# DBT-ID: Modified Dialectical Behavior Therapy (DBT) for Individuals with Intellectual Disabilities (ID)

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Diaconia in Practice Series
United Evangelical Mission
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# DBT-ID: Modified Dialectical Behavior Therapy (DBT) for Individuals with Intellectual Disabilities (ID)


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# Content



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# Foreword

Dr. Fidon R. Mwombeki

I know of a mother who experienced nightmares for many years after the death of her son, who suffered from epilepsy. In the village where they lived, people with epilepsy were stigmatized and often hidden away, and her son received no medication and no hospital was able to help him. The woman loved her son, but she did not know how to deal with him. When his epilepsy reached an advanced stage, her son was thought to be mentally ill. He was locked up in a room, and his mother permitted her elder son to tie him with ropes in the way thieves were punished. He was fed with a spoon with his hands tied behind his back and was even tied up when he slept. He eventually refused to eat and ultimately suffered such severe convulsions that he died. His agony remained etched in the mind of his loving but helpless mother until her death.

It is not easy to say how many people are forced to live in suffering simply because knowledge on how to deal with people with disabilities is lacking. In many countries diaconic services for such people are not available and trained medical professionals are not there. Where there are some services, those who provide it often have little or no special training or access to the latest developments in the field.

At the United Evangelical Mission, we believe that serving those in need in a professional manner is one of our most important missionary tasks. Many churches try their best, but most of the time specialized knowledge and skills are lacking. We do what we can to help churches offer professional training for those providing medical care for people with disabilities – but we simply cannot wait until there are enough professionals who are paid adequately to take care of those who frequently suffer hidden away from the eyes of society in the seclusion of their homes.

To support these efforts, we have decided to call on professionals to share what they know with others and to launch a book series that aims to contribute to the knowledge required to serve those in various difficult situations. The books in this series aim to help those who are willing and able to serve those in need in a more professional manner. They should be of high quality, but written in a manner that is useful not only to those undergoing professional training but also to those who simply want hints to help them in their circumstances.

We are delighted to present the first title issued in the series, *DBT-ID: Modified Dialectical Behavior Therapy (DBT) for Individuals with Intellectual Disabilities (ID)*. This manual meets the requirements we set ourselves in every way: It is of high professional quality and yet it is also simple and straightforward enough for even non-professionals to use as a handbook. Our thanks go to its authors, translators and planners, and to those who are willing to put it into practice.

Fidon R. Mwombeki
General Secretary, UEM
November 2013

# Foreword

Dr. Joseph K. Mbatia

I feel greatly honored to have been asked to write the foreword to such an excellent manual. The assumption is that my experience in psychiatry and mental health in Tanzania, particularly in training medical undergraduates and primary health care workers, allows me to judge the usefulness of this work. Moreover, I have had the privilege of working as mental health advisor to the Ministry of Health and Social Welfare in Tanzania for eleven years, as well as undertaking a number of consultancies for the WHO.

The work compiled by the team at the Treatment Center for Individuals with Intellectual Disabilities and Psychiatric Comorbidity in Berlin is impressive in being highly structured, brief and very clear. One of the main challenges in providing mental health training in sub-Saharan Africa is a lack of access to well-structured tools for hands-on skills development. This manual meets that need, and its step-by-step organization makes it a valuable tool for low-income countries in the region aiming to develop the skills of primary care workers and improve their capacity to provide clinical mental health care.

Medical schools that include psychiatry in their undergraduate programs will also find the manual quite useful in addressing suicide prevention as well as the special training needs of those working with individuals with intellectual disabilities. Those familiar with Cognitive Behavioral Therapy and other psychotherapeutic strategies that emphasize improving patients' self-management skills will find this tool very helpful and worthwhile.

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# Foreword

Prof. Dr. Ki Yan Mak

I have read this manual more than once and have also consulted my clinical psychologist for comments. As someone who has been teaching in the field of psychiatry for more than 20 years, I believe there is a real need for such an informative and practical manual and imagine that not only medical undergraduates and primary health workers will find it of value, but perhaps also quite a number of medical graduates and clinicians who work with individuals with intellectual disabilities.

Unfortunately, I am not well informed about the medical training needs in African countries in general, or when it comes to the fields of psychiatry and intellectual disability, in particular. But judging from my experience in years of service for the Hong Kong government and on the Council of the Queen Elizabeth Foundation for the Mentally Handicapped in Hong Kong, which grants funding for worthwhile projects to agencies providing valuable, innovative services to those with intellectual disabilities, I can say that I find this work very systematic and insightful. I believe it will prove very useful and break new ground in some areas in the Hong Kong scenario.

The manual was developed at the Treatment Center for Individuals with Intellectual Disabilities and Psychiatric Comorbidity, which is part of the Evangelisches Krankenhaus Königin Elisabeth Herzberge in Berlin. The foundation that holds a majority share in the hospital, the von Bodelschwingh Foundation Bethel, based in Bielefeld, Germany, is well known for its activities to improve social services and provide medical and psychiatric care to people with disabilities.

Indeed, there may be some areas that could be further elaborated and improved (e.g., applying CBT for this special group of patients), but this might best be done after testing the material in clinical practice, incorporating feedback from its users.

This is a great and meaningful project, and I am honored to have been asked to give some comments. My best wishes for its successful printing, distribution and application.

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# Preface

Dr. Christoph Schade und Prof. Dr. Albert Diefenbacher

Although the term "mental retardation" still appears in the World Health Organization's ICD-10 codes as of 2013, it is expected to be replaced by "intellectual disability" in the ICD-11, and that is the term that has been used in this manual.

Intellectual disability is a generalized disorder appearing before adulthood that is characterized by significantly impaired cognitive functioning and generally associated with deficits in language, motor and social skills. Although individuals with intellectual disabilities (ID) may also suffer from mental disorders, their emotional, behavioral and social problems are often attributed solely to their intellectual disability. Due to this diagnostic overshadowing, mental disorders in individuals with ID are often recognized late or not at all and go untreated, causing them needless suffering and placing an additional strain on their complementary care networks.

While it is still a matter of some debate whether standard methods of psychotherapy can be applied in treating individuals with ID, approaches based on the methods of behavioral therapy appear to be the most promising. However, it is clear that established psychotherapeutic methods need to be adapted to the special needs of individuals with ID.

The Treatment Center for Individuals with Intellectual Disabilities and Psychiatric Comorbidity in Berlin has been offering psychotherapy for individuals with ID on an inpatient basis since 2003 and on an outpatient basis since 2006. It draws on methods from Dialectical Behavior Therapy (DBT) and Interpersonal Psychotherapy (IPT) and has recently also started to use elements from the Cognitive Behavioral Analysis System of Psychotherapy (CBASP).

The therapy concept presented here is based on Dialectical Behavior Therapy (DBT) and was originally developed for use in inpatient treatment. However, while the inpatient phase is an essential part of the program, it can only be a beginning, and it is crucial that therapy be continued afterwards on an outpatient basis. Involving patients' complementary care networks in this ongoing therapeutic process is especially important when working with individuals with ID. Patients require support from family members and caregivers to consolidate and build on the progress made during therapy. To provide those in patients' support networks with the background knowledge they need to offer the necessary assistance, a special psychoeducation module was incorporated into the DBT-ID program.

This module is a key aspect of the program. Let me provide an example to illustrate its importance. Several professional caregivers attending one of these psychoeducation workshops emphasized that prior knowledge of the methods used in the program could have helped them avoid mistakes that undermined the progress patients had made in therapy. As a case in point, they related an incident where they confiscated the rubber band a resident at their facility was wearing around her wrist out of concern that it might cut off circulation because they were not aware that "snapping a rubber band" was one of the distress tolerance skills she had learned during the inpatient program.

We hope that the psychoeducation module and this manual in general can help avoid such mistakes in the future. Therefore this manual is explicitly addressed not only to professional therapists, but to all those in the support networks of individuals with ID, whether they are family members, friends, volunteers or professional caregivers.

# Acknowledgements

The editors and authors would like to thank the entire team at the Treatment Center for Individuals with Intellectual Disabilities and Psychiatric Comorbidity in Berlin – in particular, the art therapist Rosemarie Camatta, the occupational therapist Petra Heffter and the music therapist Thomas Bergmann – and all others who contributed to this manual.

We are especially obliged to Ms. Brunhild v. Local, who was in charge of the layout and graphic design at our publisher, UEM-Verlag, for her unfailing patience and support. We are also grateful to the rest of the staff at UEM and to Marcus Vogel for contributing the photographs, as well as to Christian Feuerherd for creating the diagrams, both of which greatly enhanced this manual.

We owe our thanks to Alexandra Barrett and Carsten Fedderke for the thought and effort they put into translating this manual and for their perceptive comments, which helped smooth out some of the rough edges that were present in the original.

Last but not least, we are indebted to all the patients who have taken part in our program so far. It was working with them that inspired us to adapt the original DBT therapy program to their needs, and neither the DBT-ID program nor this manual would have been possible without them. The progress they have achieved in the program makes us feel confident that we are on the right course.

1.

# On Using the DBT-ID Manual

Dr. Samuel Elstner

The therapy program presented here was conceived to be used in treating individuals with intellectual disabilities (ID) for problems associated with emotional Instability and poor impulse control, such as self-injuring and violent behavior. Based on Dialectical Behavior Therapy (DBT), it was initially devised for use in an inpatient setting and later expanded to allow for outpatient treatment. The well-known DBT program originally developed by Marsha Linehan has been successfully adapted in the past for specific groups of patients, such as adolescents or those struggling with addictions.

This manual is intended as an introduction to the theoretical principles behind the Modified Dialectical Behavior Therapy (DBT-ID) program and as a practical guide for use in treating patients.

The first part of the second chapter (2.1) provides the necessary theoretical background by filling readers in on essential aspects of the original DBT program. First of all, the fundamental approach and Biosocial Theory on which DBT are based are explained and readers are acquainted with basic concepts such as dialectics, radical acceptance and willingness. Then the chapter goes on to introduce the modules of the original DBT program, Mindfulness, Distress Tolerance, Emotion Regulation and Interpersonal Effectiveness, before touching on the aspects of individual sessions and setting.

The second part of the chapter (2.2) focuses on how DBT was adapted to the specific needs of individuals with intellectual disabilities and how the DBT-ID program was conceived.

The author outlines the relevance of the Biosocial Theory to individuals with intellectual disabilities before going on to describe the challenges the authors faced and the principles they applied in adapting DBT to the needs of individuals with ID. In the following, the author presents the four modules of the DBT-ID program adapted from the original DBT concept (Five Senses Group, Skills Training, Emotions Group, and Getting Along with Others) before introducing the newly developed psychoeducation module (Educating the Support Network) and going into the aspects of individual sessions and setting.

While Chapter Two provides a general overview of the DBT-ID program and the theory and principles on which it is based, the following chapter approaches the subject from a practical angle. It is based on the authors' personal experience in treating patients using the DBT-ID program and aims to serve as a guide for those interested in setting up similar programs in their facilities.

The first part of Chapter Three focuses on the inpatient phase of the DBT-ID program. Once the general framework has been outlined in 3.1, the individual modules are presented in detail in 3.2. Subchapter 3.2.1 begins with the Skills Training (Distress Tolerance) module, which aims to help patients acquire strategies to relieve tension and distress ("skills").

The remaining three modules of the inpatient program, the Five Senses Group (Mindfulness), the Emotions Group (Emotion Regulation), and Getting Along With Others (Interpersonal Effectiveness), are introduced in the following subchapters. Since all sessions in these three modules are structured in the same way, each subchapter begins by outlining the basic session format before going on to describe the specific content of the individual sessions.

Subchapter 3.2.2 focuses on the Five Senses Group, which aims to increase patients' awareness of their sensory perceptions and ultimately enable them to better recognize states of tension and distress. Subchapter 3.2.3 describes the Emotions Group, which focuses on basic emotions and on helping patients

learn to recognize them better. The module presented in 3.2.4, Getting Along With Others, enable patients to interact with others more effectively in order to establish and maintain interpersonal relationships that are satisfactory for both sides.

Subchapter 3.2.5 focuses on contingency management and describes how token plans can be used to reinforce patients' motivation to continue therapy. After all, the inpatient phase of the program presented here lasts six weeks, which is a long time for patients to be separated from their familiar environment. Moreover, they are confronted with many difficult issues and have to absorb and process a lot of new information, so it is not surprising that their motivation can sometimes wane. Therefore boosting patients' motivation to remain in therapy is a major challenge and should be one of therapists' top priorities.

Finally, subchapter 3.2.6 describes how to deal with crises of varying severity, ranging from problem behavior to violence and suicidality.

The outpatient phase of the program is introduced in section 3.3. Although patients will have acquired a range of skills that enable them to cope with their extreme emotions better after six weeks of inpatient therapy, it is almost always advisable to continue treatment on an outpatient basis. The outpatient program was conceived to allow patients to consolidate and build on the progress made during inpatient treatment, and while the issues it deals with are largely the same, it differs from the inpatient program in several significant respects. For one, it focuses primarily on Outpatient Skills Training (3.3.1) and the Outpatient Emotions Group (3.3.2). For another, sessions are considerably less frequent and experiences from patients' daily lives feature more prominently, so that greater flexibility is required in regard to the content and format of sessions.

Section 3.4 deals with educating patients' support networks, an aspect that is particularly important to the authors of this manual. We should not forget that patients are not interacting with trained therapists most of the time. They have to deal with everyday situations and often require support from family members and caregivers in applying what they learned. The psychoeducation module was conceived to give those in patients' support networks the background knowledge they need so they can provide this crucial support.

After some concluding remarks in 3.5, you will find the appendix, which contains a bibliography and larger reproductions of a number of illustrations, as well as a wealth of materials and worksheets especially created for use in the DBT-ID program.

To avoid confusion, worksheets meant to be used by patients are in color, while those intended solely for therapists are in black-and-white.

I would like to conclude with a few final remarks: The individual modules of the DBT-ID program complement and build on one another, and we have found that they are significantly less effective when offered separately. The concept presented here was developed over years of practical experience in working with patients with intellectual disabilities. We compiled this manual so others can benefit from that experience and hope that they will find it useful.