BRIEFING PAPER

Early intervention for children with learning disabilities whose behaviours challenge

The Challenging Behaviour Foundation
November 2014

Challenging BEHAVIOUR foundation

making a difference to the lives of people with severe learning disabilities

Council for disabled children

Public policy supports early intervention as a strategy for resolving problems quickly and preventing long-term poor outcomes. Early intervention (primarily through parent training) for childhood behaviour problems (where child does not have a learning disability) is a well-known example.

Children with learning disabilities (LD) 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 LD 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 LD, in partnership with families/carers.

This paper sets out the evidence currently available around early intervention approaches for children with learning disabilities whose behaviours challenge, and identifies key areas of action to help commissioners proactively target resources to deliver good outcomes.

Authors

Vivien Cooper, OBE (Chief Executive, The Challenging Behaviour Foundation)
Professor Eric Emerson (Professor of Disability Population Health, University of Sydney)
Professor Gyles Glover (Co-Director, Learning Disability Observatory)
Dr Nick Gore (Tizard Centre, University of Kent)
Dr Angela Hassiotis (University College London)
Professor Richard Hastings (Cerebra Chair of Family Research, University of Warwick)
Professor Martin Knapp (Professor of Social Policy and Director of the Personal Social Services Research Unit, London School of Economics)
Professor Peter McGill (Co-Director, Tizard Centre, University of Kent)
Professor Chris Oliver (Professor of Neurodevelopmental Disorders, University of Birmingham)
Anne Pinney (Independent Researcher)
Dr Caroline Richards (Cerebra Centre for Neurodevelopmental Disorders)
Valentina Iemmi (London School of Economics)
Jacqui Shurlock (The Challenging Behaviour Foundation)

This briefing paper does not represent a comprehensive literature review. It is a narrative review based on expert consensus. The authors were brought together by The Challenging Behaviour Foundation to produce this paper.

Early Intervention

> *"Early intervention… is about getting extra, effective and timely interventions to all babies, children and young people who need them, allowing them to flourish and preventing harmful and costly long-term consequences."* Early Intervention Foundation, 2013

1. 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.

2. This briefing note summarises the key messages from available evidence[a] about early intervention for children with learning disabilities whose behaviours challenge, and calls on policy makers and commissioners to act on that evidence.

BOX 1: Relevant early intervention policy

- World Health Organization (2008) 'Closing the gap in a generation: Health equity through action on the social determinants of health'
- Department of Health (2010) 'Fair Society – Healthy Lives: A Strategic Review of Health Inequalities in England'
- World Health Organization and World Bank (2011) 'World Report on Disability'
- Graham Allen MP (2011) 'Early Intervention: The Next Steps. An Independent Report to Her Majesty's Government'
- Department for Education (2012) 'Statutory Framework for the Early Years Foundation Stage: Setting the standards for learning, development and care for children from birth to five.'
- Department for Education (2012) 'Support and aspiration: a new approach to special educational needs and disability – progress and next steps'
- European Regional Office of the World Health Organization (2013) 'Review of social determinants and the health divide in the WHO European Region: Final report'
- Chief Medical Officer's annual report (2013) 'Our Children Deserve Better: Prevention Pays'
- Department for Work and Pensions (2013) 'Fulfilling Potential – Making it Happen'
- Department of Health (2014) 'Closing the gap: Priorities for Essential Change in Mental Health'

Children with learning disabilities whose behaviours challenge

Key message: Children with learning disabilities are at greater risk of developing behaviour described as challenging.

Learning disability[b] (LD) refers to a significant impairment of general intellectual and adaptive functioning

[a] This briefing paper draws on the following sources of evidence:
1) Systematic reviews/meta analyses;
2) Narrative reviews which the authors of this paper view as robust summaries of evidence;
3) Primary research which can be generalised to England (i.e. is based on nationally representative samples)
4) National data collections

[b] Learning disability as used in this document is equivalent to the SEN classifications of moderate or more severe learning difficulties used by the Department for Education. It is also synonymous with the term 'intellectual disability' as used in the US, Australia and by many international organisations.

that originates in childhood. Public Health England estimates that 1,043,449 people in England have a learning disability.[1] Schools in England reported in 2013 that 179,320 pupils had a learning difficulty as their main special educational need.[c 2] Having a learning disability affects the way a person understands information and how they communicate. Children with more severe LD may have no, or extremely limited, verbal communication and may require support with all everyday tasks such as dressing and toileting. Many will experience complex physical health, sensory, and mobility difficulties.

3. Behaviours that challenge can include aggression, destruction, self-injury, and other behaviours (e.g. running away) associated with personal or social risks. Children with LD are much more likely to show behaviours that challenge. For example, the prevalence of diagnosable conduct disorders is 21% among British children with LD, compared to only 4% among British children without LD.[3] These stark differences in risk for the development of behaviours that challenge emerge in early childhood,[4 5] and can be highly persistent over time.[6]

4. We estimate that in 2014 just over 40,000 English children are likely to have LD and to also show behaviours that challenge.[d] It is probable that this is a conservative estimate, as population surveys capture information about aggression but not about other forms of behaviour that are more specific to (and not uncommon among) children with LD (e.g. severe self-injury). Figure 1 shows estimates of the number of children with and without learning disabilities whose behaviours challenge at ages 3, 5, 7 and 11. As can be seen, at all ages children with LD were markedly more likely to show behaviours that challenge than their non-learning disabled peers.

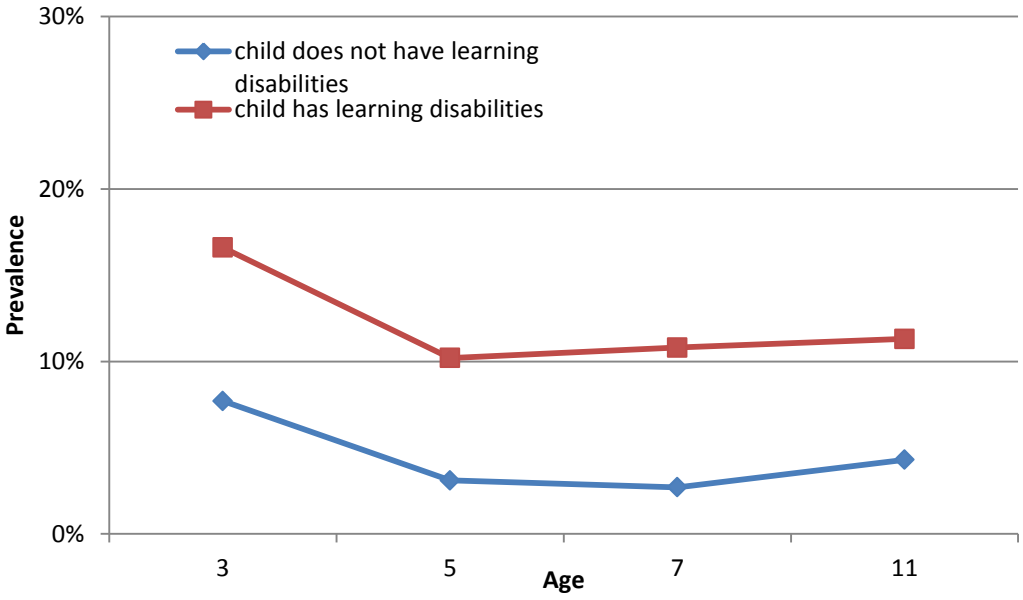

Figure 1: Prevalence of behaviours that challenge at ages 3, 5, 7, and 11 years

[c] Children with MLD, SLD or PMLD, with a Statement or at School Action Plus, in schools in England, January 2013

[d] The methodology used to determine this estimate can be found at www.challengingbehaviour.org.uk/learning-disability-files/Estimating-the-Number-of-Children-with-LD-and-CB-in-England.pdf

Expensive services delivering poor outcomes

Key message: Too many children with learning disabilities whose behaviour challenges are in costly, residential placements.

5. 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.[7] 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.[8]

6. The Department of Health review, *Transforming Care*, published following the discovery of abuse of people with learning disabilities at Winterbourne View states that "the norm should always be that children, young people and adults live in their own homes with the support they need for independent living within a safe environment. People with challenging behaviour benefit from personalised care, not large congregate settings." [9]

7. Research demonstrates that residential placements for children with LD reduce family contact; increase young people's vulnerability, and accentuate the difficulties of transition to local adult provision.[10]

8. 2013 data from the Department for Education records 1,360 children and young people with LD or autistic spectrum disorder attending residential schools, 480 of them outside of their local authority area. [11] This figure does not include those attending independent schools, representing a significant gap in the data. The most recent robust cost estimates, uprated to reflect current prices, put the average annual cost of an out of authority placement at £99,798 for a boarding place,[12] rising to £171,176 for a 52 week residential placement.[13] Return to the local area is very difficult to achieve. Instead young people often move to adult placements in residential care homes or colleges[10] out of area. Annual individual service costs of between £89,335 and £358,415 have been identified for adults with severely challenging behaviour.[14]

9. The 2013 Learning Disability Census found 236 in-patients aged 18 or under in hospital units, including 31 children aged 10 or less. 29% of these children and young people were in hospitals 100km or more from home.[g] [15]

10. Nearly two thirds of those under 18 had been given anti-psychotic medication on a regular basis. Young people were also the most likely in-patients to suffer certain types of incident in the three months leading up to the Census, notably self-harm, hands-on restraint, and seclusion.[16] Overall, the 185 inpatients aged 17 or under cost over £46 million per annum with an average annual cost of almost £250,000.[h] Young people were the most likely of any age group of inpatients with LD to be in

[g] Some caution must be attached to these figures as data quality checks raised concerns about the reporting of date of birth information, particularly for this younger age group.

[h] Estimate reached as follows: (no. of service users for each cost band) x (mid-point in weekly charges) x 52 weeks. For placements >£6499, a charge of £7000 was assumed. For placements <£1500, a charge of £1000 was assumed.

placements costing in excess of £230,000 per annum.[17] (See data supplement for a more comprehensive overview of national data.)[i]

Early intervention for children with learning disabilities whose behaviours challenge

Key message: It is generally accepted that early intervention is a sensible approach for children without learning disabilities. There is no reason to believe that this should not be the case for children with learning disabilities. In fact, it is even more likely to be relevant.

11. Population based samples show an increased risk for behaviour problems in children with learning disabilities, compared to other children, by the time they are 3 years of age.[4]

12. While challenging behaviour is the product of a complex interaction between biological, developmental and environmental factors, there is strong evidence that some of the key factors causing and/or maintaining challenging behaviour are amenable to change, and that change in these factors can be associated with marked reductions in challenging behaviour. [18]

Early behavioural interventions

13. Approaches that work well with children generally are also likely to be effective for children with LD. Knowledge drawn from behavioural research clearly indicates the potential benefits of providing evidence-based behavioural interventions and of doing so early. There is robust evidence that early behavioural interventions can have positive effects on both parent and child outcomes and NICE recommends parental training.[19] The Government has acted on this evidence through the roll out of CANPARENT parenting classes. Systematic reviews of evidence-based parenting programmes (in particular the Triple P and Incredible Years interventions) have shown the effects to be improved parenting skills, improved parental well-being and reduced behavioural problems among children.[20]

14. The Triple P Parenting Programme is a well-used example with a specific programme called "Stepping Stones" designed for parents of children aged 2-8 with LD. RCTs have found strong evidence that Stepping Stones improves child and parent outcomes.[21] Triple P is a multilevel system of family intervention that aims to prevent severe emotional and behavioural disturbances in children by promoting positive and nurturing relationships between parents and children.[22] It is also designed to address parental problems such as stress and/or depression.[23] The Triple P programme has been independently estimated to have a benefit cost ratio of 5.05.[24] That is, every £1 spent on implementing the programme produces £5.05 in benefits to society from such outcomes as reducing healthcare utilisation and incarceration, and increasing employment.

Training and support for families

15. 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 learning disabilities.[25] Emotional difficulties amongst parents and siblings of children who display behavioural

[i] See www.challengingbehaviour.org.uk/learning-disability-files/EIP-Data-Supplement.pdf

difficulties are high[26] and develop early (often by the time the child is 5 years old).[4] 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 [27] and family functioning in return has a direct impact on the wellbeing and behaviour of the child.[28]

Systematic early identification and rapid response

16. In the general population a number of factors are known to increase the likelihood that a child will develop emotional and/or behavioural difficulties, this includes exposure to social-economic disadvantage and other adversities in childhood including parental stress or mental health problems. Evidence suggests that these factors also predict the likelihood of behaviour difficulties within the LD population and are even more likely to reflect the early life experiences of children with LD relative to their typically developing peers.[29]

17. Within the LD population there are further risk factors for the development of behaviour that challenges. Factors associated with greater risk include severity of disability, communication impairment, autism, and certain genetic conditions.[30 31] This evidence suggests that screening the target population of children with LD for risk indicators is likely to be an effective way of identifying children who are at heightened risk of developing behaviour that challenges.

18. Identification of risk factors by professionals at an early stage could make a significant difference by identifying which children are most likely to develop later difficulties, and what can be done to reduce this likelihood by supporting children's individual needs.[32] See Box 2 for suggested characteristics of an effective rapid response.

BOX 2: Characteristics of effective rapid response to identified challenging behaviour/risk of challenging behaviour in children with learning disabilities:

- Integrated care approach recognising the causes of challenging behaviour (challenging behaviour is related to factors including physical/mental health issues, social circumstances, communication)
- Continued input rather than requirement for referral and re-referral (although input will vary over time)
- Positive Behavioural Support (PBS) as the framework
- Family centred (focus on whole family needs including parent training, short breaks, support for siblings)
- Systematic (regular health/sensory screening for those at risk of challenging behaviour)

Positive behavioural support

19. Positive behavioural support (PBS) represents the most effective evidence-based approach to supporting people with LD and behaviours that challenge. PBS interventions are informed by a functional assessment to determine the cause of an individual's behaviour.[33] Once the causes of an individual's behaviour are established, factors can be altered to reduce the challenging behaviour.

For example, elements of the individual's environment can be changed or the individual taught new skills, resulting in more effective and more acceptable behaviour.

20. PBS was developed from the science of Applied Behavioural Analysis (ABA)[34] and is fully consistent with the model underlying parenting programmes such as Triple P and Incredible Years. It is not a single intervention or therapy, rather a multi-component framework for delivering a range of evidence-based supports (as well as behavioural support these may include communication and sensory support and/or access to mental health services where necessary) to increase quality of life and reduce the occurrence, severity, or impact of behaviours that challenge.[35] Studies demonstrate that as well as reducing the frequency and intensity of challenging behaviour, PBS can produce intervention effects across the age span and improve quality of life.[36]

21. Positive behavioural support approaches have been documented widely as the preferred approach when working with people with learning disabilities who exhibit behaviours described as challenging. Despite this, the use of PBS in England is limited.[37]

22. Research currently underway demonstrates that PBS intervention by local behaviour support teams can lead to potential savings by improving local support and reducing out of area residential placements.[38]

Recommendations for policy makers and commissioners

Key message: Invest to save through provision of evidence-based interventions to children with LD and their families.

23. The evidence summarised in this paper demonstrates an urgent case for change. We recommend adopting joint commissioning strategies (including, from 2015, the LA led 0-5 commissioning strategies) in local areas which:
    - **Ensure that children with learning disabilities and their families are able to access existing early intervention programmes, making reasonable adjustments/adaptations as necessary.** All parents of children with LD 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 LD 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,

BOX 3: Guidance advocating use of Positive Behavioural Support (PBS)

- British Psychological Society's Guidelines (2004)
- Joint Guidelines of the Royal College of Psychiatrists, the British Psychological Society and the Royal College of Speech and Language Therapists (2007) 'Challenging Behaviour: A unified approach'
- Department of Health (2014) 'Positive and Proactive Care: Reducing the need for restrictive interventions'
- Local Government Association/NHS England (2014) 'Ensuring Quality Services: Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges'

and teachers, as well as specialists, need to be able to recognise the risk factors in order to access further help for families. LD should be flagged as one of the risk factors for challenging behaviour and local Disabled Children teams, LD teams and CAMHs teams should develop multi-disciplinary rapid response approaches (as set out in Box 2 above), in conjunction with schools and in partnership with families. This should be included within the "local offer" required under the Children and Families Act 2014.

- **Provide local specialist behavioural support to children.** For those children who need it, the local offer should include intensive behavioural support alongside training in PBS for families and staff. This should be reflected in section F of the Education, Health and Care plans of those children for whom PBS is required in order to access education. As the evidence in this paper demonstrates, such provision has the potential to deliver considerable savings in the long term care costs for an individual.

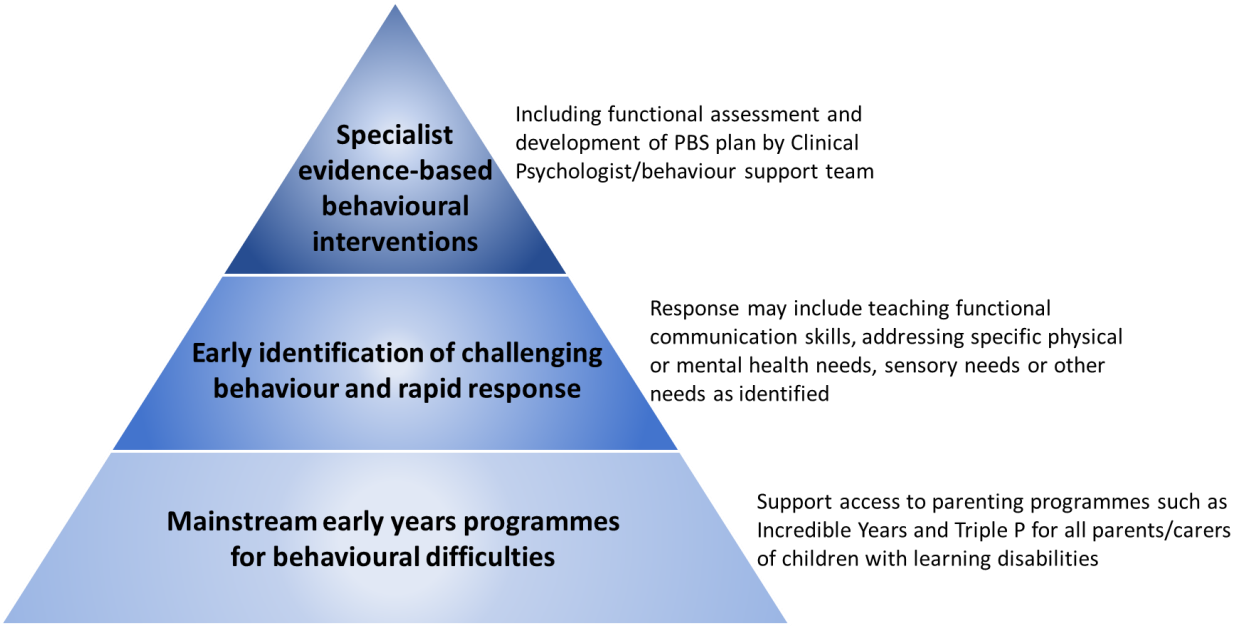

Figure 2: Recommended services to include within the local offer for children with LD at risk of or exhibiting behaviours that challenge

24. With relatively small numbers of children in each Local Authority area and in the context of huge change within the SEND and NHS systems, we recommend some national support to initiate improved local commissioning practice for children with LD whose behaviour challenges. This should include:
    - **Demonstration projects** to develop good practice and evaluate the impact
    - **An "invest to save" fund** to encourage local areas to develop their own solutions, supported by a learning set or network, to monitor results and disseminate findings.
    - **Improvements to national data collection** to include information on residential placements, provision by Independent schools and expenditure (see attached data supplement for more details).

25. Successive reforms over the past ten years (including *Valuing People*, *Aiming High*, and the current SEND reforms) have aimed to change the system of support for disabled children and young people, with a focus on better integrated local support. Despite this, *Transforming Care* found "a widespread failure to design, commission, and provide services which give people the support they need close to home, and which are in line with well-established best practice."

26. We have an opportunity now to put this right for the next generation. As well as improving the quality of children's lives, early intervention is likely to reduce the level of public spending over a lifetime on residential care for people with LD whose behaviours challenge. In the current economic climate, it is difficult to see how national Government and local commissioners can afford not to invest in the future of children with LD whose behaviours challenge.

References

[1] Public Health England (2014).

[2] Department for Education (2013). *Special Educational Needs in England, January 2013* [Online]. Available at: https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2013.

[3] Emerson, E., & Hatton, C. (2007). The mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry, 191,* 493-499.

[4] Totsika, V., Hastings, R.P., Emerson, E., Berridge, D. M., & Lancaster, G.A. (2011). Behavior problems at five years of age and maternal mental health in autism and intellectual disability. *Journal of Abnormal Child Psychology, 39,* 1137-1147.

Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology & Psychiatry and Allied Disciplines, 52,* 91-99.

[5] Einfeld, S. L., Ellis, L., Doran, C. M., Emerson, E., Horstead, S., Madden, R., & Tonge, B. J. (2010). Behaviour problems increase costs of care of children with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities, 3,* 202-209.

Emerson, E., & Einfeld, S. (2010). Emotional and behavioural difficulties in young children with and without developmental delay: A bi-national perspective. *Journal of Child Psychology & Psychiatry and Allied Disciplines, 51*, 583-593.

[6] Emerson, E., Blacher, J., Einfeld, S., Hatton, C., Robertson, J., & Stancliffe, R.J. (2014). Environmental risk factors associated with the persistence of conduct difficulties in children with intellectual disabilities and autistic spectrum disorders. *Research in Developmental Disabilities, 35,* 3508–3517.

[7] Emerson E., & Einfeld S. (2011). *Challenging Behaviour* (3rd ed.). Cambridge University Press, Cambridge: UK.

[8] Families Special Interest Research Group of IASSIDD (2014). Families Supporting a Child with Intellectual or Developmental Disabilities: The Current State of Knowledge. *Journal of Applied Research in Intellectual Disabilities, 27*, 420–430.

[9]Department of Health (2012). *Transforming Care: A national response to Winterbourne View Hospital* [Online]. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf.

[10] McGill, P. (2008). Residential Schools for Children with Learning Disabilities in England: Recent Research and Issues for Future Provision. *Tizard Learning Disability Review, 13*(4), 4-12.

[11] School Census data for England, January 2013 (special request)

[12]Cost estimate for 2008, from Regional Partnerships (July 2008), Analysis of out of authority placements. Uprated to reflect 2012/13 prices using the Hospital and Community Health Services (HCHS) Pay and Prices Index in Curtis (2013)

[13]Estimated average cost in 2011 of a 52-week boarding placement in a non-maintained or independent special school, from Clifford J., Theobald C (2012) Summary of Findings: extension of the 2011 cost comparison methodology to a wider sample, NASS/Baker Tilly. Uprated to reflect 2012/13 prices, as above.

[14] McGill, P., & Poynter, J. (2012). High cost residential placements for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 25*, 584-587.

[15] Learning Disabilities Census (2013) special data request. Data requested for 0-18 year olds inclusive.

[16] Community and Mental Health team, Health and Social Care Information Centre (2014). *Learning Disabilities Census Report – Further analysis* [Online]. Available at: http://www.hscic.gov.uk/catalogue/PUB14046/ld-census-further-sep13-rep.pdf.

[17] Community and Mental Health team, Health and Social Care Information Centre (2014). *Learning Disabilities Census Report – Further analysis*. Reference Table 6a [Online]. Available at: http://www.hscic.gov.uk/catalogue/PUB14046/ld-census-further-sep13-rep.pdf.

[18] Hastings, R. P., Allen, D., Baker, P., Gore, N. J., Hughes, J. C., McGill, P., ... & Toogood, S. (2013). A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities. *International Journal of Positive Behavioural Support*, *3*(2), 5-13.

[19] NICE (2013). *Antisocial behaviour and Conduct Disorder in Children and Young people: The NICE guidance on recognition, intervention and management* [Online]. Available at: http://www.nice.org.uk/guidance/cg158.

[20] Barlow, J., Smailagic., N., Bennett, C., Huband, N., Jones, H., & Coren, E. (2011). Individual and group based parenting programmes for improving psychosocial outcomes for teenage parents and their children. *Cochrane Database of Systematic Reviews, Issue 3*. Art. No.: CD002964. DOI: 10.1002/14651858.CD002964.pub2.

Barlow, J., & Stewart-Brown, S. (2000). Behavior problems and group-based parent education programs. *Journal of Developmental & Behavioral Pediatrics, 21*(5), 356-370.

[21] Plant, K. M., & Sanders, M. R. (2007). Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities, 28*, 362-385.

[22] Sanders, M. R., Turner, M. K., & Markie-Dadds, C. (2002). The Development and Dissemination of the Triple P-Positive Parenting Program: A Multilevel, Evidence-Based System of Parenting and Family Support. *Prevention Science, 3*(3), 173-189.

Nowak, C. & Heinrichs, N. (2008). A comprehensive meta-analysis of Triple P – Positive Parenting Program using hierarchical linear modelling: Effectiveness and moderating variable. *Clinical children and Family Psychology, Review, 11,* 44-144.

[23]Roberts, C., Mazzucchelli, T., Studman, L., & Sanders, M.R. (2006). Behavioral family intervention for children with developmental disabilities and behavioral problems, *Journal of Clinical Child and Adolescent Psychology, 35*, 180-193.

Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M.R. (2009). Stepping Stones Triple P: An RCT of a parenting program with parents of children diagnosed with autism spectrum disorder. *Journal of Abnormal Child Psychology, 37,* 469-480.

[24] The Social Research Unit (2014). *Investing in Children.* Dartington, United Kingdom http://investinginchildren.eu/search/interventions/Triple%2520p

[25]Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry*, *45*(8), 1338-1349.

[26] Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, *47*(4-5), 217-230.

Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *Journal Information*, *107*(6).

Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability*, *27*(3), 149-160.

Naylor, A., & Prescott, P. (2004). Invisible children? The need for support groups for siblings of disabled children. *British Journal of Special Education*, *31*(4), 199-206.

[27] Neece, C. L., Blacher, J., & Baker, B. L. (2010). Impact on siblings of children with intellectual disability: The role of child behavior problems. *Journal Information*, *115*(4).

[28]Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, *50*(3), 172-183.

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: a transactional relationship across time. *American journal on intellectual and developmental disabilities, 117*(1), 48-66.

[29] Emerson, E., & Brigham, P. (2014). Exposure of children with developmental delay to social determinants of poor health: cross-sectional case record review study. *Child: care, health and development*. DOI: 10.1111/cch.12144

[30] Arron, K., Oliver, C., Moss, J., Berg, K., & Burbidge, C. (2011). The prevalence and phenomenology of self-injurious and aggressive behaviour in genetic syndromes. *Journal of Intellectual Disability Research*, *55*(2), 109-120.

McClintock, K., Hall, S., & Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: A meta-analytic study. *Journal of Intellectual Disability Research*, *47*(6), 405-416.

[31] Burbidge, C., Oliver, C., Moss, J., Arron, K., Berg, K., Furniss, F., … & Woodcock, K. (2010). The association between repetitive behaviours, impulsivity and hyperactivity in people with intellectual disability. *Journal of Intellectual Disability Research*, *54*(12), 1078-1092.

[32] Gore, N. J., Hastings R., & Brady (under review for TLDR). Building the Case for Early Intervention: Making use of what we know to prevent emotional and behavioural difficulties amongst children with disabilities.

[33] O'Neill, R. E., Horner, R. H., Albin, R. W., Storey, K., & Sprague, J. R. (1990). *Functional analysis of problem behavior: A practical assessment guide*. Sycamore Publishing Company, Sycamore: IL.

[34] Horner, R. H., Dunlap, G., Koegel, R. L., Carr, E. G., Sailor, W., Anderson, J., … & O'Neill, R. E. (1990). Toward a technology of "nonaversive" behavioral support. *Journal of the Association for Persons with Severe Handicaps*, *15(*3), 125-132.

[35] Gore, N. J., McGill, P., Toogood, S., Allen, D., Hughes, J. C., Baker, P., … & Denne, L. D. (2013). Definition and scope for positive behavioural support. *International Journal of Positive Behavioural Support*, *3*(2), 14-23.

[36] Scotti, J. R., Evans, I. M., Meyer, L. H., & Walker, P. (1991). A meta-analysis of intervention research with problem behavior: Treatment validity and standards of practice. *American Journal on Mental Retardation*, *96*(3), 233-256.

Didden, R., Duker, P. C., & Korzilius, H. (1997). Meta-analytic study on treatment effectiveness for problem behaviors with individuals who have mental retardation. *AJMR-American Journal on Mental Retardation*, *101*(4), 387-399.

Carr, E. G. (ed.). (1999). *Positive behavior support for people with developmental disabilities: A research synthesis*. American Association on Mental Retardation, Washington DC: USA.

Marquis, J. G., Horner, R. H., Carr, E. G., Turnbull, A. P., Thompson, M., Behrens, G. A., … & Doolabh, A. (2000). A meta-analysis of positive behavior support. In R. Gersten, E. Schiller, S. Vaughn, & J. Schumm (eds.) *Contemporary special education research: Syntheses of knowledge base on critical instructional issues*. Lawrence Erlbaum Associates Inc., Mahwah: NJ.

Campbell, J. M. (2003). Efficacy of behavioral interventions for reducing problem behavior in persons with autism: A quantitative synthesis of single-subject research. *Research in Developmental Disabilities*, *24*(2), 120-138.

Didden, R., Korzilius, H., van Oorsouw, W., & Sturmey, P. (2006). Behavioral treatment of challenging behaviors in individuals with mild mental retardation: Meta-analysis of single-subject research. *American Journal on Mental Retardation*, *111*(4), 290-298.

McClean, B., Dench, C., Grey, I., Shanahan, S., Fitzsimons, E., Hendler, J., & Corrigan, M. (2005). Person focused training: a model for delivering positive behavioural supports to people with challenging behaviours. *Journal of intellectual disability research*, *49*(5), 340-352.

McClean, B., Grey, I. M., & McCracken, M. (2007). An evaluation of positive behavioural support for people with very severe challenging behaviours in community-based settings. *Journal of Intellectual Disabilities, 11*(3), 281-301.

Grey, I. M., & McClean, B. (2007). Service User Outcomes of Staff Training in Positive Behaviour Support Using Person-Focused Training: A Control Group Study. *Journal of Applied Research in Intellectual Disabilities*, *20*(1), 6-15.

[37] Oliver, C., Murphy, G. H., & Corbett, J. A. (1987). Self-injurious behaviour in people with mental handicap: a total population study. *Journal of Intellectual Disability Research*, *31*(2), 147-162.

Harris P. & Russell O. (1989). *The prevalence of aggressive behaviour among people with learning difficulties (mental handicap) in a single health district. Interim report*. Norah Fry Research Centre, Bristol: UK.

Qureshi, H. (1994). The size of the problem. In E. Emerson, P. McGill & J. Mansell (eds.) *Severe mental retardation and challenging behaviours: Designing high quality services.* Chapman & Hall, London: UK.

Allen, D., Lowe, K., Jones, E., James, W., Doyle, T., Andrew, J., … & Brophy, S. (2006). Changing the face of challenging behaviour services: The Special Projects Team. *British Journal of Learning Disabilities*, *34*(4), 237-242.

[38] Iemmi, V., Reid, C., Sholl, C., Buescher, A., Ferdinand, M., Trachtenberg, M., Knapp, M. (in press). Economic evaluation of intensive therapeutic intervention for children and adolescents with learning disabilities and challenging behaviours.

Iemmi, V., Jackson Brown, F., Knapp, M. (in press). Positive Behaviour Support Service (PBSS) in Bristol: An economic evaluation.