



**‘Not all Disabilities are Visible’  
What Matters To You Day  
Evaluation Report**

**Wednesday 6<sup>th</sup> June 2018  
Victoria Hospital Kirkcaldy Event**



The ileostomy & internal pouch  
**Support Group**

Listen • Inform • Support

## Acknowledgements

NHS Fife's Equality and Human Rights Team wish to acknowledge and thank the Fife branch of IA®, the Ileostomy and Internal Pouch Support Group for advising NHS Fife on the subject of 'hidden disabilities' and how this impacts on people and their day-to-day lives.

We would also like to thank Grace Warnock and her mother, Judith for granting permission for NHS Fife to use 'Grace's Sign' as a starting point for our hidden disabilities signage work within Victoria Hospital Kirkcaldy. NHS Fife is the first Health Board to be granted permission to use the sign and Grace and her mother provided a huge amount of support and input to the work for What Matters to You Day (WMTY).

It was very important that this project work was led by service users with lived experience and so we are very grateful to Fife IA® for sharing their experiences, knowledge and time to help deliver the project brief and develop the approach to the subject matter.

Volunteers from the support group also kindly gave their time to attend the 'What Matters to You' Day on Wednesday 6<sup>th</sup> June (2018) to share their personal experiences, raise awareness and educate members of the public and staff on Grace's Sign, a sign being widely promoted in Scotland to help break down barriers in the use of 'accessible toilets' by those who have a hidden disability.

During the event many other suggestions were made by members of the public and staff around other hidden disability topics for NHS Fife to work on.

Claire Fernie, winner of NHS Fife's Public Partners and Friends Award in 2017 and Chairperson of Fife IA® initially raised the issue of hidden disabilities at Fife's Health and Social Care Participation and Engagement Network meeting in November 2017.

Fife IA®'s vision and drive to see the hidden disabilities project through was integral to the success of the project work that the Equality and Human Rights team set as a priority for the 2018 WMTY Day and it has opened the door for a lot more work to be done in this area.

The approach taken with Fife IA® around the project will help shape future joint work with other Fife support groups and health and social care services, including Acute Health Services.

## 1. Background to Equality and Human Rights - 'What Matters To You Day' Event

'What Matters to You Day' is a day that aims to encourage and support more meaningful conversations between people who provide health and social care and the people, families and carers who receive health and social care.



NHS Fife has a Public Sector Duty to:

- **Eliminate unlawful discrimination, harassment and victimisation**
- **Advance equality of opportunity between different groups; and**
- **Foster good relations between different groups**

## 2. Not all Disabilities are Visible

People experience many different types of hidden disabilities e.g. sensory impairments, cancers, IBD (Inflammatory Bowel Disease), stroke, mental health issues, diabetes, multiple sclerosis, etc. all of which may require them to use an accessible toilet at some point.

Fife IA® identified and designed an Equality Campaign around the key message that **'Not all Disabilities are Visible'**.

The group felt that there needed to be much work done to increase public awareness and education around different types of disabilities and the challenges that these conditions can present to people in being judged for not appearing visibly disabled.

## 3. Campaign Brief

A campaign brief was agreed that included:

- Seeking permission to use Grace's Sign from the creator (Grace Warnock) to help raise awareness of hidden disabilities and accessible toilet areas.
- Consultation with Fife IA® at one of their branch meetings.

- Equality and Human Rights Team to project manage and to maintain contact with the Branch Chair of Fife IA®.
- Link 'What Matters to You Day' (WMTY) to a planned event for Fife IA® within Victoria Hospital Kirkcaldy on the 6<sup>th</sup> June 2018.
- Fife IA® helping to co-ordinate and support the delivery of What Matters to You Day 2018 'Hidden Disabilities' Campaign.
- NHS Fife Communications input.
- Fife IA® members to sharing personal experiences to help illustrate the issues faced by people with hidden disabilities.

#### 4. About Grace's Sign

Grace Warnock is a 12 year old East Lothian school girl who designed an award winning accessible toilet sign at just the age of nine. Since then she has been campaigning for a change in signage and to raise awareness of hidden disabilities.



In 2017 Grace won the Young Scot Award in the Health category. She is also an Ambassador for Scotland's Year of the Young People 2018 and the winner of the 2018 Evening Times Scotswoman of the Year Editor's Choice Award.

Grace, who has Crohn's Disease, raises awareness of the many issues that people with hidden disabilities and long-term illnesses often have when they need to use public facilities. She identified that people sometimes faced stigma and had comments or disapproving looks if their condition was not obvious when using an accessible toilet.

Grace's Sign features a wheelchair and two people with red hearts to symbolise hidden disabilities and aims to ask people to have a heart and not judge. She is asking those who would normally comment to be considerate and think before saying something rude which may hurt.

The first Grace's Sign appeared in the Scottish Parliament in 2017, Grace hopes the sign will eventually appear everywhere. She wants toilets to be accessible for everyone regardless of what accessibility requirements they may have.

Grace's message is a very simple one.

**Please have a heart and don't judge what you may not see** ❤️



## 5. About Fife IA®

Fife IA® is the local branch of the UK registered charity the **Ileostomy and Internal Pouch Association**. We support people who have had, or are about to have surgery to remove their large intestine, leading to the formation of an ileostomy/stoma.

This can be necessary for a number of reasons, including bowel cancer, ulcerative colitis and Crohn's disease.

For 35 years, we have been offering support, information and a listening ear to those in Fife who are facing this surgery. We also have members who have a colostomy, a urostomy or more than one stoma. All of us have experienced these procedures, so **'because we know, we care'**. It is estimated that, in Fife, between 100-150 new stomas are created every year.

For the majority of ostomates, surgery takes away much of the pain and distress associated with their condition and allows them to return to living a full life. A huge factor in that is the discreet nature of modern stoma appliances, which means that you can't tell if someone has a stoma bag by looking at them. It is a **hidden condition**. From time to time, however, we may have to use an accessible toilet to manage our stoma when we are out but because we **'don't look disabled'**, unfortunately we regularly face **disapproval and abuse** from members of the public who do not realise we have a genuine need.

## 6. Public Participation and Engagement Standards

NHS Fife is committed to ensuring that Public Participation and Engagement is integral to the work of both Health and Health and Social Care Partnership services.

Claire Fernie is a member of Fife's Health and Social Care Participation and Engagement Network and raised the issue of hidden disability discrimination meeting in a Network meeting in November 2017.

Some of the Support Group members shared their experiences and added them into a poster the support group designed for the day, examples included:

**"I was told – you've no right to use that toilet!"**

**“I creep out of the accessible toilet because I am afraid of being stopped and challenged”**

**“When I asked to use the facilities I was asked for my Blue Badge. By the time I said I didn't have one and explained about my condition, I was extremely embarrassed, and so were the receptionist and the other people in the queue”**

**“When I came out, people in the area gave me dirty looks and muttered unpleasant comments under their breath. I could tell they were angry with me.”**

**“I have cut short outings and gone home early rather than use the accessible toilet and risk getting grief”**

**“I was embarrassed to be asked “What's your disability?” by someone using a walking stick”**

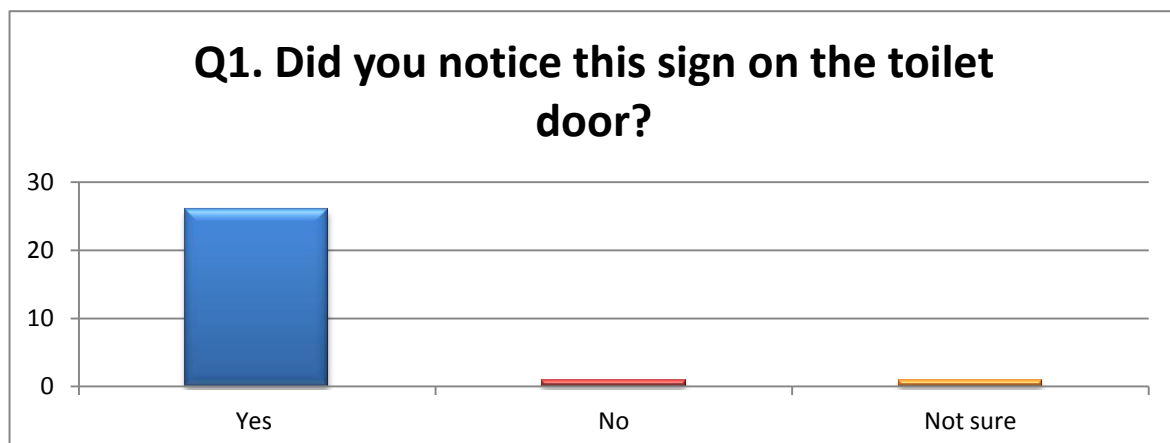
Many members of the public and staff commented on the strong impact of messages on the poster designed by Fife IA.

## 7. Results and Feedback

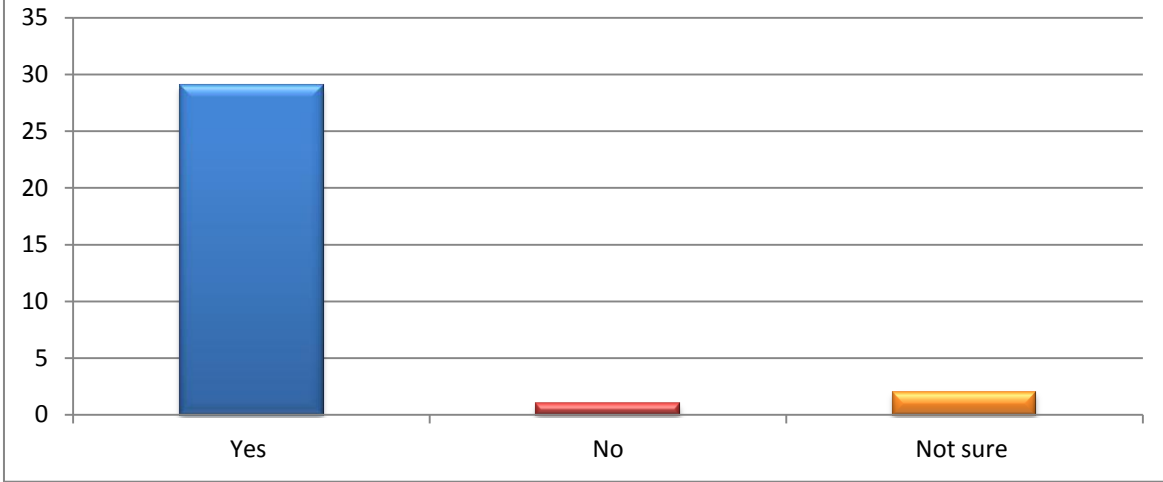
A questionnaire was developed for the day, to help gauge public awareness of Grace's Sign and hidden disabilities. The questionnaire has also helped identify other types of hidden disabilities that members of the public and around the work of hidden disabilities.

It comprised of five quick evaluation questions in relation to 'Grace's Sign' and the relevance of hidden disability awareness.

**Total Number of Responses: 32**

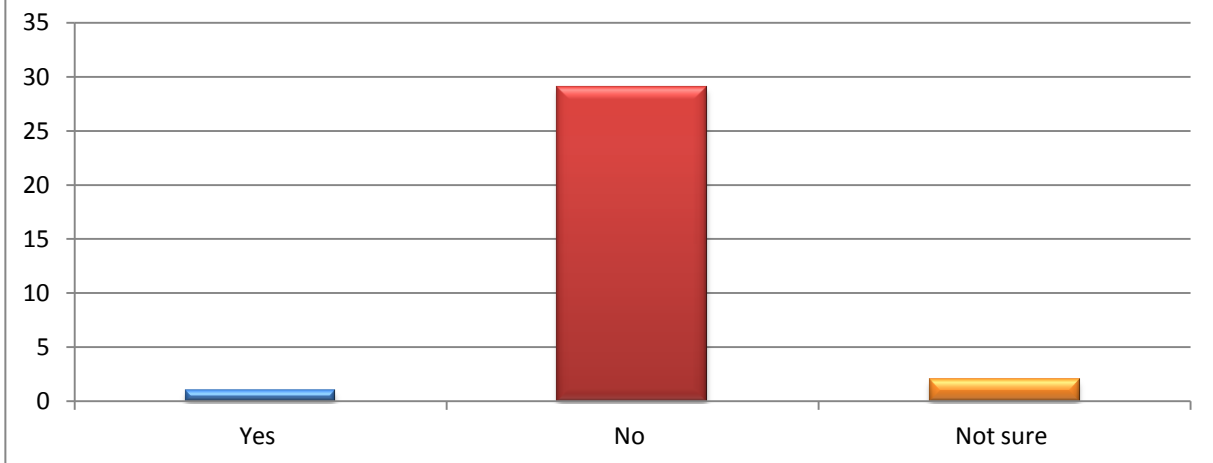


## Q2. Do you know what the sign means?

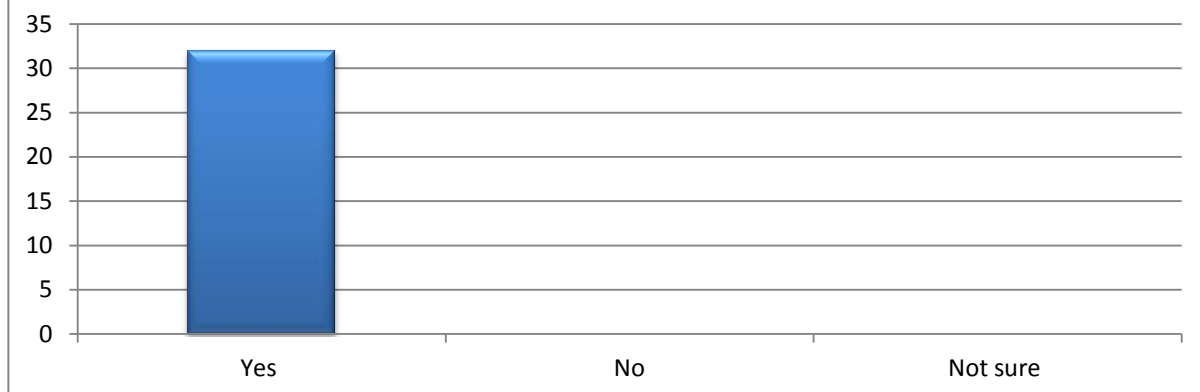


**Q3:** Had to be withdrawn from the report as it was about the Communications via staff intranet and hospital TV screens on the day which weren't available.

## Q4. Do you think there is enough awareness of issues like hidden disabilities?



**Q5: Do you think it would be a good idea to change all the toilet signs to Grace's Sign now that you know more about the sign?**



It should be noted that a number of people discussed the sign at the event stand before seeing the sign in the toilet area and/or completing the questionnaire, so some of the positive replies to questions 1 and 2 are likely due to these discussions.

## **8. Other Feedback**

Feedback on the sign was very positive and everyone who responded supported the goal of changing to using a new sign such as Grace's Sign. The 'Not all Disabilities are Visible' banner was reported to give clarification around the sign's meaning.

A number of people were confused by the heart symbols on the sign and that that they indicated solely people with heart conditions. In a hospital setting this is understandable and may need to be kept in mind when considering permanent signage in the future.



## 9. Communications

NHS Fife issued a press release and photo, created a website banner and shared information across its social media accounts highlighting the campaign.



The campaign reached 10,358 users looking at the NHS Fife Website , 190 likes/loves and 60 shares.

## 10. Next Steps

Three key actions have been identified:

1. Create a case for NHS Fife's Board highlight why the accessible toilet signage should be changed across hospital sites where it is absent.
2. Further work with staff , members of the public and patients on raising awareness of language – changing from using the term 'disabled toilets' to the more inclusive term 'accessible toilets'.
3. More work on 'hidden disabilities'

Members of the public and staff discussed the need for much more awareness, education and promotion of hidden disabilities.

Some suggestions on the day made for future topics were:

- Sensory Impairments
- Prosthetic Limbs
- Blood Cancers
- Multiple Sclerosis



Health and Health and Social Care Services are committed to ensuring there is much more understanding of hidden disabilities and how these impact on their services users.

The Equality and Human Rights Team will develop further its programme of community engagement and participation to include targeted work around hidden disabilities with Community Groups.

This work will be reported on to the Equality and Human Rights Strategy Group, NHS Fife's PFPI Committee and Fife's Health and Social Care Participation and Engagement Network.

Claire Fernie will present at NHS Fife's Equality and Human Rights Strategy Group meeting in August 2018.

**Shirley Ballingall, NHS Fife Equality and Participation Co-ordinator**

**Claire Fernie, Chairperson Fife IA**