

Privy Counsel

Issue 1

summer 2001-

Welcome

to the first issue of Privy Counsel, ITAAL's twice yearly newsletter that aims to provide a forum on issues concerned with personal care needs and the provision of accessible loos.

Background

For the last three years, ITAAL has been working to produce an **Atlas Guide to accessible loos**. The idea for the guide came from a group of disabled women, all wheelchair users, who realised that current information about accessible loos is often totally inadequate for the many and varied needs of individual disabled people.

During the course of the work, new questionnaires and computer software have been developed which means the guide will contain very detailed information about each loo location. The information has been collected mainly by an army of volunteers from all over the country.

Raising awareness

As information was being collected, a range of issues came up. Those related to the design of loo provision we could pass on to the relevant organisations. But there seemed to be no existing forum to discuss other issues about coping with personal care needs. Indeed, many disabled people find it difficult even to talk about them.

However, these are needs which raise a lot of problems for some disabled people, and

often cause much misery to the individual and to family or carers.

We hope that through the pages of Privy Counsel, we can encourage much more openness in acknowledging the problems and sharing the experience of coping day-to-day. We must challenge the 'tough – you'll have to grin and bear it' attitude which is far too often encountered.

On a broader front, Privy Counsel will aim to raise awareness, encourage debate and take action that will hopefully bring about change. (cont. page 2)

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Sharing your own experiences

There is a wealth of information available on the design and building of accessible loos, but not much practical information from disabled users that can be used to improve facilities. It is time to listen to and record what disabled users are saying. No away-from-home loo can ever be perfect for each single user, but there can be agreement on the minimum that needs to be done to make them as usable as possible by **all** disabled people.

Highlighting research needs

Disabled people need to be more aware of each other's needs and Privy Counsel can help with this. We start the ball rolling with a number of issues set out in our section on research needs. We're sure you will have others.

Personal experiences and coping strategies

Maggi Barwick McElroy, a founder member of ITAAL, gives a personal view of coping with personal care needs. If you would like to write a short piece on a specific care need please let us know. If you prefer, we will print the contribution without your name appearing on the article.

Supporters Group

A copy of Privy Counsel and an application form for the Supporters Group is being sent out to all who have had contact with ITAAL to date. However future issues will only be sent to those who become supporters. We regret having to make this restriction, but we don't have sufficient funds to post out unlimited copies of each issue. So, please support ITAAL's work by joining us as a supporter. Membership is free to disabled people and their supporters, but if you can contribute to postal costs this would be a great help.

Language

When sharing the sort of information that Privy Counsel aims to do, language becomes a significant factor. The British embarrassment at using words such as penis, rectum and vagina means that numerous colloquial – and also regional - euphemisms have developed. Radio 4's Women's Hour recently explored some of the terms used by young women about their private parts.

While there are obvious benefits for many people in having a 'euphemistic language' for everyday social interaction, there is a 'downside' in that when seeking help, misunderstandings can occur. We have an example of a young male patient who did not know what the medical terms were for his 'back passage' – rectum – or his bladder. Sadly because he could not answer the doctor's questions accurately, treatment for a cancer in the bladder was delayed.

ITAAL believes it is important to use language that everyone understands. Having given this matter considerable thought, we have decided that the Privy Counsel editorial policy will be to use medical terminology. We are happy to receive articles using the words you are most comfortable with but reserve the right to change words to ensure that the meaning is clear to all readers.

Diana Twitchin
Editor

Do get in touch

We will be very pleased to hear from you at any time, but items for our Winter Issue need to reach us by 30 October, 2001.

BTA ANNUAL CONFERENCE

Diana and Bob Twitchin report



We represented ITAAL at the British Toilet Association

(BTA) conference held at Heathrow in May and took an active part in discussion sessions.

Discussion themes over the two days included:

- Increasing numbers of local authority WC closures and its effect on communities and tourism – e.g. the growing problem of young males urinating in public in city centres at pub closing times and at other events because of lack of loos
- Vandalism and misuse of away-from-home loos; the cost to all authorities
- Portable loos - lack of fully accessible portable loos, lack of design information and the growing need for greater provision of such loos
- Should shops be forced to make their toilet facilities available to non-customers?
- Should members of the public have to pay to use a loo?

Did you know that local authorities do not have a statutory obligation to provide public toilet amenities?

BTA are campaigning for greater awareness of this fact before local authority public conveniences disappear from sight completely. Many more shops and stores now provide customer toilets, but resent their use by people who are not customers.

The conference clearly showed that loo closures have a profound affect on everyone. The problems that are forcing local authorities to close their facilities – cost of cleaning and repairs, vandalism and misuse of facilities, difficulty of maintaining standards of cleanliness – are now being passed on to stores and shops.

Unless something is done very soon, finding a loo to use when out in the town will become very difficult. Local Chambers of Commerce and local authorities need to be working together to raise awareness of the need for away-from-home loos and develop local policies for their provision.

In many areas accessible loos are still only provided by local authorities therefore disabled people will lose out yet again if the closure programmes continue.

Conference exhibition

Vandalism means that tomorrow's loos are beginning to look like armoured tanks – everything metal in an attempt to deter vandals. Some delegates felt that more attention should be paid to bringing back staffed facilities. There is a desperate need to provide a range of different facilities: not to try and force every human being to use one type of facility.

Making our presence felt

Getting the message over about accessible loos is difficult but ITAAL and PAMIS (Profound and Multiple Impairment service – more about them in our next issue) made sure the issue of space in loos was noted.

An uncomfortable night!

The conference was difficult for Diana who found herself sleeping in her wheelchair overnight. Why? The accessible bedroom turned out to be rather the opposite! However, “maybe this helped my confidence, as I found myself challenging forcefully during the conference because I

was so angry. This is the second time in 14 months that I have had this problem. And it is always a 4 star hotel!"

ITAAL and BTA

Accessible loos do not exist in isolation: they are generally found alongside facilities for non-disabled people. ITAAL are represented on the BTA Council and are working closely with them on provision of away-from-home loos. The problem of finding the right loo in the right place at the right time faces everyone not just those of us who are disabled. However it is very clear that BTA needs more support from the general public if things are to improve.

A PERSONAL VIEW

Maggi Barwick

My early induction to the art of being a disabled person involved learning that it was my job to adapt to fit 'normal' life and that this 'fitting in' was to appear effortless and seamless. No one must know that I needed to make an effort to cope.

This was especially true about anything to do with basic body functions. Other people just nipped in and out of the loo. I smiled cheekily when the mickey was taken for being so long: 'Phew! I thought you'd set up shop in there!'

No longer – I've come out. I am beginning to require that the world fits itself to ME sometimes. It is normal to be disabled, I aver, lots of people do it. Of course, this is how my initial involvement in the ITAAL steering group came about.

Now I'm into 'Coming Out: Stage 2', which explores areas never before mentioned in company - or even to myself! I have begun to talk about the unmentionables. The

difficulties of wiping my bottom; keeping un-smelly when I'm sitting all day; reaching my front area (vagina); and the difficulties of having language to use to describe what I am talking about! We need to be able to discuss things and swap solutions. It would be great if ITAAL could be a forum in which we could do this.

We also need to be able to learn how to manage our personal care when delegating some or all of it to others. And here there is an important emphasis to be made: **we DELEGATE tasks, we RETAIN authority and responsibility.** This is no less the case when an employee is wiping my bottom than it is when she is doing my shopping or typing a letter for me. It is no less the case if the person performing the task is an employee of the NHS, the social services, or is your partner or your Mum. It is YOUR body; it is YOUR responsibility; YOU have the authority. Don't allow anyone to take it away from you! Do not be lazy and abandon the responsibility or authority into someone else's lap.

So here are some of my issues and my solutions.

- ***I take as much time as I need*** - rest my arms when I need to. I am more likely to be able to complete a bottom wipe if I rest in between pads of loo paper.
- ***Keep pubic hair trimmed*** I get less sweaty that way and it's easier to wash and dry. I use a ladies razor, and/or one of those trimming combs that take a razor blade, whilst sitting on the loo. I can manage it myself as could anyone who can hold a comb and reach the area. I don't want to issue a safety warning – but obviously, appropriate care is necessary! Flush the loo before you start, in case you drop the razor and have to fish for it.

- ***The problem of urgency – or starting to wet yourself before you are on the loo seat.*** Anyone who has had a baby or has seen a continence advisor will know how helpful pelvic floor exercises are for anyone with some muscle control 'down there'. First of all, picture what is between your legs; it is actually the 'floor' of your body. You can tone up those floor muscles by doing the 'elevator' exercise.
- Relax the pelvic floor muscles as much as you can – as though you are having a wee – then gently tighten, and stop, gently tighten, and stop. Imagine that you are going up 1,2,3,4 floors in an elevator - stopping at each floor. I do this several times a day. (Usually just after wee-ing whilst still on the loo.)
- I've found that my bladder control (worsened by a hysterectomy) has been enormously improved since taking a ***dietary supplement*** that contains OPCs (also known as pycnogenols) and Ginkgo Biloba. Apart from being antioxidants, these help to tone body tissue and so help the tone of my bladder as well as reducing the oedema of my feet and ankles. Boots and Health food stores sell both of these products but I find it helpful and less expensive to buy a formulation containing both called Revenol which is made by an American firm called Neways.
- ***Liquids*** Please do not limit liquid intake all the time – it really will make urinary issues become problems. I make a practice of drinking as much water as I can whenever I am in my own environment and able to get on and off the loo more easily. Then my bladder can stand the occasional insult of a day drying myself out prior to a long car journey or flight.

Ed: If you want to know more about dietary supplements and other products visit Maggi's website www.collectiveability.co.uk or send for Maggi's leaflet Hints for Intimate Hygiene, Collective Ability, 194 Cator lane, Beeston, Notts. NG9 4BE tel. 0115 916 6453

PORTABLE ACCESSIBLE LOOS

Early this year we discovered that attending exhibitions to publicise ITAAL's work was not going to be easy. One exhibition took place on a site without access to a static Part M loo. We could only attend if a portable loo to Part M standard was provided which could be used safely by disabled users. The exhibition organisers could not guarantee this: they were completely at the mercy of the suppliers. This problem is reflected in Sarah Langton-Lockton's article on the Chelsea Flower Show. The Editor has lost count of the number of outside events she could not go to because of the lack of adequate information about portable accessible loos.

ITAAL is compiling information about portable accessible loos and their availability in order to take up the cudgels on this matter. You can help by sending us your experiences. Please contact us to obtain an information collection sheet.

Caught Short

Sarah Langton-Lockton reports on the loos at this year's Chelsea Flower Show

Two visits to the Chelsea Flower Show – on Press Day and the second Members' Day – provided the opportunity to review the provision of accessible loos. Sadly, these were as unusable by those who require Part

Provision for women was a compartment within the Ladies off Main Avenue. This had been fashioned by removing the partition between standard cubicles, adding some grabrails and a small washbasin with a vanity unit beneath that impeded leg room, and a grab rail on the inside of the door that protruded to the point of impeding clear opening width.

Alas, this depressing scenario is not unique to Chelsea. The problem appears to be a

Research Issues

It is hard to believe in this age of technology that the basic design of the lavatory pan and the works behind the scenes has not changed since they were invented. This must be a victory for good basic design. However, technology does need to catch up for some of us who need equipment to ease coping with personal care needs.

This section of Privy Counsel will list problems brought to ITAAL. For example, we would like to hear about any problems you have with equipment, existing or

M-standard unisex facilities as is all too often the case at temporary events.

Inspection revealed a compartment within the Gents, signposted on site and marked on maps in the show guidebook as 'unvisited': an antideluvian freestanding facility at the northern end of Ranelagh Gardens. It was approached by a wobbly integral ramp of precipitate gradient and the contents were so grisly as to defy description. It was unusable by anyone who transfers from their wheelchair onto the loo.

dearth of acceptable facilities in the hire pool and the unwillingness of suppliers to guarantee Part M-standard facilities to their customers.

Customers who are hiring these facilities need to be much more assertive. They need to specify dimensions and layout, and insist that these are contractually binding.

needed, and of course any solutions you have found worked for you.

Below are some already brought to our attention but we suspect there are many other seemingly small problems about personal care that people want to raise. We are also conscious that most of our examples relate more to women than to men. This is purely because more women have got in touch with us. We look forward to hearing from both men and women in the future.

Loo risers

Loo risers (raised loo seats) could do with some new thinking on design. Not only are they uncomfortable to sit on, but bulky to carry around. The Editor dreams of having a collapsible one that is strong and durable enough to put up with being dropped, easy to clean and provides more dignity to one's person when your bags are searched on entering some public places and events!

Loo bowl heights

This is a real bone of contention among disabled people as well as elderly people. There is no easy answer, but a lot could be done to help users. We want to hear from you about personal solutions, or ideas you have for a modern piece of equipment that would raise loo heights and yet be quick and easy to remove.

Split loo seats

We learned recently that split loo seats are being fitted again in some accessible loos. The reason is that some disabled women need to be able to insert a catheter to pass urine, and the split seat makes this easier. However, in the case of our informant, it meant that she could not use that loo. She could not lift herself back into her wheelchair as her leg became trapped in the split, and she could not hold herself up to transfer and lift her leg over the split. . This highlights a research design need. Can we design a double loo seat, with the lower seat having the split, the upper seat no split? This would solve the problem for both users.

Ladies urinals

There are a number around. We would like to find out just how useful these are. Is there a ladies urinal that is easy to use by someone with weak arms, on their own, sitting in their wheelchair?

Panties

A number of disabled women have said that they do not wear panties, as they find it too difficult to get them up and down when sitting in a wheelchair. This problem is not new: we can remember it being talked about by the Disabled Living Foundation way back in the 1970s! If you have a self-help solution, please write and tell us – male or female.

Calling all manufacturers

We hope you too will send us information about products. If you have a research section to your company, we would like to share concerns about lavatory equipment and fittings.

FUND RAISING

ITAAL relies on grants, sponsorship and donations. We have already found that raising money for ITAAL's work is not easy! There does seem to be a taboo at all levels of society when it comes to talking about issues of personal care and loos. So the ITAAL office would be extremely glad to hear from anyone who would like to help fundraise.

One idea floating around at the moment is to produce an **ITAAL Bathroom Book**. For this we would need personal anecdotes, limericks, cartoons, perhaps input from famous people. If anyone out there would like to take on this project, please contact the Editor.

TRUSTEES - WHO'S WHO

ITAAL's Trustees are:

Sarah Langton-Lockton
Janet Scammell
Dr. Monnica C. Stewart
Diana Twitchin
Bob Twitchin
Andrea Whittaker

We will be profiling all our Trustees in Privy Counsel in due course, and are pleased to introduce two in this first issue.

Diana Twitchin has been a wheelchair user since 1955 when she contracted polio as a teenager. After training as a secretary she joined the NHS, working at the National Spinal Injury Centre, Stoke Mandeville from 1959-70, then a community hospital for people with learning difficulties.

In 1973 she became first General Secretary of the new Spinal Injuries Association and was responsible for developing the organisation until 1976 when she joined the Kings Fund Centre. Here she worked with staff in health, local authority, voluntary sector and disabled people on a range of issues around physical disability. She was joint director of the Living Options in Practice project (1989-92) concerned with the development of comprehensive services for people with physical disabilities.

Increasing disability problems forced her to take early retirement in 1992 and allowed her to catch up on activities that she had been unable to do whilst earning her living. In 1997 she began to experience increasing problems in getting around, centring on the lack of adequate accessible loos. Discussions with a number of disabled women friends led to her setting up the ITAAL project. The rest is history!

Sarah Langton-Lockton OBE MA (Oxon)

Sarah was educated at Northampton High School for Girls and Lady Margaret Hall, Oxford, where she read Modern Languages

(Spanish and French). She worked initially as a journalist in Paris and Brussels, writing for among others The Times. From 1974 to 1976 she was Chief Executive of the International Council of Societies of Industrial Design. She joined the Centre for Accessible Environments in 1977, becoming its Chief Executive in 1979.

She is Editor of the Centre's journal Access by Design and author of many articles on access to the built environment. She is a Trustee of other charities, including The Disability Partnership, Holiday Care and Is There An Accessible Loo? She has spoken at many conferences and has carried out consultancy in the UK and overseas.

Advertising and sponsorship

ITAAL's work depends entirely on voluntary effort and grants. So, we hope that Privy Counsel will eventually pay for itself through advertising and sponsorship. Enquiries from individuals and firms interested in supporting ITAAL's work in this way will be very welcome.

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The views expressed in this newsletter are not necessarily those of ITAAL.

**Privy Counsel is the newsletter of
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