Nonpharmacological Interventions

Robert Didden, Vaso Totsika, Jeff Sigafoos, Mauro Leoni, and Roberto Cavagnola

Contents

M. O. Bertelli et al. (eds.), *Textbook of Psychiatry for Intellectual Disability and Autism Spectrum Disorder*, https://doi.org/10.1007/978-3-319-95720-3_12

Learning Objectives

The reader of this chapter will learn which interventions are available for addressing mental health and/or challenging behavior in individuals with intellectual disabilities. S/he will also learn what the evidence-base is of these interventions. Important is that interventions are directed not only toward the client but also toward caregivers. The reader will learn ways of how to adapt interventions to the learning style and characteristics of these individuals.

12.1 Introduction

A range of nonpharmacological interventions have shown promising results in the treatment of behavioral and/or mental health problems in individuals with intellectual disability (ID). This chapter presents a selective overview of interventions that are often applied in clinical practice and that have been documented in the scientific literature. Two main categories of interventions are distinguished: client-oriented and contextual approaches. In client-oriented approaches, the focus of the intervention is the client who is the main recipient of the intervention. We will describe the assumptions, common components, and evidence-base of behavioral interventions, cognitive behavior therapy, and interventions such as mindfulness and relaxation. In contextual approaches, the intervention is primarily directed at persons in the environment of the client such as parents, staff members, and others. The assumption is that a client's well-being will improve and behavioral/mental health problems will be reduced through a change in behavior and attitude of carers and other in the client's environment. Case examples will illustrate the interventions.

12.2 Client-Oriented Approaches

12.2.1 Behavioral Interventions

Behavioral interventions – now referred to as the first wave of behavioral therapies – have been widely used in the treatment of individuals with developmental disabilities. For this population, behavioral interventions have been successfully used to treat a variety of commonly reported excesses and deficits, including (a) aggression, (b) disruption, (c) elopement, (d) feeding disorders, (e) inappropriate sexual behavior, (f) pica, (g) property destruction, (h) rumination and operant vomiting, (i) self-injury, (j) sleeping disorders, (k) stereotyped mannerisms, (l) tantrums, (m) academic failure, and (n) adaptive skill deficits [1–4].

Behavioral intervention has also been successfully used to treat anxiety and mood disorders [2, 4]. Overall, behavioral intervention has a long and continuing history of success in the education, rehabilitation, and treatment of individuals with developmental disabilities. For this purpose, the behavioral approach can be considered a well-established, evidence-based therapeutic model [2, 4].

Behavioral interventions are derived from basic principles of operant conditioning [5]. A considerable amount of research has accumulated since the 1960s showing effective application of behavioral/operant principles for the treatment of individuals with developmental disabilities [2–4].

Key operant principles are listed, defined, and illustrated with examples in Table 12.1.

An important assumption associated with the behavioral treatment model is that human behavior is largely learned and sensitive to environmental contingencies [5]. Another underlying assumption is that the consequences of behavior can have powerful and predictable effects on the topography, frequency, intensity, and patterns of responding [6]. The topography, frequency, intensity, and/or patterns of responding are also assumed to be highly modifiable, provided that the environment, especially the consequences of behavior, can be modified.

In line with these assumptions, contemporary behavioral interventions include an initial assessment phase to identify the operant function(s) of the presenting problem behavior; a procedure that is called functional analysis. This assessment information is then used to design an appropriate course of treatment [7]. Identifying the operant function

Table 12.1 Key operant conditioning principles underlying behavioral interventions

Basic principle	Definition	Example
Positive reinforcement	This term refers to a relation between a response and a consequence in which the future probability of the response increases when it produces or is followed by a specific type of consequence. When a response is followed by a specific consequence and thus becomes more likely to occur in similar conditions, then that consequence can be defined as a positive reinforcer.	Bouts of self-injury by an adult with severe intellectual disability are frequently followed by a caregiver coming over and attending to the person. This attention serves as positive reinforcement and therefore the self-injury is maintained.
Negative reinforcement	This term refers to a relation between a response and a consequence in which the future probability of the response increases when it results in the removal or termination of a specific type of stimulus. When a response results in the removal or termination of a specific stimulus and this becomes more likely to occur in the future, the presence of that stimulus, then the removal or termination of that stimulus can be defined as a negative reinforcer. The stimulus can also be defined as aversive.	An adolescent with autism tantrums and hides under his desk when the teacher tries to engage him in an instructional activity. As a result of this tantrum, the teacher concludes that the student 'needs some alone time.' The teacher therefore removes the task demands and leaves the student alone. The removal of the task demands serves as negative reinforcement for the tantrum behavior.
Punishment	This term refers to a relation between a response and a consequence in which the future probability of the response decreases when it produces or is followed by a specific type of consequence. When a response is followed by a specific consequence and thus becomes less likely to occur in similar conditions, then that consequence can be defined as a punisher.	A child's frequent swearing in the classroom is reinforced by peers laughing and so the teacher decides to punish each instance of swearing by using a 2-min time-out contingent upon each instance of swearing. With this time-out procedure, the frequency of swearing decreases, indicating that the time-out period served as a punishing consequence for swearing.
Extinction	The gradual decrease in the frequency of a response when that response no longer results in reinforcement.	Tantrums that occur at bedtime might be extinguished by making sure that the child is not allowed to stay up later by having a tantrum.
Antecedent control	A stimulus that when present in the environment will either increase (discriminative stimulus) or decrease (inhibiting stimulus) the probability of responding.	A child tantrums when presented with foods that are mixed together on the plate, but does not tantrum when these same foods are arranged in separate piles.
Shaping	The gradual development of new forms of behavior by reinforcing closer and closer approximations of the final desired form.	A child might be taught to request a preferred object, rather than having a tantrum to gain that object by first making any speech-like vocalization (e.g., *ahh*). Over time, the child would be required to produce closer and closer approximations of the correct object label (e.g., *ba*, *ball*).
Chaining	The processes of developing complex skills by linking separate individual responses into an integrated sequence.	A child might be taught to speak in more complete sentences by first teaching and reinforcing single word utterances (e.g., *Ball*), then teaching 2-word utterances (*Want ball.*), and then 3–4 word utterances (*I want the ball.*).

(continued)

Table 12.1 (continued)

Basic principle	Definition	Example
Prompting	Providing an additional cue (e.g., a verbal instruction, gesture, or physical assistance) to increase the probability that a response will occur in the presence of the discriminative stimulus and thus can be reinforced.	During a receptive vocabulary task, if the child does not select the correct picture when instructed (e.g., *Point to the picture of the truck*.), then the teacher could prompt the correct response by pointing to the correct picture or by physically moving the child's finger to the correct picture.
Modeling	A special type of prompt in which the required responses are demonstrated or modeled by another person.	A job coach shows the individual how to operate the photocopier and then gives the person the opportunity to imitate.
Fading	The process of gradually removing prompts so as to promote independent responding.	If a child correctly names pictures only when given a model (*This is a cat, Say cat*), the prompt is faded by giving less and less of the model over successive opportunities (i.e., *Say caa*; *Say ca*; *Say …*).

Table 12.2 Examples of three-term contingencies and operant functions

Antecedent	Response	Maintaining consequence	Operant function or purpose
When an adult is present, but not attending to the child	The child begins to cry and quickly escalates to a full-blown tantrum.	The adult attends to the child in an attempt to calm the child and stop the tantrum.	Social positive reinforcement: Recruit attention
When asked to make his bed	An adult with autism hits the staff person and spits on the bedsheets.	The staff person removes the adult from the room and makes the bed.	Social negative reinforcement: Escape task demands
When greeted by a peer …	The student responds by attempting to bite the peer.	The peer moves away and is less likely to greet the student in the future.	Social negative reinforcement: Avoid social interaction
During playtime …	A child throws objects (e.g., sand, rocks) at peers who play with the child's preferred toys.	Peers are required to give the toy to the child.	Social positive reinforcement: Access preferred objects or activities
On the playground at school …	A child with autism pulls out some weeds and waves these back and forth.	The movement provides visual and vestibular stimulation.	Automatic reinforcement: Gain reinforcing sensory stimulation.

of problem behavior involves an analysis of the environment to isolate the variables that evoke and maintain that behavior. Behavior can be analyzed in terms of the three-term contingency [5, 8]; that is, in terms of the: (a) antecedents that set the occasion for or evoke the behavior, (b) the problematic response forms, and (c) the nature and scheduling of the consequence(s) that are reinforcing problem behavior. Examples of scenarios related to various contingencies are presented in Table 12.2.

The behavioral principles outlined in Tables 12.1 and 12.2 have been applied in numerous flexible ways to the treatment of problem behavior in individuals with developmental disabilities. Three case studies are provided here to illustrate a range of behavioral interventions. These are real cases from our own research or clinical experiences, but some details have been changed to protect confidentiality.

Case Study 1: Treatment of Aggression in an Adult Man with Severe Intellectual Disability by Pairing Staff Presence with Reinforcement and Using a Shaping Procedure

Dean was a 26-year-old man with severe ID living in a community-based group home. He attended a sheltered workshop during the day. When he returned home from the sheltered workshop each weekday, he would typically sit in his favorite chair and attempt to kick or aggressively grab anyone who came near him. Observations over three afternoons suggested that Dean was highly likely to aggress whenever staff approached him, which they often did to request that he engage in some activity, such as asking him to help set the table, come to dinner, or wash his hands. Based on these observations, it was hypothesized that Dean had learned to engage in aggression to escape from these types of staff requests. It was further hypothesized that the approach of a staff person had become a conditioned aversive stimulus that now reliably evoked aggression. To turn this around, the first step was to attempt to establish the approach of staff persons as a signal or cue for positive reinforcement. This was attempted by having staff slowly approach Dean while offering him a preferred snack or beverage. Approximately 10 times each afternoon, while Dean was seated in his favorite chair, a staff person would slowly approach him while holding out a drink or snack that Dean was known to prefer. Staff did not make any demands of Dean at these times. He only had to take the object from the staff person's outstretched hand. With this procedure in place, Dean began to tolerate staff approaching him without attempting to kick or grab them. The next step was to shape up increasingly levels of tolerance by having staff approach more closely to Dean, then approach and actually touch him briefly on the arm or shoulder. Once he was tolerating this, staff then began to approach him and make a simple request (e.g., "Hey Dean, give me a high-five"). When he was tolerating this, staff increased the complexity of the demands, such as by requiring Dean to help set the table. Within a month, aggression had decreased and compliance to staff requests had increased. To maintain these gains, it was agreed that Dean would be allowed to "cool down" for 30 min when he first returned home from the workshop. After this, staff would implement at least three conditioning trials in which they would approach with a preferred snack or beverage and deliver this freely. After this, the general plan was to then approach and present reasonable demands as necessary, which Dean was now highly likely to comply with.

Case Study 2: Treatment of Self-Injury in a Child with Severe Intellectual and Physical Disability by Teaching a Replacement Behavior [9]

Joe was an 11-year-old boy with severe intellectual and physical disability. He could not walk and had no speech and language. He was referred by his classroom teacher for the treatment of self-injury, which had begun when he was about 6 months old. His self-injury consisted of forcibly banging his forehead on the laptray of this wheelchair, hitting his nose with the base of his hand, and – when seated on the floor – banding his head against his knee. His self-injury was frequent and severe. Head banging, for example, was observed to occur at rates

that often exceeded once per second with hundreds of such responses occurring each day. His self-injury had left a permanent welt on his forehead and caused frequent nose bleeds. The first step of this treatment process involved assessing his rate of self-injury under different classroom conditions (e.g., play activity, learning tasks, snack times, independent/alone times). After 90 min of observations conducted over 3 days, a clear pattern had emerged. Joe engaged in almost constant self-injury anytime he was left alone and almost no self-injury when he was engaged in task or interacting with the teacher. Based on this, we hypothesized that Joe has learned to use self-injury as a way of recruiting attention and getting the teacher to engage with him. His intervention program thus focused on teaching him to request attention using a speech-generating device, rather than engaging in self-injury, an intervention approach known as functional communication training [10]. The intervention involved providing Joe with a communication device that required him to press a switch. When he pressed the switch it activated the prerecorded message, "Come here please." Upon production of the message, Joe would receive attention/social interaction. He was taught to press the switch using a discrete-trial training procedure [11]. Specifically, an adult would tell Joe that he had to leave and if Joe wanted to interact he should press the switch. At this point, the adult would walk away and another adult, standing behind Joe, would immediately prompt Joe to press the switch, thus preempting self-injury. Prompting consisted of guiding Joe's hand to press the switch. Over successive trials, the delivery of the prompting was delayed by 3, at which point Joe began to independently press the switch without having to be prompted. As Joe learned to use the switch, he was less likely to show self-injury. In essence, the intervention appears to have replaced self-injury by teaching Joe to engage in a requesting response that seemingly served as same purpose or operant function as his self-injury.

12

Case Study 3. Treatment of Depression Disorder and Challenging Behaviors in an Adult with Severe ID

Diana is a 55-year-old nonverbal woman living in an institutional setting since she was 10, with a diagnosis of severe ID and schizophrenia. She was evaluated for treatment because of various challenging behaviors: aggressive (physical and verbal) and destructive behaviors (throwing and destroying objects), refusing to eat, and a range of other dysfunctional behaviors (taking off clothes and wandering around naked, lying on the floor, etc.). The staff members conducted an analog functional analysis, adapting the original conditions introduced by Iwata, Carr, and Durand [12]. They also conducted a preference assessment on single stimuli. Besides, staff members were interviewed on environmental stressors, functional communication skills, support needs, quality of life aspects, and natural/family supports, medical conditions and needs. A psychiatric examination revealed a depressive disorder.

The treatment was aimed at reducing her psychosocial vulnerability and at implementing immediate support by staff on the antecedents of her challenging behaviors (i.e., irritability, low mood, isolation). Once the function (including: avoidance/escape, attention seeking, access to material, and stimulation) of each challenging behavior was assessed, the staff developed a treatment package including the following strategies:

- Modification of antecedents: daily agenda using picture communication, noncontingent reinforcement for not displaying challenging behaviors [13].
- Environmental modifications and protection from threat and physical aggression displayed by others
- Differential reinforcement
- Extinction

More specifically, the treatment was aimed at: increasing her control on environmental variables, behavioral activation (BA), increase of choice-making and self-determination opportunities, demand training (teaching Diana to make more and/or better requests), exposure to success (in order to fade the learned hopelessness), increasing motivational operations, and increasing contact with her family and friends. Diana learned to make more often and more appropriate requests, she accepted to be involved in multiple settings, she showed increased access to available reinforcers and extended her range of preferences, and she agreed to stay with all staff members including male staff members (previously she avoided men). She also began to eat regularly and sleep at night (previously she only slept 2 h per night, spending the rest of the time screaming). A substantial increase in the occurrence of indices of "happiness" was observed, and all the signs of depression decreased in frequency as well as in intensity. Concomitantly, the frequency of her challenging decreased.

12.2.2 Cognitive Behavior Therapy

Cognitive behavior therapy (CBT) – now referred to as the second wave of behavioral therapies – has received increased attention from clinicians and researchers during the past decades (see e.g., Vereenooghe and Langdon [14]). It combines principles from behavioral and cognitive psychology and is referred to as the second wave of behavioral therapies. The assumptions underlying CBT are that behavior, thoughts, and emotions are interconnected, and that cognitive distortions and maladaptive coping strategies increase the risk for psychological and behavioral problems. These problems can be reduced by improving information processing (e.g., through cognitive restructuring – see ► Box 12.1) and the learning of adaptive coping skills.

Contemporary (cognitive) behavioral and other types of interventions should be based on a comprehensive and functional assessment.

Therapists use functional analyses and case formulations to understand the nature and cause of the problems and as a guide to developing treatments (see e.g., Didden [15]). CBT is a composite therapy in which a range of components are used: some of the most common of which are listed in ► Box 12.2.

Box 12.1: Cognitive Restructuring: An Example

- Event: a client who is living in the same community home collides with A.
- Thoughts: He did this on purpose. He does not like me.
- Emotions: Angry, afraid, distressed.
- Alternative thoughts: He did not do this on purpose. He just bumped into me.
- He did not see me. He often comes into my room and starts a friendly chat.
- Outcome: Feels calm, confident.

Box 12.2: Common Components of CBT

- Cognitive restructuring: identifying and challenging negative (automatic) thoughts, also called cognitive distortions. Irrational and/or negative thoughts are replaced by rational and positive thoughts.
- Exposure and response prevention: confront the situation that induces fear or anxiety and decrease avoidance of that situation until anxiety reduces. Response prevention is often used in case of obsessive-compulsive behavior where the client is taught to not carry out his or her impulses to reduce his or her distress.

- Relaxation: any activity or method that leads to a state of calmness if a person feels distressed or tense. Often progressive muscle relaxation techniques are used, as well as breathing exercises and mindfulness.
- Problem-solving and adaptive skill building; the development of conceptual, social, and practical skills that individuals use in daily life. Adaptive skills with which a problem may be solved.
- Functional analysis: assessing the operant function of problem behavior by identifying its antecedents and reinforcers.
- Case formulation: hypothesis or model about the nature and cause of the presenting problems. It provides a framework for treatment.

12.2.2.1 Manualized CBT

CBT is a treatment package containing a large range of techniques that address thoughts, emotions, and behaviors of clients. CBT is a manualized approach in which therapeutic protocols are outlined. At present, there are many protocols available for the treatment of behavioral problems and/or mental health problems in individuals with intellectual or developmental disabilities (IDD). For example, Hassiotis and her colleagues [16] have published a therapist manual for the treatment of anxiety and depression containing case vignettes and examples, exercises, information sheets, resources, and worksheets adapted for use with clients with mild ID. The manual illustrates the process of CBT, from the introduction of CBT and initial assessments to case formulation, treatment planning, intervention, and termination.

Lindsay and his colleagues [17] used a manualized CBT approach for emotional problems (excluding anger). The treatment consists of five modules:

- Module 1: assessment of problems.
- Module 2: preparation phase promoting engagement with CBT. Introducing the concept of CBT, establishing a list with the client's key difficulties that will be addressed, and identifying a family member or carer who will support the client.
- Module 3: recognizing and differentiating between emotions through role-play and scenarios, exploring links between emotions and events that trigger them.
- Module 4: development of a formulation with predisposing factors for the emotional problems, exploring feedback loop from client's behavior to event.
- Module 5: relapse prevention which takes the form of a sort of passport that the client could continue to use following treatment. Key elements of a passport are a simple formulation, adaptive strategies, information about early warning signs, and risk factors. At this stage, the family member or carer was introduced.

12.2.2.2 Adapting CBT to Individuals with ID

Until recently, cognitive and adaptive skill deficits were seen as precluding the use of CBT in individuals with ID. Potential obstacles are limited verbal communication skills, recognizing emotions, executive functioning deficits, and limited working memory, among others. In clinical practice, CBT is often used with individuals with mild ID and CBT is adapted to their skill deficits and needs. Hronis, Roberts, and Kneebone [18] provided suggestions for adapting CBT to children with ID who present with a range of cognitive skill deficits. Below are some examples:

- Attention: use shorter, more frequent sessions, reduce task length (smaller units), and prevent distractions
- Working memory: use memory aids (e.g., visual prompts), present one task at a time, and use short, simple, subject-verb-object sentences

- Executive functions: use structured sessions (e.g., visual schedule), minimize switching between tasks, and redirect uninhibited responses

Cooney, Tunney, and O'Reilly [19] conducted a systematic review of cognitive therapy skills assisting adults with ID to participate in CBT programs. The following skills and prompts were identified that may help adults with ID to benefit from CBT:

- Recognize emotions by using photographs of people's faces.
- Discriminate between thoughts, emotions, and behavior by using personally relevant scenarios and pictorial stimuli.
- Make a connection between events and emotions, and recognize the mediating role of thoughts in the relationship between thoughts, emotions, and behavior by using examples of situations, emotions, and behaviors that are congruent and by using pictorial stimuli.

Willner and his colleagues [20] have adapted the CBT approach to the needs and skill deficits shown by individuals with ID by training their care staff to deliver the CBT. In this multicenter study, a manualized anger management group intervention was compared to a waiting-list control condition. Staff or home carers participated as lay therapists and were trained by a clinical psychologist explaining the principles of anger management and the use of the CBT manual. The outcomes showed that anger management resulted in an improved anger control by participants with ID and an overall reduction in challenging behaviors. Analyses also showed that staff members delivered the CBT intervention with reasonable fidelity.

Dagnan, Jahoda, and Kilbane [21] point to the fact that establishing a therapeutic relationship between client and therapist during CBT is of particular importance, as this has been viewed by the client as one of the most positive aspects of therapy. A positive relationship improves client's motivation to attend the sessions and his or her confidence in learning skills.

Hassiotis and her colleagues [16] have given many suggestions on how to adapt CBT interventions for clients with mild ID.

12.2.2.3 Evidence-Base of CBT

CBT has most often been applied to the treatment of anger and/or aggressive behavior in individuals with ID (see e.g., Willner et al. [20]). Nicoll, Beail, and Saxon [22] have conducted a systematic review of 12 studies assessing the effectiveness of CBT for the treatment of anger problems in adults with ID. Overall, high effect sizes were found for CBT.

However, the authors note that some studies had large confidence intervals, for example, as a result of small sample sizes. CBT has also been applied in individuals with ID who present with mood problems and anxiety. Unwin, Tsimopoulou, Stenfert Kroeze, and Azmi [23] have reviewed 11 studies and concluded that CBT is feasible and may be effective in reducing symptoms of depression in these individuals including negative automatic thoughts. No controlled studies were found for anxiety. Clients and carers perceived CBT in a positive way.

The authors found that most studies had methodological shortcomings such as small sample size and lack of procedural integrity assessments and that data were collected during short-term follow-ups only.

12.2.2.4 CBT Expanding to Other Domains

The range of behaviors or disorders in ID that are being targeted by CBT is extending: substance misuse [24], obsessive-compulsive disorders [25], sexual offending [26], and hoarding. Kellett, Mattuozzo, and Kotecha [27] have assessed the effectiveness of CBT in 14 adults with mild ID who showed hoarding behaviors. They showed excessive acquisition of objects, had a substantially cluttered home environment, and had difficulties with discarding possessions. CBT consisted of 12 individual 2-h sessions via weekly visits to the participant's home. Elements of CBT were goal setting, enhancing motivation, exposure methods, problem-solving, cognitive strategies, and relapse prevention. Carers were used as co-therapists where possible and homework

assignments were given. CBT elements were adapted by reducing the amount and complexity of homework, extending time length of sessions, and simplifying psychoeducation[1] and hoarding formulations. All 14 participants completed the CBT program. Data showed that hoarding was reduced following treatment, a finding that was maintained at follow-up.

12.2.3 Trauma-Focused CBT and Eye Movement Desensitization and Reprocessing

Individuals with ID are at increased risk of experiencing traumatic events, such as sexual and physical abuse, separation, and life-threatening illness, compared to their peers without ID. Processing potentially traumatic events is particularly difficult for individuals with ID. Also, the range of events may be greater for individuals with ID. It is assumed that events, such as early institutionalization and out-of-home placement, few positive experiences in managing negative life events, and limited availability of social support, make individuals with ID vulnerable for developing posttraumatic stress disorder (PTSD) (see Mevissen et al. [29]). Moreover, understanding oneself as having ID may be traumatic in itself. Given the disruptive effects of trauma, PTSD assessment and treatment of PTSD in individuals with ID have gained attention in the literature in recent years. Mevissen et al. [29] have reviewed the literature on two interventions for PTSD in individuals with ID: trauma-focused CBT and eye movement desensitization reprocessing (EMDR), which are evidence-based first-line treatments recommended by the World Health Organization.

Trauma-focused CBT consists of a combination of behavioral and cognitive techniques and focuses on the relationship between events and behavior, cognitions (thoughts, attitudes), and emotions (also see above). Until present, only case studies have been published on the feasibility and outcomes of CBT for the treatment of PTSD symptoms in individuals with ID. A paper by Carrigan and Allez [30] describes the case of Damon who was a 26-year-old who had been diagnosed with mild ID and comorbid autism spectrum disorder (ASD). He lived at home and had no employment. He showed anger outbursts and complained of sleep problems at the time of referral to a community learning disability team. He disclosed that he had been the victim of a sexual assault some years before. He had regularly reexperiences of the event and had nightmares about what happened. He had difficulty concentrating; he had flashbacks and did not want to leave the home because he was afraid he would meet his attackers. In the paper, a case formulation is presented on how his behaviors, cognitions, and emotions are related to Damon's trauma and other symptoms. For example, negative appraisal of the trauma produced a sense of current threat and Damon believed that people wanted to get him and that they are not to be trusted. He blamed himself for what happened. Also, he watched television programs that triggered his memory of the event. His strategies to manage his sense of threat were to avoid people and places where the event had happened and to respond aggressively. He tried to avoid thinking about what happened.

The CBT intervention took 12 one-hour sessions at a hospital. Part of the intervention was anger management for his aggressive outbursts, which was focused on cognitive restructuring of beliefs about the intentions of other people. The intervention had three goals, of

1 Psychoeducation is an intervention for clients, their family members, and/or carers in which information is provided on the symptoms and possible cause of a mental health or behavior problem. Its goal is to understand the problem and provide support, which may help in recovery and well-being. There are very few psychoeducation programs available for individuals with intellectual disabilities and/or autism spectrum disorders. A recently published study by DaWalt, Greenberg, and Mailick [12] showed that an 8-week family group psychoeducation program, called Transitioning Together, resulted in significant improvements in parental depressive symptoms and problem-solving. Social interactions improved for their children.

which the first was to modify negative appraisals of the trauma and its consequences.

Psychoeducation was used to achieve this goal. The second goal was to reduce reexperiencing the event by elaboration of the traumatic memories and discrimination of triggers. For this purpose, imaginal reliving the event was used, whereby Damon was instructed to describe the event in as many details as possible. Thirdly, Damon was helped to drop dysfunctional behaviors and cognitive strategies and to avoid not thinking about the traumatic event. The outcomes showed that trauma-focused CBT – if adapted – is a feasible treatment option for individuals with ID and that the intervention resulted in a reduction of PTSD symptoms.

Eye movement desensitization and reprocessing (EMDR) therapy is an intervention aimed at reducing symptoms that result from traumatic experiences. The theory underlying EMDR is the adaptive information processing theory. Eye movements during the recall of aversive memories reduce their vividness and emotionality. Recalling a traumatic memory is assumed to tax working memory capacity, which is limited. If a second task – for example, eye movements – is executed during recall, less capacity will be available for recalling the distressing event. This makes that the memory is experienced as less vivid and emotional.

Mevissen and her colleagues [29] distinguish eight phases in the planning and execution of EMDR:

- Phase 1: history taking and case formulation, resulting in a treatment plan.
- Phase 2: the client is prepared for the trauma work. Skill building and resource development are typically necessary.
- Phases 3–7: reprocessing of the traumatic memory. The client is asked to bring up the traumatic memory and concentrate on the most distressing image and dysfunctional negative cognition of oneself in relation to that image, as well as the accompanying emotions that go along with it. A core feature of EMDR is the performance of eye movements (typically, the therapist moving his fingers back and forth in front of the client, asking him or her to track the movements while keeping his or her head still), while concentrating on the trauma memory.

  Following the image and negative cognition, access to the emotional and somatic aspects of the memory takes place. Repeatedly, the client is asked to report emotional, cognitive, somatic, and/or imagistic experiences, until intern disturbances reach a SUD (subjective unit of disturbances scale) of zero and adaptive and positive beliefs are rated as strong on a VoC (validity of cognition) scale.
- Phase 8: reevaluation and integration.

Instructions as to how to activate the trauma memory and how to support the client during the desensitization and reprocessing phase are age related and are adjusted to the person's developmental age, taking into account any comorbid disorders such as autism. Task variations might be necessary, for instance, the therapist putting stickers on his fingers to facilitate tracking, using buzzers to vibrate alternately between the person's right and left hand, administering alternating tones via a headphone or audio speakers placed on either side of the person, or tapping on the person's hands or knees.

The evidence-base for EMDR in individuals with ID is still small. In the literature, mostly case descriptions have been published (see Mevissen et al. [29]). Mevissen, Didden, Korzilius, and De Jongh [31] assessed the effectiveness of EMDR in two individuals with mild ID who met the diagnostic criteria of PTSD. Data were collected in a multiple baseline design and EMDR comprised of four 60-min sessions. The results show that for both participants, the number of PTSD symptoms, as measured by the ADIS-C PTSD section (see Mevissen et al. [32]), decreased in response to the treatment and both no longer met the PTSD criteria following treatment.

12.2.4 Relaxation

Relaxation is often a component in a treatment package. There are few studies evaluating relaxation as a stand-alone approach in individuals with ID and/or ASD. Bouvet

and Coulet [33] assessed the effectiveness of relaxation on anxiety, self-esteem, and emotion regulation in 30 adults with mild-to-moderate ID who worked in a French center of supported employment. In 1-h groupwise sessions, clients practiced with relaxation techniques during 10 weeks. They found that, contrary to a waiting-list control condition, relaxation significantly reduced state anxiety and improved the clients' self-esteem and cognitive reappraisal. A recent systematic review by Bellemans and her colleagues [34] showed that relaxation – particularly through progressive muscle relaxation – on average was effective in reducing aggressive behavior in individuals with ID. It should be noted however that the results were somehow mixed. There are relatively many techniques of relaxation. Harris and Robbins [35] used three basic relaxation techniques in the treatment of three clients who suffered from anxiety. For example, relaxation was applied to a female with moderate ID who showed symptoms of anxiety related to the behavior of other clients in her house. The intervention started with controlled breathing (she was able to follow basic instructions regarding her breathing exercises). Unfortunately, because of her communication difficulties the second technique – guided imagery – turned out to be problematic. During guided imagery, the client is guided toward a relaxed and focused state with the help of verbal instructions from a therapist or script. A state of relaxation is reached, if the client succeeds in imaging the details of an event or a safe place, which eventually results in a decrease of tension or anxiety. In her case, the technique was applied in an adapted way, in that a script was developed in which a trip to the zoo was detailed with vivid descriptions of each animal enclosure. This imagery was chosen because she loved animals. It appeared that she responded well to imagery plus controlled breathing. In the third technique – progressive muscle relaxation – she was prompted to use stress balls in each hand to grip and promote tension of the arms. This technique was also adapted in that she was prompted to "squeezing the juice from fruit." The combination of techniques helped her to get some degree of control over her anxiety, particularly regarding her fear of other clients in her house and some of her outreach activities. The case descriptions by Hart and Robbins show that relaxation techniques can be applied to individuals with ID, provided they are adapted to the individual.

12.2.5 Psychodynamic Psychotherapy

Psychodynamic psychotherapy is based on psychoanalysis. At the center of this therapy lies the concept of defense mechanisms which may be defined as the mental operations that remove thoughts and feelings from conscious awareness. Individuals keep something out of thoughts or alter the perception of events as a strategy to manage emotional conflicts or internal and external stressors. The therapy may support individuals to identify what they are doing and to help them to come to terms with why they are doing it. In this way, individuals move beyond the level of "problem statement" (e.g., aggressive behavior). During psychodynamic therapy, a strong focus is placed on the relationship, interpersonal relations, expression of emotions, and exploration of fantasy life (see Beail and Jackson [36]). McInnis [37] reviewed the evidence-base for psychodynamic therapy in adults with ID. On the basis of 14 papers, she concluded that this type of therapy may be of benefit to these individuals. However, the review revealed a range of limitations such as the small number of studies published and the reliance on case studies.

12.2.6 Mindfulness and ACT as Examples of Third Wave of Behavioral Therapies

Behavioral treatments have developed significantly in the last two decades. After the first-generation behavioral therapies – that is, behavior modification – and the spreading of cognitive behavioral approaches (see previous section), recently a "third wave" of behavioral models have been developed. They are mainly focused on the *function* of problematic

cognitions rather than their *content* [38], and put a strong focus on private events without trying to change the form or frequency of these private events (thoughts and emotions). The third wave of behavioral psychotherapies is an important arena of modern psychotherapy development, which has added extensively to the empirically supported treatments for mental suffering [39]. These approaches include a diversity of new techniques and open up possibilities for the treatment of mental disorders. The third wave usually consists of acceptance and mindfulness procedures in combination with behavior modification principles. It is acknowledged that people with ID are more susceptible than others to challenging behavior and mental health problems, but in order to apply a psychological treatment effectively with a person with ID, a conscious effort is needed to adapt the content and the style of presentation to take account of the client's limitations. Table 12.3 [39, 40] summarizes the deficits and potential solutions in four domains of cognition: intellect, emotional literacy, memory, and executive functioning. These issues must be considered during the assessment phase to drive the adaptation of the treatment process.

The main categories of the third wave of behavioral therapies are summarized in Table 12.4.

There is a specific interest in the outcomes of mindfulness-based and ACT interventions for individuals with ID who present with challenging behaviors (mainly aggressive, self-injurious, and stereotypic behavior) and mental health problems because of the negative consequences associated with such problems including the increased risk of exposure to stressful or even dangerous events for staff [39, 49]. ACT can help people with mild-to-severe ID [50], enabling the client to participate in the therapeutic process more readily than in a more traditional CBT approach. In individuals with high-functioning ASD, for example ACT may result in reduced levels of stress, hyperactivity, and emotional distress, and in improved prosocial behavior [51]. The option of treatment using ACT for individuals with ID and/or ASD appears stimulating and convincing, for which a wide range of potential applications are available [52, 53].

Table 12.3 Cognitive deficits and their implications for therapy

Cognitive domains	Specific processes	Implications for therapy
Intellect	Verbal understanding and reasoning	Simple words and short sentences
	Nonverbal understanding and reasoning	Use of nonverbal techniques and materials
Emotional literacy	Emotional vocabulary	Psychoeducation
	CBT skills	Psychoeducation and provision of ideas
Memory	Assimilation	Frequent repetition and more sessions
	Recall of experiences	Involvement of carers
	Prospective memory	Use of reminders and involvement of carers
Executive functioning	Working memory	Chunking of information
	Behavioral inhibition	Greater use of behavioral self-control techniques
	Initiative	Provision of ideas

Research on mindfulness-based interventions and ACT for carers reports positive findings for both staff and the individuals with ID they support (see e.g., Harper, Webb, and Rayner [54], McConachie et al. [55], Noone and Hastings [56], Leoni et al. [49], Ó Donnchadha [57]). Mindfulness-based interventions can also facilitate staff to integrate behavioral and psychopharmacological treatment with more positive outcomes [58], reduce the use of physical restraints [59], and increase indices of happiness in individuals with profound ID [60].

Table 12.4 Categories of third wave of behavioral therapies

Behavioral activation (BA)	BA emerged from studies analyzing the necessary components of classical cognitive therapy [41], and has evolved from a long behavioral tradition seeking to increase positive reinforcement by scheduling appropriate patient behaviors and thus achieving antidepressant action [42].
Dialectical behavioral therapy (DBT)	DBT conceptualizes that skill deficits in the area of emotion regulation are at the center of these disorders [43]. DBT includes the practicing of different skills in the areas of mindfulness, distress tolerance, emotion regulation, and interpersonal effectiveness [[44], 45].
Metacognitive therapy (MCT)	Metacognitive therapy (MCT; [46]) postulates that at the core of depressive and anxiety disorders there is the 'cognitive attentional syndrome' (e.g., worrying, rumination, dysfunctional threat monitoring, and dysfunctional cognitive and behavioral copying). MCT uses attention training techniques to develop skills in cognitive flexibility, teaches detached mindfulness, and guides cognitive and behavioral experiments to change metacognition.
Schema therapy (ST)	ST uses emotion activation techniques originating in Gestalt and Psychodrama; but it is strictly behavioral in the models communicated to the patient [43]. A basic ability reinforced in ST is to recognize the present dysfunctional modes of functioning, such as the detached protector mode, and to have behavior guided by the healthy mode [47].
Mindfulness-based cognitive therapy (MBCT)	The focus of MBCT is to learn to experience dysfunctional thoughts as internal events separated from the self [48]. Like cognitive-behavioral therapy itself, mindfulness-based approaches encompass a wide range of techniques that are customized to the needs of the individual. MBCT uses psychoeducation and encourages patients to practice mindfulness meditation. A core goal is to develop metacognitive awareness, which is the ability to experience cognitions and emotions as mental events that pass through the mind and may or may not be related to external reality [40].
Acceptance and commitment treatment (ACT)	ACT is a behavioral therapy system that is based on functional contextualism and the relational frame theory (RFT). It postulates the following psychopathological processes as central to human suffering and mental disorders: (1) cognitive fusion; (2) experiential avoidance; (3) attachment to a verbally conceptualized self and a verbally conceptualized past; (4) lack of values or confusion of goals with values; and (5) absence of committed behavior that moves in the direction of chosen values. The treatment contains experiential modeling, psychoeducation about key mechanisms, exercises in mindfulness, and cognitive defusion. The value orientation of the patient is elicited and shared, and the patients are reinforced in value-driven behavior in contrast to behavior driven by emotional or experiential avoidance. There are an impressive number of randomized controlled trials (RCTs) testing the efficacy of ACT in heterogeneous clinical conditions. (For a more detailed description of ACT process in individuals with ID, see Leoni et al. [49].)

Case Study 4: Acceptance and Commitment Treatment (ACT) for an Adult with Mild ID

Pietro is a 45-year-old man with mild ID living in a residential setting. Prior to his admission to the residential setting, he lived in the community in a private house, with daily supports. He spent most of his time wandering in the streets, trying to talk with people or to collect money. He was constantly worried about being mislabeled and teased, to the point that he displayed severe challenging behaviors. He was charged for aggressive behavior multiple times and often refused his prescribed psychotropic medications. The community services

decided to refer him to a residential facility, with a diagnosis of psychosis and moderate ID. At admission, he showed severe limitations in communication, inclusive activity, daily routine (self-care, home care), and job activities. He displayed a high frequency of dysfunctional behavior antecedent to problem behavior: he engaged staff members in continuous talk, thereby repeating topics, questions, and phrases, and he was constantly worried about the behaviors displayed by other persons; he felt threatened and was intimidating toward others. Staff initially used a range of behavioral interventions: antecedent modifications (environment management, supports to communication, and structuring of daily activities), and contingency management (token economy), without satisfying results. At some point, the staff introduced a treatment based on acceptance and commitment treatment (ACT), using the Matrix, a tool in which the Hexagon Model used in ACT is simplified; [49, 61] (see Fig. 12.1). Individual sessions of 45 min were held twice a week in order to work with Pietro on the main levels of the Matrix.

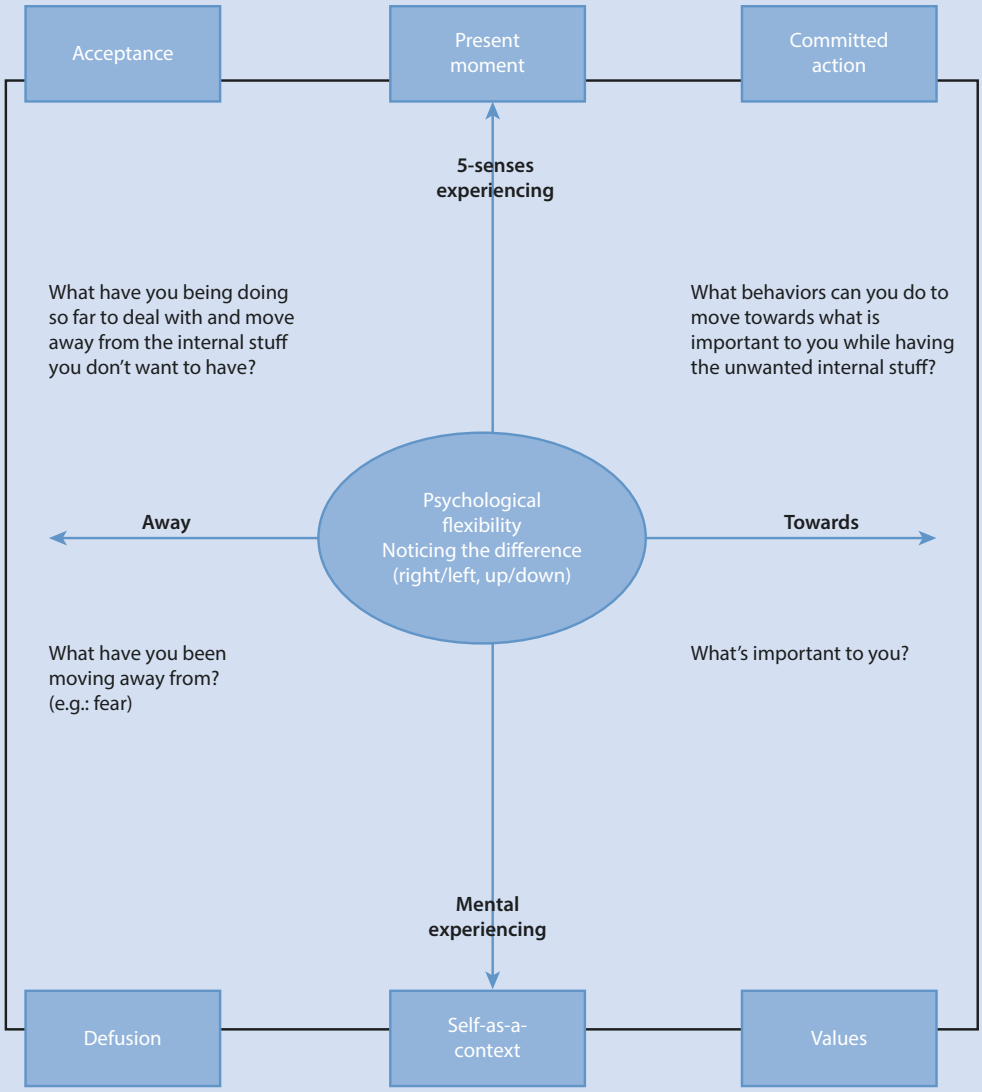

Fig. 12.1 ACT "Hexaflex" model simplified through the Matrix [49]. (Source: Polk and Schoendorff [61])

Firstly, the therapist increased Pietro's awareness of his body sensations and thoughts using instructions and physical exercises. The goal was to identify avoidance patterns in Pietro's behavior. Next to this, a preference assessment was done as well as a life-values analysis (i.e., important directions in life, to be pursued through goals and actions), and connections between values and daily choices were made. Additionally, observation and self-monitoring sheets that Pietro could use were introduced, and behaviors displayed in the previous days were evaluated using the Matrix (see Fig. 12.1), addressing the "away moves" (i.e., avoidance, usual habits, and dysfunctional problem-solving; left part of the Matrix) and the "moving forward" acts (i.e., behaviors aligned with preferences and values; right part of the Matrix). Pietro complied with the treatment (although many adaptations were required, due to his cognitive limitations), and after 4 weeks of treatment, he showed first signs of improvement.

Treatment lasted (with progressive fading of supports) for 24 months, and the staff observed a clear increase in adaptive choices, in reported and observed awareness, in the quality and quantity of the request for supports, and in the frequency and quality of activities. He was able to deal with the grief after his mother passed away, and to move in another group home and negotiate new objectives in the support plan. Challenging behaviors were significantly reduced in terms of frequency, duration, and intensity.

12.3 Contextual Approaches

Contextual approaches are very common in the treatment of mental health problems or challenging behaviors in individuals with intellectual or developmental disabilities (IDD). By contextual, we refer here to approaches that target changes in the *environment* of individuals with IDD. The environment consists of the structural environment (e.g., residential setting and its operational model) and, crucially, the social environment, that is, the people who live and interact with the individual with IDD (paid carers and family carers). The rationale underlying contextual interventions is that challenging behaviors or mental health symptoms of individuals with IDD will improve, if the people who live with them change some aspect of their own behavior (overt or covert behavior) that relates directly or indirectly to challenging behaviors or mental health problems experienced by people with IDD.

Contextual approaches *directly* targeting reductions in challenging behaviors focus on altering overt behavior of carers (i.e., parent training, staff training) so as to alter the contingencies that maintain challenging behavior. This may be combined with changes in the broader system aiming to improve quality of life or activity participation (whole environment interventions such as Active Support or Positive Behavior Support). Contextual approaches that target *indirectly* mental health problems or challenging behavior aim to alter the covert behavior or, else, emotional well-being of carers (family or paid carers). The latter approaches consist of psychological therapy for carers or psychological therapy combined with behavioral skills training.

Figure 12.2 maps some of the contextual factors related to the mental health or challenging behaviors of individuals with IDD using Bronfenbrenner's ecological systems framework. The intervention approaches described below focus on the micro- and mesosystems, though the latter ones actually span across both micro- and mesosystems.

> Challenging behaviors or mental health symptoms will improve, if the people who live with them change some aspect of their own behavior.

12.3.1 Parent Training

As a contextual intervention, parent training is a behaviorally based approach that

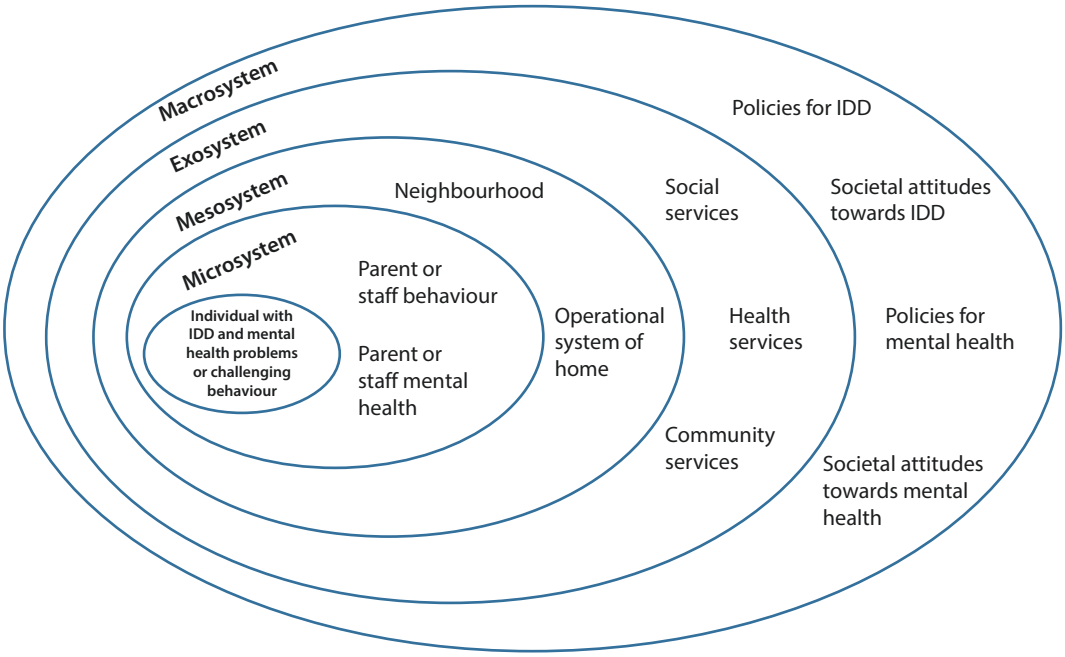

Fig. 12.2 A schematic representation of contextual influences on individuals with IDD and mental health problems or challenging behaviors

targets changes in the parenting behavior of parents of children with IDD, typically in response to emerging or established behavior problems. Most parent training models incorporate approaches from social learning theory and applied behavior analysis to reduce child behavior problems by increasing the use of positive parenting practices (e.g., praise for appropriate child behavior, use of positive behavior management approaches such as differential reinforcement; also see Table 12.1). There are several packaged models, and some may also include other theoretical principles, but social learning and behavioral principles underlie most approaches. Several randomized controlled trials (RCTs) and, subsequently, meta-analyses of RCTs indicated that parent training is effective in reducing child behavior problems (and in particular, conduct problems), increasing positive parenting (e.g., praise), decreasing negative parenting (e.g., ineffective discipline) while also improving maternal mental health, and making parent training an evidence-based (and cost-effective) approach for reducing behavior problems in childhood [62, 63]. There are various parent training models, but there is no evidence of differential effectiveness for different evidence-based models [64]. Notably, some programs, such as Triple P [65] and Incredible Years Parent Training (IYPT; [66]), have a very large evidence-base across several countries.

These parent training models address the general population. They have not been developed for families of children with IDD. However, parent training is gaining momentum as a contextual approach to reducing behavior problems in children with IDD. For parents whose children have IDD, parent training might involve one of the three options: (a) attending a parenting program that has been developed for the general population, for example Triple P or Incredible Years, (b) attending a parenting program that has been *adapted* for use with families with a child with IDD (e.g., Stepping Stones Triple P, [67]; Incredible Years Parent Training for Developmental Disabilities; IYPT-DD, [68]), or (c) a parenting program that has been developed specifically for these families (e.g., Signposts, [69]; Confident Parenting, [70]).

Table 12.5 Some key features of parent training targeting children's challenging behaviors

Content[a]	Format	Additional IDD focus
Positive parenting: when/how to use positive reinforcement; engaging in positive interactions and activities with child Child behaviors to attend to and child behaviors to ignore Behavior management: when/how to use extinction, how to use punishment (time out) Responding to the child in a consistent manner	Small group with/out 1–1 sessions Weekly meetings Facilitator led with/out parent co-facilitator Parents expected to practice new skills with own child and then report back to the group	Behavioral phenotypes of various syndromes Understanding the function of (challenging) behavior; focus on working out functions of own child's challenging behaviors and plan for change Communicative dimension of challenging behavior; adapting communication Changes in the environment to prevent challenging behaviors Supporting alternative behaviors (e.g., teaching a child to communicate a need as replacement for challenging behavior)

[a]See also Kaminski et al. [72] for a component analysis of effective parent training

At the moment, we have no evidence of the relative effectiveness of these different options, as approaches have not been directly compared.

Most parent training models involve parent training in small groups (8–12 parents), attending weekly groups ranging from 4 to 20+ weeks. Therapists are trained and/or accredited in the model delivered, and in some programs they are accompanied by parent expert trainers who have undergone similar training. The latter approach is considered to have high levels of acceptability from parents. Groups typically involve direct teaching, group discussion, modeling, experiential learning, homework, and reflection. Parent training in this population is typically available as a targeted or specialist intervention (i.e., after challenging behavior develops or worsens), whereas preventative approaches are not typically available, despite the fact that challenging behaviors are present from a very young age in children with IDD [71]. Table 12.5 summarizes some of the key features of parent training approaches.

Attending a parent training group that is not adapted or developed specifically for parents of children with IDD might not always be the preferred option for parents of children with IDD but in some areas it might be the only program to offer within a reasonable distance. A degree of inference is applied there, as we assume that families of children with IDD will benefit from programs that do not take into account the child's disability [73]. A recent evaluation with mixed disabilities (families of children with special educational needs) indicated that these families benefit from parent training similarly to families with children without special educational needs [74]. Parents in this evaluation received several programs, with about 80% attending Triple P groups. Clinicians need to be aware that where parents receive generic parent training as part of regular service provision (where services lead on all aspects of delivery including outcome evaluation), longer-term gains (at 12 months past training) are likely not maintained well, and these parents will benefit from top-up or repeat parent training.

Some parenting programs developed for the general population are adapted for families whose child has an IDD. Two such programs are worth noting: Stepping Stones Triple P (SSTP; [67]) and IYPT-DD [68]. Adaptations typically include additional content to provide IDD-specific information (for example on the nature and causes of IDD, behavioral phenotypes in various IDD), a focus on parental

adjustment (what does it mean to have a child with IDD), as well as a focus on the function of behavior problems. Stepping Stones Triple P has been based on Triple P, while IYPT-DD is an adaptation of Webster-Stratton's parent training variant of Incredible Years.

In their adapted versions, both these programs are available in a tiered format moving from less intensive to more intensive (e.g., weekly small parent groups with additional 1–1 meetings) as child need increases. At the moment, most of the evidence available to support the effectiveness of adapted parent training programs refers to small group format that meets on a weekly basis: level 4 for SSTP includes 6 group meetings and 3 1–1 consultations spanning 9 weeks in total, and 12 weekly meetings for IYPT-DD [68, 75]. In the case of IYPT-DD, a small-scale RCT with parents of young children (2- to 5-year-olds) with developmental delays suggested significant gains for observed and parent-rated behavior problems [76]. Incredible Years has also been adapted for families of children with autism and is currently being evaluated in a pilot RCT [77]. The autism adaptation places emphasis on parents helping their children with their communication needs as a functional approach to reducing behavior problems. The evidence-base for SSTP is much larger: a recent meta-analysis of 12 RCTs concluded that reductions in behavior problems of children with IDD are significant and approximately medium-sized, that is, an effect size of about half a standard deviation [75]. Of note, most of the evidence came from level 4 SSTP evaluations (i.e., small group format with 1–1 support meeting on a weekly basis for 9 weeks), whereas gains from level 2 SSTP (one or two large group seminars) were not present for child behavior problems or any other outcomes. Overall, IDD-adapted parent training is the parent training option with the largest evidence supporting its effectiveness in reducing behavior problems, though clinicians should be mindful that reductions in children's behavior problems are evident following more intense input; there might be little value in less-intense approaches.

Last, attending parent training, specifically developed for parents of children with IDD, is a very appealing option for parents who feel that being surrounded by people who experience the same challenges as them is a very important feature of parenting groups [78]. Parents value opportunities to share while not feeling judged or criticized by the other parents, and they also feel that they learn more by other parents in their group. Examples of such programs are Signposts in Australia [69], Confident Parenting in the UK [70], and (a soon to be evaluated by an RCT) Early Positive Approaches to Support in the UK (E-PAtS; Coulman et al. [79]). Some programs specifically target child challenging behavior (Signposts, Confident Parenting), but mostly take a broader view of family needs, by also addressing parental psychological well-being and other child needs, such as sleep or adaptive skills (Confident Parenting, E-PAtS). To date, we have no rigorous evidence that IDD-specific parent training improves challenging behavior or child mental health problems.

Therefore, while the option of attending an IDD-specific parent training group might be valued by parents for the social support networks, it is uncertain whether benefits in challenging behaviors or child adaptive skills will follow.

12.3.2 Parent Therapy

Parents of individuals with IDD experience significantly worse mental health than other parents, and this increases the risk for behavior and mental health problems in their offspring with IDD [80, 81]. Therapy to improve mental health in parents has focused on decreasing negative affect (e.g., CBT) or increasing mental well-being (e.g., mindfulness, positive psychology approaches). Overall, parent therapy is effective in reducing psychological distress in parents, especially mothers, of children with IDD, and the most effective approaches are the ones that combine behavioral parent training with therapy [82].

However, there is little direct evidence that parent therapy is associated with improvements in offspring mental health, as parents

tend to receive therapy because they experience poor mental health themselves (therefore, services or researchers tend not to measure offspring mental health). A contextual approach with some evidence of reduction of child aggressive behavior is mindfulness. Parents who receive mindfulness therapy tend to report lower aggression, more compliant/easier behavior for their children with IDD [83, 84], despite the fact that mindfulness therapy does not directly target parenting skills or child behavior at all. It is thought that the practice of mindfulness increases acceptance of the child with IDD and its behavior, and therefore increases positive interactions between the parent and the child. It is likely that parents who practice mindfulness become more aware of the ways they respond to their child's aggression and, as such, better able to interrupt unhelpful responses. It should be noted that other mindfulness evaluations have replicated the gains in parental mental health but did not find gains in child challenging behaviors [52].

12.3.3 Staff Behavioral Training

As with parents, staff behavioral training aims to improve staff skills in managing challenging behaviors using a variety of principles derived from applied behavior analysis. Staff behavioral training is an evidence-based approach for reducing challenging behavior in adults and children with IDD [4, 85]. See ▶ Sect. 12.3 outlining how behavioral training can support reductions in aggression and self-injury as well as anxiety. Overall, systematic evidence on the effectiveness of stand-alone carer behavioral training on the mental health of people with IDD is scarce (compared to effects on challenging behavior), and clinicians tend to implement direct interventions for mental health problems in this population (see ▶ Sect. 12.2). In the case of severe IDD, there is no evidence on how staff stand-alone behavioral training might impact on mental health problems with the exception of single case evaluations of enriched environment for low mood, and relaxation with interruption for treatment of tics [86]. More evidence is available for sleep problems. A recent meta-analysis demonstrated that carer behavioral training is a promising evidence-based approach for sleep problems, which can be symptoms of broader mental health difficulties [87]. Training caregivers on extinction, and positive reinforcement of appropriate behavior (e.g., going to bed), while also implementing environmental modifications that promote sleep (e.g., no naps during the day, exercise, no television in bedroom) were associated with very large increases in both sleep initiation and sleep maintenance behaviors [87].

12.3.4 Staff Psychological Therapy

Staff psychological therapy is a contextual approach that primarily aims to improve staff mental health. Staff who support adults with IDD and challenging behaviors, and in particular aggression, experience higher levels of burnout and emotional exhaustion [88]. Job-related stress is one of the main reasons staff in IDD services leave their jobs [89]. At the same time, it is considered that burnout and stress lead to a worsening of staff attitudes regarding challenging behaviors, which in turn has been associated with more restrictive staff practices [90]. Two staff therapy approaches that have attracted attention in the past few years are acceptance and commitment therapy (ACT) and mindfulness-based approaches. At the core of these approaches is that the increase in psychological acceptance that comes through ACT or the practice of mindfulness will lead to more positive and less avoidant interactions with adults with IDD and challenging behaviors [91]. Most of the (still very limited) evidence to date suggests that ACT and mindfulness-based approaches reduce psychological distress in staff working in IDD services [55, 56, 92]. However, despite the hypothesized relationship with challenging behaviors, there is very little evidence that staff ACT or mindfulness-based therapy impacts on challenging behaviors of adults with IDD, mostly because studies have not collected such data. There is some evidence that mindfulness-based therapy for staff leads

to a reduction in the use of restraint or similar restrictive practices from staff, especially when combined with systemic approaches (see below).

12.3.5 Systemic Approaches

Systemic approaches target at once several aspects of the environment of the person with IDD. Systemic approaches are warranted when there are concerns about the overall quality of life of people with IDD, not just their levels of challenging behavior or mental health problems.

Active Support aims to improve the quality of life of adults with IDD by increasing participation in meaningful daily life activities, with appropriate support from staff [93, 94]. Active Support was developed to provide an operational model for community homes for adults with IDD. As a philosophy of care, it promotes active participation, choice, and independence. As a systemic intervention, it focuses on each resident at a time, while changing the way the whole home operates. Active Support draws on behavior analytic principles and techniques, teaching staff behavioral skills to support resident engagement in activities, and also using behavioral technologies for organizing life in the home in such a way that opportunities for activity participation are always available along with staff support, that resident experience is monitored through ongoing data collection, and that increased independence is achieved by practicing and learning new skills [95, 96]. In community settings, Active Support significantly increases the amount of time residents spend engaged in daily life activities, and the amount of time staff support them to do so [97].

Active Support does not directly target challenging behaviors, instead it promotes engagement in activities *despite* challenging behaviors, that is, challenging behaviors should not be put forward as a reason not to support a person to participate in daily life activities, such as shopping, cooking, and looking after their own home. Active Support is considered to impact indirectly on challenging behaviors by changing the establishing or abolishing operations that facilitate them (i.e., by changing the motivation to engage in challenging behaviors): Active Support creates a "helpful environment," one where staff attention is available and contingent on appropriate resident behavior, where access to activities and food/drink is always available, where residents know their schedule, and where staff support matches resident skill, so that the "need" to escape difficult instructions or activities is minimized [94]. In other words, Active Support is expected to impact on challenging behaviors by indirectly impacting on their function(s). Active Support does not target mental health problems directly. However, increasing levels of activity should reduce depressive symptoms in adults with IDD [98].

A recent meta-analysis indicated that there was actually very little change in resident challenging behaviors following Active Support implementation, and unclear change in depressive symptomatology [97]. Overall, however, the quality of included studies was moderate to low, and until better quality studies are available it will be difficult to determine whether the hypothesized effects on challenging behavior and depression can be brought about by a systemic intervention that only indirectly targets these outcomes. Clinical case work has shown that when Active Support is combined with Positive Behavior Support (PBS), significant reductions can be achieved [99].

This raises the possibility that systemic approaches work best to improve mental health and challenging behaviors when combined with direct interventions for reducing challenging behavior. Positive Behavior Support (PBS) is a multicomponent intervention that targets change in the environment, in which challenging behavior is displayed as well as change in the individual who presents with these behaviors. Contextual approaches within PBS can take many forms (from behavioral staff training to ensuring that daycare placements are available), and this depends on (a) preferences of the person with IDD and (b) the results of a systematic, in-depth analysis of the function of challenging behaviors (i.e., functional analysis; [100]). As a systemic intervention in community settings

for adults with IDD who already present challenging behavior, PBS can reduce challenging behaviors and lower the probability of mental health disorders (namely affective, psychotic, and organic disorders; [101]). Contextual interventions within PBS are variable, and not clearly documented, whereas PBS approaches directly targeting challenging behavior reductions are more standardized, that is, functional analysis and function-based interventions. In the absence of a component analysis, it is unclear which PBS components (the contextual approaches vs the direct ones) are associated with improvements. Systemic approaches also work well when coupled with other contextual interventions, such as staff therapy. Offering staff mindfulness training (with a focus on personal meditation) alongside training in PBS seems to produce higher reductions in aggression (and staff use of restrictive practices) than just training staff in PBS [102]. It is not clear why this happens, but if PBS focuses on the reduction of challenging behavior through the implementation of positive interventions, it may improve staff skill in managing resident behavior, but does not necessarily improve staff skill in managing their own behavior consistently; the addition of mindfulness strengthens staff awareness of own thoughts and emotions leading to increased psychological flexibility, which in turn may enable a more adaptive behavioral response to resident aggression [103].

Overall, systemic approaches are not the first port of call for reducing mental health problems or challenging behaviors that are already present. Systemic approaches aim primarily to improve quality of life, but where challenging behaviors are present, a whole environment approach that combines direct work to reduce challenging behavior, environmental modifications to improve quality of life and reduce opportunities or motivation for challenging behavior, as well as support for the mental well-being of the social environment appear to be particularly beneficial for challenging behaviors and mental health problems of people with IDD.

12.4 Conclusion

In this chapter, we have summarized nonpharmacological treatments for behavioral and/or mental health problems in individuals with IDD. We provide a selective review of strategies that are often used in clinical practice and for which there is some evidence on their effectiveness for such problems. This chapter provides practical guidelines for adapting interventions to these individuals.

Adapting interventions to individuals with ID remains challenging for clinicians and established first-line interventions such as CBT may not always be accessible for these individuals, given their communication difficulties and cognitive and adaptive impairments. Clinicians and researchers continue searching for interventions that are focused on behavior change rather than cognitions. Behavioral activation may be an interesting development, in that this strategy is relatively easy to implement and it is less cognitively demanding. Recently, Jahoda and his colleagues [98] used an intervention called BeatIt in adults with moderate-to-mild ID for the treatment of depressive symptoms. The focus of BeatIt was on increasing activity, scheduling activity, and addressing barriers to activity. The results showed that behavioral activation was effective in reducing depressive symptoms, although the treatment was not more effective than a comparison condition of guided self-help intervention. A strong feature was that the intervention was delivered on an outreach basis by nurses and health professionals supporting the clients.

On the basis of this selective review and other reviews, we may conclude that a range of behavioral, cognitive, and other types of interventions are promising in the treatment of challenging behaviors and/or mental health problems in individuals with ID and comorbid conditions. The evidence-base has grown during the past two decades but is still relatively small when compared to individuals without IDD. Most studies have addressed challenging behaviors in individuals with

ID. Particularly, interventions for mental health problems in individuals with severe ID are lacking (see Vereenooghe et al. [86]). This chapter also shows that many studies reflect methodological shortcomings and that there remains a lot of work to be done by practitioners and researchers. We would like to paraphrase Vereenooghe and colleagues who state that bidirectional knowledge transfer is particularly important: research into ID making its way into the training of practitioners, as well as practitioners highlighting difficulties in assessment and treatment that need addressing (p. 18).

Tip

Adapt the intervention to the characteristics and learning style of individuals with intellectual disabilities.

Key Points

There are a range of interventions that may be effective in reducing challenging behaviors and/or mental health problems in individuals with intellectual disabilities.

Contextual interventions are just as important – and sometimes even more important – as client-directed interventions.

In both cases, interventions should be adapted to the characteristics and learning style of the client or his or her caregivers.

References

1. Machalicek W, Raulston T, Knowles C, Ruppert T, Carnett A, Alresheed F. Challenging behavior. In: Matson JL, editor. Comorbid conditions among children with autism spectrum disorders. Cham: Springer; 2016. p. 137–70.
2. Singh NN, editor. Handbook of evidence-based practices in intellectual and developmental disabilities. Cham: Springer; 2016.
3. Storey K, Miner C. Systematic instruction of functional skills for students and adult with disabilities. 2nd ed. Springfield: Charles C. Thomas Publisher; 2017.
4. Sturmey P, Didden R, editors. Evidence-based practices and intellectual disabilities. Chichester: Wiley Blackwell; 2014.
5. Skinner BF. Science and human behavior. New York: Macmillan; 1953.
6. Ferster CB, Skinner BF. Schedules of reinforcement. Englewood Cliffs: Prentice-Hall; 1957.
7. Scott TM, Cooper JT. Functional behavior assessment and function-based intervention planning: considering the simple logic of the process. Beyond Behav. 2017;26:101–4.
8. Alberto PA, Troutman AC. Applied behavior analysis for teachers. 9th ed. Boston: Pearson; 2013.
9. Sigafoos J, Pennell D, Versluis J. Naturalistic assessment leading to effective treatment of self-injury in a young boy with multiple disabilities. Educ Treat Child. 1996;19:101–23.
10. Durand VM. Severe behavior problems: a functional communication training approach. New York: The Guilford Press; 1990.
11. Lerman D, Valentino A, LeBlanc L. Discrete trial training. In: Lang R, Hancock TB, Singh NN, editors. Early intervention for young children with autism spectrum disorder. New York: Springer; 2016. p. 47–83.
12. Iwata B, Dorsey M, Slifer K, Bauman K, Richman G. Toward a functional analysis of self-injury. Anal Interv Dev Disabil. 1982;2:3–20.
13. Hagopian L, Leoni M. Self-injurious behavior among individuals with intellectual and developmental disabilities. Acta Psychopathol. 2017;3:70.
14. Vereenooghe L, Langdon P. Psychological therapies for people with intellectual disabilities: a systematic review and meta-analysis. Res Dev Disabil. 2013;34:4085–40102.
15. Didden R. Commentary on formulations of anger in a person with intellectual disabilities. In: Sturmey P, editor. Clinical case formulation: varieties of approaches. London: Wiley; 2009. p. 283–92.
16. Hassiotis A, Serfaty M, Azam K, Martin S, Strydom A, King M. A manual of cognitive behaviour therapy for people with learning disability and common mental disorders (therapist version). London: Camden & Islington NHS Foundation Trust and University College London; 2012.
17. Lindsay W, Tinsley S, Beail N, Hastings R, Jahoda A, Taylor J, Hatton C. A preliminary controlled trial of a trans-diagnostic programme for cognitive behavior therapy with adults with intellectual disability. J Intellect Disabil Res. 2015;59:360–9.
18. Hronis A, Roberts A, Kneebone I. A review of cognitive impairments with children with intellectual disabilities: implications for cognitive behaviour therapy. Br J Clin Psychol. 2017;56:189–207.
19. Cooney P, Tunney C, O'Reilly G. A systematic review of the evidence regarding cognitive skills that assist cognitive behavioural therapy in adults who have an intellectual disability. J Appl Res Intellect Disabil. 2018;31:23–42.
20. Willner P, Rose J, Jahoda A, Stenfert Kroese B, Felce D, et al. Group-based cognitive behaviour anger management for people with mild to moderate intellectual disabilities: cluster randomized controlled trial. Br J Psychiatry. 2013;203:288–96.

21. Dagnan D, Jahoda A, Kilbane A. Preparing people with intellectual disabilities for psychological treatment. In: Taylor J, Lindsay W, Hastings R, Hatton C, editors. Psychological therapies for adults with intellectual disabilities. Chichester: Wiley Blackwell; 2013. p. 55–68.
22. Nicoll M, Beail N, Saxon D. Cognitive behavioural treatment for anger in adults with intellectual disabilities: a systematic review and meta-analysis. J Appl Res Intellect Disabil. 2013;26:47–62.
23. Unwin G, Tsimopoulou I, Stenfert Kroese B, Azmi S. Effectiveness of cognitive behavioural therapy (CBT) for anxiety or depression in adults with intellectual disabilities: a review of the literature. Res Dev Disabil. 2016;51:60–75.
24. Kouimtsidis C, Scior K, Baio G, Hunter R, Pezzoni V, Hassiotis A. Development and evaluation of a manual for extended brief intervention for alcohol misuse for adults with mild to moderate intellectual disabilities living in the community: the EBI-LD study manual. J Appl Res Intellect Disabil. 2017;30:42–8.
25. Pence S, Aldea M, Sulkowski M, Storch E. Cognitive behavioral therapy in adults with borderline intellectual functioning: a case series of three patients. J Dev Phys Disabil. 2011;23:71–85.
26. Murphy G, Sinclair N, Hays S, Heaton K, Powell S, et al. Effectiveness of group cognitive-behavioural treatment for men with intellectual disabilities at risk for sexual offending. J Appl Res Intellect Disabil. 2010;23:537–51.
27. Kellet S, Matuozzo H, Kotecha C. Effectiveness of cognitive-behavioural therapy for hoarding disorder in people with mild intellectual disabilities. Res Dev Disabil. 2015;47:385–92.
28. DaWalt L, Greenberg G, Mailick M. Transitioning together: a multi-family group psychoeducation program for adolescents with ASD and their families. J Autism Dev Disord. 2018;48:251–63.
29. Mevissen L, Didden R, De Jongh A. Assessment and treatment of PTSD in individuals with intellectual disability. In: Martin C, Preedy V, Patel V, editors. Comprehensive guide to post-traumatic stress disorders. New York: Springer; 2016. p. 281–99.
30. Carrigan N, Allez C. Cognitive behaviour therapy for posttraumatic stress disorder in a person with autism spectrum condition and intellectual disability: a case study. J Appl Res Intellect Disabil. 2017;30:326–35.
31. Mevissen L, Didden R, Korzilius H, De Jongh A. Eye movement desensitization and reprocessing therapy for posttraumatic stress disorder in a child and adolescent with mild to borderline intellectual disability: a multiple baseline across subjects study. J Appl Res Intellect Disabil. 2017;30:34–41.
32. Mevissen L, Didden R, Korzilius H, De Jongh A. Assessment of PTSD in children with mild to borderline intellectual disabilities. Eur J Psychotraumatol. 2016;7:29786.
33. Bouvet C, Coulet A. Relaxation therapy, and anxiety, self-esteem, and emotional regulation among adults with intellectual disabilities: a randomized controlled trial. J Intellect Disabil. 2016;20:228–40.
34. Bellemans T, Didden R, Van Busschbach J, Hoek P, Scheffers M, Lang R, Lindsay W. Psychomotor therapy targeting anger and aggressive behavior in individuals with mild or borderline intellectual disabilities: a systematic review. J Intellect Dev Disabil. 2019;44(1):121–30. https://doi.org/10.3109/13668250.2017.1326590.
35. Harris N, Robbins L. Imagine your bedroom is the entrance to the zoo: creative relaxation – exploring and evaluating the effectiveness of a person-centred programme of relaxation therapies with adults with a mild to moderate intellectual disability. Br J Learn Disabil. 2013;42:76–84.
36. Beail N, Jackson T. Psychodynamic psychotherapy and people with intellectual disabilities. In: Taylor J, Lindsay W, Hastings R, Hatton C, editors. Psychological therapies for adults with intellectual disabilities. Chichester: Wiley-Blackwell; 2013. p. 237–51.
37. McInnis E. Critical literature review: effectiveness of individual psychodynamic psychotherapy for adults with intellectual disabilities. Adv Ment Health Intellect Disabil. 2016;10:233–47.
38. Webster M. Introduction to acceptance and commitment therapy. Adv Psychiatr Treat. 2011;17:309–16.
39. Leoni M, Corti S, Cavagnola R. Third generation behavioral therapy for neurodevelopmental disorders: review and trajectories. Adv Ment Health Intellect Disabil. 2015;9:265–74.
40. Taylor JL, Lindsay WR, Hastings RP, Hatton C, editors. Psychological therapies for adults with intellectual disabilities. Chichester: Wiley Blackwell; 2013.
41. Dimidjian S, Hollon S, Dobson K, Schmaling K, Kohlenberg R, Addis M, et al. Randomized trial of behavioral activation, cognitive therapy, and antidepressant medication in the acute treatment of adults with major depression. J Consult Clin Psychol. 2006;74:658–70.
42. Dobson KS, Hollon SD, Dimidjian S, Schmaling KB, Kohlenberg RJ, Gallop RJ, Rizvi SL, Gollan JK, Dunner DL, Jacobson NS. Randomized trial of behavioural activation, cognitive therapy, and antidepressant medication in the prevention of relapse and recurrence in major depression. J Consult Clin Psychol. 2006;76:468–77.
43. Kahl K, Winter L, Schweiger U. The third wave of cognitive behavioral therapies. What is new and what is effective? Curr Opin Psychiatry. 2012;25:522–8.
44. Linehan M, Koerner K. Doing dialectical behavior therapy. New York: Guilford; 2012.
45. McKay M, Wood JC, Brantley J. The dialectical behavior therapy skills workbook. Oakland: New Harbinger; 2007.

46. White R, Gumley A, McTaggart J, Rattrie L, McConville D, Cleare S, Mitchell G. A feasibility study of acceptance and commitment therapy for emotional dysfunction following psychosis. Behav Res Ther. 2011;49:901–7.
47. Arntz A, van Genderen H. Schema therapy for borderline personality disorder. Chichester: Wiley-Blackwell; 2009.
48. Segal ZV, Williams JM, Teasdale JD. Mindfulness-based cognitive therapy for depression. New York: Guilford; 2002.
49. Leoni M, Corti S, Cavagnola R, Healy O, Noone S. How acceptance and commitment therapy changed the perspective on support provision for staff working with intellectual disability. Adv Ment Health Intellect Disabil. 2016;10:59–73.
50. Brown FJ, Hooper S. Acceptance and Commitment Therapy (ACT) with a learning disabled young person experiencing anxious and obsessive thoughts. J Intellect Disabil. 2009;13:195–201.
51. Pahnke J, Lundgren T, Hursti T, Hirvikoski T. Outcomes of an acceptance and commitment therapy-based skills training group for students with high-functioning autism spectrum disorder: a quasi-experimental pilot study. Autism. 2014;18:953–64.
52. Jones L, Gold E, Totsika V, Hastings RP, Jones M, Griffiths A, Silverton S. A mindfulness parent well-being course: evaluation of outcomes for parents of children with autism and related disabilities recruited through special schools. Eur J Spec Needs Educ. 2018;33:16–30.
53. Tyrberg MJ, Carlbring P, Lundgren T. Implementation of acceptance and commitment therapy training in a psychiatric ward: feasibility, lessons learned and potential effectiveness. J Psych Intensive Care. 2017;13:73–82.
54. Harper SK, Webb TL, Rayner K. The effectiveness of mindfulness-based interventions for supporting people with intellectual disabilities: a narrative review. Behav Modif. 2013;37:431–53.
55. McConachie D, McKenzie K, Morris PG, Walley B. Acceptance and mindfulness-based stress management for support staff caring for individuals with intellectual disabilities. Res Dev Disabil. 2014;35:1216–27.
56. Noone S, Hastings RP. Using acceptance and mindfulness-based workshops with support staff caring for adults with intellectual disabilities. Mindfulness. 2010;1:67–73.
57. Ó Donnchadha S. Stress in caregivers of individuals with intellectual or developmental disabilities: a systematic review of mindfulness-based interventions. J Appl Res Intellect Disabil. 2017;31:181–92.
58. Singh NN, Wahler RG, Sabaawi M, Goza AB, Singh SD, Molina EJ. Mentoring treatment teams to integrate behavioral and psychopharmacological treatments in developmental disabilities. Res Dev Disabil. 2002;23:379–89.
59. Singh NN, Lancioni GE, Winton ASW, Singh AN, Adkins AD, Singh J. Mindful staff can reduce the use of physical restraints when providing care to individuals with intellectual disabilities. J Appl Res Intellect Disabil. 2009;22:194–202.
60. Singh NN, Lancioni GE, Winton ASW, Wahler RG, Singh J, Sage M. Mindful caregiving increases happiness among individuals with profound multiple disabilities. Res Dev Disabil. 2004;27:545–58.
61. Polk KL, Schoendorff B. The ACT matrix: a new approach to building psychological flexibility across settings and populations. Oakland: New Harbinger Publications; 2014.
62. Barlow J, Coren E, Stewart-Brown S. Meta-analysis of the effectiveness of parenting programmes in improving maternal psychosocial health. Br J Gen Pract. 2002;52:223–33.
63. Furlong M, McGilloway S, Bywater T, Hutchings J, Smith S, Donnelly M. Behavioral and cognitive-behavioural group-based parenting interventions for early-onset conduct problems in children age 3–12 years. Cochrane Database Syst Rev. 2012;2:CD008225.
64. Dretzke J, Davenport C, Frew E, Barlow J, Stewart-Brown S, Bayliss S, Taylor S, Sandercock J, Hyde C. The clinical effectiveness of different parenting programmes for children with conduct problems: a systematic review of randomized controlled trials. Child Adolesc Psychiatry Ment Health. 2009;3:1–10.
65. Sanders MR. Triple P-positive parenting program: towards an empirically validated multilevel parenting and family support strategy for the prevention of behaviour and emotional problems in children. Clin Child Fam Psychol Rev. 1999;2:71–90.
66. Webster-Stratton C. The incredible years: parents, teachers, and children training series. Resid Treat Child Youth. 2001;18:31–45.
67. Sanders MR, Mazzucchelli TG, Studman LJ. Stepping Stones Triple P: the theoretical basis and development of an evidence-based positive parenting program for families with a child who has a disability. J Intellect Dev Disabil. 2004;29:265–83.
68. McIntyre L. Adapting Webster-Stratton's incredible years parent training for children with developmental delay: findings from a treatment group only study. J Intellect Disabil Res. 2008;52:1176–92.
69. Hudson A, Cameron C, Matthews J. The wide-scale implementation of a support program for parents of children with an intellectual disability and difficult behaviour. J Intellect Dev Disabil. 2008;33:117–26.
70. Hames A, Rollings C. A group for the parents and carers of children with severe intellectual disabilities and challenging behaviour. Educ Child Psychol. 2009;26:47–54.
71. Totsika V, Hastings PR, Emerson E, Berridge D, Lancaster GA. Behavior problems at 5 years of age and maternal mental health in autism and intellectual disability. J Abnorm Child Psychol. 2011;39:1137–47.
72. Kaminski JW, Valle LA, Filene JH, Boyle CL. A meta-analytic review of components associated

with parent training program effectiveness. J Abnorm Child Psychol. 2008;36:567–89.
73. Petrenko L. A review of intervention programs to prevent and treat behavioural problems in young children with developmental disabilities. J Dev Phys Disabil. 2013;25:651–79.
74. Totsika V, Mandair S, Lindsay G. Comparing the effectiveness of evidence-based parenting programs on families of children with and without special educational needs: short term and long term gains. Front Educ. 2017;2:7.
75. Tellegen CL, Sanders MR. Stepping Stones Triple P-Positive Parenting Program for children with disability: a systematic review and meta-analysis. Res Dev Disabil. 2013;34:1556–71.
76. McIntyre L. Parent training for young children with developmental disabilities: randomized controlled trial. Am J Ment Retard. 2008;113:356–68.
77. Williams MA, Hastings RP, Charles JM, Evans S, Hutchings J. Parenting for Autism, Language, and Communication Evaluation Study (PALACES): protocol for a pilot randomised control trial. BMJ Open. 2017;7(2):e014524.
78. Thompson-Janes E, Brice S, McElroy R, Abbott J, Ball J. Learning from the experts: a thematic analysis of parent's experiences of attending a therapeutic group for parents of children with learning disabilities and challenging behaviour. Br J Learn Disabil. 2014;44:95–102.
79. Coulman E, Hastings R, Gore N, Gillespie D, McNamara R, et al. The Early Positive Approaches to Support (E-PAtS) study: study protocol for a feasibility cluster randomized controlled trial of a group programme for family caregivers of young children with intellectual disability. BMC. 2020;6:147.
80. Singer G. Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. Am J Ment Retard. 2006;111:155–69.
81. Totsika V, Hastings RP, Emerson E, Lancaster GA, Berridge DM, Vagenas D. Is there a bidirectional relationship between maternal well-being and child problem behaviors in autism spectrum disorders? Longitudinal analysis of a population defined sample of young children. Autism Res. 2013;6:201–11.
82. Singer G, Ethridge B, Aldana S. Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: a meta-analysis. Ment Retard Dev Disabil Res Rev. 2007;13:357–69.
83. Dykens EM, Fisher MH, Taylor JL, Lambert W, Miodrag N. Reducing distress in mothers of children with autism and other disabilities: a randomized trial. Pediatrics. 2014;134:E454–63.
84. Singh NN, Lancioni GE, Winton ASW, Fisher BC, Wahler RG, McAlevey K, Singh J, Sabaawi M. Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. J Emot Behav Disord. 2007;14:169–77.
85. Didden R, Korzilius H, van Oorsouw W, Sturmey P. Behavioural treatment of challenging behaviors in individuals with mild mental retardation: meta-analysis of single-subject research. Am J Ment Retard. 2006;111:290–8.
86. Vereenooghe L, Flynn S, Hastings RP, Adams D, Chauhan U, Cooper SA, Gore N, Hatton C, Hood K, Jahoda A, Langdon PE, McNamara R, Oliver C, Roy A, Totsika V, Waite J. Interventions for mental health problems in children and adults with severe intellectual disabilities: a systematic review. BMJ Open. 2018;8(6):e021911. https://doi.org/10.1136/bmjopen-2018-021911. PMID: 29921688; PMCID: PMC6020952.
87. Priday L, Byrne C, Totsika V. Behavioural interventions for sleep problems in people with an intellectual disability: a systematic review and meta-analysis of single case and group studies. J Intellect Disabil Res. 2017;61:1–15.
88. Hensel JM, Lunsky Y, Dewa CS. Exposure to client aggression and burnout among community staff who support adults with intellectual disabilities in Ontario, Canada. J Intellect Disabil Res. 2012;56:910–5.
89. Hatton C, Emerson E, Rivers M, Mason H, Swarbrick R, Mason J, Kiernan C, Reeves D, Alborz A. Factors associated with intended staff turnover and job search behavior in services for people with intellectual disability. J Intellect Disabil Res. 2001;45:258–70.
90. Knotter M, Wissink I, Moonen X, Stams G-J, Jansen G. Staff's attitudes and reactions towards aggressive behaviour of clients with intellectual disabilities: a multilevel study. Res Dev Disabil. 2013;34:1397–407.
91. Noone S, Hastings RP. Building psychological resilience in support staff caring for people with intellectual disabilities. Pilot evaluation of an acceptance-based intervention. J Intellect Disabil. 2009;13:43–53.
92. Smith MP, Gore NJ. Outcomes of a 'Train the Trainers' approach to an acceptance based stress intervention in a specialist challenging behaviour service. Int J Posit Behav Support. 2012;2:39–48.
93. Toogood S, Totsika V, Jones E, Lowe K. Active support. In: Singh N, editor. Handbook of evidence-based practices in intellectual and developmental disabilities. Cham: Springer; 2016. p. 537–60.
94. Totsika V, Toogood S, Hastings RP. Active support: development, evidence base and future directions. Int Rev Res Ment Retard. 2008;35:205–49.
95. Jones E, Perry J, Lowe K, Allen D, Toogood S, Felce D. Active support: a handbook for supporting people with learning disabilities to lead full lives. Cardiff: Welsh Centre for Learning Disabilities Applied Research Unit, University of Wales; 2009.

96. Toogood S. Interactive training: supporting people with severe and profound intellectual disabilities in meaningful activity. Brighton: Pavilion Publishing; 2010.
97. Flynn S, Totsika V, Hastings RP, Hood K, Toogood S, Felce D. Effectiveness of active support for adults with intellectual disability in residential settings: systematic review and meta-analysis. J Appl Res Intellect Disabil. 2018;31(6):983–98. https://doi.org/10.1111/jar.12491. Epub 2018 Jun 27. PMID: 29947444.
98. Jahoda A, Hastings RP, Hatton C, Cooper S-A, Dagnan D, Zhang R, McKeekin N, Appleton K, Jones R, Scott K, Fulton L, Knowles D, Williams C, Briggs A, McMahon K, Lynn H, Thomas G, Melville C. Comparison of behavioural activation with guided self-help for treatment of depression in adults with intellectual disabilities: a randomised control trial. Lancet Psychiatry. 2017;4:909–19.
99. Jones E, Lowe K, Brown S, Albert L, Saunders C, Hake N, Leigh H. Active support as a primary prevention strategy for challenging behavior. Int J Posit Behav Support. 2013;3:16–30.
100. Carr E, Dunlap G, Horner R, Koegel R, Turnbull A, Sailor W, Anderson J, Albin R, Koegel L, Fox L. Positive behavior support: evolution of an applied science. J Posit Behav Intervent. 2002;4:4–16.
101. Hassiotis A, Robotham D, Canagasabey A, Romeo R, Langridge D, Blizard R, Murad S, King M. Randomized, single-blind, controlled trial of a specialist behaviour therapy team for challenging behaviour in adults with intellectual disabilities. Am J Psychiatr. 2008;166:1278–85.
102. Singh N, Lancioni G, Karaszia B, Chan J, Winton A. Effectiveness of caregiver training in Mindfulness-based Positive Behavior Support (MBPBS) vs Training-As-Usual (TAU): a randomized controlled trial. Front Psychol. 2016;7:1549.
103. Singh NN, Lancioni GE, Karaszia BT, Myers RE. Caregiver training in Mindfulness-Based Positive Behavior Supports (MBPBS): effects on caregivers and adults with intellectual and developmental disabilities. Front Psychol. 2016;7:98.