Human Rights and Dementia Project

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Human Rights and Dementia Project

Background

• Traditionally we as a society have not treated people with dementia well
• Designing a new model of care for dementia inpatient services based on person centred principles
• Traditionally these principles have been difficult to embed and difficult to research because they are ‘soft’
• Human Rights Based Approach offers a more robust framework encompassing many of the person centred principles but take it a step further as it is law
• Suggested by Dept of Health Lead we could become part of the HR in health care project as a parallel project
Human Rights & Dementia

- Our society values people with intact cognition above those whose cognition is compromised.
- This had led to people with dementia being treated in ways that have undermined their personhood and infringed their human rights.
- ‘Often care is about meeting basic care needs and supervision and human rights have been marginalised or ignored’ (Boyle 2010).
- The presence of dementia has been used to justify the denial of human rights to older people who are cognitively impaired.
- Erroneous assumptions about capacity have led to people with dementia being detained in institutional care against their wishes, sometimes unwittingly (Boyle 2008).
- People with dementia need positive rights—help with communication and decision making to help them to exercise autonomy.
Human Rights & Dementia

- With regard to self determination (autonomy) until recently people with dementia were assumed incapable of making any decisions simply because of the presence of dementia.
- They were inappropriately excluded from decision making processes.
- As a result people with dementia were deprived opportunities for self determination even when they retained capacity.
- With regard to independent living there remains a lack of recognition that people with dementia should also have a right to independent living.
- The risk averse culture which has developed has led to people with dementia admitted to care homes before they really needed to go.
Why now?

• We live in an ageing society and there is growing recognition that dementia is a growing issue that will have health, social and economic consequences for the nation.

• Prime Minister’s challenge on dementia

• Dignity in Care report
Rights and Health Care

• Some Human Rights are more obviously applicable to a health care setting than others:

• Think about a person with dementia in an in-patient setting- how may the rights listed below be an issue?

• Right to life
• Right not to be tortured or treated in an inhuman or degrading way
• Right to liberty
• Right to respect for private and family life, home and correspondence
• Right to freedom of thought, conscience and religion
• Right to freedom of expression
• Right not to be discriminated against
• Right to peaceful enjoyment of possessions
Commonly occurring dilemmas

- Locked doors – what do we do about them? People aren't detained under the mental health act – where do we stand
- Restraint – how much is ok without infringing people’s human rights? we have to protect other people and ourselves
- Medication- is it really ok to put medication in a sandwich?
- Incontinence- if someone gets really distressed during help with personal care how should I intervene?
- Possessions- how can people have their own things when others will pick them up and take them?
- Time out- is it ok to take people to their room when they are unsettled and encourage them to stay in there?
- Care home admission- Sometimes lack of community resources mean that least restrictive option is not available i.e. care home or hospital necessary because this is a restricted right and care is insufficient to meet people’s needs
A Framework for Balancing Rights-how to make decisions

- A Human Rights Based Approach helps us to make difficult decisions because it provides a decision making framework

- Is it Lawful
- Is it a Legitimate aim
- Necessary in a democratic society
Human Rights Based Approach

Principles

• Proportionality
• Least restrictive option
• Balancing rights and risks
• Proactive strategies
Proportionate Action

• A proportionate response to a problem is one that is appropriate and not excessive in the circumstances.
• Proportionality
  Is there anything that you could do that would interfere with the right less? i.e. choosing the least restrictive option
• It provides a very important mechanism to ensure that the infringement of rights is kept to a minimum and is always reasonable.
• Proportionality also allows NHS organisations to balance competing interests, e.g. the rights of the individual with the rights and needs of others.
• It requires a balance between the rights of the individual and potential risk to the individual. This may encourage positive risk taking
• Proportionality means not using a sledgehammer to crack a nut!!
• If all you have in your toolbox is a hammer everything looks like a nail
• Abraham Maslow
Least Restrictive Practice

• In any given situation there are always a number of ways that you could respond.
• It is important in maintaining an individual’s human rights that all options are considered and the least restrictive option chosen.
• The least restrictive option is the one which will impact least on an individual’s rights whilst keeping them safe.
Example

- A care home takes a decision to have a blanket policy of placing CCTV in the bedrooms of all residents, for safety reasons.
  - **Outcome**
    This interferes with the right to respect for private life of all residents.
  - **Alternative**
    A decision is made that only residents who pose a risk to themselves and/or others will have CCTV placed in their rooms. Their decision will be made on a case-by-case basis.
  - **Outcome**
    Some residents have their right to respect for a family life interfered with for their own safety or the safety of others; other residents so not have their right to respect for family life interfered with.
Balancing rights and risks

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**
Proactive strategies

• This involves taking action before something bigger happens
• e.g. If you see John getting really unsettled and agitated do something then rather than waiting until he’s at fever pitch and about to thump Betty
• Don’t wait until the event to do something
• Look for warning signs, e.g. is John starting to get restless
• Meet people’s expressed need to avoid the need to utilise more restrictive strategies- if you don’t do something before it may result in John being restrained or having to use medication
• Formulation around behaviour encourages use of proactive strategies
Applying a Human Rights Based Approach to Health Care

- Lawful
- Legitimate
- Necessary
- Proportionate
- Proactive
- Least Restrictive
- Balancing rights and risks
Group exercise

- George hits out at staff regularly…
The project

• Set up a group of motivated practitioners from different professions as a project team
• Initial brainstorm about how to proceed and what exactly was going to be developed
• Project brief and plan
• Training for wider team from British Institute of Human Rights
What we did (and are doing..)

1. Assessment tool

- Review of the literature
- Focus groups with staff and service users
- Combine the two to develop assessment domains
- Link assessment domains to FREDA principles
- Develop accompanying staff manual containing prompt questions for staff for all domains to ensure service users receive a standardised assessment
Getting it Right Assessment

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Getting it right

A Human Rights Based Assessment

with people with dementia
Getting it Right Assessment

- Consists of a person held copy and a staff manual
- The staff manual is a list of questions to ask the person
- There is a pre compiled list of prompts/actions to help when you are completing it
- The assessment is divided into 3 stages to avoid the person being subjected to a long and complicated assessment on admission
- Red to be completed within the first 24 hours
- Yellow within 3 days of admission
- Green within a week
- However as always the wellbeing of the person has to be the guide for how much to complete at each session
2. Development of resource pack

- To accompany assessment to maximise person with dementia’s understanding and help staff who are completing the assessment
- Contains information leaflets
- Pain chart
- Family tree
- Pictures/ emoticons to explain feelings
- Pictures of activities
3. Training package and DVD

- All staff who will be completing the assessment will attend training day
- For the purposes of other services where live drama cannot be used a DVD is being produced
- Training uses drama to portray a familiar situation of a person with dementia on a ward which contains human rights issues
- Staff then discuss the scenario
- Human Rights training
- Human Rights and dementia training
- Human Rights Based Approach (HRBA) Training
- Introduction and practice completing the assessment
- Re run the scenario but staff stop it when they see a human rights issue and suggest alternatives using a HRBA
4. Evaluation

- One of the most difficult parts of the project
- Worked with a senior research fellow from London Met University
- Evaluation takes 3 parts
  - A) Pre and post implementation audit of care plans (hypothesis does using this assessment impact the quality of care plans)
  - B) Use of vignettes pre and post training with staff. They present scenarios containing human rights issues and staff are asked what they would do and how they make the decision about what to do (hypothesis- does HRBA affect staff’s decision making)
  - C) Pre and post training knowledge and attitudes questionnaires
Next steps

- Filming of DVD
- Completion of learning resource
- Intellectual Property Rights
- Rolling out use of assessment tool internally and externally
- Possibility of large scale research project
- Production of the assessment tool
Summary

• Human Rights are everybody’s irrespective of race, gender, disability etc
• We have a legal responsibility to uphold the human rights of people using the ward
• People with dementia are particularly vulnerable in terms of having their human rights disregarded on the basis of their diagnosis
• Human Rights based approach provides a helpful decision making focus
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