

**ATTACHING LABELS THAT MAY NOT PEEL
OFF: EXPLORING THE EFFECTS OF
LABELLING ON CHILDREN AND
ADOLESCENTS WITH DISABILITY**

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Abstract

Labelling is a multifaceted concept and a number of theorists have contributed to the development of labelling theory through different perspectives. In this paper the works of key contributors to the theory of labelling will be reviewed with special reference to Howard Becker and Pierre Bourdieu. Labelling is not inherent to the individual but is a concept applied by society. Thus, in this paper, the key role of society in labelling will be discussed. Persons with disability consider labelling as an important issue as labels given in childhood often have a long term impact on their lives. The effects of labelling on persons with disability are presented in this paper through first-hand accounts by persons with disability themselves. Their voices are recounted through retrospective reflections on their experience of labelling in childhood. Additionally, parental accounts highlighting the effects of labelling on their children are outlined. These personal accounts will be discussed in the light of the theory of labelling.

Keywords: labelling, childhood, society.

Introduction

Labelling is a multifaceted concept and a number of theorists have contributed to the development of labelling theory through different perspectives. These theorists have focused on the idea of deviance and have highlighted the dominant discourse on labelling which is rooted in power relationships, social construction and social control. Whilst a medical diagnosis is a value-neutral process that determines a name for a condition based on signs and symptoms, a social label is not intrinsic to the individual but is applied from the outside and is very much value-judgement. A label often describes a person's behaviour, physical appearance, language usage or family connections. A label can be either positive or negative but it always categorises people. "Labelling is the term used for stereotyping and categorising someone as being in a particular group and then attaching a label to denote that group and its characteristics" (Brain & Mukherji, 2005, p.160).

Children and adolescents with disability regard labelling as a relevant issue due to the long term impact on their lives. Labels that are attached to one in childhood may determine an individual's perspective of his /her own life and their identity. Labelling may affect access to education and determines the individual's place in society. Furthermore, parents, siblings and other family members of children with disability may also be affected by the impact of labelling. In this paper the works of key contributors to the theory of labelling will be reviewed with special reference to the work of Howard Becker and Pierre Bourdieu. Labelling theory examines the behavioural consequences of society's reaction to deviance, which is socially constructed and is related to the effects of the label on the individual's identity. This will be followed by the voice of persons with disability who recounted retrospective reflections on their experience of labelling in childhood and by parental accounts highlighting the effects of labelling on their children. These personal accounts will be discussed in the light of the theory of labelling.

Key contributors to the theory of labelling

Labelling theory has its origins in the works of Émile Durkheim. In his book *Suicide* (1897), he argued that crime and deviance are socially constructed and that they are created by society as a means of social control. This led him to apply his beliefs about crime to the phenomenon of

labelling and then started developing the theory of labelling. Similarly Frank Tannenbaum influenced the development of labelling theory through his works *Crime and Community* (1938). He highlighted the social interaction involved in crime through his studies with delinquent youth where he concluded that those who were labelled were more likely to repeat delinquent activities. Eventually the label becomes part of the individual's identity and the more emphasis is laid on the label the more likely it is that the individual comes to identify with the label. In an article on the *Self-Fulfilling Prophecy*, Robert King Merton (1948) used this term to describe the individual's behaviour in reaction to society's expectations of the particular label that the individual is tagged with.

Edwin Lemert introduced the key concepts of labelling theory when he made a distinction between primary and secondary deviance (Lemert, 1951). Whilst primary deviance is related to behaviours where rules are not adhered to, secondary deviance refers to the negative label given by society to the individual which becomes part of the individual's identity. An important contribution to labelling theory was made by Erving Goffman. In *Asylums* (1961) he explored the reasons why individuals were labelled and the effects on the labelled individuals. He noted that it is the label that creates deviance because the individual behaves in line with the label. In *Stigma: Notes on the Management of Spoiled Identity* (1963) he described how society treated individuals whose identity was tarnished. These contributors to the concept of labelling led to the full development of labelling theory by Howard Becker.

Becker's theory of labelling

It was when Howard Becker published the book *Outsiders* (1963) that labelling theory was more clearly articulated. Becker (1963) uses the term 'outsiders' to refer to labelled individuals who deviate and do not conform to society's rules. Society's reaction to a particular behaviour makes it deviant or acceptable. Hence it is society that decides what behaviours are tolerated and what behaviours are not.

Deviance is not a quality of the act the person commits, but rather a consequence of the application by others of rules and sanctions to an "offender". The deviant is one to whom that label has successfully been applied; deviant behaviour is behaviour that people so label (Becker, 1963, p.9).

As Becker argues it is not the act itself that leads to labelling, but society's response to that act. Hence labels do not always explain deviant behaviour. Moreover Becker (1963) claims that there are individuals who are labelled as deviant by society but have not broken any rules. Contrastingly, he mentions individuals who break the law but are not convicted. Thus they deviate but are not negatively labelled. Hence he refers to the process of labelling as unreliable as it is not consistent. However, he argues that those who are labelled deviant are able to share a common experience: that of being labelled as outsiders.

Becker (1963) defines behaviours in relation to society's reactions. He refers to 'rule-breaking behaviour' as behaviour where rules are not observed but where society does not label, while he terms 'deviant' that behaviour that is labelled by society as it does not adhere culturally created norms. Becker (1964) stresses the nature of the relationship between those who commit a deviant act and society, which he describes as complementary. "Deviance is not a quality that lies in behaviour itself, but in the interaction between the person who commits an act and those who respond to it" (Becker, 1963, p.14). He remarks that there are institutional labellers who have the authority to attach labels to people, leaving an impact on their lives. Becker's theory of labelling presents society's reactions as the main factor that leads an individual to be labelled or not. Hence I will explore further society's key role in labelling through the work of Bourdieu.

Bourdieu's concepts: Society as a key factor in labelling

In view of society's key role in accepting or labelling a particular behaviour, Pierre Bourdieu's concepts of social capital, economic capital and cultural capital are relevant. These concepts highlight the issue of power as an essential factor in labelling. Bourdieu refers to individuals who aim at improving their reputation at the expense of others by applying negative labels (Jenkins, 1992). He adds that the more powerful the negative label is, the greater the damage and the stigma.

Bourdieu, as cited in Jenkins (1992) refers to social practices and habits in our daily lives. Practising these habits shapes us: a process which Bourdieu defines as habitus. Habitus involves the interaction of the individual with others and with the environment. Thus the concept of habitus unifies the individual and the social. One's physical and psychological states are

reflected in one's behaviour and are manifested in one's attitudes towards society. The effect of a number of factors such as one's family, level of education, socio-economic status, religion and ethnicity are determinants of habitus as this is socially acquired. Hence these factors may determine whether an individual is labelled or not. Our actions, behaviour and reasoning are partly a result of what we were subjected to in our life, a product of the factors that shaped us. Hence what we absorb is manifested in our behaviour. Thus individuals who are labelled make the label theirs and in turn act in relation to that label. In Bourdieu's (1977, p.72) words there is "internalisation of externality and the externalisation of internality" as these individuals unify with the label and with society's views which they then express in their actions and attitudes. Persons with disability call this 'internalised oppression'.

As Becker and Bourdieu argue, society labels individuals and labelled individuals more often than not endure the effects of labelling throughout their life. Persons with disability are labelled on the basis of their impairment and consequently they live the effects of labelling and moreover such labels determine the paths they take in their life. Scott-Hill (2004) argues that non-disabled persons perceive persons with impairment as not "normal" but as different primarily due to their impairment. This leads to prejudice, which becomes evident in the negative labels that are assigned to persons with disability.

Labelling persons with disability

Persons with disability are labelled because they are different. Similar to society's key role in labelling individuals, is society's role in disabling individuals with impairment. In view of society's effects on persons with disability the social model of disability, as originally defined by UPIAS (1976) and refined and standardised in the UNCRPD (2006), fits with this conceptual framework as society labels persons with disability. This model defines disability as socially constructed and recognises cultural attitudes, physical barriers and social barriers as limitations. Shakespeare and Watson (1997) identify prejudice and discrimination as main problems faced by persons with disability. Prejudice hinders persons with disability from becoming properly included within society (Oliver, 2004).

The social model encourages persons with disability to express themselves. The voice of persons with disability is a key factor in the social model of disability (Oliver, 2004). Therefore, personal accounts of persons with disability focusing on their childhood experiences of labelling will be discussed. There are numerous accounts widely available, and this proves that persons with disability are capable of expressing themselves as they are the only ones who can depict a truly accurate picture of their own lives. The issue of labelling children is of considerable importance as labels applied in childhood last a lifetime. Adults with disability and mothers of children with disability reported a strong correlation between labelling and negative connotations in life (Green, Davis, Karshmer, Marsh, & Straight, 2005). Hence, negatively labelled children carry the impact of labelling with them through various life stages and environments: at school, the workplace and in their local community. In the rest of this essay, accounts of persons with disability and of parents of children with disability recounting their experience of labelling will be presented and the theory of Becker and Bourdieu will be applied.

Accounts of persons with disability on their experience of labelling in childhood

Personal accounts of children with disability are scarce as most children do not have the opportunity to write their own story. However retrospective accounts of adults with disability who recount their personal experience of their childhood years are widely available. Individuals with disability recounting their story give prominence to their childhood as this left an impact on their life. I will be discussing personal accounts of persons with disability with a variety of impairments as the main focus is not on the impairment but on their experience of labelling in childhood. As Oliver (2004) argues, a number of persons with disability face difficulties into living with their impairment in a society where persons with disability are not considered as equal. Clearly the main problem is a society which at once labels persons with impairment and 'disables' through culturally and socially constructed physical barriers, (for example, lack of accessibility to public areas). These individuals have their own personal experience of labelling and its effect on their life. Although these individuals are all labelled, the impact of labelling on these individuals is unique. When describing the accounts of persons with disability, except for the citations to their work, I will be referring to them by their first name to highlight their personal experience as children with disability, rather than their role as writers.

There are individuals who prefer to have a 'name' for their symptoms and actions, and therefore they are relieved when a condition is properly diagnosed as they feel they can then understand themselves better and consequently may find a way of better coping with their problems. This is the case of Donna Williams, a woman who was diagnosed with autism at the age of twenty-six. After spending a childhood where she was often thought to be deaf, she was labelled psychotic and she began believing she was mad. In her book *Somebody Somewhere: Breaking Free from the World of Autism*, she narrates her experience with her inner self, and the discovery of the self that she found in her diagnosis (Williams, 1994). Autism was the way in which she could understand herself, others, and the world.

This book is a sequel to her first book *Nobody Nowhere*, where Donna describes how she survived abuse and trauma and lived within a dysfunctional lower class family until she left home and ended up homeless (Williams, 1992). In *Somebody Somewhere*, Donna manages to "pick up the pieces... to build a somewhere out of a nowhere and a somebody out of a nobody" (Williams, 1994, p. 6). Donna expresses satisfaction that she was diagnosed: "I have finally found I can be myself" (Williams, 1994, p. 188). Whilst she accepts this label and its definition, she refuses to let it define her: "Autism Is Not Me" (Williams, 1994, p. 238). Donna speaks of the people around her who were not aware of her diagnosis and thus could not understand her actions. Her high functioning abilities were making her difficulties invisible to others.

On the contrary Temple Grandin, a woman who was diagnosed with autism in childhood and lived all her life with that label, refers to her diagnosis as being a part of herself. Unlike Donna, she embraces her lifelong diagnosis as this guided her to become what she is today. In her first book *Emergence: Labeled Autistic* Temple mentions that once she was diagnosed with autism her parents were advised to place her in an institution (Grandin, 1986). However, her young mother was determined to educate her as she was an intelligent child who was unable to express herself, or control her behaviour. Temple mentions the numerous struggles that she had to face at school that led her to change school, from mainstream education to special education (Grandin, 1986).

Looking back at her life, in her book *Thinking in Pictures, Expanded Edition: My Life with Autism* Temple, speaks proudly of her diagnosis which contributed to her being moulded into

what she is today (Grandin, 1986). She used the strengths that emerged out of the diagnosis to build her life and her career. She strongly points out that she would not choose not to be autistic - if she had the opportunity, as she found her personal abilities in this diagnosis (Grandin, 2006).

Whereas Temple was diagnosed and labelled as fit to be placed in an institution at a young age, Sally French's experience was different. She was not labelled with visual impairment as a young girl but was encouraged to act in a normal way. Sally wanted professionals to acknowledge her difficulties but was taught to deny her difficulties so as to be able to carry on in life (French, 2004). "By denying the reality of my impairment and disability I protected myself from the anxiety, disapproval, frustration and disappointment of the adults in my life" (French, 2004, p.82). She recounts episodes where relatives, professionals and educators were not believing and acknowledging her concerns as she was a "mere child" (French, 2004, p.81).

Sally was constantly encouraged by relatives to act in a 'normal' way and, in order not to ruin their expectations, she decided to keep to herself her doubts and anxieties. Sally refers to the constant insistence from adults that she should participate in regular daily tasks and the adults' denial to her difficulties "which was often motivated by a benign attempt to integrate me in a world which they perceived as fixed" (French, 2004, p.82). Sally could read the adult's clear message "you are not acceptable as you are" (French, 2004, p.83). Her family wanted to label her 'normal' however she preferred that they accept and acknowledge her difficulties. Sally believes in the affirmative model, in accepting that she is different, and in considering impairment as part of human diversity (Swain & French, 2008).

Whilst the doctors and her family were denying young Sally's impairment, Ross Flood was labelled by doctors as good for nothing and a "vegetable" for life when he was diagnosed with cerebral palsy in infancy. However, his mother "through her veil of tears ... peered into her baby's smiling face and saw the spark of intelligence" (Flood, 2004, p. 3). From that instance she did what she could to help Ross improve so that he would not fit that label. Ross continued to improve, thanks to the support of his family and his own efforts. Ross believes that he challenged the label that the medical professionals gave him and wryly observes that "in my humble opinion, I ain't done too badly for a cauliflower" (Flood, 2004, p. 6). This label was applied to

Ross as a frail baby: it was judgmental and premature as Ross was still too young to show his true abilities.

The diagnosis of cerebral palsy and the labels associated with it did not give him the opportunity to attend mainstream from an early age and he had to attend a special school. However aged twelve, he started attending mainstream and later on graduated from university. He became a freelance writer, obtained his driving license and became a paralympian. The achievements that Ross accomplished in his life challenged the label of being “of limited use” (Flood, 2004, p. 6). Ross speaks of his daily challenges and acknowledges that everyone experiences them but bravely he concludes that “the optimist within me hopes that we can all shake off negative labels and pursue our dreams unhindered” (Flood, 2004, p. 6).

Similarly to Ross’s experience of labelling is Frejya’s and her parents’ experience. Frejya Haraldsdóttir, a woman with a physical disability who was born with osteogenesis imperfecta, speaks of her childhood where the doctors diagnosed and labelled her with a severe disability. Great emphasis was placed on her physical impairment. The doctors advised her parents to bring her up as a child with a physical impairment. However when her parents did not conform, the medical professionals thought that they “were out of their minds raising me as a child - not as a physical impairment” (Haraldsdóttir, 2013, p. 14). Hence Frejya’s parents were labelled because they were treating Frejya as a non-disabled child. In contrast with Sally’s family, Frejya’s parents were not denying the impairment but were looking beyond the negative labelling applied to her diagnosis. As a child, Frejya did not consider herself to be disabled; “I didn’t realise about my impairment, or at least found it as normal as having glasses, blond hair or brown eyes. I even thought that breaking a bone a few times a month was what everyone did” (Haraldsdóttir, 2013, p. 14).

When starting school she was made aware of her disability. When the children were staring at her, passing remarks on her appearance and were labelling her, she realised that she was different from the others. Frejya recounts the negative effects of labelling by the professionals “the problems and difficulties always seemed to outweigh the positive factors, and there never seemed to be anything good to say about my existence” (Haraldsdóttir, 2013, p. 15). Frejya recounts her struggles during rehabilitation. She describes the visits to the physiotherapy where

she used to hurt and beg them to stop. Also during her visits to the psychologist, she was asked “childish questions”, and when she refused to answer she was labelled as having selective mutism (Haraldsdóttir, 2013, p. 15).

Another boy who defeated the odds and proved the doctors wrong, similarly to Temple, Freyja and Ross, was Jason Kingsley who has Down Syndrome. Jason was labelled by the doctors as an individual who would not be able to learn, who would not be able to recognise his parents and would only be suitable to live within an institution (Kingsley, 2004). However Jason challenged those labels and in contrast he lives a full adult life. He lists numerous activities that he succeeded in achieving despite the labelling he was given. Jason appeared in “The Fall Guy” as an actor and wrote a book *Count Us In: Growing Up with Down Syndrome*. He plays the violin and the piano, sings and produces oil paintings.

Socially, Jason has many friends and lives independently with two other roommates with little supervision. At home he does the cooking, shopping and cleaning, and works at the public library. Jason encourages the medical professionals to be more cautious and less judgmental, because if he had been placed in an institution as recommended he would not have realized his potential in life (Kingsley, 2004).

From these personal accounts, I will now look at the experiences of the immediate family members, namely the parents’ experiences. This is because the labelling of the children has an impact on the parents themselves, and possibly may affect the upbringing of their children. Hence, I will be discussing the effects of labelling on the parents and their reactions to labelling as parents of children with disability.

Parents’ accounts of their children’s labelling

Parents’ accounts of labelling are rich experiences since they are the first to witness negative labelling about their children. Parents are often the ones who know their children best and who can provide the right degree of assistance, so that they can help to achieve their full potential and also challenge negative labelling. Parents are affected by labelling applied to their children; Hayden (1993) states that when a family member has a disability the whole family is affected. Similarly, Seligman and Darling (2009) present the family system theory which specifies that if a

family member is experiencing difficulties, the other family members are affected. Some parents are relieved that there is a 'name' for the difficulties their child is encountering and argue that the label will provide them access for services and early intervention. Other parents think that a label will stigmatise and exclude their child and their family and they argue that the damage that labels create out-weigh the benefit attained from the specialised services (Duchan & Kovarsky, 2005). In the following accounts, the experiences of parents whose children were labelled, and the effects of that labelling on the parents will be discussed.

In his paternal account Michael Blastland writes about his only son, *Joe the only boy in the world*. Michael is the father of ten-year old Joe who is labelled autistic. Michael explains that the best way to define his son is exactly through the title of the book as Joe is the only boy in the world since Joe is not connected to others and he lives in a world of his own (Blastland, 2006). Michael describes his son through numerous labels which include the positive and negative characteristics of Joe's behaviour. He refers to Joe as being "vulnerable, charming and tyrannical" (Blastland, 2006, p.1). He also refers to him as having "mind-blindness" as he cannot understand emotions and cannot understand what others are feeling (Blastland, 2006, pp.73-74).

Michael speaks of the labels that he himself applied to his son which refer mostly to his behaviour. In his writing his love for Joe is coupled with the pain and frustration that Michael experiences due to Joe's difficulties in social skills. Michael admits that the label of autism that Joe has been given as a diagnosis is somewhat inadequate. However, as a father he has no option but to accept this label as he acknowledges that it is the way through which his son can fit in society.

Similarly to Frejya's parents' experience of labelling is that of a young mother of a child who was diagnosed with deafness. Tressa Bowers recounts her story when her baby Alandra was given the diagnosis of deafness, but was also additionally given a label of ignorance and ineptitude. In her book *Alandra's Lilacs: The Story of a Mother and Her Deaf Daughter*, Tressa writes about when she was told by the doctor that her daughter was deaf. The doctor added that the "baby most likely will never be able to talk, and probably will not get much education because of the limitations of communication" (Bowers, 1999, p.17). The doctor warned her that this child would stand out in public "she will probably make a lot of 'different' sounds. Someday

she will probably make sounds in public that will embarrass you” (Bowers, 1999, p.17). On listening to these comments, the mother decided not to share with her daughter what the doctor had told her. The mother expresses how shocked she was with the doctor’s insensitive attitude and his unkind thoughts about her baby.

At that time, she was unprepared to defend her baby as she was an inexperienced young mother who felt powerless at the doctor’s office. However she decided to find a way to prove the doctor wrong. She “just needed to find the way to unlock all that intelligence” (Bowers, 1999, p.18). Tressa recounts her experience when she was very disappointed with people’s attitudes towards persons with disability and she says “I consoled myself with the knowledge that my daughter would never have to hear that kind of ignorance from people” (Bowers, 1999, p.26). This metaphor reflects the pain that parents endure when their children are labelled and judged by others. When Alandra started attending school, she was encouraged to learn how to verbalise since sign language was not allowed. Later on Alandra moved to a residential school where she learned sign language and was able to communicate with other deaf persons.

In my opinion children who are medically diagnosed with a condition should not be additionally labelled but offered the opportunity to develop their full potential through available services. Tressa’s determination and perseverance led Alandra to be able to communicate with others in her preferred style, by using sign language.

A life story which is full of instances of anxiety and hope is of Nia Wyn that she shares in her book *Blue Sky July: A Mother's Story of Hope and Healing*. Like Frejya and Alandra’s parental experiences, Nia writes about the way the doctors give her and her husband the diagnosis of her son’s condition. Wyn (2008) recounts the birth of her first son Joe. She starts by describing the joy that she felt when she was expecting her baby and how this baby brought happiness to the family when he was born.

A few days later the doctors tell Nia and her husband that Joe had severe cerebral palsy. Nia describes this as a tough moment in her life and for her the world had ended and that there was no hope. The doctors inform them that Joe would be blind, unable to speak, unable to move and unable to recognise his mother and father. Devastated by this news the parents refused to accept the prognosis and they were constantly attending visits to specialists, therapists and healers

(Wyn, 2008). The courage and determination of Nia and her husband are the main characteristics of this account, who despite the labelling and prognosis given by doctors, do their best to find a ray of hope and Nia dedicates her life for Joe.

Similarly Martha Beck's experience of her second pregnancy demonstrates the pain of labelling but also her sheer determination in her book *Expecting Adam*. Martha and her husband, who are both scholars, discovered half way through the pregnancy that their baby Adam has Down Syndrome (Beck, 1999). Martha gave birth to Adam despite being warned by their colleagues that their unborn baby would ruin their careers. This baby was already labelled even before it was born. Martha recounts a shopping experience where her son was positively labelled by an old man. This man noticed that Adam paid equal attention to smelling both the roses and the bushes in the garden section of the shop, something which other people rarely do. The man looked at Martha and told her "things aren't always what they seem, are they?" (Beck, 1999, p. 141). This man did not look at his facial features and his disability but admired his actions and looked beyond the impairment.

Martha appreciated these comments as she was mostly used to receiving negative comments or strange looks in her daily encounters with people. Martha speaks of her disappointments when people use prejudice or hostility which she describes as something that "can burn like acid" (Beck, 1999, p. 141). Despite these daily hurts Martha feels that the joy that Adam brought into her life is greater than all the pain of labelling. Martha speaks of school where she encounters prejudices as Adam is negatively labelled at the beginning of every academic year just because he has Down Syndrome. Before the school gets to know Adam, he would have been already labelled.

Despite the negative labelling, courage and hope, shine through every account presented. These reflections are written by people who genuinely want to share their experience of struggles and joy. In today's world, parents and persons with disability log their experiences on the web. Unlike the previous reflections, which are written retrospectively by a parent of a child with disability, these web logs are the daily experiences that parents share together with the aim to support each other.

In an interview on healthtalk.org Lynne, a mother of a child with autism, comments about having a diagnosis for her son. Lynne preferred to have a name for her child's difficulties. Like Donna and Sally she argues that having a diagnosis is the first step to receiving the necessary services. Lynne does not consider autism as a label but as a signpost. By being diagnosed her son became eligible for the right support that he needs. She was in favour of getting a diagnosis as this facilitated in addressing the related difficulties that children with autism encounter (Lynne, 2015).

In her web log in Parenting magazine, Teri Cettina reports the experience of the parents of a four year-old boy. The parents were approached by their son's pre-school teacher who was noting that something was not quite right with the child. They were worrying that being diagnosed at such a young age would stigmatise him. However, when their son turned eight they felt just the opposite. Similar to Lynne, they were grateful that he had a diagnosis that explains his difficulties and they felt that it was time to come to terms with their son having a diagnosis. They were ready to share that diagnosis with the school so that he gets the necessary educational services (Cettina, 2012).

The accounts presented above offer us a first-hand experience of the daily encounters with labelling, which come about because of the negative connotations attached to having an impairment and society's equally negative reactions to such a situation. Landsman (2008, p.66) mentions that parents of children who are labelled find themselves in an awkward position as "when doctors label a child with a disability, they are in many instances asking women to apply to one body two seemingly incompatible concepts: their loved child and a diagnosis culturally associated with less than full personhood". The latter concept fits in directly with the theory of labelling, which I will be discussing in relationship to the accounts presented.

Discussion of personal accounts in view of the theory of labelling

In the personal accounts of persons with disability and their parents presented above, different perspectives on labelling emerged. Some people regard value-neutral medical diagnosis as positive as this helps them to understand themselves better and can be used as a tool to access services. Other people argue that having a diagnosis may lead the individual to being negatively labelled and stigmatised. This negative value judgement is usually imposed as a result of

established social and cultural norms. A recurrent theme that emerges from these accounts is the social attitudes and the negative labelling that non-disabled individuals use towards persons with disability. Labelling is usually applied by society in general, but medical and educational professionals may also label children with disability. This happens when the diagnosis is accompanied by subjective, negative value-judgements, not scientific objectivity. Becker (1963) refers to those individuals who, although they have not broken any rules, are labelled abnormal by society. These individuals who have impairment are labelled just because they have a medical diagnosis, a phenomenon which Thompson refers to as disablism. “Disablism refers to the combination of social forces, cultural values and personal prejudices which marginalizes disabled people, portrays them in a negative light and thus oppresses them” (Thompson, 2012, p. 124).

In a number of the accounts presented the doctor who gives the diagnosis plays a key role in also labelling children, what Becker (1963) refers to as ‘institutional labellers’. This was highlighted in Temple, Ross, Freyja and Jason’s personal accounts as well as in the maternal accounts of Alandra and Joe. Landsman (2008, p.64) argues that “physician labeling of a child with a particular disability challenges the mother’s ability to define her own child”. Similarly McLaughlin et al., (2008, p.53) suggest that disability in childhood “contributes to the disintegration of expected narratives” as a disabled child is “read as out of place with the ‘normal’, and the assumption of an ‘ordinary’ childhood is exchanged with ‘regulative stories of childhood identity and potential that are assumed to be less than those of other ‘normal’ children”. Hence mothers need to accept the label, look beyond the impairment and believe in their child’s potential. This is a reality which mothers may take time to adjust to.

A common issue reported by parents in their reflections was feeling powerless in the doctor’s office. This clearly indicates the power relationship which exists within a clinical setting where the doctor is a figure of authority. Bourdieu (1986) refers to this possession of power as being the effect of cultural capital in an “institutionalized” state which is the cultural capital held by an individual that is recognised by the institution. Hence, the doctor is empowered through his/her academic qualifications that are recognised within the social institution. Moreover in the case of Frejya, even the parents were labelled by the doctors, who dictated the way that they (the parents) should bring up their child. Thomas and Pierson (2010) highlight the power relationship

between the labelled individual and the person who is attaching a label onto that individual. When defining labelling, they identify the power imbalance as a key factor. Labelling is thus “the process whereby people holding positions of power or influences sometimes attribute generalised negative characteristics to particular categories of individuals, tending to produce or amplify those behavioural characteristics attributed” (Thomas & Pierson, 2010, p.286). Furthermore, people visit the doctor as the doctor is considered to be a trustworthy person, an expert in the medical field and a person who is able to offer good advice.

However, it is interesting to note that in most of the parental accounts presented, despite receiving expert advice from the doctor, the parents still decided to follow their own instincts. This is similar to the findings reported by Landsman (2008) where she found that mothers of disabled children reject negative labels that lead to stereotypes. Gallagher (1976) observes that labelling may be used to reduce opportunities for children of minority groups so that they remain in the lower social classes. Similarly, Bourdieu (1986) refers to the forms of social and cultural capital that the person in authority, in this case the doctor, uses in the process of labelling. The high level of social and cultural capital that the doctor holds due to his/her knowledge and education empower the doctor to diagnose and label. Individuals regard the doctor as a figure of authority. This is reflected in the style of speech used and level of cultural capital that the doctor possesses. These characteristics lead individuals to request the doctor’s advice, although as previously discussed they may challenge this advice through their subsequent decisions and actions.

Martha speaks of people in the streets who stare at Adam, or at times do not acknowledge his presence, as they pretend only to see her other two pretty girls. She describes these attitudes as very painful. She mentions the negative attitudes at school where Adam is labelled at the beginning of every academic year even before teachers get to know him. Similarly, Jason’s experience of labelling because of his diagnosis describes the reality expressed by Gallagher (1976, p.3) who maintains that “labeling is always an incomplete statement about an individual child, ignoring some facets of importance”. Gallagher argues that labelling can be beneficial if it leads the individual to receiving the right treatment and if it increases public awareness on a specific condition. Thus, I would argue that diagnosis can be beneficial, but labelling never is.

These accounts also relate to what Becker (1963) identifies as people sharing a common experience: that of being labelled as ‘outsiders’. Parents of children with disability are aware of society’s perceptions towards individuals that society itself labels. These negative attitudes applied by society on labelled individuals are also explained by Bourdieu (1977) through the concept of habitus. These socially acquired cultural practices categorise children with disability and in turn parents of labelled children use their time and energy to advocate for their children. The role of society in labelling as developed in Becker’s (1963) theory of labelling is a factor which is evident in the accounts presented. In Freyja’s account she describes how she used to consider herself ‘normal’ until she was made aware of her differences when she started attending school. Freyja was given the label once she came out of her family’s protective environment and started integrating in society. Albrecht and Levy (1981, p. 14) claim that “disability definitions are socially constructed and what becomes a disability is determined by the social meanings individuals attach to particular physical and mental impairments”. Freyja absorbed the label imposed on her by others and made it hers. In her case, the process of habitus can be observed in the interaction with other students at school - that led her to being labelled.

Bourdieu’s concepts of social and economic capital, including the family background and social status, play a role in the process of labelling. For instance, Temple Grandin, was taken to a neurologist at a young age and her family had the means to send her to a small special school. Thus, the family’s social and economic capital helped her to be diagnosed early and to receive the necessary interventions rather than being labelled without having a formal diagnosis. On the other hand, Donna Williams did not have a formal diagnosis until adulthood. In childhood Donna was labelled with various labels, which did not define her main difficulties, and as a result she did not receive the necessary interventions. Another factor which might have contributed to Donna being labelled and not formally diagnosed was that as a child she lived within a dysfunctional low class family. Moreover children who are born in families who have the means to pay for therapies, as in the case of Nia, will be able to move away from the labels and take the necessary actions so that they will change the prognosis that they received from the doctors.

The way forward

As it was clearly seen in the accounts presented obtaining a medical diagnosis can be a potential for good outcomes. This is especially so, if the positive is emphasised and if it is used as a signpost as it opens the door for the necessary services. On the other hand, applying a label is not beneficial to the individual and to his/her family, in a society where social and cultural norms tend to view the person with an impairment in a negative light.

As Gallagher (1976) argued it is improbable that we will ever remove labelling completely. As can be seen from the personal accounts presented above, Gallagher's statement is still valid today and labelling is still being applied on disabled people in our society even by many medical and educational professionals. Whilst recognising that a certain amount of labelling may be inevitable, it is important that the process of labelling is articulated and critiqued so that we are aware of the pitfalls as well as the advantages of labelling. In Malta parents are becoming aware of their children's difficulties earlier. Easier internet access and better child-care services and pre-school education may have contributed to earlier identification of the difficulties which lead to receiving early intervention. In 2012, over 12,000 children were spending an average of 6 hours a day at day-care centres and over 9,000 children were attending pre-school education (National Statistics Office, 2014). Unfortunately, at times the diagnosis is accompanied by categorisation and labelling.

Hence, whilst acknowledging that labelling is still being applied to individuals, we can diminish the negative effects of labelling by using labels as a signpost. Therefore labelling should be regarded as a tool to help the child rather than a name to define who the child is. An optimistic approach focusing on the positive characteristics of the child and encouraging further development of these positive aspects should be used to overcome any other difficulties being presented. Labels should lead to an increase in awareness and understanding rather than to categorisation and highlighting of weaknesses. A strength-based focus should be adopted aiming at developing abilities rather than focusing on the weaknesses and the needs.

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