Early intervention for children with learning disabilities: making use of what we know

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Abstract

Purpose – The purpose of this paper is to present a rationale for increasing initiatives for early intervention of emotional and behaviour difficulties.

Design/methodology/approach – The authors draw on existing literature regarding rates of emotional and behavioural difficulties together with risk factors and processes related to the development of such difficulties.

Findings – Rates of emotional and behavioural difficulties amongst children with learning and developmental difficulties are high. A combination of factors relating to the child, the family system, and wider social contexts is likely to account for this.

Research limitations/implications – Increased attempts to provide early intervention to children with learning and developmental disabilities together with their families are warranted. Recommendations are made regarding how the development of such supports might best be taken forward.

Originality/value – Whilst drawing on pre-existing literature, the value of this paper is the way in which this has been drawn together to provide an overview of risk and development of behavioural and other difficulties amongst children with learning/developmental disabilities.

Keywords Intellectual disability, Children, Prevention, Learning disability, Challenging behaviour, Early intervention

Paper type Conceptual paper

Background

Multiple forms of early intervention exist (see Baker and Feinfield, 2003; McCollum, 2002) but all are concerned with pre-emptive investments to prevent development, escalation, or impact of a difficulty. Rather than waiting for the full impact of difficulties to be experienced, the rationale for early intervention is to minimise or even avoid future suffering that might be predicted for individuals, families, and society.

Despite the logic of early intervention, funding, service developments and research for such approaches have often not been forthcoming. Typically, those in the field of disability have focused on responding to immediate difficulties or crises and tended to evaluate intervention effectiveness by focusing on reductions in these difficulties.

When pressed about preventative approaches, most agree in theory but feel under immense pressure to try to alleviate suffering that is immediately apparent. A second line of argument may follow that, given time, predicted difficulties may not arise after all. This corresponds to the methodological complication of “proving” that early intervention really makes a difference (and so should be funded).

There have been relatively few early intervention initiatives for challenging behaviour, but times do seem to be changing. In the wake of the Winterbourne View scandal there has been increased pressure to respond to the needs of people with learning disabilities and their families.
from an early stage. Significantly, the Department of Health (2012a, b) concordat recognised that planning for people with learning disabilities must begin in childhood.

In this paper we focus on “early” in terms of the early years of the life-course of individuals who have learning/developmental disabilities. An emphasis on intervention to reduce the occurrence of emotional and behavioural difficulties at this stage is highly justified since:

1. emotional and behavioural difficulties (at least in proto-type form) emerge early in the life course of people with learning/developmental disabilities and have an impact on the individual and others even at this stage;

2. these difficulties and the impact they pose for the individual and others tend to persist over time without intervention;

3. there is high potential for being able to identify those subgroups of children and young people who are at heightened risk of developing emotional and behavioural difficulties and those conditions that increase this risk; and

4. those factors that relate to risk and the development of emotional and behavioural difficulties appear amenable to intervention.

We cite evidence that supports these key points to present a case for early intervention to improve emotional and behavioural wellbeing for children with learning/developmental disabilities. Whilst the “proof” for early intervention is still some way off, we suggest enough is known about risk and development of these difficulties to plan and implement preventative supports.

Emotional and behavioural difficulties amongst children with learning disabilities

Children with learning/developmental disabilities are at increased risk of experiencing emotional and behavioural difficulties, relative to other children. Even by age five, these children are at heightened risk of developing an emotional or behavioural difficulty (Totsika et al., 2011a, b) with 30 per cent of young children with learning disabilities (aged zero to three) displaying behaviour problems (Emerson and Einfeld, 2010).

Across a wider range of ages, 21 per cent of children with learning disabilities meet diagnostic criteria for conduct disorder (Emerson and Hatton, 2007) compared to around 4 per cent of children without disabilities. A high proportion also display behaviours such as aggression, property damage or self-injury (Kiernan and Kiernan, 1994). When surveyed, 93 per cent of head teachers in specialist schools estimated that up to a quarter of the students in their school display challenging behaviours of this nature, with 7 per cent estimating that between 25 and 50 per cent of students in the school display challenging behaviour (Male and Rayner, 2009).

Finally, children with disabilities caused by certain genetic conditions are at even greater risk of displaying particular forms of challenging behaviour (Arron et al., 2011) and children with learning disabilities overall are more likely than their peers to experience developmental difficulties in areas such as sleep and feeding (Gal et al., 2011; Krakowiak et al., 2008; Quine, 2001).

Persistence and impact

Early challenging behaviours are persistent in the absence of effective intervention and frequently continue into later life (Murphy et al., 2005). Challenging behaviours have widespread negative impact on individuals and their families. For the individual, challenging behaviour increases risk of injury, abuse, and harsh restrictive management approaches (Allen et al., 2006; Emerson and Einfeld, 2011).

Children who display behaviour difficulties struggle to access community and educational services and those who display severe forms of challenging behaviour may be forced to enter residential school placements. These are costly and may be some distance from the family home (Pilling et al., 2007). Emotional difficulties amongst parents and siblings of children who display behavioural difficulties are also high relative to members of other families (Baker et al., 2003; Hastings, 2002; Naylor and Prescott, 2004). Again, such difficulties appear to develop
early, with parents of children with learning/developmental disabilities likely to experience elevated stress by the time their child is five years old (Totsika et al., 2011a, b).

High stress levels amongst caregivers are not inevitable and the literature also cites positive experiences amongst family carers of children with disabilities (Hubert, 2010; Kenny and McGilloway, 2007). Some of the variation in emotional wellbeing may relate to other psychological characteristics of caregivers (Glidden and Natcher, 2009; Resch et al., 2012; Totsika and Hastings, 2009).

The development of emotional and behavioural difficulty

Child factors

Several “child-related” risk factors for the development of behavioural difficulties amongst children with learning/developmental disabilities have been identified. These include gender, severity of disability and communication impairment (McClintock et al., 2003). Autism and a number of other conditions are also associated with greater risk (e.g. Aron et al., 2011) and other patterns of behaviour (impulsivity, hyperactivity, and repetitiveness) appear to predict later development of behaviour difficulty amongst both children with and without disabilities (Burbidge et al., 2010). Links are often apparent between different risk factors and occurrence of challenging behaviour. For instance, children with Cornelia de Lange Syndrome have a predisposition to experience gastro-intestinal reflux (Hall et al., 2008) and pain caused by this condition may account for the high number with the syndrome who engage in self-injurious behaviour (notably when reflux is treated, self-injury is seen to decrease; Peebles and Price, 2012). This is an important point because it means risk factors can help to identify who is most likely to develop later difficulties and what can be done to reduce this likelihood by supporting children’s individual needs.

Whether or not those who present with individual risk factors later develop emotional or behavioural difficulties is likely to reflect interplay with other socio-environmental factors. Notably however, in the general population, low intelligence is associated with reduced resilience in the face of adversity and children with learning disabilities appear to be as (and potentially more) vulnerable than children without disabilities to the influence of adverse life experiences (see Emerson, 2013).

The caregiver system

Complexities of need for children with disabilities at risk of emotional and behavioural difficulties can present caregivers with a high number of unusual and, at times, extreme challenges that extend beyond those encountered when supporting a typically developing child. For instance, children with Smith-Magenis syndrome frequently develop self-injurious behaviour that emerges at a very early stage and can include illomania (pulling out finger and toe nails) and polyembolokomnia (insertion of objects into body orifices) (Finucane and Haas-Givler, 2009). Whilst many caregivers are able to respond to these challenges in effective, supportive and positive ways it is likely that, for some, little of what they have experienced previously will have fully or directly prepared them to do this. The responses and actions of those who support the child are, however, known to significantly influence future development of emotional and behavioural difficulties.

Challenging behaviour amongst people with learning disabilities is often maintained by social consequences that follow the behaviour and relate to ongoing interactions with caregivers. In relation to the early development of challenging behaviour, the critical role of social reinforcement has been particularly well evidenced in relation to self-injury (though these principles can be extended to other forms of challenging behaviour). Caregivers (in the very early years this will mainly be family members but later will include teachers and other professionals) experience early behaviour difficulties as aversive (Hastings, 2002, 2005; Male, 2003) so often act in ways that stop the behaviour from happening in the short term. In the long term, however, these responses may increase the likelihood that the behaviour occurs again (a “mutual reinforcement process”; Oliver, 1995; Oliver et al., 2005). The broader parenting literature has also demonstrated that overly permissive, inconsistent or inflexible and harsh caregiver-child interactions are predictive
of behaviour difficulties amongst typically developing children (Eddy et al., 2001; Patterson, 1982). These associations have also been considered to understand and reduce behaviour difficulties amongst those with learning/developmental disabilities (Sanders et al., 2004).

Both lines of evidence highlight the profound influence that caregivers have on the development of children. However, it is important to note that we are discussing the caregiver system here. Thus, the behaviour and wellbeing of caregivers affects the development of children. Equally, children’s behaviour and wellbeing have an impact on caregiver emotional functioning and behaviour (Hastings, 2002). This bidirectional influence has been demonstrated in several longitudinal studies (Baker et al., 2003; Lecavalier et al., 2006; Neece et al., 2012).

Interaction styles and responses are therefore best conceived as behaviours that have been shaped by caregivers’ own experiences (including being parented and educated themselves) and the child’s behaviour, and continue to be influenced by their own emotional state and access to support (Chen and Kaplan, 2001; Kochanska et al., 2012; Waylen and Stewart-Brown, 2009). Caregivers are typically doing the best that they can to support a child who (as previously described) may present with exceptionally high levels of need, often with little additional support for themselves.

**Social context**

Whether or not a child who presents with known risk factors later develops emotional or behavioural difficulties is likely to be further influenced by their social circumstances, life experiences and systems of support. Note that, as discussed earlier, the impact of adversities such as these on wellbeing is likely to be moderated by an individual’s level of resilience. Further research is required to determine more fully how individual factors influence resilience for those with disabilities (Emerson, 2013) but it is known that children with learning disabilities have an increased chance of encountering adversity overall.

First, there is a higher incidence of poverty amongst families of children with disabilities (Emerson, 2012a, b) and children with learning disabilities are known to experience more adverse life events than their peers. They are more likely to experience problems within the family including parental separation and bereavements (Hatton and Emerson, 2004).

In addition to familial instability, children with disabilities are at heightened risk of being mistreated. Sullivan and Knutson (2000) found this group are three to four times more likely to experience neglect, physical abuse and sexual abuse and that this is most likely at the preschool age. Children with learning disabilities are also more likely to be bullied (Department for Children, Schools and Families, 2008) and excluded from school (Department for Education, 2010).

At the level of the caregiver system, parental emotional difficulties and problematic parenting styles are both more likely amongst families of lower social-economic status in the general population (Emerson, 2004). The Family Stress Model (Conger and Donnellan, 2007) may be one way of understanding how these multiple relationships contribute to the development of emotional and behavioural difficulties amongst children with disabilities (Emerson, 2013; Totsika et al., 2014). The model suggests that parental experience of economic difficulties increases the potential for emotional and mental health difficulties which, through their impact on caregiver interactions, have implications for the wellbeing of their children.

**Discussion**

This paper has aimed to bring together some of what is known about rates and impact of emotional and behavioural difficulties amongst children with learning/developmental disabilities and factors that influence risk and development of these difficulties to help inform and encourage future early intervention practice. In summary, it is suggested that:

1. children with learning/developmental disabilities are more likely than those without such disabilities to develop emotional and behavioural difficulties and this is recognisable even in the very early years;

2. these difficulties impact on the wellbeing of the child and caregivers, are persistent and can result in costly placements;
3. some sub-groups of children with more complex needs are at even greater risk of emotional and behavioural difficulties;

4. interactions between caregivers and children play a large role in how and why some emotional and behavioural difficulties develop;

5. caregiver interactions occur within the context of supporting children with an unusually high level of need and are further shaped by their own experiences, emotional wellbeing and access to support; and

6. the broader social context (exposure to poverty, experience of adverse life events, access to resources) must also be taken into account when considering how and why emotional and behavioural difficulties arise.

This paper has not provided a complete review of the literature nor attempted to discuss fully the intricate relationships between different risk and protective factors (for a more detailed account we refer the reader to Allen et al., 2013). We do, however, suggest that the literature thus presented has a number of implications for supporting children with learning/developmental disabilities and their families at an early stage.

Despite the high risk, prevalence and impact of emotional and behavioural difficulties, support and services for children with disabilities and their families are frequently lacking. Accessing mainstream health and educational services is often difficult due to the failure of such services to respond with flexibility to specific needs of the child. Further to this, families of children with learning disabilities often report dissatisfaction following their involvement with specialist services (Mansell, 2010; McGill et al., 2006).

Whilst complete coverage of the intervention literature is beyond the scope of this paper, some key areas that stem from our discussion might usefully be considered to strengthen and expand early intervention supports in this area:

1. A number of supports can be structured at a universal level to better meet the needs of all children with learning/developmental disabilities and their families. This should include ensuring smooth access to both generic and specialist physical health services and professional support to children and families regarding communication development (e.g. Luczynski and Hanley, 2013; van der Schuit et al., 2011).

2. Children who are at increased risk for developing emotional and behavioural difficulties can be identified and early years services/professionals (i.e. those working in nurseries and child development centres) should support early screening so that additional supports can be made available (Allen et al., 2013).

3. There is a strong evidence base for the effectiveness of function-based behavioural interventions (often as part of a Positive Behavioural Support framework) in reducing challenging behaviours and a variety of demonstrations of how these can be implemented in the early years (Carr et al., 1999; Lang et al., 2013). These approaches relate directly to the central processes that account for how behavioural difficulties develop and are maintained and should therefore form the bedrock of service delivery.

4. There is a need to recognise the significant role that caregivers play in a child’s development and wellbeing and to form collaborations with a range of stakeholders throughout assessment and intervention practices. Such relationships are increasingly recognised as an essential ingredient of Positive Behavioural Support (Gore et al., 2013). Caregivers are also likely to need support in relation to emotional wellbeing and to gain additional strategies for supporting a child with complex needs. There is now a promising evidence base for the effectiveness of parenting programmes that focus on the particular needs of children with learning/developmental disabilities (McIntyre, 2013).

5. In the long term continued attempts need to be made to reduce exposure to impoverished living conditions and adverse life events for children with disabilities and their families. This is likely to necessitate wide scale socio-political intervention but at a more local level means developing more services that proactively aim to engage with families who...
may be living in poverty to provide financial, educational, social and emotional support (e.g. Fox and Holtz, 2009).

Clearly there remains a need for future research to examine in further detail the interplay of risk factors and the generalised and combined use of intervention approaches in applied settings. In the wake of Winterbourne and the resulting policy and work streams there is, however, great potential to draw upon a large body of pre-existing evidence to good effect. This is not new evidence but reflects an accumulation of findings over a number of decades. We therefore encourage those working in services and those tasked with commissioning and designing services to be confident in utilising this information to increase early intervention supports for children with learning disabilities and their families. We know enough to do this now.

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