



Centre on Human Rights
for People with Disabilities

Know the 'right' approach

A seminar for Health and Social
Care Professionals

Tuesday 28 June 2011



Centre on Human Rights
for People with Disabilities

Welcome

Kevin Doherty,
Director of Services,
Disability Action



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for People with Disabilities

Opening Address

Michelle Gildernew (MLA, MP),
Chairperson of the Committee for Health,
Social Services and Public Safety



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My life, my right, my choice

Dermot Ferris,
REAL Network

(Rights, Empowerment Action and
Lobbying)



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My life, my right, my choice

Timothy Brooker,

REAL Network

**(Rights, Empowerment Action and
Lobbying)**



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What is a disability and human rights approach to health and social care?

Dr Colin Harper,
Manager,
Disability Action's Centre on Human Rights for People with Disabilities

‘Disability’



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- Individual people may have impairments of various kinds, but it is in interaction with society that they become ‘disabled’.
- “Disability is a **social** condition, not a **medical** condition.”
- Recognise and respond to a person’s integral **humanity**, not their health **condition**.

A Human Rights Based Approach



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A human rights-based approach to health and social care draws on the principles of human rights to guide policy, practice and the design and delivery of services.

Human Rights Based Approach



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A disability and human rights-based approach to health and social emphasises:

- the right of people with disabilities to enjoy the highest attainable standard of health and social care without discrimination; and
- compliance with the **Human Rights Act 1998**

Human Rights



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- Human Rights Act
- Disability Discrimination Act
- UN Convention on the Rights of Persons with Disabilities

Human Rights Act (1998)



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- In the domestic law of Northern Ireland, our human rights are supported by the Human Rights Act (1998) which came into effect in October 2000.
- Health and Social Care providers are affected by the Human Rights Act in almost every aspect of their work.

Disability Discrimination Act (1995)



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- The Disability Discrimination Act 1995 (the DDA) and its subsequent amendments also provide protection for people with disabilities in Northern Ireland against discrimination on the grounds of disability.

Disability Discrimination Act (1995)



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- The DDA recognises that barriers exist within society, which present difficulties for people with disabilities and creates a positive duty on employers, education and service providers to make 'reasonable adjustments' to their policies and premises where reasonable and appropriate.

UN Convention on the Rights of Persons with Disabilities



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- An international agreement which confirms that people with disabilities have the same human rights as non-disabled people. It protects the rights of people with disabilities in all areas of life including health and social care, independent living, personal mobility and access to justice.

UN Convention on the Rights of Persons with Disabilities



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- The United Kingdom ratified the UNCRPD in 2009, which means that the Government is legally bound to protect the human rights of its citizens with disabilities.

UN Convention on the Rights of Persons with Disabilities



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The principles of a disability and human rights approach to health and social care are based on the General Principles in article 3 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRPD).

Principles of a human rights based approach



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- **Dignity**
People with disabilities have the same worth and value as everyone else. A rights based approach ensures that people with disabilities are treated with dignity and recognised as rights-holders.
- **Independence**
People with disabilities are independent people and should be supported to live independently.

Principles of a human rights based approach



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- **Freedom to make choices**

People with disabilities have **the right to make choices** and decisions about their treatment and care options and to be facilitated in doing so. People with disabilities should have access to appropriate **advocacy** as and when required.

Principles of a human rights based approach



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- **Non-discrimination**

People with disabilities should not be discriminated against. This does not just mean treating everyone the same. Such an approach can inadvertently violate disabled people's human rights by ignoring the cumulative effects of past disadvantage. Health and social care services should be particularly sensitive to identifying and addressing the individual needs of people with disabilities.

Principles of a human rights based approach



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- **Participation and Inclusion**

People with disabilities have the right to participate in and be as fully included in society as anyone else. Free, meaningful and effective participation by people with disabilities should be actively encouraged and facilitated. Health and social care providers and staff should actively **consult** and engage with people with disabilities.

Principles of a human rights based approach



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- **Acceptance by other people**

People with disabilities should be accepted for who they are. A rights based approach ensures that people with disabilities are treated with the same respect shown to others.

- **Equality of opportunity**

People with disabilities should have the same opportunities as everyone else.

Principles of a human rights based approach



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- **Access**

People with disabilities have the right to access the full range of health and social care services including information, communications, facilities and services, and the physical environment on an equal basis with others.

Why a human rights based approach?



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- A human rights-based approach provides a framework of core values and principles upon which services can be based. This framework supports health and social care staff in meeting their professional ethical obligations.
- Respecting and promoting human rights improves both the quality and effectiveness of health and social care, improves decision-making processes and enhances the health and well-being of all service users.

Why a human rights based approach?



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- A rights-based approach sends a message to society that people with disabilities are first and foremost equal persons with human rights.
- A rights-based approach leads to more meaningful participation and engagement of people with disabilities in the design and delivery of health and social care services.

Why a human rights based approach?



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- A rights-based approach sends a message to society that people with disabilities are first and foremost equal persons with human rights.
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Why a human rights based approach?



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- A rights-based approach helps health and social care staff to better understand the range of societal and cultural factors that impact upon an individual's health and well-being.
- A rights-based approach utilises international best practice and ensures that health and social care is available and accessible to all people on a fair basis.
- A rights-based approach reduces complaints and costly litigation.

How to implement a human rights based approach?



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- Train staff
- Share learning and lessons on good practice
- Ensure policies impact on practice
- Seek outside advice/expertise as appropriate
- Allocate key responsibilities



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Case Studies

Paul McAleer,
Health Care Facilitator,
Northern Health and Social Care Trust

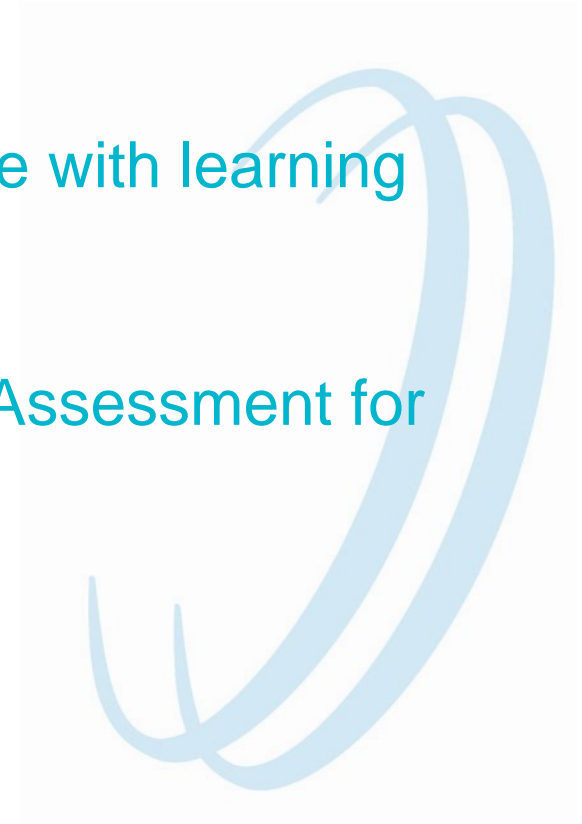
MEETING THE PRIMARY CARE NEEDS OF PEOPLE WITH LEARNING DISABILITIES

Health Facilitator
Paul McAleer



Enhanced Services

- Established in 2009 in the Northern Trust
- Currently, 7 Health Facilitators practicing in 4/5 Trusts in Northern Ireland
- Direct Enhanced Service (DES) for people with learning disabilities
- Provides Comprehensive Annual Health Assessment for People with Learning disability



SETTING THE SCENE

- **Disability Discrimination Act (1995)**
- **Same as you (2000)**
- **Valuing People (2002)**
- **Equal Lives (2005)**
- **Statement of Policy and Practice for People with a Learning Disability (2007)**



In 2006 the Disability Rights Commission stated:

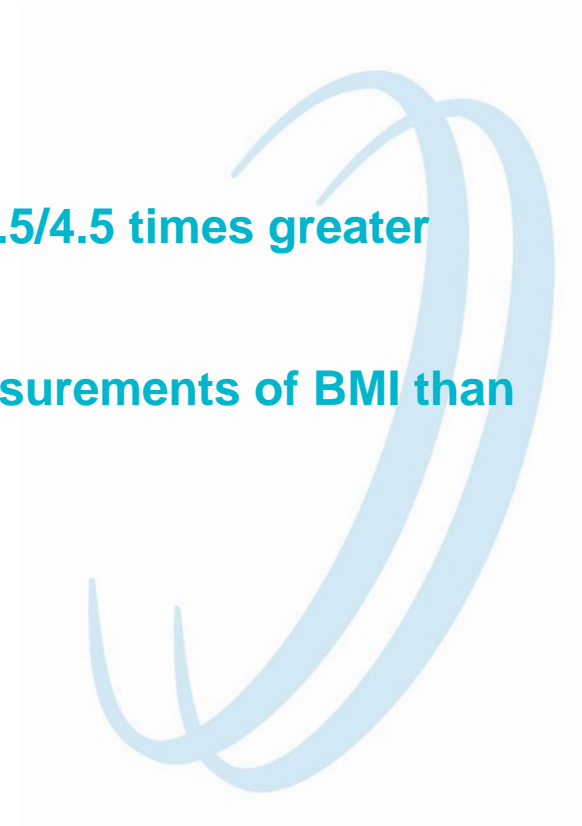
“...in England and Wales, people with learning disabilities and people with mental health problems are much more likely than other citizens to have significant health risks and major health problems. For people with learning disabilities, these particularly include obesity and respiratory disease...”**They went on to say.....**

*“In **primary care**, these high risk groups are actually less likely to receive some of the expected, evidence-based checks and treatments than other patients and efforts to target their needs specifically are ad hoc.”*

Equal Treatment: Closing the Gap, Disability Rights Commission, 2006

SETTING THE SCENE

- **Increased risk of early death. 58 times more likely to die before age of 50 years (many of these deaths are avoidable)**
- **Respiratory disease leading cause of death. 3 times higher than general population**
- **Higher rate of gastrointestinal cancer (45% v 25%)**
- **Children reported to have only fair/poor health is 2.5/4.5 times greater than non disabled peers**
- **People with LD who have diabetes have fewer measurements of BMI than non disabled**
- **Those with stroke have fewer BP checks**



SETTING THE SCENE

- **Prevalence of epilepsy is 20 times higher**
- **Less likely to access national screening programmes**
 - Cervical Screening 3-17% v 85%
 - Breast Screening 17-52% v 76%
 - Routine dental care and assessment for vision/hearing impairments
- **40% of people have additional mental health needs**
 - Prevalence rates for schizophrenia 3% v 1%
 - Prevalence rates for dementia 21.6% v 5.7%
- **People with a learning disability are less likely to be given pain relief and less likely to receive palliative care**
- **Consider the needs of those with mild LD, severe LD and demographics (those with complex needs and older people)**



Barriers to Access

- **Administrative procedures**
- **Diagnostic overshadowing**
- **Limited collaboration**
- **Attitudes, assumptions and negative predictions**
- **Limited understanding around capacity, consent and best interests**



Health Facilitation

Health Facilitation is described as;
‘the process of enabling people to understand health issues and to access mainstream health services’.
(Bernal 2006)

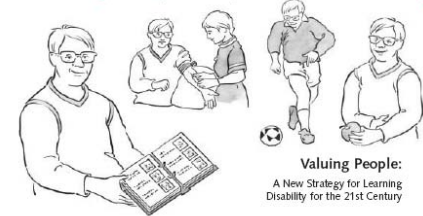
The DH divide this into 2 levels:

Level 1 = Service development work, informing, planning and commissioning

Level 2 = Person to person work with people with learning disabilities

Action for Health – Health Action Plans and Health Facilitation

Detailed Good Practice Guidance on Implementation
for Learning Disability Partnership Boards



Health Facilitation

- Comprehensive Annual Health Assessment
- Health Action Plan
- Systematic review of outcomes



Annual Health Assessments

- Provides an opportunity to ensure health needs are identified and met.
- Provides an opportunity to check & review patients Health Action Plan.
- Provides an opportunity to offer health promotion advice.
- Provides an opportunity to build relationship & desensitise any fears.



Health Action Planning

A health action plan (HAP) details:

- ‘the actions needed to maintain and improve the health of an individual and any help needed to accomplish these. It is a mechanism to link the range of services and supports they need, if they are to have better health.....’
- The plan is primarily for the person with learning disabilities and is usually co-produced with them.



Health Action Planning

- Improves sense of empowerment
- Promotes greater awareness of needs:
 - Reasonable Adjustments to practices
 - Best interests/capacity
- Better awareness of individual communication methods
- Person centred approach – puts client at centre of decision making process.



***“Every human being is the author
of his own health”***

Buddha

***“He who has health has hope, and
he who has hope has everything”***

Unknown



Thank You

Reading:

1. RCGP Clinical Innovation and Research Centre (2010): A step by step guide for GP Practices (annual health checks for people with learning disabilities. Royal college of General Practitioners.
2. Hardy et al (2006): Meeting the Health Needs of People with Learning Disabilities (Guidance for Nurses). Royal College of Nursing.
3. DoH (2009): World Class Commissioning for the Health and Well Being of People with Learning Disabilities. www.orderline.dh.gov.uk
4. Mansell (2010): Raising our Sights (services for adults with profound or multiple disabilities). Tizard Centre Kent. Printflow.
5. DoH (2008): Health Action Planning and Health Facilitation for people with a learning disability - good practice guidance. London, Social care policy and innovation Dept.
6. DoH (2001): Seeking Consent - working with people with learning disabilities. London. DoH Publications
7. www.improvinghealthandlives.org.uk/





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Case Studies

Pat McAteer,
Head of Sensory Disability Services,
Southern Health and Social Care Trust

A disability and human rights approach to Health and Social care draws on the principles of the United Nations Convention on the Rights of Persons with Disabilities to guide policy and practice and service delivery

These principles are:

- Dignity
- Independence
- Freedom to make choices
- Non-discrimination
- Participation and Inclusion
- Acceptance by other people
- Equality of opportunity
- Access



Improving Communication



News and Views

An unique concept in bringing Information to
People with a Visual Disability



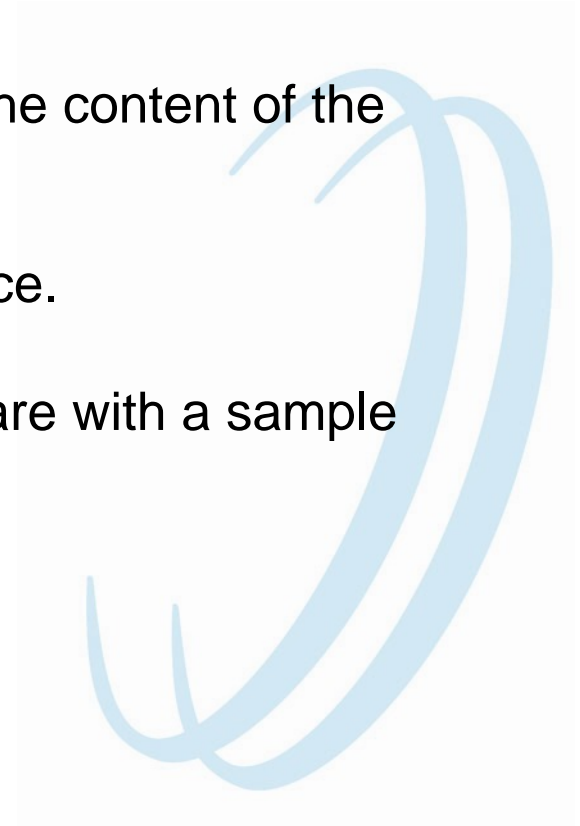
What is it?

- A Newsletter for People with a Visual Disability.
- Developed by the Visual Disability Team within the Southern Health & Social Care Trust in conjunction with service users.
- Provides relevant and up to date information to 1200 recipients twice a year.



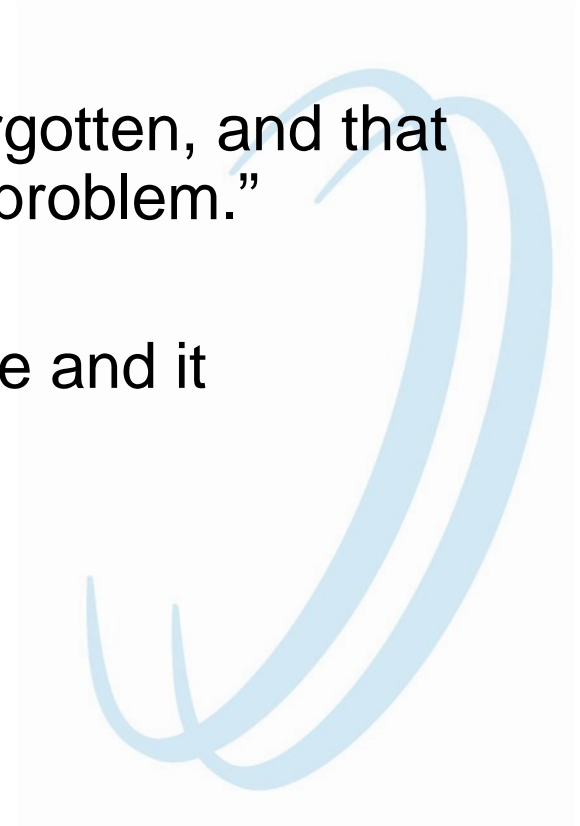
The Process

- **Information was actively sought by:**
- Sharing the idea with members of the Vision Forum
- Discussions with Voluntary Groups that support People with a Visual Disability.
- Formation of a Focus Group to provide ideas on the content of the Newsletter.
- Research any similar projects currently in existence.
- Create a draft of the proposed Newsletter and share with a sample group of service users



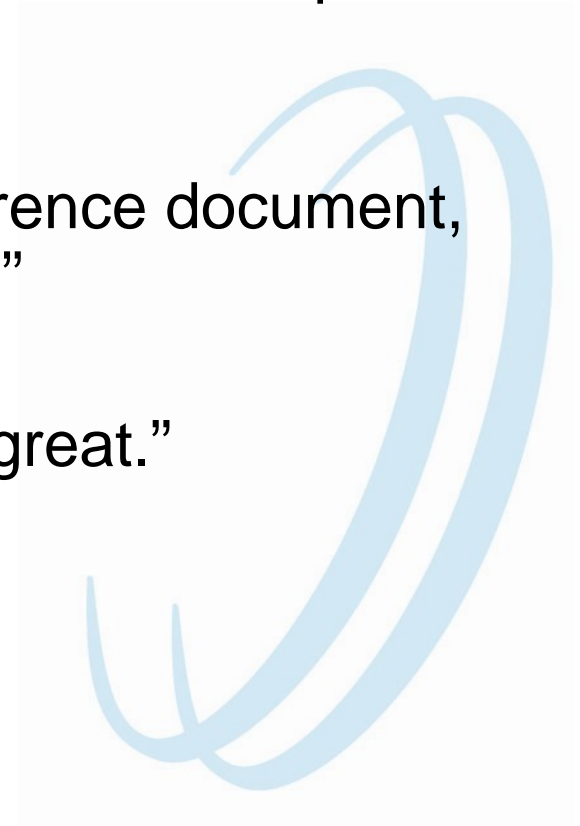
Comments

- “Newsletter is great and text was very useful... contained lots of appropriate information.”
- “It keeps me up to date with new information about eyesight.”
- “I’m glad to know that I have not been forgotten, and that someone remembers that I have a sight problem.”
- “A lot of work has gone into this magazine and it contains lots of useful contact numbers.”



Comments continued..

- “I would like it on CD as I find reading print very difficult.”
- “My family had to read it for me, could I have it on tape next time.”
- “I found it very wordy and more of a reference document, could it have more hints and tips please?”
- “When is the next one due out, that was great.”



The Next Step

- **Editorial committee** – consists of five Service Users and three members of staff.
- Identify all Service Users with a vision difficulty who are and were known to the Sensory Disability Teams.
- Identify with Service Users, the range of mediums they would require the Newsletter produced in.
- Invite feedback from all recipients of the Newsletter as to the content for future productions.



How Feedback was used?

The Newsletter is produced using a range of formats:

Large print

Audio CD

Braille

Email



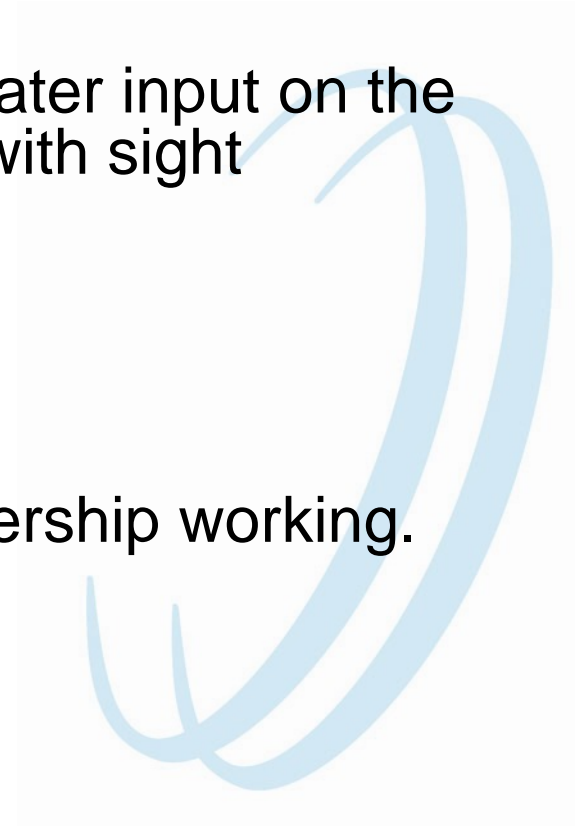
- More articles on different Eye Conditions are included in each edition.
- The style and content of the Newsletter has been changed to include more articles from service users on personal experiences.
- The Editorial Committee are responsible for the selection of all the articles which are included in the Newsletter.
- More and more Service Users contribute to its content.



Conclusion

The Newsletter has

- Enabled the Southern Trust to maintain contact with 1200 Service Users twice a year.
- Empowered Service Users to have a greater input on the range of information provided to people with sight difficulties.
- Provides a choice of format.
- Instilled a much greater concept of partnership working.



Improving Access

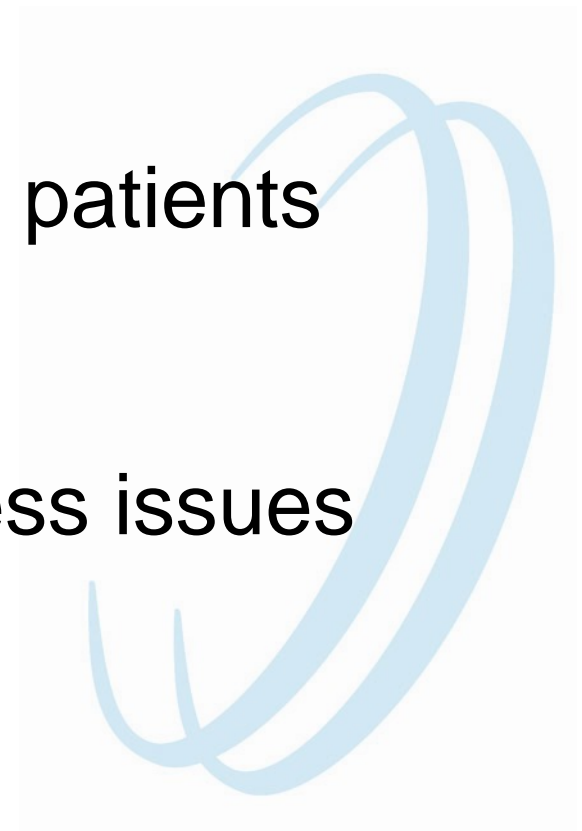


Low Vision Services Daisy Hill Hospital Newry

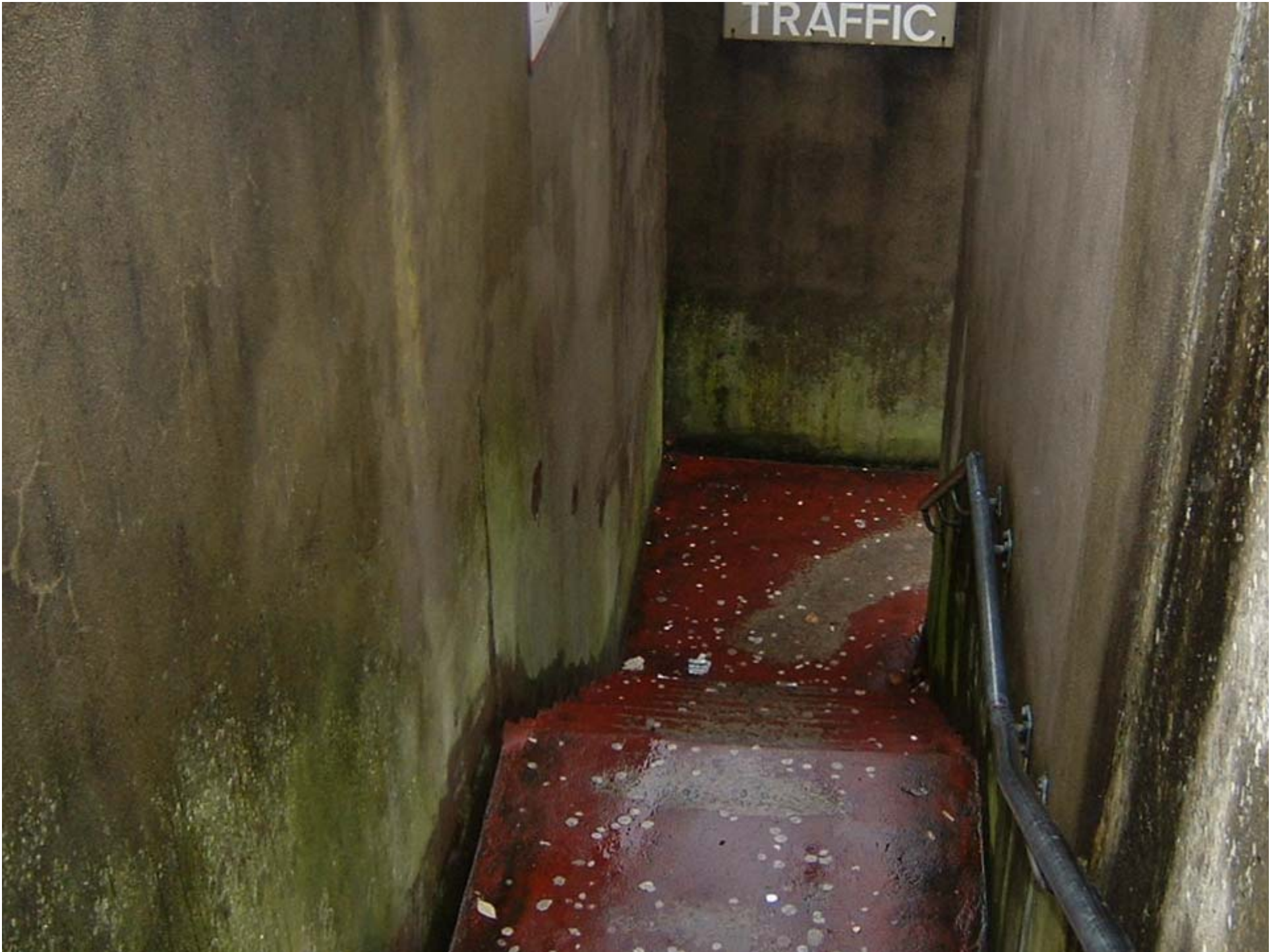


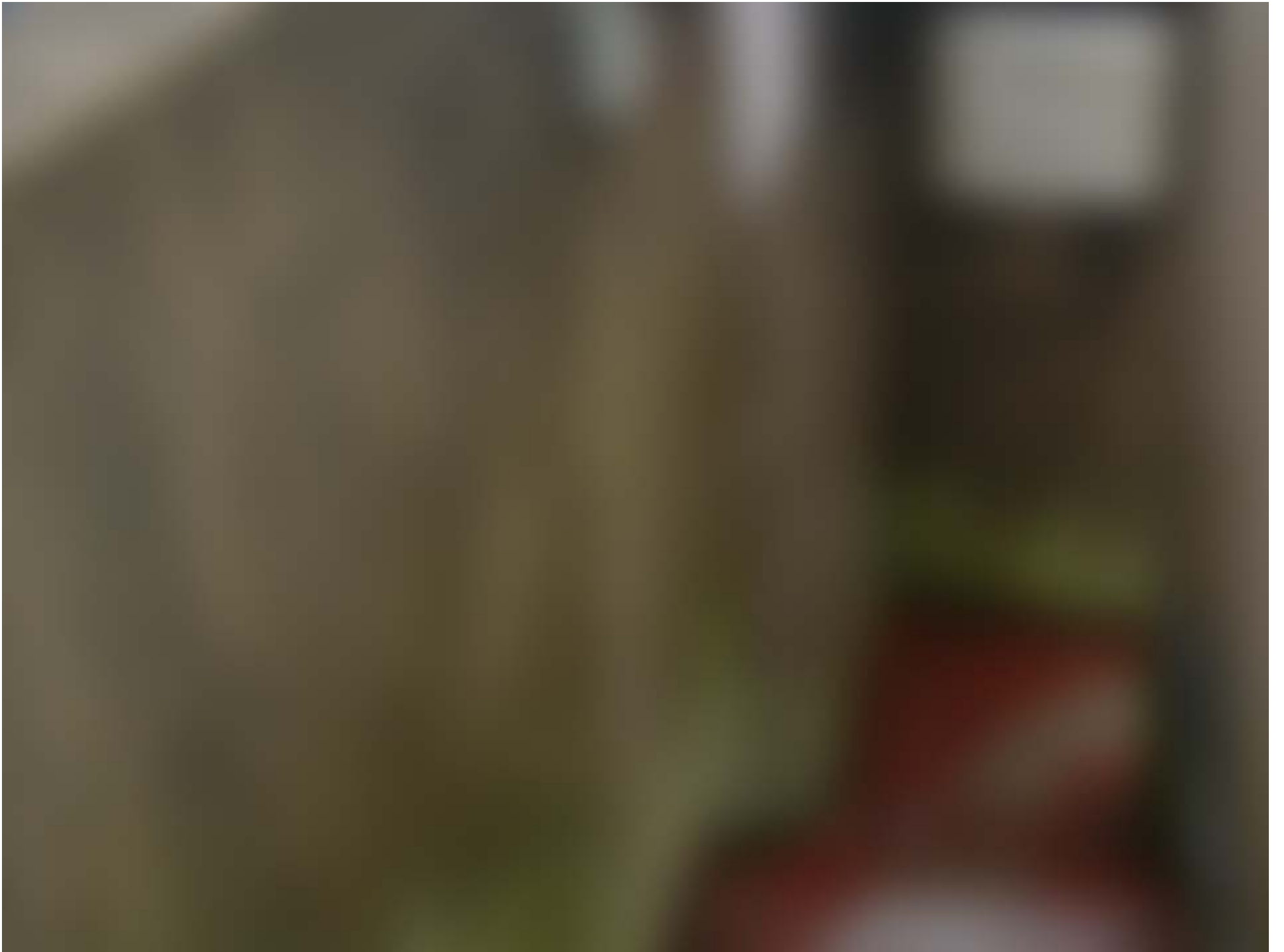
The Process

- ***Photo Journey*** –
 - Site visit with Service User
 - Carried out during busy out patients period
 - Highlighted significant access issues

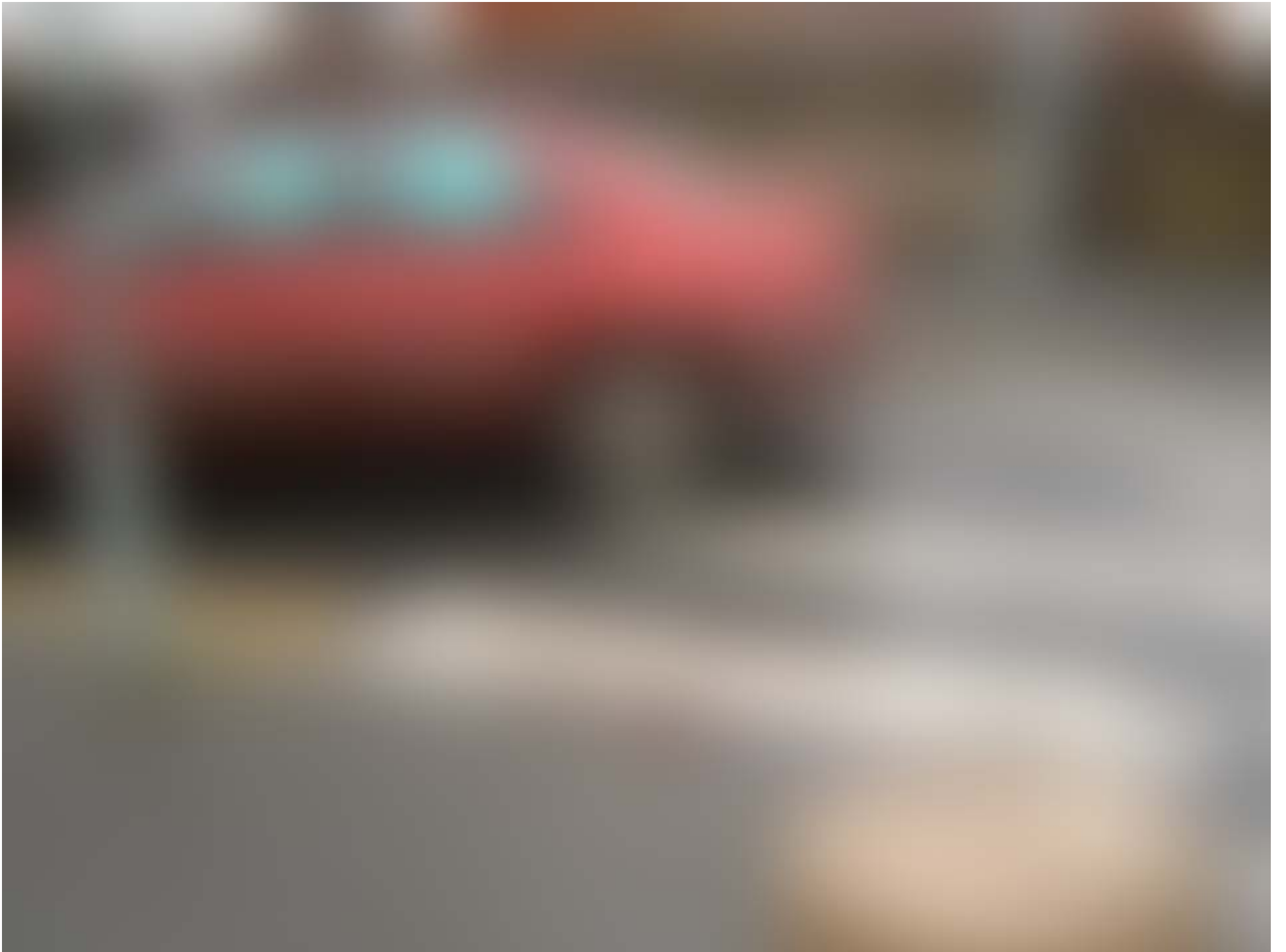


TRAFFIC











Maternity wards
Occupational therapy
Sector administration
G.U.M. clinic
General wards
Lifts
Disabled Toilets

← HAEMODIALYSIS UNIT

Accident & Emergency
Out-patients
X-Ray
Physiotherapy
Administration
Disabled Toilets
Cardiology

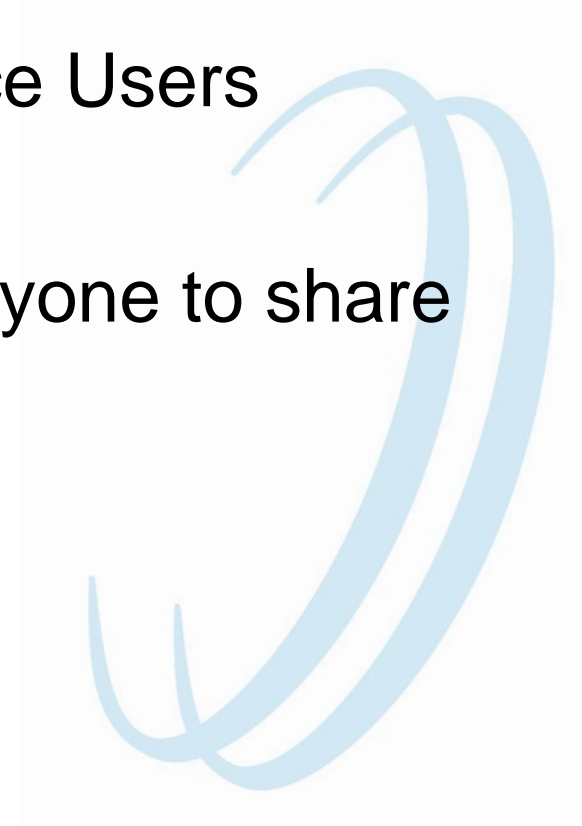
← Social Work Social Work



The Process

- ***Process Mapping*** –

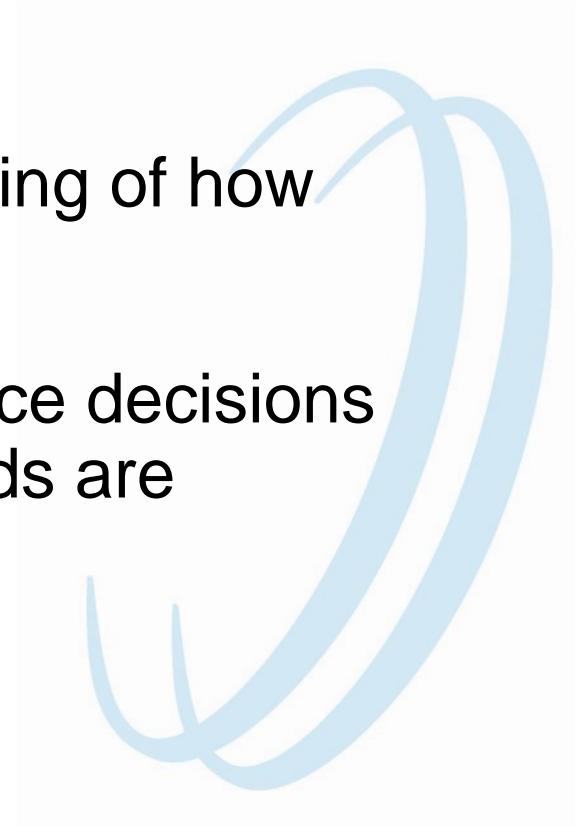
- Involve key stake holders
- 50% of attendees were Service Users
- Created opportunities for everyone to share their experiences



What's In It For Me?

By Getting Involved;

- Your Views will be listened to;
- Your opinion will be valued;
- You will develop a better understanding of how Health and Social Services work;
- You'll have the opportunity to influence decisions about how your health and care needs are planned, delivered and provided.



What was achieved?





Maternity wards
Occupational therapy
Sector administration
G.U.M. clinic
General wards
Lifts
Disabled Toilets

← HAEMODIALYSIS UNIT

Accident & Emergency
Out-patients
X-Ray
Physiotherapy
Administration
Disabled Toilets
Cardiology

← Social Work Social Work



← HAEMODIALYSIS UNIT
← RENAL OUT-PATIENTS CLINIC
← MATERNITY WARD
← CHILDREN'S WARD
← PAEDIATRIC AMBULATORY WARD
← GYNAE/MATERNITY OUT-PATIENTS
← G.U.M. CLINIC
← OCCUPATIONAL THERAPY DEPARTMENT

↑ GENERAL WARDS ALL FLOORS
↑ LIFTS ALL FLOORS
↑ RESTAURANT LOWER GROUND FLOOR
← COMMITTEE ROOMS 1 & 2
← PUBLIC TOILETS ♀♂
GENERAL OUT-PATIENTS →

ACCIDENT & EMERGENCY →
X-RAY/MAMMOGRAPHY →
PHYSIOTHERAPY →
CARDIOLOGY →
AUDIOLOGY/E.N.T. →
ORAL SURGERY →
PUBLIC TOILETS ♀♂ →

← HOSPITAL CHURCH

Reception







DANGER
BEWARE OF
ONCOMING
TRAFFIC

Beware of
oncoming
traffic





NM
New Mexico
Department of Health
Danger
Beware of
oncoming
traffic

NM
New Mexico
Department of Health
Danger
Beware of
oncoming
traffic

Outcomes

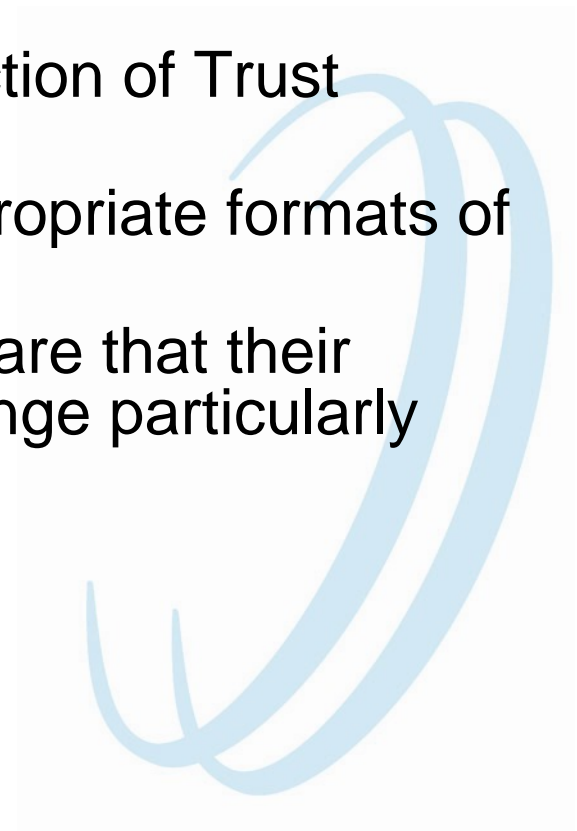
- Service Users felt valued
- Service Users realised they can influence change
- Service Users are much more interested in partnership working



Summary

Both of these projects have ensured that:

- Service Users with a sight difficulty were extensively involved in the development and implementation of both projects
- Service Users continue to influence direction of Trust services
- Service Users receive information in appropriate formats of their choice
- Service Users do feel valued and are aware that their participation can and does influence change particularly surrounding improved access



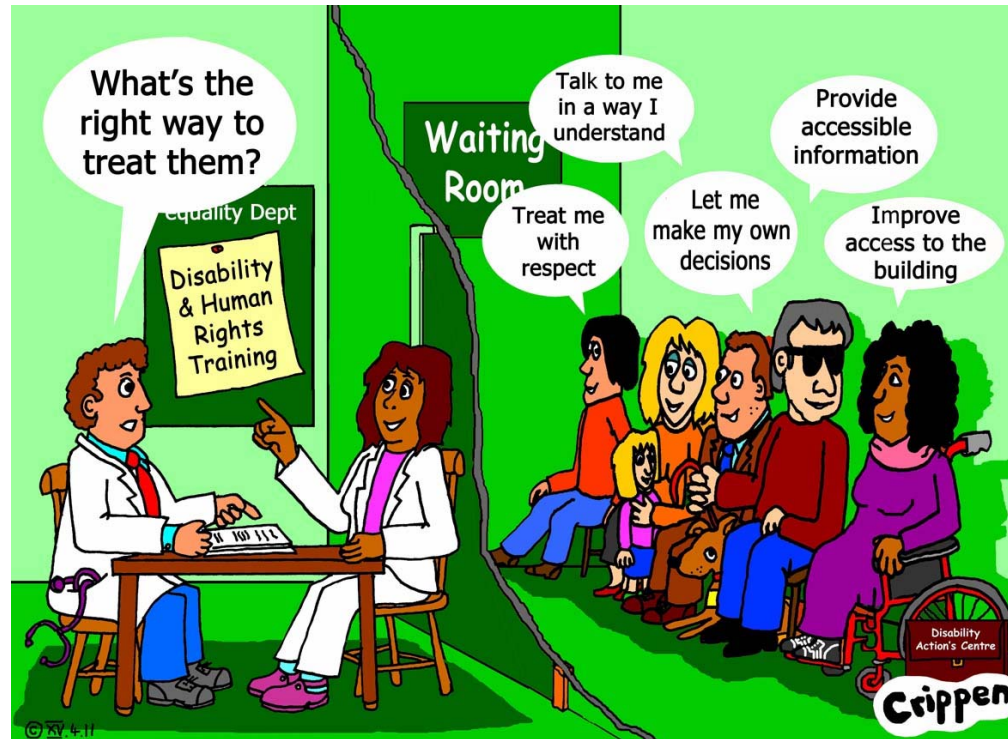


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for People with Disabilities

Do you know the ‘right’ approach?

Heather Logan,
Training Officer,
Disability Action’s Centre on Human
Rights for People with Disabilities

Do you know the 'right' approach?



Tuesday 28 June 2011

By : Heather Logan

Training Officer - Centre on Human Rights for People with Disabilities, Disability Action

Training Course:



“A Disability and Human Rights Approach to Health and Social Care”

Training Overview



- **Section 1 – WHY** are human rights important for Health & Social Care organisations?
- **Section 2 – WHAT** does the UK Human Rights Act mean for Health & Social Care organisations in everyday work?
- **Section 3 – HOW** can Health & Social Care organisations develop human rights based approaches in practice?

Training Outcomes



- You will understand the barriers faced by people with disabilities when it comes to health and social care
- You will learn what is meant by a disability and human rights approach to health and social care
- You will understand the benefits of a human rights based approach to disability
- You will know how to apply this approach practically in your job; and
- You will feel empowered to pass on your learning to your staff and colleagues.

Who?



- **Target Audience**

- Primarily ‘frontline staff’ including clinicians and support and administrative staff
- “Development Masterclass” for all managers and other training leads

- **Design and Delivery**

- Interactive – presentation, discussion groups and individual exercises

What and How?



- Course Structure
- Full Day Sessions
- Half Day Session
- ‘Development Masterclass’ Session
- Online resource (Microsite) – www.disabilityhealthtoolkit.org

Benefits of the Training Programme



This training programme will support you and your team to:

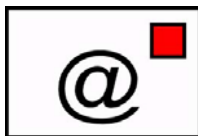
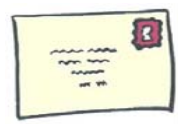
- Understand the barriers faced by people with disabilities in accessing health and social care;
- Know how to remove these barriers in your job;
- Follow international best practice;
- Meet your professional ethical obligations;
- Further enhance the quality of your service to people with disabilities; and
- Minimise complaints.



Further Information



The Centre on Human Rights for
People with Disabilities
Disability Action
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189 Airport Road West
BELFAST
BT3 9ED



Email : humanrights@disabilityaction.org
Website : www.disabilityhumanrights.org



Tel No : 028 90 297880
Fax No : 028 90 297881
Textphone : 028 90 297878



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Any questions?



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Closing Comments

Kevin Doherty,
Director of Services,
Disability Action



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Evaluation forms:

Please take a moment to tell us what you
thought of the event



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Know the 'right' approach

Register with the new website for the
health and social care sector:

www.disabilityhealthtoolkit.org