

Early Intervention for children with intellectual disabilities

Dr Susheela Narang
Principal
Kenway College of Education, Abohar

Abstract

Children with intellectual disabilities are at greatly increased risk of behaviour problems but less likely to receive early intervention. Instead, responses from services are limited (if not non-existent), reactive, lacking in expertise, and include residential care and/or problematically restrictive approaches. As a result it is not surprising that children with intellectual disabilities who present behaviour problems have poor outcomes, both as children and later as adults who continue to display (often much more serious) challenging behaviour. This is to the detriment not only of children and their families, but also wider society, due to the financial costs; negative health outcomes, and foreshortened, lower quality lives that result. There is an urgent need to identify risk factors and provide evidence-based intervention as early as possible in the lives of children with intellectual disabilities, in partnership with families/carers. This paper sets out the evidence currently available around early intervention approaches for children with intellectual disabilities whose behaviours challenge, and identifies key areas of action to help commissioners proactively target resources to deliver good outcomes.

Introduction

Early intervention is playing an increasingly prominent role in the field of intellectual disabilities. Early intervention for children with intellectual disabilities involves timely provision of an optimal nurturing and learning environment that aims to maximise developmental and health outcomes and reduce the degree of functional limitations. It is a system of coordinated services that promotes the child's growth and development and supports families during the critical early years. Early intervention can provide primary, secondary and tertiary prevention. Promotion of long term health and wellbeing through early detection of determinants of adverse outcomes should be a feature of early intervention programs. Early intervention is of clear benefit to children with intellectual disabilities. This position statement focuses predominantly on intervention for children with intellectual disabilities during the early childhood years, often referred to as early intervention by families and service providers.

- Identifying difficulties early in childhood and using evidence-based approaches to address those difficulties has the potential to deliver significant social and economic benefits. This is particularly true where problems are likely to escalate over time; limit the life chances of the individual, and result in significant costs to society. The rationale for evidence-based early intervention (both early in life and early in the onset of problems) is now widely accepted as part of public policy in the UK and beyond across health, education and social care

- A child with intellectual disabilities refers to a significant impairment of general intellectual and adaptive functioning that originates in childhood. Having intellectual disabilities affects the way a person understands information and how they communicate and may require support with all everyday tasks such as dressing and toileting. Many will experience complex physical health, sensory, and mobility difficulties.
- Behaviours that challenge can include aggression, destruction, self-injury, and other behaviours (e.g. running away) associated with personal or social risks. Children with intellectual disabilities are much more likely to show behaviours that challenge. These stark differences in risk for the development of behaviours that challenge emerge in early childhood and can be highly persistent over time.
- Children displaying challenging behaviours are at greater risk of social exclusion, institutionalisation, deprivation, physical harm, abuse, misdiagnosis, exposure to ineffective interventions, and failure to access evidence-based interventions. Poor outcomes are experienced not just by children themselves but by their families too. Carers face an increased risk of physical and mental-ill health, physical injury, increased financial burdens, and reduced quality of life.
- A review of the effectiveness of early intervention identified that there was limited research specifically related to intervention for children with disabilities. Further high quality research exploring the benefits of early intervention is urgently required in order to inform more effectively how early intervention can be delivered to achieve best outcomes for children and families.
- Research evidence on its own is not sufficient to determine access to and the type of early intervention required. The UNCRPD and UNCRC clearly articulate the human rights imperative to provide support to enable the child to access educational and other services. Specialist therapy and educational intervention may be required during preschool years in order for the child to be in the mainstream or supported education system.
- Support for families is well accepted as a key component of effective support for children. Population data demonstrates that this is the case for the families of children with intellectual disabilities. Emotional difficulties amongst parents and siblings of children who display behavioural difficulties are high and develop early (often by the time the child is 5 years old). Families often face unusual and distressing challenges. Longitudinal studies show that children's behaviour and wellbeing has an impact on the emotional functioning and behaviour of parents/carers and family functioning in return has a direct impact on the wellbeing and behaviour of the child.

Recommendations for policy makers and commissioners

Ensure that Children with intellectual disabilities and their families are able to access existing early intervention programmes, making reasonable adjustments/adaptations as necessary. All parents of Children with intellectual disabilities should be given the opportunity and be supported to participate in local early intervention activities such as parenting programmes. Barriers to access should be removed and Children with intellectual disabilities identified as one of the priority groups for inclusion. Develop more specific capacity to identify and respond rapidly to challenging behaviour Health Visitors, GPs, Early Years Practitioners and teachers, as well as specialists, need to be able to recognise the risk factors in order to access further help for families.

Early intervention for children at risk and for those with established intellectual disabilities is now firmly embedded in the context of general early childhood development. An overarching developmental framework has been advanced and has achieved a high level of consensus; one that is relevant to typically developing children and to those vulnerable to a range of developmental problems, particularly intellectual disability. The importance of the convergence of the developmental science of normative development, the developmental science of risk and disability, and intervention science cannot be overstated. It is important to note that most of these results were produced by 'model' programmes with considerable resources and highly skilled staff. The extent to which community programmes can achieve similar outcomes is a concern and will be discussed shortly. Finally, our knowledge base also includes general agreement with respect to the practice components of early intervention in the form of resource supports, social supports, and information and services. Taken together, our current knowledge clearly reflects the important advances that have taken place in the field of early intervention and have created meaningful prospects for preventing or minimizing intellectual disability. Even considering the high expectations for the benefits of early intervention, it is evident that the concepts and practices of early intervention have made important contributions to understanding and promoting the development of children with intellectual disabilities. Developmentally oriented approaches, in particular, have provided a rich and stimulating framework. Clearly much remains to be accomplished, and the issues of specificity, translational research, mental health and social competence, and systems development at the community level constitute a demanding agenda for the future. Should we take this agenda seriously and achieve even modest degrees of success, we may well be able to fulfill the high expectations for early intervention.

References

- AAMR. (2002). *The AAMR definition of mental retardation*. Retrieved April 4, 2016, from http://www.aamr.org/Policies/faq_mental_retardation.shtml.
- Achenbach, T. M., Howell, C. T., Aoki, M. F. & Rauh, V. A. (1993). Nine-year outcome of the Vermont Intervention Program for Low Birth Weight Infants. *Pediatrics* 91, 45–55
- American Academy of Pediatrics, Committee on Children with Disabilities. (1999). Care coordination: Integrating health and related systems of care for children with special health care needs. *Pediatrics*, 104, 978–981.
- American Association on Mental Retardation (2002). *Mental Retardation: Definition, classification and systems of supports*, (10th ed.). Washington, DC: *American Association on Mental Retardation*. Retrieved December 30, 2016 from [http://www.aamr.org/mental retardation](http://www.aamr.org/mental_retardation).
- Barnett, D. (1997). *The effects of early intervention on maltreating parents and their children*. In: *The Effectiveness of Early Intervention* (ed. M. J. Guralnick), pp. 147–170. Brookes, Baltimore, MD
- Cooper, V., Emerson, E., Glover, G., Gore, N. J., Hassiotis, A., Hastings, R., ... & Richards, C. (2014). Early intervention for children with learning disabilities whose behaviour challenges. Briefing Paper. *Challenging Behaviour Foundation*.
- Collins W. A., Maccoby E. E., Steinberg L., Hetherington E. M. & Bornstein M. H. (2000) Contemporary research on parenting: the case for nature and nurture. *American Psychologist*, 55, 218–232.
- Duncan G. J., Brooks-Gunn J. & Klebanov P. K. (1994) Economic deprivation and early childhood development. *Child Development* 65, 296–318.
- Wishart J. G. & Pitcairn T. K. (2000) Recognition of identity and expression in faces by children with Down syndrome. *American Journal on Mental Retardation* 105, 466–479.