

## **Thesis Title:**

*So Who's Normal? The Relationship between Policy and Practice in the Care of People with ID,*

## **Sterilisation**

The sterilisation of people with ID is often associated with eugenicist theories, as sterilisation provided a means by which genetic traits that rendered people unable to contribute to society, could be eliminated through selective breeding (Hume 1996). This narrow view of sterilisation does not consider other possibly beneficial impacts of sterilisation on people with ID. While the rights of the disabled (Office of the United Nations High Commissioner for Human Rights 1975) guarantee all people with disabilities the right to marry and have babies, such a blanket proposal seems irresponsible with regard to people with ID. Being denied the right to keep your baby, as is the case for many of these mothers, seems a cruel and avoidable life experience (D McConnell et al. 2000). Sterilisation is a highly contentious issue from a rights perspective, but it may provide a more humane outcome for some people with ID, who require more support to parent effectively than is available to them. That such support is not available must be part of the decision to have children, rather than inflicting the trauma of removing the children because expectations of vital support were not met, as Gallagher (2002, p.209) found:

Unfortunately, patterns of official neglect followed by coercion are common for some adults with intellectual disabilities. This is dramatically so for many parents with an intellectual disability, who receive little or no support until their children are removed from them (personal experience, correspondence and McConnel, Llewellyn & Ferronato, 2000).

Involuntary sterilisation had been used irresponsibly in the past. Carlson et al.

(2000) found one instance in the USA where 656 castrations were performed to stop the men with ID from masturbating. Medication and vasectomies are still used, but rarely, to control sexual feelings and fertility in young men in Australia (Carlson et al. 2000). These treatments for males, however, are rarely recorded; the only recorded child sterilisations performed are on female children with ID (Brady & Britton 2011). While sterilisation may seem a harsh option for young women with ID, the alternatives may be much harsher for women with ID than for normal women, including: unwanted pregnancy; illness in pregnancy; miscarriage; difficult childbirth and other health risks, including a heightened risk of pre-partum depression (D McConnell et al. 2008). Inadequate capacity to mother, and removal of the child from the mother are common outcomes, as evidenced by Mayes et al. (2011, p.1) in their research into mothers with ID, which found one mother with ID who was seeking an ally or supporter for her pregnancy:

Andrea, pregnant with twins, changed her allegiance toward the end of her pregnancy. When she first discovered she was pregnant her mother, Eileen, was the only person who told her it was okay she was pregnant, in stark contrast to the concerned reactions of other people. She began to question whether her mother's assistance would be forthcoming, and more importantly whether her assistance would be of help. Eileen had had all of her nine children removed from her care through allegations of neglect.

Mayes et al. (2011) largely reflect normal people's romantic attitudes towards motherhood in their study of pregnant women with ID. They take the perspective that a woman with ID gains from the experience of pregnancy and from the experience of mothering, but do not take into account the consequences for the children and nor do they report on the women's experiences after the birth, which may well cancel out any benefits from the experience of pregnancy. Mothers with ID are referred to in the study as *other* mothers, which groups them with other marginalised but normal mothers. This seems a denial that it is the disability that is the issue, not simply being marginalised. Mayes et al.

(2011, p.1) suggest that another reason for their marginalisation is that mothers with ID often do not get to keep their babies:

Perhaps a key difference between the “other mothers”, such as welfare, single and lesbian mothers in the literature is that their lives and identities as mothers are discussed. The lives of mothers with intellectual disabilities remain virtually hidden: either through silence or through their children being removed by those in positions of authority.

McConnell et al. (2000) also found that the children of people with ID were removed more frequently than was the case for normal people, even when neglect had not been proved or the parent was taking steps to overcome their deficiencies. Perhaps the courts ignore the emotive arguments and acknowledge the intransigence of ID and the likelihood that training may not be retained and that adequate support was unlikely to be provided.

Australia does not provide specialist pregnancy services to people with ID. Mayes et al. (2011) found there were no such services to provide for pregnant women with ID in Sydney and the high number of forced surrenders of their children loudly confirms the inadequacy of support for these parents. That the support is often essential is largely ignored when normal people encourage situations that may not come close to expectations for people with ID and may well be beyond their abilities. Weiber et al, (2011, p.2) found that parents with ID often lacked the emotional understanding required in parenting:

Those who have ID are usually aware of their shortcomings concerning practical things, such as cooking, cleaning, handling money and arriving on time. But the awareness of other demands connected to parenthood, such as meeting the child's emotional needs, is often failing. When people around them point to shortcomings regarding their responses to their child's needs, people with ID in general have difficulties recognising those shortcomings (Hindberg 2003).

## **Carol**

Baum (1994) tells the disturbing story of a young woman, Carol, with an IQ of less than 40, who was discovered to be 24 weeks' pregnant as the result of a sexual assault. Because the legal position of the service was unclear and finally because nobody could be found to perform a termination at such an advanced stage, the pregnancy was allowed to proceed with an order for the baby to be taken away at birth. The focus then became about calming this women's distress, educating her about what was happening to her body and preparing her for the birth and subsequent surrender of her baby. It is extraordinary that a person of such low IQ with few verbal, comprehension or self-care skills should have been allowed to continue her pregnancy, because, despite the confusing legal situation, there was certainly provision for professional discretion. Although ambulant, Carol was doubly incontinent, wore large incontinence pads and needed assistance to bathe. She demonstrated distress by pulling out her own hair, which behaviour she was exhibiting regularly by the time of the intervention, as well as being more averse than usual to being touched or bathed.

Despite the conclusion that Carol was not coping at all with what was happening to her, and was unaware of her condition and an abortion could have been effected immediately, there was a great deal of relief amongst the team of interventionists, because of anti-abortion sentiments, when it was decided that the pregnancy should proceed. This is a stunning example of how deeply care can be influenced by the moral values held by carers. The goal of the team then became about giving Carol private and pleasant surroundings. As she lived in a large facility, securing a partitioned-off space for her was considered a major victory. Carol received various aromatherapies, music therapy,

massages, counselling, and lots of one-on-one attention.

The team spent three months attempting to prepare Carol for the pain of a vaginal delivery, without even considering the much more expedient and much less potentially traumatic option of a caesarian section. As it happened, a caesarian was medically necessary. There was little time to prepare Carol for this, but she weathered it all, identified her offspring as a baby and handed it over to its adoptive parents. The team was concerned that a caesarian would disconnect Carol from the birth, when minimising the trauma should have been a major consideration. It is unclear why the team felt this connection was desirable, beyond projecting emotions, symbolism and meaning onto the pregnancy and birth that they felt Carol should be feeling. What is clear is that the team treated Carol and the birth as if she and it were normal and Carol would receive some mystical benefit from labouring and giving birth vaginally. It would seem more beneficial to downplay the birth, especially as Carol would be allowed to have no relationship with the baby, rather than turn it into a spiritual rite of passage, when it is likely that Carol had no awareness of any such effects. The team became alarmed when they realised the baby was leaving the hospital for good and hastily arranged a final farewell for Carol, chastising themselves for such a serious omission. Carol was sad, although how much of this was generated by the team's sympathy would be difficult to determine. The fact that she did not pull her hair out until she returned to the institution, perhaps indicates she suffered a greater loss there. Those assisting her with her pregnancy identified two main reasons for Carol's deteriorated behaviour; grieving at the loss of her baby and the dramatic drop in attention. It seems likely, given that Carol appears to have shown little attachment to the baby that the latter cause was more significant to Carol.

While Baum (1994) admits that the reporting of this story was largely impressionistic, it seems that those impressions may be greatly influenced by the projection of the team's own sentiments onto these events, which may have had completely different meanings for their client. The large number of people on the team, all providing therapies, was not normal for Carol, despite the stated fact that the intervention was about making the experience normal, informed and rewarding for Carol. In fact, the team decided what her needs were, based on what their needs would be in that situation, because those things were normal for them. Carol could possibly have viewed this as a very special time in her life, only because of the extra attention. It is not reported if Carol retained her comfortably and tastefully decorated, nice-smelling, single room with a CD player, rather than returning to a room shared with seven others. It is also possible that Carol, who largely kept herself isolated, liked the company in the ward and may have needed it. It seems likely she was never asked. Research for this thesis revealed that some people with ID do prefer to share a room, but it would be assumed that privacy was more important because normal people would want it for themselves.

Baum (1994) concludes by presuming that the success of this intervention would translate into success in similar situations, where continuing a pregnancy could not be avoided. This notion that a process and outcome with one person with ID will be replicated in another person with ID in a similar situation is unrealistic, because people with ID are highly idiosyncratic in terms of needs, communication and skill levels, regardless of their IQ. Carol, for example, was found to have greater comprehension abilities than could be expected from her IQ rating. It is also debatable that the therapies: soothing music; nice smells; back rubs and talking needed a trained therapist to administer.

The best way of avoiding the potential trauma from an unwanted pregnancy is sterilisation, which was still not considered in Carol's follow-up. The follow-up training focussed on self-protective behaviour, despite the admission that nobody could guarantee that Carol would remember what to do in a real situation. Carol was so angry at this time that she kicked her main pregnancy carer in the groin. This was interpreted as a subconscious attack on the carer's reproductive organs, symbolising Carol's distress at the loss of her child, but may have been something she learned in protective behaviour classes. This carer was deeply hurt by Carol's attack on her after she had given so much of her own time to keep Carol company. The worker's reaction suggests that she expected a normal response from Carol, and was disappointed because she did not get it. There seems there was an expectation that if Carol was treated as if she is normal, she would behave normally in response. The carer's reaction also indicates that she expected Carol to understand and accept the sudden abandonment, when it seems likely she had no such comprehension.

Interestingly, the perpetrator of the sexual assault was never found, despite establishing that he must have been someone Carol knew, as she would rarely let anybody touch her, thus greatly limiting the possible suspects. The case was closed before the baby was born and Carol's rights to natural justice, and the desirability of removing the perpetrator from Carol's life, were treated as unimportant and forgotten. The team did consider whether anybody would want to continue with a pregnancy that was the result of an assault, and knowing that the baby would be taken away soon after birth. These considerations were also put aside when the pregnancy was not terminated and, as with many of the well-meaning impositions, the team could determine the priorities because Carol would not and probably could not, as she would not have been aware of and

possibly had no understanding of alternatives. The team had a clean slate on which to lay their own morality, aspirations and sentiments without censure, because of the normalisation imperative in current disability policy. This story also confirms that by trying to make things normal for Carol, the team only succeeded in creating an environment that was not normal to Carol.

## **Marie**

Roets' (2006) report on one case of involuntary sterilisation involving a woman with ID, Marie, reflected an abuse of power by the professionals involved, who ordered the sterilisation without consultation or the consent of her mother or Marie. It is difficult to construe, however that Marie would not have benefited from the procedure on medical grounds, given that it would relieve existing conditions, including incontinence that were causing her considerable discomfort. Marie actually denied any interest in having sex or a baby. The professionals believed differently as she was hiding baby clothes and toys in her room. She did, however, fear pregnancy from rape, which fear would also have been alleviated by the procedure. With the assistance of an advocate, Marie was able to avert the operation. That the emphasis became about rights rather than the situation and the specifics of the individual involved, pretends that Marie is normal and that she is fully aware of all the implications. This further implies that she would be able to be normal in whatever situation she ends up in as a result of her fertility and able to cope with the consequences. The victory for human rights did not seem to translate into an improvement in quality of life for Marie as it did not relieve any of her health issues or fears. Halstead (2002, p.36) commented on the meaningless of the faith normal people have in rights and autonomy for people with ID, as a means of correcting injustices. The

benefits of rights are often immaterial and do not address the reality of living as a person with ID in a community, for whom autonomy may be neither valuable nor achievable:

The rise of autonomy as a moral value cannot provide an answer to the question of what values are worth pursuing. The notion of the 'good life' as a result of individual achievement continues the cultural marginalization of people with ID:

My son has all the rights the ADA [Americans with Disabilities Act] can secure, but he still has no friends.

## Conclusion

Idealised notions of parenthood are rarely borne out even for normal people.

Normalisation, the rights of the disabled and neo-liberal thinking do not colour the reality of life for people with ID as much as they affect the thinking of disability human rights' activists, such as is evident in the following quotation from the former Disability Discrimination Commissioner, the late Elizabeth Hastings, speaking out against sterilisation: ... *such as that the law had failed to protect significant numbers of children from abuse of their fundamental human right to bodily integrity.* (Brady & Britton 2011).

Such an emotive statement, which reinforces politically correct ideals, does not allow for individual characteristics, health, ability or circumstance and makes sterilisation always a negative option when it could have many positive consequences for people with ID, most importantly, the ability to have the emotional benefits of intimate relationships, without the risk of unwanted pregnancy. As women and girls with ID who have an IQ of less than 55, at least in Britain, are considered incapable of consenting to sex and, therefore, any pregnancies are deemed the result of sexual assault (Baum 1994), it would seem that their fertility can only lead to grief. It is difficult to understand why the government is so

determined to protect the fertility of people with ID, which may only cause them loss and distress and a physical experience, from which they may not gain anything but confusion and pain. People with ID can only be treated as individuals. Making rules that apply to all are bound to cause gross inhumanity to some. Ultimately, banning the sterilisation of women with ID denies rights available to everybody else and is discriminatory.

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