back each transcript to the respective mother. The purpose of this was to avoid a top-down relationship, show each interviewee that she was in control of her own story, and give her an opportunity to comment on the research process. The result was an overwhelmingly positive experience, some of the mothers said that they felt “cleansed” afterwards and that they had never been able to talk so much and for so long about themselves before as everything in their world
mostly centers around their child with special needs. The follow-up interviews took place during this spring and summer and serve the purpose of giving me an up-date on what is happening in the participants’ lives, as well as giving the participants a chance to discuss my research findings.

A preliminary analysis of my research findings so far suggests that there is a change in attitudes amongst mothers in Ireland today. They are prepared to fight for their children’s rights to a greater extent and are less likely to accept what is handed to them. Many of my interviewees use the word “fight” or “battle” when they describe their attempts to gain access to education for their children with special needs. For some mothers this struggle is about not having a place for the child at all within the services or the educational system, or having to accept sub-standard services that normally would not be considered suitable for able-bodied school going children. The following extracts from the interviews vividly portray the battles in which the mothers are engaging:

When the Department still hadn’t found a place for him I said, that’s it, I’m taking it to court. So in May of that year, when he was four, the case was in court and a place was found for him. (Caitriona, mother of Donnacha, born in 1994 and autistic with a moderate learning disability)

I remember being horrified when I saw the building, because the then Minister of Education came to see it…and I remember thinking is he not shocked that six little boys started school in basically a shed…would they not have better facilities in Romania? And obviously he wasn’t, because he cut the ribbon and we had tea and scones and everybody celebrated, looking back I don’t know what the hell we were celebrating because it was awful, but I had to go along with it because at least then we were in the system and I thought, well, I’ll make the system suit me, it’ll have to get better….we were always fighting, really…. (Marie, mother of Eion, born in 1992 and autistic with a severe learning disability)

I’m going to fight tooth and nail for this, we (husband) both are, that it’ll be the care that we want him to get… I feel I’ve made noise and I want to continue to make noise, they know that I’m not going away…you know, there are no small Gods, for want of a better word, anymore. People don’t take what’s handed and given to them anymore…. (Mary, mother of Patrick, born in 1992 and autistic with a severe learning disability)

Four of my interviewees are mothers of children with Down syndrome, and they all describe the paradox between recommended statutory policy of integrating their children into mainstream education and the reality of prejudices and lack of support on the ground in the schools.

She (speech therapist) knew that we had a battle on our hands, trying to get him into mainstream school, cause Michael had behaviour problems, and things weren’t going to be easy for us, so it wasn’t just a battle, it was a war! (Betty, mother of Michael, born in 1993 with Down syndrome)

Basically I was going mainstream, and I’ll stay mainstream as long as it suits Andrew, as long as he is able for it….when my husband and I went to speak with her (Principal) concerning Andrew going into the school, we told her that he had Down syndrome. She said ‘Down syndrome, snotty nose and frothing of the mouth’….those were her very words! There was no question about a little boy….I think things like that would make me dig in my heels, and say, Ah, Ah, Ah, the battle is on! (Helen, mother of Andrew, born in 1993 with Down syndrome)
“The system” refers to the State, the medical profession or service providers, and there is a unanimous reference to the lack of support from “the system” in the majority of the interviews. The general consensus is that it is up to the mothers to look for everything themselves, including finding someone to diagnose their child, find appropriate help and education and also be informed about existing allowances and entitlements. Many mothers with children with Autistic Spectrum Disorder and Attention Deficit Hyperactivity Disorder will have known for years that things are not they way they should be as far as their children’s development and behaviour are concerned. They are therefore very exhausted and vulnerable by the time they meet the professionals and the thought of a potential struggle with “the system” is regarded as another heavy task.

So then you take on the fighting of the system. You’re not wrecked enough before this, you’re not totally fecked up as a family, and then you start with the system.
(Mary, mother of Patrick, born 1993 and diagnosed ADHD.)

Many mothers give an account of people in authority such as paediatricians, doctors, psychiatrists or psychologists, attempting to patronise or intimidate the already stressed and marginalized women who, although seeking help from experts, are themselves well read up on their child’s particular condition. They are also made feel guilty that they are not grateful for what they have or because they are demanding too much, in terms of either educational help or financial support. My interviewees have no intentions of “carrying a cross” and being grateful for what is handed to them. They persist in their efforts to improve the lives for their children and themselves despite the resistance they meet from professionals.

So I thought, good Lord above, a woman… asking for a five-year-old to have nappies, isn’t that bad enough, like, will you just give a pack of nappies and I’ll come back when I need another one…but it took me awhile to get used to that, to go down to that clinic and sign out those nappies, you’re made to feel very, you know, that I’m coming here robbing something from the State. (Julie, mother of John, born in 1994 and high functioning autistic.)

The majority of my interviewed mothers would have been working outside the home if their child had been able-bodied, but due to lack of appropriate childcare or frequent appointments with professionals, they cannot hold down a job.

It came to the stage where I was having difficulties kind of working, so I decided to give up work. My income was always part of our budget, so this was coming up as a big drop...I couldn’t go back for the one reason, like I mean, I had got to be there for the schools if they contacted me for Noel. (Anne, mother of Noel, born in 1994, diagnosed ADHD and Asperger syndrome.)

Five of the mothers are, or have been, involved in providing intensive time and energy to teach and train their own children and feel that their hard work has never been recognised by the State. Financially the reward is very little, the Domiciliary Care Allowance is paid monthly to families who have a child with special needs living at home, currently €179 per month. My participants express their anger at being discriminated against financially by having a child with a learning disability, and by the feeling of being left on their own by the State:

But at this stage I did not give a shit. I thought, this is my entitlement and you’re failing him in enough ways, you know, and if I had gone out to work, what would have become of my son? I’m giving him an intensive ABA programme at
home, and ye basically don’t care, and I’m looking for nappies! For goodness sake! So I got that, but it took a while to get that kind of pigheadedness into me... (Julie, mother of John, born in 1994 and high functioning autistic. Julie taught John at home for nearly two years with the help of a manual on Applied Behaviour Analysis.)

He (the politician) was on my doorstep last night, I talked to him, Andrew was screaming, Andrew was hyper, and I said: Did you hear that? And he said: Yes. And I said: Well, I have four of that... you’ve got four kids, but your wife is able to work. Would you work with that? And he just said: No. And I said that Charlie McCreevy (minister for finance) expects me to go out with that. Who would mind them? I mean, at this stage Andrew was getting worse, he couldn’t have timed it better, and he said: No, you couldn’t, nobody would mind them... (Margaret, mother of four children with ASD, aged 6 to 17, who gave up a career as a writer to support her four children.)

**Void of Voices in Feminist Literature**

Feminist writers on motherhood, starting with Adrienne Rich’s classic book *Of Woman Born – Motherhood as Experience and Institution* (1976), seldom mention children with special needs, whereas differences are made regarding sex, ethnic group, social class and even the mother’s disability (Ribbens, 1994; Abbey & O’Reilly, 1998; Benn, 1998). It appears to be taken for granted that all children are able-bodied and develop normally, thus feminists endorse the image of “the perfect family” while campaigning for more family friendly policies such as subsidized childcare and improved maternity/paternity leave.

My native country Sweden is often referred to as a “model” for family-friendly policies. My MA-thesis in Women Studies (1995) analysed the Swedish Women’s Movement in the 1990s and the findings suggest that Swedish mothers favour a system where they can combine a career and motherhood on their own terms and in order to obtain this, good quality child care and generous parental leave are necessary. Nevertheless, mothers of children with learning disabilities in Sweden, like their peers in other countries, seem to be deprived of this choice. According to a recent study (Broberg Olsson, 2001), Swedish mothers with children with special needs are working fewer hours and stay at home more often than do mothers of able-bodied children. The researcher suggests a possible link between this restriction of choice and a higher incident of depression among the mothers in comparison to fathers:

> Working is the norm in Swedish society and mothers who have to adjust their work situation may find it more difficult to redefine their goals in life from working to parenting, as compared with mothers in other cultures where home-making as opposed to paid employment, is more common. The sense of meaningfulness may be threatened by not being able to pursue personal interests and goals in life. (Broberg Olsson, 2001:33)

Research elsewhere (Traustadottir, 1991) has also shown that families with special needs children are more likely to follow the traditional pattern of a bread-winning husband and a fulltime wife and mother.

> As soon as there is an increased demand for traditional women’s work within the home – such as caring for a child with a disability – the boundaries shift and women come under tremendous pressure to leave the public arena and go back into the home. (1991:225)
The mother’s confinement to the home, and the emphasis on how successful she is in her “job” as a mother is reflected in the language we use; comments like “he’s a credit to you”, regarding a child’s behaviour and his upbringing. It is understandable that a sense of failure with a child with special needs easily occurs, even more so when the apparently able-looking autistic child misbehaves in public. One of the very few feminists dealing with this particular challenge is Jane Taylor McDonnell (1991). A mother of an autistic child, she challenges other feminist writers and our cultural beliefs about good mothering and the mother-child relationship.

**Concepts of Care**

The mothering concept is often absent in feminist critique on women’s general care in society. Caring for children with disabilities seems to fall between two main strands of care in our society. One debate focuses on able-bodied pre-school children where society’s interest and policies are reserved “to ensure that children’s talents are groomed for successful integration into the adult world of social cohesion and paid work” (Ungerson, 1990:181). A second large debate concerns the elderly in our society; their working lives are over and so is the State’s interest in investing in care for them. Children with learning disabilities also seem to fall in to the latter category, rather than the first, as far as State policies and financial investments are concerned. Nevertheless, I would argue that the mothers of these children certainly do not agree; they are also interested in “grooming” their offsprings into the adult world, often in direct conflict with the State’s interventions.

The concepts of care for and care about are discussed by Traustadottir (1991), who introduces a third, and in my view, very important concept of care, “the extended caring role” (1991:217). According to her, this is a role many mothers of children with disabilities take on as a consequence of their own experience. They extend their caring to other people with disabilities in general, and they start caring about how society treats these people. Despite very difficult circumstances at home, in the day-to-day caring of the child, and where the mothers are very limited in pursuing other roles, such as a professional career, many of them start advocating and campaigning in order to change existing services and policies. Janet Read (2000) takes this even further as she sees that these mothers are forced to take this action, as their relationship with the educational system or the service provider causes conflicts and stress, rather than the perhaps long awaited and expected support it was meant to give. Read uses the word “agent” rather than advocate, in the context of “women’s surprising resilience in the face of oppression and their rebelliousness against practices that cause hardship and suffering” (2000:83). In the role as an agent for her child, the mother goes to meetings, lobbies politicians, sets up parents’ groups and so on. This active role in the public sphere is in sharp contrast to the traditional view of the mothers’ passive role within the private sphere where her activities are seen as private and not concerning society in general.

**What can feminists do?**

The first step towards empowering and emancipating mothers of children with learning disabilities is to encourage more feminist research in this area. By unearthing these women’s voices and analysing their experiences we can present evidence of their isolation and lonely struggle in a patriarchal society. According to all existing disability research, as far as I have seen, the majority of primary care givers are mothers. These women display remarkable resilience in very difficult circumstances, but they struggle as individuals, without any real organized support. This is particularly true within the disability movement, which emphasises the human rights of the person with a disability, and often overlooks other issues, such as the right of the carer. The focus on mothers of children with disabilities is seen as outdated and over represented, whereas research and advocacy of the whole family as a unit is encouraged (Herbert & Carpenter, 1994; Arber & Ginn, 1995; Ballard, 1997). Mothering has become parenting in most research literature on childhood disabilities, and although I do not dispute the argument for a holistic approach, I feel that as a feminist researcher of mothers living with
children with special needs, we must acknowledge the deep gender divide that still exists. I would argue that instead of moving away from these mothers, and focusing on the fathers, we should continue to present the facts as they emerge from the narratives of these women.

As a second step towards emancipation, feminists should bring these research findings to the public forum with the aim of challenging existing policies and practices regarding learning disabilities. This means bringing the feminist agenda into the debate and suggesting changes accordingly. One example is to increase fathers’ responsibilities, and perhaps thereby also engage them more emotionally, in the day-to-day care of their children. One argument for the fathers’ lack of involvement in the care of children with special needs is that they, as main breadwinners, do not have the time. The fact that appointments with professionals are mostly made during the hours when the fathers are at work, make them lose out in the ongoing dialogue with the professionals regarding their child with special needs (Herbert & Carpenter, 1994). Policy makers and service providers should of course consider this dilemma while planning for services, but this in itself is not enough. In many cases where fathers are actively taking part in dialogues concerning their children’s educational needs, the day-to-day care is still left to the mother.

As already mentioned, Sweden is seen as one of the most gender equal societies in the world, yet when the Government introduced legislation in order to encourage fathers to take more paternal leave it did not have the anticipated effect. Only ten percent of Swedish fathers avail of their paternity month, and it is often used as an extra month’s holiday rather than a genuine attempt to take over the responsibility for the child caring (Gould, 2001). In this sense, despite legislation, Swedish mothers might only be marginally better off than Irish mothers when it comes to equally sharing the care. If this is the case for mothers with able-bodied children, those who care for children with special needs on a long-term basis are affected even more. Sweden has yet again, at least in theory, acknowledged this discrimination of the carer and her right to a quality life. In 1993 a law was passed that gave the person with a disability a right to choose a personal assistant and gave the county councils new obligations to provide various services such as short-stay respite care (Gould, 2001). This new legislation focused on the individual with a disability foremost, but in the actual wording of the law the right to a quality life for the individual’s family was also stressed (FA, 2001). I see this as a step towards supporting the whole family, and in particular the mother, towards “getting on with life” despite having a child with special needs. Most important is the thinking behind a service such as short-term respite: offering this service is not seen as “relieving the burden” for the carer, but instead to give the person with the disability “a life of her/his own”, to actually give that person a break from his carer/family. This kind of thinking is vital for the majority of mothers, as they reject the notion of being “relieved” from a burden and will sacrifice themselves totally for the sake of their children.

This “strong maternal conviction” leads us to the third and most difficult task for feminist researchers on mothers of children with special needs. In order to make their personal struggle political, we have to raise awareness among the women themselves. This has to be done carefully to avoid intruding in these women’s lives or alienating them even more. Mothers of children with learning disabilities already empower each other through talking about shared experiences in local and national support groups. Mothers across the world make use of new technology, such as the Internet, to try and improve the situation for their own children. Through various websites, mothers of children with special needs are able to educate themselves regarding their child’s particular condition and link up with global networks for advice on education, medication and other relevant information. With this gained knowledge these mothers are empowered and strengthened in their relationship with professionals and service providers as they challenge existing power structures. They start to view themselves differently and become determined to fight for their children’s rights, and will no longer accept that a child with special needs is “a cross that has to be carried”.

Feminists should build on this emerging change of consciousness and use existing networks to feedback research analysis of women’s lived experiences. Hopefully this will shift the focus from the child with special needs to the mother, yet with the child’s best interest as the main priority. This change of focus, emphasising the important role of the
mother while at the same time challenging existing patriarchal structures, is a subtle way of raising the awareness and thereby change the orientation of these women’s networks. The dilemma is not what the women are doing while they care for their children, but the political context in which they are doing it. As long as it is taken for granted that mothers care for their children with special needs without recognition or financial compensation, they have no choice but to be left isolated and marginalized in our society.

**Conclusion**

My research including 18 mothers of children with learning disabilities in Ireland shows that they all have experienced, or are experiencing, a significant lack of support services for their children. Firstly, the majority of them embark on a road of “fighting” or “struggling” to obtain an appropriate education for their children, secondly, the majority of my participants have given up their careers in order to educate or care for their children with special needs at home, and they feel that the Irish State in no way is rewarding them or compensating them for this.

While Irish mothers of children with learning disabilities are struggling in a context of a strong anti-feminist society, they still share a life of isolation with their peers in other European countries. The role of the feminist movement, therefore, is to break this isolation and unearth the voices of these mothers. Furthermore, feminists should use these research findings to raise the awareness among these women and empower them to challenge existing patriarchal structures.
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