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A review of the NCSE guidance for the education of children on the autism spectrum

By Damian E M Milton

Whether it is the funding arrangements supporting research or the evaluation of policy implementation, educational research is inherently political (Cohen, 2000). My own area of interest concerns the experience of autistic people regarding their own education and is itself a highly politicised topic. Educational policies regarding special educational needs in Britain have, however, been non-autism specific.

This essay examines the evidence and research base used to support the findings of a report (Parsons et al. 2009) commissioned by the National Council for Special Education (NCSE) in Ireland. The NCSE was established following the Education for Persons with Special Educational Needs Act (2004) in order to improve educational practices for this group. The report provides a review of international literature regarding educational provision for people diagnosed with an autistic spectrum disorder (ASD), followed by recommendations for future practice.

Due to a number of autistic spectrum subgroups being defined in recent years and the growing acknowledgement of the notion of the 'autistic spectrum,' the authors of the report decided to review literature that had been published between 2002-08. Two main search strategies were utilised in the review: a systematic search of electronic databases focusing on empirical studies (both quantitative and qualitative) and collating articles, reviews and guidance from expert/professional experience and opinion. Inclusion/exclusion criteria were applied to empirical papers with single case studies and theses being removed, with 499 articles being reduced to 100 retained for review. The report suggests that this limitation is due to the difficulties in producing 'robust' and ethical research within this area of educational practice. Following the emphasis of the tender document received from the NCSE, Parsons et al. (2009) concentrated upon research regarding 'best outcomes' for the individual (e.g. attainment, confidence, self-esteem and independence). Selection criteria for articles followed the guidance outlined by Rix et al. (2006), although not all protocols were followed due to practical constraints; for example the setting up of a separate advisory group or the grading of all papers on weight of evidence. Twelve articles were selected as offering a 'high weight of

evidence'. Some articles were included for review despite not meeting all inclusion criteria, due to a focus on important and yet under-researched themes, particularly that of the 'autistic voice'.

"Traditionally, research has tended to overlook these views, favouring those of parents/carers or teachers...Our own professional and research experience (and interests) unapologetically guide us towards inclusion of this emerging literature. We consider it essential to 'best provision' that all stakeholder views are sought wherever possible." (Parsons et al. 2009, p.41-2).

Despite this attention only seven of the studies reviewed, actually took the approach of looking at the experiences and perspective of autistic people themselves, with only two referring directly to experiences of school. Although 'outcomes' were not reported in these studies, the reviewers included them as they considered the autistic 'voice' to be essential for informing high quality educational provision. This assertion by the researchers reflects an underlying tension between preferred epistemological criteria between them and the policy-makers commissioning the research, although this is not made explicit in the text. Levin (1991) argued that there is a significant tension present between researchers and policy makers due to often contrasting agendas, audiences, terminology and issues of concern. Cohen et al. (2000) suggest that there is often a political favouring toward positivist research methods, particularly with recent assertions for 'evidence-based practice', a term borrowed from health care research that promotes quantitative methodologies above qualitative ones; and the notion of the randomised controlled trial design as a 'gold standard'. Usher and Scott (1996) argued that a predominance of positivist research allows traditional notions of society to appear unproblematic, excluding marginalised 'others' as illegitimate 'knowers'. Although the tender document for this article asked for a review of literature concerning 'outcomes' and the vast majority of literature reviewed were quantitative in design, the researchers deliberately usurp this dominant ideology by highlighting issues such as the autistic 'voice'.

The second strand consisted of selected reports and policy guidelines from the UK and Ireland, drawn from 'known sources, relevant websites and practitioner journals', also dated between 2002-08, that were specifically concerned with educational provision and policy for autistic people and that were on permanent record. Literature concerning post-compulsory education was found to be limited and thus the report also reviewed non-peer-reviewed, practice-based articles regarding this age group. It was thought that this was due to a genuine lack of empirical research studies in this area, rather than any failure in the search strategy adopted.

Moving beyond the basic distinction between quantitative and qualitative methodologies in social science research, as exemplified by Finch (1986), Trowler (2003) distinguishes between two models

of the relationship between education policy and research: the 'engineering' model characterised by positivist epistemological and foundationalist ontological positions; and the 'Enlightenment' model characterised by an interpretive and relativistic positions. This distinction clarifies the philosophical differences between the two main approaches and not just those of a methodological nature. The 'engineering' model attempts to inform policy, by reporting on 'facts' and solutions to 'problems', whilst the 'enlightenment' model often attempts to reframe traditionally accepted definitions of educational 'problems'. The former enables policy-makers to propose top-down measures, by producing explanations of the educational environment and making suggestions regarding practices based on their results. In criticism however, this model often assumes that the recommendations of research reports can be translated into practice without difficulty. For Trowler (2003), however, such suggestions are not uniformly implemented in practice, and the concept of evidence-based practice and the limited standardised techniques that it encourages are fundamentally flawed. Therefore, Trowler (2003) positions himself within the 'enlightenment' camp, arguing that a good teacher needs to be a reflective practitioner able to deal with the unpredictability of diverse everyday situations.

Nearly two-thirds of the included articles adopted in this study were deemed to have used 'robust' methodologies, described as 'utilising multiple-baseline designs', 'comparison groups' or implementing a randomised controlled design; yet the small sample sizes of the majority of studies were said to present a difficulty when attempting to generalise from the data. Therefore, the researchers conform to the intentions of their sponsors (Burgess, 1993). Somewhat contrastingly, Parsons et al. (2009) also suggest that the analysis of qualitative data can offer important insights and is particularly relevant for researching the autistic 'voice', considered as a 'substantially under researched aspect of educational provision' (Parsons et al., 2009, p.122). This apparent contradiction in the discourse may well be hiding a wider tension between researchers wishing to follow an 'enlightenment' model and policy-makers wishing to follow the 'engineering' model, exemplified by the researchers including certain articles despite their not having a focus on outcomes as intended by the NCSE tender document.

The report found that within the sampled empirical research, articles focusing on early-intervention strategies and behavioural approaches for autistic children were dominant. Forty-nine percent of the studies reviewed concerned the pre-school age group, with a further third concerning primary schooling. Post-compulsory education only appeared in eight percent of the literature. Parsons et al. (2009) argued that these figures reflect the importance of 'early intervention' for autistic children, as well as the fact that diagnosis was occurring at a younger age than in the past and thus

more children had entered such programmes. Contrastingly, Parsons et al. (2009) also suggest that these figures reflect a serious lack of research concerning the educational needs of older children and adults. The latter of these points reflects a genuine area of concern; however it cannot be extrapolated from the dominance of articles concerning 'early intervention' that this reflects a real 'importance' over other areas, as this could be due to an unfounded paradigmatic dominance in the research area of behaviourism, and its accompanying theoretical assumption that a 'cure', 'normalisation', or a vast improvement in 'outcomes', is possible via an educational intervention.

Due to the lack of robust empirical evidence in many areas of provision, Parsons et al. (2009) regarded the views of 'experts (including parents)' as a 'vital source of information and guidance'. The main finding from the second strand adopted in the report, was the need for a 'seamless' multi-agency service for children and families. Parsons et al. (2009) argue, however, that there is little empirical evidence to inform how this goal should be achieved and that evidence of this nature was more prevalent in studies in other areas and thus beyond the scope of the report.

In the conclusion to the report, Parsons et al. (2009) argue that autistic people do not represent an homogenous group with similar needs and that decisions regarding educational practice should be made in reference to individual needs and preferences, yet whilst also taking into account the views of parents, practitioners and providers. It is clearly stated in the report that given the diversity of needs that autistic people may have, one type of intervention is unlikely to be effective for all. Parsons et al. (2009) therefore argue that a range of provision should be provided and maintained, providing a better chance of giving appropriate support, and that more research is required regarding the effectiveness and relevance of various interventions and types of provision.

Parsons et al. (2009), following the advice of Kasari (2002), attempted to compare the evidence relating to a number of early intervention programmes. They found that the studies that had 'robustly' explored the comparative benefits of various approaches, reported mixed findings as to the superiority of any one approach. They argue that from these findings, coupled with the consensus view amongst experts and policy documents, an 'eclectic' approach to provision should continue to be funded and provided for families. This recommendation does not necessarily logically follow from the available evidence however. Little attention was given in the report as to whether any of the approaches commonly used had resulted in damaging or negative effects being reported. Perhaps this was due to a lack of evidence regarding this issue in the studies under review. It would be illogical, however, to recommend an 'eclectic' utilisation of a variety of non-effective techniques. The report does, however, recommend that further study is needed to ascertain the relative merits of the various approaches on offer.

The key recommendations of the report included the need for more evidence-based practice across a range of ages and sub-categories, hence seemingly promoting the traditional dominance of the 'engineering model' (Trowler, 2003), yet also promoting the expansion of research on the autistic 'voice', considered the 'main client' by the researchers. They recommend that guidelines should be developed on how to ensure that the views of autistic people are sought and 'taken into account' in everyday practice in schools and in decision making. By making this recommendation, the researchers uncover a potential preference for the 'enlightenment' model and a potential tension with their sponsors. Other recommendations included the evaluation and implementation of training programmes for practitioners; the promotion of coordinated multi-agency service provision; working with families to ascertain the needs of parents and make high quality training available for them; and planning transition services for further and higher education.

Prior to the report being written, Brian Hayes, education spokesman for the opposition Fine Gael party argued that behavioural approaches be made available to autistic children 'where it has been recommended by psychologists', that the government's policies were 'greatly misguided', and that they were biased against the use of ABA (cited at www.yfg.ie/article.php?sid=862, 2010). The report was thus written within a political context where the findings would further anger pressure groups such as the 'ABA pilot schools' in Ireland (cited at www.thereddoorsschool.com/About-The-Red.../autism-ireland.html, 2010). Parent groups can place a great deal of pressure on political parties that are in search of votes, presenting 'evidence' with their claims. Despite this report using strict criteria for inclusion of articles for review and the vast majority reviewed, being of a behavioural focus, it is likely to be rejected by stakeholders who either have vested interests in a practice ideology or base their views on 'research', without having the training to navigate such material. In a case like this, the researchers have to weigh up evidence on a matter of great political, social, personal and economic significance. Yet when the audience scrutinise the authority of the work, without the relevant tools being applied, the consequences could be far more 'misguided'. Interestingly, within this political nexus, the opposition to the government policy is being led by 'psychologists' of only one philosophically moribund paradigm, largely thought of as outdated within the discipline (Oates et al., 2005), and 'parental choice'. This opposition does not mention the 'voice' or needs of autistic people themselves, or evidence that is critical of ABA methods, thus supporting an approach to concentrate resources in this area, despite its lack of a sound evidence-base.

Burgess (1993) states how the traditional power of researchers to formulate topic areas has been usurped by the sponsors of research. For Thomas (1991), due to politicians wishing to promote their

own programmes and being fearful of their own political survival, the impact of research on policy is highly dependent on its conclusions being consistent with the political agenda of the day. Wineburg (1991) argues that research all too easily becomes an 'affirmatory text' exonerating the existing system. The power relationship between the researchers and their sponsors can be unpacked from the contradictory discourse within the text and the primary focus on 'outcomes', despite the researchers subverting this approach with an 'unapologetic' appeal for more notice to be taken of the autistic 'voice'.

The research and evidence base used in this study was unfortunately skewed toward the younger age group and toward evaluations of various intervention programmes. This was not due to the ideological and philosophical preferences of the researchers, however, who highlighted research into older children, adults and the autistic 'voice' as much needed, yet sparsely reported upon, but rather those of their sponsors and the dominant paradigms within research into autism. It seemed that the researchers were constrained to a great extent as to the kind of search strategy that they employed, despite subverting the criteria that they had been given, highlighting the difficulty in maintaining professional autonomy in the conclusions attainable in such a report and an unequal power relationship between researcher and sponsor.

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