

TRAINING FOR CONTINENCE AMONG CHILDREN WITH SEVERE DISABILITIES

GILLIAN PARKER

Social Policy Research Unit
University of York, U.K.

Introduction

Over recent years the application of behaviour modification techniques and the Portage system (Connolly 1976, Smith *et al.* 1975, Williams, 1978, Revill 1979) has shown that even profoundly disabled children can sometimes acquire skills that might previously have been considered impossible. Washing, dressing and toileting skills can be broken down into small components and a child's behaviour shaped towards a greater degree of independence and control. Some workers have shown that even the most severely mentally disabled adults can be taught to regain control over their own toileting. (Giles 1976, Azrin 1971).

A recent survey, concerned mainly with the provision of incontinence services to the families of severely disabled children (Parker 1983), carried out by the Social Policy Research Unit at the University of York, also gathered information about the training for continence children had received. This article discusses some of these findings and their implications for special schools.

The survey

A postal survey of 372 families with a severely disabled child formed the basis of the research. All the children were aged between four and 16 years at the time of the survey and were selected from the records of the Family Fund¹⁾. All had been given help by the Family Fund at some time and all had been recorded as incontinent at the time their parents first applied to the Fund. In addition, 73 of the families were interviewed in depth at home.

Degree of incontinence

Forty-two (11 per cent) of the 372 children whose parents completed the postal questionnaire had become completely continent by the time of the survey. As might be expected age was an important determining factor in this; those who had become continent were significantly more likely to be aged 12 years or over than those who had not. The incidence and frequency of wetting and soiling in the children who were still incontinent is summarised in Table 1.

1) The Family Fund was established in 1973 by the government of the time to provide financial assistance to the families of children with severe physical disabilities. Its terms of reference were later extended to include children with severe mental disabilities.

Table 1:
Incidence and frequency of wetting and soiling
in those children never continent.

<i>Frequency</i>	<i>Wet by day</i>	<i>Wet by night</i>	<i>Dirty by day</i>	<i>Dirty by night</i>
	%	%	%	%
Never	21	4	33	42
Less than 1 p.m.	14	11	18	19
More than 1 p.m.	11	9	9	11
More than 1 p.w.	12	16	17	13
Every day/night	40	57	21	14
Wears a bag	3	2	1	1
Base: 100% =	318	325	321	308

Where base is not equal to 330 information on frequency is missing.

In all, 85 children (26 per cent of 330) were wet at night only.

Training for continence

Parents were asked to record whether their child was receiving or had received any training for continence, where this had been done, what type of training it was and how successful it had been.

Over half of the 372 children (210) in the postal survey were reported to have received training at some stage. Table 2 summarises both the type of training received and parents' assessments of its effectiveness.

Table 2:
Training received and perceived effect

<i>Type of training/ treatment</i>	<i>Perceived effect</i>				<i>Total</i>	<i>100% = Base:</i>
	<i>None</i>	<i>A little better</i>	<i>A lot better</i>	<i>Clean and/or dry</i>		
Behaviour modification	5	24	43	29	11	21
Regular potting/ waking	18	35	30	17	49	96
Regular potting and other technique	7	29	43	21	7	14
Special potty, bed or pants alarm	22	33	44	—	5	9
Training to use equipment, bag, etc.	—	43	43	14	4	7
Not known/unsure/ unspecified	32	37	16	16	19	38
TOTAL %	18	34	31	17	100	
Base: 100% =	33	63	57	32		185

21 respondents did not answer question about type of training.

4 cases excluded where perceived effect of training is not recorded.

It was sometimes difficult to assess from parents answers whether their child had undergone a behaviour modification programme or simply a regular potting regime. If any mention was made of consistent rewards or praise for dryness, or appropriate use of the toilet, or of minimal attention while changing the child after an 'accident', the training was recorded as behaviour modification. Many parents may not have mentioned these aspects of the training programme, especially if there had been no liaison between school and home over use of the technique. For this reason the 'regular potting' figures may include children who were in fact on behaviour modification programmes. As can be seen both behaviour modification and regular potting regimes were said by parents to be successful in making their child clean or dry or in improving incontinence.

Children with spina bifida and/or hydrocephalus were significantly more likely to have received or be receiving training. This may be due, firstly, to greater emphasis on regular bladder emptying by, perhaps, expression to reduce the risk of urine infection and as an alternative to surgical intervention and, secondly, for those few children who had ileal diversions, to self-care training. Children with Down's syndrome or other, non-specific, mental handicaps were apparently no more likely to have received training than the other children.

Whether or not a child had been or was being trained also varied significantly with age. Children aged between six and eight years were much more likely to be reported as receiving or having received training while those above this age were less likely to be. While the parents of older children may forget *details* of their child's training it seems unlikely that many would have forgotten about it completely. In any case, as most of the children, regardless of their age, were still incontinent one might have expected that training would be continuing.

There are two possible explanations for this age differential. Firstly, it is possible that the expansion of training programmes in schools is a very recent development and thus younger pupils are more likely to be benefitting. Alternatively, it could be that when children reach a certain age and are still not entirely continent schools tend to discontinue toilet training in favour of teaching other skills.

The home interviews revealed a rather higher incidence of toilet training; only nine (12 per cent) of the 73 children had had, to their parents' knowledge, no training at any stage. Thirty-two (44 per cent) were receiving training at the time of the interview and the same number had done so in the past. The higher incidence of training revealed may reflect the selection of the home interview sub-sample which excluded children with the mildest degrees of incontinence, leaving those with more persistent problems which may have attracted more deliberate and systematic attempts to toilet train.

Home or school?

Although, as was mentioned above, training was most often carried out at home and/or school, there were a substantial number of cases in the postal survey where training appeared to have been carried out only at one or the other and not both. Fifty-five children (28 per cent of those receiving training) seemed to have received training at school but not at home as well. In addition 26 children (13 per cent of those receiving/having received training) had apparently received training only at home, from their parents, although all were still incontinent and attending school.

Both findings suggest a lack of liaison between home and school and a possible waste of effort. Training programmes that are not continued at home cannot be as effective as quickly as those that are. Indeed, there was a tendency for parents to report that training carried out at school alone was less successful than that carried out either at home alone or at home and school together. Whether this was rationalisation on the parents' part or a true reflection of effectiveness is, in this context, irrelevant. Similarly, many of those

children whose parents said that they were being trained at home only may, in fact, have received training at school as well. What is important is that the parents did not appear to know about it.

The home interviews revealed a lower incidence of training received at school but not at home. This was mostly due to the closer questioning and checking possible during a personal interview which picked up information about 'ordinary' potty training done at home. However, there was no indication that the training received at home was such that it necessarily consolidated school training. Parents were not always clear about what was done while their child was at school; indeed only half of those whose child was said to have received training both at home and at school had ever talked with anyone from the school *about* training (see below).

Advice about training

All parents who were interviewed at home, regardless of whether or not their child had been or was being trained, were asked whether anyone, from school or elsewhere, had ever talked to them about what they could do to help their child become clean or dry. Just over half (42) said that they had discussed this at some time. The responses are summarised in Table 3.

Table 3:

People who had discussed toilet training with parents

<i>Person mentioned</i>	<i>% of those mentioning anyone</i>
Teacher or head teacher	50
Health visitor or community nurse	21
GP or other doctor (not school doctor)	12
Relative or friend	12
Psychologist	10
Social worker	10
School nurse	10
School doctor	5
Base: 100% =	42

School personnel were clearly the most important sources of advice about training followed by health visitors and community nurses.

Those who recalled some discussion about training were also asked about the nature of the advice given; their answers are summarised in Table 4.

Table 4:**Methods of training suggested to parents**

<i>Method of training</i>	<i>% of those ever discussing training</i>
Regular potting	55
Behaviour modification*	38
Lifting at night	12
Leaving off nappies/waterproof pants, etc.	10
Restriction of fluid intake	10
Use of alarms	12
Change of diet	2
Other method	17
No information	10
Base: 100% =	42

* As with the information from the postal questionnaire 'behaviour modification' was recorded when there was any mention by the parents of consistent rewards or praise for dryness or appropriate use of the toilet, minimal attention when the child was wet or dirty.

Information about whether or not parents had actually implemented the advice given and, if so, whether it had been successfully is, unfortunately, patchy. Of the 25 families for whom information is available, 12 had implemented all that had been advised with some degree of success and three had used some of the methods suggested, again with some success. Five families reported no improvement even though they claimed to have done as recommended. Four parents had not implemented any of the advice given, in one case because the child would not co-operate and in three because they did not believe that the techniques would work.

Even allowing for the fact that some parents might have forgotten ever having been advised about training for continence, it is clear that there is some scope for improvement in advice giving and guidance of this sort.

Conclusions

A substantial proportion of the severely disabled children surveyed in the research reported here had received or were receiving some form of training for continence. Almost a half of these had, by their parents' assessment, experienced a considerable improvement in the degree of their incontinence as a result. These findings are a testament to the quiet revolution that has taken place over the last twelve years in the education of children with disabilities and, especially, to the gradual introduction of behavioural techniques.

However, the research revealed a disturbing gap in communication between parents and schools concerning training. In some cases it seemed that parents did not know whether their child received training in school or not, in others parents were not consolidating the training done at school by carrying on with it at home. In either case a lack of liaison between home and school was indicated and also, in the latter case perhaps, a lack of understanding on the part of parents.

These *lacunae* are all the more unfortunate because of the repeated emphasis over recent years on the importance of 'parents as partners' (Pugh, 1981). This research has indicated that parents were not always seen by schools, nor always saw themselves, as partners in the process of training for continence. The success of pre-school training programmes has shown that such involvement is not only possible but can be effective (Cunningham, 1979). It is to be hoped that those special schools which do not already do so can, in the future, be encouraged to inform and guide parents in the implementation of training programmes at home.

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