Complicating a Rudimentary List of Characteristics: Communicating Disability with Down Syndrome Dolls

Introduction

When Joanne Faulkner describes public criticism of dolls designed to look like they have Down Syndrome, she draws attention to the need for an examination of the way discourses of disability are communicated. She calls, in particular, for an interrogation of people’s reactions to the disruption of the idealised human form that most dolls adopt. The case of Down Syndrome dolls is fascinating, yet critical discussion of these dolls from a disability or cultural studies perspective is conspicuously lacking. To address this lack, this paper draws upon theories of the cultural construction of disability, beauty, and normalcy (Garland-Thompson, Kumari Campbell, Wendell), to explore the way ideas about disability are communicated and circulated.

The dominant discourse of disability is medical, where people are diagnosed or identified as disabled if they meet certain criteria, or lists of physical impairments. These lists have a tendency to subsume the disparate qualities of disability (Garland-Thompson) and remove people considered disabled from the social and cultural world in which they live (Snyder and Mitchell 377). While Down Syndrome dolls, produced by Downi Creations and Helga’s European Speciality Toys (HEST) in the US and Europe respectively, are reflective of such lists, they also perform the cultural function of increasing the visibility of disability in society. In addition, the companies distributing these dolls state that they are striving for greater inclusion of people with Down Syndrome...
However, the effect of the dominance of medicalised discourses of disability can be seen in the public reaction to these dolls. This paper seeks also to bring an interrogation of disability into dialogue with a critical analysis of the discursive function of lists.

The paper begins with a consideration of lists as they have been used to define disability and organise knowledge within medicine, and the impact this has had on the position of disability within society. In order to differentiate itself from medical discourses, the emerging social model also relied on lists during the 1980s and 1990s. However, these lists also decontextualised disability by ignoring certain factors for political advantage. The social model, like medicine, tended to ignore the diversity of humanity it was apparently arguing for (Snyder and Mitchell 377). The focus then shifts to the image of Down Syndrome dolls and the ensuing negative interpretation of them focusing, in particular, on reader comments following a *Mail Online* (Fisher) article. Although the dolls were debated across the blogosphere on a number of disability, special needs parenting, and Down Syndrome specific blogs, people commenting on *The Mail Online*—a UK based conservative tabloid newspaper—offer useful insights into communication and meaning making around disability. People establish meanings about disability through communication (Hedlund 766). While cultural responses to disability are influenced by a number of paradigms of interpretation such as superstition, religion, and fear, this paper is concerned with the rejection of bodies that do not ascribe to cultural standards of beauty and seeks to explore this paradigm alongside and within the use of lists by the various models of disability.

This paper interrogates the use of lists in the way meanings about disability are communicated through the medical diagnostic list, the Down Syndrome dolls, and reactions to them. Each list reduces the disparate qualities and experiences of disability, yet as a cultural artefact, these dolls go some way towards recognising the social and cultural world that medicalised discourses of disability ignore. Drawing on the use of lists within different frameworks of disability, this paper contrasts the individual, or medical, model of disability (that being disabled is a personal problem) with the social model (that exclusion due to disability is social oppression). Secondly, the paper compares the characteristics of Down Syndrome dolls with actual characteristics of Down Syndrome to conclude that these features aim to be a celebrated, not stigmatised, aspect of the doll. By reasserting alternative notions of the body, the dolls point towards a more diverse society where disability can be understood in relation to social oppression. However, these aims of celebration have not automatically translated to a more diverse understanding. This paper aims to complicate perceptions of disability beyond a rudimentary list of characteristics through a consideration of the negative public response to these dolls. These responses are an example of the cultural subjugation of disability.

**Lists and the Creation of Normative Cultural Values**

For Robert Belknap, lists are the dominant way of "organizing data
relevant to human functioning” (8). While lists are used in a number of ways and for a variety of purposes, Belknap divides lists into two categories—the practical and the literary. Practical lists store meanings, while literary lists create them (89). Belknap’s recognition of the importance of meaning making is particularly relevant to a cultural interrogation of disability. As Mitchell and Snyder comment:

Disability’s representational “fate” is not so much dependant upon a tradition of negative portrayals as it is tethered to inciting the act of meaning-making itself. (6)

Disability unites disparate groups of people whose only commonality is that they are considered “abnormal” (Garland-Thompson). Ableism—the beliefs, processes, and practices which produce the ideal body—is a cultural project in which normative values are created in an attempt to neutralise the fact that all bodies are out of control (Kumari Campbell). Medical models use diagnostic lists and criteria to remove bodies from their social and cultural context and enforce an unequal power dynamic (Snyder and Mitchell 377).

By comparison, the social model of disability shifts the emphasis to situate disability in social and cultural practices (Goggin and Newell 36). Lists have also been integral to the formation of the social model of disability as theorists established binary oppositions between medical and social understandings of disability (Oliver 22). While these lists have no “essential meaning,” through discourse they shape human experience (Liggett). Lists bring disparate items together to structure meaning and organisation. According to Hedlund, insights into the experience of disability—which is neither wholly medical nor wholly social—can be found in the language we use to communicate ideas about disability (766). For example, while the recent production of children’s dolls designed to reflect a list of the physical features of Down Syndrome (Table 2) may have no inherent meaning, negative public reception reveals recognisable modes of understanding disability.

Down Syndrome dolls are in stark contrast to dolls popularly available which assume a normative representation. For Blair and Shalmon (15), popular children’s toys communicate cultural standards of beauty. Naomi Wolf describes beauty as a socially constructed normative value used to disempower women in particular. The idealisation of the human form is an aspect of children’s toys that has been criticised for perpetuating a narrow conception of beauty (Levy 189). Disability is likewise subject to social construction and is part of a collective social reality beyond diagnostic lists (Hedlund 766).

**Organising Knowledge: The Social vs. Medical Model of Disability**

Disability has long been moored in medical cultures and institutions which emphasise a sterile ideal of the body based on a
diagnosis of biological difference as deviance. For example, in 1866, John Langdon Down sought to provide a diagnostic classification system for people with, what would later come to be called (after him), Down Syndrome. He focused on physical features:

The hair is [...] of a brownish colour, straight and scanty. The face is flat and broad, and destitute of prominence. The cheeks are roundish, and extended laterally. The eyes are obliquely placed, and the internal canthi more than normally distant from one another. The palpebral fissure is very narrow. The forehead is wrinkled transversely from the constant assistance which the levatores palpebrarum derive from the occipito-frontalis muscle in the opening of the eyes. The lips are large and thick with transverse fissures. The tongue is long, thick, and is much roughened. The nose is small. The skin has a slight dirty yellowish tinge, and is deficient in elasticity, giving the appearance of being too large for the body. (Down)

These features form what Belknap would describe as a “pragmatic” list (12). For Belknap, scientific classification, such as the description Langdon Down offers above, introduces precision and validation to the use of lists (167). The overt principle linking these disparate characteristics together is the normative body from which these features deviate. Medicalised discourses, such as Down’s list, have been linked with the institutionalisation of people with this condition and their exclusion from the broader community (Hickey-Moody 23).

Such emphasis on criteria to proffer diagnosis removes and decontextualises bodies from the world in which they live (Snyder and Mitchell 370). This world may in fact be the disabling factor, rather than the person’s body. The social model emerged in direct opposition to medicalised definitions of disability as a number of activists with disabilities in the United Kingdom formed The Union of Physically Impaired Against Segregation (UPIAS) and concluded that people with disability are disabled not by their bodies but by a world structured to exclude their bodies (Finkelstein 13). By separating disability (socially created) from impairment (the body), disability is understood as society’s unwillingness to accommodate the needs of people with impairments.

The British academic and disability activist Michael Oliver was central to the establishment of the social model of disability. Following the activities of the UPIAS, Oliver (re)defined disability as a “form of social oppression,” and created two lists (reproduced below) to distinguish between the social and individual (or medical) models of disability. By utilising the list form in this way, Oliver both provided a repository of information regarding the social model of disability and contextualised it in direct opposition to what he describes as the individual model. These lists present the social model as a coherent discipline, in an easy to understand format. As Belknap argues, the suggestion of order is a major tool of the list (98). Oliver’s list suggests a clear order to the emerging social model of disability—disability is a problem with society, not an individual. However, this list was problematic because it appeared to disregard impairment within the experience of
disability. As the “impersonal became political” (Snyder and Mitchell 377), impairment became the unacknowledged ambiguity in the binary opposition the social model was attempting to create (Shakespeare 35). Nevertheless, Oliver’s lists successfully enforced a desired order to the social model of disability.

<table>
<thead>
<tr>
<th>The individual model</th>
<th>The social model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal tragedy theory</td>
<td>Social oppression theory</td>
</tr>
<tr>
<td>Personal problem</td>
<td>Social problem</td>
</tr>
<tr>
<td>Individual treatment</td>
<td>Social action</td>
</tr>
<tr>
<td>Medicalisation</td>
<td>Self help</td>
</tr>
<tr>
<td>Professional dominance</td>
<td>Individual and collective responsibility</td>
</tr>
<tr>
<td>Expertise</td>
<td>Experience</td>
</tr>
<tr>
<td>Adjustment</td>
<td>Affirmation</td>
</tr>
<tr>
<td>Individual identity</td>
<td>Collective identity</td>
</tr>
<tr>
<td>Prejudice</td>
<td>Discrimination</td>
</tr>
<tr>
<td>Attitudes</td>
<td>Behaviour</td>
</tr>
<tr>
<td>Care</td>
<td>Rights</td>
</tr>
<tr>
<td>Control</td>
<td>Choice</td>
</tr>
<tr>
<td>Policy</td>
<td>Politics</td>
</tr>
<tr>
<td>Individual adaptation</td>
<td>Social change</td>
</tr>
</tbody>
</table>

Table 1 The Individual v Social Model of Disability (Oliver)

The social model then went through a period of “lists,” especially when discussing media and culture. Positive versus negative portrayals of disability were identified and scholars listed strategies for the appropriate representation of disability (Barnes, Barnes Mercer and Shakespeare). The representations of impairment or the physical markers of disability were discouraged as the discipline concerned itself with establishing disability as a
political struggle against a disabling social world.

Oliver's lists arrange certain "facts" about disability. Disability is framed as a social phenomenon where certain aspects are emphasised and others left out. While Oliver explains that these lists were intended to represent extreme ends of a continuum to illustrate the distinction between disability and impairment (33), these are not mutually exclusive categories (Shakespeare 35). Disability is not simply a list of physical features, nor is it a clear distinction between individual/medical and social models. By utilising lists, the social model reacts to and attempts to move beyond the particular ordering provided by the medical model, but remains tied to a system of classification that imposes order on human functioning. Critical analysis of the representation of disability must re-engage the body by moving beyond binaries and pragmatic lists. While lists organise data central to human functioning, systems of meaning shape the organisation of human experience. Down Syndrome dolls, explored in the next section, complicate the distinction between the medical and social models.

**Down Syndrome Dolls**

These dolls are based on composites of a number of children with Down Syndrome (Hareyan). Helga Parks, CEO of HEST, describes the dolls as a realistic representation of nine physical features of Down Syndrome. Likewise, Donna Moore of Downi Creations employed a designer to oversee the production of the dolls which boast 13 features of Down Syndrome (Velasquez). These features are listed in the table below.

<table>
<thead>
<tr>
<th>HEST Down Syndrome Dolls</th>
<th>Downi Creations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small ears set low on head with a fold at the top</td>
<td>Small ears with a fold at the top</td>
</tr>
<tr>
<td></td>
<td>Ears set low on the head</td>
</tr>
<tr>
<td>Small mouth</td>
<td>Small mouth</td>
</tr>
<tr>
<td>Protruding tongue</td>
<td>Slightly protruding tongue</td>
</tr>
<tr>
<td>Shortened fingers</td>
<td>Shortened fingers</td>
</tr>
<tr>
<td></td>
<td>Pinkie finger curves inward</td>
</tr>
<tr>
<td>Almond shaped eyes</td>
<td>Almond-shaped eyes</td>
</tr>
<tr>
<td>Horizontal crease in palm of hand</td>
<td>Horizontal crease in palm of hand</td>
</tr>
<tr>
<td>Gap between first and second toe</td>
<td>A gap between the first and second toes</td>
</tr>
</tbody>
</table>
Shortened toes

<table>
<thead>
<tr>
<th>Flattened back of head</th>
<th>Flattened back of head</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flattened bridge across nose</td>
<td>Flattened bridge across nose</td>
</tr>
<tr>
<td>Optional: An incision in the chest to indicate open-heart surgery</td>
<td></td>
</tr>
</tbody>
</table>

Table 2: Down Syndrome Dolls (Parks, Velasquez)

Achieving the physical features of Down Syndrome is significant because Parks and Moore wanted children with the condition to recognise themselves:

> When a child with Down’s syndrome [sic.] picks up a regular doll, he doesn’t see himself, he sees the world’s perception of “perfect.” Our society is so focused on bodily perfection. (Cresswell)

Despite these motivations, studies show that children with Down Syndrome prefer to play with “typical dolls” that do not reflect the physical characteristics of Down Syndrome (Cafferty 49). According to Cafferty, it is possible that children prefer typical dolls because they are “more attractive” (49). Similar studies of diverse groups of children have shown that children prefer to play with dolls they perceive as fitting into social concepts of beauty (Abbasi). Deeply embedded cultural notions of beauty—which exclude disability (see Morris)—are communicated from childhood (Blair & Shalmon 15). Notions of bodily perfection dominate children’s toys and Western culture in general as Cresswell comments above.

Many bodies, not just those deemed “disabled,” do not conform to these cultural standards. Cultural ideals of beauty and an idealisation of the human body according to increasingly narrow parameters are becoming conflated with conceptions of normality (Wendell 86). Recognition of disability as subject to cultural rejection allows us to see “beauty and normalcy [as] a series of practices and positions [taken] in order to avoid the stigmatization of ugliness and abnormality” (Garland-Thompson). The exaggerated features of the doll problematise the idea that people with disability should strive to appear as nondisabled as possible and in turn highlights that some people, such as those with Down Syndrome, cannot “pass” as nondisabled and must therefore navigate a life and community that is not welcoming.

While lists of the features of Down Syndrome store associated medicalised meanings, the discussion of the dolls online (the medium through which they are sold) provides insight into the cultural interpretation of disability and the way meaning is made. The next section of the paper considers a selection of negative responses to the Down Syndrome dolls that followed an article published in Mail Online (Fisher).
What Causes Offence?

Prior to Down Syndrome dolls, the majority of “disability dolls” were constructed through their accessories rather than through the dolls’ physical form and features. Wheelchairs, white canes, guide dogs and harnesses, plastic walkers, leg braces, and hearing aids could be purchased for use with dolls. Down Syndrome dolls *look* different as the features of impairment are embedded in the dolls’ construction. While accessories have a more temporary feel about them, the permanence of the impairments attributed to the doll was problematic for some who felt it projected a negative image of disability. Listed below are several negative comments following an article published in *Mail Online* (Fisher):

- What a grim world we are living in. No longer are dollies for play, or for fun. Now it all about self image and psychological “help.” We “disabled” know we are “disabled”—we don’t need a doll to remind us of that! Stop making everything PC; let children be children and play and laugh once again!
- I think it’s sick and patronising.
- Who on earth are those education “experts?” Has nobody told them that you don’t educate children by mirroring their defects/weaknesses/negative traits but by doing exactly the opposite, mirroring back the BEST in them?
- The Downs Syndrome doll looks like they took the physical traits and presented them in an exaggerated way to make them more noticeable. That doll does not look attractive to me at all. If someone has a child that WANTS such a doll, fine. I can’t really see how it would help many of them, it would be like a huge sign saying “You are different.”

The terminology used (grim, sick, patronising, defect, weak, negative, unattractive, different) to describe disability in these posts is significant. These descriptions are ideological categories which disadvantage and devalue “bodies that do not conform to certain cultural standards” (Garland-Thompson). Implicit and explicit in all of these comments is the sense that disability and Downs Syndrome in particular is undesirable, unattractive even. When listed together, like Belknap’s literary lists, they are not random or isolated interpretations; they form part of a larger system of meaning making around disability.

These responses are informed by the notion that in order to gain equality in society, people with disability must suppress their difference and focus instead on how they are really just like everybody else. However, this focus ignores barriers to inclusion, such as in the rejection of bodies that do not ascribe to cultural standards of beauty. An increasing visibility of impairment in popular culture such as children’s toys advances an understanding of disability as diversity through difference and not something inherently bad.

**Conclusion**

Peter Laudin of Pattycake Doll, a company which sells Black,
Hispanic, Asian, and Disabled dolls, has found that children “love all dolls unconditionally whether it’s special needs or not” (Lee Adam). He suggests that the majority of the negative responses to the Down Syndrome dolls stem from prejudice (Lee Adam). Dolls popularly available idealise the human form and assume a normative representation. While this has been criticised for communicating damaging standards of beauty from childhood (Levy, Blair and Shalmon), critiques about disability are not as widely understood.

The social and medical models of disability focus attention on certain aspects of disability through lists; however, the reduction of diagnostic criteria in the form of a list (whether medical or social) decontextualises disability from the social and cultural world. Thus, the list form, while useful, has elided the disparate qualities of disability.

As Belknap argues, lists “ask us to make them meaningful” (xv). Although the dolls discussed in this paper have been criticised for stereotyping and emphasising the difference between children with disability and those without, an inclusion of the physical features of Down Syndrome is consistent with recent moves within critical disability studies to re-engage the body (Shakespeare 35). As Faulkner notes in the epigraph to this paper, an examination of negative reactions to these dolls reveals much about the cultural position of people with disability.

References


Liggett, Helen. “Stars are not Born: An Interpretive Approach to


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