



The Experiences of Mothers with Children with Disabilities

In the past 30 years there has been an enormous amount of scholarship about the practice of mothering and the institution of motherhood. There have been two key streams of work: the theorising of motherhood, and the empirical investigation of mothering experiences.

A particular stream of theoretical scholarship has been interested in how a mother must behave in order to be perceived as a 'good mother'. The prescriptions of what a 'good mother' means come from intensive mothering ideology. According to this ideology, a 'good

mother' must be the primary caregiver of her children, must be nurturing, and must have a wholly child-centred focus. Mothers must meet particular expectations in order to be considered 'good mothers'; however, these expectations are often impossible to meet. A failure to be a 'good mother' can impact in deleterious ways on a mother's life and sense of self.

A number of empirical studies have focused on particular 'categories' of mothering and how the 'good mother' concept impacts varying mothers' experiences. However, one group of

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mothers who have been under-represented in the literature and research so far is mothers of children with disabilities.

Flor negra



The 'Good Mother' Concept Specific to Mothers with Children with Disabilities

The concept of 'good motherhood' for mothers of children with disabilities is an intensified version of the general model of the 'good mother.' Mothers of children with disabilities are subject to similar types of pressures. The normative nature of the 'good mother' concept means that while some mothers may openly recognise and even challenge what the concept dictates, they also seem to judge themselves against their perception of the 'good mother' concept. The internalisation of this ideal becomes a benchmark against which mothers judge themselves.

Mothers of children with disabilities wrestle with concepts of 'good motherhood' in multiple ways: they may go out of their way to conform to it, but at the same time fiercely resist it. The way mothers negotiate their relationship to motherhood as an institution and the 'good mother' concept is complex. Interviews with ten mothers with children

with disabilities from Australia reveal five expectations that the 'good-mother-of-a-child-with-a-disability' concept encompasses. These expectations are also largely present in the lives of mothers with non-disabled children, yet they are often perpetuated more forcefully and intensively for mothers of children with disabilities because of their child's challenges. However, the expectation that mothers of children with disabilities are 'special' and capable of 'doing it all' is formed in contrast to experiences of mothers of children without disabilities. Similarly, the expectation that mothers should maintain the appearance of 'normality' comes from normative images of how the 'normal' child (and family) looks and behaves. Therefore, although there is some overlap in expectations for the two sets of mothers, there are elements of the 'good mother' concept that will undoubtedly differ because of the experiences and challenges that mothers of children with disabilities uniquely face.

1. She is and will forever be the child's primary caregiver

the 'good mother' is expected to entirely define her existence in terms of her child's real and perceived needs. However, this expectation seems to be intensified for mothers of children with disabilities, and they are expected to take on this primary caring role well beyond when their children reach adulthood. Further, the intensity of the care required from them can often increase rather than decrease as their children become older.

All of the participants interviewed identified themselves as the primary caregivers for their children, even though 90% are still married to the father of their child with a disability. Why are mothers so often the primary caregivers rather than fathers, or even other family or members of society? The explanation some of the participants offered was an essentialist one: because the role of the mother is, according to this view, rooted in biology

and her body, it is therefore her responsibility to bear and nurture children to adulthood. While not all of the participants embraced such an essentialist notion, they did struggle to resist the gender roles and social and economic constraints that reinforced them.

All did, however, reflect on a sense of permanency of their caretaking role. Half of the participants expressed a resigned acceptance that they would be the primary caregivers for their children for the rest of their lives, while the other half were quite resistant to the idea of indefinitely being the primary caregivers for their children. However, there is little institutional support available for mothers of children with disabilities – they are often left with few choices and are forced to take on the primary caring responsibilities for their child with a disability.



Eflorescencia abriéndose



Reconexión

2. She is 'special' and capable of 'doing it all'

The second expectation that constitutes the concept of a 'good-mother-of-a-child-with-a-disability' is the idea that mothers of children with disabilities are 'special'. They are expected to be self-sacrificing, forever resilient, and able to seamlessly deal with any problem that confronts them. This idea is present within orthodox conceptions of 'good mothering,' but for mothers of children with disabilities this expectation of devotion is magnified. Expecting mothers of children with disabilities to be able to cope better than other mothers can often provoke feelings of loneliness and isolation.

While the participants were critical of an expectation of hyper-ability, they also often expressed views that conformed to it, perceiving themselves as the best and only person able to care competently for their child. Their assimilation of this normative construction reveals its power.

Most of the participants identified the lack of social support for their children as the cause of their isolation rather than their children's disability. Participants further placed a significant amount of importance on the support of family and friends, and they saw a lack of support from family and friends as a major factor contributing to their feelings of isolation. Many participants pointed out that greater social understanding as well as social and institutional support is needed to alleviate the severity of experiences of isolation.

3. She is not to work in paid employment

the third expectation that emerged from the participants' experiences is that mothers of children with disabilities are expected to refrain from paid employment outside the home. This expectation was reinforced by attitudes of friends and family, as well as by a lack of institutional support. Whether this is an expectation present

in original conceptions of 'good mothering' is contested, and historically dependent. In a 21st century context in order for a mother to be seen as a 'good mother' as well as a good citizen, she often must engage in paid work on top of caring work. Yet even so, there still exists a contradiction between a mother's commitment to paid work, and her commitment to mothering work. This is particularly true for mothers of children with disabilities, who feel that they will be perceived as 'bad mothers' if they're not constantly available to provide care for their children.

However, while many participants felt a pressure to remain out of the workforce, many of them contested this expectation through engaging in paid work. All participants were engaged in some type of paid work before they had their child with a disability, and after they had their child all but one changed their work hours or their occupation in order to accommo-

date their new caring responsibilities. All of the participants who engaged in paid work said that while managing work and home life was demanding, working outside the home gave them an important sense of self-worth, purpose, and social connection.

It is important to point out though, that the participants interviewed were from relatively privileged backgrounds and many mothers have no choice but to engage in some type of paid employment. It may be that some mothers inevitably fail to meet this 'good mother' model because of their socio-economic status. However further research needs to be conducted before specific links between class and good mother ideology can be made.



Flor encarnada



Weib 2013

4. She will be nurturing

The fourth expectation of the concept of a 'good-mother-of-a-child-with-a-disability' is that a mother will be nurturing. This idea of nurturance is not unique to mothers of children with disabilities. However, the expectation of nurturance is extended, and intensified for these mothers. Not only are these mothers expected to be the primary caregivers for their children, but also the way in which they give this care is highly regulated by themselves, other mothers, and others in society.

Many of the participants spoke about the fact their child prefers their care over anyone else's care with a sense of pride, because it confirms that they are doing a 'good job' in their nurturing role. However, they also spoke about the same thing with a hint of annoyance, as their child's preferences also reinforced the enormity of their caring obligations.

5. She will maintain the appearance of 'normality'

The final expectation of a 'good-mother-of-a-child-with-a-disability' concept is that the mother is expected to present her family as 'normal'. 'Normal' is a contingent and debated term, and was often used by the mothers to point to what their family would be like if their child was not disabled. While sometimes the mothers contested what the term denotes, they also used it quite openly to describe familial situations in contrast to their own.

To be 'good mothers' of children with disabilities these women are expected not only to cope with difference, but also to present difference as normal. Mothers tried to negotiate the boundaries of what is considered 'normal' in order to construct an image of a well-coping, well-adjusted family. However, in trying to cope with difference and present it as normal, many participants experienced alienation and stigma. This was particularly

so when it came to their child with a disability and the school system, as well as experiences within social circles of family and friends. Many mothers described how isolating it could be to have a child with a disability, and claimed that no one truly understood unless they had gone through the experiences themselves.

Conclusion

It seems that from the research conducted so far – at least in an Australian context – there exists a concept of ‘good motherhood’ specific to mothers of children with disabilities that is a similar but intensified version of orthodox understandings of ‘good motherhood’ that impacts all mothers. There are many complexities in the experience of mothering a child with a disability –all of which cannot be communicated in a few thousand words. The existence of conceptions of ‘good motherhood’ –specifically for mothers of children with disabilities– have

profound effects not only on the way women parent, but also on the ways in which they see themselves as individuals. Hopefully through creating awareness that these types of expectations exist for mothers of children with disabilities, we will be able to generate some changes in social understandings that these mothers and their children so keenly require and deserve.



Heart blossom

REFLECTIONS

The experiences of mothers of children with disabilities have largely been overlooked in both academic literature and broader society. Understandably, much of the discussion about the lives of children with disabilities focuses on the children themselves, but can neglect the experiences of primary carers –usually mothers. The burden of caring for a child with a disability often becomes too much to bear. In response to the lack of support for children with disabilities, the National Disability Insurance Scheme (now called Disability Care) has been developed in Australia to address the needs of all people with disabilities.

The Scheme launched in four areas within Australia –now called ‘trial sites’– in July 2013. The Scheme is person-centred and aims to assess the individual needs and goals of the person with a disability. A care plan is then created to work towards and fulfill these goals and needs. The person with the disability or their carer is then awarded funds in order to carry out the care plan they have developed. In the eyes of the public, the Scheme is going well, and the media

has been very responsive to the idea of the Scheme, with very little negative coverage.

However, there are already a number of issues with the Scheme that have begun to surface. These include: a lack of guidance for staff, family members, and persons with a disability on the way the Scheme operates; a delay in clarifying who is eligible within the State service system; a lack of information for carers on how to prepare for the Scheme and their care plan; and there has been a lack of planning for the next stage of the Scheme (Whalan et al 2014).

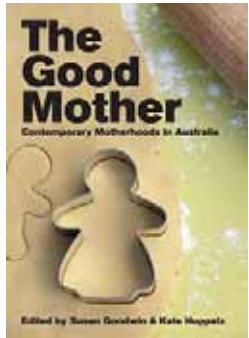
In addition to these concerns about the implementation of the Scheme, it also does not address the needs of carers, who are still expected to bear the burden of care. Carers need to be fully informed about how the system operates, and on how to communicate the specific needs of their child with a disability. Otherwise, the care plan organized with an Agency worker will fail to meet the needs of the child. There is a huge amount of confusion when it comes to the Scheme. Pressure needs to be put on local MPs as well as Federal members to under-



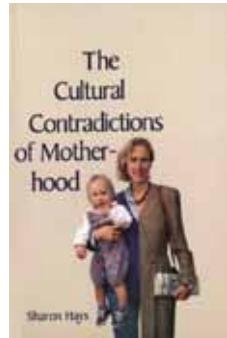
Rosa mística

stand the challenges families and mothers face when participating in the Scheme in order for it to work successfully to address the needs of people with disabilities and their families.

FURTHER READING



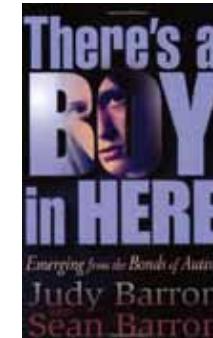
Goodwin, S. & Huppertz, K. (2010) *The Good Mother: Contemporary Motherhoods in Australia* Sydney: Sydney University Press



Hays, S. (1996) *The Cultural contradictions of motherhood* New Haven, CT: Yale University Press.



O'Reilly, A. (2007) *Maternal Theory: Essential Readings* Toronto, Canada: Demeter Press



Barron, J. & Barron, S. (1992) *There's a boy in here* New York: Simon & Schuster

The Good Mother is a collection of essays that examine the relevance of the 'good mother' in a contemporary Australian context. The concept of the 'good mother' has changed over time, yet expectations about what makes a 'good mother' persist in public policy, the media, and popular culture. This collection demonstrates the diversity of the 'good mother' concept and how it impacts upon all types of mothers. The 'good mother' is no longer exclusively white, heterosexual, economically-dependent and child-focused, yet prevailing ideas about motherhood continue to influence the ways all mothers are represented and expected to behave.

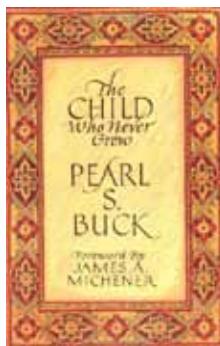
Hays traces the concept of intensive mothering ideology through an overview of mothering since the Middle Ages, an examination of childrearing manuals, and an analysis of in-depth interview with mothers from a range of socio-economic backgrounds. The ideology of intensive mothering demands that mothers be primarily responsible for child-rearing, and that the experience of mothering should be wholly child centred, expert-guided, labour-intensive, and emotionally all-encompassing. Hays argues that it demonstrates the ambivalence our society has towards individual interests (where we normally champion individuals pursuing their own interests above all else, yet expect mothers to adhere to an ideology that is all-consuming).

O'Reilly has produced the first-ever anthology on maternal theory – a distinct body of work within Motherhood Studies and Feminist theory. The anthology contains 50 chapters, and covers more than three decades of scholarship of 'must reads' within maternal theory. Authors include: Adrienne Rich, Nancy Chodorow, Sara Ruddick, Alice Walker, Barbara Katz Rothman, bell hooks, Sharon Hays, Patricia Hill-Collins, Julia Kristeva, Kim Anderson, Audre Lorde, Ellen Lewin, Daphne de Marneffe, Ariel Gore, Ann Crittenden, Judith Warner and many more. *Maternal Theory* is essential reading for anyone interested in motherhood as experience, ideology, and identity.

There's a boy in here tells two stories: that of the mother of a child with autism, and that of the child. Barron describes in great detail her son Sean's difficult behaviors, his tantrums, his compulsions and fixations, his seeming indifference to his family, and her own tumultuous efforts to simultaneously understand his behaviors and help him diminish them. Sean then retells some of these accounts with his own memories, emphasizing how these behaviors were not only pleasurable for him, but were an attempt to control his environment and lessen the possibilities of failure. While the account provides the perspectives of both the parent and the person with autism, unfortunately, the narrative ultimately reinforces the idea that autism is something to be cured or overcome.



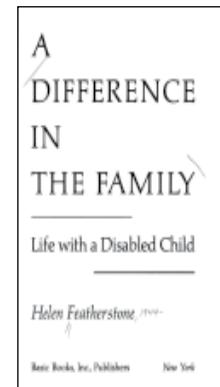
Beck, M. (2000) *Expecting Adam: A true story of birth, rebirth, and everyday magic* New York: Berkley



Buck, P.S. (1992) *The child who never grew* Bethesda: Woodbine House. (Original work published 1950)

Expecting Adam is an autobiographical tale of an academically-oriented Harvard couple who conceive a baby with Down's syndrome and decide to carry him to term. Despite everything Martha Beck and her husband John know about themselves and their belief system, when Martha accidentally gets pregnant and the fetus is discovered to have Down's syndrome, the Becks find they cannot even consider abortion. As Martha's difficult pregnancy progresses, odd coincidences and paranormal experiences begin to occur for both Martha and John, though for months they don't share them with each other. Martha's pregnancy and Adam become the catalyst for tremendous life changes for the Becks (Source: Excerpted from Ericka Lutz, Amazon.com).

This edition brings back into print a classic in disability literature. Written by a Nobel and Pulitzer prize-winning author, this personal account broke a national taboo when it was originally published in 1950. Buck's inspiring account of her struggle to help and understand her daughter with mental retardation was perhaps the first disclosure of its kind by a public figure. Today, much of the emotional experience Buck so eloquently describes still rings true. New material written especially for this edition amplifies her story and gives the book an important historical perspective (Source: WoodbineHouse.com).



Featherstone, H. (1981) *A difference in the family* New York: Basic Books

FURTHER VIEWING



The Black Balloon
Directed by E. Down
Australia, 2008
97 min.

All Thomas wants is a normal adolescence but his autistic brother, Charlie, thwarts his every opportunity. Will Thomas, with the help of his girlfriend, Jackie, accept his brother?



My Sister's Keeper
Directed by
N. Cassavetes
USA., 2009
109 min.

Anna Fitzgerald intenta conseguir la emancipación médica de sus padres, quienes hasta ahora han confiado en ella para ayudar a su hermana mayor, enferma de leucemia, a permanecer con vida.

LINKS DE INTERÉS

Mothering kids with special needs

This is a website with links to different blog extracts posted by mothers of children with special needs.

Motherhood Initiative and Community Involvement

The Motherhood Initiative and Community Involvement is a feminist, scholarly, and activist organization on mothering-motherhood, and houses the *Journal of the Motherhood Initiative* as well as other forums and initiatives designed to discuss experiences of mothering and advocate for maternal empowerment.

Association for Children with a Disability

It is an association run by parents who have children with disabilities. They provide advocacy, support, and information for families who have a child or young adult with any type of disability or developmental delay.

Her Bad Mother

Her Bad Mother is a blog about surviving motherhood, womanhood, and advocating that more often than not, 'bad' is the new 'good' when it comes to mothering. She rejects the idea of the 'good mother', beyond an expectation of love and care, and argues that if society still maintains that mothers must meet the 'good' standard, then she will proudly deem herself 'bad'.

ABOUT THE AUTHOR OF THE TEXTS

Sophie Brock

is a Ph.D. candidate at The University of Sydney, Australia, researching the experiences of mothers of children with disabilities. She is interested in how having a child with a disability impacts a mother's networks of support, friendships, family, employment, and sense of identity. She is linking two areas of study – Family Studies and Motherhood Studies – in order to ask new and important questions about the role and meaning of 'mother,' and the changing meaning of 'family' and 'personal life' in the context of having a child with a disability.

ABOUT THE AUTHOR OF THE IMAGES

Magdalena Duran

is a visual artist, art therapist and teacher of art and art therapy. She has participated in multiple individual and joint exhibits since the 80s and has received grants from the Generalitat de Catalunya and the Binz de Zürich Foundation. Her work is found in collections such as that of La Caixa Foundation and Nordstern Versicherunguen.

The paintings that accompany the texts in this issue are part of a series about creativity from the point of view of femininity. They are borne of spontaneous expression connected to the present moment, inspired by the practices of Tibetan yoga and Chi Kung. These disciplines make it possible to move internal energies of the subtle body, and from there, express them in the form of painting. Her current research focuses on the relationship between art and the inner world and human psyche.

EL APERITIVO DEL JUEVES EN LOS SEMINARIOS AFIN*

Sala de Juntas - Facultat de Filosofia i Lletres
Universitat Autònoma de Barcelona
13:00 - 14:30 h.

* Los workshops son abiertos y se organizan en el marco del proyecto de I+D+i
Adoptions and fosterages in Spain: tracing challenges, opportunities and problems in the social and family lives of children and adolescents (CSO2012-39593-C02-001)



19 de febrero 2015
Cómo escribir un artículo académico para una publicación indexada
SUSAN FREKKO (Goucher College/ Grup AFIN)

26 de febrero 2015
Afrontar el proceso de "revise and resubmit" con una revista indexada
SUSAN FREKKO

5 de marzo 2015
La metodología de los itinerarios comentados en el contexto de la adopción
DIANA ARIAS (UB/ Grup AFIN)

12 de marzo 2015
Apropiación de niños y sustracción de bebés en España: Miedo, secreto y estado de excepción
DIANA MARRE (UAB/ Grup AFIN)

19 de marzo 2015
Antropología i Política
DOLORS COMAS (URV/ Grup AFIN)

26 de marzo 2015
Entendiendo los flujos de la demanda de la adopción transnacional
BEATRIZ SAN ROMÁN (UAB/ Grup AFIN)

9 de abril 2015
Retos y estrategias de organización del cuidado en Catalunya: (re)organización o reproducción de desigualtats?
MIREIA ROCA (UAB/ Grup AFIN)

16 de abril 2015
Afrontando la llegada de los hijos/as adoptados a la adolescencia: Competencias familiares y apoyos del entorno
TOMASA BÁÑEZ (UB/ Grup AFIN)

23 de abril 2015
El deseo de tener hijos/as
BRUNA ALVAREZ (UAB/ Grup AFIN)

30 de abril 2015
Análisis de datos etnográficos con Dedoose
M. ANTÒNIA ARRECIADO
PAOLA GALBANY (UAB/ Grup AFIN)

7 de mayo 2015
Espacios y estigma
VICTÒRIA BADIA (UB/ Grup AFIN)

14 de mayo 2015
National Family Planning Indonesia (NFPI): Cuestiones sobre reproducción en la Isla de Flores (Indonesia)
ALICIA P. REBUELTA (UAB/ Grup AFIN)

21 de maig 2015
Mujeres y cuidado a caballo de los siglos XIX i XX
DOLORS COMAS D'ARGEMIR
PAOLA GALBANY

28 de mayo 2015
Maternidad e "infertilidad estructural" en España
BRUNA ALVAREZ

4 de junio 2015
"Vosotras no dais una respuesta: hacéis muchas preguntas": la antropología en la atención y acompañamiento de las familias adoptivas
BEATRIZ SAN ROMÁN