

National Federation of Voluntary Bodies
Living Options Seminar
July 10th & 11th 2009.

Some key points and reflections on the U.K. House of Lords / House of Commons Joint Committee on Human Rights: Seventh Committee Report Session 2007 -08

Focus of this Committee for their seventh report ~ Adults with Learning Disabilities in the U.K.

Report Title:

"A Life Like Any Other? Human Rights of Adults with Learning Disabilities."

Observations and Comment: (N.B. Where referred chapters and paragraphs are as numbered throughout the Committee report)

It is positive to see that the focus of the work of the committee as expressed in the title of the report is on the lived experience of people as in "a life like any other", and that their work was not merely a high level governance review of policy practice and regulatory systems based on meetings and review of work reports and future stratagem of the providers and commissioners. By contrast the committee went out to meet these bodies and organisation but significantly focused on meeting and listening to the people who receive the services and giving weight and focus in their report to what people, their families and advocates expressed.

Background to Report:

The background to the engagement of this committee on this topic was initially "The National Survey" published 28-9-2005; it had found that "*adults with learning disabilities are often socially excluded, have little control over their own lives, and were more likely than others to have bad things happening to them*".

The second motivator was a series of reports described as "stark" and within the last two years from a number of U.K .bodies including the Healthcare Commission, the Commission for Health and Social care, Mencap and the Disability Rights Commission.

(Above references from the report chapter 1 paragraphs 1, 2, and 3. where full details can be found)

Context of Report:

The report examines evidence from across sectors working as significant stakeholders in the care and support of adults with a learning disability. It captures the rights agenda in policy and practice from the perspectives of statutory authorities, service providers (for profit and voluntary), housing associations, hospital and health facilities, training and education. The committee examined 200 pieces of evidence for people with disabilities and their families engaging across this spectrum of stakeholders.

The National policy context against which services were to be guided and statutory direction given was the 2001 Valuing People. There were a number of regional policy and strategy documents in parts of the U.K. such as Wales, N. Ireland, etc but they all reflected the core values and delivery principles of Valuing People 2001.

In summary the key context points were:

- Strong National Policy Lead through Valuing People 2001.
- A doubling in real terms of funding to the sector within the decade.
- A well established regulatory and monitoring structure.

(The Terms of Reference of the Committee are outlined in Chapter 1 paragraph 8).

Scope of Issues arising from Evidence and Basis of Committee Recommendations:

- Key Issues for Adults with a Learning Disability:

Abuse and Neglect

Failures in Healthcare

Victims of Crime

- Living with a Learning Disability

Access to Services, Housing, Employment

Relationships

Participation in decision making

Participation in Community

The Gap experienced between what policy says and what the reality is.

- Treatment of Adults in Health and residential Care settings.
- Parenting and Family Life
- Treatment of People with a L.D. in the criminal justice system
- Barriers to "An Ordinary Life"

An Overview of Key Issues for adults with a learning disability within Health/Care:

- Attitudes Practice and Awareness were lacking across all strata
- At Statutory Level even within the D.O.H.
- At Local Authorities which deliver or commission the delivery of services awareness, adaptability and flexibilities were deficient
- Within service providers in the disability sector responsiveness to choice, meeting individual need and implementing the principles of Valuing People are happening in an inconsistent way. Despite some significant National progress on closing major institutional settings this has not translated consistently into enhanced sense of wellbeing and personal autonomy and outcome for people.
- Secondary health care facilities (hospitals) were among the examples from the evidence of where serious episodes of neglect and infringement of basic rights could occur.

One Example:

The C.E.O. of a Cornish Primary care Trust requested an external investigation of its L.D. services in 2007 following a number of allegations concerning abuse including physical and sexual. The outcome indicated outmoded institutionalised care with systems and structures revolving around the needs of the institution at the expense of its clients. This include poor environments lack of space and support for peoples privacy and dignity and the inappropriate use of physical restraint.

This report in 2007 led to the first audit of specialist inpatient healthcare services for people with a L.D. in England. The report published in December 2007 is titled "The Healthcare Commission Audit". Its findings were surprising given the policy, fiscal and regulatory context in which services operate in England.

In summary it found:

- poor environments,
- poor standards of care,
- poor support in treating people with dignity,
- poor leadership,
- few personal choices and isolation from community.

(Chapter 2 paragraphs 19, 20 & 21 give fuller details)

While the Joint Committee bases its report on the evidence of the 200 engagements it reviewed and references the above Audit and other various reports there is no statistical analysis provided in Volume I of the report on the percentage of People or Families / Advocates reporting on the various degree of occurrence of abuse / neglect. (The above audit referred has not been reviewed for this presentation and may well contain such information.)

Broad Scope of Recommendations from the Joint Committee Report Encompassed: ~

- ✓ Information and advocacy to support people understanding and progressing their rights
- ✓ Implementation by statutory bodies, trusts, organisations etc. of the law in respect of rights and equality.
- ✓ Societal acknowledgement, awareness and intervention to promote and support rights as an equality issue.

Reflections:

The comparable Irish position at this time included: ~

- National Health Policy, Quality and Fairness (2001) with its underpinning principles of Person Centredness, Accountability, Quality and Equity.
- The National Disability Strategy as a progression on Quality and Fairness for citizens with disabilities.
- The emergence of a set of National Residential Standards through N.D.A. and H.I.Q.A. with the intent to progress to implementation.

- Enhanced funding to the sector.

A key question that arises in reflecting on the unexpected findings of the U.K. joint committee report and the adoption of a similar pathway in Ireland is does having a rights based approach supported by legislation and regulatory structures ensure you achieve the lived experience the system would seem to imply ? And if you don't then why?

In fact this was the perspective of the committee when they set an ordinary life as the benchmark for what the system should be delivering as it is what people are asking for. If the system is falling down on delivering the basic rights of aspects of privacy and dignity what needs to happen to ensure it will achieve the more ambitious objectives of support to live an ordinary life of a Person's choice?

Will the response through regulatory and evaluation systems be one of enhancing outcomes and standards on the basic rights of dignity and respectful treatment first or should it be an holistic response i.e. ~ to the dignified ordinary life now!

Is the question *what mechanism most effectively supports rights into action?*

Question?

If you have and enjoy the life you wish then you probably have good relationships in your life and aren't too worried about your rights. If however you don't will rights with legislation and regulation but without relationships achieve this for you ~ probably not.

Reflecting on the real and potential empowerment of "Person Centredness" in the 2001 Health Strategy "Quality and Fairness a Health System for You" Dr. Fergus O'Ferrall of the Adelaide trust made the following observations.

Including the concept of Person Centredness in the Health Strategy was right and powerful and would correctly imbue people with the right to expect to be considered and treated in that way. He followed this by posing the question as to whether having it as a right in policy would deliver it as the lived experience of the person receiving the service. In essence his reflection seemed to hark back to what the core value might be behind the right to be treated in a Person Centred way, and that this was necessary if the people who were to make that right a reality could appreciate and understand that core value; in other words it is not some new thing which we all now have to deliver along with all the other requirements of our role.

In elaborating on this in his paper in 2003 he returns to some core concepts such as Duty and Service. The sense that he approaches Duty from is not wholly from the professional "duty of care" concept but more an inherent duty of presence and sharing with others where the necessity that initiated the point of care of the other and that brought us into contact with them was a particular clinical of care skills we bring but ultimately that care is more holistic and relational in all its encounters and in its healing or nurturing.

Equally on the concept of Service he distinguishes what we do as "the service" from a probably older notion again originating in the notion of relationships or "to serve". In a paper in 2002 Professor Jeanne Matlary of the Institute of Political Science, University of Oslo, picks up on this theme in comparing the notion of service and work and how we approach it from a "Work"

and a "personal or family life" perspective. The interesting link here being where she notes that what we do for our family or children we do as a service of love in the ordinary things of life, yet in many of the engagements of delivering an ordinary life to people with disabilities we expect and measure in a way analogous of a performance based business system when what people are asking for and what we are telling our staff to do is to deliver an ordinary life with meaningful relationships. There is a paradox of thought and practice, of value and right, are we delivering because the person has a right to the service or because we believe in them and in what we want to bring relationally to our work.

In a separate paper addressing Human Rights in 2008 Professor Matlary draws further on a theme which may lead to further reflection as to why rights statements and international articles may not of themselves lead to the changes we would wish or expect to follow upon their declaration. Her central point being that a pluralist society can agree and evolve a set of rights which are accepted by that society, the difficulty arises around a core concept of equality which is fundamentally held as a right. Where this has transitioned to the equality of individuals rather than collective society defining values and beliefs then the implementation of one set of rights may infringe the right to the individual belief and values of another, i.e. the difficulty of individual relativism. So while collective rights might be agreed their implementation may become problematic within this paradox. *"There are thus at least two paradoxes at work here. While Europe and the West exhort the rest of the world to follow human Rights, and in fact make this a condition for aid and cooperation, European politicians simultaneously refuse to define, in an objective manner, what these rights really mean. Secondly, while these rights are appealed to more and more, they are undermined as sources of authority by erosion of the belief that they can be defined in a clear and objective way"*.

Writing in like manner on this topic in her analysis Rights Talk Harvard Law professor Mary Ann Glendon has written that *"discourse about rights has become the principal language that we use in public settings to discuss weighty questions of right and wrong, but time and again it proves inadequate, or leads to a standoff of one right against another. As various new rights are proclaimed and proposed, the catalogue of individual liberties expands without much consideration of the ends to which they are oriented, their relationship to one another, to corresponding responsibilities, or to the general welfare. These two processes are intertwined, and are symptoms of a deeper crisis in European politics: that of an ever greater irrationality and relativism"*.

Reflecting on this and our hopes for a rights based enablement of significant change for our peoples lives probably raises some questions, or may in fact be part of the answer as to why despite having codified rights documents we do not have the progress we may have anticipated. Returning as Fergus O'Ferrall did to the value behind the right (of Person Centredness), or why is a particular right important in the first place and what lead to it being ratified and codified may be a worthwhile exercise.

In searching here the work of professor Paul Vitz The Institute for the Psychological Sciences, University of New York has some interesting avenues of exploration. Part of his work has examined the historic Judeo- Christian influences as against the more contemporary or modern philosophical influences including those from the field of Psychology as it pertains to the

conception of the person. Such contemporary thinkers and practitioners would include the personality theory work of Freud, Carl Jung, Alfred Adler, Erik Erikson. The route taken by Vitz again explores the basis on which man as an individual or as a Person belonging to a collective (Society) establishes his values and describes his moral "rights" and "wrongs" and then acknowledges them by committing them in a codified description such as a charter. Even in society where there may be two starting positions (Relative Morality v Moral Standards) on this journey of collectively agreeing what is right it may well be possible to establish a set of rights held in common, the difficulty arises in how these two starting points then direct values in systems and structures of delivery within society (which may be why politicians actually find it hard to objectively define what a right means; as the relative morality position presupposes the right of the individual to define his / her own values system as an equal right).

Interestingly while Vitz doesn't journey directly into the debate on rights but rather stays focused on the person, personality theory and the individual, he does venture into the arena of relationships and the significance and genesis of the importance and intention of relationship for man from the Christian perspective. *"Christianity postulates interdependence and mutual but freely chosen caring for the other as the primary type of adult relationship. Personality is fulfilled in self-giving love and not in isolation:*

Final Thought:

While the rights committee report in the U.K certainly raised many surprises it has equally raised as many questions as to why the experience may be as described for people with a disability in a leading developed Society. Possibly the question it asks is if developed Society is overly defined and understood in economic terms while the measures of worth, care, and respect for its most vulnerable citizens supported through adequate fiscal and regulatory structures does not resonate with what reasonable people in a developed society would expect. If this is so then people with disabilities may be performing a most important role in assisting all of us come to an appreciation of the meaning of dignity for all of man; every person can be as or more fragile and vulnerable upon the turn of a day as anyone with a disability.

Do we need to ask these questions at all or are we merely at a stage of evolution that will correct itself and bed down without intervention? Possibly the answer to this lies in a sobering reflection of the joint Committee on the recently published new strategic document Valuing People Now (2008) namely *"In the light of the evidence which we received on the gap between the aims of Valuing People and the experience of adults with learning disabilities, we are concerned that in Valuing People Now there appear to be few measurable targets for action nor precise proposals for monitoring progress on their achievement".*

(P. Henry, Pobal Research Project, Br. Charity Services, Co. Roscommon)