

Water Consumers Research Project 2

High water needs of people
living with disability and their
families in South Australia

*To research and document the particular conditions
for people living with disability which necessitate the
high use of water in South Australia.*

AUGUST 2019



JFA Purple Orange is an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

Our work is characterised by co-design and co-production, and includes hosting a number of user-led initiatives.

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1. Executive summary

JFA Purple Orange led a State-wide project to research and document the particular conditions for people living with disability which necessitate the high use of water in South Australia. People provided a glimpse into their particular circumstances through 1:1 semi structured interviews. They provided insight into the disability they (or their family member live with), what they use the most water on, how their high use of water impacts on their lives, how they go about managing their water needs and identified what would be most helpful to them in assisting with high water needs.

One of the key themes that emerged through this project was that many of the participants expressed their sense that water is a precious commodity, one person referred to it as 'sacred', another as 'precious'. These people had paused to consider what life would be like without water and that was not a palatable thought. It was clear that the participants were not only water conscious but that they think water should be revered. It was clear from the narratives that using lots of water has a psychological impact on people.

Over two thirds of the participants spoke about showers and personal health care as their main use of water and documented why this was important to them. Those participants living with neuro muscular conditions spoke about how access to long warm/hot showers was absolutely necessary to warm up the muscles to function for the day. Without it these participants' bodies simply do not work.

Participants also talked about how high water use impacts upon their lives, either financially or otherwise. Participants spoke about being unable to participate in the community because water costs are too high, or of not being able to afford other items because paying for water was a priority. Others spoke about the anxiety over whether they would be able to pay their bill and the consequences of water being disconnected.

A key message to emerge throughout the consultation is that people living with disability should always be involved in any decision-making that affects their lives. This includes the development, implementation and monitoring of programs and services. A number of people living with disability noted that they are often consulted by governments, but do not always see their ideas being put into action.

Participants urged the state government to lead the way in implementing measures that could significantly assist people living with disability who have high water needs. One measure would be a single priority needs register for all essential services for people who will be significantly impacted by disconnection. Others identified the importance of easily accessible and understandable water rebates or concessions which are not only based on narrow medical conditions but would cover the particular conditions of people in this report. Others recommended wider use of assistive technology and modifications which would be funded under the National Disability Insurance Scheme.

JFA Purple Orange also notes the final report of the SA inquiry into water prices released in July 2019 and the urgent need to cut inflated household water bills for people living with high water needs.¹

1 https://treasury.sa.gov.au/__data/assets/pdf_file/0004/36193/20150331-Water-Regulatory-rate-of-return-Final-Report.

2. Background

2.1. Previous work

The South Australian Department of Human Services (DHS) currently contracts the South Australian Council of Social Service (SACOSS) to identify priority projects for potential funding under the Consumer Advocacy and Research Fund constituted within Section 87 of the *Water Industry Act 2012*.

In 2017, SACOSS identified consultation with people living with disability as water consumers as a priority and JFA Purple Orange was commissioned by DHS to deliver the project. The six month project documented the particular issues arising for people living with disability in respect of the use of, cost of, quality of and access to water in South Australia. Consumers of water living with a range of disabilities were engaged, in both metro Adelaide and regional areas of South Australia, using appropriate qualitative and quantitative research techniques. The final report served to promote the interests of people living with disability as consumers of water and led to a forum through which consumers living with disability could have their voices heard on essential services issues. It provided comprehensive understanding of the issues faced by consumers of water living with disability to ensure effective policy and regulatory mechanisms exist which give full consideration to stakeholder concerns and provide for the needs of all water consumers in South Australia.

2.2. This project

In 2018, based on this previous report, SACOSS identified people with high water use as a result of their disability as a priority area for further research. JFA Purple Orange was again commissioned to research and document the particular conditions for people living with disability which necessitate the high use of water in South Australia. This is the report of that project.

3. Methodology

This current project was led through a process of co-design, where people living with disability, as members of a steering group, co-designed the methodology and project materials, monitored the progress of the project, provided feedback, and contributed to the final report. The co-design group consisted of four individuals living with disability and project staff from JFA Purple Orange. The co-design group met three times across the duration of the project, with some written feedback on documents provided from group members outside of the meetings.

Thirty interviews were conducted with people living with disability and family members. All participants self-identified as having high water usage because of disability. While data was collected on participants' quarterly use of water and average daily use for the year, what is considered high water usage varies greatly depending on a household's circumstances (for example, size of property, size of garden, time of year, type of appliances and number of occupants)². Without access to detailed water usage data by customer household type, it was decided to rely on participants' own self-identification as a person with high water user or on their perception that they used more water than they would otherwise do as a result of the disability they live with.

Participants were recruited through Social Media, JFA Purple Orange stakeholder networks, SA water stakeholder networks and the SA Government's State Disability Register.

2 See <https://www.sawater.com.au/accounts-and-billing/current-water-and-sewerage-rates/residential-water-supply> (accessed on 24 July 2019)

3.1. Interview Details

The project involved 1:1 semi-structured interviews with 30 people who had high water use. Interviews were conducted throughout the months of April to June 2019 and were held over the phone, at the interviewee's house and at JFA Purple Orange's office. Four interviews were conducted at JFA Purple Orange, three were conducted at participant's homes and 23 were conducted over the phone. Participants were provided with the interview questions prior to the interview taking place. Interviews ranged from 11 minutes to 38 minutes in length.

Participants were asked 33 questions about water use in 5 main areas:

- Their particular circumstances
- Their use of water
- The impacts of having high water use
- Their management of water use
- Their suggested solutions/improvements.

The previous JFA Purple Orange water report³ and further desk top research identified 5 key initiatives that consumers identified as being useful in addressing high water needs. Participants of this project were asked to rate how helpful these same five key initiatives would be for them:

1. Concession/rebate for excess water usage
2. Installation of a smart meter
3. Priority Needs register
4. Priority notice of water disconnection
5. Water bill in plain English

Participants made these ratings by selecting the number that best represented their answer on a 7-point scale where 1 indicated 'not very helpful' and 7 indicated 'very helpful'.

All of the survey questions and measures are presented in Appendix 1.

Participants also provided information about the type of disability they live with, and their housing status.

3.2. Data Collection on billed on water consumption

Participants provided copies of water bills where they received them and wished to provide them.

Data was collected on the quarterly use of water and also the average daily use for the year.

3.3. Ethical Considerations

Data was de-identified prior to data analysis. All data has been stored confidentially and will be reported in a way that ensures identification of participants is not possible. Participants were able to choose which questions they wished to respond to, and could elect to exit the interview at any time.

Prior to commencing the interviews, background information about the project and how participant personal information would be kept confidential, and also how participation would have no negative impact on utility services received, was provided to participants. All participants provided informed written consent. Some interviews were audio recorded, after verbal consent to record was received from participants.

3 <https://www.sacoss.org.au/water-consumers-disability-research-project-jfa-purple-orange>

4. Participants

There were 30 participants in total, of these, 16 participants lived with disability, 12 had a family member living with disability and 2 participants lived with disability and also had a family member who lives with disability.

The below table displays the types of disabilities participants and their family members live with.

Type of disability	Number of participants
Vision Impairment	1
Physical Disability	14
Autism	3
Acquired Brain Injury	2
Intellectual Disability	1
Multiple Disabilities	8
Huntington's Disease	1

The residential status of each participant was as follows:

Property status	Number of participants
Physical	10
Intellectual	19
Neither (other family members owned their property)	1

The household occupancy of the 30 participants was as follows:

Household occupancy	Number of participants
Single Occupant	11
Two Occupants	3
Three Occupants	7
Four Occupants	6
Five Occupants	3

5. Results: Water Usage

5.1. Data from water bills

Billed consumption of water was wide-ranging among the participants, suggesting that at least some participants might not be regarded as high consumers of water if compared to a larger population. This might be expected, given that participants self-selected based on perceived high use of water.

This suggests there are a variety of perceptions about what constitutes high water use, which might be explained by:

1. Variations in participant economic status, affecting the perceived affordability of water, and/or
2. Variations in participant perceptions about water as a precious or scarce commodity.

To illustrate key points, participant accounts feature throughout this report. The first two below give an indication of the levels of water consumption:



Participant one

Personal profile: 41-year-old living with neuro-muscular condition – Centronuclear myopathy

Housing profile: Living alone, has a large garden, no swimming pool, water usage in 2016 was 1500 litres per day and in 2019 reduced to 500 litres a day

“I do use water a lot for hygiene because I have to be careful about bugs and stuff because my lungs are very poor so I am always washing my hands and getting other people to wash their hands. In 2016 it was 1500 litres a day. I think there was a leaking toilet and stuff and some plumbing issues. Now it is about 500 litres per day. I do have trouble reading and understanding the bills. I look at it and consider myself quite intelligent and I look at it and I can’t work it out. Surely they can make it less complicated.”



Participant two

Personal profile: 57-year-old family member of adult aged 24 who lives with autism

Housing profile: Three people living in a house on a medium size block with a swimming pool

“We always tend to use the same amount of water. We use a lot of water. Our average daily water use in summer is 20,172 litres and (according to the bill) a large family of 5+ has a range of around 1,189 litres per day. There’s two reasons: one is because we have a pool and the reason we got the pool because of the therapeutic effects for people with autism for swimming and the other reason is that he spends a lot of time in the shower... And two things: one is that it’s expensive and the second is that it is a sacred resource and I feel bad about it.”

5.2. Activities consuming the most water

In response to the question, “What do you use the most water on per week?”, and where more than one option could be selected, participants reported the following:

Activity using the most water	Number of participants
Showers	23
Laundry	22
Support Worker	15
Garden	4
Pool	3
Baths	2
Sterilization of equipment	2
Cleaning	2
Dishes	1
Cleaner	1
Personal Care	1
Assistance animals	1

Several of these high-use activities are reported in more detail below.

5.3. Showers and hydrotherapy

The majority of participants (23) spoke about showers and personal health care as their main use of water and documented why this was important to them. Those participants living with neuro muscular conditions such as centronuclear myopathy¹, muscular dystrophy², familial spastic paralysis³ and multiple sclerosis⁴ stated the importance of warm/hot showers on their ability to function for the day and how it was necessary to warm up the muscles and get moving. A long shower ranged from 5 minutes to 40 minutes but the main function of the shower was to warm the muscles.

“In summer I have shorter showers, in winter longer showers – weather is colder it takes longer to warm up and a warm shower does help my condition and helps my breathing as well.” – Participant

4 Centronuclear myopathy is a condition characterized by muscle weakness (myopathy) and wasting (atrophy) in the skeletal muscles, which are the muscles used for movement..

5 Muscular dystrophy (MD) is a group of muscle diseases that results in increasing weakening and breakdown of skeletal muscles over time.

6 Familial spastic paralysis refers to a group of inherited disorders that are characterized by progressive weakness and spasticity (stiffness) of the legs.

7 Multiple sclerosis (MS) is a condition of the central nervous system, interfering with nerve impulses within the brain, spinal cord and optic nerves.

5.3. Showers and hydrotherapy cont.

One participant spoke about the therapeutic nature of water use:

"Positively, in the winter I do use a little bit more hot water almost like therapy to warm the muscles up and get everything sort of going and just refreshing as well, and in the summer the opposite, I use the water to cool me down because I can over heat a little bit during the night especially in the hotter weather so a cooler longer shower helps as well." - Participant

"In some ways yes, I have a lot longer showers but I only have them every second day and I wash my hair every time. I have the shower because a carer is here, and because I don't get one every day I take longer showers and I enjoy the heat." - Participant

As one of the co-design members noted, hydrotherapy and hydrothermal therapy are traditional methods of treatment that have been used by many cultures. Water therapy has been around for millennia. Water is used for the treatment of joint stiffness, painful scars, adhesions, arthritis and as a warm-up to assist with exercise. Water therapy is used for the effects on body tissues of heating, cooling, debridement, pain relief and relaxation of muscles. Participants made the point that not only is it therapeutic, it is necessary for them to be able to function.

"I use the shower to get clean but I do like having a shower because it helps my muscles relax in the heat. My knees because of my condition they get quite clenched and really stiff and the hot water helps them to relax." - Participant

One family has installed a hydrotherapy bath in their house but are only able to use it sparingly because of the amount of water required:

"He showers - daily showers, longer showers/ at least 5 minutes. He finds the warm water therapeutic for aches and pains. One of the reasons we don't use it (the hydrotherapy bath) a lot is because we thought that the rain water tanks we got would be able to be plumbed in it but that is going to be too expensive.... So he uses it about twice a month at the moment but he would benefit from using it weekly." - Participant

Other participants spoke about the need to use more water due to hygiene reasons:

"Because I have to wash more, incontinence, keeping myself clean. I have a really sensitive nose, so if I sense something is dirty, I have to clean myself. If I have an accident, I have to have two per day. The average person, has one shower per day, sometimes I have two. You have to do what you have to do" - Participant

"Showers and washing. Living with a person with a disability they sometimes have 2-3 showers per day depending on how they manage their toilet issues." - Participant



Participant three

Personal profile: 51-year-old living with rheumatoid arthritis – juvenile

Housing profile: Living alone as an owner occupier of a unit with a small garden

"Because I've got rheumatoid arthritis, I often or I always wake up stiff and I always have and the showers are the only thing that actually help me loosen up in any given day. It's just one way to make the body start moving and to make it actually function or get a good start to functioning and that's usually prior to the medication kicking in. I could take up 20-25 minutes to take a shower and that's just to loosen up. I don't take multiple showers per day because I can't afford it."

5.4. Laundry

Twenty two participants identified laundry as the other major use of their water. Nine of the participants spoke about daily laundry needs due to hygiene and meeting incontinence needs. One participant particularly mentioned that:

“Acquired Brain Injury (ABI) is often a cause of incontinence and possible bladder infections which of course are the reason why personal hygiene needs more water, as discussed for other disabilities.” - Participant

“Constantly washing, second load on now today and another two loads to go. With daughter’s bed it’s not just the sheets it’s the extra blankets to keep her joints warm, extra cushion covers for different things she has.” - Participant

“Have a lot more washing mainly because I can’t shower. So then we use more flannels and towels. Heaps of washing: I use mattress protectors at night which you can’t put more than two in washing machine at a time so I have to wash every second day. I have a large washing machine because nothing else would take the quantity.” - Participant

“Need to be understanding that people living with disability don’t have any other options, we need it for health and sanitary reasons which a lot of other people can go without.” - Participant

“If he wets the bed four days in a row, I’m doing two loads every day and clothes on top of that.” - Participant

5.5. Support Workers

Fifteen participants identified that a Support Worker uses water in their home for work purposes. One person stated that a cleaner uses water in their home for work purposes. While these participants did not see this as the main reason for their high water use as support workers seem to be using water for normal household tasks rather than creating additional tasks. Some participants could only shower with the assistance of a support worker and, because they do not get daily support, they have longer showers on those occasions. Support workers are using water on various household tasks such as cleaning the house and doing washing and laundry.

“Yes a lot, everything doing the dishes washing the floor doing the laundry, watering the plants, washing me. Everything seems to need water.” - Participant

Participants mentioned that the support workers are not always ‘water conscious’ and the key issue appears to be the lack of incentive for them to be water conscious given they are not the bill payers. One participant said:

“People don’t care about water usage as much as you do. Like, if I turn on the tap, I try not to turn it on for long, I’m not knocking carers because they do a wonderful job but maybe carers aren’t as conscious as I would be” - Participant

Others had a similar experience:

“We also have support workers who do things differently than I do and are not as mindful of water use as I might be.” - Participant

“They use a lot of water. 3-4 minutes to wash hands, always under running water. In an hour shift they would wash hands six or seven times at least.” - Participant

5.6. Gardens

Four participants mention the use of water on maintaining their gardens. In particular some participants emphasised the importance of growing their own vegetables and fruit trees not only so they could source their own food but because the disability they live with requires an organic, chemical-free diet. Having a garden was also important as a hobby and source of enjoyment for many participants.

"I use more water because of the daily baths and showers and also because I am so conscious of having to eat well. I have an organic garden so that I can eat fresh produce and not commercial products. I grow my own fruit and vegetables – and have more than 20 fruit trees/gardens on property. I need to maintain inner health and as a coping mechanism. It makes me feel better and have more energy." - Participant

Many participants who had gardens said they didn't water them often because of the cost and some participants had also gone to great lengths to conserve water and had adhered to water restrictions.

"Gardener does front yard under NDIS. I won't water, besides once a week in summer. Don't have money to do extra. Collecting grey water for a while but became difficult to do." - Participant

"We have a small garden, a lot of paving and not much garden. I used to water garden using irrigation system, but I hand water now due to cost" - Participant

5.7. Animal assistance

One participant identified that they use a high amount of water because of their assistance dog. When asked why they use more water than others because of their disability, they responded:

"Because trying to keep the dog smelling sweet in public, in restaurants and hotels and public places and her bedding. The cooling to keep them cool during summer, it sounds stupid but even the amount she drinks" - Participant

6. Perceptions of water

6.1. Water as a precious commodity

For many of us, clean water is so plentiful and readily available that we rarely, if ever, pause to consider what life would be like without it.

- Marcus Samuelsson⁴

South Australia is the driest state in the driest inhabited continent on Earth, where there is relative scarcity of a commodity that is essential to life.

One of the key themes that emerged through the interviews, and that the co-design group felt was important, was that many of the participants expressed their sense that water is a precious commodity, one person referred to it as 'sacred', another as 'precious'. These people had paused to consider what life would be like without it and that was not a palatable thought. It was clear that the most participants were not only water conscious but that they think water should be revered. It was clear from the narratives that using lots of water has a psychological impact on people:

"The sense of using too much water if you know what I mean – a little bit of guilt because I am not wasting but just using more than everybody else especially when we are in a really dry State."

- Participant

"I hate seeing my garden die around me but because I can't afford to spend that little bit extra sometimes; it makes me a little bit depressed. I hate how much water I use sometimes because water is so precious, but if I need to use it, I need to use it."

- Participant

"Two things: one is that it's expensive and the second is that it is a sacred resource and I feel bad about it. But I'd like to say the second reason is the main reason."

- Participant

"There is a real need for extra water, you know and, it's not as if I'm wasting it; we are trying to save it. We are trying to improve, we are trying to save it but we are battling against it because, especially someone with autism, they don't have the skill to turn the tap off quickly and every time he does it, I think that's another litre and I write it off in my head, but it adds up, I'm sure it adds up all the time."

- Participant

6.2. Water as an expensive commodity

We asked participants about how high water use impacts upon their lives, either financially or otherwise. Four participants spoke about being unable to participate in the community because water costs are too high, or of not being able to afford other items because paying for water was a priority.

"I've just paid one actually, it was \$607 for three months."

- Participant

"Less money for our things. We probably stay at home an extra night per week. Less money on petrol."

- Participant

"I'm the only one that works so I know that our water bill is going to be around that mark so to me it means that I need to make sure I have \$200 per month to put in the account. So it puts restrictions on other things, so the person likes to go to the movies but that's the sort of thing that we go 'we can only do this once a month' because of the cost, it just means that we have to be very tight with our budgeting."

- Participant

"Money is limited, only on a pension. I have sacrificed enjoying alcohol and don't go out. Have financial hardship, the children need food on the table and the kids can't always go on school excursions because there is not money for extras. We tried to put in solar heating on property to make bills cheaper and don't use the air-conditioner. The impacts are great."

- Participant

6.2. Water as an expensive commodity cont.

The following account shows a range of issues that can influence a customer's perceptions of water cost:



Participant four

Personal profile: 64-year-old living with Multiple Sclerosis and lupus

Housing profile: Living alone as an owner occupier of a house, has support workers daily at the house

"I use 364 litres a day. Only me. Comes under medium on form. Fits in on medium for one person. To me, is false reading because I buy bottled water to drink. If it is a major wash my carer takes home to wash, or I go to the laundromat. I try to keep it under control as much as I can because being on a DSP, you really have to be careful. Because if your water bill gets too high, you're in trouble. Try to conserve as much as I can. Because I'm on such a small income and have a mortgage on house. Buy medication and unforeseen things then I would really struggle to pay water bill. I put some money each fortnight on pension. I have to put about \$20 – 30 per fortnight to pay bill. But, if I leave the taps on, or had a leakage then I would be in lots of trouble, like if my bill got bigger than what it is I would be in trouble."

6.3. Water as an essential commodity

We asked participants what impact a water disconnection has had or would have on their lives. We asked about both a disconnection for a day and a disconnection that lasted longer. Participants responded with horror at the prospect of not having water supply and detailed the impacts that that would have on their daily lives. This included both health and wellbeing and also the practical considerations that they are less able to easily leave their homes and go and stay in temporary accommodation. The responses below are useful to show how water is viewed as a necessity in people's lives and that the thought of a disconnection causes genuine anxiety and concern.

When asked what impact a water disconnection would have, 4 of the participants were very clear about how dependent they are on water as an essential service:

"No idea, I wouldn't be able to go to hospital because they don't cater to me and my sister's needs. We'd be pretty much screwed."

- Participant

"Oh my god, I probably wouldn't be able to cope and wouldn't know where to go to get support with that. Drinking water I can get but to shower and wash would be extremely difficult. Being people living with disability, we don't lead ordinary lives but we do live an ordinary life. To be able to keep on with routines, and things like that I wouldn't be able to do those routines. I would get quite upset about not being able to clean. A week would be a long time. I don't have any family that I could stay with, could ask carer but wouldn't be able to stay with them."

- Participant

"Disconnection would have a huge impact – it would be devastating because the baths and spas are pain relief and so it would be devastating without water."

- Participant

We document a case study below of one participant's experience of a water disconnection.



Participant five

Personal profile: 51-year-old man living with muscular dystrophy

Housing profile: Living alone and has lived in the same house for 20 years, cannot access his water meter, uses 18 kilolitres of water per quarter.

"In summer I have shorter showers, in winter longer showers – weather is colder it takes longer to warm up and a warm shower does help my condition and helps my breathing as well. The impact of a disconnection would be huge. About a month ago I had one day that they turned the water off overnight without letting me know. I think it was a water leakage in an adjoining street so they closed the water off overnight and for half a day and that impacted my shower and going to the toilet and so there was a hygiene issue as well. If the disconnection had gone on longer I would have had to leave the house."

It should be noted, however, that 24 participants stated that they had thankfully not experienced any disconnections to their water supply or had received adequate notice if there was one.

Fifteen respondents rated priority notice of water disconnection a 7 ('very important') on the 1-7 rating scale. This was the most important thing to them in terms of planning. The more notice the better and participants suggested that a number of modes of communication be used to notify them of a possible disconnection.

7. Managing water usage

Participants were asked a number of questions about how they manage their water use in terms of reading and understanding their water bills, access to their water meter, communication with their water supplier and the impact, if any of the National Disability Insurance Scheme. This gave an indication of how much control people felt they had and the information they were able to access in managing their water use.

7.1. Understanding the water bill

Three participants stated that they are unable to read their water bill and three participants stated that they struggle with understanding their entire water bill. They suggested the provision of an Easy English version of the water bill with simpler wording that is easier to read and understand. It was suggested that perhaps bigger font could be used, with more symbols and additional lifestyle options within the chart.

"I'd really like clarity of bill so I can control the money I put in it but with the cognitive disability, I can't. It's all small print so I'd like larger. Easier to read and negotiate."

- Participant

"I don't think that well, not that user friendly. Plain English, don't think it's that great, comparing with your quarter for previous years, doesn't mean you can look as easy from one bill to the previous bill. I would rather this is how far you're up/down from this quarter last year. 4-page document whether it could be reduced to 2 tidied up a bit."

- Participant

"To a degree I am. I know they do as much as they can and they give you the comparisons on the back about the large garden and the number of people, which is interesting but the actual meter readings itself, is just like figures and KL and L and all the readings. I am just like WHAT? That part is the nitty gritty that people need to understand. It's just not good."

- Participant

7.2. Reading the water meter

While water meters remain the property of the water companies and they visit properties to inspect, maintain and repair or replace it as necessary, there remains a general assumption that people are able to access and read their water meters, and are therefore able to easily access information about their water usage.

For example, the SA Water website has the following instructions⁵:

"When you have located your meter, lift the cap to see the display. Not all displays are the same, but all meters are colour coded to indicate litres and kilolitres.

In this diagram, the black and white numbers represent kilolitres (one kilolitre is 1000 litres) and the red and white numbers represent litres."

Eleven participants interviewed, however, told us a very different story and that this assumption that people can read their water meter is in fact far from the truth.

"I know where it is but it is in the far corner of my front yard but in a wheelchair I can't access it. No, I have never looked at it and I don't know how to read it either. I've never seen it in 20 years."

- Participant

"I do know where it is but being in a wheelchair I can't actually access it. I would have to call somebody to help, even if it was at the right height I physically wouldn't be able to turn it off."

- Participant

This made things extra difficult when participants suspected that their water reading was inaccurate:

"That to me, is a false reading because I buy bottled water to drink and if it is a major wash often my carer takes my stuff home to wash, or I might go to the laundromat."

- Participant

9 <https://www.sawater.com.au/residential/your-meter/reading-your-meter> (accessed on 24 July 2019)

7.3. Getting notice of a water disconnection

Participants stated the importance of receiving notification that water was going to be disconnected. This was crucial for planning for people living with disability who cannot easily locate to alternative accommodation. We have noted above the impacts that a water disconnection would have on many of the participants interviewed.

"If it's a couple of hours, no big deal. Any more than 12 hours, then advance notice would help so if they know there's going to be a disconnection then you can usually work around it. Notified via letter or email or text. Letter is usually easiest for me."

- Participant

"He wouldn't be able to have showers and that's where the stress and anxiety would kick in and his behavior would impact the whole family. He doesn't have the ability to understand that the water is cut off, we have no water for 24 hours. He doesn't have the capability to understand that sort of concept."

- Participant

"A nightmare and because I live with disability I can't easily go to a friend's place and I can't, a lot of accommodation in hotels doesn't work either because they don't have the set up that I've got to make it easy to do so the beds would be different, the access would be different. I have the same support people to do that, you know, it would be a huge impact."

- Participant



Participant six

Personal profile: Family member of 19-year-old who lives with autism

Housing profile: Living as a family of four in a house with a medium sized garden, no support workers

"Our son has 5-6 showers per day that last 20 minutes. Also when he washes his plate the water is running full on whilst washing and drying. Same when filling water bottle. Trying to do it for him takes a longer process. He would just have a meltdown if he turned on the shower and there was no water, he would have a breakdown. He wouldn't be able to have showers and that's where the stress and anxiety would kick in and his behaviour would impact the whole family. He doesn't have the ability to understand that the water is cut off, we have no water for 24 hours. He doesn't have the capability to understand that sort of concept."

8. Solution improvements

8.1. Understanding the water bill

As mentioned in the methodology, participants were asked to complete a rating scale questionnaire consisting of five ideas that could help with high water usage.

For each idea, participants were asked to rate how helpful each idea would be in addressing their high water use. Participants were asked to rate each idea on a scale from 1 to 7 with 1 being not very helpful and 7 being very helpful.

We have focused on those recommended improvements that attracted the highest number of 7s from participants. These are set out in the table below:

Recommended improvement	Number of participants reporting the top score of 7
Concession	15
Priority notice of disconnection	15
Priority needs register	14
Installation of a smart meter	10
Water bill in plain English	9

Since many participants rated multiple ideas as very helpful, participants were also asked which of the 5 ideas would be the most helpful (if they had to choose only one). As shown in the table below, 12 participants stated that a concession would be most helpful in regards to water usage, 3 people stated priority notice as being most effective, and 3 people identified installation of a smart meter as being most effective and 2 people identified a water bill in plain English as being most effective. Two participants answered both a concession and priority notice as being most effective in terms of assistance. Seven participants did not answer the question.

Recommended improvement	Number of participants selecting this as the most helpful
Concession/Rebate for excess water usage	12
Priority notice of water disconnection	3
Implementation of priority needs register	3
Installation of a smart meter	2
Water bill in plain English	2
Concession and priority notice	1
Unanswered	7

8.2. Concession/rebate for water usage

All state governments offer a water concession to people with an eligible card such as a Pensioner Concession Card or Health Care Card (noting that, while owner occupiers are always eligible, eligibility for tenants varies by state). In South Australia, the concession is administered by DHS, applied to both owners and tenants, and is calculated at up to 30% of the annual water bill (subject to a maximum amount of \$310.70) and up to \$115.90 of the annual sewerage rate⁶. In addition, Housing SA may pay part or all of a tenant's water use invoice if someone in a tenant's household has special needs that contribute to exceptionally high water use⁷. In England and Wales, some water companies offer people on low incomes a social tariff that can provide concessions of up to 90% off water bills.

One third (1/3) of the participants stated that they received a Disability Support Pension but only four of those currently received any rebate for water. Some participants received concessions for electricity and indicated that they received heating and cooling rebates. Of the 30 participants, only 9 are currently receiving any concession or water rebates and many were unaware that such a concession was available.

Australian water companies typically offer flexible payment options for those experiencing financial hardship e.g. payment extension, a payment plan or individualised support. For example, SA Water has a Customer Assist Program to help customers having difficulty paying a bill⁸. However, many participants had difficulty accessing this or were unaware of it.

Most Australian water companies only offer a specific medical concession in relation to the use of home dialysis machines or other similar life support machines. For example, SA Water offers a special dispensation for home dialysis patients, providing 180 kilolitres of water per year without charge⁹.

SA Water plans to extend medical use benefits to more groups from 2024. They have to undertake some research to identify who this would apply to and establish the costs and then test the willingness to pay with their customer base. Our research shows that this should be a broad definition and apply to consumers who have high water use because of the disability they live with rather than be restricted to customers with specific medical conditions.

Most participants identified that a rebate/concession for water usage would help them most in regards to their water usage, and most said the paperwork involved in applying for concessions made it too hard. It was clear that most participants thought that there should be greater collaboration between the essential service providers so that *"one form gets you a concession for water and power"* and that one priority register should be set up by the Government for all essential services.

When asked if they would benefit from a concession or rebate for water usage, one participant said:

"Yes, I think I would. Most people living with disability would. Because we have a disability we are home more, we wash more, have showers, we probably go to the toilet more. More inclined to hang around at home." - Participant

One participant who is a family member noted that their son lives with disability but, because the house is in their name, no subsidies or concessions are awarded.

"I suppose, he is our son which means he is the one on a disability pension. Because the water bill is in our name, we don't get any discounts or subsidies. So perhaps if it got recognized that we do have someone on a disability pension in our home that we could still receive those concessions." - Participant

10 <https://www.sa.gov.au/topics/care-and-support/financial-support/concessions/water-and-sewerage-rate-concession> (accessed on 24 July 2019)

11 <https://dhs.sa.gov.au/services/sa-housing-authority/housing-policies/rent-debt-and-charges/water-policy> (accessed 24 July 2019)

12 https://www.sawater.com.au/_data/assets/pdf_file/0009/17388/SA-Water-Customer-Assist-Brochure.pdf (accessed on 24 July 2019)

13 https://kidney.org.au/cms/uploads/docs/sa_financial_fact_sheet_2017.pdf (accessed on 24 July 2019)

UK Water Sure scheme

All water companies in England and Wales operate the Water Sure scheme¹⁰, which caps qualifying customers' water bills to an average price, based on what other customers pay. Eligibility is dependent on financial criteria and having one of the following medical conditions, which causes significant extra water use:

- Desquamation (flaky skin disease)
- Weeping skin disease (eczema, psoriasis, varicose ulceration)
- Incontinence
- Abdominal stoma
- Crohn's disease
- Ulcerative colitis
- Renal failure requiring home dialysis (except where the health authority contributes to the cost of the water used in dialysis)
- Other medical conditions can be accepted if the condition uses significant amounts of water and is supported by a signed certificate issued by a Doctor or registered practitioner

The list of medical conditions is substantially broader than those typically listed by Australian water companies, and the scheme provides a guaranteed water bill cap rather than the more limited free water allowance that Australian water companies typically offer.

8.3. Concession/rebate for water usage

The NDIS website provides a response to the question of whether the NDIS pays household bills such as water: "NDIS participants remain responsible for meeting their day-to-day living costs, including rent, groceries, utilities, telephone or internet costs. This is the same for general household items such as a bed, fridge or cooking utensils. There are some limited circumstances where the NDIS may make a contribution to these costs. This is in cases where the participant only incurs the cost because of their disability or their costs are substantially higher because of their disability. For example, a participant with limited mobility requires a modified bed to prevent bed sores¹¹." This reasoning could be applied to cover the cost of modifications to the home with regard to managing water, taps, assistive technology, installation of smart meters or hydrotherapy baths. If a hydrotherapy bath is installed as an NDIS home modification to provide treatment then the NDIS should also help with the water costs of using the bath.

"There should be allowances for home hydrotherapy in the NDIS where it has health benefits and alleviates pain and also the benefits of organic gardening should be recognized."



Participant 7

Personal profile: Aged in 50s, family member of person who lives with muscular dystrophy

Housing profile: Owns a house with a large backyard, installed a hydrotherapy bath

"We have a hydrotherapy bath we bought in from Sydney and you can sit in it and immerse in it, depending on if someone is here to help my husband get out of it. One of the reasons we don't use it a lot is because we thought that the rain water tanks we got would be able to be plumbed in it but that is going to be too expensive.... So about twice a month at the moment but he would benefit from using it weekly. Some financial assistance would be nice and then that way my husband could have more hydrotherapy baths at home when he doesn't feel like going to hydrotherapy at a pool if he is feeling unwell or just fatigued."

¹⁴ <https://www.citizensadvice.org.uk/consumer/water/water-supply/problems-with-paying-your-water-bill/watersure-scheme-help-with-paying-water-bills/> (accessed on 24 July 2019)

¹⁵ <https://www.ndis.gov.au/participants/housing-and-ndis> (accessed on 24 July 2019)

8.4. Smart meters

Many participants thought that a smart meter would assist them in managing water use. Smart meters are devices that measure water usage like a conventional meter but are able to log the data at regular intervals (e.g. hourly) and then send the data to a computer dashboard (usually daily). This means that both the customer and the water company can view water usage information online without having to physically look at the meter.

Most Australian water companies are at least piloting use of smart meters, but they are more likely to be offered to business customers than residential customers. In South Australia, smart meters are only currently available in Adelaide CBD and in Penneshaw, Kangaroo Island¹². In the UK, water companies can choose whether or not newly installed meters are smart, and they can forcibly install meters in water stressed areas (e.g. South East England)¹³. For example, Thames Water is fitting smart meters for all of its customers, starting in London¹⁴.

Advantages of smart meters include:

- Accurate meter readings without the water company having to visit your property
- There is no need to ever have to physically access the meter yourself to view usage
- It being much easier to identify leaks as usage can be tracked by the hour
- The ability to set alarms to highlight excessive water use and to track usage on an ongoing basis, reducing the likelihood of bill shock
- The ability to see which times, days and seasons water usage is highest and use this information to try to reduce water usage – and the ability to track the impact of efforts to reduce water usage
- Reduced water usage – Thames Water claims customers use 12% less water on a smart meter (although it is unclear if the comparison is against customers on a standard meter or against customers with no meter at all)¹⁵.

The main disadvantage of smart meters is the potential additional costs from the water company for installation and maintenance of the devices.

For people living with disability who have high water use, smart meters may help them to reduce their discretionary water use but they are unlikely to help them to reduce water use that is necessary to manage a condition. However, smart meters can at least provide more transparency on usage so that large bills are not unexpected.

SA Water Smart Water Network

SA Water has been trialling Smart Meters both for business and residential customers. They explain the benefits of this technology on their website:

“The Smart Water Network has seen SA Water invest in technology and install sensors to monitor water pressure and flow across Adelaide’s central business district. Smart meters were also installed for business customers to help them better manage their water use and costs.

The combination of this technology has improved how we identify leaks so we can fix them while the city sleeps, minimising service interruption and commuter delays, while also demonstrating how customers can benefit from receiving smart meter data via our customer portal, mySmartWater.

Leading the way, starting with Penneshaw:

“The smart water network is now evolving. In Penneshaw we are installing flow and pressure sensors, plus 300 smart meters for residential and business customers, making it the first complete South Australian community to be part of our smart future.

The pilot will help improve our understanding of the supply network so we can detect, prioritise and repair existing faults within the network. Penneshaw customers will also have the opportunity to better manage and understand their own water use, while also detecting leaks within their own water system, with a smart meter and mySmartWater access.

We will test and investigate all aspects associated with this technology, with a dedicated team on hand to provide Penneshaw customers with a great experience¹⁶.”

¹⁶ <https://www.sawater.com.au/residential/penneshaw-smart-meters-pilot-program> (accessed on 24 July 2019)

¹⁷ House of Commons Library – Water meters: the rights of customers and water companies June 2019 (accessed on 24 July 2019 via <https://researchbriefings.files.parliament.uk/documents/CBP-7342/CBP-7342.pdf>)

¹⁸ <https://www.thameswater.co.uk/my-account/water-meters/more-information/Why-are-we-fitting-meters> (accessed on 24 July 2019)

¹⁹ <https://www.thameswater.co.uk/my-account/water-meters/more-information/what-is-a-smart-meter> (accessed on 24 July 2019)

²⁰ <https://www.sawater.com.au/current-projects/smart-water-network>

SA Water has also completed some formal research to test for future services for Smart Meters. This came out from the Wider World program and was incorporated into a recent Smart Meter sizing report that it commissioned:

“A smart water meter is installed and you get access to an easy-to-use secure online dashboard, with alerts sent to you (any anyone else relevant) through SMS and/or email. The dashboard is accessible on mobile phones, tablets and computers¹⁷.”

SA Water tested carer alerts with both unpaid carers of elderly people and people with a disability (tested with 224 respondents) and with businesses (100 respondents) that are aged care facilities, disability care facility or other type of residential care facility:

“Data from smart water meters is used to let carers or those who look after someone know when something may have gone wrong – this includes alerts to continuous water usage (tap not turned off), no usage (hasn’t used water for a specified period), or irregular usage (a lot more or less water is used, or used at times when there is usually no usage¹⁸.”

8.5. Priority Needs Register

Throughout the UK and Ireland, water companies typically have a free priority services register that allows people to indicate they need extra support, whether relating to age, ill health, disability, mental health problems, financial worries, language barriers, etc. This relates to prioritisation during water outages but also to methods of communication (e.g. reading meters or bills, concerns about unwanted callers). In England and Wales, Ofwat (the economic regulator of the water sector) sets out guidance to the water companies on the services they should offer to customers who need extra help¹⁹.

There is an ambition in the UK that, by 2020, there will be a fully joined approach to Priority Services for Energy and Water companies that will see data and registration of Priority Service

customers shared (where consent is given) across Energy and Water companies in the UK²⁰.

When we asked participants if a similar register would be helpful in South Australia, 14 respondents rated priority needs register a 7 on the rating scale.

“Yes (to a priority register), this would alleviate anxiety about what would happen if water disconnected.”
- Participant

8.6. Notice of disconnection

In addition to financial medical concessions, Australian water companies may provide priority treatment during outages (e.g. advance warning, priority reconnection), but these appear to be restricted to the same medical reasons, such as for those who use home dialysis machines²¹.

As noted previously, participants living with disability needed prior notice of disconnection where possible.

“If it is a disconnection do what you do with electricity. Maybe have a ruling like with Telstra, can’t totally disconnect if you live with disability or on DSP. We really need to have people we can approach quickly. Some access to water.”
- Participant

“It is such a wonderful privilege to just turn taps on and water comes out. Life without it would be so hard. It is never more obvious than when it is disconnected.”
- Participant

Participants stated that communication is really key and that as much prior notice and information as possible really assists with planning.

Participants were more concerned that they actually receive notice rather than the method of notice. Some participants suggested a text message and regular updates would be very beneficial and that the priority needs register would alleviate anxiety about whether or not they would be notified.

21 <https://www.sawater.com.au/news/sa-water-shapes-industry-leading-support-for-customers-living-with-disability>

22 Ibid

23 <https://www.ofwat.gov.uk/households/customer-assistance/special-assistance/> (accessed on 24 July 2019)

24 <https://www.water.org.uk/news-item/water-and-energy-join-up-to-give-more-help-to-customers/> (accessed on 24 July 2019)

25 See, for example: https://www.citywestwater.com.au/help_support/customers_special_needs.aspx (accessed on 24 July 2019)

"Yes, that would be a marked improvement. If they did email and text that would be great, we would get the message."

- Participant

"Advance notice would help so if they know there's going to be a disconnection then you can usually work around it. Notified via letter or email or text. Letter is usually easiest for me."

- Participant

Other participants stated that water retailers really need to go beyond just giving notice of a disconnection and provide temporary relief for residents who can't easily move out of home to alternative accommodation. This might include delivery bottled water in the interim, especially in the hot summer months.

"It would be good if we could a) get clean water in interim b) be communicated to tell us when it was coming back on."

- Participant

"Have water restored or some sort of way to help manage laundry that would need to happen very frequently. Have drinking water available or have known where in the community I could get that from."

- Participant

8.7. Co-design

SA Water has initiated a program of work called Wider World to design and deliver much needed changes and truly make a difference in the lives of people living with disability when it comes to their essential water services.

By working across government agencies and engaging widely with stakeholder groups, SA Water are now identifying solutions that are both viable and feasible. Its approach has been recognised by the Department of Human Services as being significant, and they are now looking to take the methodology across other government agencies.

The participants we spoke to were clear that their voices as consumers living with disability and their families also needed to be heard loud and clear in any policy or operational decisions.

"There's a lot of information that needs to go to the right authorities and I'm happy to provide it. I think it's important for them to realize that a good rebate for someone living with a person with a disability is essential because were not using it for the fun of it. It's actually just extra usage for the person who has that problem. There is a real need for extra water, you know and, it's not as if I'm wasting it - we are trying to save it."

- Participant

9. Summary and recommendations

Underlying the experiences reported here is the sense that in the delivery of services like water, the experiences and needs of customers living with disability are often not well-heard or understood. This can lead to perceptions by those customers that water services are expensive, inaccessible, poorly communicated, and inflexible.

Our interviews with consumers living with disability and their families document the real life experiences of water use, how important water is to people's quality of life and some of the stresses that come with managing water use. Based on the stories told here, we propose a number of recommendations to improve water service delivery for people living with disability and their families.

Recommendation 1 Expand the eligibility of water bill medical concessions to cover any medical condition or disability that creates the need for significant extra water use, whether or not this use is therapeutic, and automate the process for receiving a concession.

Recommendation 2 Work with the National Disability Insurance Agency (NDIA) to resolve an approach for subsidising water costs for NDIS participants in SA where National Disability Insurance Scheme (NDIS) funding is being used for home modifications such as hydrotherapy baths.

Recommendation 3 Implement a single Priority Needs register for all essential services across SA that allows any customer to indicate the extra support they need (whether relating to disability, ill health, mental health, age, financial worries, language barriers, etc.) and is taken into account by essential service providers in all interactions with that customer (including in relation to outages).

Recommendation 4 Implement a standard requirement around the minimum notice period for scheduled works that involve the disconnection of water (e.g. Two weeks where possible and 48 hours minimum) via various modes of communication such as letter, email, hand-delivered mail drop, and SMS.

Recommendation 5 Review the accessibility of water meters and look at the availability of assistive technology to make them accessible including free re-siting of meter, help reading the meter and extra meter reads.

Recommendation 6 Continue to increase the availability and accessibility of Smart Meter technology.

Recommendation 7 Make water bills more accessible by offering a variety of formats such as Easy English, bigger font with more symbols, a relay service, braille, audio bill, and talking bill and additional information in the household comparison section.

Recommendation 8 Establish an advisory group of people living with disability who regularly meet with water retailers and the Energy and Water Ombudsman SA to consider issues and design improvements.

Recommendation 9 Utilities policy-makers, legislators and regulators demonstrate careful regard for the findings of this report, so that policies, legislation, and regulations are properly responsive to the diversity of water consumers and the particular issues faced by consumers living with disability.

10. Concluding remarks

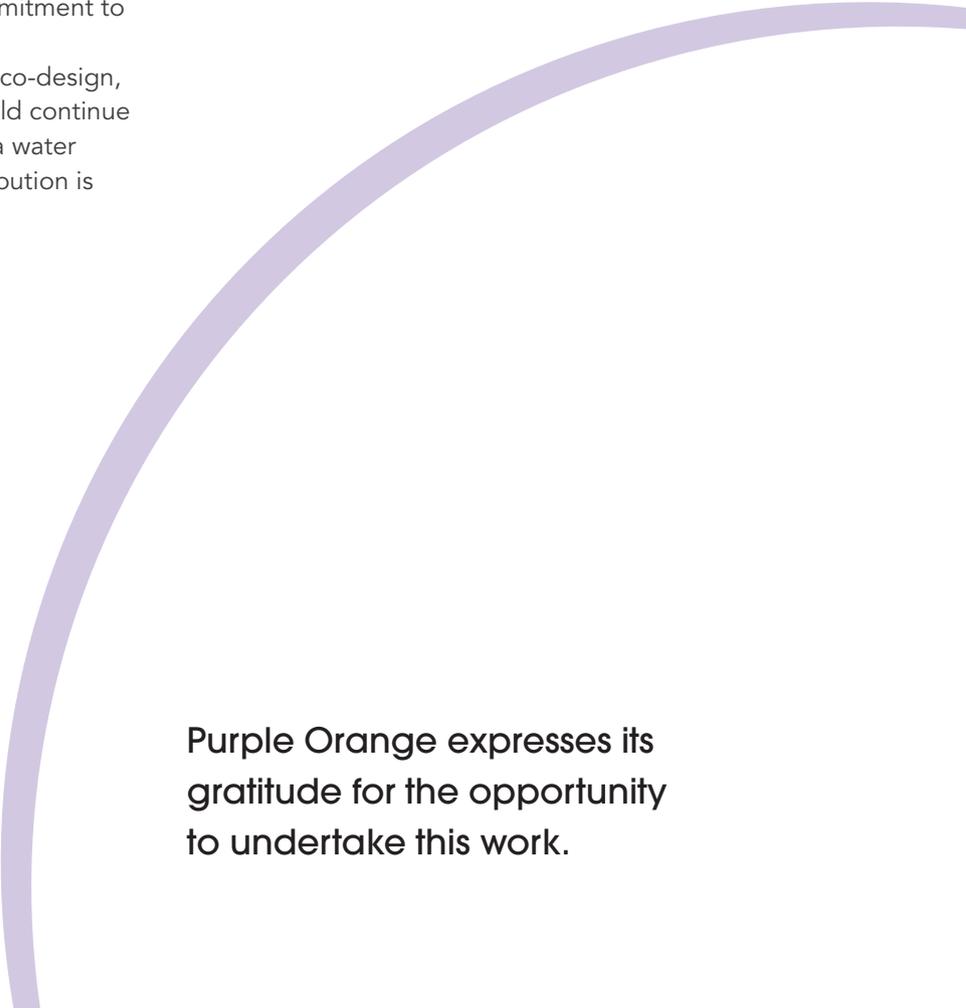
This project was funded by the Consumer Advocacy and Research Fund as constituted within Section 87 of the *Water Industry Act 2012*. The water consumers who participated in this project were pleased to be involved and keen to document the particular conditions influencing their water use. The participants felt that this Purple Orange project was therefore important and significant.

“It has been a very easy and worthwhile process – a very important piece of work. Good incentive, government needs the information, they know the reality but they need to hear it from us.”

- Participant

We found that the consumers involved in this project were very constructive in their contributions and provided valuable suggestions on how current practices could be improved in the future. The key message is that a coordinated approach across all essential services would be helpful and that it might be more efficient and effective for the water company to provide a rebate, reflecting that company's commitment to diversity and inclusion

We strongly believe that ongoing co-design, consultation and communication should continue with people living with a disability as a water consumer group, and that their contribution is essential in future priority projects.



Purple Orange expresses its gratitude for the opportunity to undertake this work.

11. Appendices

11.1 Interview questions

GENERAL CONSENT

PROJECT TITLE : Water Consumers Research Project 2

RESEARCHERS' NAMES : Kathryn Mills and Jackie Hayes, JFA Purple Orange

- I understand the purpose of the project and my involvement in it.
- I understand that my involvement in this project may not be of any direct benefit to me.
- I understand that I may withdraw from the project at any time and that my water service will not be affected if I choose not to be involved.
- I understand that while information gained during the study may be published, I will not be identified and my personal information will remain confidential.
- I understand that any feedback by way of compliments, concerns or complaints can be directed to Mr Robbi Williams, Chief Executive Officer, Julia Farr Association telephone 8373 8302; email: robbiw@purpleorange.org.au or in writing to the Chief Executive Officer, PO Box 701, Unley Business Centre SA 5061.

Name of participant

.....

Signed

.....

Date

.....

Signature of witness

.....

Printed name of witness

.....

I have provided information about the research to the research participant and believe that he/she understands what is involved.

Researcher's signature

.....

Date

.....

Interview questions

What is your age?

.....

Are you a person living with disability or a family member?

.....

.....

Are we able to have a look at your water bill?

.....

How many people do you live with?

.....

Do you live in a house, unit, townhouse, etc.?

.....

What size is your garden, for example small, medium or large?

.....

.....

Do you have a pool or is there anything else you might use a significant amount of water for?

.....

.....

Are you the owner or tenant of the place you live?

.....

.....

What is your postcode?

.....

Do you currently have a concession for other essential services, for example electricity??

.....

.....



MY WATER USAGE

What do you use the most water on per week?

Do you know your average water bill per period in liters?

Why do you use more water than others because of your disability?

Does a Support Worker use water in your home for work purposes?

If yes, what do the Support Workers use water for and how much?

IMPACTS

How does your high water usage impact upon your life?

What impact would a water disconnection have to you on the day it happened?

What impact would a water disconnection have to you if it went on for a week?

MANAGING WATER USE

Are you able to understand your water bill?

Do you know how to access your water meter?

Do you know how to read your water meter?

Do you know how to contact your water supplier if you need to?

Do you get notice of disruptions to water?

Do you currently get a hardship concession or rebate for water usage?

Do you currently receive any NDIS funding to cover high costs of water usage?

If no, have you requested this funding?

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