

National Federation Voluntary Bodies

Residential Weekend on Living Options

10 – 11 July 09

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Presentation

- A Life Like Any Other?
- Human Rights of Adults with Learning Disabilities
 - Report from Joint Committee on Human Rights
 - The Joint Committee is appointed by House of Commons and House of Lords
 - Seventh report of Session 2007 -08

Rationale for choosing this paper

- Recent publication of Ryan report
- People with intellectual disability still living in institutions
- Vulnerable group – people with learning (intellectual) disability
- Paper published in 2008

A Life like any other is A Comprehensive Inquiry:

- To question whether we are meeting our obligations to respect the human rights of adults with learning disabilities and whether as a result adults with learning disabilities in the U. K. are likely to be able to lead ordinary lives
- Ensuring that the report is accessible and relevant for adults with learning disabilities

The Report identified the following as key issues for people with learning (intellectual) disabilities

- Abuse & neglect
- Failures in Healthcare
- Victims of crime
- Evidence from the inquiry suggests that adults with learning disabilities are particularly vulnerable to a lack of respect for their human rights

Key Issues for people with learning disabilities

- According to the report for many adults with learning disabilities the violation of their human rights is seen as a normal part of their everyday lives

Key Issues for people with learning disabilities

- It was reported that:
- The human rights of some groups of people with learning disabilities were likely to be particularly at risk, including people with profound and multiple disabilities who may not be able to communicate through speech, people whose behaviour poses a challenge to staff and services that work with them

Key issues for people with learning disabilities

- It was reported that:
- The human rights of some groups of people with learning disabilities were likely to be particularly at risk including people from black and minority ethnic communities, who may not find accessible information or appropriate and culturally sympathetic support available

Key issues for people with learning disabilities

- It was reported that:
The human rights of some groups of people with learning disabilities were likely to be particularly at risk including people who have been placed in service settings many miles away from their families and communities of origin

Key issues for people with learning disabilities

- The evidence suggest that such people face additional hurdles in securing support for their human rights or in disclosing infringements of them

The Policy context

- Valuing people – people with learning disabilities are people and citizens – rights independence, choice and inclusion
- The story so far Valuing People.... Progress
 - Listened to more
 - Person centred planning
 - Direct payments
 - Yet despite such progress for people with learning disabilities
 - “Most people’s lives are still not what a non-disabled person would say was OK for themselves”

Living with a learning disability

- People with a learning disability are less likely to :
- Have access to public services and healthcare, education, transport, benefits, social care
- Have access to housing and choosing where and with whom
- Have access to paid employment
- Have relationships with friends and family and sexual and other personal relationships
- Participate in decision making, speaking up and making complaints
- Play a part in the local community

Living with a learning disability

- People with a learning disability are more likely to be on the receiving end of:
- Negative attitudes, assumptions and stereotypes about people with a learning disability

Living with a disability

- Malnutrition and dehydration
- Two middle managers have been trying for 8 years to get a “dysphagia” service (eating and drinking) for people with high support needs. This group of people have problems swallowing and so the position they sit in and their nutrition intake as well as thickness of food/fluids have to be taught to medical professionals providing care for them. In this primary care trust this service is only provided if the person is an inpatient in acute services

Living with a learning disability

- Neglect or carelessness by health and social care services
- “Her relatives visited after the operation and found Susie lying on her back, eyes open but not saying a word which was unlike her as she is usually very talkative and lively. Her relatives were worried and asked the Sister why Susie couldn’t talk. The Sister looked up Susie’s notes and commented “well she can’t talk if she has a learning disability”. Susie was re-examined and found to have had a minor stroke

Living with a disability

- Lack of dignity in respect of personal care needs
- "They want me to bath twice a day, the water is often cold."

Living with a learning disability

- Abusive & degrading treatment – locked in a minibus overnight
- B a young man with down syndrome and autistic spectrum disorder was locked in a day centre mini bus overnight in a garage. One week later four male members of staff at his day centre broke his foot whilst trying physically to force him onto a mini-bus

Living with a disability

- Lack of privacy in health and social care settings
- “ I clean my room, when I get home to the community house they’ve done it all again. Why should I do it if they (staff) want to do it again?; I have a street door key but I can’t lock my room door.”

Living with a learning disability

- Inappropriate use of restraint and/or medication
- Diana, who has a visual impairment and scoliosis, kept colliding with people and furniture and falling, resulting in injuries. The staffing levels at her home were not sufficient to support her when walking round her home so she was strapped into her wheelchair
- K a middle aged woman with down syndrome threw a cup at a wall in her care home on the first anniversary of her mother's death. Instead of trying to find out why she had thrown a cup, the woman was prescribed anti-psychotic medication

Living with a learning disability

- Negative, patronising and infantilising attitudes towards people with learning disabilities
- Manny suffered from arthritis in his hands and was in constant pain. His GP refused to prescribe medication on the grounds that he “wouldn’t understand” because he has down syndrome”

Living with a learning disability

- Discriminatory treatment of adults with learning disabilities in access to mainstream services on grounds related to their disability
- The GP refused to refer Andy to a neurologist for further investigations to clarify the diagnosis on the basis that any further investigations might cause Andy distress and that it was unlikely that any treatment would be offered due to his learning disability and associated behavioural issues, which would make it difficult for him to tolerate any surgery."

Living with a disability

- Problems with communication particularly where patients have complex or profound learning disabilities
- "Staff on the ward may not understand the communication system used by a learning disabled patient. They misinterpret or even ignore what the learning disabled patient is trying to communicate."

Living with a learning disability

- Fear and difficulties in making complaints
- "Someone made a complaint about the manager, I got the blame. They excluded me and said things like 'go to your room and eat your breakfast'".

Living with a learning disability

- Malnutrition and dehydration
- Abusive and degrading treatment
- Neglect or carelessness by health and social care services
- Lack of dignity in respect of personal care needs
- Inappropriate use of restraint and/or medication
- Problems with communication, particularly where patients have complex or profound learning disability
- Negative, patronising and infantilising attitudes towards people with learning disabilities
- Discriminatory treatment of adults with learning disabilities in access to mainstream services on grounds related to their disability
- Fear and difficulties in making complaints

Living with a learning disability

- Parenting and family life
 - Children of people with a learning disability are more likely to be removed from the care of their parents
 - Limited or no access to support for parents with learning disabilities and their children
 - Limited or no access to information for parents with learning disabilities

Living with a disability

- Treatment of people with learning disabilities in the criminal justice system
 - Serious crimes against people with learning disabilities are not taken seriously but are diminished by using the label of abuse
 - People with learning disabilities aren't able to report crimes easily or aren't taken seriously when they do report crimes
 - Not enough is being done about disability hate crimes

Living with a learning disability

- Prison reform trust
 - When people with a learning disability come into contact with the police and the courts service they are less likely than people without learning disabilities to receive a fair hearing
 - Gaps in the provision of services and support to prisoners with learning disabilities and lack of clarity on how to access services

Living with a disability

- Barriers to an ordinary life
 - Access to information
 - Accessible information on human rights
 - Access to independent advocacy
 - Voting rights
 - Support to participate in the local community

Conclusions & Recommendations

- 81 in total
- We recommend the amendment of “Valuing People Now” to remind all public authorities, including government departments, local authorities and NHS trusts that the aim of the Government’s policy is grounded both in the need to respect the human rights of adults with learning disabilities and in the binding obligations of the Human Rights Act 1998 and the Disability Discrimination Act

Conclusions & Recommendations

- We recommend that as part of their proposal to support advocacy to have an increasing impact, the Government ensures that independent advocates, including independent mental capacity advocates and others, have an understanding of human rights principles and the positive duties of public authorities and service providers towards adults with learning disabilities

Conclusions & Recommendations

- We recommend that in the review of the No Secrets and the proposed Valuing People Now guidance on crime and people with learning disabilities the Government provides clear and accessible guidance on protecting people with learning disabilities from abuse and ensuring that if a crime is suspected, effective steps are taken to inform and involve the police. We urge the Government to ensure that the relevant criminal justice agencies, and organisations of and for people with learning disabilities are closely involved in shaping this guidance

Recommendation & Conclusions

- We recommend that the Dept of Health should use the 60th anniversary of the NHS to gain maximum exposure for its positive commitment to ensure that "Human rights are at the centre of the values of the health and social care system in this country. We consider that the adoption of a clear strategy on human rights policy making by the Dept of Health would set a positive example on the type of culture change which will be necessary to ensure that human rights are really at the heart of service delivery.

Recommendations & Conclusions

- Taking a human rights based approach to service provision could contribute to reversing negative attitudes, assumptions and stereotypes. The Dept of Health and the Office for Disability Issues should take a lead in creating a positive approach to the implementation of both the Human Rights Act 1998 and the Disability Equality Duty. However taking a human rights based approach means more than

Conclusion & Recommendations

- However taking a human rights based approach means more than just using the appropriate language in policy documents or in statements to parliamentary committees. A proactive and practical approach to the implementation of individual rights for people with learning disabilities is needed to replace the existing culture, which has allowed society to “dehumanise” people with learning disabilities for centuries.

Conclusion & Recommendations

- Investigation of Healthcare Commission and CSCI into the treatment of people with learning disabilities in Cornwall was that " many of the staff did not believe and understand that what they were doing was wrong".
- This provides an example of how a lack of awareness of the human rights of people with LD can have a devastating effect, leading to situations where the right to be treated with respect for private life is ignored and the rights to life and to be free from inhuman and degrading treatment are endangered.

Conclusion: Future residential options in Ireland

- Based on what has been learned from this report the following should be considered:
- Develop a human rights based approach to service delivery
- Establish what evidence should be present to demonstrate that service delivery upholds the human rights for each person availing of the service
- Regularly examine that the evidence is present in the service delivery to each person that demonstrates that their human rights are being upheld

Conclusion Future residential options in Ireland

- If there is no evidence to confirm that the service delivery to each person availing of the service is upholding their human rights then:
- Establish what evidence should be present in the service to demonstrate that the service delivery to each person is upholding their human rights
- Decide what should stop happening and what needs to happen to ensure that the evidence is present in the service delivery to demonstrate that the human rights of each person availing of the service are being upheld
- Establish who is responsible and accountable to ensure that what needs to happen happens and set timelines for this to occur
- Monitoring and review of service delivery

Conclusion Future residential options in Ireland

- Information – accessible information on human rights
- Training on human rights – for people who avail of services, their family members, staff members, monitoring agencies etc.
- Independent Advocacy
- Monitoring & Review

NFVB Residential Weekend

- A Life Like Any Other?

Human Rights of Adults with Learning Disabilities

- Thank you!