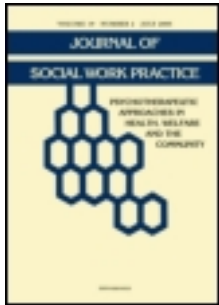


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Brian Watermeyer and Judith Anne McKenzie

MOTHERS OF DISABLED CHILDREN: IN MOURNING OR ON THE MARCH?

A traditional psychoanalytic view of parenting a disabled child emphasises responses of shock, grief and depression. Parent activists and social model disability authors dismiss such accounts as destructive and prejudiced, foregrounding structural barriers to accessing services and resources. Further, psychoanalysis is criticised for its anachronistic, ideologically uncritical discourse. Each position brings valuable insights as well as silences. This paper seeks to overcome an assumption of mutual exclusivity by creating a new synthesis, drawing on the work of Winnicott and Kittay. Conclusions are that it is both possible and necessary to allow for ambivalent feelings within parents, while attending to the external, material realities of contextual factors.

Keywords disability; mothers; psychoanalysis; disability rights

Introduction

While the role of mothers is central to any discussion of child rearing, the vicissitudes of mothering are arguably amplified when the child is disabled. This situation is largely absent from parenting discourses, typically appearing only as a possibility in discussions of prenatal screening and healthy pregnancy (Landsman, 2003). Indeed, the entire domain of disability is one surprisingly under-represented in academic writing in the behavioural sciences, inclusive of psychology (Abberley, 1998).

One psychological discipline in which parenting issues related to disabled children have been raised over many decades, albeit intermittently, is psychoanalysis (Asch and Rousso, 1985; De Groef and Heinemann, 1999; Watermeyer, 2013). In the main, this line of research and theory emphasises experiences of shock and disappointment in parents, who struggle to grieve the presumed loss embodied in their baby. As evidenced in this journal (Brandell, 2013), the relevance of psychoanalysis to this and many other areas of social work practice is a matter of robust debate. Opposing the psychoanalytic construction of disability in childhood are parents and researchers operating from the 'social model of disability', a strongly contextual view of disability inequality which foregrounds structural barriers to equity and participation (Barnes, 1990; Oliver, 1990; Swain *et al.*, 1993). From this second vantage point, psychoanalytic constructions of disability in families reflect the worst of a decontextualised,

individualistic and medicalising view of impairment-based inequality, muddying the political struggle for equal access. But the discourse of human rights brings with it a dampening down of some aspects of life with disability.

In this paper, we explore the divergence of these stances, and important influences of each on constructions of the support needs of parents. Each orientation carries its own entitlements and prohibitions. The stances are located at opposing ends of the individual-social continuum, and are, in our experience, often applied in clinical practice as if mutually exclusive. We therefore attempt to develop a unified position to support parents in forming psychologically healthy relationships with their children, while remaining cognizant of a broader social context characterised by ongoing discrimination. Our focus on mothers is based on evidence that in most cases, it is mothers who carry much of the responsibility for care (Kittay, 1999). However, the ideas we present may apply equally to fathers in caring roles. Mothers in such circumstances are compelled to shift from taken-for-granted assumptions about parenting, under the strain of material barriers to equity in education and social life, as well as the psychological reverberations of parenting a child who is impaired. One writer characterises the challenge in the following way:

Conscious reembodiment of the social category of parent takes place through myriad daily activities, including the intimate and private management of a child's physical and emotional needs, public presentation of self as parent of an impaired child, and public representation of parent and child across a variety of public domains. (Kelly, 2005)

In the following discussion we begin by presenting elements of the psychoanalytic construction of parental reactions to childhood disability. These ideas are then contrasted with the writings of first parents, and then theorists, who position themselves within the social model, or 'citizenship rights' perspective, often stridently opposing the purported pathologisation of psychoanalysis. Here, the debate regarding views of disability in families is but one battle, set against the backdrop of a 'war' against medicalisation in its myriad forms. To move towards a new synthesis, we then draw on the work of Donald Winnicott in reconstructing mothering of a disabled child in terms empathic towards both the emotional relationship and material, contextual reality. Winnicott's position is combined with concepts gleaned from the work of the philosopher Eva Kittay to create an approach to the family which remains analytic, but is also empathic to both subjective and objective realities, and pragmatic. Of interest are the particular ways in which 'medical model' psychoanalytic and 'emancipatory' social model perspectives *both* carry elements of acknowledgement as well as invalidation of the predicaments of mothers. It is at once disempowering to pathologise parents of disabled children, and harmful to deny real feelings and needs for support which grow out of the emotional ramifications of difference.

The view from psychoanalysis

Psychoanalytic approaches to the birth of a disabled infant have in the past been located within a grief and bereavement model, which emphasises parents' presumed need to

mourn the loss of the ideal, hoped-for child (e.g. Burlingham, 1961; Solnit and Stark, 1961; Pinkerton, 1970; MacKeith, 1973; Drotar *et al.*, 1975; Boukobza, 1999; De Groef, 1999; Korff-Sausse, 1999). These writers draw on Freud's (1917) work *Mourning and melancholia*, applying bereavement concepts in constructing a stage-wise picture of appropriate parental loss. The assumption here is that parents must successfully traverse this stage process if there is to be any hope of healthy relating to the child (Drotar *et al.*, 1975). Drotar *et al.* (1975, p. 711) describe some of the features of these stages as overwhelming shock, irrational behaviour, uncontrollable tearfulness, helplessness, denial, disbelief, sadness, anger and anxiety. In their view, distressed mothers may (consciously or unconsciously) experience violently negative feelings towards self and baby, including hatred of the infant's malformation, extreme self-blame and a feeling of 'not caring if the baby dies' (Drotar *et al.*, 1975). The discrepancy between the disabled baby and an imagined ideal child is viewed as a source of trauma for parents, leading to the disruption of early attachment (Boukobza, 1999; Korff-Sausse, 1999), and the family becoming 'enveloped' in a state of 'chronic sorrow' (Drotar *et al.*, 1975, p. 710). MacKeith (1973, p. 133) describes two primary types of maternal reaction – protection and revulsion – which may exist in complex, alternating relation to one another. In her psychoanalytic work with mothers of blind infants, Burlingham (1961, p. 122) describes feelings of 'injury, of hurt pride, of guilt, and of . . . depression', which may cause the parent to withdraw emotionally from her child, and, sometimes 'irrationally wish for his [sic.] death'. As will be noticed, the tone of much of the psychoanalytic writings in this area seems starkly out of step with a present-day concern with politically sensitive terminology and human rights. While it is tempting to attribute this to the fact that such sources are largely dated, the feeling of anachronism is also, to varying degrees, a feature of many newer sources (e.g. De Groef and Heinemann's edited volume (1999)). Thus, what seems to be demonstrated is an aspect of the character and approach of psychoanalysis as a discipline, past and present. It is an approach which, according to a familiar critique, sidelines socio-political realities, as the primary task of analytic work is exploration of *internal* oppressions and how these limit the capacity to relate in the social world (Samuels, 1993; Figlio and Richards, 2002). Besides this issue, there is simply a shortage of sustained or recent attention paid by psychoanalysis to disability, contributing to poor grasp of a shifting ideological environment. While both criticisms remain very relevant, we wish to temper the argument by pointing to the valuable, even unique, contribution which psychoanalysis' close attention to the internal has to make to the disability puzzle. It is the remit of psychoanalysis to explore unconscious life; it should thus not surprise us that it is darker aspects of the disability experience which it shines its light on. Previously, psychoanalysis has promoted the idea that these painful, partially hidden aspects are primary, even definitive of the experience of disability in families. This is harmful and incorrect, yet it is equally important to allow for grief and struggles with difference (Watermeyer, 2009, 2013).

Perhaps unsurprisingly, many parents of disabled children and adults have expressed vociferous objections to these psychoanalytic assertions. In addition, social model writers have rejected psychoanalytic work on disability more generally, seeing it as typifying the pathologising, ideologically uncritical stance of the medical model. Let us consider accounts of the position of parents.

The response of parents

The often dark assessments of psychoanalysis have felt offensive to many parents of disabled children. Associating feelings such as unconscious hatred or unbearable grief with one's parental relationship seems unthinkable, tending to shore up defences against painful threads of one's role as parent, rather than the opposite.

Ferguson and Asch (1989) attempt to realign the debate in a manner they see as more respectful to parents. The following statement seems impossible to contradict:

The most important thing that happens when a child with disabilities is born is that a child is born. The most important thing that happens when a couple becomes parents of a child with disabilities is that a couple becomes parents. (Ferguson and Asch, 1989, p. 108)

Taking issue with psychoanalysis in a similar way, Yuker (1994) implores us to simply 'stop studying the presumably horrible negative effects of a child with a disability on parents and siblings' (cited in Olkin, 1999). Ferguson (2001), himself the father of a disabled son, emphasises that parental reactions are 'inescapably embedded within a sociohistorical context'. He regards the 'persistent pessimism' and 'horror stories' of psychoanalytic (and other psychological) writers as nothing short of slanderous, and evidence of a destructive intellectual attitude (pp. 375–376). The logic of these accounts, for Ferguson, presents a reversal of an earlier, even more crude view: while religious or superstitious beliefs previously saw disabled infants as damaged by the prior misdeeds of their parents, in the new schema it was the disabled child who brought damage and suffering to the family (Ferguson, 2001, p. 379). The alleged 'tragic connotations' of such births, Ferguson (2001, p. 376) argues, remain 'consistently presented as inherent and immutable'. Whether family researchers in the second half of the last century chose to focus on attitudinal categories (such as guilt, denial, displaced anger, or grief), or behavioural aspects (including role disruption, marital discord, or social withdrawal), the consistent assumption was that disability 'distorted the connection between child and parent in ways that were both intrinsic and harmful' (Ferguson, 2001, p. 379).

The sacredness of parental bonds

Also speaking as a parent, Linderman (cited in Olkin, 1999) echoes Ferguson's tone, objecting thus to the pathologising of relationships with disabled children:

How can we call such a daughter a 'burden'? On what basis do textbooks repeatedly claim that parents of children with disabilities 'cannot make an honest attachment to their real child until they have withdrawn their affection from the normal, wished-for child'? (Linderman, 1981 cited in Olkin, 1999, p. 92)

Linderman's (1981) words communicate the quite natural sense of sacredness which most parents attach to relationships with children. Such relationships include a

welter of unseen emotional investments, and are ongoing realities which involve knowing, feeling human beings. As such, the notion of appraising a relationship with detached objectivity seems both dangerous and disrespectful. Furthermore, individuals struggling with the material, physical and emotional demands of parenting a disabled child may feel undermined and destabilised by criticism, cementing a reluctance to reflect at all on relationship difficulties. Worse still, this ‘criticism’ from psychoanalysis can place parents in a double-bind. Here, dissatisfaction with health professionals may be seen as displaced anger with their child or with fate, which cannot be acknowledged because of guilt. From this vantage point, it would be hard to see such behaviour as part of a healthy drive to protect the parental bond. The analytic lens’ accentuation of loss and its denial (Watermeyer, 2009) make it difficult to see parents’ protection of the sanctity of relationships as, at least in part, healthy and normative. Interpreting parents’ behaviour as reaction formation may in this way render the miserable presuppositions of psychoanalytic researchers self-fulfilling (see also Heifetz, 1980; Turnbull and Summers, 1987). At the same time, parents with real grievances regarding health care needs are disenfranchised. Harris and Wideman (1988) – themselves working within a psychoanalytic paradigm – concur, slamming what they view as the use of theory by professionals as a mechanism for distancing disabled clients and their families. Analytic interpretation here serves the purpose of stilling the clinician’s anxieties about complex social injustices, rather than illuminating the experience of families (Foster, 2001; Watermeyer, 2013).

The social model view from disability studies

Authors assuming the social model stance agree that a grief model replaces socio-political difficulties (such as discrimination and poor services) with an illusory psychological problem of failure to ‘come to terms’ with impairment (Abberley, 1993; Finkelstein and French, 1993; Lenny, 1993; Oliver, 1996). Problems are thus attributed to individual factors based on ideas about the presocial consequences of difference. The centrality of parents’ grief paints the meaning of infantile impairment as something independent of environmental factors, including interactions with health professionals (Dreger, 2006). While intra-psychic, historical factors may be seen to mediate the degree of pathology in responses to an impaired birth, the reality of ‘what must be dealt with’ is effectively presented as a constant. Called forth here is a familiar cultural phenomenon – the irresistible equating of a ‘defective’ body with a maladjusted existence (Kriegel, 1987). To combat this sort of reduction, movements lobbying for social change strategically promote a collective analysis, carefully avoiding the complication of unique subjectivities. Exploring individual inner life opens the way for psychological attributions; by contrast, a myth of in-group homogeneity directs attention outward towards social forces. Unfortunately, though, one consequence is an unhelpful separatism between marginal minorities (for a critique, see Fraser, 2000).

Although the critique from social model quarters holds much truth, the imperative to distance one’s identity from a pathologising stereotype comes at some cost, as it can disallow feeling. While staying aware of the sanctity of relationships as well as material access concerns, researchers must hold in mind that disabled people, like others, do have a family (that is, formative relationships). The plight of many families, struggling

against discrimination and exclusion suffered by their child and often themselves, easily contributes to a politically driven idealisation, limiting our ability to think clearly about the formative lives of disabled people. In research as well as public discourse, the need to overturn demeaning, hegemonic ideas about disability can make clear, nuanced thinking difficult.

The cost of deflecting stereotypes

Social model critics and parent activists are responding to the tainting of disability-families as miserable, disturbed and unstable, and assumptions about how bodies shape psychology and self. But a paradoxical danger arises from contrarily reauthoring these narratives. Consider Olkin's (1999) words:

Although initial reactions to the birth of a child with a disability may be stressful and negative, parents often quickly exhibit coping behaviours. (p. 95)

Assessing this statement requires making sense of a complex interplay between parents' inner struggles with difference, and material, emotional and political imperatives to cope. Olkin's book *What Psychotherapists Should Know About Disability* (1999) is a sensitively written and very useful resource. But in the aforementioned statement, one discerns the difficulty in separating how parents may cope from how they ought to cope. It is an uncertainty which pervades the discourse of disability parenting. On the emotive terrain of child-rearing, guilt over what one feels or does not feel, does or does not do, is seldom far away. Added to this, it is a hallmark of disabled life in a prejudiced society that constructions of experience, identity and self may be made in opposition to dominant stereotypes (Watermeyer and Swartz, 2008; Watermeyer, 2009, 2013). Ferguson and others object to the assertion that an impaired child brings disruption and struggle to the family, offering a certain politicised 'optimism' in response to medical model 'pessimism'. But in our view, a rebuttal of denigrating assumptions can distract from investigating how the disruptions and struggles which may – do – occur impact on early relationships, and the formation of the disabled self. The words of Miller (2006), who has achondroplasia (formerly *dwarfism*), provide an interesting, first-person contrast to Olkin's position cited above:

The birth of a disabled child to able-bodied parents is often met with disappointment, or even anger, due to the loss of the idealised child . . . The birth of a disabled child often leads to a period of grief. (Miller, 2006, p. 218)

The simple authenticity of Miller's (2006) words rings true, notwithstanding the political complications which are introduced. To all but the most extreme of materialists, the proposition that adjustment to the birth of an achondroplastic infant would be a complex, evocative and difficult experience for most parents seems reasonable. For Ferguson and others, this simple observation is difficult to allow, as it confirms a host of deeper, constrictive stereotypes. The need to overtly 'value' families can render such critics, as well as politically informed practitioners, unable to look directly at the unconscious emotional currents which surround infantile disability.

The ‘baby in the bathwater’

As is so often the case in debate on the politics of oppression, what we see here is an unhelpful, oversimplified split. At risk are the potentially valuable insights of both the positions sketched above. In comparatively reading these opposing streams of theory, it became clear to us that the psychoanalytic model, with its concern for the fine description of emotional states, bears precious knowledge about the conscious and unconscious psychic milieu in which disabled children develop (De Groef and Heinemann, 1999; Marks, 1999; Watermeyer, 2006, 2013). Familiarly, the unconscious conflicts evoked by disability have produced a potentially paralysing split; that is, between the ‘pathologising’ and equally ardent ‘de-pathologising’ of families, in a manner which will inevitably silence something of subjective reality. In other words, the ‘de-pathologising’ position risks disallowing parents from consciously acknowledging feelings which may be politically inconvenient or unpalatable, hence obscuring awareness of the intersubjective roots of disabled subjectivity. There is a baby in the psychoanalytic bathwater. However, it is essential to hold in mind that both accounts, as currently applied, are partial, and hence distorted. Further, the tone and ideological ignorance of the majority of prior psychoanalytic work on disability in families are a blight; future work must build social realities and critique into its application.

The normative presence of parental ambivalence

Parenting is hard. Yet, unconscious struggles with unmet early dependency needs inform a culturally embedded propensity to criticise parents. We are expected to love and care for our children absolutely and constantly, no matter the challenges or circumstances (Read, 2000). These cultural expectations make it hard for parents to acknowledge to themselves or others that their role can be painful, arduous and unpleasant, as well as joyous and fulfilling. Naming such darker feelings consequently causes guilt, surrounding the idea that ‘I shouldn’t feel this way’. This occurs amid the reality that part of parenting involves making oneself available as a container to be emotionally ‘used’ by children. We must think about our children, but cannot (for the most part) expect the same mature consideration in return.

We suggest that these elemental demands of parenting can be amplified when a child is disabled. Physical and emotional requirements of parents are heightened by a child’s functional limitation and possible emotional and physical suffering. Material expenses, often very substantial, are a further challenge. But also amplified is the cultural eliciting of guilt. If it is shameful to acknowledge (and potentially process) the burdensome aspects of rearing a nondisabled child; it is much more so in the case of a disabled one.

Winnicott (1947/1992) provides a conceptual space for difficult feelings towards an infant which puts the foregoing in a different light. He writes:

I suggest that the mother hates the baby before the baby hates the mother, and before the baby can know his mother hates him [sic.]. (Winnicott, 1947, p. 200)

With these rather dramatic words, Winnicott (1947) introduces the idea of parental ambivalence towards an infant as a wholly normative, even necessary part of child-

rearing. The presence of conflict in the mother of a new born, in his view, is both rational and instinctual. Among much else, the baby has been 'a danger to her body in pregnancy and at birth', 'an interference with her private life', a cause of pain to her nipples, the reason for immense fatigue; in short, the baby has replaced her needs and comforts with the prioritisation of her or his own (Winnicott, 1947, p. 201). As noted, part of parenting means allowing oneself to be 'used'; to Winnicott (1947, p. 201), the mother is treated as 'an unpaid servant, a slave', who must love her child 'excretions and all'. This corrective to the unidimensional, romantic idealisation of motherhood focuses empathic attention on the needs and struggles of mothers, aiming to provide space for natural feelings of resentment. In the guilt-ridden cultural evaluations of 'good' motherhood, such feelings are very often repressed or experienced as evidence of failure. The implications of this are powerful, and can be dire.

It is a psychoanalytic axiom that feelings which cannot be consciously allowed will tend to be enacted in unconscious, symbolic ways. Thus, it is that, for Winnicott (1947, p. 202), a culture of acceptance of aversive feelings about parenthood has direct implications for the psychological well-being of children, and hence of adults. Paradoxically, Ferguson (2001) and others, through countering pathologising ascriptions to the families of disabled children, risk de-legitimising the actual experience of parents in situations of crisis – the very parents these writers seek to support. Their focus on enforcement of rights to the material resource needs of parents is correct. And indeed, descriptions of the hateful feelings towards a new born provided by Solnit and Stark (1961), Drotar *et al.* (1975), MacKeith (1973) and others certainly carry the bias of a view which is ignorant of material circumstances as well as the social construction of disabled lives. But ironically, what we see is a situation in which politically driven positions actually leave the parents of disabled children – parents often in especially challenging roles – less entitled to their own feelings of struggle. Instead, political imperatives, in conjunction with an entirely understandable adversarial attitude towards a neglectful social world, can feed into a constriction of what parents are allowed to feel towards their disabled children. When it is quite rational to view the world as opposing one's child's well-being – her needs for accessible education, health care and other services, as well as simple social inclusion – it is extremely difficult to contemplate one's own hardships brought on by her disability. What is required is psychoanalytically oriented investigation with a tone which makes it safe enough for parents to express a normal human mix of feelings about their disabled child – not pathologising accounts delivered as accusation.

An integrated view

We believe that it is possible to support parents of disabled children in a manner which allows for aversive and conflicted feelings, while addressing material and contextual concerns impacting on the child's development. The impasse outlined earlier creates the illusion that these clinical positions are mutually exclusive. And it is worth noting that the very split at the centre of this paper reflects how hard it can be for practitioners to escape the idealisation and identification so often brought on by disability (Foster, 2001). The need to further develop an understanding of disability that can challenge the split between (a) the effect of the impairment on individuals and their families, and

(b) the environmental barriers which they face together is supported by disability theory that adopts a more integrated and interactional view of disability (Thomas, 2004; Shakespeare, 2006; Watson, 2012). As Watson (2012) points out, there are a range of possible theoretical positions in support of this, but the challenge to a rigid adherence to either a social or a medical model of disability is clear. How can this more fluid and dynamic perspective on disability be integrated within social work practice? We begin with some suggestions regarding the maternal perspective that are proposed by Eva Kittay (1999).

Drawing on the work of Sarah Ruddick, Kittay (1999) identifies three requirements of maternal work: preserving the life of the child, socialising her for acceptance, and fostering her development. In relation to mothering a disabled child, Kittay draws on her own experience to examine the place of each of these requirements. She notes that preservative love, being the most fundamental, often occupies a more central place for a disabled child. The complex and demanding health-related needs of some disabled children positions the preservative function as an arduous, conscious effort, often at the expense of the other two requirements. This can extend to a life-long commitment to providing physical care in the case of profound disability.

In the role of socialising for acceptance, mothers come face to face with the world, with its hatreds and fears. Kittay (1999) writes:

The parental task involves then both socializing the child for the acceptance, such as it might be, of the world, and socializing the world, as best you can, so that it can accept your child. (p.169).

Thereafter, she makes a crucial point about how this balance can be achieved:

Yet a precondition for both requires socializing yourself [as a mother] for the acceptance of the child with her disability, and establishing a sense of normalcy, for yourself and for the face you present to the world (Kittay, 1999, p.169).

As will be clear, this process of 'self-socialization' is, for Kittay, a substantial, difficult and legitimate challenge awaiting parents of disabled children. In mediating the space between a physically and/or behaviourally different child and a prejudiced world, compassionate acknowledgement of a mother's own struggles with the difference characterising her life must be a basic priority. Medical and rehabilitation services are geared towards supporting the preservative and developmental functions, through health care and the striving for independence. The latter aspect is also prized by social model-oriented activists and researchers, through an emphasis on material barriers. Neither is well placed to support mothers in socialising (of self and others) for acceptance. While the foregoing applies to a large majority of social work texts, which place heavy emphasis on application of the social model view, there are exceptions to this rule. A minority position has also become evident, where a more courageous, even-handed approach to the thorny questions of parenting and disability is taken. For example, in a social work text concerned with disability-related family work, Burke (2008) appears very much at ease with the ambivalences of parenting. With a pragmatic, real-world tone, data from disability families are explored, showing up love, dread, hope, grief and much else. Such realities as altered expectations, stress,

difficult family dynamics, the restriction of family activities and the emotional predicaments of siblings are recognised as central concerns deserving close examination. The fact of complexity – that is, of mixed feelings – is admitted as a foundation of all relationships.

Conclusion

The unconscious evocations elicited by disability can powerfully mediate relationships, in ways harmful to emotional development (Watermeyer, 2013). Various fears induced by bodily difference are almost certainly carried by all, and should not be a cause of shame. But to prevent these from impacting on the developing selves of disabled children, it is essential that a place be made for feeling and exploration without judgment. It is possible to achieve this without neglecting the material and contextual challenges which disability poses to families.

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