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ORIGINAL ARTICLE OPEN ACCESS

Urinary Tract Infections Amongst Adults With Intellectual Disabilities With Urinary Incontinence

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Keywords: adults with intellectual disability | health screening | incontinence | urinary tract infections | urine sample contamination

ABSTRACT

Background: Between 26% and 52% of adults with intellectual disability experience urinary incontinence (UI). Little is known about the implications of urinary tract infections (UTIs) for this group. The aim was to screen for UTIs in a sample of adults with intellectual disability and UI.

Method: Twenty adults with intellectual disability and UI recruited via community intellectual disability health care teams and provided a urine sample. Each sample was tested for the presence of UTI bacteria.

Results: Half of the sample were found to have a possible or probable UTI. Nine adults had also been treated for a UTI within the previous 12 months; six adults had more than once.

Conclusion: UTIs appear to be very common amongst adults with intellectual disability and UI, and careful attention to UTI symptoms, screening and treatment options for this group are recommended. Larger studies on UTI prevalence and associated factors are also warranted.

Trial Registration: ClinicalTrials.gov: NCT05626062

1 | Introduction

Urinary incontinence (UI) (lack of voluntary control over urination) is common amongst adults with intellectual disability, yet it is anunder-researched area (Keenan et al. 2018; Von Gontard et al. 2014). Between 26% and 52% of adults with intellectual disability experience UI (Keenan et al. 2018; van Timmeren et al. 2016; Finlayson et al. 2010; de Waal et al. 2009); this compares with 11% of adults without intellectual disability in the general population (Medina and Castillo-Pino 2019). Urinary tract infections (UTIs) for adults with intellectual disability and UI are an important concern for two main reasons: UTIs can cause or exacerbate UI; and people who use aids for their incontinence (e.g., pads or panty liners) may be more prone to developing UTIs (Chapman, Price, and Barber 2008).

UTIs are a collective term for any infection of the urinary tract, including the upper tract (kidneys and ureters) and lower tract (bladder and urethra) (Tan and Chlebicki 2016). Alongside UI and use of incontinence aids, factors associated with UTIs include being female (due to anatomical reasons, pregnancy or menopause), sexual intercourse, history of UTIs, uncontrolled diabetes mellitus, uteral obstruction (e.g., kidney stones), catheter use (Tan and Chlebicki 2016), not drinking enough fluids and being prescribed drugs with associated side-effects (Dobrek 2023). The conventional treatment for an uncomplicated UTI is a course of antibiotics (National Institute for Health and Social Excellence, 2015).

Untreated UTIs can lead to serious consequences, such as hospitalisation, kidney damage, or sepsis (Öztürk and Murt 2020).

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A previous study conducted in England, United Kingdom (UK) found that patients with intellectual disability were five times more likely, compared to the general population, to be admitted to hospital in an emergency with a UTI (Hosking et al. 2017). UTIs therefore have been identified as a common preventable cause of emergency hospital admission for people with intellectual disability (Hosking et al. 2017; Ailey and Hart 2010). It is not currently known whether or why people with intellectual disability may be more prone to UTIs, but due to their communication and support needs, they require support to ensure timely identification and treatment of UTIs. This support includes, for example, adapting communication, involving the person's family or carer (who knows them well) and providing longer appointment times (National Institute for Health and Social Excellence, 2015).

One previous study identified in the literature has conducted urine sample analysis, to screen for UTIs, with 33 community-based adults with intellectual disability in England, UK who used incontinence products such as pads (Chapman, Price, and Barber 2008). Of these adults, 9 (27%) were found to have a UTI. The aim of this study is to present UTI screening results for a purposive sample of community-based adults with intellectual disability. In doing so, we provide a more current snapshot of UTIs amongst adults with intellectual disability with incontinence and highlight this important but neglected issue.

2 | Method

2.1 | Participants and Procedure

Adults with intellectual disability with UI were invited to take part in this research, as part of a larger research project about toileting assessment and implementing individualised toileting plans for adults with intellectual disability and incontinence (reference blinded for review); the project results on UTIs only are being presented in this report (Finlayson, Gore, and Skelton 2024). A researcher (initials blinded for review) gave information about the project to community intellectual disability health care teams in NHS (blinded for review) and NHS (blinded for review), at their team meetings. All individual healthcare professionals within these teams were then asked to give information about the project to any adults with intellectual disability on their caseloads, who met the inclusion criteria, so they could choose whether or not they wanted to take part. The inclusion criteria were that the adult with intellectual disability currently experienced UI and was able to sit on a toilet for up to 3 min (a requirement for the intervention element of the project).

Each participant with intellectual disability, and their supporter (relative or support worker), was visited in their home by the researcher, to complete the consent process, take part in a research interview and provide a urine sample (with the exception of one participant, who preferred to visit the first author's university for their research interview). Each participant was also asked to record their daily fluid intake on a chart for the next 3 days.

Twenty adults with intellectual disability and UI provided a urine sample. Their characteristics and UTI screening results are presented in Table 1. The majority of participants were female (12 adults), and mean age was 43 years (standard deviation (SD) 17 years, range 18–71 years). Eleven participants have mild to moderate intellectual disability, and 9 participants have severe to profound intellectual disability. One participant wore a removable sheath catheter during the day, and another participant had his bladder emptied via a catheter once per week by a home-visiting nurse (the nurse was present when the researcher was requesting the urine sample). Only two participants were able to provide a urine sample on their own, independently.

Eleven of the adults with intellectual disability lived with their family, eight adults lived in individual or group tenancy-supported homes and 1 adult lived on their own, independently. Comorbidities and polypharmacy were common in this sample. The mean number of known health conditions was 5 (SD 2, range 1–10), and the mean number of prescribed drugs was 6 (SD 4, range 0–13).

2.2 | Project Materials

All accessible project materials (project information, consent forms, interview schedule and fluids intake chart, using easy read format, pictures and symbols) were developed with input from 2 mothers of adults with intellectual disability as advisors. Copies are available directly from the research team. A structured interview schedule not only collected demographic (including age, sex and accommodation type) and incontinence history information (including incontinence history, diagnosed health conditions, current prescribed medications, whether the person uses incontinence products and possible UTI symptoms) but also contained open-ended questions to record descriptions of participants' responses (with assistance from their supporter) for example, further describing their incontinence history and any UTI symptoms. A copy of the interview schedule is available from the research team. A fluids intake chart was used to collect information about the person's daily fluids intake over a 3-day period.

2.3 | Urine Collection

Participants and their supporters were advised to collect urine samples mid-stream where possible. Each urine sample was collected in a specimen container with boric acid (to further ensure preservation) (Lum and Meers 1989), tested in the person's home with a reagent strip by the researcher (Siemens Multistix urinalysis strips), and then returned to the university laboratory for immediate analysis, to screen for the presence of a UTI. UTI samples were plated onto selective and differential primary UTI chromogenic media (EO labs) using the calibrated loop technique, followed by incubation at 37°C for 18 h (Haugen, Strøm, and Østervold 1968).

Prior to urine collection, Newcastle urine collection packs (Chapman, Price, and Barber 2008) were made available—with advice to follow the instruction leaflet contained in each pack—to those who preferred to use them. The instructions are available here: https://www.beaucare.com/nursing-consumables/medical/diagnostics/urinalysis/newcastle-urine-collection-pack#how_to_use. These packs enable a person with

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TABLE 1 | Sample characteristics and UTI screening results.

ID No.	Age category in years	Sex	Intellectual disability level	Urine collection method	Relevant health condition	Faecal incontinence	Incontinence aids	Daily fluids intake (ml)	UTI in previous 12 months	Urination discomfort/ pain	Drugs with associated side effects	Urinalysis strip result	UTI? (laboratory analysis)
1	50–59	Female	Severe	Supported	Diabetes	No	Yes	2263	No	Stinging	Sertraline	Glucose & blood	Probable
2	20–29	Male	Severe	In situ catheter	Cauda equina syndrome	No	Yes	2333	Yes*	Stinging	Sertraline	Protein	No
3	30–39	Female	Moderate	Supported	No	No	No	1316	No	Cramps	No	Glucose	No
4	20–29	Male	Severe	Supported	No	Yes	Yes	2300	Yes*	No	No	Negative	No
5	40–49	Male	Moderate	Sheath catheter	No	No	Yes	1916	Yes*	Stinging and cramps	No	Negative	Possible
6	30–39	Male	Moderate	Supported	Cystic kidney disease	No	No	2733	No	No	Chlorphenamine	Negative	No
7	30–39	Female	Moderate	Supported	No	No	Yes	1156	Yes*	No	No	Leukocyte esterose	Probable
8	60–69	Female	Moderate	Newcastle	Diabetes and Irritable bowel syndrome	Yes	Yes	2040	Yes	Stinging	Sertraline	Glucose	Possible
9	30–39	Male	Severe	Supported	No	No	Yes	2947	No	No	Tegretol	Negative	Probable
10	18–19	Male	Severe	Supported	No	Yes	Yes	3000	No	No	Risperidone and Fluoxetine	Negative	No
11	20–29	Female	Mild	Independent	No	No	Yes	2637	No	No	Risperidone and Fluoxetine	Negative	No
12	70–79	Male	Profound	Supported	No	No	No	2267	No	No	Chlorpromazine and Tegretol	Negative	No
13	20–29	Female	Severe	Independent	No	No	Yes	1385	No	Stinging	No	Glucose and protein	Probable
14	40–49	Female	Profound	Supported	Diabetes	Yes	Yes	2310	Yes*	No	No	Blood	Possible**
15	60–69	Female	Moderate	Supported	No	Yes	Yes	1333	No	No	No	Negative	No
16	60–69	Female	Mild	Supported	No	No	No	1687	Yes*	Stinging and cramps	No	Negative	Possible
17	18–19	Male	Moderate	Newcastle	No	Yes	Yes	1600	No	No	Sertraline	Negative	No
18	50–59	Female	Severe	Supported	No	No	Yes	965	Yes	No	No	Negative	Probable
19	50–59	Female	Moderate	Supported	No	No	Yes	1416	No	No	No	Negative	No
20	50–59	Female	Moderate	Supported	Diabetes	Yes	Yes	770	Yes	Stinging	Sertraline	Glucose	Probable

(Continues)

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TABLE 1 | (Continued)

ID No.	Age category in years	Sex	Intellectual disability level	Urine collection method	Relevant health condition	Faecal incontinence	Incontinence aids	Daily fluids intake (ml)	UTI in previous 12 months	Urination discomfort/pain	Drugs with associated side effects	Urinalysis strip result	UTI? (laboratory analysis)
Total	18–19 (2) 20–29 (4) 30–39 (4) 40–49 (2) 50–59 (4) 60–69 (3) 70–79 (1)	Male, 8 Female, 10	Mild, 2 Mod., 9 Severe, 7 Prof., 2	Supported, 14 Independent, 2 Catheter, 2 Newcastle, 2	Diabetes, 4 Cauda equina syndrome, 1 Irritable bowel syndrome, 1 Cystic kidney disease, 1 No, 14	Yes, 7 No, 13	Yes, 16 No, 4	Mean 1919, SD 663, Range 770–3000	Yes, 9 No, 11	Stinging, 5 Cramps, 1 Both, 2 No, 12	At least 1 drug, 10 No, 10	Positive result, 7 Negative result, 13	Probable, 7 Possible, 3 No, 10

intellectual disability, with assistance from their supporter, to draw the sample from a urine-soaked pad with a syringe. Previous research has indicated that Newcastle urine collection packs may result in fewer contaminated urine samples than alternative methods used with people who cannot provide a mid-stream specimen of urine on their own (Diviney and Jaswon 2021; Whiting et al. 2005).

2.4 | Analysis

All data were inputted into the statistical package, *IBM SPSS version 28*, to generate descriptive and frequency statistics. The sample size was too small to be able to conduct basic inferential statistics.

Urine samples are prone to contamination with organisms from the individual providing the specimen. As such, the results of the samples were categorized as follows (Public Health England 2019; Prandoni et al. 1996):

1. Probable UTI: one isolate at $\geq 10^8$ cfu/L; two isolates at 10^7–10^8 cfu/L with one isolate predominant at $\geq 10^8$ cfu/L.
2. Possible UTI: one isolate between 10^6 and 10^7 cfu/L; two isolates between 10^6 and 10^7 cfu/L, with each isolate being $\geq 10^6$ cfu/L and including a common UTI pathogen; one isolate at 10^7–10^8 cfu/L; ≥ 3 isolates at 10^7–10^8 cfu/L with one predominant at $\geq 10^7$ cfu/L; two isolates at $\geq 10^8$ cfu/L with both being $\geq 10^8$ cfu/L, or one being $\geq 10^8$ cfu/L and the other being $\geq 10^7$ cfu/L; two isolates with one isolate predominant at $\geq 10^7$ cfu/L.
3. No UTI present: No growth ($< 10^5$ cfu/L); no growth of common UTI pathogens.

Mean daily fluid intake was calculated for each participant, based on the mean of their 3-day fluid intake data.

2.5 | Ethics and Consent

This research project was ethically approved by Scotland A research ethics committee to conduct the research with adults with intellectual disability across all levels of intellectual disability (mild to profound). In keeping with the Adults with Incapacity (Scotland) Act 2000 (Scottish Government 2000), for the proportion of adults with intellectual disability within the sample who did have capacity to consent, their written consent was obtained; and for those who did not have capacity to give their consent, written consent was obtained from their nearest relative or welfare guardian.

3 | Results

3.1 | Incontinence and Previous UTI History

The mean length of time the participants had been experiencing UI was 8 years (SD 9 years, ranging from 5 months to 34 years). Seven of the adults also had bowel incontinence. Sixteen adults used aids (e.g., pads or panty liners) for their

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incontinence. Nine adults had been treated for a UTI in the previous 12 months; six of whom had a UTI more than once in the 12-month period.

3.2 | Fluids Intake

The mean daily fluid intake of the participants with intellectual disability was 1919 mL (ml) (standard deviation 663 mL, ranging from 770 to 3000 mL). Nine adults were drinking less than the recommended 1500–2000 mL on average per day (United Kingdom Government 2016), 3 were drinking within that range and 8 (40%) were drinking in excess of the recommended amount.

3.3 | Urine Sample Results and Symptoms

Following urine analysis, 6 out of the 20 adults with intellectual disability were found to have a probable UTI, and a further 4 were found to have a possible UTI. The remaining 10 adults tested negative for a UTI. Six urine specimens contained pathogens which were not common UTI pathogens, suggesting contamination. Only 2 of the 20 adults were able to provide their urine sample on their own, independently. The others either provided samples with assistance from their supporter (16 adults), or the sample was obtained from a catheter (two adults).

The UTI bacteria types identified for the 10 probable and possible cases were as follows: *Escherichia coli* (6 cases); Enterobacter species (3 cases); Enterococcus species (2 cases); Staphylococcus species (1 case); and Klebsiella species (1 case). Two participants tested positive for two UTI bacteria types, explaining why these numbers do not add up to 20 cases.

In terms of UTI symptoms, 8 of the 20 adults with intellectual disability were able to self-report, or convey to their supporter, that they were experiencing pain or discomfort around using the toilet to pass urine. Six of these adults were found to have a possible/probable UTI. Of these, five adults reported a stinging sensation when passing urine, one adult reported stomach aches or cramps from delaying urination and a further two adults experienced both simultaneously. In addition, one adult's urine sample was cloudy. Reagent strip urinalysis also demonstrated that five adults (three with diabetes) had glucose present in their urine (which is not indicative of a UTI), two adults had protein present, two adults had blood present and one adult had leukocyte esterase present. All of the urine samples had normal pH levels (between 4.5 and 8).

The outcome of each participant's urine sample analysis was reported to their general practitioner (GP), with their consent (or consent from their nearest relative or welfare guardian, where appropriate). All of the 10 adults with intellectual disability identified as having a probable or possible UTI, and their supporters, consulted with their GP separately, and were subsequently commenced on an appropriate course of antibiotic treatment.

4 | Discussion

4.1 | UTIs and Symptoms

Half of this sample (10 adults) were found to have a possible or probable UTI, and nine of the whole sample had been treated for a UTI in the previous 12 months (six adults more than once). Chapman, Price, and Barber (2008) previously found that 27% of 33 adults with intellectual disability had a UTI following screening but the results between both studies are not directly comparable, due to the differing samples (adults with intellectual disability and UI who are able to sit on a toilet for up to 3 min versus adults with intellectual disability who receive incontinence products), and Chapman, Price, and Barber (2008) not describing their laboratory UTI screening criteria. Larger representative studies will be required (which may include secondary analysis of existing health data sets for adults with intellectual disability) to determine the actual prevalence of UTIs, and associated factors, amongst adults with intellectual disability and UI, and adults with intellectual disability more widely.

Eight of the adults with mild to profound intellectual disability conveyed that they were experiencing symptoms associated with UTIs (stinging or cramps); six of whom were found to have a possible/probable UTI. Two of the adults with intellectual disability who reported symptoms, and one of the adults with protein in his urine, were not found to have a possible/probable UTI. There may be other reasons for this which warrant further investigation/advice, including for example, bladder pain syndrome for symptoms, and for example dehydration for protein in urine. In addition, if a person is drinking an excessive amount of fluids, this can impact on whether or not a UTI is identified via urine analysis. One adult with intellectual disability had cystic kidney disease but was not found to have a UTI at this time, or in the previous 12 months. UTIs are a serious concern for people with this health condition, as it can worsen their condition. Annual health checks, which are recommended for adults with intellectual disability, provide the opportunity to screen for UTIs, and consider possible UTI symptoms, in the context of the person's overall health and well-being (Public Health England 2016; Robertson et al. 2011).

Possible UTI symptoms were identified, using reagent strips, for 4 out of the 10 adults who were then found to have a possible or probable UTI. Reagent strip urinalysis is useful for health monitoring, including UTI symptoms, when used in combination with other methods. A thermometer can be used to check for symptomatic changes in body temperature (high temperature or very low temperature), alongside self or proxy-reported symptoms for example, pain or stinging or an increased need to urinate during the night.

4.2 | Sample Contamination

Six (30%) of the 20 urine specimens indicated contamination of non-UTI pathogens. Urine sample contamination is a commonplace issue (Hayward et al. 2022). Across populations, the urine sample contamination rate varies between 0.8% and 42% of samples, with contamination being more likely for women, pregnant women and people who are obese (Hansen et al. 2022).

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Contamination occurs when bacteria from a person's skin, clothing, or other materials enter the specimen container (Hayward et al. 2022). At the time of conducting this research, the researcher gave the adults with intellectual disability, and their supportive carers, verbal instructions on urine sample collection, to stress the importance of collecting each sample mid-stream. (This, of course, did not apply to the 4 participants who provided a sample via a catheter or Newcastle urine collection pack). A mid-stream specimen of urine is less likely to be contaminated by bacteria around the person's urethra (Pernille et al. 2019). In hindsight, it is likely that the adults with intellectual disability and their supporters would have benefitted from information and advice being available to them beforehand, in accessible format using easy read, pictures and symbols. This could have included a pictorial demonstration of collecting a urine sample mid-stream, as well as advice on not touching the rim of the specimen container, and washing hands and the genital area prior to collecting the sample. Urine sample collection by a community health professional, such as a practice or intellectual disability nurse, may also reduce the likelihood of contamination.

4.3 | UTI Causes and Associated Factors

A UTI often occurs when bacteria from the gut enter the urinary tract, through faecal contamination (Flores-Mireles et al. 2015). People who do not wipe their bottom from front to back after passing a bowel movement can experience this, as well as those who use incontinence products for urine and faecal incontinence. More than one-third of the adults (seven adults) with UI in this sample also experienced faecal incontinence, and the majority (16 adults) used products such as pads for their incontinence. Some skin-associated Staphylococcus species are also common UTI pathogens. Not drinking enough fluids can also lead to a UTI. Seven of the adults with intellectual disability reported that they were drinking less than the recommended amount per day on average. Accessible information and advice should also be made available to adults with intellectual disability, and their supporters, on how to reduce the risks of developing UTIs. This would include, for example, the importance of wiping their bottom front to back, changing soiled pads immediately, daily fluids intake recommendation and other advice, such as wearing loose and breathable clothing to inhibit bacterial growth (Centers for Disease Control and Prevention 2021).

Seven out of 12 women with intellectual disability were found to have a possible or probable UTI, compared to two out of eight men with intellectual disability. Four out of 10 adults who were prescribed drugs with associated UTI side-effects were found to have a possible or probable UTI. Only one of the two adults who uses a catheter was found to have a possible UTI. However, due to the small descriptive sample, these are merely observations. This study did not ask questions related to sexual health during data collection, nor conduct wider health assessment around for example, possible kidney stones or diabetes management.

Further research is warranted, as the population of adults with intellectual disability do experience higher rates of health issues, which have been found to be associated with the risk of developing UTIs in the general population; this includes incontinence alongside the use of incontinence products, diabetes and polypharmacy (drug side effects). Further research is also warranted because of this study's findings that some adults with intellectual disability and incontinence may be experiencing recurrent UTIs, further increasing their risk (Dobrek 2023; Chapman, Price, and Barber 2008; Tan and Chlebicki 2016).

4.4 | Treatment

All 10 adults with intellectual disability with a possible/probable UTI consulted their GP and were commenced on antibiotic treatment. It is not known whether their GPs considered alternatives or further investigations or were influenced by their patient with intellectual disability's participation in this research (which required them to be clear of any UTI prior to commencing the intervention stage of the project). Antibiotics are the conventional treatment for UTIs, but there are concerns around developing antibiotic resistance through over-prescribing, and for people with intellectual disability in particular, the issue of polypharmacy (participants in this study were being prescribed 6 drugs on average) (Lonchampt et al. 2021). There are a number of nonantibiotic treatments for UTIs available, which seem promising but have still to be established as best evidence/practice. These include for example, cranberry juice/extract, probiotics, nonsteroidal anti-inflammatories and methenamine hippurate (Sihra et al. 2018). In addition to consideration of good antibiotic stewardship with regards to antibiotic resistance, there are additional risks to the broad spectrum of antibiotic treatment, such as the development of Clostridioides difficile-associated disease and fungal infections (Zhang et al. 2022; Krčméry et al. 1999).

Conversely, antibiotic treatment is not recommended for asymptomatic bacteriuria in vulnerable populations (i.e., older adults), as they may be ineffective. However, this evidence is based on institutionalised, not community-based, older adults (European Association of Urology 2024). Three adults with intellectual disability in this study were found to have a possible/probable UTI with no symptoms (although we did not check their body temperature as a potential symptom, or whether they were experiencing an increased need to urinate during the night), although two of these adults had been treated for a UTI within the previous 12 months.

4.5 | Strengths and Limitations

The main strength of this research is that it focuses on a neglected but common health concern, which is incontinence in adults with intellectual disability and implications for UTI risk, and provides a current snapshot of the UTIs amongst adults with intellectual disability with UI.

The main limitation is that the study excluded adults with intellectual disability and UI who cannot sit on a toilet for up to 3 min, due to the intervention component of the research. Furthermore, the study did not collect relevant data around participants' sexual health (associated factors), nor body temperature (high or very low) or any increase in the need to urinate during the night (as potential UTI symptoms). We would advise researchers and clinicians to consider these in future

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research and practice. In addition, two adults with intellectual disability were supported to provide a urine sample using a Newcastle urine collection pack. This method has not been tested for validity and reliability with people with intellectual disability.

5 | Conclusion

UTIs appear to be very common in adults with intellectual disability with UI, and careful attention to UTI symptoms, screening and treatment options in this group is recommended. Working with adults with intellectual disability and their supporters is also recommended to increase awareness around reducing UTI risk and developing more usable methods for sterile urine sample collection to avoid sample contamination.

Further research to establish the prevalence of UTIs, and associated factors, amongst adults with intellectual disability and UI, and adults with intellectual disability more widely, is warranted.

Author Contributions

J.F. designed the study, analysed the data and drafted the manuscript. D.S. codesigned the study and contributed towards the manuscript. N.G. reviewed data during data collection and contributed towards the manuscript. P.O. and F.R. recruited participants, collected data, inputted data and contributed towards the manuscript. J.B. and R.K. analysed data and contributed towards the manuscript.

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The research team would like to thank all of the adults with intellectual disabilities and their supporters for their participation in this study.

Ethics Statement

This research project was ethically approved by Scotland A research ethics committee to conduct the research with adults with ID across all levels of ID (mild to profound).

Consent

In keeping with the Adults with Incapacity (Scotland) Act 2000 (Scottish Government 2000), for the proportion of adults with ID within the sample who did not have capacity to give their consent, written consent was obtained from their nearest relative or welfare guardian.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Copies of all project materials and anonymised data sets are directly available via the research team.

References

Ailey, S. H., and R. Hart. 2010. "Hospital Program for Working With Adult Clients With Intellectual and Developmental Disabilities." *Intellectual and Developmental Disabilities* 48, no. 2: 145–147.

Centers for Disease Control and Prevention. 2021. "Urinary Tract Infection." Centers for Disease Control and Prevention: Atlanta, Georgia, USA.

Chapman, M., J. Price, and A. Barber. 2008. "Urine Screening for Clients With Learning Disabilities." *Nursing Times* 104, no. 46: 38–40.

De Waal, K. H., B. M. Tinselboer, H. M. Evenhuis, and C. Penning. 2009. "Unnoticed Post-Void Residual Urine Volume in People with Moderate to Severe Intellectual Disabilities: Prevalence and Risk Factors." *Journal of Intellectual Disability Research* 53, no. 9: 772–779.

Diviney, J., and M. S. Jaswon. 2021. "Urine Collection Methods and Dipstick Testing in Non-toilet-Trained Children." *Pediatric Nephrology* 36, no. 7: 1697–1708.

Dobrek, L. 2023. "Lower Urinary Tract Disorders as Adverse Drug Reactions—A Literature Review." *Pharmaceuticals* 16, no. 7: 1031.

European Association of Urology. 2024. "EAU Guidelines on Urological Infections." European Association of Urology: Arnhem, the Netherlands.

Finlayson, J., N. Gore, and D. A. Skelton. 2024. *Final Report to Baily Thomas Charitable Fund: Toileting Assessment and Toilet Training for Adults with Learning Disabilities and Incontinence*. Luton, UK: Baily Thomas Charitable Fund.

Finlayson, J., J. Morrison, A. Jackson, D. Mantry, and S. A. Cooper. 2010. "Injuries, Falls and Accidents Among Adults with Intellectual Disabilities. Prospective Cohort Study." *Journal of Intellectual Disability Research* 54, no. 11: 966–980.

Flores-Mireles, A. L., J. N. Walker, M. Caparon, and S. J. Hultgren. 2015. "Urinary Tract Infections: Epidemiology, Mechanisms of Infection and Treatment Options." *Nature Reviews Microbiology* 13, no. 5: 269–284.

Hansen, M. A., M. Valentine-King, R. Zoorob, et al. 2022. "Prevalence and Predictors of Urine Culture Contamination in Primary Care: A Cross-Sectional Study." *International Journal of Nursing Studies* 134: 104325.

Haugen, J., O. Strøm, and B. Østervold. 1968. "Bacterial Counts in Urine: 1. The Reliability of the Loop Technique." *Acta Pathologica et Microbiologica Scandinavica* 74, no. 3: 391–396.

Hayward, G., S. Mort, L. M. Yu, et al. 2022. "Urine Collection Devices to Reduce Contamination in Urine Samples for Diagnosis of Uncomplicated UTI: A Single-Blind Randomised Controlled Trial in Primary Care." *British Journal of General Practice* 72, no. 716: e225–e233.

Hosking, F. J., I. M. Carey, S. DeWilde, T. Harris, C. Beighton, and D. G. Cook. 2017. "Preventable Emergency Hospital Admissions Among Adults With Intellectual Disability in England." *Annals of Family Medicine* 15, no. 5: 462–470.

Keenan, P., S. Fleming, P. Horan, et al. 2018. "Urinary Continence Promotion and People With an Intellectual Disability." *Learning Disability Practice* 26, no. 4: 28–34.

Krčméry, V., F. Matejička, E. PichňovÁ, et al. 1999. "Documented Fungal Infections After Prophylaxis or Therapy With Wide Spectrum Antibiotics: Relationship Between Certain Fungal Pathogens and Particular Antimicrobials?" *Journal of Chemotherapy* 11, no. 5: 385–390.

Lonchampt, S., F. Gerber, J. M. Aubry, J. Desmeules, M. Kosel, and M. Besson. 2021. "Prevalence of Polypharmacy and Inappropriate Medication in Adults With Intellectual Disabilities in a Hospital Setting in Switzerland." *Frontiers in Psychiatry* 12: 614825.

Lum, K. T., and P. D. Meers. 1989. "Boric Acid Converts Urine Into an Effective Bacteriostatic Transport Medium." *Journal of Infection* 18, no. 1: 51–58.

Medina, M., and E. Castillo-Pino. 2019. "An Introduction to the Epidemiology and Burden of Urinary Tract Infections." *Therapeutic Advances in Urology* 2, no. 11: 1756287219832172.

National Institute for Health and Social Excellence. 2015. *Urinary Tract Infections in Adults: Quality Standards*. London, UK: National Institute for Health and Social Excellence.

14683148, 2025, 1, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13317 by Test, Wiley Online Library on [13/11/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

Öztürk, R., and A. Murt. 2020. "Epidemiology of Urological Infections: A Global Burden." *World Journal of Urology* 38: 2669–2679.

Pernille, H., B. Lars, M. Marjukka, S. Volkert, and H. Anne. 2019. "Sampling of Urine for Diagnosing Urinary Tract Infection in General Practice – First-Void or Mid-Stream Urine?" *Scandinavian Journal of Primary Health Care* 37, no. 1: 113–119.

Prandoni, D., M. H. Boone, E. Larson, C. G. Blane, and H. Fitzpatrick. 1996. "Assessment of Urine Collection Technique for Microbial Culture." *American Journal of Infection Control* 24, no. 3: 219–221.

Public Health England. 2016. "Annual Health Checks and People With Learning Disabilities." Public Health England: London, UK.

Public Health England. 2019. "UK Standards for Microbiology Investigations: Investigation of Urine." Public Health England: London, UK.

Robertson, J., H. Roberts, E. Emerson, S. Turner, and R. Greig. 2011. "The Impact of Health Checks for People With Intellectual Disabilities: A Systematic Review of Evidence." *Journal of Intellectual Disability Research* 55, no. 11: 1009–1101.

Scottish Government. 2000. "Adults With Incapacity (Scotland) act 2000." Scottish Government: Edinburgh, UK.

Sihra, N., A. Goodman, R. Zakri, A. Sahai, and S. Malde. 2018. "Nonantibiotic Prevention and Management of Recurrent Urinary Tract Infection." *Nature Reviews. Urology* 15: 750–776.

Tan, C. W., and M. P. Chlebicki. 2016. "Urinary Tract Infections in Adults." *Singapore Medical Journal* 57, no. 9: 485–490.

United Kingdom Government. 2016. "Eatwell Guide." United Kingdom Government: London, UK.

Van Timmeren, E. A., A. A. J. Van der Putten, H. M. J. van Schrojenstein Lantman-de Valk, C. P. Van der Schans, and A. Waninge. 2016. "Prevalence of Reported Physical Health Problems in People with Severe or Profound Intellectual and Motor Disabilities: A Cross-Sectional Study of Medical Records and Care Plans." *Journal of Intellectual Disability Research* 60, no. 11: 1109–1118.

Von Gontard, A., T. P. d. Jong, A. Rantell, A. Nieuwhof-Leppink, J. K. Badawi, and L. Cardozo. 2014. "Do We Manage Incontinence in Children and Adults With Special Needs Adequately?" *Neurourology and Urodynamics* 35, no. 2: 304–330.

Whiting, P., M. Westwood, I. Watt, J. Cooper, and J. Kleijnen. 2005. "Rapid Tests and Urine Sampling Techniques for the Diagnosis of Urinary Tract Infection (UTI) in Children Under Five Years: A Systematic Review." *BMC Pediatrics* 5: 1–13.

Zhang, J., L. Chen, A. Gomez-Simmonds, M. T. Yin, and D. E. Freedberg. 2022. "Antibiotic-Specific Risk for Community-Acquired Clostridia Difficile Infection in the United States From 2008 to 2020." *Antimicrobial Agents and Chemotherapy* 66, no. 12: e01129-22.

14683148, 2025, 1, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13317 by Test, Wiley Online Library on [13/11/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License