Keeping Me Safe and Well – A Human Rights Based Approach to Risk Assessment and Risk Management with People with Learning Disabilities

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Why Human Rights in Healthcare Matter…

• 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’.
Common Human Rights Issues

• healthcare and treatment
  (DH, 2001; Mencap, 2007; 2012; Lunsky et al., 2009; Wullink et al., 2009)

• service responses to behaviour which ‘challenges’
  (Emerson, 2000, 2002; McGill et al., 2009; Webber et al, 2011)

• sexuality
  (Abbott & Howarth, 2005; Joint Committee of Human Rights, 2008; Richards et al., 2009)
Rights are often understood as risks

• ‘Risks to’ and ‘risks from’ people with learning disabilities

• Instead of thinking about human pain, anger, & attraction, we do “risk assessment and management”

• Clinical risk as a distiller of practitioner’s and service’s values
Tug of War

‘Duty of Care’
(Sellars, 2002)

‘Dignity of Risk’
(Perske, 1972)

Paralysis, Getting Stuck
Problems....

“Risk assessment needs to be put in its place as an imperfect tool which vast amounts of research have not improved very much over the years”

(ID 452, *Royal College of Psychiatrists Report CRI5O, 2008*)
Defensive Risk Management

Defensive approach to risk

Increasingly defensive approach: Escalating risk

‘Negative Events’

Negative experience for the service user

Disengagement from services

No strategies to manage risk positively

(Whittington & Logan, 2011)
Positive Risk Management

Collaborative approach to risk

Open approach: User engaging with planning

Positive experience for the service user

Lower risk: strategies designed & acted upon

More engagement with process

Greater collaboration with services

(Whittington & Logan, 2011)
• Taking a rights based approach is not just about *preventing* human rights abuses . . .
• The NHS also has a *positive obligation*.
• This means we should be *proactive* in ensuring that the rights of both staff and service users are being *protected* and *fulfilled*. 
United Nations
Universal Declaration of Human Rights
UN Convention on Disability

Council of Europe
European Convention of Human Rights

UK Government & devolved administrations
Human Rights Act (1998)

British Institute of Human Rights, 2008
Human Rights Act: Articles Relevant to Healthcare

- The right to life.
- The right not to be tortured or treated in an inhuman degrading way.
- The right to liberty.
- The right to respect for private and family life, home and correspondence.
Introducing a Human Rights Based Approach (HRBA) to Healthcare

• Putting human rights and principles at the heart of policy and planning

• Empowering service users

• Ensuring accountability

• Enabling meaningful involvement & participation of all key people

• Paying attention to vulnerable groups
The Aims and Scope of the Work

Make the person central to clinical practice

Positive Risk Management & Least Restrictive Practice

Legal Rights and Frameworks (HRA, MCA, MHA)

Human Rights Based Approach to Risk

Values based approaches e.g. Person Centred Planning and Recovery Model

Relationships and relational context: Collaboration, formulation & dialogue

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Making Human Rights Real for People

- Difficulties for people with Learning Disabilities in accessing their Human Rights are well documented.

- Disconnect: translating legislation into policy then translating policy into practice.

- Lofty sentiments of international and national law will have little impact on services.

- Human Rights Based Approach provides this translation from the European Convention and Human Rights Act into practical ways Human Rights can be used in the real world.
Human Rights Risk Tools

- Human rights are considered in the formulation of the person’s difficulties
- Proportionality
- Risk Balancing
- Impact of proactive and reactive strategies for supporting service users
Human Rights Risk Assessment for people with an Intellectual Disability

• Developed with BiHR

• Practical tools to guide clinical judgement

• Supported by staff training & Service User human rights workshops
Key Concepts in HRBA to Risk: Proportionality

• ‘Not using a sledgehammer to crack a nut’
• A strategy should
  – Be appropriate and not excessive to the risk
  – Ensure that any restriction of rights is kept to a minimum
• Always use the least restrictive strategy
Key Concepts in HRBA to Risk: Balanced Decision Making

We need to balance the rights associated with:
• the risk posed (for the person or other people)
• and the strategy employed (for the person or the other people)

In practice you may be trying to balance:
• the Service User’s different rights
• Service User, staff and community rights
Human Rights in practice . . .

Patrick is a 45 year old man with a learning disability who lives in a residential care home. He recently ran out of the home onto a busy road and sustained minor injuries. Following this, Patrick has been restrained to a chair for 3 hours a day (when staff levels are low) to prevent the incident occurring again.

(BIHR)

- This raises Patrick's
  - Right to life (associated with the risk)
  - Right to liberty
  - Right not to be treated in an inhuman or degrading way
  - Right to respect for private and family life
Facilitating Service User Involvement

- A human rights based approach to risk, means ensuring service users are as involved as they can possibly be in their own risk assessment process.
- Whether the service user participates fully or contributes to a small aspect of their risk assessment, some involvement will almost always be possible.
- Speaking to the service user to find out who they would like to be involved in their risk assessment is essential.
- Where full participation isn’t possible, the practitioner would be expected to work through the risk assessment on the service user’s behalf with the help of family members, the person’s advocate or chosen support staff.
Facilitating Service User Involvement

- Led and initiated by the practitioner. Service user is not aware of the process.
- Service user Consultant is involved.
- Service user is asked if they want to participate.
- Service user chooses who wants to be involved in the process.
- Service user is involved in aspects of the process.
- Service user is fully involved with the process (i.e., the process is adapted so it is accessible. The service user has a choice as to who is involved).

Continuum of service user involvement
‘Keeping Me Safe and Well’ Risk Assessment
‘Keeping Me Safe and Well’ Risk Assessment

• Looks at risk through a ‘human rights’ lens
• Identifies equality and diversity issues
• Maximises participation and empowerment
• Includes guidelines to individualise the screen
• Includes good practice examples

Human rights which may be engaged:

FREDA: Fairness, Respect, Equality, Dignity, Autonomy.

Is the person being treated with dignity, equality, autonomy with regards to their physical health?

Article 2: Right to life:
• Does the person have access to appropriate health care services?
• Has the person been refused any treatment for physical health on grounds of their disability? Is the person supported to make informed choices around medical treatment (e.g. attending the doctors)?
• Is the person supported to access medical checks/clinics? In extreme cases, a denial of any of these things could lead to death.

Article 3: Prohibition of torture, inhuman and degrading treatment—e.g. Are facilities available to enable persons with physical health needs to be cared for effectively? (e.g. hoists or changing facilities). Are there enough staff available to ensure aspects of the person’s physical health needs are met with dignity? (e.g. if incontinent, is the person changed on a regular basis so they do not have to sit in ‘wet clothing’?). If not, this could be classed as inhuman or degrading treatment.

Article 8: Right to respect for private and family life—A physical health problem could have an impact on the person’s physical and psychological well-being.

Article 14: Prohibition of discrimination—e.g. does the person have access to medical treatment they need regardless of their learning disability?
HRJRAMP

• About me.
• Who’s filling this in?
• Where did the information come from?
• Why is the assessment being carried out now?
HRJRAMP

• When will we look at my plan again?

• My wishes

• Critical Event History:
  (Date / Event / Context and Comment)
HRJRAMP

- Historical
- Clinical
- Social Factors
- Actuarial
HRJRAMP

• What does this mean?
• Analysis and Summary.
HRJRAMP

• Look at my risks. What options have I got? Significance of the risk.

• Where’s the best place for me to live?

• What legal documents are important?

• My Risk Management Plan.
A Framework for Evaluating Human Rights Work (Donald, 2012)

Knowledge
- What someone knows about human rights
- Familiarity with facts, information, debates

Understanding
- How someone processes human rights knowledge using critical thinking
- How someone ascribes relevance or importance to human rights

Skills
- How someone applies knowledge and understanding of human rights
- How well or confidently they do it

Behaviour
- How readily someone uses human rights to make decisions and priorities
- How someone treats and relates to others day-to-day

Perspective
- How someone sees themselves in relation to others
- The values someone holds

Experience
- How someone experiences others’ treatment of/behaviour towards them
- How that treatment or behaviour makes them feel

Outcomes
What changes for a person, service or organisation in the short-medium term
Whether human rights are better respected, protected and promoted in the short-medium term

Impact
What changes for a person, service or organisation in the longer-term, including changes to the culture of the organisation
Whether human rights are better respected, protected and promoted in the longer-term
Human Rights and UK Mental Health Legislation

- Guiding Principles of the Mental Health Act (MHA) suggest a person’s human rights are central to the use of the Act.

- Unfortunately guiding principles are not always considered when using the MHA.

- Growing legal awareness that these principles need to be considered when using MHA.
People from Minority Groups and Intellectual Disability

- People from minority groups tend not to access our services.

- Initial work developed booklets with Chinese community of Liverpool.

- Developed booklet with Moslem community carers linking Koran and duas with information about Intellectual Disability.
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