

family

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Abstract

This paper is based upon a project that explores the pressures facing mothers of children with disabilities. In particular the paper touches on how policies relating to housing, education, childcare, and community living impact on the lives of women. "...the impact of a disability on a person and their family, and the subsequent handicapping effect of the disability is directly related to social factors: issues of public policy. The disability can't be changed but public policy and practice can and should be changed". **Keyword: Families**

DOUBLE DISADVANTAGE

Public Policy...Private Lives of Women as Mothers of Children with Disabilities

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In 1989 a small group of women formed a collective called Life Works. We wanted to explore the pressures facing mothers of children with disabilities.

We developed a project outline and successfully applied for funding for the project from Victorian Women's Trust. We spent some time developing the ideas underpinning the project then advertised, by word of mouth and in newsletters for women who were willing to share their stories with us. The response was overwhelming.

Rather than fragment women's experiences we decided to interview ten women in depth to explore the link between private life and public policy. We chose ten women to represent a range of background and experiences. We knew some of the women, others were introduced to us. The project has taken some three years. This paper is based on the book which grew out of the project.

Our roles in researching the project have ebbed and flowed in response to the ebb and flow of our family and work

responsibilities. Both Melanie Virtue and I have worked in developing the ideas, in interviewing the women, in transcribing and editing the stories.

We focus on women rather than on the child or other family members because women are the primary carers. When people talk about 'community care' it is care by women. We focus on women because we are women and we have been mothers of children with disabilities; we let men and people with disabilities speak for themselves.

Melanie and I have had four children. We each have had a daughter with severe disabilities. Our lives were forever changed by our daughters' birth. Our daughters have since died. Our experience as mothers of children with disabilities informs our analysis and underpins our commitment to people with disabilities and the women who care for them.

Caring for our daughters was hard but it was made so much harder by lack of support, lack of information, lack of child care, inadequate housing, living on a low income and struggling through the medical maze, - all issues of public policy. In this paper we touch on how policies relating to housing, education, childcare and community living impact on the lives of women. In the book policy impacts are explored more fully.

We never expected to have a child with a disability. None of the women we interviewed expected that their children would have a disability. We all have the unrealistic expectation that we will sail through life unscathed. As Samantha says:

I thought I would get pregnant, have a child like everybody else does, disability never occurred to me. It was a shock.

We interviewed ten women over a period of a year. We edited the transcript of each interview while allowing each woman to tell her own story and to make her own analysis of her situation. The women shared their stories with gut wrenching honesty; most felt that we wouldn't judge them because we have shared similar experiences - we know how hard it can be. Most of the women were fearful of negative impacts for their children, as Judy says:

I shouldn't have said some things ... I'm frightened that the staff would hurt David. I shouldn't feel like that but I do...

Women's experience as mothers of children with disabilities is often ignored or turned into human interest stories for mass consumption. Women's magazines and current affairs Info-tainment programs frequently feature stories about heroic mothers and their children who are battling disease or disability. These stories elevate the women to super mums and they make us feel better because we can abrogate any responsibility.

Stereotypes of 'good' mothers who sacrifice and by implication 'bad' neglectful mothers are reinforced. Most of us are 'good enough' mothers who don't want pity but support. As Ingrid says:

People feel sorry for you, but I mean, with sorry you can't get anything...I was pitied by a lot of people but I have said to them, I don't need pity. I only want to be treated as an equal.

Public Policy: Private Lives

We cope with the challenges we face in different ways depending on the resources that are available to us. We all have a differing range and degree of resources depending on personal strengths, life experiences, cultural backgrounds and family situations. Choices and options are further defined by practical constraints such as economic circumstances, housing, access to transport, employment, education, etc. Our lives are moulded by the personal and practical resources available to us and are further shaped by public policy.

Public policy is based on the assumption that women will be available to provide care and nurturing to young people, sick people, old people and for people with disabilities. The trend towards community care and away from institutional care is accompanied by a widening gap between rhetoric and resources. The gap is filled by women, often at enormous personal cost. The ten women's stories highlight the large gap between the policy rhetoric and private reality.

The women's stories illustrate the haphazard development of change. Services are developed and then cut back, policies adopted then reversed. Women's lives are the backdrop to this everchanging policy. The change in public policy can place additional pressure on mothers. Mothers are judged harshly as fashions in policy change.

The rhetoric surrounding motherhood puts women and children first and values motherhood highly when the

reality is that women and children are often marginalised, devalued and exploited. Motherhood as an institution is valued; women as mothers are not. If the child has a disability the situation is intensified. A woman's identity is bound up in her status as a mother and if her child is less than perfect it reflects on the mother. Several of the women we interviewed reveal their deep sense of hurt because their husbands blame them for their child's disability.

Ingrid who is now divorced, says of her son's birth:

We were so happy. For half an hour we were so happy it was a boy! It was a son, I thought, Thank God it is a boy! And then...the time bomb came and it just broke my husband. It really broke him and he has never come to terms with it. He was playing around all the time after that. It makes it so hard for me.

Nora tells the story of her son asking why his sister was disabled:

'Mum, why is Cath like that?' I said to him - 'Nobody knows, darling' and he stopped and he looked up at me and he said 'Well, Dad says it's your fault!...He said that there was something wrong with you.' Obviously my husband had never been able to accept that it was unknown and he would never blame himself but he would blame me. There was no way I could undo that damage...my son's beloved mother had become a monster, as distant and incomprehensible as his sister.

And later she says:

I began to realise that my whole sense in myself as a woman had been affected. My whole sexuality. My whole sense in myself as someone who could create had been smashed because my body had created what was to everybody else, a monster.

Life: Rights & Responsibilities

People with disabilities are living longer. Babies who would have died at birth are now surviving due to medical

intervention and technological developments. It is easy to focus on the achievements in medical care and to gloss over social impacts. When Julie was five and a half months pregnant she had what even ten years ago would have been considered a miscarriage. In Indonesia (where Julie comes from) the baby would have died. Due to intensive medical intervention the baby survived and is now two and a half years old. She is visually impaired and has hydrocephalus and after much suffering is now beginning to gain skills and develop. Her mother expresses many mixed feelings about the medical intervention:

I say to them - it's not fair for the baby - if they want it as an experiment. We are the parents, we have to grow up with the baby, forever, if she has a handicap.

There is an expectation that mothers will be there to care for their children. The experience of mothers of people with disabilities is similar to that of other mothers and while there are similarities: lack of sleep; loss of income; social isolation; and low status; babies grow up. As Judy says:

You've both got young babies and you know what broken nights are like but there's an end to those.

As the children grow older and the disability becomes more of an obvious handicap, social contacts can fall away leaving the woman with little support. Judy says:

People are bored with it because it never changes. I am saying the same thing I was saying sixteen years ago. Whereas if you talk to someone else they say 'Johnny's got his license or Sarah is doing music' - they are doing something different. Our story is the same.

Most of the women interviewed were married and in general their husbands were supportive. However they often had high expectations of their wives'

role. Of the ten women we interviewed, three were single parents the other seven had all experienced difficulties with their partner to some extent. Most of the women were very loyal to their husbands. Like many of us they contorted themselves around their husbands' expectations and demands. Samantha's husband is Maltese and has cultural difficulties with strangers coming into the house:

I had some help for a while but Charlie wasn't all that thrilled about the idea. He didn't like strangers coming into the house...so I did it about six months without him knowing.

Iris's husband has very traditional expectations of his wife:

During the last couple of years he's been on nights and he has been expecting me to jump when he said jump and jump higher than he said. I got sick of jumping.

Margaret says:

My husband was marvellous. Some husbands have left their wives to it. Dave was marvellous, he coped with everything. Even now he is a nervous wreck when Mike is home because he has the brunt of it because Mike is apt to attack me rather than him.

Respite Care

Mothers of children with disabilities often experience extreme, ongoing stress. In recent years, respite care programs have been developed in an attempt to alleviate that stress. When respite care works, it can enable a family to keep on going and can provide a good alternative to family care. However, many of the programs are underfunded, reliant on community management and inadequate to meet the increasing need. After twelve years of caring for her severely disabled daughter at home Nora was desperate for respite care:

The only place that would take her was a hospital that had a ward for disabled children. I took her down there one afternoon and it was like putting a knife into my belly. She was going to be in a bed all day, every day. There was no therapy, no stimulation of any kind. I just felt I couldn't make the choice to keep on. I was only barely, barely scraping the floor so I left her there.

Nora worked to establish the first Community Residential Unit in Victoria. She says:

So much committee work is crashing into brick walls over and over until you get a chink in the mortar. I've been doing it for 16 years. There are just not enough parents who have the time... It is hard work and you do feel, particularly with this preponderance of always women on committees and women providing care, the women doing the lobbying, the women doing the deputations that it is just a perpetuation of our stereotypes. I had to be involved it was the only way I was going to get Cathie a place to live... my fight for survival.

Samantha regularly uses a community residential unit for respite care:

I should say it wasn't always a wonderful experience. I'd go down to pick Craig up and they really would make me feel guilty for leaving him there because he had been such a shit...

No Place Like Home?

There is a myth about the average Australian family: Mum at home, Dad at work, two kids and a brick veneer house on a quarter acre block. While this may be reality for some, it is not for the vast majority. Families are changing: there are more divorces, blended families, single parent families, more women are in the paid workforce. Not everyone lives in decent housing.

Edith faces serious difficulties as the single mother of a boy with cerebral palsy. She doesn't have the support of

her natural family although her foster parents have been supportive. After years of struggling to find suitable permanent accommodation, of living in private rental flats and emergency accommodation, Edith and her son Marcus moved into a Ministry of Housing flat. This only compounded her problem as the neighbourhood was very rough:

I've tried to get a Ministry of Housing house and they kept saying, 'Yes, you are on the list, you're on the waiting list'. I've been on the list since 1983. So I got jack of it and said, 'Look, I don't like the flat, we were broken into twice'. Marcus was getting scared because the two times we were broken into they got in his window. I had to change the bedrooms around because he wouldn't sleep. When this attack happened then he was just terrible. A girlfriend of mine and me moved in here and went private. Although it's a lot more money, it's a lot better.

Iris struggled to care for two disabled children in a walk up flat in the inner city:

We tried to move to another area. Anyway I get a phone call from the Ministry of Housing office offering us a 24th floor highrise flat. I told them where to go. I said 'no thanks'. They said 'why not?' and I said 'because a highrise is the last option and we are going to have to be bloody desperate to take it. We need a back yard. All you are offering is a highrise which in my books have not got backyards for the boys'.

Judy and Margaret don't live full time with their sons with disabilities. They have struggled to find appropriate accommodation for their sons. Margaret is unsure and anxious about the trend towards community living. She kept her son at home for 21 years caring for him with little support. When her son's behaviour became violent towards her she was obliged to find accommodation for him. There was nothing available and she had to place him in a State run institution. This institution is synonymous with

the worst kind of institutional care with all the attendant abuses and loss of dignity. She sold her house and moved to be near her son and she has become involved as much as possible in his care.

Women feel the opprobrium of others for their decision to place their children in an institutional setting, even though the decision is made in the framework of very limited options. For Margaret there was no choice:

I would never have wanted him to go there. I cried every time he went there. Well, there was no option.

Judy's son lives in a private residential facility and comes home on weekends. Judy says:

Let's face it we all make mistakes, that's life. You do what you think is best at that particular time in your life. But they say that there is only one direction. I think it is fine if they pick up the pieces afterwards... It is just a lot of hot air to say that he should be able to do this or do that... There is no way he could do it anyway.

School Days

There have been major changes in education with the trend towards integration and away from segregated special schools. Ingrid's story shows the reality behind the rhetoric can be very grim. Although her son is attending the local primary school, at times he has done nothing other than sit in the principal's office flicking through comics. She has been subjected to extreme stress when, ironically, her son's teacher went on work-care for stress as a result of having Ingrid's son in the class.

Ingrid says:

The government wants to cut costs and we are the meat in the sandwich... because we are the ones that fight on the front with the teachers... It's just promises, promises, promises, that's all they do!... We as parents

are just thrown in the dirt and I am angry, bitter and angry about the whole thing... It is cruel and criminal what they are doing...

(Things haven't changed: note the Teacher's Union action in banning teaching children with disabilities)

Judy has two sons: the younger one became disabled after an illness when he was two and a half. One of Judy's sons attended a local school, the other a special school, she is in a good position to comment on the different systems:

With normal schools you just enrol and that's it nobody questions whether your child is eligible for school. There is no fight, your child just goes to school.

Women's Work

All of the women interviewed were doing something else before they had their children with disabilities. All of the women had hopes, expectations and dreams. Leanne only ever wanted to be a mother but she wasn't prepared for this kind of motherhood. The rest of the women all gave up their jobs when they had their children (although they didn't give up work!) Nora, Judy, Samantha, Margaret and Ingrid work part time. Iris had just started to study. Edith was excited at the prospect of a new job. Julie was feeling desperate and despairing about coping being at home with her school age son and her two year old who has severe disabilities.

Women with children are disadvantaged in the work force. Mothers of children with disabilities are further disadvantaged through limited access to child care. Many mainstream child care services are unprepared or unable to meet the needs of children with disabilities. Specialist services provide very limited support for child care. Funding cuts and restrictive guidelines further limited access to child care for children with disabilities. Whereas other women can

look forward to their children becoming more independent, mothers of children with disabilities face a prolonged, often life-time, period of dependency. Mothers of young children often develop informal support networks to provide child care. When a child has a disability, it is more difficult to rely on informal support.

Judy says:

People were prepared to take David for half an hour or an hour because they had little kids of their own... but once their kids went to school he was just too much bother and so this hour's break or change of scenery for David just didn't happen.

Ingrid says:

Before I had Paul I had been teaching for eighteen years and all of a sudden, I was at home, stuck. A big change for any person with either a handicapped or normal child. But a normal mother has a child to talk to and sooner or later the child will answer back. I didn't have anyone to talk to.

Julie says:

The Government could help people like me by giving us child care. Child care that you don't feel guilty to leave the children then go to work. Home help is just a couple of hours when you go to dinner or to something. That's why a lot of women get stuck and can't go to work because we have to pay the child care and it's just too expensive... I am used to being a working person. I'm not one of those mothers who are happy just to be a mother. Here I am because of this situation. They force me. They say here you are and you have to be happy even though there is no way for you to work because there is no way that Ebony can be looked after.

Of the ten women we interviewed three were sole parents, three had husbands who were retired, two had husbands who worked in blue collar jobs and one was a farmer. Most had experienced financial hardship as a result of the additional costs of disability yet, paradoxically, they were unable to

work due to their additional responsibilities.

If women can't work because of their family responsibilities they require some kind of financial support. The only additional financial assistance women receive for the care of their children with disabilities is the Child Disability Allowance.

Edith says:

I get a letter from Social Security about my handicap allowance. To them because he is now fully integrated he doesn't need that care and attention any more. I said, 'Listen you take him for a weekend and tell me on Monday what he needs and what he doesn't need.' They think that because you are going to a normal school now, that you are normal. You are not disabled any more, you are normal. I just say to them you can take him then you can tell me what he needs.

Taking Care

Women are pushed into and out of the labour force depending on the economic climate. The pushing is often accompanied by philosophical changes in policy.

It is easy to be cynical about the government embracing policies of community care and integration which while in themselves are valid policies have been accompanied with a withdrawal of funds. Women are providing the care - just as they always have.

Community care doesn't have to be like that. The rights of one group of disadvantaged people must not be used as an argument to disadvantage women. Society needs restructuring so that the needs of people who are young, sick, weak, have a disability or are old, can be met.

Judy says she thinks people need to be paid to care:

The community doesn't care, unless they are paid to care. If you don't pay people you are not going to get people. One of the things I would like for David is a friend. Nobody is going to be a friend to David unless they are paid to do it or somebody is paid to coordinate a scheme like Citizen Advocacy - I don't think it would happen naturally. I can't see it happening. There are hundreds of people in a similar situation. It's not just David's personality or our personal problem. It's a general thing that people don't care.

Margaret says that times have changed and there is no longer a sense of honour:

I think things have changed when they stopped having churches in schools and they have no sense of values or honour... in our day we respected other people generally and their feelings and everything else counted. Now, if you are not related or something you can just go by the board.

It is tempting to see disability as a personal tragedy. There is no denying that any disability may be tragic, but the impact of a disability on a person and their family, and the subsequent handicapping effect of the disability is directly related to social factors: issues of public policy. The disability can't be changed but public policy and practice can and should be changed.

Family responsibilities aren't going to go away. There always will be people who need care because they are young, old, sick or have disabilities and can't care for themselves. The last few decades have seen changes in women's participation in the paid work force but as most women know, the roles and responsibilities haven't really changed, rather they have been increased. More and more women are dissatisfied with the double burden, and yet we don't want to return to the oppressive roles of the past. More and more people (men and women) realise that we have to restructure society so that family responsibilities can be shared more equally.

The family isn't the whole answer; some families haven't got the resources to take care of themselves let alone members who have special needs, and often relatives are too far away to help. Families are bound by the constraints imposed by work responsibilities. We need to develop options so that people can make choices about the way they will live and so that we can all have a fair share of rights and of responsibilities.

Judy says:

Just listen to parents. Do something that they want and not what you think they want. Be flexible and don't make rules like everybody should be out of institutions in ten years regardless. Try to meet individual needs.

Ingrid says:

I would love to talk to politicians. I would tell them how frustrating it is. I wish they would have a very disabled child for a week and let them see what a strain it is on the family and then put them back in the office. I call them parasites, these people who develop policies. They are not practical thinking people. They develop a policy but they don't know how it works in practical life.

The women tell their stories with honesty, humour and compassion and in doing so they open up a world of struggle and of survival. Too often women can't be heard because they are too busy caring for others. We hope that we have given some women the opportunity to be heard.