• Setting the scene: menstrual hygiene management definition, the crisis, menstrual hygiene management and disability

• Disabling Menstrual Barriers research: aims, objectives and study location

• The Bishesta campaign: developing, implementing and evaluating the campaign

• Strengths and limitations

• Conclusions and next steps
Setting the scene

- Menstrual hygiene management definition
- The crisis
- Menstrual hygiene management and disability
Menstrual hygiene management – a definition

- A clean menstrual management material
- A private and accessible place to change the menstrual product
- Water and soap to wash the body and materials used
- Proper disposal of used materials in a safe and dignified way
- Accurate information on the menstrual cycle and how to manage it with dignity
- Addressing harmful social beliefs and taboos
Menstrual hygiene management – the crisis

• One quarter of the global population is made up of people of menstruating age
• Lack of accurate information
• UK: 14% of girls did not know what was happening when they first menstruated
• The silence fuels menstrual related misconceptions and taboos
• Lack of available, affordable menstrual products
• Western Kenya: some adolescent girls have transactional sex to obtain sanitary pads; many drop out of school
• Low and middle income countries: some people use bark, paper, sand, mud or cloth to absorb menstrual blood
• Lack of access to safe and private water, sanitation and hygiene services makes managing menstruation difficult

• People with disabilities in LMICs often lack access to water, sanitation and hygiene services, or may not have enough to meet their needs

• Menstruation and disability carry stigma in many places

• People with disabilities might face layers of discrimination when menstruating but very little evidence exists, even in grey literature

Disabling Menstrual Barriers research

• Aims and objectives
• Study site
Disabling Menstrual Barriers research aim and objectives

**Aim:** to investigate and address the barriers to menstrual hygiene management that adolescents and young people with a disability face in Nepal

**Objectives:**

1. **Systematically review** relevant literature
2. Do **qualitative research** to understand MHM for a) adolescents and young people with a disability and b) their carers in the Kavre district, Nepal
3. **Identify strategies** to improve MHM of people with intellectual impairments
4. **Develop a MHM behaviour change intervention** for this group
5. **Evaluate** the feasibility and acceptability of the intervention
Study site: Kavre district, Nepal
The Bishesta campaign

• Creating
• Delivering
• Evaluating
Creating the campaign (Feb-Aug 18)

- Followed the Behaviour Centred Design model in the study\(^1\)
- Creative team: LSHTM, WaterAid, Down Syndrome Society Nepal, KIRDAC, Centre for Integrated Urban Development, Local government mobilisers, artist, entrepreneur

<table>
<thead>
<tr>
<th>Target groups</th>
<th>Target behaviours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with an intellectual impairment</td>
<td>1. Use a menstrual product</td>
</tr>
<tr>
<td></td>
<td>2. Use pain relief</td>
</tr>
<tr>
<td></td>
<td>3. Don’t show menstrual blood in public</td>
</tr>
<tr>
<td>Carer</td>
<td>1. Provide enough menstrual products</td>
</tr>
<tr>
<td></td>
<td>2. Provide pain relief</td>
</tr>
<tr>
<td></td>
<td>3. Show love and emotional support</td>
</tr>
</tbody>
</table>

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1. Aunger and Curtis, 2015
Bishesta (‘extraordinary’ in Nepali) is a girl with an intellectual impairment, with hidden, extraordinary talents.

Whenever she needs support to understand the changes she faces when growing up, Perana (‘motivation’ in Nepali) motivates and helps her.
Delivery (Sept-Nov 18)

- Recruited 5 facilitators
- Trained facilitators
- Tested and revised campaign components
- Study population: 10 people with an intellectual impairment and 8 of their carers
- Delivered 3 group training sessions
- Household monitoring visits between group training sessions

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Baseline, process / outcome evaluation methods

• **Baseline**: structured questionnaire on target behaviours

• **Process monitoring**: attendance of group training, if the intervention was delivered as intended, use of campaign components

• **Evaluation**
  
  • Methods: structured questionnaire and in-depth interviews
  
  • Study population: 8 carers, 10 people with intellectual impairment, 5 facilitators, 3 WaterAid staff
Evaluation findings

• Progress against target behaviours
• Accessible information
• Strengths and limitations
• Conclusions and next steps
# Evaluation findings: improvements across all target behaviours

<table>
<thead>
<tr>
<th>Target groups</th>
<th>Target behaviours</th>
</tr>
</thead>
</table>
| Person with an intellectual impairment     | 1. Use a menstrual product  
2. Use pain relief  
3. Don’t show menstrual blood in public |
| Carer                                      | 1. Provide enough menstrual products  
2. Provide pain relief  
3. Show love and emotional support         |
Evaluation findings

• More people with mild-moderate intellectual impairments wearing a menstrual product and disposing of them hygienically

• Increased comfort and confidence during menstruation

“She learnt many things, she knows where to keep her pads. When I tell her to change her pads and clothes, she does them by herself, and she also washes them. She didn’t use the menstrual products before, but after the three trainings, there have been good changes in her behaviour.”

(Family carer)
“Her parents told me that she did not do anything bad, they felt that she behaved like a grown up when she was taking care of the menstrual materials.”

(Professional carer)
• Carers reported taking the young person out when menstruating because they now wear a menstrual product

“I didn’t use to take her when I went somewhere. Because if she menstruates when we are out somewhere, like in a bus, she didn’t put on the pads, then I would be in trouble. Now, we have dustbin, storage bag, shoulder bag. There have been many changes.”

(Family carer)
Evaluation findings

- Carers had an increased understanding of pre-menstrual symptoms
- Carers now respond more compassionately when the young person is upset or angry
- Carers reported being able to provide better care throughout the menstrual cycle

“Before, I used to get irritated when they got angry or upset during menstruation. I used to scold them, I thought they are not obeying me and creating problems for me...... But now after the training, I have realized that this is natural, getting angry and upset is natural.”

(Professional carer)
“She was very happy. She got to learn many new things [...] now she is more confident. She realized that menstruation was natural, and the book helped to clear those things to her. Also, the drama made her clearer.

“Before she didn't used to tell us when she was on her period, she used to sit in a corner and cry, now she tells us that, she is feeling pain, she is having high bleeding. She shares those things to us now.”

(Professional carer)
Strengths and limitations

**Strengths**

- Systematic approach
- First stand-alone MHM package for people with intellectual impairments and carers
- Campaign components could be used with different groups

**Limitations**

- Tight timeframe
- Indications of behaviour change – not actual behaviour change
Conclusions and next steps

• The Bishesta campaign is acceptable and feasible
• Needs testing at a larger scale ....needs funding
• It is an opportunity to ensure people with intellectual impairments are not left behind

“...one of the biggest problems, when they have menstruation, some of the families they tie-up the girls at home, because the girl is running here and there.”

(DSSN facilitator)
Acknowledgements

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• **WaterAid**: Thérèse Mahon, Om Prasad Gautam, Sandhya Chaulagain, Tripti Rai, Shikha Shrestha, Louisa Gosling, Erik Harvey

• **Implementing organisations**: Down Syndrome Society Nepal (DSSN), KIRDAC, CIUD

• **Supervisors**: Hannah Kuper, Belen Torondel, Shaffa Hameed

• **Advisory committee**: Robert Dreibelbis, Sian White
Parking lot
### Pilot study vs at scale costs

<table>
<thead>
<tr>
<th>Activity</th>
<th>Detail</th>
<th>Total Cost: Pilot Study (n = 10 Young People)</th>
<th>Total Cost: Scale Up (n = 1000 Young People)</th>
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</thead>
<tbody>
<tr>
<td>Production</td>
<td>Campaign components</td>
<td>$852</td>
<td>$40,410</td>
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<tr>
<td>Production</td>
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<td>Delivery</td>
<td>Group training and monitoring visits</td>
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<tr>
<td>Grand total</td>
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<td>$89,674</td>
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<tr>
<td>Cost per young person</td>
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<td>$90</td>
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</table>