Title

Behaviours that challenge in Adults with Intellectual Disability; Overview of Assessment and Management

Angela Hassiotis MA PhD FRCPsych*

Professor of Psychiatry of Intellectual Disabilities, UCL Division of Psychiatry and Hon Consultant Camden and Islington Foundation NHS Trust and Camden Learning Disability Service

a.hassiotis@ucl.ac.uk

6th Floor, Maple House, 149 Tottenham Court Road, London W1T 7BN

*: correspondence

Sonya Rudra MRCPsych MBBS BSc

Higher trainee in Psychiatry of Intellectual Disability, North London HigherTraining Scheme and Fellow in Medical Education, East London NHS Foundation Trust

sonya.rudra@nhs.net

Abstract

Up to a fifth of people with intellectual disabilities display behaviours that challenge which has a significant impact on the person's health and quality of life. The National Institute for Health and Care Excellence (NICE) recommends that in adults, positive behaviour support should be first line treatment. Psychotropic medication does not appear to confer any clinical benefits beyond risk reduction in acute situations. However, very few non-pharmacological treatments have clear evidence of clinical and cost effectiveness and therefore, often, there is a dearth of advice as to which components or interventions would be helpful in order to reduce the display of behaviours that challenge. To our knowledge there is no single model that has been developed to provide a clear path from understanding the behaviour to the implementation of a therapeutic approach for such a complex clinical problem. In this article we describe a stepped care model that needs to be further operationalised in the assessment and management of behaviours that challenge in adults with intellectual disabilities

.

Learning objectives

After reading this article you will be able to:

- Understand the complexities associated with the treatment of behaviours that challenge in adults with intellectual disabilities
- Consider the relative importance of non-pharmacological approaches to the management of behaviours that challenge in adults with intellectual disabilities
- Become aware of a stepped and structured approach to the management of behaviours that challenge in this population

_____

Behaviours that challenge are a significant clinical problem in the field of intellectual disabilities. Recent prevalence rates indicate that it is present in almost a fifth of people with intellectual disabilities and often different types of behaviours that challenge coexist, for example aggressive behaviour towards others with self-injury or stereotypy (Bowring et al, 2017; Crocker et al., 2006). The definition of behaviours that challenge most often used identifies the behaviour as challenging to those who support or come into contact with a person with an intellectual disability, recognises that it may be a means of communicating unmet need and such behaviours can result from an interaction between intrinsic and extrinsic-to-the-person factors, the latter including systems of provision of care (Emerson, 2001a).

Risk factors associated with the display of behaviours that challenge include severe intellectual disability, autism, communication deficits, demographics such as male sex, and physical conditions such as epilepsy. In particular, severe intellectual disability is mostly associated with self-injury and stereotypies whilst male sex with outwards directed aggression (Visser et al., 2015; Crocker et al., 2013).

People with intellectual disabilities who display behaviours that challenge suffer from a number of poor outcomes including physical health problems, increased risk of hospital admissions and increased use of restrictive practices (Emerson & Enfield, 2011; Lloyd & Kennedy, 2014). As many as two thirds may be prescribed psychotropic medication especially sedatives, antipsychotics and antidepressants (Hassiotis et al, 2018). The rates of these prescriptions may vary over time with antidepressants currently being the most prescribed psychotropic although unclear whether it is for its primary indication of treating affective disorders (Sheehan et al, 2015; Branford & Shankar, 2022). Despite evidence that pharmacological interventions may do little to reduce behaviours that challenge on their own, they are often seen as the first or necessary option in cases of elevated risk during a crisis and also prescribed for the management of irritability, hyperactivity or aggression in autism spectrum disorders in children (McQuire et al, 2015). The evidence in adults is equivocal mainly due to the lack of good quality randomised controlled trials of pharmacological treatments. Many parents of people with intellectual disabilities who display behaviours that challenge along with clinicians and arms-length bodies have been advocating for the reduction of psychotropic medication through national initiatives such as audits of prescribing practices and the STOMP and STAMP (Stopping over medication of people with a learning disability, autism or both-Supporting Treatment and Appropriate Medication in Paediatrics, NHS England; https://www.england.nhs.uk/publication/stomp-stamp-pledge-resources/) campaigns. It is recognised that medication side effects and the multi-morbidity and polypharmacy that is often seen in a vulnerable population such as people with intellectual disabilities can be detrimental to their overall health and wellbeing and that non-pharmacological approaches must be made available. To address this global concern and to optimise psychotropic prescribing, professionals, academics and experts by experiences have produced clinical guidelines aimed at clinicians and oversight organisations to ensure high care standards in this area (RCPsych, 2016; National Centre for START Services, 2020).

The National Institute of Health and Care Excellence in England, as well as similar organisations in other countries, have produced guidelines to support the assessment and management of behaviours that challenge in the community, with an emphasis on psychosocial approaches. The NICE Guideline 11 (2015) includes specific recommendations about the structure of care to be delivered to people with intellectual disabilities and promotes a holistic understanding of behaviours that challenge. The guideline makes specific mention of functional assessment of behaviour, preventive strategies, interventions for family carers and the use of behaviour support plans. For adults, there is special reference to interventions based on behavioural management and to Cognitive Behaviour

Therapy for anger management. Other modalities include availability ofstructured daytime activities and an assessment of the person's sensory profile prior to considering use of sensory interventions. The guideline also cautiously suggests that medication, if needed, should not be used exclusively but *in combination* with psychological approaches and that it should be reviewed within 6 weeks of treatment commencing. NICE Quality standard [QS101] identify12 quality standards that refer to person and service related care elements. These statements are developed in such a way as to allow the measurement of progress against the standard e.g. through audit.

One of the principal challenges in developing the guideline was the lack of high quality randomised controlled trials that could further guide the recommendations for which psychological interventions to use, especially in adults. In the intervening years, there has not only been an increase in the number of randomised controlled trials of psychosocial (also called complex, Skivington et al, 2021) interventions for behaviours that challenge funded and published but there has also begun a debate about the need for increasing the range of approaches to incorporate current understanding of the multiple underpinning aetiologies of such behaviours, which range from neurocognitive to environmental to emotional to whole systems.

In this context, single interventions may be less effective in the face of multiple interactions and comorbidities in this population group. As Woodcock and Blackwell (2020) argue "existing approaches have not provided the whole solution for everyone".

Assessment and Formulation

Identifying the cause behind the display of behaviours that challenge can be difficult as the clinicians must establish a change from the person's usual behaviour and often can only rely on carer reports which can be inconsistent. Further, presentations of mental illness may be atypical especially in adults with more severe intellectual disabilities and therefore, an accurate description of sustained changes in sleep or appetite (indicating at least moderate depression) may not be available. Research in other mental disorders, e.g. dementia, has identified several frameworks that may be used to provide a holistic conceptualisation of behaviours that challenge; The Unmet Needs Framework (Cohen-Mansfield, 2013) theorises that the person who displays behaviours that challenge tries to communicate a need or a distressed emotional state. Unfortunately, diagnostic overshadowing, whereby behaviour is attributed solely to the intellectual disability, rather than a treatable cause, still occurs. This

can lead to delayed diagnosis of an underlying physical or mental health condition and, on occasion, to death (Ali and Hassiotis, 2008).

Given the diagnostic challenges, careful formulation is key in the assessment of an individual who displays behaviours that challenge. Formulation allows professionals in a clinical situation to generate hypotheses about the onset, maintenance and resolution of psychological problems in a patient seeking help. Ultimately, the formulation leads to the delivery of interventions and further revisions of the original formulation.

Although there are different understandings of this process, Sidhu (2020) defined formulation as professionals "*making sense of a person's life, by thinking through their problems, how they might have developed in the first place and what keeps them going".* Therefore, some aspect of formulation is part of every assessment of challenging behaviour. Formulation can be done informally or using frameworks such as "Five Ps" (Ingham et al., 2008). Formulation can be done by an individual or a team and may be used to identify unmet need and several versions of the approach may be in operation in a service specific to a professional group.

Team formulations are particularly valuable in intellectual disabilities as they involve the collaborative development of a formulation by the whole team working with the person with intellectual disabilities (Hymers., 2021). Involving the multi-disciplinary team and utilising a biopsychosocial approach in these formulations is vital in order to integrate different strands of information. A systematic review (Geach, Moghaddam, DeBoos, 2017)included 11 articles that have used team formulations to develop treatment plans for people with intellectual disabilities who access services. It identified three types of practice that could be defined as team formulation including, "*highly structured consultation*, *reflective practice meetings* and *informal sharing of ideas".*

Team formulations have also been used to enhance the patient contribution to care planning, through networks such as Quality Improvement Programmes. In one inpatient service (Rowe & Nevin, 2014), patient input was encouraged in multidisciplinary team case formulations using the biopsychosocial model whilst acknowledging the significant resource implications required to achieve this aim. Ingham, Clarke and James (2008) showed the multi-disciplinary team used biopsychosocial formulation to improve direct care staff attitudes towards and understanding of people with intellectual disabilitieswho display behaviours that challenge. They found that workshops on how to use team formulations had positive outcomes for staff. Turner, Cleaves and Green (2018) reported on the use of team formulation in an inpatient unit for people with intellectual disabilities. Staff found that the use of team formulation assisted them in gaining greater understanding of the patients although

Hymer, Dagnan and Ingham (2021) identified "*poor communication and interaction and inconsistent staff attendance*" as factors that hinder team formulation meetings. More recently, Ingham et al (2020) published on the psychometric properties of the Formulation Understanding Measure that evaluates team formulation for direct care staff.

However, as is the case in other fields, there is a poor description of harms as a result of applying the team formulation model or of the outcomes that could be directly linked to it. (Geach, Moghaddam, DeBoos, 2017) , It is argued that formulations can be resource intensive, require training in order to be delivered effectively and they may not be needed at all times (James et al, 2021). There is not a universally agreed perspective on what should and should not be included in the process of developing a formulation and a systematic review (Holle et al 2016) of individualised formulation-led care failed to identify one that is superior to the others.

The stepped care model

Taking together the existing literature, we argue that it can foster variability in practice which has consequences for the care of people with intellectual disabilities. We propose that a revised paradigm of the care pathway for the assessment and management of behaviours that challenge may sidestep some of the limitations of the models currently in use. Whilst obtaining in depth information about a person is an important step in the care pathway, it must be balanced with the provision of actions and strategies that will ultimately demonstrate improved outcomes for the adults with intellectual disabilities.

The assessment of a person who displays behaviours that challenge has two objectives: first, to help the person with intellectual disability, and/or family or direct care staff to cope with the behaviour and second, to aid recovery and the adoption of prosocial behaviours via the delivery of non-pharmacological interventions (Hastings 2010).

A stepped care approach is a useful structured way in which to tailor formulations and hence interventions to the efficient management of the presenting complaint. Multi-disciplinary team formulations utilising a biopsychosocial approach usually require skilled practitioners to carry them out. Therefore, it stands to reason that there should be a tiered route to these more intensive supports depending on the nature and severity of the presentation. Furthermore, such an approach is arguably more helpful to take in the case of a disorder that remits and relapses over time.

According to this approach, initial steps may require little or no action from family carers or direct care staff. Behaviours that are very low risk of harm to the person or others (including

to physical health and general wellbeing) could be tolerated whilst various factors that might precipitate the onset of such behaviours are explored. Common problems that should be excluded early on include pain, side-effects of medication, pre-existing or emerging mental ill-health, constipation and delirium. It is advisable for direct care staff or family carers to raise concerns with the health teams the person is registered with who will advise on next steps and facilitate, if needed, contact with General Practitioners (GPs) for screening or review.

Once any immediate concerns are addressed, it is important to use low intensity interventions, e.g. functional assessment, to understand the reasons for the behaviour that challenges. Functional assessment of behaviour that challenges is used with many population groups including without intellectual disabilities to identify the cause of the behaviour leading to the development of hypotheses that are then tested to find a solution. It comprises the collection of data from direct observations of the person with intellectual disability and indirectly from carers, followed by functional analysis. The latter assumes that the function of behaviour relates to one of four reasons: 1. Attention from social or caring network; 2. Escape/avoidance of a situation, person or activity; 3. Tangible in obtaining a preferred object or activity, and; 4. Sensory, in that the behaviour fulfils a sensory need (Cooper, Heron & Heward, 2014).

Non-specialist health professionals can be trained to carry out these assessments with the view of then developing a positive behaviour support (PBS) plan that guides carers to focus on areas of change which are likely to improve communication between family, the person, care staff and professionals. This may include development of joint understanding of the person's preferences and personal histories, improvements in the physical environment, finding new occupational opportunities, and anticipation of times when behaviours that challenge may be more likely to occur, e.g. at the time of giving personal care.

At the same time, there should also be attention to the family carers' and direct care staff wellbeing and resilience with the attention on gradually building competencies that aid both the management (reactive) and prevention of behaviours that challenge. Competencies must include the use of basic de-escalation skills and the assessment of triggers for aggressive behaviour, in particular.   Basic de-escalation skills may overlap to an extent with and can be supplemented by distraction or delaying techniques depending on the level of the adult's intellectual disability. In many cases, this may be enough to bring about resolution of an episode of behaviours that challenge (Inglis & Clifton, 2013). Tools to help anticipate and plan for managing risk due to aggressive challenging behaviour are available and tested in

several mental health facilities but also in community settings and emergency departments (Hassiotis, Almvik, Fluttert, 2022).

If those initial strategies do not reduce or eliminate the behaviours that challenge or risk is increasing, the next step is to turn to manualised interventions that are carried out by trained clinicians. Interventions include specialist therapies such as Cognitive Behaviour Therapy for anger management, Dialectical Behaviour Therapy and Mindfulness for behaviours that challenge and Intensive Intervention to enhance communication in people with more severe cognitive limitations. More recently, there is interest in the utilisation of Eye Movement Desensitization and Reprocessing (EMDR) in the treatment of behaviours that challenge in adults with intellectual disabilities who have experienced trauma (Karatzias et al, 2019). These interventions, when available, are usually delivered by professionals from Specialist Community Intellectual Disability Services or Mental Health Services through locally agreed clinical pathways, e.g. Increasing Access to Psychological Therapies (see Box 1 for a list of interventions that have been adapted or developed for people with intellectual disabilities and behaviours that challenge). This step also includes a range of other approaches along the biopsychosocial spectrum for which there is evidence, such as improving physical health, exercise and activities regimes, social interaction and the use of systematic medication reviews in order to optimise prescription and administration of medication (https://evidence.nihr.ac.uk/alert/wheld-dementia-care-homes-person-centred-care/).

Box 1: Single Interventions for behaviours that challenge in adults with intellectual disabilities

*Group Cognitive Behaviour Therapy (CBT) for Anger Management (Willner et al, 2013)

Dialectical Behaviour Therapy (Sakdalan, Shaw & Collier, 2010)

Mindfulness informed approaches (Griffiths et al, 2016) including hybrid interventions (e.g. Mindfulness based CBT Singh et al, 2008; Mindfulness based Positive Behaviour Support, Singh et al, 2018)

*Who Challenges Who? (Hastings et al, 2018)

*STEPS: Steps to Effective Problem-solving (Ailey et al, 2018)

*Staff Training in Positive Behaviour Support (Hassiotis et al 2018; McGill et al 2018)

Eye Movement Desensitization and Reprocessing (EMDR) (Karatzias et al, 2019)

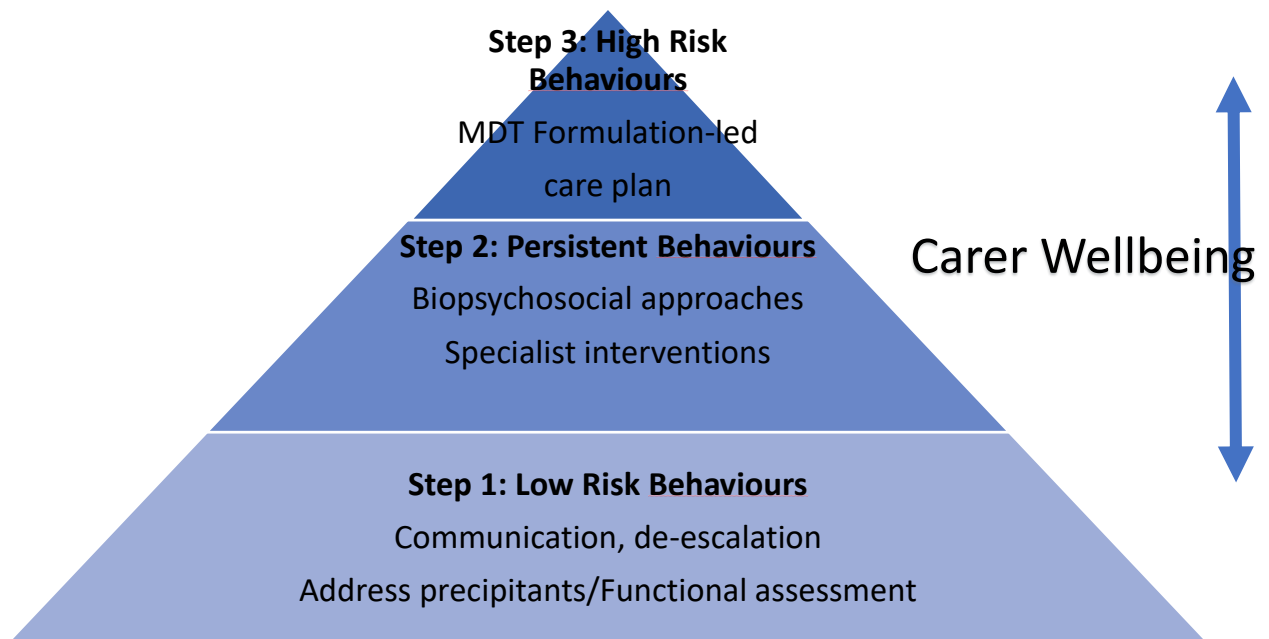* there is at least one adequately powered randomised controlled trial of clinical and/or cost effectiveness

The final step is for the most high risk cases or those who have not responded to steps 1 and 2. These cases are likely to require an in-depth multi-disciplinary team formulation for a more detailed understanding of the underlying problems leading to a conceptualisation of the intervention that may be needed within the formulation-led care plan. In the most serious cases it is likely that clinicians may need to consider the option of psychiatric inpatient admission or of alternatives such as crisis team intervention or respite care.

An important part of the assessment and management of behaviours that challenge is the family and paid carer psychological wellbeing. There is evidence to show that family carers living with children who display behaviours that challenge can experience psychological harm (Flynn et al, 2018). However, the authors conclude that the evidence for the impact of particularly aggressive challenging behaviour on paid carers' psychological wellbeing is equivocal with some studies showing an association and others not. Therefore, we propose that part of the assessment should include a discussion of the carer's psychological wellbeing and that simple advice and resources be made available where there appear to be concerns raised.

During all of the proposed steps, materials to monitor impact of treatment and symptom trajectories should be used to support personalised care. Please also see Ali, Blickwedel and Hassiotis (2014).

Figure 1 illustrates the stepped care model for the assessment and management of behaviours that challenge. As indicated by the double headed arrow, the stepped care model may not function in an entirely linear way and patients may go up or down the model and even skip steps in the model with their complex presentations of behaviours that challenge. Behaviours that challenge can become chronic if not addressed effectively and efficiently. Therefore, if there is no response at lower stages in the model, it is important to move up to the next stage.

Figure 1: Stepped care approach for managing behaviour that challenges

Step 3: High Risk Behaviours

MDT Formulation-led care plan

Step 2: Persistent Behaviours

Biopsychosocial approaches

Specialist interventions

Step 1: Low Risk Behaviours

Communication, de-escalation

Address precipitants/Functional assessment

Carer Wellbeing

Box 2 is a presentation of a Behaviours that Challenge pathway as an example of care currently provided in one service. The pathway is multi-disciplinary, led by staff trained as Positive Behaviour Support coaches and includes regular basic training in behavioural principles of all service staff as a minimum.

Box 2: A service pathway for the management of behaviours that challenge; what should be included

Set Objectives (who to work with; prevention or treatment only?)

New referrals and crisis management

Initial assessment (who will complete it) and risk assessment

Outcome of initial screening-is referral accepted to the pathway following multidisciplinary discussion. Consider allocation of care co-ordinator(s), plan for assessment and interventions, degree of urgency and level of risk

Those on the pathway to receive *profession specific input* (e.g. PBS trained professionals, Speech and Language Therapy, Occupational Therapy, Psychiatric review, Nursing, Social Work) and *network involvement* (e.g. carer education and monitoring plan)

Use of outcome measures (*Behaviour Problem Inventory) and multi-disciplinary/multi-agency reviews

If progress satisfactory decide on whether to discharge and involve carer and service user to feedback on experience

Contact with care coordinator at 6 months post discharge

There are currently 80 intensive support teams identified in England which follow an enhanced or independent care model (Hassiotis et al, 2020). Although these do not usually manage crises arising from behaviours that challenge, may have a role to play within services. They could complement the clinical pathway, providing an enhanced response to persistent behaviours and would fit at step 2 or 3 depending on localised operational policies.

Conclusion

The stepped care model described in this paper follows evidence and best practice found in many different guidelines and used by the majority of clinicians, although there is variation across services. Since the publication of the NICE guideline 11 (2015), there is cautious optimism generated by emerging directions in understanding the underlying aetiologies of behaviours that challenge and the relative proliferation of adapted or newly developed psychosocial therapies for the treatment of such behaviours.

However, clear evidence drawn from large randomised controlled trials is still lacking; the health economic evaluation of psychological interventions in the field of intellectual disabilities is in its infancy with only a few studies including such approaches (Romeo & Molosankwe, 2010; Hunter, 2016; Hunter et al, 2020).   Both of those are necessary conditions for the rollout of the interventions in the NHS intellectual disabilities services and beyond. Good quality evidence is pivotal in offering interventions that work in pragmatic conditions, are cost effective and do not cause harm. Whilst behavioural approaches are the mainstay of management of behaviours that challenge, they fail a significant minority of cases. As multiple comorbid conditions contribute to the complexity of the display of behaviours that challenge this should also be reflected in the treatment approaches used; one such is the standardised delivery of care alongside a multimodal and multicomponent perspective using a logical needs led formulation and, most importantly, specific intervention options.

We have outlined a revised approach to the concepts of assessment and management of behaviours that challenge drawing from existing and emerging evidence utilising a variety of

11

concepts, some outside the field of intellectual disabilities. As such, this is a companion to a previous paper by Ali, Blickwedel & Hassiotis (2014); in the present overview we propose a framework that if further developed can lead to a more efficient tailoring of resources and skills to addressing behaviours that challenge and improve the lives of people with intellectual disabilities and of their family carers.

We have not discussed the management of behaviours that challenge in autistic individuals. Overall, for autistic adults with coexisting intellectual disabilities and autism, behaviours that challenge appear to correlate with severity of autism symptoms, of intellectual disability (McCarthy et al, 2009). Whilst principles of management as described in this article may apply, more autism specific interventions will be required that are tailored to underpinning processes such as physiological hyper- or hypo- arousal . (McDonnell et al, 2015). The National Autistic Society in the UK, has produced guidance to support carers at times when the autistic child or adult display behaviours that challenge (https://www.autism.org.uk/advice-and-guidance/topics/behaviour/distressed-behaviour/all-audiences). However, the management of behaviours that challenge for autistic people without intellectual disabilities is outside the remit of this work and merits a separate consideration.

Funding

Declaration of Interest

None

Author contributions

Hassiotis accepted the invitation and prepared the first draft and contributed to the revisions of the iterations; Rudra contributed to the content and revisions in all iterations. Both agreed on the submitted version

MCQs

Select the best single option or each question stem

1.   NICE Guidelines on the management of behaviours that challenge in adults with intellectual disabilities recommend that antipsychotics:

   a. Are first line treatment

   b. Are preferable to antidepressants

   c. Must never be used in adults with intellectual disabilities

   d. Must be reviewed around 6 weeks from commencing treatment

   e. Must not be combined with psychological treatments

Answer: d

2.   The following is NOT part of the initial management of low risk behaviour in the stepped care approach for managing challenging behaviour:

   a. Cognitive behaviour therapy

   b. Distraction techniques

   c. Physical health review

   d. Review of medication side-effects

   e. Verbal de-escalation

Answer: a

3.   The stepped care model for behaviours that challenge

   a. Advises paid carers about stopping psychotropic medication

   b. Includes a treatment plan of interventions based on severity of behaviours

   c. May not be used in family homes

   d. Uses a traffic light system to indicate risk level

   e. Uses theory of behaviour change

Answer: b

4.   A clinical formulation

   a. Can be used by professional teams to better understand the presenting complaint

   b. Can not be used in the care of people with intellectual disabilities

   c. Does not include patient perspectives

    d.   Must only be used by psychologists

    e.   Must be used at all times before developing a treatment plan

Answer: a

5.   De-escalation includes

    a.   Asking the individual to have time out

    b.   Be empathetic and non judgemental

    c.   Call emergency services

    d.   Mirror the individual's behaviour

    e.   Review of daily activities

Answer: a

References

Ailey SH, Miller AM, Paun O, Schoeny M, et al. Steps to Effective Problem-Solving in group homes, Contemporary Clinical Trials, 2018; 72; 62-72

Ali, A., Blickwedel, J., Hassiotis, A. (2014). Interventions for challenging behaviour in intellectual disability. Advances in Psychiatric Treatment, 20(3), 184-192. doi:10.1192/apt.bp.113.011577

Ali A, Hassiotis A. Illness in people with intellectual disabilities BMJ 2008; 336 :570 doi:10.1136/bmj.39490.543137.80

Bowring, D.L., Totsika, V., Hastings, R.P., Toogood, S.,Griffith, G.M. (2017), Challenging behaviours in adults with an intellectual disability: A total population study and exploration of risk indices. Br J Clin Psychol, 56: 16-32. https://doi.org/10.1111/bjc.12118

Cohen-Mansfield J. Nonpharmacologic treatment of behavioral disorders in dementia. Curr Treat Options Neurol. 2013 Dec;15(6):765-85. doi: 10.1007/s11940-013-0257-2.

Cooper, J.O., Heron, T.E. and Heward, W.L., 2014. Applied Behavior Analysis . Edinburgh gate.

Crocker AG, Mercier C, Lachapelle Y, Brunet A, et al. Prevalence and types of aggressive behaviour among adults with intellectual disabilities. Journal of Intellectual Disability Research. 2006;50:652-61

Crocker A, Prokic A, Morin D, Reyes A. Intellectual disability and co-occurring mental health and physical disorders in aggressive behaviour. Journal of Intellectual Disability Research. 2013.

Emerson E, Kiernan C, Alborz A et al. The prevalence of challenging behaviours: a total population study. Research in Developmental Disabilities. 2001a:22:77-93

Emerson E, Einfeld S (editors). Challenging Behaviour. Third edn. Cambridge: Cambridge University Press; 2011

Flynn S, Hastings RP, Gillespie D, McNamara R, Randell E. Is the amount of exposure to aggressive challenging behaviour related to staff work-related well-being in intellectual disability services? Evidence from a clustered research design, Research in Developmental Disabilities, 2018; 81: 155-161

Geach N, Moghaddam NG, De Boos D. A systematic review of team formulation in clinical psychology practice: Definition, implementation, and outcomes. Psychol Psychother. 2018;91(2):186-215. doi: 10.1111/papt.12155

Griffith, G.M., Jones, R., Hastings, R.P. et al. Can a mindfulness-informed intervention reduce aggressive behaviour in people with intellectual disabilities? Protocol for a feasibility study. Pilot Feasibility Stud 2, 58 (2016). https://doi.org/10.1186/s40814-016-0098-3

Hassiotis, A., Poppe, M., Strydom, A., Vickerstaff, V., et al. (2018). Clinical outcomes of staff training in positive behaviour support to reduce challenging behaviour in adults with intellectual disability: Cluster randomised controlled trial. The British Journal of Psychiatry, 212(3), 161-168. doi:10.1192/bjp.2017.34

Hassiotis, A., Walsh, A., Budgett, J., Harrison, I., et al. Intensive support for adults with intellectual disability and behaviours that challenge: A survey of provision and service typologies in England. BJPsych Open, 2020, 6(2), E20. doi:10.1192/bjo.2020.2

Hassiotis A, Almvik R, Fluttert F. Coercion as a response to violence in mental health-care settings. Lancet Psychiatry. 2022 Jan;9(1):6-8. doi: 10.1016/S2215-0366(21)00476-4. PMID: 34921797.

Hastings RP. Support staff working in intellectual disability services: The importance of relationships and positive experiences, Journal of Intellectual & Developmental Disability, 2010; 35:3, 207-210, DOI: 10.3109/13668250.2010.492710

Hastings, R.P., Gillespie, D., Flynn, S., McNamara, R., et al. (2018). Co-produced training to improve support staff attitudes and empathy towards adults with intellectual disability and behaviours that challenge: A cluster randomised controlled trial of the Who's Challenging Who? intervention. Journal of Intellectual Disability Research, 62(9), 798-813. doi: 10.1111/jir.12536

Holle D, Halek M, Holle B, Pinkert C. Individualized formulation-led interventions for analyzing and managing challenging behavior of people with dementia - an integrative review. Aging Ment Health. 2017 Dec;21(12):1229-1247. doi: 10.1080/13607863.2016.1247429

Hunter RM, Vickerstaff V, Poppe M, Strydom A, et al. Staff training in positive behaviour support for behaviour that challenges in people with intellectual disability: cost-utility analysis of a cluster randomised controlled trial. BJPsych Open. 2020 6(2):e15. doi: 10.1192/bjo.2020.1.

Hymers, G., Dagnan, D. and Ingham, B. (2021), "Change processes within team formulations in intellectual disabilities services: what do multi-disciplinary staff find helpful?", Advances in Mental Health and Intellectual Disabilities, Vol. 15 No. 6, pp. 241-252. https://doi.org/10.1108/AMHID-03-2021-0016

Ingham, B, Bentley, A, Rhodes, J, Dagnan, D. Development and psychometric properties of a team formulation measure in intellectual disabilities services. J Appl Res Intellect Disabil. 2020; 33: 625– 631. https://doi.org/10.1111/jar.12699

Ingham B, Clarke L, James IA. Biopsychosocial Case Formulation for People with Intellectual Disabilities and Mental Health Problems: A Pilot Study of A Training Workshop for Direct Care Staff, The British Journal of Development Disabilities, 2008; 54:106, 41-54, DOI: 10.1179/096979508799103323

Inglis, P. and Clifton, A. (2013), "De-escalation: the evidence, policy and practice", Journal of Intellectual Disabilities and Offending Behaviour, Vol. 4 No. 3/4, pp. 100-108. https://doi.org/10.1108/JIDOB-01-2013-0001

James IA, Mahesh M, Duffy F, Reichelt K, Moniz-Cook E. UK clinicians' views on the use of formulations for the management of BPSD: a multidisciplinary survey, Aging & Mental Health, 2021; 25:12, 2347-2354, DOI: 10.1080/13607863.2020.1830944

Lloyd, B.P. and Kennedy, C.H. (2014), Assessment and Treatment of Challenging Behaviour for Individuals with Intellectual Disability: A Research Review. J Appl Res Intellect Disabil, 27: 187-199. https://doi.org/10.1111/jar.12089

McCarthy J, Hemmings C, Kravariti E, Dworzynski K, et al. Challenging Behavior and Co-Morbid Psychopathology in Adults with Intellectual Disability and Autism Spectrum Disorders. Research in Developmental Disabilities 31, no. 2 (2010): 362–66.

McDonnell, A, McCreadie M, Mills R, Deveau R, et al. The Role of Physiological Arousal in the Management of Challenging Behaviours in Individuals with Autistic Spectrum Disorders. Research in Developmental Disabilities 36 (2015): 311–22. doi:10.1016/J.RIDD.2014.09.012.

McGill P, Vanono L, Clover W, Smyth E, et al. Reducing challenging behaviour of adults with intellectual disabilities in supported accommodation: A cluster randomized controlled trial of setting-wide positive behaviour support. Res Dev Disabil. 2018 Oct;81:143-154. doi: 10.1016/j.ridd.2018.04.020

McQuire, C., Hassiotis, A., Harrison, B. et al. Pharmacological interventions for challenging behaviour in children with intellectual disabilities: a systematic review and meta-analysis. BMC Psychiatry 15, 303 (2015). https://doi.org/10.1186/s12888-015-0688-2

National Health and Care Excellence. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. Published May 2015. Accessed February 2022

NICE Quality standard [QS101]. Learning disability: behaviour that challenges. Published: 08 October 2015. Last updated: 24 July 2019. Available: https://www.nice.org.uk/guidance/qs101/ Accessed April 2022

Rowe, G. and Nevin, H. (2014), Bringing 'patient voice' into psychological formulations of in-patients with intellectual disabilities, autism spectrum disorder and severe challenging behaviours: report of a service improvement pilot. Br J Learn Disabil, 42: 177-184. https://doi.org/10.1111/bld.12026Sakdalan, J. A., Shaw, J., Collier, V. (2010). Staying in the here and now: A pilot study on the use of dialectical behavior therapy group skills training for forensic clients with intellectual disability. Journal of Intellectual Disability Research, 54, 568-572.

Sheehan R, Hassiotis A, Walters K, Osborn D, et al. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study BMJ 2015; 351 :h4326 doi:10.1136/bmj.h4326

Sidhu K. Team formulation in intellectual disability services. ClinPsy Thesis, Cardiff University, 2020 https://orca.cardiff.ac.uk/129740/ Accessed February 2022

Singh, NN, Lancioni, GE, Winton, AS, Singh, AN, et al. Clinical and benefit—cost outcomes of teaching a mindfulness-based procedure to adult offenders with intellectual disabilities. Behavior Modification, 2008; 32(5), pp.622-637.

Singh NN, Lancioni GE, Karazsia BT, Myers RE, Hwang Y-S, Ana layo B. Effects of Mindfulness-Based Positive Behavior Support (MBPBS) Training Are Equally Beneficial for Mothersand Their Children With Autism Spectrum Disorder or With Intellectual Disabilities,. Front. Psychol. 2019;10:385.doi: 10.3389/fpsyg.2019.00385

Skivington K, Matthews L, Simpson SA, Craig P, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ. 2021 Sep 30;374:n2061. doi: 10.1136/bmj.n2061.

Turner, K, Cleaves, L, Green, S. Team formulation in an assessment and treatment unit for individuals with learning disabilities: An evaluation through staff views. Br J Learn Disabil. 2018; 46: 278– 283. https://doi.org/10.1111/bld.12249

Willner P, Rose J, Jahoda A, Kroese BS, et al. Group-based cognitive-behavioural anger management for people with mild to moderate intellectual disabilities: cluster randomised controlled trial. Br J Psychiatry. 2013 Sep;203(3):288-96. doi: 10.1192/bjp.bp.112.124529.

Woodcock, K. A., & Blackwell, S. (2020). Psychological treatment strategies for challenging behaviours in neurodevelopmental disorders: What lies beyond a purely behavioural approach? Current Opinion in Psychiatry, 33(2), 92–109. https://doi.org/10.1097/YCO.0000000000000571

Visser, E. M., Berger, H. J. C., Van Schrojenstein Lantman-De Valk, H. M. J., Prins, J. B., and Teunisse, J. P. (2015) Cognitive shifting and externalising problem behaviour in intellectual disability and autism spectrum disorder. *J Intellect Disabil Res*, 59: 755– 766. doi: 10.1111/jir.12182.