Exploring the Lived Experience of Bilingual Parents of Children with Autism Spectrum Condition in Wales: An Interpretative Phenomenological Analysis

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Introduction and Rationale

Autism Spectrum Condition (ASC)
Baron-Cohen et al. (2009) concluded that the prevalence of Autism Spectrum Conditions (ASCs) is rising across the UK, and that the number of pupils with an ASC diagnosis in schools has increased. In the Welsh context, Latif and Williams’ (2007) estimated the prevalence of ASC within schools in Wales at 60 pupils in every 10,000. Furthermore, ASC is the most prevalent special educational primary need of maintained school pupils who have statements of Special Educational Needs (SEN) in Wales (Welsh Government Statistics for Wales, 2016).

Linguistic Context of Wales
Since 1993, Wales has two official languages: English and ‘Cymraeg’ (Welsh) (Welsh Language Act, 1993). The 2011 Census figures report that English is the most widely spoken language in Wales, with Welsh spoken by nearly one fifth (19%, 562,000) of usual residents in Wales aged three and over (Census figures, 2011). Recently the Welsh Government (WG) (2012) has actively promoted bilingualism and the sustainment of the Welsh language. Education and parenting are highlighted as core and vital instruments in promoting and developing a fully bilingual culture.

What does the Literature Say?
• A multitude of research documents a common belief among parents and professionals that bilingual exposure may be detrimental to the language development of children with neurodevelopmental and other related disabilities (Drysdale et al., 2015; Reetzke et al., 2015; Hambly & Fombonne, 2012; Bird et al., 2012).
• North American qualitative ethnographic and survey-based studies indicate that parents of children with ASC express uncertainty when making decisions about bilingual exposure for their children (Reetzke et al., 2015; Bird et al., 2012).

Primary Research Question:
What is the lived experience of bilingual parents raising their children with ASC in Wales?

Methodology and Results

Methodology
• 5 participants recruited from 2 LAs in Wales (all Mothers).
• 1 pilot interview.
• Semi-structured interviews (conducted in Welsh).
• Data analysed using IPA (Smith et al., 2009).

Results


Conclusions

Conclusions and Implications for EP Practice
• The complex interaction between the parent and child being conveyed as a journey or process of understanding and acceptance (reiterating findings by Hutson & Carron, 2005; Dashe & Rees, 2008). The participants recognised the need for more awareness and information, and a process of communication with other parents as the most effective and impactful source of support.
• All participants expressed a desire for their child to become bilingual, albeit there existed differing views in terms of how they perceived this as a priority. It was interpreted that the importance placed on bilingualism related to two aspects – the desire to fully belong and function in a bilingual community, and a perception that language is a core aspect of an individual’s identity.

Future Research?
• Developing a questionnaire on the basis of the current findings, which could then be completed by a much larger sample of parents in order to determine their level of agreement with the reality of these findings.

References: