

TOILET TRAINING

FOR CHILDREN WITH AUTISM OR INTELLECTUAL DISABILITIES

Developmental Information and Practical Procedures

Sue Bettison

T. Cert., B. A. (Hons.), Dip. Ed., Ph. D.



FOREWORD

For typical children, daytime and night time continence is usually achieved without resorting to a manual. However, children who have a disability can be significantly delayed in learning how to use the toilet. That delay can be expensive in terms of laundry costs, and exhausting and time consuming in terms of changing clothing and cleaning the child. Parents who have a child with special needs can long for the day when the child can see to his or her own toileting needs. They know there would be more time for other activities, the family finances would improve, and there would be less stress for everyone in the family. Now parents have a practical toilet training manual that is based on scientific knowledge of bladder and bowel functioning and established learning principles for children with special needs, and will answer parents' questions about why they have been unsuccessful.

We take going to and using the toilet for granted, and it is only when a child has difficulty acquiring the necessary skills that we truly appreciate the complex techniques involved. Sue Bettison is an expert on toilet training children with a range of disabilities. She has persevered with some very challenging incontinence problems, designed new strategies and resources and been able to succinctly explain in plain English what to do. Due to her frequent successes, I am sure that many parents would want to nominate her for a prestigious national award, or create a new award or title such as the Order of the Bathroom or Empress of the Toilet.

As a clinician, I am often asked by parents how to achieve a successful outcome in toilet training of a child with specific or multiple developmental disorders. My knowledge is very limited in comparison to the expertise of Sue Bettison, and I will absorb her assessments and strategies in my own clinical practice. I highly recommend her book to both fellow clinicians and especially to parents. If you have just bought this book, be comforted to know that rescue is at hand and the cost will be repaid manyfold by savings in laundry costs and freedom.

Professor Tony Attwood MSc, PhD, AFBPsS, MCCC

Adjunct Associate Professor

Griffith University in Queensland.

Author of *The Complete Guide to Asperger's Syndrome*

Contents

	Page
Introduction	8
Chapter 1	10
Bladder and bowel functioning	
<i>Question: How is it that children don't use the pot or toilet straight away?</i>	10
<i>Question: Why can my child use the toilet but still wets the bed?</i>	12
<i>Question: My child is 5 and has Down syndrome. I always put him on the toilet before we go out in the car but I can't get him to go. Many times he wets his pants before we get to the park or store.</i>	12
Review	13
Conclusions	13
Chapter 2	14
Toileting skills	
Bed-wetting	14
Day-time toileting	14
<i>Question: My son can use the toilet but can't pull his pants up.</i>	15
Review	17
Conclusions	18
Chapter 3	19
The effect of developmental disabilities	
Intellectual problems	19
Sensory and discrimination problems	20
Failure to 'hold on'	21
Difficulties with bodily movement	22
Motor planning difficulties	23
Behaviour	23
Mobility handicaps	23
Sensory impairments	24
Review	24
Conclusions	24
Chapter 4	25
The effect of medical problems	
Urinary tract infection	25
Wide bladder neck or defective bowel or bladder sphincter	25
Bowel infection	26
Coeliac disease	26
Diarrhoea	26
Constipation	26
Impacted faeces/bowel fissure	27
Spinal cord dysfunction	28
Poorly controlled epilepsy	28
Conclusions	29

Review	29
Chapter 5	30
How to teach when toilet training	
Copying	31
Behavioural consequences – rewards	31
Behavioural consequences – punishment	32
Sequencing skills	33
Behavioural moulding – graduated physical guidance	33
Increasing behavioural control	35
Extra fluids	37
Pants alarm	37
Wet Pants Alarm Instructions	39
The startle response	41
Behavioural moulding – increasing physiological control	41
Psyllium	41
<u>Constipation:</u>	41
<u>Loose bowel motions:</u>	42
Glycerine suppositories	42
Arranging your training	43
Number of trials	43
<u>Repetition:</u>	43
<u>Toilet timing:</u>	43
Length of daily training time	44
Other activities during training	44
Non-programmed procedures	45
Question: My child will sit on the toilet and begin to urinate to get a reward but only produces a small amount and then will "hold on".	46
Keeping and transferring skills	45
Question: My child, who is 10 years old and has Fragile X Syndrome has stopped using his toileting skills. What can I do?	46
Question: My son is severely delayed but is now totally self-toileting at home	46
Review	47
Conclusions	47
Possible training procedures (checklist)	48
Chapter 6	49
Assessment	
Assessment of medical problems	49
Possible medical problems (checklist)	50
Questions to ask yourself (checklist)	51
Assessment of toileting skills	52
Baseline and recording procedure	54

<i>Pants checks</i>	54
<i>Record of toileting</i>	55
<i>How long to observe</i>	56
<i>Review</i>	57
<i>Conclusions</i>	57
Baseline observation record sheet (record form)	58
Chapter 7	60
Programs to teach single skills	
Question: <i>My child is fully toilet trained but continues to have accidents some of the time. What should I do?</i>	60
<i>Preparations for training</i>	60
<i>Learning to sit on the pot or toilet</i>	61
Question: <i>My child becomes upset when I try to get him to sit on the toilet.</i>	61
Shaping sitting on the toilet (training procedures)	62
Teaching correct sitting on the toilet (training program)	63
Question: <i>How do I help my son who sits on the toilet properly but urine spurts upwards and goes on the floor when he urinates?</i>	65
<i>Programs for wetting</i>	65
<i>Retention control training</i>	65
Question: <i>My 8 year old child has mild autism and is fully toilet trained. She goes to the toilet frequently and still wets the bed. She often starts urinating in her pants before she can get onto the toilet. Is there a way to help her?</i>	65
Question: <i>My child has a severe developmental disability but has learned to take herself to the toilet. However, she is still having accidents 2-3 times a</i>	66
<i>Reward for using the toilet</i>	67
A program for wetting (training program)	68
Record form for wetting/HITT programs (record form)	70
<i>Some partial successes</i>	71
Question: <i>We have five paid carers looking after our 4 year old child with Down Syndrome in our home five days a week. He can count to ten but still does not use the toilet. What can I do?</i>	71
Question: <i>Our 18 year old son with severe intellectual disability lives with us. He helps with many household jobs and knows all the routines for self care, but he always waits to be told to go to the toilet. Will he ever learn to take</i>	71
<i>Programs for soiling</i>	72
<i>Soiling as a result of bowel dysfunction</i>	72
Question: <i>My child has been taking psyllium and his bowel motions now occur once every day and are fully formed. However he cries just before he has a bowel motion and says that his tummy hurts. What is wrong?</i>	73
<i>Bowel motions in places other than the toilet</i>	74
Question: <i>My 12 year old child with ASD has been toilet trained for urine for years but insists on me putting a nappy on him so that he can then hide and have a bowel motion. I have tried everything we can think of. Is there a way</i>	74
Bowel training using suppositories (training program)	76
Bowel training record form (record form)	78

Review	79
Conclusions	79
Chapter 8	80
Programs for children with few toileting skills	
Conditions for training	80
Question: How much time do I have to allocate to toilet training?	80
Question: How can I fit a toilet training program into our busy family life?	81
Question: Can I have other people helping with toilet training?	82
Question: Do I have to prepare anything before training?	82
Question: Why do you insist on keeping records?	83
HITT procedures	83
Question: What happens if my child does not urinate in the toilet at this	85
Question: Shouldn't my child be perfect before training moves on to the next	86
HITT – Home Intensive Toilet Training (training program)	87
Record form for wetting/HITT programs (record form)	92
Program variations	94
Question: My child is not good at managing her clothes. What do I do if she	94
does not appear to be learning to pull her pants up or down?	
Teaching pants up for toileting (training program)	95
Pants up record sheet (record form)	99
Teaching pants down for toileting (training program)	101
Pants down record sheet (record form)	104
Question: I don't think that my child could go to the toilet by himself. How	106
can I teach him to tell me when he needs to go?	
Teaching your child to let you know when toileting is needed	106
Review	107
Conclusions	107
Chapter 9	108
Guide to using this book to set up a toilet training program	
The child	108
Assessment	108
Medical problems	108
Questions to ask yourself	109
Observation	110
Choosing procedures	110
References	114
Tables and Figures	
Figures	
Figure 1. Urinary system	10
Figure 2. Digestive system	10
Figure 3. Schematic representation of reflex voiding	14
Figure 4. Representation of the self-toileting sequence of tasks	16, 36

<i>Figure 5. Expansion of the pants up elements in the self-toileting sequence</i>	17
<i>Figure 6. More detailed expansion of grasping the waist band in the pants up</i>	17
<i>Figure 7. Possible medical problems</i>	25
<i>Figure 8. Action model</i>	49
<i>Figure 9. Improvement during baseline</i>	56
<i>Figure 10. Home Intensive Training program</i>	84
<i>Figure 11. Pants up and down sequences for self-toileting</i>	93
Tables	
<i>Table 1. Frequency and quantity of urinary voiding distributed by age</i>	11
<i>Table 2. Developmental sequence for bladder control</i>	12
<i>Table 3. Extent of incontinence</i>	19
<i>Table 4. Incontinence and intellectual disability</i>	20
<i>Table 5. Procedures used in toilet training</i>	30

INTRODUCTION

The contents of this book are the result of eight years of research, and thirty years of professional practice. During that time I have taught parents and professionals how to use my programs and helped families and staff to apply the programs for the benefit of children and young people with developmental disabilities.

The reason that I have written this book now is to provide parents and others with as much as possible of my toilet training approach and methods. I have been repeatedly asked to do this by parents and people working in the developmental disability field, especially as my full retirement from professional life loomed. So here it is. I won't be able to set down everything that I do because some of it relies on clinical judgment of the people, circumstances and other areas of a child's functioning, besides toileting, at the time of the assessment, program design, and follow-up. However, because you know your children well, many of you will be able to get enough out of this to successfully train your own child.

People have different styles of learning. Some learn by reading, others by seeing, others by doing. If you do not feel comfortable relying on reading this, enlist someone who is used to reading and following written instructions to work with you or, at least, discuss the material with you. Often, two heads are better than one.

I have divided the information into discrete chapters. It is best to read one chapter at a time, in order from the beginning, then think about what you have read in relation to your child before going on to the next chapter. Each chapter is built on the one before, so they need to be read in order. Don't leave out any chapter or section. I have found that an understanding of every aspect of theory, principles and procedure is necessary to ensure success for each child. Even the 'theoretical' material has direct practical application and therefore may influence how you train your child.

Any training requires the trainer to commit to the process until success is achieved, and to give full concentration to what he or she and the child are doing during the

training process. It is quite a demanding process, but very interesting. Each of us who has been through this process has learned a lot about ourselves and the child – always a positive experience. A few parents have found that the material in the earlier chapters of this book has led them to change their practises enough for their children to reach full self control of both bladder and bowel without needing the more formal procedures. If this happens for you, celebrate! However, this is unusual when the child has already demonstrated that he or she is unable to learn self control of bladder and bowel in the usual way.

Hopefully, this material will stand alone. However, I am planning to provide a way for you to get advice and answers from me or others when necessary. Nevertheless, please do try to use all your own problem-solving ability before you seek outside help. That is what I and parents who have used my programs have done very successfully. No amount of knowledge and skill can prepare any of us for every situation, especially if we have never met it before. It takes thought and trial and error until we find something that works. The key is to believe that you **can** teach your child successfully and that your child **can** learn.

My experience is that every child with a developmental disability can be toilet trained, as long as the correct procedures are used which compensate for his or her particular set of disabilities and problems. Of course, this assumes that there is no physical cause behind the incontinence and, even then, many children can still learn some or all of the tasks required for continence. My first research was aimed at procedures for children with profound and severe intellectual disabilities. They were the first to successfully learn to toilet themselves with one of my programs (*Bettison, 1982*). The procedures widened as I worked with a wider range of disabilities and levels of severity to become the multiple program set you will find in this book.

The names used throughout the book are not of real children. Most of the examples used are a composite of a number of children and their situations to better give you an idea of what can happen. The questions posed in the book have been asked over the years by parents and others who were about to or were already training one or more children. I have included some actual program instructions and record forms in chapters 6 - 8. I give you permission to print any instructions and forms that you need.

Now go ahead and enjoy the surprises and excitement of helping a child conquer a very important area of functioning.