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For publication in Tizard Learning Disability Review

The NICE guidelines on learning disabilities and behaviour that challenges.

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Introduction

People with learning disabilities, of all ages, are at a higher risk than others of being born with and/or developing health difficulties. It is surprising, then, that until recently the well known national organization for developing guidelines on assessments and interventions in relation to health needs, i.e. NICE, the National Institute for Health and Care Excellence, had ignored people with learning disabilities. However, in 2013, NICE decided that it was time to change this, and there are now two guidelines relating to learning disabilities, one on behaviours that challenge and one on mental health needs, with more guidelines on the way.

Aim

This article aims to summarise the NICE guidelines on learning disabilities and behaviours that challenge, giving insights on how these were developed.

NICE

NICE, as an organization, was set up in 1999 and has two offices, one in London and one in Manchester. Over the years, NICE has published over 260 sets of guidelines on all aspects of health and, although the guidelines technically only apply in England, the devolved administrations of Northern Ireland, Wales and Scotland can consider adopting them.

The various guidelines are developed by multi-disciplinary teams, over a period of about 18 months, with the help of NICE staff, and are very strictly based on evidence, with particular attention being paid to systematic reviews and randomized controlled trials. The recommendations produced in the guidelines are advisory, not mandatory, but 'professionals are expected to take (the) guidelines fully into account, alongside the individual needs, preferences and values of their service users.' The quality standards, which follow the guidelines, are a set of statements designed to help health and social care providers and commissioners to improve the quality of services. The standards are deliberately phrased in such a way as to allow the measurement of progress against the standard (for example, through audit).

Developing the Guidance

The work of NICE is managed through a number of 'collaborating centres' which receive funding from NICE for their work, and through which NICE staff are directly employed. In the case of the learning disabilities guidelines on challenging behaviour, the relevant centre was the National Collaborating Centre for Mental Health, which also was responsible for the later mental health and LD guidelines (recently published), while for the LD service model guidelines (not yet published), the collaborating centre concerned is SCIE.

These collaborating centres are responsible for numerous guidelines and they adopt a very organised, very fixed process:

- Publication of the draft Scope of guideline, which details the questions to be considered
- Wide public and professional consultation on Scope, leading to a finalised version
- Appointment of the Guideline Development Group (GDG), by open advert and interview. The aim is to appoint an expert chair from the field, and a large multi-disciplinary group (of approximately 20 people), with appropriate experience. In our case, the GDG included clinical psychologists, psychiatrists, nurses, a GP, a pharmacist, a speech therapist, an OT, social workers, parent representatives, charity

representatives (from the British Institute for Learning Disabilities, BILD; Research Autism; and the Challenging Behaviour Foundation, CBF). It was hoped to appoint a teacher from a special school but this proved not to be possible. People with learning disabilities themselves were consulted through a parallel process of small group meetings, led by NICE.

- GDG then met on a series of full days, spread over about 18 months, in order to examine & discuss evidence in relation to all the questions in the scope. The evidence itself was collected by the NICE staff, allocated to the project, who completed very sophisticated literature searches and who presented the evidence they had found to each GDG meeting. The job of the GDG was to discuss and interpret the evidence.
- Once all the questions in the Scope had been considered, the Guidance was drafted & refined
- The Guidance then was sent out very widely for consultation. Individuals and organisations sent comments and these were then considered by the GDG and the Guidance was redrafted as necessary and then was published (May 2015)

Quality Standards

Following the publication of the Guidance, a completely separate group, which develops quality standards for NICE, considered the Guidance and drafted quality standards. This Quality Standards (QS) group again has a very fixed and rigid process and a limited time for developing the quality standards. A small number of the GDG group members were invited to join the standing QS committee for two half day meetings in order to draft quality standards, which were then sent out for consultation. The comments which came back were considered and the quality standards finalised (and published in October 2015).

What was in the Scope?

The Scope gave the formal definition of learning disabilities and the widely accepted definition of *behaviour that challenges*¹: culturally abnormal

¹ After discussion the group decided they preferred this term to the phrase 'challenging behaviour' because they felt it was less likely to be thought a

behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use, or result in the person being denied access to, ordinary community facilities (Emerson, 1995). The Royal College of Psychiatrists (2007) had a similar definition: 'Behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.'

The series of questions to be covered were listed in the Scope and included evidence relating to the identification and prevention of CB; family support; staff & family training; types of assessments, and types of intervention (behavioural, CBT, medication, etc).

How exactly is the evidence considered and analysed in the GDG?

NICE staff conduct a very thorough systematic literature review for each question in the Scope. The methods are thoroughly described in chapter 3 in the full guideline (page 34-51). Typically, in evaluating evidence, NICE use what is termed a PICO analysis – i.e. they specify what population (P); what intervention (I); what comparison groups (C); and what outcomes (O) were achieved for each study reviewed. They also examine risk of bias (due to the method of randomising, extent of blinding, attrition rates, etc, in each study). Providing there are suitable data, a meta-analysis and plot of standardised mean differences (intervention vs comparison) is performed and the health economics of any intervention is considered. The GRADE (Grading of Recommendations, Assessment, Development and Evaluation) approach is then employed to classify the quality of the evidence as high, moderate, low or very low (Guyatt et al 2011). All this, of course, works best where there are a large number of randomised controlled trials to consider, which is not the case in learning disabilities.

diagnosis and more likely to be considered socially constructed and dependent on the social environment. 'CB' will be used here at times, for brevity.

In the GDG meetings, this evidence is presented by NICE staff to GDG members and is discussed. Any published literature that GDG members are aware of, which has not been included, is considered and the group debates what guidance can be given on the basis of the evidence found.

It is important to note that NICE uses two different words in the Guidance: '**Offer**' and '**consider**'. The former is a stronger instruction than the latter, and the word used is determined by the strength of the evidence. NICE also sometimes uses the phrase 'do not offer' where it finds no evidence/negative evidence for some interventions.

What do these Guidelines say?

The full guidelines are 371 pages long and include:

- Preface & Introduction (definitions, prevalence & causes)
- Methods used in producing the Guidelines
- Experience of care (service users, families, carers)
- Interventions for carers
- Organisation and delivery of care (including training staff/carers)
- Risk factors and antecedents of CB
- Assessment
- Interventions
- Environmental interventions
- Psychosocial interventions
- Pharmacological interventions
- Reactive strategies
- Summary (see www.nice.org.uk/guidance/ng11)

The contents of the guidelines for the above topics are summarized below.

Experience of care

Two qualitative meta-syntheses were found which reviewed service users' and carers' experiences of care. In Griffith et al (2013) a review of 17 studies of service user experiences resulted in a number of themes: imbalance of power;

uneasy atmosphere; staff as a trigger; difficulty coping; restrictive practices (purpose, ethics, discomfort; distress & medication); opportunities for learning and benefitting (relationships; coping strategies etc). Most of these studies were of people with mild or moderate disabilities in residential care of some kind, often in hospital settings.

In Griffith & Hastings (2013) a review of 17 further studies resulted in themes of: love for the person with LD; altered identity for families; crisis management; a battle for (in)adequate services; low expectations & high hopes. Consultation by NICE GDG members with various service user groups and family and carer groups broadly supported the systematic reviews.

As a result, the Guidelines recommended professionals should:

- work in partnership with carers and service users
- offer independent advocates
- provide accessible information
- aim to provide support in the least restrictive settings and use least restrictive practices
- share their understanding with carers and service users
- adopt early intervention practices
- focus on increasing skills and quality of life, and not just on decreasing the levels of behaviour that challenges

Interventions for carers focused on their health and well-being

The GDG recognised that there was considerable evidence that caring could be extremely stressful, especially when the person cared for engaged in behaviour that challenges. The systematic review of the relevant evidence by NICE staff revealed 10 randomised controlled trials of interventions for improving family/carer health and well-being with various cognitive behavioural methods (for example, psychoeducation, stress management, mindfulness and other methods). There was moderate evidence in 5 of these of CBT being effective in reducing depression in family carers, and some lesser evidence of a better

quality of life and lower stress levels as a result. There was no health economics evidence.

The GDG considered that carers should always be involved in designing and providing any interventions intended to reduce the behaviour that challenges but there was no hard evidence of the benefit of this. Consequently the recommendations for support for carers were that:

- carers had a right to an assessment themselves and should receive respite care
- professionals should **consider** offering emotional support and/or interventions for ensuring good mental health for families
- professionals should **consider** family support and information groups
- professionals should involve family members in the design and delivery of interventions for the person with behaviour that challenges (this last recommendation was based on GDG consensus rather than evidence)

Organisation and delivery of care

It was recognised by the GDG that a major problem in the delivery of care was often encountered at the point of transition, especially between children's and adult's services (made worse by the poorer funding for adult services). However, no systematic reviews or RCTs were found of interventions to reduce these difficulties, and as a result the GDG could only recommend that professional should follow the generic NICE guidance on transitions.

The GDG also considered the evidence for training staff to deliver care, i.e. training them to intervene with people when they showed behaviour that challenges. While no RCTs were found, there was a systematic review of 14 studies in which positive behaviour support (PBS) training was provided for staff (MacDonald & McGill, 2013). The review found that the training did produce better staff knowledge about PBS and reductions in challenging behaviour. The recommendation was that staff should be trained in proactive strategies to reduce the likelihood of challenging behaviour, including:

- developing personalised daily activities

- adapting a person's environment and routine
- helping the person develop a functionally equivalent behaviour
- involving the person and their family in the support and intervention
- using strategies to calm and divert people showing early signs of distress
- delivering reactive strategies

It was also recommended that staff delivering interventions should use routine outcome measures of behaviour, and should monitor the progress of interventions (for example, using the Periodic Service Review).

Risk factors and antecedents

A good review of risk factors was found (McClintock et al, 2003) and it was updated. In all, there were 32 relevant studies (including 127,000 individuals altogether), producing sufficient data for a meta-analysis. A series of clear risk factors for behaviour that challenges emerged: autism (associated with more CB for most types of CB); severity of disability (most CB was worse in people with more severe disability, the exception being verbal aggression); epilepsy (associated with worsening of some forms of CB); mental health needs (which were associated with worse physical & verbal aggression); expressive & receptive communication (where the more limited the skills, the worse were all forms of CB); physical mobility (where there was some evidence of worse SIB); visual impairment (which seemed to result in worse SIB & stereotypy). Gender and hearing impairment were not overall associated with raised risks for behaviour that challenges.

The Guidelines recommended that carers and professionals needed to be aware of these personal risk factors such as a severe learning disability; autism; dementia; communication difficulties (expressive and receptive); visual impairment (which may lead to increased self-injury and stereotypy); physical health problems; and variations with age (peaking in the teens and twenties). In addition the Guidelines noted that a variety of environmental factors, such as abusive or restrictive social environments, barren environments, developmentally inappropriate environments, environments where disrespectful social relationships and poor communication were typical and/or

where staff do not have the capacity or resources to respond to people's needs were all liable to be associated with worsening challenging behaviour, as were changes to the person's environment (staff changes or moving to a new care setting).

Assessment

A large number of assessment measures for behaviour that challenges were found in systematic literature searches and the evidence on their reliability, validity and utility were considered by the GDG (see Chapter 8 of the full Guidelines). It was recommended, from the experience and expertise in the GDG, that any assessment of the person with LD and behaviour that challenges needed to be broad-based, to include the family and the person themselves, and their environment. Recommendations of suitable tools for assessing behaviour included the Aberrant Behavior Checklist, the Behavior Problems Inventory, the Challenging Behaviour Interview, and the Strengths and Difficulties Questionnaire, amongst others. Suitable tools for initial functional assessment of behaviour that challenges included brief structured assessments (such as the MAS, FAST and QABF), and suitable measures of mental health included the DASH-II, the PAS-ADD and the PIMRA. Measures of carer stress, burn-out and coping were also evaluated.

It was proposed that assessments should be phased, with a broad-based initial assessment and formulation, followed by a detailed and fuller functional assessment if behaviour that challenged persisted. The importance of taking account of the person's physical health, their environment (and recent changes to this), of family member and carers' views and resources, and using interviews and direct observations, as well as a review of records, were all recognised. It was recommended that Behaviour Support Plans should be developed with the person and their family/carers, and should include proactive strategies, such as improvements to the environment and appropriate activities, preventive strategies, skill development, reactive strategies, resource evaluation, and proper monitoring and review.

Preventative interventions

A small number of RCTs were found that showed that training family members and/or teachers to deliver early interventions for emerging CB for very young children with LD/autism was effective (eg Rickards et al 2007; Tonge et al 2006; Roberts et al, 2011). The Guidelines therefore recommended that:

- professionals should **consider** preschool interventions for children aged 3– 5 years with emerging/developing CB, to include the development of communication and others skills.

Evidence regarding underlying health problems and the prevention of challenging behaviour were also considered. There were 4 RCTs providing evidence of the importance of hand-held health records (Lennox et al, 2010; Turk et al, 2010) and/or annual health checks for uncovering previously undiagnosed health conditions in people with LD (eg. Lennox et al, 2007; Lennox, et al., 2010). Since these health conditions are known to often underlie a sudden worsening of CB, the Guidelines recommended that GPs:

- should **offer** an annual physical health check to children, young people and adults with an LD, using a standardised template, such as the Cardiff template.
- this health check should include a review of physical health but also of behaviour that challenges, any medication and behaviour support plans

Environmental interventions

In considering environmental interventions, one systematic review of interventions involving motivating operations (Simo-Pinatella et al., 2013) and 4 RCTs of sensory/activity interventions were found (Chan et al., 2005, Lundqvist et al., 2009, Martin et al., 1998 & Gencoz, 1997). The RCTs showed that sensory interventions, like Snoezelen rooms, were not effective (Chan et al, 2005; Lundqvist et al 2009; Martin et al 1998) while structured activity was effective (Gencoz, 1997) in reducing CB. As a result the Guidelines recommendations were that sensory interventions (for example, Snoezelen rooms) **should not be offered**, without a full functional assessment to establish the person's sensory profile. Secondly, it was recommended that professionals should **consider**

developing and maintaining a structured plan of daytime activity, to reduce CB. (Recommendations regarding motivating operations were included below).

Psychosocial interventions

There were a number of randomized control trials (15, of which 13 had sufficient data for analysis) showing that parent training was more effective than a control condition in producing a reduction in CB for children who were already showing CB, and there was also some evidence of increases in adaptive behaviour in the experimental groups. Many of these trials had taken place in Australia, often using variations of the Triple P Stepping Stones approach, for young primary school aged children. A further 4 RCTs tested different forms of parent training against each other (eg. group vs individual training) but mostly found only small non-significant differences. It was therefore recommended that:

- professionals should **consider** parent training programmes for parents or carers of children with an LD who were under 12 yrs of age.

In addition, there were 7 RCTs (4 with sufficient data for analysis) evaluating cognitive behaviour therapy (mostly anger management, eg. Willner et al. 2013), and one evaluating behaviour therapy (Hassiotis et al, 2009) as interventions for CB. There were also 7 RCTs of behavioural interventions for sleep problems in children and young people with LD (eg. Stores and Stores, 2004; Moss et al 2014) and a systematic review of single case studies (Heyvaert et al, 2012) showing that individualized behavioural interventions with a functional analysis were effective in reducing CB. As a result it was recommended that:

- professionals should **consider** personalised multi-element interventions that are based on behavioural principles & a functional assessment
- CBT was recommended (**'consider'**) for those with anger management difficulties
- behavioural interventions were recommended (**'consider'**) for sleep problems in children and young people.

It appeared that anger management and behaviour therapy were cost effective, economically (Felce et al, 2014; Hassiotis et al 2009). In addition there were 3

pilot trials of cost effectiveness of PBS services for children with LD and behaviour that challenges but these showed a very large variation of costs. Meanwhile, as regards parent training and sleep interventions, economic modeling suggested that, while there were no direct studies of the cost effectiveness of these, parent training may well be cost effective, especially for more severe behaviours, and that combination therapy (melatonin and psychosocial interventions combined) was the most cost effective intervention for sleep problems in children and young people with LD.

Pharmacological interventions

A number of studies have shown that pharmacological interventions are very commonly used for people with LD and behaviour that challenges, especially anti-psychotic medication, frequently in the absence of any evidence of a psychosis.

Remarkably, given the rarity of RCTs in learning disabilities, reviewing the evidence on medication led to over 30 RCTs being identified, over 20 for children and young people with LD, and the remainder for adults (though the quality of evidence for almost all the RCTs was rated as 'low'). The RCTs, for children and young people with LD, compared risperidone (n=5) or aripiprazole (n=2) against placebo, risperidone vs aripiprazole (n=1) and olanzapine vs haloperidol (n=1). The medication did generally lower challenging behaviour but was associated with severe side effects (sedation, weight gain, elevated prolactin). Two RCTs of withdrawal of risperidone and aripiprazole showed CB did recur after withdrawal of medication, but side effects also reduced. In addition, there were three RCTs of anti-convulsants, 4 RCTs of other medications (one each for GABA; anti-oxidants, omega-3, ginkgo-biloba), which suggested some effectiveness of anti-convulsants, but no effect of omega-3 or ginkgo-biloba. Finally, for children and young people, there were 4 RCTs of melatonin vs placebo for sleep problems, suggesting melatonin was effective in reducing sleep problems.

For adults with LD, there were 3 RCTs of risperidone vs placebo, and one of haloperidol vs placebo, giving mixed evidence of effectiveness for reducing CB.

Two RCTs compared medications (one risperidone vs haloperidol, one olanzapine vs risperidone), giving mixed evidence of benefits. There was one RCT of lithium vs placebo, suggesting lithium did reduce CB somewhat. There were also 3 RCTs with adults examining the effects of withdrawal of zuclopenthixol, suggesting increases in CB occurred but also reductions in side-effects on medication withdrawal. Finally, there were two systematic reviews of naltrexone and clomipramine for self-injury (suggesting naltrexone was effective but clomipramine was not).

The economic evidence suggested that while risperidone may be cost effective for children, aripiprazole was not (it is much more expensive), and that neither risperidone nor haloperidol were cost effective for adults. For sleep problems melatonin was considered cost effective.

The Guidelines recommended that professionals should:

- **consider** medication for coexisting mental or physical health problems underlying CB, as for any other population.
- **only offer antipsychotic medication in combination with psychological or other interventions for the reduction of CB**
- only **consider** antipsychotic medication to manage behaviour that challenges if:
 - psychological or other interventions alone had not produced change within an agreed time or
 - treatment for any coexisting mental or physical health problem had not led to a reduction in the behaviour or
 - the risk to the person or others was very severe (for example, because of violence, aggression or self-injury).

Psychiatrists were advised that if they decided to use medication, they needed to ensure they used minimum doses, had regular and frequent reviews, used proper data (not just word of mouth) on the effects, and side effects, of the medication, and that they should ensure medication was only used alongside psychological forms of intervention.

Reactive strategies

Reactive strategies were considered to include physical holds/restraint, mechanical and manual restraint, seclusion or 'time out' and prn medication. No RCTs of such interventions were found but there was one systematic review of single case and small n studies (Heyvaert et al., 2014), which suggested that such strategies could lead to a reduction in CB.

It was recommended that professionals should

- **Consider** using reactive strategies as an initial intervention & introduce proactive interventions as soon as possible
- Ensure that the reactive strategies were ethically sound, least restrictive, and in the person's best interests

It was also recommended that such strategies should only be used alongside a risk assessment (as described in the NICE violence and aggression guidance, see www.nice.org.uk). Moreover it was recommended that such procedures should be fully documented, reviewed very regularly, and only ever used alongside a Behaviour Support Plan.

Quality Standards

In the quality standards meetings that followed the publication of the Guidance, eight quality standards were chosen, that were all considered measurable and important reflections of the use of the NICE guidelines on behaviour that challenges:

1. Annual health checks
2. Parent training programmes (for parents of children under 12 yrs)
3. Early functional analysis
4. Behaviour Support Plans (named co-ordinator; review)
5. Personalised day activities (to be specified in the behaviour support plan)
6. Antipsychotics only to be used with psychosocial interventions
7. Regular multi-disciplinary review of anti-psychotics (in 12 wks; then 6 mthly)
8. Documented multi-disciplinary review after use of restrictive interventions (every time)

Full details of the quality standards can be found at www.nice.org.uk/guidance/qs101

Impact of NICE guidelines

Health organisations are expected to take note of NICE guidance and to follow all new guidelines, even though they are not technically mandatory. Most NHS Trusts, for example, have procedures to keep staff aware of new guidance and they encourage staff to conduct audits to examine how well the Trust is following the guidance. NICE's quality standards are deliberately phrased in such a way that they are each measurable, for exactly this purpose. In the next few years it will be important to look at the results of these audits.

The guidelines also provide an opportunity for CQC, the Care Quality Commission, to ensure that it is measuring the extent to which health organisations are following the guidance. Likewise, carers can use the guidance to argue for health support that meets the standards set, and for this reason it is important for them to be aware of the guidance and associated standards. For example, given that one of the standards is for parent training programmes for young children, carers can use this to argue that these should be available in their local area.

What NICE guidance does *not* do is to provide advice about new assessments or interventions that have yet to be tested in research. They are often criticised for this, especially in fields where research funding is extremely limited, as in learning disabilities. One of the ways in which NICE tries to ameliorate this problem is by linking research suggestions to its guidelines, and advising NIHR, the National Institute for Health Research (the major research funder for health in the UK) of these. In the case of the guidelines on learning disabilities and behaviour that challenges, announcements of research funding are already beginning to appear. It is the responsibility of all of us to continue to argue for better research funding and better services for people with learning disabilities.

References

Chan S, Fung MY, Tong CW, Thompson D. (2005). The clinical effectiveness of a multisensory therapy on clients with developmental disability. *Research in Developmental Disabilities, 26*,131-42.

Emerson, E . (1995). *Challenging behaviour: analysis and intervention in people with learning disabilities*. Cambridge: Cambridge University Press.

Gencoz, F. (1997). The effects of basketball training on the maladaptive behaviors of trainable mentally retarded children. *Research in Developmental Disabilities, 18*, 1-10.

Griffith, G. & Hastings, R.P. (2013). He's hard work, but he's worth it.' The experience of caregivers of individuals with intellectual disabilities and challenging behaviour – a thematic synthesis of qualitative research *Journal of Applied Research in Intellectual Disabilities, 27*, 401–19

Griffith, G.M., Hutchinson, L., Hastings, R.P. (2013). "I'm not a patient, I'm a person": the experiences of individuals with intellectual disabilities and challenging behavior - A thematic synthesis of qualitative studies. *Clinical Psychology: Science and Practice, 20*, 469-88.

Guyatt G, Oxman AD, Akl EA, Kunz R, Vist G, Brozek J, et al. (2011). GRADE guidelines: 1. Introduction - GRADE evidence profiles and summary of findings tables. *Journal of Clinical Epidemiology, 64*, 383-94.

Hassiotis A, Robotham D, Canagasabay A, Romeo R, Langridge D, Blizard R, et al. (2009). Randomized, single-blind, controlled trial of a specialist behavior therapy team for challenging behavior in adults with intellectual disabilities. *American Journal of Psychiatry, 166*, 1278-85.

Felce D, Cohen D, Willner P, Rose J, Kroese B, Rose N, et al. (2014). Cognitive behavioural anger management intervention for people with intellectual disabilities: costs of intervention and impact on health and social care resource use. *Journal of Intellectual Disability Research*.

Heyvaert M, Maes B, Van Den Noortgate W, Kuppens S, Onghena P. (2012). A multilevel meta- analysis of single-case and small n research on interventions for reducing challenging behavior in persons with intellectual disabilities. *Research in Developmental Disabilities, 33*, 766-80.

Heyvaert M, Saenen L, Maes B, Onghena P. (2014). Systematic review of restraint interventions for challenging behaviour among persons with intellectual disabilities: focus on effectiveness in single-case experiments. *Journal of Applied Research in Intellectual Disabilities, 27*, 493–510.

Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. (2007). Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *International Journal of Epidemiology, 36*,139-46.

Lennox N, Bain C, Rey-Conde T, Taylor M, Boyle FM, Purdie DM, et al. (2010). Cluster randomized- controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings. *Journal of Applied Research in Intellectual Disabilities, 23*, 303-11.

Lundqvist LO, Andersson G, Viding J. (2009). Effects of vibroacoustic music on challenging behaviors in individuals with autism and developmental disabilities. *Research in Autism Spectrum Disorders, 3*, 390-400.

MacDonald, A. & McGill, P. (2013). Outcomes of staff training in positive behaviour support: a systematic review. *Journal of Developmental and Physical Disabilities, 25*,17-33.

Martin NT, Gaffan EA, Williams T. (1998). Behavioural effects of long-term multi-sensory stimulation. *British Journal of Clinical Psychology, 37*, 69-82.

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*, 405-16.

Moss AH, Gordon JE, O'Connell A. (2014). Impact of Sleepwise: an intervention

for youth with developmental disabilities and sleep disturbance. *Journal of Autism and Developmental Disorders*, 1-13.

NICE Guideline (2015). *Challenging Behaviour and Learning Disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges*. British Psychological Society and Royal College of Psychiatrists.

Royal College of Psychiatrists & British Psychological Society (2007). *Challenging behaviour: a unified approach*. College Report CR144. London: Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists.

Rickards AL, Walstab JE, Wright-Rossi RA, Simpson J, Reddihough DS. (2007). A randomized, controlled trial of a home-based intervention program for children with autism and developmental delay. *Journal of Developmental and Behavioral Pediatrics*, 28, 308-16.

Roberts J, Williams K, Carter M, Evans D, Parmenter T, Silove N, et al. (2011). A randomised controlled trial of two early intervention programs for young children with autism: centre- based with parent program and home-based. *Research in Autism Spectrum Disorders*, 5, 1553-66.

Simo-Pinatella D, Font-Roura J, Planella-Morato J, McGill P, Alomar-Kurz E, C. G. (2013). Types of motivating operations in interventions with problem behavior: a systematic review. *Behavior Modification*, 37, 3-38

Stores, R. & Stores G. (2004). Evaluation of brief group-administered instruction for parents to prevent or minimize sleep problems in young children with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, 17, 61-70.

Tonge B, Brereton A, Kiomall M, Mackinnon A, King N, Rinehart N. (2006). Effects on parental mental health of an education and skills training program for parents of young children with autism: a randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45, 561-69.

Turk V, Burchell S, Burrha S, Corney R, Elliott S, Kerry S, et al. (2010). An

evaluation of the implementation of hand held health records with adults with learning disabilities: a cluster randomized controlled trial. *Journal of Applied Research in Intellectual Disabilities*, 23,100-11.

Willner P, Rose J, Jahoda A, Stenfert Kroese B, Felce D, MacMahon P, et al. (2013) A cluster randomised controlled trial of a manualised cognitive-behavioural anger management intervention delivered by supervised lay therapists to people with intellectual disabilities. *Health Technology Assessment*, 17:i-xv+1-138.