



Human Rights in Healthcare

Richard Whitehead
(Clinical Psychologist)

Amanda Roberts
(Assistant Psychologist/Service User & Carer Lead)

Beth Greenhill
(Clinical Psychologist/Human Rights in Healthcare Project Lead)



Ted



"Ted may have had a learning disability, but he was still a human being and had rights. You hear people always ready to quote the Human Rights Bill. What happened to his rights?"

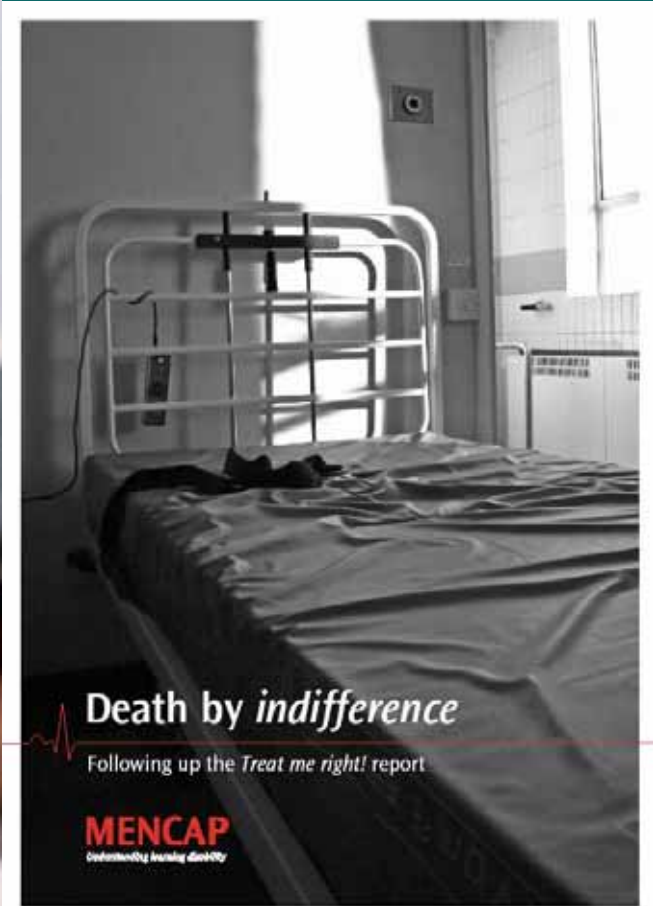
Death By Indifference, Mencap, 2007



Emma

"Determined, fun, caring,
loving...these are the things I think
about when I think of Emma."

Death by indifference, Mencap, 2007



“if they had listened to us we think Warren would still be alive today”



“If she had been a normal young woman we would not hesitate to treat her”

A Human Rights Based Approach to Healthcare

- ◆ Putting Human rights and principles at the heart of policy and planning
- ◆ Empowering staff and service users with knowledge, skills and organisational leadership/commitment to achieve human rights based approaches
- ◆ Enabling meaningful involvement & participation of all key people
- ◆ Ensuring clear accountability
- ◆ Paying attention to vulnerable groups



A Human Rights Based Approach to Healthcare: FREDA

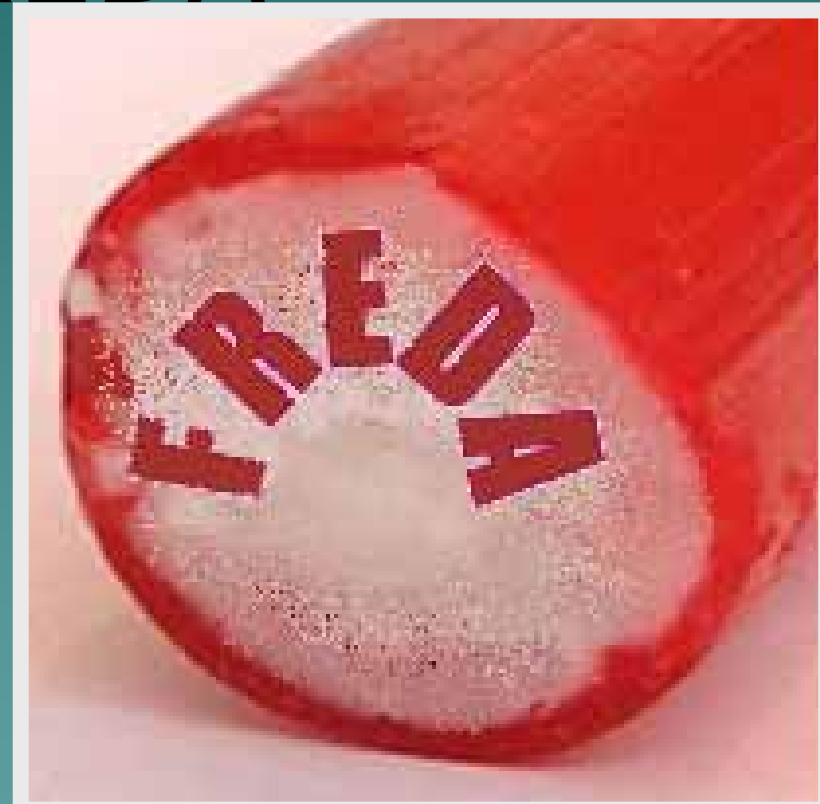
FAIRNESS

RESPECT

EQUALITY

DIGNITY

AUTONOMY



Why Human Rights in Healthcare Matter...Service Users

- ◆ Historically, Service Users with LD have had their basic human rights denied
- ◆ Deaths by indifference still occur today...and in our area
- ◆ ' He who forgets his history is destined to repeat it' (*George Santayana; Auschwitz*)

Why Human Rights in Healthcare Matter...Our reputation

Positive Achievement
Award

Collected by
Carol
Legge



Why Human Rights in Healthcare Matter...Our reputation

- ◆ **Invitations to present at:**
 - Royal College of Psychiatrist's Annual Conference;
 - LD North West Development Team;
 - LD London Development Team;
 - British Psychological Society's Faculty of LD and;
 - Department of Health
- ◆ **Invitations to contribute to books:**
 - Risk chapter (*Logan, 2009*);
 - BILD;
 - Nursing and LD textbook;
 - Advances in mental health and LD Journal
- ◆ **Interest in training and consultancy from:**
 - Kingston-upon-Thames;
 - Calderstones; Salford, Trafford and Bolton

Why Human Rights in Healthcare Matter...Policy context



Phase 1: The Story So Far...

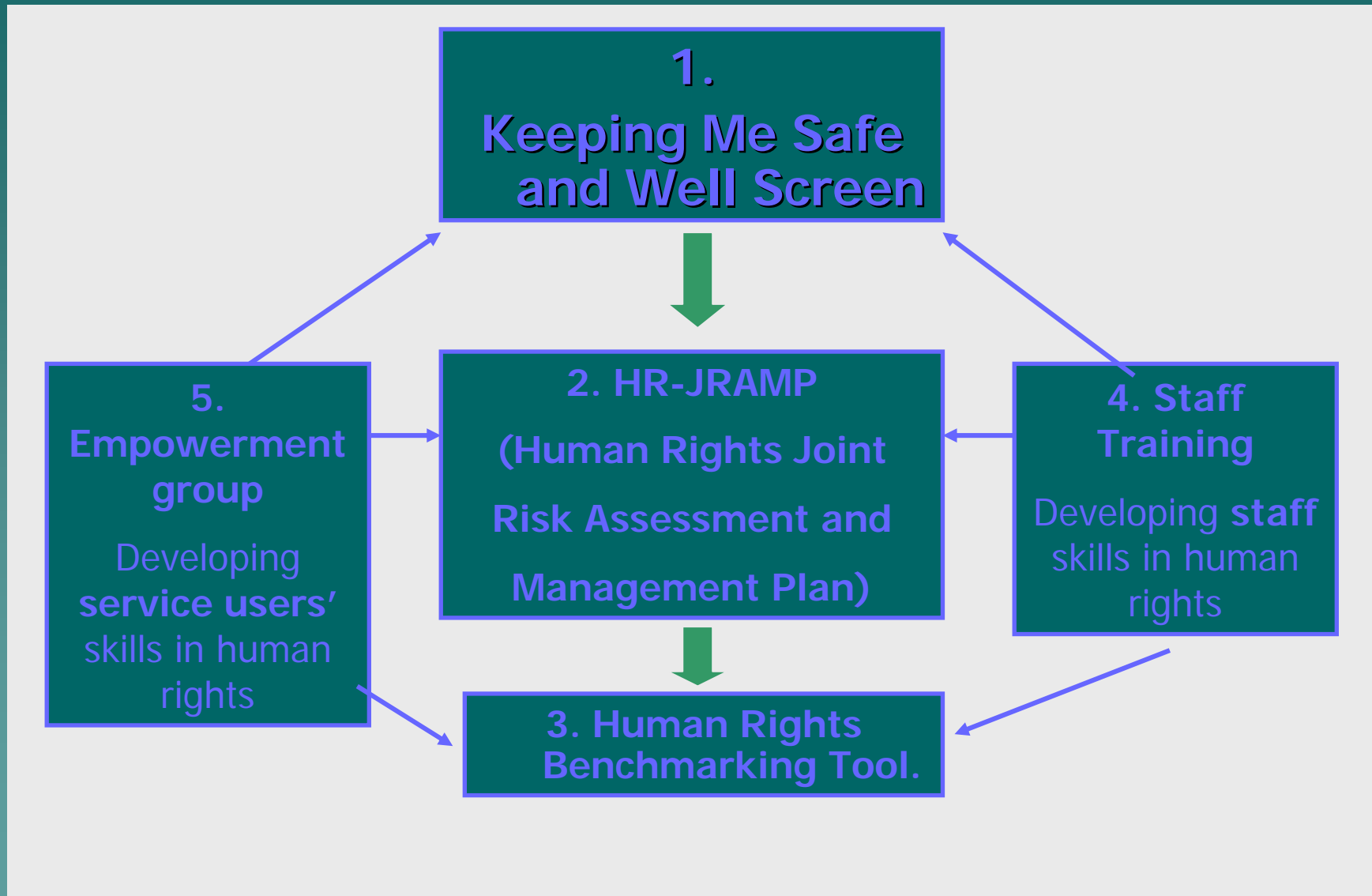
- ◆ Review of inpatient services
- ◆ Star Unit
- ◆ Questionnaire/Interview for service users in acute care

Phase 2

Risk Assessment & Management as Human Rights



Phase 2: The Story So Far....



Human Rights Based Risk Screen

‘Keeping Me Safe and Well’

The HR risk assessment is completed before the HR-JRAMP and the benchmarking tool

Aim - To create an ‘off the peg’ risk screen that:

- ◆ Looks at risk through a ‘human rights’ lens
- ◆ Identifies equality and diversity issues
- ◆ Maximises participation and



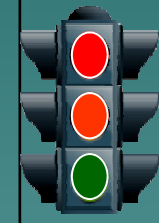
Example from Risk Screen

3.6) Risks about skin colour and culture

People treat me differently because my family are from a different country



People pick on me
People hurt me
When people don't understand why I do things differently, I can get angry



e.g. Bullying, intimidation, physical aggression, behaviours?



Example from Risk Screen

Human rights issues:

- The right not to be treated in an inhuman or degrading way.
- Fairness, respect, equality, dignity and autonomy.
- The right not to be discriminated against.
- Freedom of thought and religion.
- Freedom of expression.



Management Plan (HR-JRAMP)

Aim – To develop a human rights & risk management tool with guidance notes

- ◆ HR are considered in the formulation of the person's difficulties
- ◆ Proportionality
- ◆ Risk Balancing
- ◆ Impact of proactive and reactive

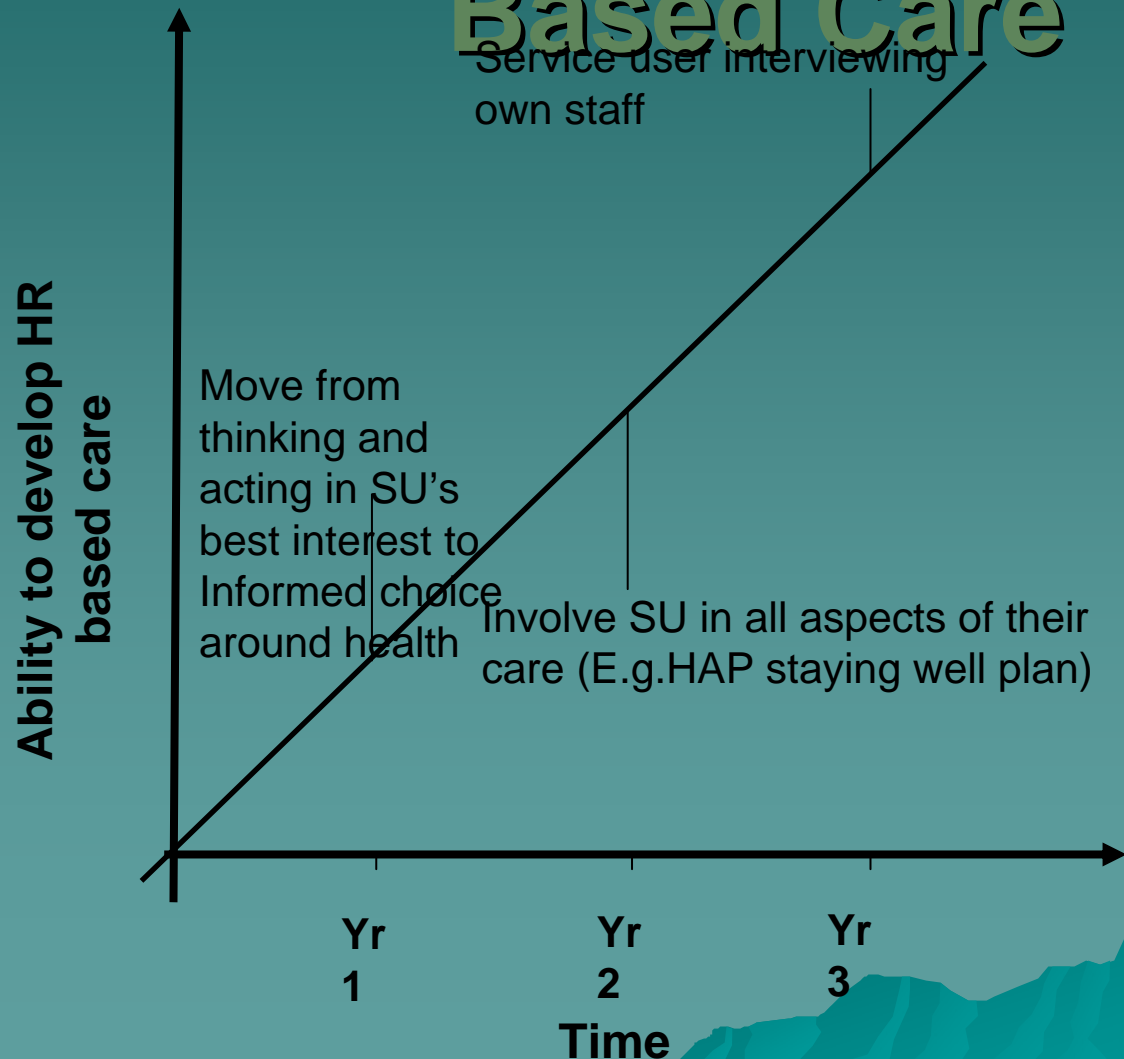
Human Rights Benchmarking Tool

Aim - to produce a tool to evaluate how well the Human Rights based approach has been incorporated in the complex care pathway

This is done by a set of standards for agencies to meet at key points in the service user's journey through the complex care pathway.




Development of competency to implement Human Rights Based Care



The Future

- ◆ (Clinical Business Unit) CBU developments.
- ◆ Resources: Utilisation of trainees , Nursing students, Volunteers.
- ◆ Different cultures of services
- ◆ Change at different paces
- ◆ Measuring what we value rather than valuing what we measure: KPI's



**Do the
assessment
tools make any
difference?**

Phase 3: Evaluation Phase



Steering Committee

- ◆ Malcolm Dickson
(Ipsos MORI)
- ◆ Lucy Matthews *(BIHR)*
- ◆ Meryl Cuzack,
Lindsey Dyer, Beth
Greenhill *(Mersey Care)*
- ◆ Peter Fleet
(ROI Operations)

Keeping Me Safe & Well Screen

Aim

- ◆ To what extent has the screen been integrated into our risk assessment work across the three sites?
- ◆ Does it make a difference? (i.e. are more human rights principles brought to the forefront of clinical practice when compared with the previous screen?)

Keeping Me Safe & Well Screen

Method

- ◆ Clinical audit of uptake (*across three sites*)
- ◆ Discourse analysis (*cases with new screen – v- cases with old screen; language constructions and meanings*)
- ◆ Staff interviews (*views and perceptions of the screen*)
- ◆ Service User interviews (*views of the process*)

HR-JRAMP and Benchmarking Tool

Aim

- ◆ To establish and evaluate whether the introduction of the HR-JRAMP has improved service users' access to their human rights
- ◆ To assess how effective the Benchmarking Tool is at monitoring this?
- ◆ To gain a deeper understanding into any organisational factors that may facilitate or obstruct the introduction of a Human Rights Based Approach

HR-JRAMP and Benchmarking Tool

Method

- ◆ Structured by the three-pronged method of evaluation (*measurement of outcomes, description of process and sampling of multiple stakeholder perspectives; Ellis and Hogard, 2006*)
- ◆ Audit of uptake of HR-JRAMP and Benchmarking Tool (*select sample of cases*)

HR-JRAMP and Benchmarking Tool

Method

- ◆ Small sample of HR-JRAMP clients – analysis of changes over time (*T1 – T2*)
- ◆ Benchmarking Tool (*Inter-rated by 2 clinicians*)
- ◆ BILD Life Experiences Checklist (*Ager, 1998; concurrent validity with BT*)
- ◆ 'My Life' schedule for service user Interviews (*Institute of Health Research, Lancaster University*)
- ◆ Staff interviews- assessment tools (*views, perceptions and experiences of using the tools*)

HR-JRAMP and Benchmarking Tool

Method

- ◆ Staff interviews- organisational culture
- ◆ 'Beliefs, values, attitudes and norms of behaviour' (*Davies et al, 2000*)
- ◆ 'culture eats strategy for breakfast, every day, every time' (*Davies, 2002*)
- ◆ 'Psychological reactance' (*Kinderman and Butler, 2006*)
- ◆ Question whether there is any resistance to the incorporation of human rights based approaches

Staff Training

- ◆ Rueben Furlong (CRS Manager)
- ◆ MSc

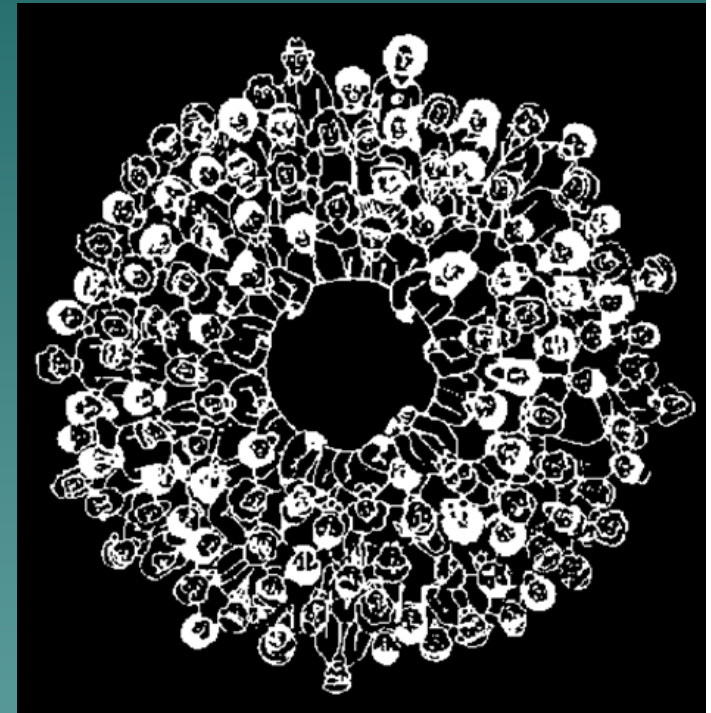
- ◆ **Question: How can we respect the rights of people with LD if the people supporting them do not understand Human Rights or have insufficient knowledge of a HRBA?**

- ◆ Training for support staff
- ◆ Pre and post training measures
 - Human Rights Attitudes Questionnaire (Devised in-house)
 - Human Rights Quiz
 - Maslach Burnout Inventory (Maslach, 1986)
- ◆ Correlation analysis

'Speaking Up for Myself Group'

Aim

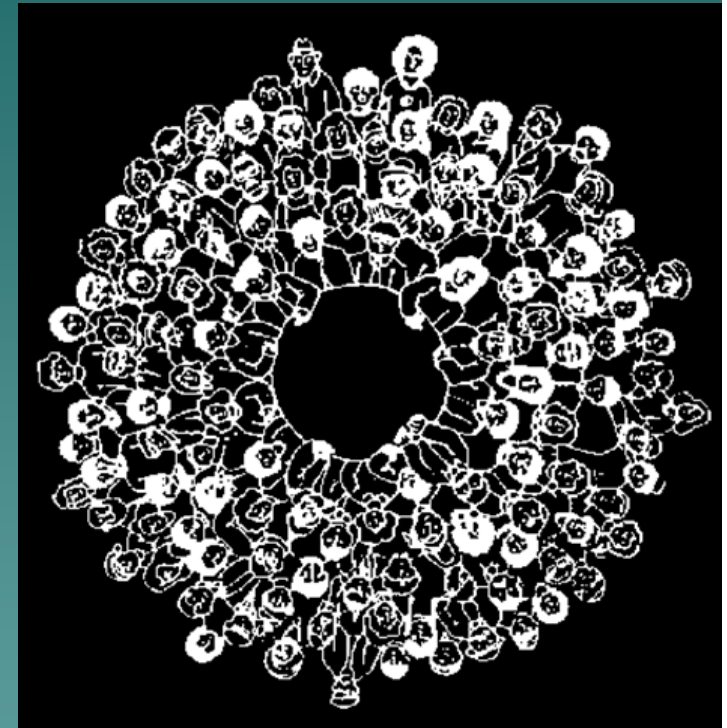
- ◆ Empower service users to challenge and change services
- ◆ Increase knowledge of human rights
- ◆ Act as a foundation for future initiatives (service user and carer agenda)
 - Service user consultants
 - More integral to the service as a whole



'Speaking Up for Myself Group'

Approach

- ◆ 'Stories & statistics'
- ◆ Pre and Post measures
 - Semi-structured interview
 - Human Rights vignettes
 - Individual Goals for group
 - Adapted Rosenberg SES
 - BILD Quality of Life Measure
- ◆ External Evaluation (SURE)



'Speaking Up for Myself Group'

- ◆ Session five
- ◆ 6 service users
- ◆ Learning outcomes so far:
 - Cohesive group
 - Sessions need to be as interactive as possible
 - Creativity challenge
 - Pace adapted
 - Dynamics between clients sensitively managed
 - Meaningful outcomes (3 client examples)
 - Service user consultants

Initiatives

- ◆ **Service User Consultants**
–to enable service users to become more integral to the service as a whole eg SLT, Service Governance, Research
- ◆ **Partners in Policy making for Health service.**
- ◆ **Human Rights and Health Action Plans**
(Rachel, Amy, Beth)
- ◆ **Human Rights and Dementia**
(Serena, Jimmy, Beth, Richard)
- ◆ **Management of violence and aggression**
(Beth and John O' Neil)

Initiatives

- ◆ **Dissemination** of human rights knowledge to other areas of the CBU
- ◆ **Integrating Recovery model** and Human Rights based approach for Psychiatric rehab
- ◆ **Human Rights based approach** into Brain Injuries unit for service users and carers
- ◆ **Web page resource** for service users around Human Rights resources and
- ◆ **Structure and Business** of CBU/Mersey Care
- ◆ **Service User Consultants** working in accredited therapeutic roles
- ◆ **CBU appraisal** by trust board in accessible format

Initiatives

- ◆ **Innovate Now Bid** (*Richard and Amanda*)
 - Innovation Bursary Award (£21,700) and Innovation Sharing Award (£5000)
- ◆ **Human Rights Board Game** (*Amanda and Beth*)
 - Integrating existing work on serious board games and adapting for use with Human Rights issues
- ◆ **Rights Assessment** (*Beth*)
 - Newer version of tool looking exclusively at rights rather than at risk assessment then incorporating HR
- ◆ **Human Rights and Challenging Behaviour**
(*Sandra Bailey, Beth, Jimmy*)

Future

What are we prepared to do differently to ensure a culture of respect for Human Rights has continuing commitment within Rebuild CBU and Mersey Care as a whole

