Northern Ireland Assembly

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Knowledge Exchange Seminar Series (KESS)

Early intervention for Autism Spectrum Disorder: Comparing international policies with developments in NI[1]

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Autism Spectrum Disorders (ASD) are pervasive developmental disorders that are diagnosed along a continuum of behavioural variants in social interaction, communication, and imagination. Some individuals on the spectrum are 'high-functioning' and able to cope in every day environments, while others are severely affected, non-verbal, and may have comorbid diagnoses, such as intellectual disability, epilepsy, and/or obsessional, conduct, or mental health disorders.

ASD diagnosis can be formulated from as early as 6-months to one year of age, although it is more common that children are aged 2-3 years before diagnosis is affirmed. Frequently, higher functioning individuals are not diagnosed until adolescence or even adulthood.

Present figures indicate that 2% School children in Northern Ireland are affected (DHSSPS, 2014), with prevalence rates even higher in the general child population in the UK (3.5%; Dillenburger, Jordan, McKerr, & Keenan, 2014). It seems that males are affected more frequently than females (estimated ration of 4:1), although this may be due to under diagnosis in girl. Similar prevalence rates have been found across racial, ethnic and socioeconomic groups.

The exact etiology of ASD remains unknown although genetic, immunological, neurological, and allergenic roots have been investigated. Early theories of maternal unresponsiveness have been discredited as mentalistic and sexist while recent neurological studies have shown physical differences in early brain growth

[1] Updated from previously published version in Dillenburger**, K. (2012) Autism Spectrum Disorder: Evidence-based interventions.** *National Association of Primary Care Review* (Spring/Summer 2012) p134-135

and functioning and family studies point to the possibility of genetic links. It is not clear yet if these differences are cause or effect, and it is likely that ASD is caused by a combination of genetic and environmental risk factors (Dawson, 2008).

General Practitioners (GP) are the first port of call for most parents who are concerned about their children's behaviour and subsequent referral to an assessment team is required for a full diagnosis based on behavioural observations and caregiver reports. Presently, there are no medical tests for ASD. The diagnostic team usually includes pediatricians and allied health professionals.

If untreated, the lifetime cost to society for each individual with ASD is estimated between £0.9-1.5 million depending on the level of functioning (Buescher, Cidav, Knapp, & Mandell, 2014). Of course, the cost for quality of life for the individual and their family is much higher and the potential economic and social impact of effective interventions is enormous.

It is not surprising therefore that the intervention market is booming. As governmental investments into ASD services are increasing, fad treatments abound. In fact, the struggle for a slice of the market has been called the Autism Wars (Freeman, 2003). Primary care and education workers have a key role to play in protecting families and individuals affected by ASD from fads and ineffective, controversial or dangerous treatments.

Currently there are no pharmacological treatments for the core symptoms of autism and interventions that based on the scientific discipline of behaviour analysis offer the only evidence-based treatment. MRI scans have shown that appropriate behaviour analytic interventions do not just lead to behavioural improvements (with some individuals becoming 'indistinguishable' from neurotypical peers) but that they lead to improved neurological development, i.e, neurological plasticity allowing for compensatory development.

These kinds of findings have lead to nearly all US States having adopted or being in the process of adopting laws that ensure that medically necessary ABA-based interventions are covered by health insurances. In fact the US Surgeon General stated over 13 years ago, that 'Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.' (U.S. Public Health Service, 1999). Further endorsement comes from

- New York State Department of Health: *Guidelines: Autism/Pervasive Development Disorders, Assessment and Intervention for Young Children (0-3), Chapter IV - Behavioral and Educational Approaches*;
- California State Department of Developmental Services: *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment*;
- Florida State Department of Children and Families: *Procedures for Implementation of the Developmental Services Home and Community Based Services*; and
- Maine Administrators of Services for Children with Disabilities: *Report of the MADSEC Autism Task Force*, to name but a few.

Despite this general endorsement of evidence-based behaviour analytic interventions across most of North America, a more controversial approach is taken by governments across much of Europe (including UK and Ireland) to support an 'eclectic' approach, although there are no clear guidelines what this entails and not a single study is published anywhere to show effectiveness of an eclectic approach being equal or superior to ABA-based interventions (Dillenburger, 2011).

The evidence base showing the efficacy and effectiveness of ABA-based interventions spans all valid and recognised research methodologies, including

- over 2000 replicated **Single-System Design (SSD)** studies, where internal validity is achieved by each participant serving as his/her own control and external validity is achieved through numerous replications (cf., *Journal of Applied Behavior Analysis*);
- a substantial number of **Randomised Controlled Trials (RCT)** that compare ABA-based interventions either with Treatment as Usual; specific commercially available intervention packages, such as TEACCH; high vs low intensity behaviour analytic interventions; or waitlist contols. While some of these are true RCTs, others are non-randomised comparison group designs (Keenan & DIllenburger, 2010);
- a growing number of **Meta Analysis** and **Sequential Meta Analysis** (SMA), that use valid indices, e.g., the Reliable Change Index (RCI) to show with 95% certainty that effects are not due to measurement error, variation in sample etc.. SMAs are conducted where enough cumulative knowledge is available through meta-analysis to draw convincing statistical conclusions;
- **Systematic Reviews**, that use clearly defined criteria for inclusion, carry out detailed searches of data banks, offer thorough reviews by multiple experts, and summaries of selected studies; and finally
- **Social Validity** studies that assess (1) the social significance or importance of treatment goals, (2) the social appropriateness of the procedures, and (3) the social importance of the effects.

All of these studies supply ample evidence of the effectiveness and efficacy of applied behaviour analytic (ABA-based) interventions, in achieving individual potential in a full range of areas, including intellectual, social, and verbal, functioning, ASD symptomatology, and challenged behaviour.

Applications of behaviour analysis include but is not restricted to established interventions such as antecedent package, comprehensive behavioural treatment, joint attention intervention, modelling, naturalistic teaching strategies, peer training package, pivotal response treatment, schedules, self-management, and story-based intervention package, as well as a number of emerging treatments include imitation, initiation training, language training, peer-mediated instructional arrangement, picture exchange communication system, social communication intervention, social skills package, structured teaching, and some technology-based treatment (National Standards Project, 2009).

A skilled Board Certified Behaviour Analyst (cf. BACB.com) identifies the appropriate intervention on the basis of a *functional assessment and analysis* of the *target behaviour.* It is important to note that *behaviour* is defined holistically as the interaction of an organism with their environment, including anything we do, e..g, feeling, thinking and acting.

After taking a stable baseline of the *target behaviour* along at least one behavioural dimension, e.g., frequency, duration, latency, intensity, the behaviour analyst designs the intervention based on fine tuned changes in the contingencies of reinforcement, while at the same time continuing to collect data on the target behaviour. As such changes in the target behaviour are early and easily identified and any necessary adjustments to the intervention can be made quickly, accurately, responsively, and child/behaviour centered. Generally, behavioural data are graphed for efficacious visual analysis.

Thus, an individually tailored programme evolves that meets the needs of the person in their context. Behavioural achievements are generalized and maintenance programs become integral part of the intervention (cf. for training materials see www.stamppp.com; www.simplestepsautism.com).

Primary health and education professionals usually are the first port of call for parents of children with ASD. Therefore it is important that these professionals are aware of evidence-based, effective and medically necessary behaviour analytic interventions (Dillenburger, 2014).

Given the lack of adequately trained behaviour analysts in Europe and therefore the potential for misinformation, primary health and education professionals should familiarize themselves with training requirements (cf. bacb.com) and international best practice (cf. behavior.org).

In Northern Ireland, both UU and QUB offer approved training in behaviour analysis at Undergraduate and postgraduate levels. In addition, QUB has offered the MSc Autism Spectrum Disorders since 2002, The course is tailored for professionals in this field and includes modules that focus on children and adults with autism.

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