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Language, disfigurement, stigma and clothing

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The language we use shapes the encounters we have with children, young people and their families. The words we choose carry power to support, label, positively affect or diminish self-esteem. The words we select either consciously or unconsciously have impact. Words are culturally, contextually and temporally bound. They are political, shifting both in response to situations and in order to reframe situations. Words evolve. Words that were acceptable and commonplace can soon be perceived as being demeaning, mocking and stigmatising. Words carry meaning. Assaultive speech can produce victimising effects (Butler, 1997). The notion that speech wounds relies on the inseparable and incongruous relation between body and speech. Importantly, as Butler (1997) tells us, efforts to establish the wounding power of certain words depends on who is interpreting what the words mean and what they perform. This raises concerns about which words wound and which representations offend.

Health professionals need to take account of the fact that words can wound. Whereas the language of the clinical encounter has traditionally been medically driven, the shift to personcentredness has required a more sensitive consideration of how language is used. Like others we are aware of the negative connotations of terms such as abnormality, deformity and defect. Much agonising has already taken place concerning the most appropriate language to describe a visible difference (Rumsey and Harcourt, 2004). Within the UK, the terms visible difference and disfigurement are currently recognised as being the most sensitive and appropriate terminology. Changing Faces (2016), a charity which helps people with a disfigurement to live the way they want to live, uses the term disfigurement to describe when someone looks: different or unusual; has scarring; looks asymmetrical; a part of them does not work in the way it did/should. Whether present at birth or acquired later in childhood, a disfigurement can have a profound effect on the individual concerned. Difficulties include adverse effects on body image, quality of life, and self-esteem (Rumsey and Harcourt, 2004). As Goffman (1963) argues in his discussion of the management of ‘spoiled’ identity and the

associated stigma, people with such ‘spoiled identities’ may be stared at in public, questioned about their impairment and made conscious that their body does not fit normative ideals. Stigmatisation can occur at several levels, depending on the degree to which the body is blemished or deformed, and the character of the person discredited (Goffman, 1963). Stigmatisation of children due to visible difference can occur Masnari et al.’s (2012) work on stigmatisation and quality of life in children and young people with a facial disfigurement (aged 9 months–16 years) reveals that parents of children < 7 years report no impairment whereas parents of children aged 7–16 report impairment to their child’s health related quality of life (HRQOL). Children’s and adolescents’ self-reported HRQOL was lower in terms of psychological well being than the community reference group.

Clothing may be used to camouflage/hide certain disfigurements, or to detract attention from ‘imperfections’ (Clarke et al., 2009). Goffman (1963) notes that many ‘blemished’ individuals suffer devaluation because of their reduced participation in the normal world, and their own reflections on a poorly idealised body image. Parents may select particular clothing for their child as a form of camouflage or as they get older children may select certain styles or types of clothing. Clothing can be seen as a coping strategy, what Goffman (1963:92) terms “‘passing’”, for individuals to protect themselves and their senses of self from detection by ‘normal’ others and to avoid the full weight of stigma. Clothing is also a positive way in which children with disfigurements can ‘do’ their identity differently (Valentine, 2000). In producing their own narrative of self, children and young people increasingly have to learn to negotiate their identity to position themselves correctly within adult and peer cultures (Valentine, 2000). Making decisions about how to dress draws on personal creativity, but also on social constraint, and clothing’s semiotic and sensual material propensities embody conventions about propriety, gender, ways of moving, and encode social relationships, status, biographies and identities (Candy and Goodacre, 2007).

Just as words carry meaning, so does clothing, and the ways in which this is used to communicate, reveal and conceal are interesting, particularly in conversation with disfigurement and stigma.

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