

Privy Counsel

Issue 6

Spring 2005

www.itaal.org.uk

CONTENTS

- 2 Editorial
- 3 Personal Experience
 - Hidden disability and managing continence
 - To charge or not
 - Dog Loos
- 4 Changing facilities for adults
- 4 Information
 - Progress in loo design
 - Merseyside loos
 - Using the Directory in Huddersfield
- 6 Research
 - 1000 Loo Experts
 - Vivacity 2020 – Inclusive design of Away from home Toilets

**Free Directory offer
see back page**

ITAAL TO CLOSE

Statement from Trustees April 2005

At their March meeting, ITAAL's trustees reluctantly decided that ITAAL should be wound up. This decision followed yet another funding rejection. There was sadness that yet again ITAAL had not been able to make the case for funding, coupled with anger and frustration that the vital lifestyle issues which lie behind all ITAAL's work still continue not to be taken seriously in so many quarters.

ITAAL work has always been carried out by a small number of dedicated volunteers. We have made things as economical as possible by setting up systems that make the most of computer technology. We have kept meetings (which cost money) down to a minimum. However, we found ourselves in a cleft stick. We cannot bring in new trustees without being able to meet their expenses (which in some cases may be high because of disability support needs). Neither can we pay for the admin support so desperately needed in the ITAAL office. (It is difficult to attract volunteers to do the boring paper work!)

The Chair of Trustees and her husband have contributed not only their time but also financially to ITAAL since it was set up. They are no longer prepared to absorb the increasing costs nor the increasing workload.

The decision had the full approval of all Trustees and Treasurer.

Over the next six months the Trustees will consult with the Charity Commission and Companies House regarding the winding up of the charitable company, and the disposal of assets and remaining funds.

We will clarify with existing funders the position regarding work proposed during 2005 and explore avenues for passing on existing work to other organisations.

EDITORIAL

Following the Trustees' decision to close ITAAL, we need to inform readers that this will be the last but one issue of *Privy Counsel*. We have enough funding for two more issues. We aim to publish the final issue in September and the closing date for contributions will be August 22.

Hidden disability is a major topic in this issue. Ron Flintham's piece 'Those Keys Again!' (*Privy Counsel* - Issue 4 - autumn/winter 2003) sparked an angry e-mail from Terry Gallagher which we have printed in full on pages 3-6.

We are very aware that there are different opinions amongst disabled people about who can use accessible loos and how to define 'a disability'. Amongst loo providers there are major issues about how to manage public toilet facilities to ensure the safety of users and to prevent social misuse of facilities (drugs/sex/general vandalism). These issues were obviously in the forefront of Ron Flintham's mind when writing. Having seen Terry Gallagher's e-mail, he replied that he had not meant to upset anyone but that experience with his local access group had caused him to raise the issue of misuse of accessible toilets.

We invited Terry to write an article exploring the need for greater understanding between disability groups and individual disabled people about hidden disability. His paper *Hidden disability issues and managing continence*, is a personal view of a personal issue which we hope will encourage discussion and debate. ITAAL would welcome feedback.

A number of the points he raises are not new to ITAAL. Many wheelchair users also have continence problems and we have heard many times from disabled people who have been verbally abused when accessing toilets. The wheelchair symbol is international and meant to be a sign indicating special facilities for all disabled

people. Unfortunately, as Terry Gallagher says, it is more often interpreted as meaning for wheelchair users only.

However, as a wheelchair user all my adult life I feel I must take issue with him about wheelchair users being a minority of disabled people. Yes, wheelchair users are a minority in terms of disability figures but their needs in terms of environmental design are of paramount importance. In our efforts to improve public toilet access for people with a wide range of disabilities, we must not lose sight of the vital importance of high-standard adapted toilet facilities for those of us who are '24-hour wheelchair users' and have no other feasible option. Seven years after being set up, ITAAL continues to hear about so-called accessible loos that wheelchair user women in particular, cannot use without difficulty.

Many of the issues raised by Terry are being researched by the Vivacity 2020 work and this includes looking closely at the precept that 'one loo design fits all users'. See Vivacity 2020 update on pages 9-11. they want to hear from you.

In 2004 the new Part M document was produced that covered design needs for a wide range of disabled people and was accompanied by the publication of the Centre for Accessible Environments Good Loo Design Guide. Sarah Langton-Lockton reports on page 8 on further developments to loo design which should help the cause of universal accessibility.

We must do all we can to ensure that loo providers use these documents to ensure that newly finished or refurbished toilets really do help all disabled people. As the Japanese experience (see page 10) shows, there would be less 'fighting' over who gets to use an accessible loo if there were better provision of public toilets for everybody.

PERSONAL EXPERIENCE

Hidden Disability - E-mail from Terry Gallagher

I was horrified to read Ron Flintham's comments about a young man 'who was obviously fit' walking out of a disabled toilet. How could he tell? What a gross assumption! Admittedly I am not young any more but I look as if I am not disabled. It just shows how you can fool most of the people most of the time. My disabilities date back to when councils still registered people as disabled: I still have my registration as 'severely or appreciably disabled' and things have got much worse for me since then!

I have a urostomy and an ileostomy, apart from other disabilities, so need the facilities in a disabled toilet (access to water to wash out the tail of my ileostomy pouch, a clean floor so I can kneel to empty my pouches or the space to change my pouches in the case of a leak) and have a RADAR key. Ron, however, thinks he can tell whether I have a disability just by looking! That, to me, is appalling discrimination on his part. It reminds me of my former head teacher, who when I claimed rights under the Disability Discrimination Act, said: "You can't be disabled – you're not in a wheelchair!" What about incontinent people who need to use an accessible toilet to change their pads. Would he deny them access because they 'don't look disabled'? It is bad enough being challenged by mothers with young children in shops with a joint disabled/baby changing toilet (a personal hate of mine) without the ignorance of other disabled people who assume that, because I don't look disabled, that I can't be disabled.

I look forward to Ron Flintham publishing an apology to those of us who are very disabled, yet whose disabilities are hidden by our clothing.

A very angry - Terry Gallagher

Hidden disability issues and managing continence – Terry Gallagher

In the eyes of most of the public, a disabled person is a person in a wheelchair, an attitude perhaps fostered by the disability symbol illustrating a person in a wheelchair. Perhaps what is worse, and less understandable, is that some wheelchair users consider this to be true as well, sometimes challenging those of us, like myself, who are disabled, but our disabilities are hidden by our clothing so that we receive discrimination from both able bodied and some of the disabled community as well.

The legal definitions of 'disability' are enshrined in the Disability Discrimination Act. It is important to understand exactly who is disabled, and therefore entitled to use facilities reserved for disabled people. The list includes both physical and mental disabilities. Mobility and manual dexterity are the first two conditions mentioned which cover those in wheelchairs as well as people like my wife with her arthritis, which means that she cannot use conventional taps and benefits from the lever taps found in disabled toilets. Other conditions qualifying are physical co-ordination, continence, sensory problems, severe disfigurement and certain progressive conditions such as cancer and MS.

Let's look at some of these conditions and both how and why there is a need for people with these conditions to use a disabled toilet. My own experiences with my various disabilities will illustrate some of the points at issue. At one time, I had to intermittently self catheterise because of an atonic bladder (my bladder had stretched and would not empty properly). I was advised to obtain a RADAR key so that I could have access to a space with water to wash my hands both before and after the procedure, water to fill the catheter sleeve to activate the lubricant coating and also privacy and space enough to actually carry out the procedure. A little thought will show that this would be impossible inside a 'normal' public

toilet. Later I had a suprapubic catheter (inserted through a stoma or fistula through my abdomen directly into my bladder) with a leg bag. Again personal hygiene is essential to try to prevent infection (regrettably a common occurrence with suprapubic catheters) with the need to wash hands both before and after emptying the leg bag. Privacy and dignity are key rights protected in the European laws on human rights. On the odd occasion when there has not been a disabled toilet available, I have had to use a wall mounted urinal. If you can imagine having to place one's foot on the urinal in order to empty the leg bag into it, you can understand how one gets very strange looks and comments from other users of the toilet and how one's privacy and dignity are compromised under such conditions. The key point here is that I have a 'continence' problem which renders me disabled, yet, at that time, I looked otherwise perfectly healthy but have a definite need to use disabled toilets.

In the same way, people who are incontinent of urine, faeces or doubly incontinent and who manage their problem with pads, all-in-one garments (rather like an adult sized disposable nappy) or urinal sheaths need the space and privacy of a disabled toilet to change their pads, garments or to empty their urinal as well as the availability of water for cleansing purposes. Seeing these people walking into a disabled toilet with spare pads or garments discretely concealed in a shopping bag or brief case, they do not look 'disabled', yet there are struggling to be as normal as possible with what can often be a degrading disability to cope with. These people also have a right to use a RADAR key to access disabled toilets. On a related point, I despair when disabled toilets do not have a proper clinical waste disposal bin for disposing of incontinence pads, garments, wipes and ostomy products. In 'bin-less' toilets, there is often no alternative but to leave the soiled item, hopefully, in a disposal bag on the floor of the toilet cubicle – far from hygienic or ideal. One lady who wrote to me said, “I can walk (albeit with a

stick) fairly well and I look, in the words of my friends, "radiant with health". But beneath the clothing lies another story - a story of pain, pads, leaks, muscle spasms etc. Just because the condition I suffer hasn't yet put me in a wheelchair, it's assumed I'm fine.” How can one question her need to use a disabled toilet?

Back in the days of my having a suprapubic catheter, my county council registered me then as 'severely or appreciably disabled' because of my 'continence' issue. Apart from the disabilities which have replaced the catheter and are mentioned below, I have asthma, sleep apnoea (requiring the use of a CPAP machine, or air pump, every time I go to sleep) PSVT (paroxysmal supra ventricular tachycardia) an aortic valve lesion (my aortic heart valve leaks so some of the blood supposed to be pumped round my body goes back into my heart) as well as hearing loss treated with a hearing aid in my left ear. The only visible disability, apart from when I need to use an inhaler in public, is my hearing aid. These days, my internal 'waste disposal system' has been much modified. I have no colon and no bladder so I have both an ileostomy and a urostomy. I need access to water to wash my hands both before and after emptying my urostomy, again to reduce the risk of infection, as well as to wash out the tail of my ileostomy pouch together with the very necessary hand-washing afterwards. I find it easiest to kneel in front of the toilet to empty my ileostomy, so requiring a clean floor to kneel on, as well as the privacy and dignity of being able to deal with my pouches in private. There are 100,000 people of all ages with ostomies in this country. All of them are recognised as 'disabled' by the Disability Discrimination Act, yet many of them will outwardly appear as if they do not have a disability. We ostomists do not shout about our disabilities from the roof-tops, yet receive discrimination from both the general public as well as some wheelchair users who would deny both our need and our right to use disabled toilets.

My personal 'hate' is the combined disabled toilet with baby changing. Personally I feel that disabled toilets should include baby changing for those disabled people who have children, but there should be separate facilities for able-bodied parents to deal with their off-spring. At my local Asda, when using the combined disabled toilet and baby changing, I have been sworn at by a mother who was waiting with a child desperate to use the toilet. I was told that "You obviously aren't disabled, so why are you using the baby changing toilet?" I pointed out to her that I very definitely am disabled, not that it was any of her business, and, if she had a problem with the baby changing being inside the only disabled toilet, then perhaps she would like to take up the issue with Asda? In the same way, I have come out of a disabled toilet to find a wheelchair user waiting to use the toilet. I have been very aggressively challenged about my using such toilets and, on occasions, been incorrectly informed by the wheelchair user that disabled toilets are only for the use of people in wheelchairs. I would have expected more tolerance and understanding from other disabled people. There needs to be an acceptance that disabled people do not necessarily look 'disabled'. The classic example of this is my former head teacher who, when I informed him that I wished to claim protection under the Disabilities Discrimination Act, told me, "You can't be disabled: you're not in a wheelchair!" It is important to realise that less than 5% of disabled people are actually wheelchair users, leaving over 95% of disabled people who may not look disabled, but are and so entitled to use disabled facilities.

In conclusion, I would appeal for all disabled people to respect other disabled people with different disabilities. I would hope never to be challenged again by a wheelchair user for using a disabled toilet. I look forward to all disabled toilets being equipped with a proper clinical waste disposal bins. I know we should be pleased that there are disabled toilets in supermarkets (and all praise to Sainsbury's for equipping their toilets with RADAR keys!), but I suspect that

many of us would be grateful if separate baby changing toilets were provided. I also look forward to disabled toilets **not** being accessed through another toilet. My local IKEA has recently been revamped so that the disabled toilet is accessed through the ladies toilet entrance: I get strange looks for going in there to use the disabled toilet!

No one likes to have disabilities which make using disabled toilets a necessity, so let's accept that some people have their disabilities hidden by their clothing and not challenge them when they use facilities which they have a genuine need to access. Such people may include people with ostomies, the incontinent or, indeed, those with arthritis who cannot work conventional taps and need the lever taps and large lever flush handles which are a feature of disabled toilets.

Disabled toilets are for disabled people whatever the nature of their disabilities: the Disability Discrimination Act defines those disabilities and those entitled to use those facilities. Those toilets are **not** just for those in wheelchairs.

To charge or not to charge

Over the last few months John David Taylor from Cambridge has been in regular contact on loo issues. In February he emailed asking for views on charging for accessible toilets. His local authority has begun charging for use of some of its toilets and wants feedback from toilet users. So over to readers, please let us have your views. They will be passed on to John as well as the British Toilet Association.

Dog loos

ITAAL does receive the occasional intriguing enquiry and this one raises an interesting issue. Geoff Palmer from Bristol seeks information about 'dog loos' to assist his wife and her guide dog. He wants to know of any 'dog loos' available alongside accessible toilets that could be used by guide dogs. ITAAL had never heard of 'dog

loos' - though come to think of it, it would seem to be a sensible option for those travelling with dogs, particularly on motorway service sites. So if anyone has any relevant information please contact ITAAL.

Changing facilities for adults

Johanna Da Haag and her mother describe their experience

Johanna is 17 years old, has severe cerebral palsy and is unable to stand. She is small - only 6 stone - so I am **just** able to lift her by myself. When Johanna and I are out alone we rely on the goodwill of others. I ask people until somebody agrees to help!

Johanna wears continence pads though she is usually clean, especially when away from home. She can use her own commode but not a public toilet. We keep her clean by putting her on her commode twice a day. She avoids dirtying her pad, so away from home she needs her pads changed because they are wet. I use hugely absorbent pads.

Johanna only drinks 500mls a day. She doesn't like the feel of drink. This is part of her disability not an attempt to avoid public toilets. So I don't need to change her until we have been out for six or seven hours. Often we are home again before this length of time has expired. However when we need it I do things like -

- go into a hotel, order tea and cake for myself and then ask them if they have a bed I can change my daughter on
- arrive at a pub as they open, and ask for help to use a quiet room, with a carpeted floor. I choose recently refurbished pubs!
- ask somebody to help me lift Johanna onto an accessible toilet floor. This is a desperate measure as they are often too small and not always clean!

In Johanna's class at school there are young people who don't go out because of the need for gastrostomy feeds or catheterisation to empty their bladders. There are also twins who are both wheelchair users: their mum can only go out with them with a helper.

We are grateful to Johanna and her parents for allowing us to publish this additional information, sent in with their completed survey form. ITAAL has received 46 survey forms from parents and disabled youngsters who require adult changing facilities, roughly a third of the total forms returned. This indicates how important this issue is for so many disabled people and their families – and again points to the need to keep up the pressure on loo providers for better toilet facilities for everyone.

INFORMATION

PROGRESS IN LOO DESIGN

Sarah Langton-Lockton

The Approved Document M that supports the revised Part M Building Regulation, *Access to and use of buildings* that came into force in May 2004 is more comprehensive than earlier editions and contains a number of recommendations that advance the cause of universal accessibility.

One of these is for a WC compartment that is intended to serve the needs of all users in buildings where there is space for only one loo. This can be of particular advantage for small service providers such as cafés and restaurants, keen to respond to their duties under the DDA but constrained by lack of space and the impracticability of providing male and female facilities and a unisex accessible loo.

The universal WC compartment can be achieved by increasing the width of the compartment from 1500mm (as in the conventional unisex accessible corner WC layout) to 2000mm to accommodate a standing-height washbasin, at 780-800mm rim height, as well as the finger-rinse basin located within reach of the WC.

CAE's new edition of the Good Loo Design Guide provides some suggested Layouts. It is available from Centre for Accessible Environments, 70 South Lambeth Road, London SW8 1RL
Tel 020 7840 0125 fax 020 7840 5811
www.cae.org.uk

LOO LOCATION - MERSEYSIDE

Phil Dooley of Skelmersdale sent us a number of completed loo location sheets. This information would have formed part of a UK loo directory had ITAAL been able to continue the work. We give the basic information here for those of you who may find yourselves in the Merseyside area. We hold detailed information on each site that we will be happy to supply on application. All sites are unisex.

ASDA, Birchwood Mall, Birchwood, Warrington, Cheshire (free shop hours)

Birchwood Mall, Birchwood Mall, Birchwood, Warrington, Cheshire (RADAR/shop hrs)

Pizza Hut, Racecourse Retail Park, Aintree, Liverpool, Mersey (free shop hours)

McDonalds, McArthur Glen, Cheshire Oaks, Ellesmere Port, Cheshire

Shop Mobility Information Kiosk, McArthur Glen, Cheshire Oaks, Ellesmere Port (free/shop hours)

Indoor Market (by bus station) Ashburner St., Bolton, Lancs (RADAR/shop hours)

Tesco, Cross St., Hindley, Wigan, Lancs. (RADAR/shop hours)

B & Q Warehouse, Coffee Shop, Saddle Junction, Wigan, Lancs. (Free/shop hours)

Wayfarers Arcade, Lord St., Southport, Merseyside (RADAR/shop hours)

USING THE DIRECTORY IN HUDDERSFIELD

Jane Fairbank,
Information Officer, Huddersfield Social Services Information Point

I have community funding which enables me to attend exhibitions and conferences to gather information to share with staff and others. I have an information table and give a talk called "Good Sound Social Information".

I take this talk and information table to groups and organisations in and around Huddersfield to tell people what equipment and services are available. This covers equipment such as the type of shower or bathing aids they might need, information about holidays, transport and organisations that relate to their disability or their particular circumstances.

Many people ask about accessible loos so this is where ITAAL comes in. People are very interested to hear how much you are doing around this subject. They are pleased to know there is someone to turn to and also a very useful directory with all the information they need on this subject. I sometimes have to lend my copy to groups for them to jot down the address of various loos in – or en route to - their holiday destinations.

Thank you for your good work. People do need this vital information to carry out their daily lives.

RESEARCH

1,000 LOO EXPERTS WANTED SURVEY

Work has begun to analyse completed survey forms and the results will be published in the last issue of Privy Counsel in the autumn of 2005. The survey went out with Issue 5 to 750 individuals or organisations. Strong interest was expressed by several organisations who copied and sent the survey to their memberships, thus increasing the circulation by several hundred. ITAAL now holds about 150 completed surveys. It had been intended to use the survey as part of a major advertising campaign in the disability press during 2005 to reach a total of 1000 respondents. However, since ITAAL is winding up, this will not now take place. We are looking for a partner to take up the survey work and continue it. Once it is clear who this will be we will be writing individually to everyone who submitted a completed survey to seek their permission to pass survey information on.

VivaCity 2020:

The Inclusive design of away-from-home (public) toilets in city centres

Julienne Hanson, Jo-Anne Bichard & Clara Greed

University College London (UCL) & University of the West of England (UWE).

Jo-Anne Bichard gives an update on progress in this research and details of ways you can become involved.

The numbers of people participating in the research continues to grow. Articles in newsletters produced by Arthritis Care, The Polio Fellowship, The Spinal Injuries Association, The Disabled Drivers' Association, Age Concern and the National Childcare Trust have generated interest from many people all over the United Kingdom. In response to the large number of people offering to participate we have

decided to incorporate telephone interviews into our research so that we include the views and experiences of as many people as possible.

The development of *Personas* as tools to communicate people's toilet needs has continued. We have now developed a persona representing people who experience Parauresis (Shy Bladder), and one about the difficulties experienced by older people when local toilet provision is closed. In addition the research has developed a *Toilet Audit Tool* that allows users and providers to assess toilets quickly and note the successes and failures in the design and management of facilities.

A visit to Japan

In February this year, with funding provided by the *Foreign and Commonwealth Office*, we visited Tokyo and Kyoto in Japan. During this visit we were invited to see a toilet research laboratory operated by *TOTO*, Japan's leading sanitary-ware manufacturer. The lab had adjustable walls, fixtures and fittings so that users could show researchers how they entered and exited facilities and in which position all fixtures and fittings would be better placed to suit their needs.

Japan is considered to be one of the leaders in toilet provision. In areas of Tokyo and Kyoto there are extensive toilet building and refit programmes in line with access legislation. One major difference in design between UK and Japanese toilet facilities, especially for people with disabilities, was the inclusion of 'family' facilities. These toilets included baby-changing and low-level urinals, and in some facilities a specially adapted sink with shower head for people with stomas. Family toilets were quite numerous, with some areas of Kyoto having these accessible toilets located every 500 yards. The design of some facilities also includes solar power and water recycling systems.

Inclusive design was common in many of the standard toilets, the majority being fitted with grab bars. Consequently more people who may need a certain level of support were able to use standard facilities. This, together with public provision being widely available, helped relieve the pressure of numbers using the accessible or the family toilets.

Do you have a favourite toilet?

Is it well designed, has it a high standard of cleanliness and can it be used with safety, privacy, comfort and dignity? We learn about many examples of 'bad practice' but would like to hear from readers about the 'good practice' that is out there. Examples we know about include the facilities at Milton Keynes Shopping Centre. These toilets are well-favoured with many users and are one of the few facilities in the country that offer an adult changing bench. This important fixture together with superb baby changing provision highlights what can be achieved with inclusive toilet design and provision.

Please contact us with details of why your favourite toilet is a joy to use! If possible, please take a photograph.

Focus groups and personas

Recently, we asked our Advisory Group to suggest priority user groups to approach with regard to future collaborations for persona development. Much to our surprise, it seems there is still a perceived need to investigate the design requirements of able as well as disabled users. In particular the needs of children and families were highlighted.

We have identified five questions for focus groups to consider when thinking about toilets.

1. Are the facilities safe?
2. Do they provide adequate privacy?
3. Are they clean?
4. Are they comfortable to use?
5. Can the toilet be used with dignity?

We are keen to hear from all users about their experiences of away-from-home (public) toilet facilities and will continue our consultations until November 2005.

We ask support and community groups to contact us regarding paid focus groups. We offer £15 to each participant for a 90-minute meeting. Individuals can also contact us for one-to-one paid interviews (£10 for a one hour chat).

Contact

For more details on the research and how to be involved, please contact Jo-Anne Bichard at:

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PRIVY COUNSEL – final issue

Closing date for items

22 August 2005

**This is your last chance to
make a contribution and
have your say.**

PUBLICATIONS

The A to Z of London for Blue Badge Holders

The London Blue Badge Parking Guide is a must-have for anyone with a Blue Badge who drives in London. As well as fully indexed mapping, this guide includes clarification of all parking rules across the 33 London Boroughs and is a unique accessibility profile of London's car parks.

Sponsored by the Association of London Government it costs £4.50 + 60P (P&p) = £5.10 can be bought on line at www.thePIEguide.com or call 0870 444 5435, they accept all major credit cards. Or by post and cheque made payable to PIE Enterprises Ltd, and sent with your address to PIE Enterprises Ltd, The Bridge, 12-16 Clerkenwell Road, London EC1M 5PQ.

CONFERENCES

The World Toilet Summit 2005 takes place in Belfast 26 – 29 September 2005, hosted by the British Toilet Association it will be the first global conference dedicated to 'away-from-home' toilets ever held in the West. Previous summits have been held in Singapore, Korea, Taiwan and China. The conference themes are Setting Standards and Satisfying Needs Globally.

It will include the 2005 UK Loo of the Year Awards Ceremony.

For further information contact Summit organisers: Happening, 9 Wellington Park, Belfast BT9 6DJ, Northern Ireland. Tel +44 (0) 2890 664020 email aisling@happen.co.uk

ITAAL DIRECTORY OF ENGLISH LOOS & ESSENTIAL COMPANION

We are disposing of remaining copies (free), if you would like one please contact ITAAL office (**by post**) giving full address and cheque to cover postage and packing for £4.50. Cheque should be made out to ITAAL. Allow 28 days for delivery please. It's a case of first come first served with remaining stock.

Bulk copies (10, 20 or more) of Essential Companion are also available. This was checked and updated in summer 2004. If you would like a supply for teaching purposes please contact ITAAL office for details of p&p costs.

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

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