ENCYCLOPEDIA
on Early Childhood
Development

Early Intervention in Autism

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July 2012

Introduction

Many interventions for autism have been promoted within and outside mainstream health systems, often making startling claims of effect. Pressure from families, service providers and policy makers for new intervention programs is understandable, and these are reinforced in some areas by statutory imperatives. In such a context the need for rigorous evaluation is clear but has often been lacking. Fortunately there is now increasing resource devoted to sophisticated intervention testing, and substantive progress beginning. This review focuses on early intervention programs in the pre-school period that have been subjected to rigorous evaluation.

Subject

Autism is a severe, highly heritable[1] neurodevelopmental disability, with an estimated prevalence of 0.4% for the core disorder and about 1% for the broad autism spectrum.[2] Impairments in social reciprocity, communication, and behaviour have a profound effect on children's social development into adulthood[3] and result in a high economic cost for families and the community.[4] Diagnosis by three to four years of age is now common in developed health systems[5,6] and the importance of early intervention has been advocated in reviews.[7,8]

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Problems

There are relatively few well-conducted published trials in autism at any age.[8-11] Many (highly quoted) early trials of interventions were of poor qualityand there are indeed many challenges in designing such studies and in detecting relevant change; “the heterogeneity in this disorder, both behaviourally and etiologically, works against even the most well-designed trials.”[9]

Research Context

Autism is multi-dimensional and heterogeneous; no single intervention is likely to address all aspects. A central challenge is the identification of what it is appropriate and susceptible to change. Linked to this is important debate about choice of outcome measures. Autism is a chronic disorder and interventions also need to be seen within the context of chronic health care within medical, social care and educational systems.

Key Research Questions

Which is the best theoretical model to approach autism intervention? Systematic enquiry aims to differentiate *specious* claims from valid paths.

What outcome measures? An obvious focus is on the defining symptoms of the disorder itself; but arguments can also be made for addressing quality of life for child or family, school performance, emotional adjustment or modification of co-occurring behavioural difficulties.

Who should rate outcome? Family or user ratings are highly relevant but prone to biases from hope and expectation; “objective” measures blinded to treatment received are taken more seriously as evidence of actual treatment effect but often less sensitive.

What works for whom? Trials need to be designed to address the heterogeneity in the disorder.

Recent Research Results

Behaviour-learning approaches

Interventions based on psychological learning theory were some of the earliest to be widely adopted in autism – typical would be Early Intensive Behavioural Intervention (EIBI, previously known as ABA). EIBI involves multiple therapists working with the child for 30-40 hours/week, plus additional consultation time for parents, typically over a duration of 2 to 4 years.[12] Two small

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RCTs (randomized controlled trials) recently tested EIBI against less intensive parent training. Children treated ranged greatly in severity; outcomes were general development rather than autism-specific. The first study (n=28)[13] suggested superiority for EIBI, mainly in the less severely autistic children in the sample, on general cognitive ratings but not in adaptive functioning or behaviour. The second study (n=23)[14] showed no comparative advantage for EIBI, with about half of both groups showing relatively good progress at follow-up after four years. The Early Start Denver Model (ESDM) expands the behavioural approach to include developmental elements and work with parents on shared engagement and responsivity.[15] A recent medium sized RCT (n=58),[16] compared ESDM with mean 15 hours/week therapist input and 16 hours/week parent work at home over a two-year period with less intensive general community-intervention. ESDM showed relative improvements in language, language aspects of IQ and adaptive behaviour, but no treatment effect on other autism-specific symptoms.

Communication approaches

These approaches focus on developmental aspects of parent-child social interaction and communication; they tend to be less intensive and involve parents more centrally. A recent moderate sized RCT (n=62) tested Hanen's "More than Words" (HMTW) – a group parent-training[17] provided over 3.5 months –against "*usual care*" and illustrates treatment effect heterogeneity:[18] children with less developed object interest at baseline showed positive effects with HMTW on communication, children with better object interest did worse than usual care. A more individualized approach tested a targeted six-month program to improve *interpersonal synchrony* in toddlers with autism spectrum disorder[19] and found a related specific outcome – socially engaged imitation improved, but not initiation of joint attention or shared positive emotion. A larger recent RCT (n=152) compared "Preschool Autism Communication Therapy" (PACT), a parent-mediated intervention over a year using video with biweekly to monthly therapist input and daily parental homework,[20] to usual care in children with core autism. It measured specific autism outcomes as well as detailed measures of the process of intervention.[21] PACT showed a strong effect on parental communicative behaviour and improvement in child communication with parent, but greatly attenuated effects when more generalized language and autism symptom outcomes in other settings were looked at using objective tests (parents reported strong intervention effects on communication and adaptation in everyday life).

Overall, recent autism trials have reported many positive results, largely in "proximal" outcomes of intervention, such as dyadic interaction, joint attention, and child imitation. Less treatment

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effect has been found on more general child functioning; two studies report improvements on standardised measures of child language and communication[16, 22] but three do not.[18,19,21] The two studies to use a standard autism diagnostic symptom measure as outcome[16,21] found no significant intervention effect on this.

Research Gaps

A common set of measures for comparison across studies needs to be debated and developed. Given the complexity of autism, trial designs need to become more sophisticated, with a focus on layers of measurement and understanding the process of intervention effect.

Intervention trial work needs to link more with developmental neurobiological research to identify biomarkers for differential treatment effects – this will then help address the heterogeneity issue. Much larger sample sizes will be needed to understand heterogeneity better.

Trial designs need to address autism as a long-term developmental disorder, with a greater focus on service delivery and use of approaches developed in relation to other chronic illnesses.

An ideal would be a sequence of trials on common cohorts extending from the earliest infancy interventions onwards – to test long-term outcomes and the added value of using sequentially-phased and developmentally-adapted interventions over time.

Conclusions

Many approaches to autism intervention are passionately advocated but a systematic evidence base on effectiveness is only recently emerging. Findings from recent studies are convergent; well targeted interventions of various kinds can indeed improve developmentally important immediate outcomes such as parent-child communication and joint attention, but generalising such change “downstream” to core autism symptoms and adaptation in real world contexts is much more challenging. Since we know that children with autism find generalising new learning across contexts very difficult, this is not a surprising result – even if it is sobering. There has been little testing of how well sustained any early treatment effects will be in the longer term. Nevertheless, as the evidence grows, we are getting a much better insight into the process of change in autism and the methods we can use to measure it. We are beginning to understand which children may benefit from which type of intervention at what time – the goal of

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personalised healthcare across medicine. Accelerating basic science work is bound to suggest previously unanticipated forms of intervention in the future. We are increasingly in a position to debate best treatments on the basis of shared evidence from better quality studies. That's where real progress lies – even if it takes time.

Implications for Parents, Services and Policy

Faced with the difficulties and perplexities of autism, parents are understandably desperate for guidance and hope, and policy makers for models to use. In the end, cumulative effectiveness research is going to be the best guide – even though this can seem slow when definite help is needed immediately. The pace of research into treatments is quickening but in comparison with many other areas of health is at an early stage. We have models of stunning intervention success against what were initially thought intractable disorders (such a childhood cancer or HIV-AIDS), growing out of a well funded, cumulative collaborative international effort involving iterations of systematic trials and basic science work. We can see the beginning of this in autism – but the key will be now to sustain this effort for enough time to get the progress we want.

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