

**THE JOURNEY UNDESIGNED: BECOMING THE PARENT OF A
DISABLED CHILD**

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ABSTRACT

The birth of a child with a disability, or the discovery that a child has a disability, can have profound effect on the family. This paper has explored the parents' experiences of coming to terms with living with a disabled child. It is based on the case studies in Delhi and NCR region, India. When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance, understanding, and support.

Keywords: Disability, Birth Defect, Diagnostic limbo.

MEANINGS

Disability- a person who has a physical or mental impairment that substantially limits one or more major life activity

Birth Defect-A birth defect is a problem that occurs when a baby is developing in utero (in the womb).

Diagnostic limbo-

(a) A region or condition of oblivion or neglect: *Management kept her promotion in limbo for months.*

(b) A state or place of confinement.

(c) An intermediate place or state

INTRODUCTION

When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance, understanding, and support. The birth of a child with a disability, or the discovery that a child has a disability, can have profound effects on the family.

PLANTED REACTIONS

The impact of the diagnosis of the impairment comes as a shock to the parents and they are likely to experience as mixture of emotions, ranging from disappointment to anger, denial and grief [1]. In order to understand the parents' reactions to having a disabled child, we have to take society into accounts as [2] writes 'family's reactions to having a child with a disability are inescapably embedded within a socio-historical context, how a family interprets the meaning of disability cannot help but reflect to some degree the larger context of social attitudes and historical realities within which that interpretations emerges'.

Having a 'normal' child was usually perceived as the natural process of their transition to parenthood and thus was taken for granted. When the parents expressed concerns about the health of their unborn child, these concerns were usually discounted by friends, relatives, and others. Even when the parents, particularly the mothers, had worried about the possibility that their child might be born with a problem, any mention of 'birth defects' was forbidden. Within the Indian culture of which emphasizes the pregnant woman's foetal education, prospective parents are very strongly encouraged to think about only good, beautiful and happy things in this process, as the mother's experience shows, it is strictly forbidden for them to express doubts about the unborn child's normality.' It is also a cultural taboo even to mention a possible impairment or birth defect during pregnancy. What should be noted here is that this lay cultural practice resonates with, and often facilitates, the social marginalisation associated with parenting a disabled child in India. Under the conditions in which the idealised notions of a healthy and perfect' child are naturalised, the birth of a disabled child is identified as the most tragic and dreadful life event. In addition, the possibility of having a disabled child is usually consigned to the domain of the 'unmentionable' and, thus, all discussion is 'silenced' in the transition to parenthood. It has long been argued that the segregation and exclusion of disabled people from mainstream society has contributed to their invisibility in everyday life. In such a deeply segregated society, the parents are likely to encounter their disabled child with little or no prior personal experience of interactions with disabled people and their families. Like. Most of the parents reported that they had grown up with little contact with disabled people. It seems that the social invisibility of disabled people and their families was a main factor in determining the

parents' holding of a very narrow, distorted view of disabled families, and hence they regarded having a disabled child as an 'abnormal' phenomenon.

Most of the parents pointed out that, before having a disabled child, they had held values about disability similar to those that they now found problematic. Interestingly, the belief that the birth of a disabled child is due to the 'pathology' of the family was shared by a number of parents. It was a result of their socialisation, particularly of the dominant cultural perceptions of families with a disabled child. Such perceptions are still prevalent among Indian people and even among the educated.

All the individuals are filled with joy and dreams at the news of the wives. But the birth of the disabled child shelters such dreams and joys of parenting. Mostly the parents do not realize at an early stage that their child is not a normal child. The way the parents admit the impairment of their child varies from person to person.

An analysis of the initial response of parents was done by the investigator.

Table No. 1: Mothers Reaction

| Response of mother | No. of Respondent=80 | Percentage |
|--|-----------------------------|-------------------|
| 1. Lamentation and sorrow | 51 | 63.7 |
| 2. Denial | 8 | 10.0 |
| 3. Avoidance and rejection | 7 | 8.7 |
| 4. Guilt | 3 | 3.7 |
| 5. Anger and hostility | 6 | 7.5 |
| 6. Self-doubt | 9 | 11.25 |
| 7. With drawl and depression | 20 | 25.0 |
| 8. Embarrassment and social isolation | 40 | 50.0 |
| 9. Fear confusion and frustration | 32 | 40.0 |

Table No. 2: Father's Reaction

| Response of Father | No. of Respondent=70 | Percentage |
|--|-----------------------------|-------------------|
| 1. Lamentation and sorrow | 35 | 50.0 |
| 2. Denial | 32 | 45.7 |
| 3. Avoidance and rejection | 21 | 30.0 |
| 4. Guilt | 8 | 11.4 |
| 5. Anger and hostility | 11 | 13.7 |
| 6. Self-doubt | 14 | 17.5 |
| 7. With drawl and depression | 12 | 17.1 |
| 8. Embarrassment and social isolation | 13 | 18.5 |
| 9. Fear confusion and frustration | 7 | 8.75 |

If we look at table number 1 and 2, we shall find that total number of respondent is 80 this is because some of the subject did not wish to answer the question.

The number of respondent is more than the number of respondents because some of them show more than one reaction. Most of the mothers and the fathers were sorrowful on learning about their child's disability and some of them even tended to avoid this child. A few of the parents attributed their child's disability to their sins.

LEARNING ABOUT THE CHILD'S IMPAIRMENT

When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services[2]. It might be stated that the moment when the parents learn the news of their child's impairment is generally dependent upon the nature of the impairment. If their child is born with an obvious impairment, the parents usually know straight away that there is something wrong. On the other hand, some impairment, such as autistic syndrome, may not be readily apparent in the child's early development stage, and so the parents may not be aware of their child's condition until much later [3]. However, the nature of the impairment is not the sole factor determining the process of the parent's discovery of their child's impairment. The extent of the

public awareness of disabled children, the parents' or lay knowledge about impairment, the socially arranged forms of diagnostic systems and the medical professionals' attitudes all influence the process of the parents' discovery of their child's impairment and related experiences [4]. Among the parents who took part in the study. In only four cases had their child been born with obvious signs of impairment? They had noticed the child's strangeness' through their daily interactions with him or her. As illustrated below, when the signs of impairment were naturally apparent in the early stage, the parents usually considered their child's difference as a 'normal' child's developmental variation and identified it as the sign of a slow developer.

As their child's difference persisted or developed, the Parents reached the point where they could no longer avoid their suspicion that something might be seriously wrong. Once they reached this point, the parents took the next step sooner or later, namely, seeking a diagnosis of their child's condition. However, seeking a diagnosis did not necessarily mean receiving one. The problem of a delayed diagnosis was raised by most of the parents in the; present study. Some reported that the medical professionals knew but avoided giving a frank explanation of their Child's impairment.

Issues around diagnosis came up repeatedly as the parents described their early lives with their disabled children. A diagnosis, the identification of the condition of the child's impairment by recognizing signs or symptoms, may seem like a straightforward scientific procedure, however, as [5] underscore, a diagnosis does not occur in a vacuum: a range of social and cultural factors influence the ways in which the parents experience the diagnostic process. For example, the mother's concerns over their children's difference were discounted very easily by the medical professionals on the basis of the cultural assumption about protective mothers who were neurotic about their children [6].

When the parents were told that something was wrong with their child but a complete diagnosis was delayed, many had to suffer a prolonged period of uncertainty and anxiety. While the label at the time of identification and diagnosis was seldom considered by the parents to be a life-long sentence, they often felt that, without the label, they could not move forward. This led the parents to shop around for medical advice in order to obtain a precise identification of their child's condition.

Such a diagnostic limbo between suspicion and confirmation can be extremely stressful. Nearly all of the parents in the study argued that it would have been better to be aware of their child's condition and receive diagnostic information as early as possible. The delay in informing them of the child's condition and providing diagnostic confirmation- driven by the doctors 'wait and see' attitudes- always increased rather than alleviated the parents anxiety and uncertainty. The parents generally looked for honest information and openness from the medical professionals, even

though it might not be possible to give a definitive identification of their child's condition until a later stage of development.

DISCLOSURE AND PROFESSIONALS

Whether it takes place at birth or later, the disclosure of their child's impairment is a key moment in the early lives of the parents of disabled children. Besides the parents understandable feeling of traumatic crisis or initial shock driven by the news of their child's impairment, it should also be recognized that the nature of the information or the message that the parents receive have repercussions for both the parents reactions to the child and their immediate course of action. It has been widely reported that there continue to be problems with the manner in which the information is conveyed and with the information itself. The accounts of the parents in this study confirm this, and further reveal that the medical professionals often act as a conduit for disabling values.

A substantial number of parents in the present study suffered traumatic experiences in the diagnostic setting owing to the medical professionals failure to value their child.

Like the parents of non-disabled children, the parents of a disabled child want him or her to be taken seriously and treated with respect. The medical professionals did not appreciate the child's unique personhood, instead condemning the child to a bleak future in terms of his or her development. In addition, the medical professionals were usually more negative about the disabled child's quality of life than the parents had expected who has a son with Down's syndrome, described the medical professional's reaction.

Some of the parents were traumatized by a medical professional's blaming-victim attitudes. In particular, psychoanalytically oriented physicians often tended to attribute the cause of a child's disability to parental failure, especially a lack of maternal care or affection. This placed an additional burden on the parents who were already stressed by the news of the child's disability and often exacerbated their feelings of guilt.

The medical professional's relationship with the parents in connection to the child's impairment was based on a medico-functional perspective. In the diagnostic setting, the medical professionals generally identify child with impairment in terms of having a physiological deficiency and functional limitation. The medico-functional perspective is not entirely wrong. The parents have to learn the nature of their child's impairment and its bodily effects in order to provide relevant treatment and develop competent care practices. However, it is also important to note that the professional's attitudes towards and way so dealing with disabled children often reflect and reproduce disabling ideologies. The medical professionals often served as agents re producing and imposing disabling ideologies in their interaction with the parents:

In the disclosure of the diagnosis, as the narrative above illustrates, the disabled child was often defined as incapable of being normal. It does not simply inform the child's impairment in terms of a divergence from the milestone of a normal child's development. The message conveyed to the parent was that the life of a disabled child was meaningless and hopeless. In this case, the medical professionals nourished fears and prejudices about disabled people in their interaction with parents.

THE INSUFFICIENT EXPLANATION

When the parents recalled their experiences in the immediate period following the diagnosis, they underlined the fact that their initial fear and frustration were not simply driven by the fact that their child had impairment. Although a diagnosis had been obtained, many of the parents were typically still left feeling uncertain about what the diagnosis meant. When the implications of the child's impairment were not precisely stated or were discussed in vague terms, some of the parents remained confused and anxious.

Many of the parents reported that they had not been given a sufficient explanation by the doctors in the first diagnostic setting indeed, a significant number of parents perceived their child's impairment as a rare illness or disease. Some of the parents learned about their child's impairment and its longer-term implications through alternative sources that they personally sought out, and sometimes by chance.

In contrast, the parents who met medical professionals who showed emotionally and practically supportive attitudes evaluated their assistance as most helpful resource for their early coping with their child's needs and preparation for their new life.

OBSTACLE IN ACCESSING INFORMATION

As widely acknowledged, the provision of information and advice is central to the parents managing and coping with the difficulties they encounter in the early years. The need for information about a valuable service is not instrumental in terms of the child's improvement but also important in developing the parents skills and knowledge.

Once an accurate diagnosis and prognosis have been established, parents generally want to know what can be done to help their child. They feel a strong need to do something to maintain their self-esteem as parents.

GIVING VOCATIONAL TRAINING

If sufficient information is unavailable, they are likely to feel that they are powerless and lack control. This, in itself, can lead to anxiety and a crisis of parenthood. It has been suggested that

around the time of the identification of their child's impairment, it is particularly important for the parents to receive information and resourceful, realistic advice for both themselves and their children.

Nearly all the parents in the present study reported that one of the most common experiences in the early years was difficulties in accessing information and knowledge about services, either directly related to their child's needs or to guide the parents.

Many of the parents had to depend upon their own personal, informal resources and make extraordinary efforts to obtain such crucial information. Unsurprisingly, this process often depleted their energy and led to stress.

THE REACTIONS OF RELATIVES

The attitudes of relatives are particularly significant in the very early stages. Unsurprisingly, the extended family members' emotional support and full acceptance of their disabled child in spite of his/her difference is a most powerful resource for the parents in the early period. Unfortunately, some of the parents had to experience a very stressful period in dealing with negative reactions towards their disabled child. According to the parents, to think that the presence of a disabled child is a sign of a 'family blemish' remains prevalent in lay people's perceptions.

A mother also talked about her sister reactions towards the child. Like others of the older generation, her sisters insisted that the disabled child should be sent to an institution, believing that he would bring her only continual pain and tragedy.

Another crucial feature of Indian culture was the mother-blaming attitudes that ascribe the birth of a disabled child to some defect in the mother's lineage. When the parents faced such negative reactions from other family members, they tried to resolve the situation but sometimes had to break off the relationship in order to protect both their child and themselves. In a culture that devalues disabled children it is too easy to adopt a negative view and dismiss children with impairments as worthless. The negative perception of the disabled child often leads to the deprivation of the disabled infant's right to receive relevant medical treatment in the name of the familial love of the sister.

IDENTIFY ROLES IN THE EARLY YEARS OF PARENTING

Despite variations in the children's impairment effects, nearly all of the parents had been overwhelmed by the anxiety that they had to change their child's condition with the hope of a cure or converting them into a 'normal' child as soon as possible. While seeking treatment which

had been conducted primarily within the regimes of modern (clinical) therapeutic practice, such as special stimulation programmes, many of the parents had also had recourse to traditional medicine (e.g. Oriental herbal medicine, acupuncture). In some cases, this hunt for a treatment led the parents to explore pre-modern forms of ritual or folk healing practices.

The fact that the parents' clung to therapy at any cost cannot be understood in isolation of the social context. Indeed, parental obsession about treatment was a reflection of the social uncertainty surrounding their child's future life.

In a sense, these responses were understandable in view of their previous internalization of negative values regarding impairment and the cultural pressure to be 'normal.' Despite variations in timing, the parents' obsession with finding a treatment that would 'cure' their child had gradually diminished and was replaced by a redefinition of their child and an acceptance of his limitation. The parents, as will be discussed in the next section, through their revaluation of the child's impairment, particularly their continual relationship building and inter-subjectivity, changed their early ideas about 'fixing' their child's impairment and came to see his or her limitations as a part of the child's unique personality.

CONCLUSION

This study has explored the parents' experiences of coming to terms with living with a disabled child. Generally, they previously had little or no contact with disabled people, and many of them had been socialised to hold negative perceptions of disabled people. Hence, this early period proved to be emotionally demanding for many parents. I also highlighted the fact that their feelings of disruption and experiences of anomie were shaped to a great extent by unsupportive social conditions. Many of the parents experienced negative reactions from disabling professionals and inadequate explanations of their child's condition. Most of the parents also experienced difficulties in finding out basic information about their child's needs and others discovered the key services by chance.

Usually, despite the variations in timing, the parents came to develop their own ways of living with the child and sought to create equilibrium in their lives. However, they persistently encountered practical problems in the daily management of their family lives.

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