http://jppbr.ub.ac.id/
DOI: 10.21776/ub.jppbr.2025.006.02.4
eISSN: 2723-083X pISSN: 2723-0821

Journal of Psychiatry Psychology and Behavioral Research
Vol. 6 No. 2, September 2025

JPPBR

ACCEPTANCE AND COMMITMENT THERAPY FOR PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY

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REVIEW OPEN ACCESS

ABSTRACT

Introduction – Intellectual disability is one of the most common disabilities of children worldwide, and it becomes a stress burden among parents. Acceptance and Commitment Therapy (ACT), which goals to increase valued action and behaviour in the present moment, has been suggested as an alternative approach. This literature review aimed to explore the effect of acceptance and commitment therapy for parents of children with intellectual disability.
Methods – The searches of this literature review were conducted in Google Scholar, ScienceDirect, PubMed, and Wiley Library, ranging from 2010 to 2023. The literature search involved articles that focused on the effect of ACT in parents of children with intellectual disability.
Results – Four research articles were included. All of the article's studies are about the use of ACT in parents of children with intellectual disability, but in different interventions and study designs.
Discuss – Most parents stated that the struggles of caring for a child with significant behavioural challenges, both emotionally and physically, and the level of isolation they experienced, consequently, was great enough to generate stress. This programme gives a new perspective on their difficulties, enhancing their ability to deal with stress, and enabling parents to maintain their emotional well-being by "getting back on the track" of what parents should be based on their personal values.
Conclusion – ACT may play a significant role in helping to improve the psychological well-being of parents with intellectual disability child. However, further investigation with interventions for each group based on precipitating factors is required to evaluate and to predict when the right time is to do this therapy.

Keywords: ACT, IDD, anxiety, depression.

Article History:
Received: July 9, 2023
Accepted: September 5, 2023
Published: September 30, 2025

Cite this as: *Fadriyana, A.P. Acceptance and Commitment Therapy for Parents of Children with Intellectual Disability. Journal of Psychiatry Psychology and Behavioral Research; 2025.6:2. p21-26.*

INTRODUCTION

Intellectual disability – previously known as mental retardation – is a generalized neurodevelopmental disorder characterized by significantly impaired intellectual and adaptive functioning that begins early in the developmental period.[1] The following cognitive processes are considered to be intellectual functions, including academic learning, reasoning, abstract thought, problem-solving, judgment, planning, learning from instruction and experience, and practical comprehension that has been validated by both clinical assessment and standardized testing. Adaptive functions are characterized in terms of intellectual, social, and practical abilities regarding activities carried out by people in their daily lives, such as communication and dependent living.[2] The UNICEF Disability Report 2022 estimates that there are about 236.4 million, or 10.1% of all children worldwide aged 0 to 17 years with intellectual disability.[3] Every parent wants to see their child's development from time to time and hopes their child can grow according to their age. However, children with intellectual disability will independently need parents or caregivers in various aspects of daily activities. Once the diagnosis is made, we need to emphasize identifying the children's strengths, needs, and the supports required for them to function at home, at school or work, and in the community, especially from their parents. Being the parent of a child with intellectual disability is a time of enormous tension and upheaval. Parenting is a demanding profession, and becoming a parent to a child with intellectual disability is one of the most pressured life events.[4] In developing countries, this is coupled with economic problems that frequently add to the complex lives of parents.

In psychology, there is a method of psychotherapy based on action that evolved from traditional behavior therapy and cognitive behavioral therapy called acceptance and commitment therapy (ACT). In the case of ACT, people learn to stop avoiding, rejecting, and resisting their inner emotions and instead conceive that these deeper feelings are rational responses to events and should allow them to go ahead. With this knowledge, people learn to overcome their difficulties and decide to implement necessary behavioral adjustments, regardless of what is going on in their lives or how they feel toward it.[5] Interventions have primarily focused on directly increasing the parents' capacity to handle the child's impairments. Parent-centered therapeutic approach of children with disability seems to be rare and remains unclear. Addressing this problem may enhance parents' well-being, quality of family life, and adjustment to the current life scenario. This review aims to explore the effect of acceptance and commitment therapy in parents of children with intellectual disability.

METHOD

The databases used to identify the studies were articles in Google Scholar, ScienceDirect, PubMed, and Wiley Library. The studies classified in this review included those published in the year 2010 to 2023. The search terms or keywords used were: (Acceptance and Commitment Therapy) OR (ACT) AND (Parent of children with intellectual disability). We included all publications that covered the effect of ACT in parents of children with intellectual disability.

RESULT

Based on search results from the database, a total of 43 articles were obtained. Then we made a selection based on the title and abstract of the articles the resulting in 5 potential articles. Out of 5 full-text articles we read, we obtained 4 research articles that are relevant for this literature review study. The process of selecting articles for this review is shown in Fig.1, and the summary of included articles is shown in the Table. 1.

Figure 1. Flowchart for selecting articles

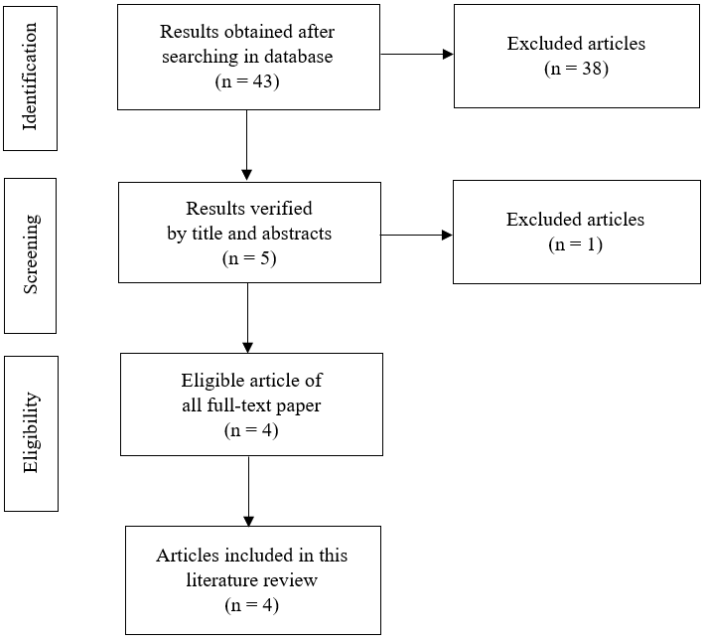

Table 1. Summary of included articles

Reference	Type of Study	Groups	Durations	Participants	Methods of Measurement	Main Results
Poddar et al., 2015[6]	A repeated measures study design	Intervention group only	10 session protocol in 2-month	5 parents	○ STAI ○ BDI ○ AAQ ○ WHOQOL-BREF	ACT significantly decrease in state anxiety, level of subjective distress, increase in physcological flexibility, and improvement in quality of life
Reid et al., 2016[7]	A qualitative study design	Intervention group only	2 weeks interview after two workshops	5 parents	○ Semi-structured interviews	ACT encourage and keep up family emotional health. The Parent Well-Being Workshops based on an ACT framework were able to integrate acceptance and mindfulness into daily live.
Lobato et al., 2022[8]	Open clinical trial	Intervention group only	3 weeks of intervention with 2 months after intervention follow-up	36 parents	○ 6-PAQ ○ PSS-14 ○ GHQ-12 ○ WBSI ○ Behavioural self-monitoring	ACT significantly increased physiological flexibility, decreased perceived stress, improvement pyschiological health, and decreased suppresion of unwanted thought, increase supportive interactions, and decrease aversive interactions with the size effect of medium-large.
Lobato et al., 2023[9]	A single-centre randomised clinical trial with two arms	Training programme group (intervention group) vs waiting list group (control group)	3 weeks of intervention with 3 months after intervention follow-up	14 parents (8 parents in intervention group and 6 parents in control group)	○ 6-PAQ ○ PSS-14 ○ GHQ-12 ○ WBSI ○ Behavioural self-monitoring	ACT significantly increased physiological flexibility, decreased perceived stress, and decreased suppresion of unwanted thought, increase supportive interactions, and decrease aversive interactions with the size effect of medium-large. While there is no statistically significant changes were observed in control group.

6-PAQ: Parental Acceptance Questionnaire, **AAQ:** Acceptance and Action Questionnaire, **BDI:** Beck Depression Inventory, **GHQ-12:** General Health Quistionnaire, **PSS:** Perceived Stress Scale, **STAI:** State-Trait Anxiety Inventory, **WBSI:** White Bear Suppression Inventory, **WHOQOL-BREF:** The World Health Organization Quality of Life Assesment BREF

DISCUSS

Stress Between Parents of Children with Intellectual Disability

Intellectual disability is becoming the most common disability in children globally.[3] Most professionals attempting to obtain the right diagnosis and appropriate therapy for the child, while on the other side, the parents experience unutterable stress. Stress can manifest as physical health problems or psychological disorders such as anxiety, depression, and a decreased quality of life. After knowing that their child has intellectual disability, a parent exhibits a certain number of emotions such as shock, guilt, sadness, denial, rejection, and acceptance. A cross-sectional study shows parents of children with intellectual disability had a bigger stress scale than parents of children with no intellectual disability, both mentally and physically.[4,10] Intellectual disability also becomes one of the positive predictors of subjective and objective burden in parents of children with autism spectrum disorder.[11]

Stress in parents looks to be related to gender. Mothers of intellectual disability appear to experience more stress than fathers. Mothers are under more pressure and responsibility to keep raising children while managing the household.[4,10] Azeem et al. discovered that 89% mothers of intellectual disability in Pakistan undergo more anxiety, depression, or both as compared to fathers.[12] Some factors also contributed to the quantity of stress among parents, including the child's intellectual disability level, parents' coping mechanisms, socioeconomic background, and community support. A study showed that parents of children with moderate and severe intellectual disability had greater stress than parents of children with mild intellectual disability. Unemployment significantly increases stress in parents of children with moderate and severe intellectual disability.[13]

Family, especially parents, is the primary support for disabled children at every level of society. Having a problem with a parent's health may affect the quality of parenting. Thus, interventions for mental and physical stress of the parents, along with provision of treatment and rehabilitation needs for the children, were required to reduce the stress burden among parents of children with intellectual disability. Support from family members, relatives, neighbors, and professional supervision may help strengthen parents' psychological well-being.[4,10-13]

Acceptance and Commitment Therapy

Acceptance and commitment therapy (ACT) is a type of psychotherapy that uses mindfulness and behavioral approaches. ACT was first introduced by a professor and psychologist, Dr. Stephen Hayes, in 1986. This developed from Hayes' personal experience, specifically his history of panic attacks. Hayes proposed the idea that difficult thoughts and feelings are natural. Some techniques used to control or prevent them will cause more suffering [14]

Unlike other therapies, the purpose of ACT is to encourage individuals to act in ways that are essential to them, even if it means having uncomfortable thoughts and feelings. ACT also becomes one of the third-wave therapies that emphasize the comprehensive stimulation of psychological and behavioral processes related to health and well-being over the reduction or elimination, though this is usually a "side-benefit". The goal of this therapy is to develop psychological flexibility and to live with meaningful life. Psychological flexibility is defined as the ability to maintain contact with the present moment in the face of unpleasant thoughts, feelings, and physiological sensations; to identify their personal values and use these to help people make better decisions and actions. When a person has a goal to achieve a particular thing because it is really meaningful to him, then he keeps trying and stays determined to achieve it, even though the way is hard and the goal is difficult, it can be an example of psychological flexibility.[14,15] Through this purpose, ACT is widely developed for treating mental illness (such as anxiety, obsessive compulsive disorder, depression)[16], chronic diseases (such as cancer, autoimmune, diabetes, chronic pain, drug abuse)[17,18,] and many other stressors (such as divorce, interpersonal conflict, burn-out). A review stated that cancer patients who participated in ACT had a better quality of life and emotional state, as well as increased psychological flexibility.[19] ACT in chronic pain cases was more clinically effective than control in a variety of outcomes.[17]

In ACT, six inseparable core processes help in building psychological flexibility. Those processes are 1) contact with the present moment (being completely aware and enganged in the present without judging through "mindfullness"); 2) cognitive defusion (also known as deliteralization, distance one thought from the other); 3) acceptance (to instead open up and welcome those feelings in); 4) self as context (observing self so people can realize how their tought affecting them); 5) personal values (identify meaning and purpose of their life and demonstrate each values to their life); 6) commited action (take action in the direction of chosen value even in the presence of obstacles).[14-15,20]

ACT therapists usually utilize metaphors (such as a beach ball underwater, quicksand, and driver's vs passengers) in the beginning of therapy to teach clients new ways of perceiving their emotions and responding to them. Some therapists also use experiential techniques that help to illustrate key concepts of therapy under several conditions. ACT session may appear as individualized therapy or group forms, which in common practice will be divided at least into 4 session: 1) identify things that are considered a problem and what efforts have been made and the impact on individual behavior; 2) Help the individual to realize inappropriate behavior and reveal the consequences if stress is not handled immediately; 3) Practice ways to deal with problems (such as stress) according to the way the individual chooses; and 4) Commitment and maintaining behavior.[15, 20]

The Effect of Acceptance and Commitment Therapy in Parents of Children with Intellectual Disability

We found four research articles that study Acceptance and Commitment Therapy in parents of children with intellectual disability. Lobato et al. (2023) give a strengthening result to their previous study with a waiting-list control group.[8,9] Three articles were quantitative studies, and one article was a qualitative study. A qualitative design may provide an open-sided view of opinion about therapy methods from participants in many ways. Most parents stated that the struggles of caring for a child with significant behavioural challenges, both emotionally and physically, and the level of isolation they experienced, consequently, were great enough to generate stress. This programme gives a new perspective on their difficulties, enhancing their ability to deal with stress, and enabling parents to maintain their emotional well-being by

"getting back on track" with what parents should be based on their personal values.[7]

The other three studies included in this review were quantitative. Both articles applied a questionnaire as a method of measurement, but in different types. Poddar et al. (2015) used STAI to measure anxiety level, BDI to measure depression level, AAQ to measure psychological flexibility, and WHOQOL-BREF to measure quality of life. Instead, Lobato et al. (2022 and 2023) used 6-PAQ to measure parental psychological flexibility, PSS-14 to measure perceived stress, GHQ-12 to measure psychological health, WBSI to measure suppression of unwanted thoughts, and Behavioural self-monitoring to measure supportive or aversive interaction.[6,8-9] These questionnaires complement each other and might be applied in a clinical setting depending client's needs.

All inclusion studies performed ACT-based intervention by a psychologist trained with a group design. Reid et al. (2015) used workshops and training as a medium to share acceptance and mindfulness-based therapy, while Lobato et al. (2022 and 2023) stated that the intervention was done in a room of the collaborating NGO.[7-9] Some parents think participating in the courses with other parents who had similar conditions was crucial. They experienced the same feeling and discarded the thought of loneliness. Besides, for research purposes, this can be an efficient technique of explaining ACT to a broad group in a short period of time. But we might also consider a one-to-one therapy session in a clinical setting for personal confidentiality purposes. The use of metaphor and experiential technique in all inclusion studies implies that this technique is the best method for trainers to teach and easiest for clients to understand [15,21]

The duration of therapy is diverse among these studies: 2 sessions of 4 hours each week, 3 sessions of 3 hours each week, and 10 sessions within 2 months. Based on the results of respective studies, this amount of time is adequate to produce meaningful change.[6-9] However, the quality of change is required so we can evaluate whether the success of therapy can be maintained over a span of weeks, months, or years, as ACT requires time to be developed.[22]

According to Poddar et al. (2015) and Lobato et al. (2022 and 2023), ACT significantly decreases anxiety level, decreases perceived stress, increases psychological flexibility, improves psychological health, decreases suppression of unwanted thoughts, increases supportive interactions, decreases aversive interactions, and improves quality of life. These results showed that ACT has a great impact on parents' psychological well-being. This therapy is especially given to the parents of children with intellectual disability. However, we also might consider that the family member, caregiver, or family carer who is directly responsible for nurturing the child may experience the same thing.[6-9]

CONCLUSION

From this review, we can conclude that acceptance and commitment therapy has many benefits for parents of children with intellectual disability. ACT may improve psychological well-being by increasing physiological flexibility, decreasing perceived stress, decreasing suppression of unpleasant thoughts, increasing supportive interactions, as well as decreasing aversive interactions, so that parents may achieve a better quality of life. Further investigation with more than 3 months of follow-up is needed to evaluate long-term outcomes and possible debilitating factors. Another research study about the effect of ACT in parents of children with intellectual disability based on the precipitating factor may predict the appropriate time to do the therapy for each parent.

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