Autistic tendencies: Are there different pathways for blindness and Autism Spectrum Disorder?

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For many of the children who are blind and who also display features of Autism Spectrum Disorder (ASD) it is possible that their characteristics, while being representative of ASD, actually follow a different pathway to those children who have ASD and are sighted. It is proposed that these children should be viewed as having specific features rather than being a part of the collective of ASD. This article explores this issue by comparing the criteria for ASD with behaviours of both children who are sighted and those who are blind. Additionally, the diagnoses of blindness associated with neurological involvement and early medical complications are discussed. The effectiveness of intervention strategies and programmes is explored.

Introduction

There are many children who are blind who are also recognized to have Autism Spectrum Disorder (ASD). It is also accepted that ASD is over-represented within the population of children who are blind (Hobson, 2002). However, for many of the children who are blind and who also display features of ASD it is possible that their characteristics, while being representative of ASD, actually follow a different pathway to those children who have ASD and are sighted. The evidence to be examined in support of this hypothesis comes from a range of disparate studies, many of which have not directly addressed the issue of autism and blindness. These studies nonetheless document the behaviours known to occur frequently in children who are blind and are also associated with autism. Evidence from these studies provides insight into the possible aetiologies of these behaviours. The indicators for this hypothesis are: the visual diagnosis including the age at onset and severity (Bahar et al., 2003; Brown et al., 1997; Cass, 1996; Ek et al., 1998; Hobson et al., 1999; McHugh and Lieberman, 2003), early medical complications (Bahar et al., 2003; McHugh and Lieberman, 2003; McHugh and Pyfer, 1999), the quality of socioemotional impairment (Brambring and Troster, 1992; Fraiberg, 1977; Gense and Gense, 2002; Hobson et al., 1999), specific aspects present in language and communication skills (Fraiberg, 1977; Gense and Gense, 2002; Olymbios, 1999), patterns of stereotypies (Bak, 1999; Gense and Gense, 2002), and the children's reactions to intervention programmes (D'Allura, 2002; Estevis and Koenig, 1994).

Terminology

The International Classification of Impairments, Disabilities and Handicaps defines blindness as 'the inability to see or the loss or absence of perception of visual stimuli' (World Health Organization, 2004). When considering more specific definitions of blindness, internationally these can vary. According to VanNewkirk et al. (2001: 961) the US definition of legal blindness is '≤ 20/200 or 6/60 and/or ≤ 20° visual field', whereas the World Health Organization definition for blindness is '<3/60, <5° field'. For the purposes of this article either of these definitions is acceptable. The studies discussed will involve children who are blind or very close to blind from birth. It is particularly relevant to determine whether the blindness in the children discussed is congenital or occurring at a later time, as this has specific ramifications for the child's development (Hobson, 2002).

ASD is defined by the presence of major impairments in the areas of social interaction, communication, and behaviour. The Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision (DSM-IV-TR) (2000) states that the impairments in social interaction and communication should be 'gross and sustained' (p. 70). The manual indicates that the characteristics of the social behaviours should include

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impairments in the use of such non-verbal behaviours as a mutual eye gaze, difficulties in establishing peer relations, a lack of socio-emotional reciprocity, and an impaired awareness of others. Additionally, children with ASD have difficulties with and often do not develop any pretend and imaginative play skills. Communicatively, both verbal and nonverbal abilities are affected. The speech of a child with ASD can be echolalic and/or abnormal in terms of tone, rate, rhythm, etc. Furthermore, children with ASD have 'restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities' (DSM-IV-TR, 2000: 75). These can include a strict adherence to particular routines and/or stereotyped body movements. Many children with autism also have sensory sensitivities. There is good evidence that an early diagnosis of autism is now possible. This evidence can be seen, for example, in the work of Volkmar et al. (2004).

Diagnoses with neurological involvement

Historically, retinopathy of prematurity (ROP) and Leber's amaurosis have been identified as problematic diagnoses that may be associated with ASD in children who are blind (Chase, 1972; Keeler, 1958; Rogers and Newhart-Larsen, 1989 as cited in Brown et al., 1997). However, this early research has not been viewed as definitive in that Fraiberg (1977) and later Hobson et al. (1999) presented conflicting conclusions, specifying that the existence of ASD is not directly connected with any particular visual diagnosis.

Cass (1996) investigated the different types of opthalmological diagnoses based upon the relationship between a particular visual disorder and the probable levels of neurological involvement. There were 102 participants in the study. Cass divided the degrees of vision impairment into three groups. Group A involved those children who had diagnoses that are specifically connected to the brain, for example, ROP, blindness due to rubella. These children were excluded from the study as they did not fit the inclusion criteria of normal development at their first assessment. Group B were those children who had a diagnosis that involved the neurological aspects of the visual system, for example, optic nerve hypoplasia and Leber's amaurosis. Group C incorporated those children whose diagnoses existed in the global or peripheral region of the eye, for example, cataracts, a condition which is recognized as having no neurological component (Cass, 1996). Cass found that these children in Group C were not associated with any developmental delay, whereas all of the children in Group B were affected and displayed developmental setbacks.

Brown et al. (1997) conducted a study with a group of 24 participants. The participants' diagnoses, optic nerve hypoplasia, Norrie's disease, ROP and Leber's amaurosis, would have met the classification for Group B or possibly Group A as established by Cass (1996), that is, these diagnoses involve neurological aspects of the visual system or more profound neurological damage. Brown et al. (1997) found that 10 out of the 24 congenitally-blind participants met the criteria for ASD. They determined the verbal IQ of the individual participants. Of the nine congenitally-blind children with an IQ of less than 70, seven of these children presented as having ASD. Brown et al. (1997) therefore concluded that those children who met the ASD criteria tended to be those with cognitive impairments.

Ek et al. (1998) also conducted a study that examined the relationship between blindness due to ROP and ASD. All of the children were blind due to either ROP or hereditary retinal disease. Through their controlled population-based study they determined that 15 of the 27 participants with ROP had ASD. Additionally, all of these children showed clinical evidence of brain damage. Comparatively, those children who were blind due to hereditary retinal disease had a significantly lower rate of autistic-type symptoms, with only two of the 14 participants showing signs of ASD. Ek et al. (1998) also concluded that a diagnosis of ASD in children who are blind is likely to be mediated by brain damage or dysfunction.

Interestingly, Bahar et al. (2003) in a recent paper have identified common traits associated with optic nerve hypoplasia and septo-optic nerve dysplasia. They suggest that those children who are diagnosed with these conditions that incorporate neurological aspects of the visual system and who attend their early intervention centre 'exhibit noted global delays that are not typical of children whose only diagnosis is blindness' (Bahar et al., 2003: 16). While it is not specified that these children have ASD, many of the characteristics as observed by Bahar et al. are similar to the DSM-IV-TR criteria for ASD. For example: 'moderate to severe delays in information processing, extreme tactile and auditory defensiveness, difficulty with transitions, rigid adherence to routine . . . avoidance of social interaction and engagement . . . atypical language development' (p. 16). This connection between the brain, visual diagnosis, developmental setback or delay and ASD is consistently apparent, yet more research is needed to clearly identify the parameters of the phenomenon.

Early medical complications

Other aspects worthy of consideration are the outcomes evident for those children who experience early medical complications. Typically, children who are premature at birth and as a consequence develop ROP have complicated medical histories (McHugh and Lieberman, 2003; McHugh and Pyfer, 1999). Additionally, many of those children identified as having optic nerve anomalies also are noted to have complicated medical histories (Bahar et al., 2003; McHugh and Lieberman, 2003). These children typically faced multiple surgeries coupled with long periods of time in hospital and other medical complications needing treatment by numerous specialists during infancy (McHugh and Pyfer, 1999). In their early childhood period they are noted to need ongoing therapeutic and educational intervention services (Bahar et al, 2003; McHugh and Pyfer, 1999). These children frequently display stereotypic behaviours that are representative of ASD (Bahar et al., 2003; McHugh and Lieberman, 2003; McHugh and Pyfer, 1999). Therefore it is possible to link these autistic-type behaviours to incidents in the life of a child who is blind, whereas this is not necessarily so for sighted children who are autistic and who have not endured early and ongoing medical complications and procedures.

Sighted children who are later diagnosed with ASD are typically healthy in their early years. Frequently for sighted children the diagnosis of ASD occurs between the ages of two and three years when evidence of a social, communication and behavioural impairment becomes more apparent (Frith, 2003). In corroboration of this Baghdadli et al. (2003) found that early medical conditions are linked to both the early recognition of ASD and its severity. From their study it appears that neurological disorders and auditory deficits were strong predictors of early detection of ASD. However, in their sample of 193 children, only 10.4 per cent were noted to have a neurological disorder and 18 per cent had an auditory deficit, indicating that most children did not have significant medical problems that predicted the severity and early diagnosis of ASD.

Impairments in reciprocal social interaction

In the diagnostic criteria for ASD it is specified that there must be a 'qualitative impairment in reciprocal social interaction, relative to developmental level' (Frith, 2003: 9). Peer interactions including play behaviours, particularly pretend play, form a large component of this aspect of development. Both children who are blind and autistic and children who are sighted and autistic experience difficulties with peer and other social interactions (D'Allura, 2002; Fraiberg, 1977; Gense and Gense, 2002; Kamps et al., 2002). Many of these difficulties are manifested in behaviours that are similar between the two groups. For example, both groups of children tend to lack spontaneous and imaginative play, they enjoy playing repetitively and frequently, and they do not use toys for their intended purpose; they also display little social curiosity and prefer to spend time alone rather than with others (Frith, 2003; Gense and Gense, 2002).

When considering the behaviours of children who are blind singularly, it is evident that they too exhibit limitations in their social interactions. These children tend to choose to spend approximately half of their time in solitary play (Brambring and Troster, 1992; Lechelt and Hall, n.d.), they prefer to seek adult interaction rather than engaging their peers (Lechelt and Hall, n.d.), they display play behaviours that are perseverative (Brambring and Troster, 1992) and they tend to exhibit minimal spontaneous imitation due to the lack of a visual model (Brambring and Troster, 1992; Fraiberg, 1977; Gense and Gense, 2002). Consequently it is difficult to determine whether these behaviours exhibited by children who are blind are characteristic of true ASD or perhaps another pathway. Hobson et al. (1999) conducted a study of nine congenitally-blind children, who presented with a clinical picture indicative of ASD. A minority of these blind children scored positively on 'abnormalities in their ways of relating to people and their emotional expression', whereas in contrast, the majority of the sighted children who were also autistic scored positively in these areas (Hobson et al., 1999: 53). Furthermore, they determined that when tested on the Behaviour Checklist for Disordered Pre-schoolers a relatively low proportion of the blind children were abnormal on items relating to affect. Additionally, several of the blind children showed instances of pretend play. Hobson et al. (1999) tentatively concluded that it is possible that, for some children who are blind, ASD can occur without the quality of socio-emotional impairment that is characteristic of children who are sighted and autistic.

Joint attention and social referencing behaviours are another area where both children who are blind and autistic and children who are sighted and autistic experience difficulties (Frith, 2003; Loots et al., 2003; Recchia, 1997). Loots et al. (2003) state that when a child is vision impaired the infant/carer dyad has difficulties establishing and maintaining 'symbolic and linguistic meaning during moments of joint attention'

(p. 411). However, it is possible that there are compensatory mechanisms available in terms of the actual infant's developmental pathway and the infant/carer dyad. Some suggested mechanisms are such behaviours as body pointing, body stilling, leaning towards an object and other non-visually-orientated signs (Cass, 1996; Loots et al., 2003; Moore and McConachie, 1994). The existence of these subtle behaviours may assist infants and children who are blind in developing joint attention and social referencing behaviours. It is also believed that children with ASD make gains in socialization over time (Frith, 2003). The distinction possibly lies in the fact that children with ASD need to be taught appropriate responses and are unable to make useful generalizations and adaptations to unknown situations. Furthermore, often they are resistant to intervention strategies.

Language and communication

There are specific difficulties present in the language and communication skills of children who are blind and autistic and children who are sighted and autistic. Both these groups of children frequently exhibit echolalia and display problems with pragmatic features of conversation like topic switching and initiating conversations (Fraiberg, 1977; Frith, 2003; Gense and Gense, 2002; Olymbios, 1999). Frequently they also have problems with the use of personal reference and deictic terms (Frith, 2003; Gense and Gense, 2002). It is possible that when these features of language and communication are present in children who are blind, they are not solely features of ASD but rather adaptive functions assisting in development. Echolalia in children who are blind can be viewed as an attempt to initiate and/or participate in social interaction, and it can also be considered useful for children who are blind to develop an understanding of social situations (Wills, 1978 as cited in Olymbios; Peters, 1994 as cited in Perez-Periera and Conti-Ramsden, 1999). Perez-Periera and Conti-Ramsden (1999) further state that it is imperative that in the future researchers need to try to adopt the perspective of the child who is blind and to try to understand the child's intentions. If this does not happen, the abilities of these children who are blind and autistic-like will continue to be misunderstood and underestimated.

Stereotypies

Stereotypies are restricted, repetitive and stereotyped behaviours associated with children who are blind and autistic and children who are sighted and autistic (Frith, 2003; Gense and Gense, 2002). These can be motor movements, thought processes and/or elaborate routines of behaviour (Frith, 2003). Frith (2003) states that repetitive actions and stereotypic movements are a common component of mental disturbance and severe brain disorders. If these stereotypies are in fact mediated by neurological dysfunction it is necessary to allow for the impact of this upon both blind and sighted children who display behaviours associated with ASD. It has been determined for congenitally-blind children that there is a high correlation between the severity of stereotypies and reduced intellectual and receptive and expressive communication abilities (Bak, 1999).

Other research has shown that it is particular repetitive behaviours such as body-rocking and eye-pressing which occur more persistently in the population of children who are blind (McHugh and Lieberman, 2003; McHugh and Pyfer, 1999; Troster et al., 1991). Additionally, Troster et al. (1991) in their study of 85 congenitally-blind children found that a wide array of stereotypic behaviours occurs during the first and second year of life, and that many of these decrease from age three onwards. It is probable that these behaviours when found in congenitally-blind children are not the stereotypic behaviours associated with ASD but rather a different set of behaviours. This is not to say that these behaviours are desirable. Many interventions have been followed to try to reduce the occurrence of these behaviours. It is this aspect of reaction to behaviour modification programmes that is of interest. It appears that if the child who is blind is motivated to control a particular behaviour then there is a greater chance of success (McHugh and Lieberman, 2003). This strategy of utilizing a cognitive approach has been found to be effective in reducing stereotypic body-rocking (Estevis and Koenig, 1994).

Early intervention

Early intervention 'provides support for infants and young children who have developmental delays or disabilities, their families and communities, in order to promote the child's development and inclusion' (Early Intervention Association of Australia, n.d.). This usually occurs through programmes or models of practice. There has been a multitude of intervention programmes developed to assist with the management and treatment of autism. Identifying the most effective models or programmes is a complex task as evidence supports a range of treatment and intervention models as being desirable, dependent upon the individual characteristics of each child with ASD (Roberts, 2004). The complexities are magnified when considering the effectiveness of

programmes for those children who are blind and who also display characteristics of ASD. Numerous articles have been published that include recommendations for intervention programmes to be developed and used with the population of children who are blind and who also exhibit behaviours associated with ASD. The inherent problem associated with these recommendations is that if there are differences in the pathway to the development of autistic tendencies in children who are blind, then it may be that different intervention approaches are required. Unfortunately there is little published research detailing the specifics of the types of programmes currently being used with this particular population and their subsequent effectiveness.

Several studies have noted particular strategies that are successful in mediating these problematic social, communicative and stereotypic characteristics and behaviours for sighted children with ASD. For this group there are several key aspects that are identified as being effective strategies in intervention programmes. Some of these are a need for highly supportive teaching environments and generalization strategies together with predictability and routine, time to process information and the involvement of family and inclusion of peers (Roberts, 2004). These are noted to be effective strategies for use with children who are blind and also displaying behaviours representative of ASD (Ingsholt, 2002; Jamieson, 2004). However, it does not appear that there is empirical evidence to support these claims. The following approaches have been successfully utilized when devising intervention and educational programmes to assist children who are blind: the use of cognitive approaches (Estevis and Koenig, 1994; Ingsholt, 2002) and the use of cooperative learning strategies (D'Allura, 2002).

Conclusion

It seems that those diagnoses that involve neurological aspects of the visual system and perhaps more extensive neurological impairment account for multiple cases of ASD among children who are blind. However, there continues to be confusion regarding the nature of the behaviours and other developmental problems experienced by children who are blind and suspected of displaying features of ASD. The empirical evidence to support many of the conclusions does not exist. For the benefit of these children and their families, it may be useful for professionals to view them as having specific behaviours, stereotypies or features rather than being part of the collective of ASD.

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