TOILET TRAINING TO INDEPENDENCE

FOR CHILDREN
WITH SEVERE AND PROFOUND DEVELOPMENTAL DISABILITIES

A Manual for Trainers

Revised edition

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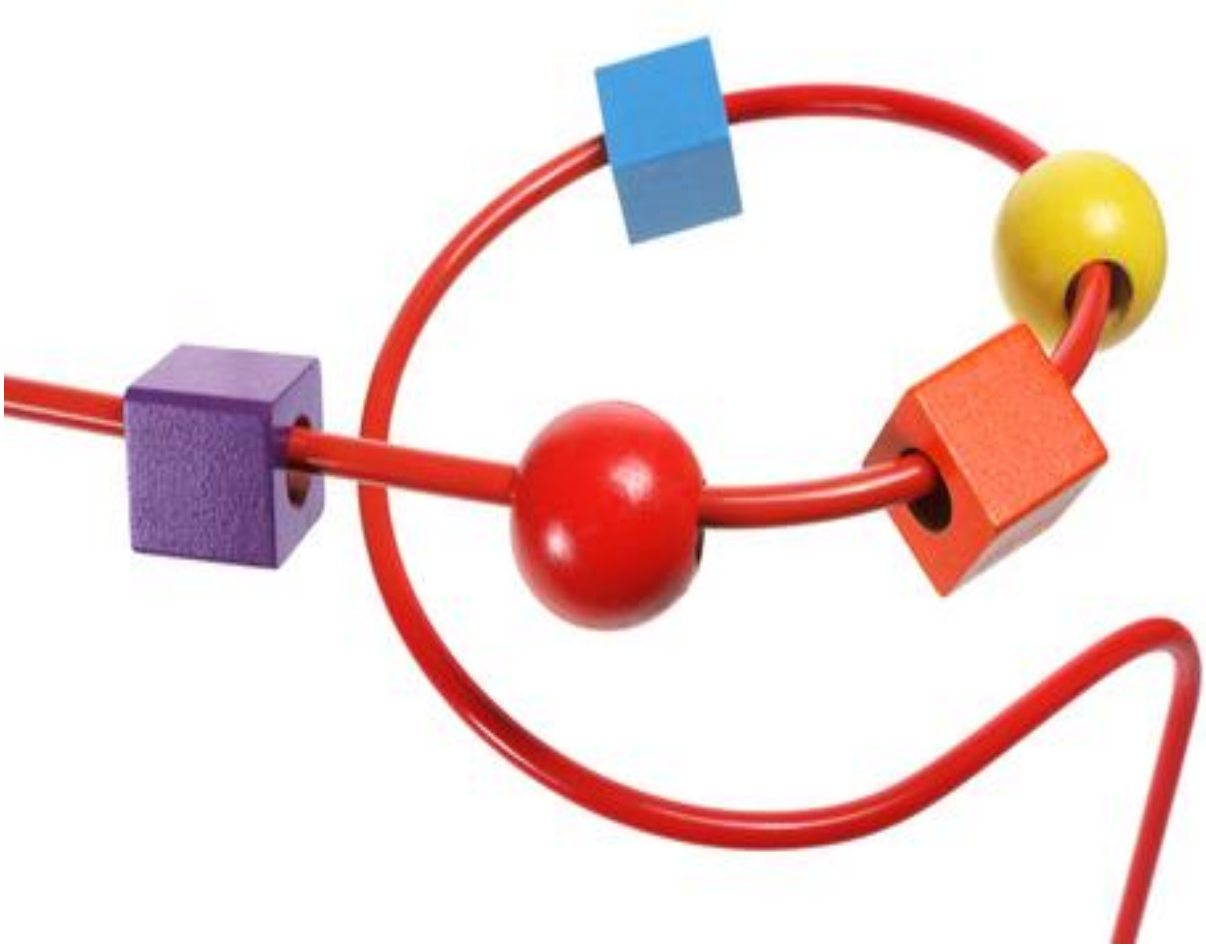

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INTRODUCTION

This Manual is a revision of the first edition, titled *Toilet training to independence for the Handicapped*, published in 1982. I wrote the first edition specifically for my staff who continued the work of *The Intensive Training Unit* at Strathmont Centre after the research was finished and I transferred to another position. It is therefore aimed primarily at professionals and other workers who have training and/or experience in the field of developmental disabilities. Some parents have also used some aspects of this program with support when they have been toilet training their children.

The terminology in this revision has been updated. Some of the problems which were recognised in the early trials have been solved and these solutions have been incorporated into this revised version. Equipment has improved greatly since the research which established this program, so we are now referring those who wish to run a toilet training program to the current manufacturers.

Since the 1970s and early 1980s, the attitude of professionals and others who work among people with developmental disabilities has changed dramatically. Incontinence is no longer regarded as an inevitable part of severe disability that must be tolerated and kept out of public view. It is now recognized that most incontinence is a result of learning difficulties, which can often be overcome with specially designed, systematic teaching. It is also recognized that some incontinence can be a direct result of overprotection, inconsistent handling, institutionalization, and low expectations.

This change in attitude has both led to and been fostered by the development of systematic and effective toilet-training methods. Since 1960 there have appeared well over a hundred published papers and books describing research or service programs whose aims were to provide effective training in daytime bladder and bowel control. The early reports were of relatively simple procedures, but there has been a significant trend towards more complex and systematic methods. Most programs are based on behavioural principles, although they differ markedly in the actual training procedures used.

In the 1970s, I and a small team of staff within the Intellectually Retarded Services (as they were then called) in South Australia developed a variety of training programs in a range of living skills for people with developmental disabilities. A major project was the development of toilet training programs. The initial stages in this project involved trials of a number of programs reported in the literature, together with the establishment of two specialized training units and the training of people to staff them. Some of the trials were primarily service oriented; others were fully controlled research programs.

During this time we worked with a wide variety of children and adults. They ranged from four to fifty years of age. They included non-disabled children and people with all levels of intellectual disability or autism spectrum disorders, as well as a variety of physical, sensory, and learning disabilities. Training took place in their own homes, in schools, and in residential facilities, and was

carried out by parents, teachers, residential staff, psychologists, physiotherapists, paramedical aides, and volunteers working alongside our team.

Our experience with these people has shown us that there are many different reasons for incontinence. Differences exist in the number and kind of toileting skills which are lacking, in the learning difficulties and physical disabilities which interfere with learning and performance, and in the environmental influences on learning. These differences cannot be catered for by one packaged toilet-training program. Effective toilet-training services need to
offer a variety of programs that can be matched to the needs of each child. The two specialized training units between them therefore came to provide a range of programs and training environments to suit a wide variety of needs. *The Intensive Training Unit* was based in the residential training institution, Strathmont Centre, and provided a highly controlled learning environment and individual training for clients. The work of this unit resulted in a significant decrease in the number of incontinent residents living at Strathmont Centre so the Unit went on to work with non-residents and their families. *The Family Training Unit* specialized in teaching parents and others working with children with intellectual disabilities or autism spectrum disorders to run their own programs within normal daily routines. In addition, members of the two units provided consultation and advice to schools, community health centres, and other centres for people with developmental disabilities.

A few children had special problems or lived in situations that prevented them from responding to training even with the range of program choices that were available. They helped extend our understanding of the nature of the toileting process. As a result, several new programs and techniques were developed. *The Intensive Training Unit* developed a complex bladder-training program especially for children who had not developed past the infant stage in relation to bladder and bowel function. *The Family Training Unit* developed a program that parents could use to teach young children to indicate when they needed to go to the toilet (Kaines, 1979). Bowel-training programs were developed for children who were bladder trained but still soiled or suffered from constipation. A variety of potty and pants alarms and reward devices were developed that could be assembled cheaply and which were light, durable, and reliable. Some of these were made by adults with intellectual disabilities in sheltered employment.

The program described in this manual was also developed in this way. Initially, we planned to provide the program developed by Azrin and Foxx for people with profound and severe intellectual disabilties who needed both extensive practice and training in all the component skills of toileting (Azrin and Foxx, 1971; Foxx and Azrin,1973). During 1975 and 1976, we offered this program to forty residents at Strathmont Centre as part of a controlled study.

The first trials were published (Bettison, Davison, Taylor, and Fox, 1976). and further papers followed as we continued our research (see the bibliography at the end of this Manual). We found that the program was effective for many clients, but for others progress through the training stages was too rapid. Some were confused by the teaching of many skills at the same time. In addition, we found that the program did not teach all the components and failed to teach sphincter control specifically. Furthermore, the component skills were not

adequately joined in a smooth sequence.

The toilet training program described in this Manual arose out of our further research to develop procedures which dealt with every aspect of self-toileting and thus to overcome the problems mentioned above. It was designed to meet the needs of people with severe or profound developmental disabilities who were not progressing with other training techniques used by parents, teachers, and residential staff. It has also been useful for children who have learned some toileting skills, but whose slow progress is denying them access to appropriate educational and developmental opportunities. It has been specially designed to overcome many of the learning difficulties resulting from developmental disabilities.

The new program was tested by *the Intensive Training Unit* during 1979 and 1980 with the help of twenty children with developmental disabilities. Half of them lived at home and half lived at Strathmont Centre. During the trials, we limited training time to thirty-four days for experimental purposes. Of the twenty children, ten completed training successfully, three had not completed the last phase but achieved complete mastery during the Maintenance Phase in their normal environments, and six more had not completed the last one or two phases but probably would have if they had been given more time. They are now mostly accident free and often toilet themselves. The remaining child did not progress past the first phase and was discovered during training to have severe visual deficits, which were not accommodated by the program.

We do not expect 100 percent success with all children, even when no time limit is placed on training. As with any teaching program, there is still room for improvement. Some of the problems we met and our solutions are outlined in Chapter 5, "Common Problems and How to Handle Them." You may find others as you use the program. More recently I have published a set of home intensive toilet training programs which solve more of the problems we have met during our work with children and families (*Toilet training for children with autism or intellectual disabilities: Developmental Information and Practical Procedures,* available as a download from http://www learn2do.net.

I am sure that there is more to learn about the nature of bladder and bowel control. I am also sure that further refinements in training techniques are possible. We hope that some of you will carry on our work by further analysing the component skills that are involved in self-toileting and testing improved procedures for teaching them. However, with the present state of knowledge and techniques, few people with developmental disabilities need remain incontinent. The problem now is not primarily lack of effective techniques, but rather service and funding priorities.