National Federation of Voluntary Bodies

Literature Review

Intellectual Disabilities, Capacity, Autonomy, and Self-determination

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A. Introduction

Electronic and print resources were screened in order to identify articles for inclusion in this project. Most of this screening was carried out in the library of the National University of Ireland, Galway, while some research was performed using search engines on the Internet. Initially the criterion for inclusion was extremely broad, encompassing all articles relevant in any way to intellectual disabilities, capacity, autonomy, and self-determination. Articles were then narrowed down to include only those that were of recent publication and that would be easily understandable for all readers.

The articles which were chosen for inclusion in this project were subjectively selected by the authors and do not represent a definitive list of reading in this area.

B. Research Results

I. Importance of Capacity and its Determination

1. Determining Capacity

Bartlett, Sandland, "Tests of Capacity" in *Mental Health Law Policy and Practice* (Oxford, 3rd ed. 2007) 505

Keywords Tests of Capacity, Presumption of Capacity, Choice.

Under the leading theme "Mental Capacity: Broad Issues and Basic Concepts" the authors describe different tests to define capacity or rather – under the presumption of capacity – to prove that a person lacks capacity.

Bartlett and *Sandland* discuss status approaches, the test whether an individual can evidence a choice, and the question whether the outcome of a choice has to be 'reasonable' or reached on the basis of rational reasons. It is further scrutinized whether a person's *general* ability to understand or her *actual* understanding should play a determinative role or how appreciation of information contributes to the determination. All of those tests are examined under the aspects of benefits and drawbacks, where suitable with regard to philosophical and social implications, and their practical relevance in adjudication, reform models, and medical treatment.

Particularly useful for Although intended as academic study, by asking the reader questions on the virtues of each testing approach rather than providing definite answers, this chapter may enlarge the reflection of inherent premises or preconceptions for both legal scholars and everyday-readers.

Dörte Herrmann

Silver, "Reflections on Determining Competency," (2002) 16 Bioethics 455

Keywords Psychiatrists, Autonomy, Best Interest Approach.

Silver uses the examples of Hamlet, Dr. Jekyll and Mr. Hyde as well as Ebenezer Scrooge to illustrate the role of psychiatrists in determining capacity from a philosophical point of view.

As a starting point, *Silver* provides an - admittedly non-empirical - overview of practitioners' motives when determining capacity and tries to connect those to the respective determination approach utilised.

In connection with his strong approval of autonomy, he addresses the conflict between a person's autonomy as "great intrinsic value" and her welfare under a best interest approach that may arise if one does not understand autonomy merely as capacity to make a *good* decision.

The last part of the article consists of an effort to define the concept of autonomy with regard to philosophical and cultural considerations. As a result, the author argues in favour of a very high threshold to claim a person to be incapable; this should in fact only be possible if "the best interpretative efforts fail to construct a plausible story of freedom."

Particularly useful for The article is demanding yet recommendable for carers of disabled persons because it achieves to illustrate the abstract philosophical implications of capacity determination in a very understandable way.

Dörte Herrmann

Donnelly, "Assessing Legal Capacity: Process and the Operation of the Functional Test," (2007) 7 Judicial Studies Institute Journal 141

Keywords Determination of Capacity, Functional Approach, *Mental Health Act 2001,* Procedural Requirements.

The article addresses the question of the formal determination of incapacity. After a historical overview of capacity determination *Donnelly* elaborates on the functional approach as "widely accepted" one to assess capacity. She submits that this test also applies to wards of court under the Lunacy Act 1851, at least where medical decisions are at stake, and to persons who are involuntarily admitted under the Mental Health Act 2001. Whereas the author states that - under the premise of human dignity and individual rights - there won't be any alternative to the functional approach, she also acknowledges "the pressures which this approach places on capacity assessors and on the capacity assessment process."

Where suitable, *Donnelly* seeks to make use of legislative and factual experience in England and Wales as possible sources for findings under the Irish legal order as well as of cases decided by the European Court of Human Rights.

One of the main focuses of the article lies in the discussion of specific procedural requirements during the judicial assessment of capacity to make due allowance for the "therapeutic impact of legal rules." The most fundamental requirements she identifies are

- the independent legal representation of the individual concerned,

- an obligation to consult the individual or other interested parties in a respectful, accepting and welcoming manner, and
- a sensible and critical approach to necessary expert evidence.

Particularly useful for The article is written from a high-level, academic perspective. However, it conveys the relevance of capacity assessment as pivotal question for preserving and enforcing individual rights in a way that will be comprehensible for persons without a legal background, too. It may well serve professional carers and physicians to fully understand the legal ramifications of their individual assessments. It may also help them not to see the judiciary as opponent who shall be convinced at any cost but rather as part of an alliance to make the most adequate individual decision.

Dörte Herrmann

II. Consent to Medical Treatment as Specific Aspect of Capacity

Chris Fitzpatrick, John Ryan v. F.K., The Attorney General, **Judgement of High Court, [2008] IEHC 104 (unreported)**

Keywords Consent to Life-saving Treatment, Determination of Capacity, Fully Informed Decision-making.

In *Chris Fitzpatrick, John Ryan v. F.K., The Attorney General* the High Court was concerned with the question whether a court could intervene in the case of an adult patient who refused life-saving medical treatment but was generally legally capable. It had to discuss the issue - hitherto unanswered by Irish courts – of how to *test* the capacity to refuse consent to medical treatment on the part of an adult.

The defendant, Ms. K, gave birth to a baby boy in a hospital and shortly thereafter suffered from a massive haemorrhage. Only when the medical staff prepared for a blood transfusion they were told that Ms. K would not take blood because of her membership of Jehova's

Witnesses. However, after the responsible physicians had obtained an order from the High Court they conducted the transfusion.

In the present proceedings plaintiffs sought an injunction stating that they were justified in administering the abovementioned treatment. They argued that there were doubts as to Ms. K's ability to make a fully informed decision concerning the refusal of medical procedures necessary to save her life.

With regard to the capacity question the High Court stated that in

> "[…] determining whether a patient is deprived of capacity to make a decision to refuse medical treatment […] the test is whether the patient's cognitive ability has been impaired to the extent that he or she does not sufficiently understand the nature, purpose and effect of the proffered treatment and the consequences of accepting or rejecting it in the context of the choices available (including any alternative treatment) at the time the decision is made."

With regard to *Re C (adult: refusal of medical treatment)* [1994] 1 All E.R. 819 the court invoked a three step approach as tool in implementing the test. Accordingly, a patient lacks the capacity to make a valid refusal if he or she

- does not *understand* the information concerning the necessity and scope of the intended treatment or is not able to *retain* it
- or does not *believe* it,
- or is not able to *weigh* the information and balance risks and consequences which would be connected with the decision.

The court found that the physicians were justified in doubting Ms. K's capacity to make an informed refusal on the ground that there had been communication difficulties. Ms. K's first language was not English so that she needed the help of an interpreter who happened to be a relative and also a member of Jehova’s Witnesses. Furthermore, in the decisive situation of emergency, she did not believe in the likeliness of her death without the transfusion and did not weigh that substantive risk against the consequences not only for her but also her new-born baby.

Particularly useful for The judgement is vitally important for policy-makers, service providers and medical practitioners because it clarifies the applicable capacity test in Ireland. Above all, its main benefit lies in its distinct and comprehensible operation of the three step approach. Further significantly, the court emphasized the difference between misunderstanding or misperception of information (which has to be considered in assessing capacity) and irrationality (which is irrelevant to the assessment).

Dörte Herrmann

Inclusion Ireland, “‘Who Decides & How?’- Making Medical Decisions - An Information Booklet for Parents and Families of Children with Intellectual Disabilities,” available at: http://www.inclusionireland.ie/documents/MakingMedicalDecisions_001.pdf

Keywords Consent, Capacity, Legal Rules on Decision-making, Children, Incapacitated Adults.

The booklet covers four distinct areas related to medical decisions which are

- explaining ‘consent & capacity,’
- deciding on the capacity of a person,
- ward of court and power of attorney, and
- approaches in other countries and future development in Ireland.

It specifically explains the presumption of capacity, the rules relating to consent with regard to children and adults, emergency and non-emergency situations, and intrusive and nonintrusive treatment. In particular, it clarifies that an adult making a ‘bad’ decision must not be overruled simply on the ground that he lacks capacity to make the decision. Furthermore, the role of the family is stressed as presumably being the best source of information about the individual. However, the booklet is very clear on the fact that so far there is no legal rule to allow decision-making of a family member on behalf of the incapacitated adult. For those occasions, it refers to the Medical Council’s “Guide to Ethical Conduct and Behaviour” as decisive authority for doctors providing for a wide-ranging consultation process.

Particularly useful for The booklet is designed in a question-answer mode and specifically addresses parents and families of children with intellectual disabilities. In its appendix it contains some useful contacts, pointing, *inter alia*, to the website of the Medical Council where the abovementioned guidelines can be found.

Dörte Herrmann

Department of Health, “Consent - A Guide for People with Learning Disabilities,” available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006066

Keywords Consent to Medical Treatment, Functional Approach.

This leaflet is also concerned with the necessity of consent to medical treatment. It explains the different ways of how consent can be expressed. It further describes the scope of information that necessarily has to be given prior to the treatment as well as the option to ask additional questions or to seek assistance of friends, relatives and carers. Although drafted in the England, it relates to the now generally accepted rule that consent to medical treatment shall be obtained from an adult as far as the functional approach to capacity allows it.

Particularly useful for Because it is designed in a very clear style with lots of pictures, it may be valuable illustrative material for people with intellectual disabilities. As such it constitutes a good supplement to the guide of *Inclusion Ireland*.

Dörte Herrmann

III. Autonomy, Self-Determination and Ethical Considerations

1. General

Harris, "Respect for Persons I" in Harris, *The Value of Life* (London, 1985)

Keywords Respect for Persons, Autonomy, Mental Illness, Control.

Abstract The foundation of respect for persons is the acknowledgment that what each person considers valuable and important in their lives will differ from the next and that these differences make no one life more valuable than the next. In Harris' opinion people who have 'respect for persons' will exhibit both concern for their welfare and respect for their wishes. Although both elements are fundamental requirements of respect for persons they are not always easily reconcilable in the medical field. It is extremely difficult for health care professionals to respect the wishes of their patients when they make decisions, which are in no way conducive to their situation and may even be harmful to their health. Problems can occur when doctors or nurses override their patients' autonomy believing that they are acting in their patient's best interests.

What is autonomy? Autonomy is the ability to choose and control your own path in life through exercising your own faculties. The article proposes that there are four main defects that weaken or reduce a person's autonomy. (i) Defects in Control. A person may suffer from a severe mental illness that has such an effect on their ability to control their own lives that they are deemed as being out of their control whilst this illness is present. Once concrete evidence is provided to support such an assumption decisions made by this person will not be regarded as autonomous. (ii) Defects in Reasoning. Once an individual allows prejudices, the views of others or those of society to influence their decisions to such an extent that it interferes with their reasoning process then the legal validity of these decisions will be destroyed or impaired. They are in effect accepting the views of others rather than reaching their own autonomous decisions. (iii) Defects in Information. Choices will not be considered as autonomous if they are based upon false or incomplete information. Others may have provided them will this incomplete or incorrect information or they themselves may have misunderstood these facts and reached the wrong conclusions. (iv) Defects in Stability. Decisions made at a young age are often in hindsight embarrassing or absurd and may differ greatly from what your wishes in later life may be. This defect in stability is often used as a justification for paternalism however decisions which you now regret do not mean that these decisions were not based on your beliefs at that time and were completely autonomous.

Particularly useful for This article does not specifically discuss intellectual disabilities and is therefore extremely useful for anyone interested in obtaining a broad understanding of the concepts of self-determination and autonomy.

Aoife Maeve Clarke

Walker, "Autonomy, Beneficence, and Justice in the Wider Context," (2002) 12 Ethics & Behaviour 273, 291

Keywords Autonomy, Beneficence, Social Environment, Functional Approach.

The author explains the concepts of autonomy, beneficence and justice on the basis of three case vignettes that are concerned with characteristic problems arising during the contact with mentally impaired persons.

She clarifies that, although autonomy is most closely related to the individual, it does not mean that it could be implemented without regard to the social environment and support, and the necessity to protect in certain situations. Furthermore, she submits that the capacity of a person is dependant of time and issue concerned. Finally, *Walker* emphasizes that one has to acknowledge the reciprocity of relations between disabled persons and their families and carers as well as the wider community to prevent excessive demands from the latter.

Particularly useful for The author succeeds in explaining difficult philosophical concepts in a simple and understandable language which in connection with illustrative case examples make the article a valuable starting point for further ethical consideration of an interested every-day reader.

Dörte Herrmann

Inclusion International, “This is our Convention too! People with Intellectual Disabilities & the Right to Make Decisions,” available at: http://www.ii.tomekklas.com/site_uploads/File/Legalcap.%20bulletin.pdf

Keywords Legal Capacity, UN Disability Convention, Self-determination.

This document is aimed at explaining the way people with an intellectual disability can make decisions and choices and what impact this ability has for them. It describes capacity as basis to make use of any right guaranteed under the UN Disability Convention. In this regard, it explains the content of ‘legal capacity’ and the concept of supported decision-making as well as the key terms ‘self-determination’ and ‘personhood’ in a comprehensive and clear scheme. Furthermore, it illustrates its points by including statements of self-advocates who vividly explain, how it feels to be ignored.

Particularly useful for The language is plain but does not amount to an easy-to-read style. Therefore, it is most suitable for carers and family members of intellectually disabled persons.

Dörte Herrmann

Inclusion Europe, "Your Rights as Citizens - Being a Person before the Law," available at: http://www.inclusion-europe.org/Justice/EN/EN_ETR_Capacity.pdf

Keywords Status Approach, Functional Approach, Decision-making, Self-determination.

The booklet describes how the notion of capacity has changed from a status approach towards a functional point of view over the last years. It points out how the ability to make a decision can vary depending not only on the severity of the disability but, at least equally, on the issue concerned or the time the decision has to be made. To implement effective self-determination as far as possible the booklet provides guidelines of the way a system of supported decision-making should be operated.

Particularly useful for It addresses the reader with an intellectual disability directly, is written in an easy-to-read style and contains a number of auxiliary pictures.

Dörte Herrmann

2. Determinants of Self-Determination

Wehmeyer, Garner, "The Impact of Personal Characteristics of People with Intellectual Disability on Self-Determination and Autonomous Functioning," (2003) 16 *Journal of Applied Research in Intellectual Disabilities* 255

Keywords Intellectual Disabilities, Self-determination, Prejudice, Intelligence levels.

Background Due to the presence of their disability it is often assumed that people with intellectual disabilities are incapable of being self-determined. This assumption is based largely upon societal prejudices but has some basis in studies which show that people with intellectual disabilities are not very self determined. Current debate in the area, however is now focusing on the determinants of self determination. Results show that work, living and learning environments play a more important role in building self-determination in individuals with intellectual disabilities than intelligence levels.

Method This study examined the self-determination and autonomous functioning of 301 individuals. There were 140 male and 161 female participants recruited from advocacy and support agencies across 10 different states in the U.S.

Results and Conclusions Intelligence levels do not predetermine either self-determination or autonomous functioning of individuals with intellectual disabilities. IQ levels do however impact directly upon their employment and living opportunities, which in turn affect self-determination, but of itself, intellectual capacity does not contribute to self-determination levels.

Particularly useful for As this study addresses the determinants of self-determination and autonomous functioning, it is of extreme value to service providers and all those working in the care and education of people with intellectual disabilities.

Aoife Maeve Clarke

3. Influence of Cultural Values on Self-Determination

Turnbull, Turnbull, "Self-Determination for Individuals with Significant Cognitive Disabilities and Their Families," (2001) 26 *Journal of the Association for People with Severe Handicaps* 56

Discussion In a short and rather complex article Turnbull and Turnbull address a number of key issues with regard to self-determination, writing both as professionals and as parents of an adult child with significant mental and physical disabilities. They explain in detail the barriers which they have had to overcome to help their son become self determined and humbly show that irrespective of their university degrees and experience in this field that this has been an extremely daunting task. Interestingly, for the purpose of this project they discuss the influence of cultural values upon our understanding of self-determination. As huge numbers of people from varying countries immigrate to Ireland this issue is of growing importance for professionals working with these patients and their families. Our understanding of self-determination is deeply rooted in our cultural beliefs, values and practices. Consequently these cultural differences should be reflected in the care patients are afforded.

Particularly useful for This article is aimed at an academic audience but may also be helpful to parents of children with intellectual disabilities as the authors are writing not only as professionals but also as parents of a child with significant mental and physical disabilities.

Aoife Maeve Clarke

4. Outcomes of Self-Determination Interventions

Algozzine, Browder, Karvonen, Test, Wood, "Effects of Interventions to Promote Self-Determination for Individuals with Disabilities," (2001) 71 *Review of Educational Research* 277

Keywords Self-determination, Literature review, Research, University of North Carolina.

Discussion Self-determination for individuals with disabilities is a relatively new concept and therefore little research has been undertaken on the effects of self-determination outcomes. Through the University of North Carolina, these authors have provided the first comprehensive review of literature to determine what self-determination interventions have been studied, what groups of individuals these studies entailed and the results of these investigations. The 51 studies which are discussed cover all areas of disabilities and participants aged from 3 years old to adulthood. All articles in this study are relatively recent, dating from 1972 to 2000. The general aim of this project was to demonstrate that self-determination can be taught and learned through varying methods and the effect which this has upon the lives of individuals with disabilities.

Particularly useful for This is the first comprehensive literature review of self-determination studies and is therefore very valuable to anyone undertaking research in this field.

Aoife Maeve Clarke

IV. Planning for the Future

1. General

Carney, Keyzer, "Planning for the Future: Arrangements for the Assistance of People Planning for the Future of People with Impaired Capacity," (2007) 7 *Queensland University of Technology Law and Justice Journal* 255

Keywords Informal Carers, Parents, Children, Wills, Estate Planning, Powers of Attorney, Trusts, Guardianship, Reform.

Abstract Parents of children with disabilities often assume the role of primary carer upon the birth of their child and continue this role until they predecease their child or loose the capacity to continue caring for them. As these parents reach old age they begin to worry about what will happen to the care of their child when they are gone but are reluctant to rely upon legal services to help them plan for the future. In many cases some amount of informal planning is exercised but this is usually in the form of an unspoken expectation that siblings will take over as successive caregiver.

The death or incapacitation of a parent is a very traumatic experience for children with disabilities and if no formal plans have been made for the child they are often placed in unsuitable accommodation or care. Formal planning is therefore essential to ease this transition and to help allocate the child in suitable care. This article analyses and critiques numerous legal tools which can be used to help carers plan for the future and how to legally replace their informal position as carer. A number of substitute decision-making positions are addressed and also ways in which to manage economic matters. The authors discuss the advantages and disadvantages of wills, estate planning, powers of attorney, trusts and guardianship and conclude with a short discussion of possible reforms in this area. The article is written from an Australian stance but nonetheless is extremely useful for legal practitioners and informal carers in any country to inform them the number of possibilities, which are available.

Particularly useful for This article is aimed at carers and parents of children with intellectual disabilities, who are concerned about their future care. As it is extremely informative on the numerous legal options available, it may also be useful to lawyers.

Aoife Maeve Clarke

Herr, "Self-Determination, Autonomy and Alternatives for Guardianship" in Herr, Hongju Koh, Gostin (eds.), *The Human Rights of Persons with Intellectual Disabilities: Different but Equal* (Oxford, 2003)

Keywords Guardianship, Reform, Sweden, Mentorship, Contact Person. Escort Person, Personal Assistant, Germany, Austria, Israel, Holland, Spain and New Zealand.

Abstract Once guardianship proceedings have been initiated the individual is prevented from exercising control over their lives and all power is shifted to the guardian allowing them to decide upon all financial and personal matters. In recent years many countries have abandoned or have began to limit the usage of guardianship for these reasons. Legislative reforms are now focusing upon the autonomy and self-determination of individuals with intellectual disabilities by adopting less restrictive measures. This article comparatively examines these reforms and related reforms in the area of intellectual disability in eight differing countries. The author uses Sweden as the anchor of the discussion discussing their laws in great detail.

The comparative analysis adopted in this article portrays the diversity of alternatives to guardianship. Sweden is the world fore runner in respecting and enforcing the self-determination of individuals with intellectual disabilities. Through a legislative amendment in 1989, they restricted the use of guardianship to minors under the age of eighteen. For adults, mentorship is now the most common support service. Once a mentor has been appointed the civil rights of the person with a disability are unaltered and the relationship between mentor and the individual is tailored to the needs of the individual. Mentors powers are only to be exercised where and when they are needed and they are restricted from acting where the individual themselves could have done so. Mentors are appointed when possible but in extreme situations an administrator can be appointed to act as substitute decision maker. This type of support service is only used as a last resort when all others options have been deemed insufficient. Sweden offers numerous other support options for people with disabilities including a contact person to offer companionship, an escort person to accompany them on excursions and personal assistants to allow people to act autonomously and to improve freedom of choice.

The article uses Sweden as an excellent example of legislative reforms that strengthen the autonomy and self-determination of people with intellectual disabilities. The guardianship laws of Germany, Austria, Israel, Holland, Spain and New Zealand are also briefly discussed but no reform has been as successful as Sweden.

Particularly useful for This article comparatively examines the many alternatives to guardianship which have been adopted in a number of countries in favour of more autonomous methods. It is easy to read and therefore accessible to all readers interested in this topic.

Aoife Maeve Clarke

2. European Perspective

Inclusion Europe, “Justice, Rights and Inclusion for People with Intellectual Disability,” available at http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1279&context=gladnetcollect.

Keywords Inclusion Europe, European Commission, Intellectual disabilities, Legal Capacity, Guardianship, Reform, Sweden, Germany, Spain, France, Ireland, Belgium, the Netherlands, Slovenia and Poland.

Abstract Inclusion Europe with the aid of the European Commission undertook a survey of European Countries discussing the themes of legal capacity and guardianship, rights to services and support and access to rights and justice of people with intellectual disabilities. The chapter on legal capacity and guardianship comparatively examines European laws in this area. Although surveys were completed for all countries, the reports from Sweden, Germany, Spain, France, Ireland, Belgium, the Netherlands, Slovenia and Poland were selected for discussion so as to provide an overview of the varied laws governing guardianship in Europe. Sweden and Germany are commended for their successful legislative reforms and provide a template for other countries to copy or build upon. In France there are three different measures of protection, legal safeguard, trusteeship and protection, afforded to those who lack the necessary capacity to make decisions. The individual needs of each adult determine which type of protection they require. Belgium offers a number of legal protection measures but the two most frequently used are the extended minority and provisional administration. Under extended minority the individual is considered as a minor incapable of controlling all aspects of their lives. This is reserved for individuals with severe intellectual disabilities. Provisional administration only concerns the goods of the individual, while their personal well-being remains within their own control. In the Netherlands full legal guardianship still exists and involves complete substitute decision-making powers. They also offer two partial guardianship measures; one covering only material matters ("*Beschermingsbewind*") while the other only covers immaterial matters ("*Mentorship*"). The Spanish system has established guardianship, protection and the judicial advocate. The legal measure of Protection provides an alternative to guardianship offering less protection and the judicial advocate is established to negotiate conflicts between the legally incompetent person and their advocate. Ireland's

laws, on the other hand, are outdated and quite archaic offering only wardship proceedings. However, there is intense lobbying for reform so change in the laws is pending. Others countries such as Poland maintain traditional guardianship laws for fully incapacitated persons rendering them incapable to marry or become employed. Slovenia's laws allow for an extension of parental rights and obligations as a substitute to guardianship for adults.

Conclusion Sufficient laws concerning capacity and guardianship are prerequisites for individuals with intellectual disabilities to remain autonomous and self determined. The country reports show enormous deficiencies in these laws throughout numerous European countries and highlight the necessity of reform.

Particularly useful for This report comparatively examines European guardianship laws, discussing the reforms which have been undertaken in many countries. It is written in a clear and accessible fashion and is therefore accessible to all readers.

Aoife Maeve Clarke

3. Wardship

O'Neill, "Wardship in Ireland," (2005) 8 *Irish Journal of Family Law* 1

Keywords Ward of Court, *Lunacy Regulation (Ireland) Act 1871*, *Rules of the Superior Courts 1986*, Unsound Mind, Incapacity, Declaration Order, Committee of the Person and Estate of Ward.

Abstract The ward of court system under Irish law is a substitute decision-making regime. The origin of this system is found in the fourteenth century statute De *Praerogativa Regis* wherein the notion of the Crown as *parens patriae* (guardian of the people) was established. The criteria and procedure for taking a person into wardship is set out in detail in the *Lunacy Regulation (Ireland) Act 1871* and Order 67 of the *Rules of the Superior Courts 1986*.

The High Court has full original jurisdiction in wardship proceedings while the Office of Wards of Court deals with all wardship applications. A person will only be taken into wardship when it is has been established that the person is both of unsound mind and incapable of managing his/her person and property. A family member under section 15 of the 1871 Act usually initiates wardship proceedings. Petitions to the High Court need to be accompanied by supporting affidavits of two registered medical practitioners. There are numerous other procedures outlined in the 1871 Act to make a person a ward of court.

Once the judge or jury is satisfied that a person is of unsound mind and incapable of managing his/her person and property a declaration order is made admitting the person to wardship. The declaration specifies a particular person to be appointed committee of the person and estate of ward and the powers that will be placed upon them. Once a person is made a ward of court they loose complete control of their lives and this jurisdiction now rests in the Court.

[For a more detailed discussion of wardship proceedings in Ireland see generally, O'Neill, *Wards of Court in Ireland* (Dublin, 2004) and Law Reform Commission Consultation Paper on the Law and the Elderly, LRC CP 23-2003, Chapter 4]

Particularly useful for Although this article was originally published in a legal journal, it is easily readable for all those interested in the ward of court system under Irish law.

Aoife Maeve Clarke

4. Enduring Powers of Attorney

O'Connor, "Enduring Powers of Attorney-Planning for the Advent of Mental Incapacity," (1998) 16 *Irish Law Times* 153

Keywords Enduring Power of Attorney, Autonomy, *Powers of Attorney Act 1996.*

Abstract An enduring power of attorney is created by a donor whilst still of full capacity. This mechanism allows the donor to plan for the future where deterioration in mental health is pending. The donor can autonomously appoint an attorney and grant them certain decision-making powers. Power will only become effective once the donor is proven to be incapable and if this never occurs the donor retains complete control over their lives and property. The *Powers of Attorney Act 1996* outlines the regulations concerning the appointment and registration of an enduring power of attorney. This article discusses the form and content of statements creating an enduring power and those who are disqualified from acting. The author practically addresses how the enduring power is brought into effect and the procedure of registration.

[This article briefly addresses the mechanisms of appointing an enduring power of attorney. For those interested in a more comprehensive discussion of enduring powers of attorney see Law Reform Commission Consultation Paper on the Law and the Elderly, LRC CP 23-2003, Chapter 3]

Particularly useful for This article was originally aimed at an academic audience, however it is quite short and easy to understand so is therefore of value to those interested in the mechanisms of appointing an enduring power of attorney.

Aoife Maeve Clarke

5. Guardianship

Law Reform Commission, "Vulnerable Adults and the Law," LRC 83-2006

Keywords Ward of Court, Guardianship, Autonomy, Least Intervention, Guardianship Board, Personal Guardian, Office of Public Guardian, Intervention Orders, *Mental Capacity and Guardianship Bill*, *Lunacy Regulation (Ireland) Act 1871*.

Abstract In previous publications, Consultation Paper on Law and the Elderly and the Consultation Paper on Vulnerable Adults and the Law: Capacity, the Commission found the ward of court system extremely unsatisfactory. The Commission recommends that the Ward of Court system be abolished and replaced by a "modern, comprehensive substitute decision-making scheme…which will balance the rights of self determination and autonomy and the need for protection" (*at* 115). They recommended the establishment of a new Guardianship system which will maximize personal autonomy and minimize the level of intervention. In the report the Commission proposes that a Guardianship Board consisting of a High Court judge acting as chairperson, a registered medical doctor and a health professional with training and experience in the field of capacity will be established. The functions of this Board are to make Guardianship Orders, to appoint Personal Guardians and to make Intervention Orders.

The Board will only make a guardianship order and appoint a personal guardian when an adult lacks legal capacity and such an order is completely necessary. The order sets out in detail the authority of the personal guardian and the supervision and review required. The powers conferred upon a personal guardian are limited to the scope of the order, therefore some personal guardians may make substitute decisions regarding property while others may make them with regard to the personal welfare of the adult who lacks capacity. Due to this, the terms of each order will vary depending upon the individual needs of each case. Personal guardians are prevented from making substitute decisions where they know or believe that the person concerned has the capacity to make the decision himself or herself. Where an adult lacks the capacity to make one particular decision an intervention orders may be granted where a once-ff decision is required.

The recommendations also provide for the establishment of an Office of Public Guardian to take over from the current Registrar of Wards of Court. The Office would also have new extended powers and functions. The primary function of the Office is to supervise all personal guardians and enduring powers of attorney whilst also fulfilling an educative role to the general public on all issues concerning vulnerable adults.

The Commission concludes their report with a draft Scheme of *Mental Capacity and Guardianship Bill* which they propose to replace the *Lunacy Regulation (Ireland) Act 1871.*

Particularly useful for As with all Law Reform Commission publications, this report is well written, easy to understand and accessible to the general public while also being extrememly useful for academics and professionals.

Aoife Maeve Clarke

6. Wills

Inclusion Ireland, "Making a Will, An Easy to Read Guide to Making a Will," available at: http://www.inclusionireland.ie/documents/WILLDOC.pdf

Keywords Inclusion Ireland, Intellectual Disabilities, Will.

Abstract Inclusion Ireland is an organization whose aim is to promote the rights of individuals with intellectual disabilities. In this publication they explain clearly and precisely the procedure of making a will. They discuss that a will is a special document, which lists the things you own, and allows you to leave them to a particular person when you die. If this document is not made your belongings go automatically to your next of kin. In order to make a will the article clarifies that you must be over 18, understand the concept of a will and sign it and the assistance of a lawyer will usually be needed. If you change you mind about the will at a later stage you can change your will with the help of your lawyer.

Inclusion Ireland have also published another document entitled "Making a Will, What you should know, A guide for parents and families of people with intellectual disabilities" available at http://www.inclusionireland.ie/downloads/booklet_make_a_will.pdf. This booklet discusses the special considerations which parent of children with intellectual disabilities should take into account when executing a will in order to provide for continued financial support and care for their child and avoid their exploitation.

Particularly useful for These booklets are aimed at individuals with intellectual disabilities and their parents and families to provide them with valuable information regarding the making of wills.

Aoife Maeve Clarke

V. Self-advocacy

Owen, Downer, "Why is it Important for People with Intellectual Disabilities to Have a Voice of Their Own," available at: http://www.intellectualdisability.info/values/self_advocacy.htm

Keywords Self-advocacy, Self-esteem, Inclusion.

This article emanates from a citation of a self-advocate explaining the concept of self-advocacy. Using this citation the article gives further details of its aspects, such as the building of self-esteem, ways of communication, different choices to make, inclusion into society, and enjoying a so-called normal life with all its benefits and risks. However, it also emphasizes the occasional need for help of the disabled persons

Particularly useful for It is addressed to disabled persons directly and seeks to provide them with an understanding of the concept of self-autonomy by presenting a statement of a positive role model. It is accompanied by some pictures and written in an easy-to-read style to a large extent.

Dörte Herrmann

European Platform of Self-Advocates, Inclusion Europe, "People with Intellectual Disabilities can Decide More by Themselves - How Family Members and Professionals

Can Promote Self-Advocacy," available at: http://www.inclusion-europe.org/documents/2201.pdf

Keywords Self-advocacy, Self-esteem, Adequate Support.

The leaflet promotes the issue of self-advocacy as effective method to ensure the influence of disabled people on their daily lives in families and communities. To implement that aim it basically recommends the following steps and approaches:

- involving disabled persons and developing their self-esteem,
- learning to listen what they say,
- providing adequate information and training,
- not being overprotective, and
- supporting self-advocacy groups and positive role models.

Each point is specified under an individual heading with due regard to possible concerns and difficulties.

Particularly useful for The brochure is recommendable to family members and professionals as crucial persons to facilitate self-advocacy – which will finally lead to a more independent and fulfilled life.

Dörte Herrmann

Levitz, "Voices of Self-Advocates" in Herr, Hongju Koh, Gostin (eds.), *The Human Rights of Persons with Intellectual Disabilities: Different But Equal* (Oxford, 2003) 453

Keywords Independent Living, Participation, Self-advocacy.

Levitz, who suffers from Down Syndrome, gives an overview about how he has succeeded in leading an independent life, actively participating in community life, and representing the issues of intellectually disabled people. He mentions several aspects that he deems especially important to support an independent and meaningful life, such as the availability of public transport, access to public services, and a network of family, friends, and co-workers. Furthermore, he stresses the importance of understandable written and explained information as well as transition planning and assistance when it comes to a career. He is of the opinion that involvement of disabled persons in the community work and the employment of self-advocates would serve both the effective mediation of their concerns and their self-realization.

Particularly useful for The style of *Levitz* is sophisticated and very pleasant so that the article is highly recommendable for families, friends and other self-advocates providing an ostensive example of how things should ideally work out.

Dörte Herrmann

VI. Daily Life Issues

1. Family Life

Inclusion Europe, "Families and Intellectual Disability in Europe," available at: http://www.inclusion-europe.org/documents/999.pdf

Keywords Families with Disabled Children, Social Exclusion, Parenthood of Disabled Persons, Human Rights.

This Report considers the issue of families with disabled children and intellectually disabled persons as parents themselves. It assumes that nowadays the problems of families have changed: while services may have improved over the last years, parents now face the challenge to be the "professional parent" or the "expert of their disabled child" and to coordinate all the service providers who are approaching them. Still, other prevalent concerns might be social exclusion of the family from community life, discrimination, and substantial founding issues. The report describes the different agendas of parents with disabled and non-disabled children during the different stages of life. It suggests helpful services both directed to the disabled child and its family as a whole, with a particular mentioning of the problems of older carers and their concerns of how to provide for a future without them.

Another main issue of the report is the parenthood of intellectually disabled persons themselves. An automatic exclusion of them from the possibility to start a family has to be considered a violation of a basic human right. Once more, a case is made for a functional approach in assessing the capability of parents to raise their children, where necessary with support and help from the community and professional carers. The report also contains very illustrative results from a study conducted at the University of Bremen concerning the situation of intellectually disabled parents.

Particularly useful for By its own account, the report wants to reach "European politicians, decision-makers, professionals and organisations" to become fully aware of the problems and challenges that families with disabled children or disabled parents may face. Simultaneously, it intends to show that there are the very same love, relatedness and care for each other as in families without disability issues.

Dörte Herrmann

Brighter Futures, Early Intervention Program of Department of Community Services, "Brighter Futures Practice Resource - Parental Intellectual Disability/ Learning Difficulties Vulnerability," available at: http://www.community.nsw.gov.au/docswr/_assets/main/documents/brighterfutures_disability.pdf

Keywords Parenthood of Disabled Persons, Family Support Services.

This resource elaborates further on the issue of parents with an intellectual disability who were identified as one group facing major challenges in the report of *Inclusion Europe*. It particularly contains thoughts on the impact of parental disability on the child, an area where ostensibly only scarce empirical research is available. It is recommended that a "holistic view" upon the family unit shall be taken, that support shall be provided where necessary but that the positive aspects shall be emphasized rather than simply taking the child out of its family home.

Particularly useful for The paper is suitable for carers who work with disabled parents, especially since it names a number of strategies that should be employed when assisting and planning their family life. It provides a list of the available research for further recourse as well as a number of online resources from Australia and England.

Dörte Herrmann

2. Sexual Health and Well-Being

Eastgate, "Sex, Consent and Intellectual Disability," (2005) 34 *Australian Family Physician* 163, also available at: http://www.racgp.org.au/Content/NavigationMenu/Publications/AustralianFamilyPhys/2005Issues/afp200503/200503eastgate.pdf

Keywords Sexual and Reproductive Health, Adolescence, Family Planning, Abuse.

The article contains three case studies designed to highlight major issues arising in the context of sexual and reproductive health and well-being. It covers the different stages of childhood, adolescence, and adulthood, and elaborates on sexual abuse, consent to medical treatment, and contraception. Thereby, the main focus is laid upon women although the issues of abuse and family planning may equally apply to male disabled persons.

Particularly useful for It is written in an understandable style and might be of good value to general practitioners who are confronted with parents' or carers' requests. It could also help carers themselves in acknowledging and respecting the sexuality of intellectually disabled persons.

Dörte Herrmann

Abbott, Howarth, Gyde, “Secret Loves, Hidden Lives? Exploring Same Sex Relationships for People with Learning Difficulties - Easy to Read Summary,” (Bristol, 2005), available at: http://www.bristol.ac.uk/norahfry/download/easyreadsummary.pdf

Keywords Homo- and Bisexuality, Concerns of Carers, Positive Images.

This is the summary of research that has been carried out to explore the long neglected issue of homo- or bisexual affections of intellectually disabled persons. 20 persons with learning disabilities identified as being homo- or bisexual and 71 staff members from the United Kingdom have been interviewed about their experiences. The summary describes which difficulties people might face having a different sexual orientation than many others of their peers or their carers. They are under a high risk to become depressed or suicidal because of the bullying they experience or because they simply feel left alone and misunderstood. However, the document also contains information about the uncertainties and worries of carers who work with them. Most of the questioned carers were not even aware of the possibility that the people could be homo- or bisexual. The summary also provides for some ideas to proactively enhance the positive image of being gay or lesbian, such as using positive role models from TV or the music scene.

Particularly useful for It is written in an easy-to-read style and could be a good starting point to enter the dialogue on this issue with disabled persons, be it to reduce homophobia or raising the awareness that feeling in this particular way is perfectly normal sexual behaviour too.

[If suitable the summary might well be accompanied by the following documents: Abbott, Howarth, “Jan's Story. A Photostory about a Lesbian with Learning Difficulties,” available at: http://www.bristol.ac.uk/norahfry/download/jan.pdf; Abbott, Howarth, “Phil's Story. A Photostory about a Gay Man with Learning Difficulties,” available at: http://www.bristol.ac.uk/norahfry/download/phil.pdf; Abbott, Howarth, Gyde, “A Booklet about Challenging Homophobia and Heterosexism for People with Learning Difficulties and the Staff that Support Them," available at: http://www.bristol.ac.uk/norahfry/download/challenging.pdf. All documents are authored in a consistent style and aimed at the individually affected person.]

Dörte Herrmann

VII. Practical Guidance for Service Providers

1. Nurses and Doctors

Wilson, Clegg, Hardy, "What Informs and Shapes Ethical Practice in Intellectual Disability Services?," (2008) 52 *Journal of Intellectual Disability Research* 608

Keywords Intellectual Disability, Autonomy, Professional Codes of Practice, Doctors, Nurses, Ethical Advisory Group, Ethics, Conflict, Vulnerable, Relationships, Anxiety, Uncertainty.

Background Professional Codes of Practice provide little guidance to those working in the field of intellectual disability. They assume that clients are autonomous when in reality, patients with intellectual disabilities often struggle to achieve autonomy. They also adopt numerous and varying definitions of autonomy which further complicate the situation. Professionals are left with basic guidelines to help them provide ethical services to those with intellectual disabilities. This study aims to ascertain how professionals build upon these principles and treat these patients all the while respecting their autonomy.

Method Nine professionals, three women and six men, were recruited from different areas of ID care to take part in this research project. All had referred to a local Ethical Advisory Group for advice when dealing with ethical issues in the past. Interviews were conducted using a narrative methodology to allow the professionals to discuss whatever aspects of intellectual disability care they wished. They were all asked one basic question "Can you tell me about your experience from the time that you realized that there was an ethical issue that needed addressing within your work?”

Nature of Ethical Issues A number of areas of concern were identified. Professionals felt uncomfortable administering invasive treatments or medication which were in the patient’s best interest but which the patients themselves strongly disliked. The professionals also struggled with the care of patients that posed a threat to themselves or to others and had to be restrained. All professionals showed an interest in changing these practices. Parents often request that their child with ID is preventing from entering relationships or performing sexual activities. If the patient subsequently partakes in such activities should the patients be informed or should this information be withheld form them?

Results The treatment of patients with ID is a complex matter which often involves conflicting principles. Participants identified that this conflict comes from numerous different sources including colleagues, ethical codes and the differing values of communities and care service. Due to the lack of concrete guidelines in ID care professionals are often forced to make important decisions themselves which leaves them feeling extremely vulnerable as they are fully accountable for wrong decisions. Even after making important decisions, the participants continued to live with considerable doubt as it was often impossible to ascertain the wishes of the patients and the lack of empirical research meant that they were never sure that their decisions were right. The professionals highlighted the importance of maintaining a good relationship with the patient as once this is established they can then understand more fully the needs and wishes of the patients. Where patients are fully dependent or maintain a very close relationship with their families a strong relationship also needs to be established with them in order to create an element of trust between patient, doctor and family. Maintenance of moral integrity was also identified as core to the care of patients with ID.

Conclusions Professionals working in the field of ID are guided more by their emotions and their relationships with patients and their families than by abstract guidelines and codes of practice. They are often unable to establish the preferences of patients and are forced to make decisions which they can never concretely conclude as ‘right’ decisions. This results in high levels of uncertainty and anxiety permeating ID care.

Particularly useful for Medical Professionals caring for patients with intellectual disabilities.

Aoife Maeve Clarke

Jackson, Warner, “How Much Do Doctors Know about Consent and Capacity?,” (2002) 95 *Journal of the Royal Society of Medicine* 601

Keywords Capacity, Knowledge of Medical Practitioners, Decision-making.

This survey has been conducted in England to find out to which extent medical practitioners are familiar with legal issues of capacity given the fact that many of them are highly likely to be confronted with those issues during their career. So far, research on that issue has never been conducted with regard to the actual knowledge-base at hand for the decision-making.

The scientists provided 190 individuals with questionnaires of whom 129 responded. The tested group included 35 general practitioners, 31 psychiatrists, 29 old-age physicians and 34 final year medical students. The questionnaire comprised questions designed to test the profound decision-making ability in different areas, such as consent/refusal of medical treatment, consent to research, testamentary capacity, *etc*. The results clearly showed that the present status of knowledge of doctors has to be assessed as insufficient.

Particularly useful for Therefore, the survey might to some extent provide a basis for policy-makers or staff claiming to have in place better and more specialized training on the *legal* issues of capacity for medical practitioners as well.

Dörte Herrmann

National Disability Authority, "Review of Access to Mental Health Services for People with Intellectual Disabilities," available at: http://www.nda.ie/__80256F4F005C7F9E.nsf/0/815EB07591494D9D80256F62005E6964?Open&Highlight=2,review,of,access,to,mental,health,services

Keywords Intellectual Disability, Mental Illness, Access to Health Services, *Mental Health Act 2001.*

The report is concerned with the issue of persons whose needs are caused by both an intellectual disability and psychiatric illnesses and/or challenging behaviour. It purports to assess the special needs of those persons and whether they are met under current legislation in consistency with Ireland's international obligations.

It found that whereas people with mental health conditions are provided with services by the generic mental health services, people diagnosed with an intellectual disability in the first place find it considerably more difficult or impossible to gain access to appropriate mental health services for assessment, treatment or continuing care. Those difficulties essentially arise because of the confusion which of the relevant service institutions has the main responsibility for planning and/or delivering mental health services to the intellectually disabled population. The majority of persons with intellectual disabilities as receivers of psychiatric treatment are not covered by the protective legislation, such as the Mental Health Act.

The report contains models of therapeutic interventions and service models for the concerned group with a dual diagnosis. It results in the pivotal claim that "service delivery should largely focus on specialist multi-disciplinary teams who are dual trained in intellectual disability and mental health" under a national policy statement and service framework rendered by the Department of Health and Children and subject to planning of the Regional Health Offices for their respective residents. In its appendix it provides two case studies illustrating the current legal and service status of the group concerned.

Particularly useful for The report may be a good source of information for policy-makers who would like to lobby in favour of that underrepresented and particularly vulnerable group.

Dörte Herrmann

Inclusion Europe, "Guidance on the Difference between Mental Health Problems and Intellectual Disabilities," available at: http://www.inclusion-europe.org/MMDP/EN/EN_Leaflet.pdf

Keywords Intellectual Disability, Mental Health, Services, Early Intervention, Stigmatization.

The brochure emanates from the assumption that people with intellectual disabilities and those with mental health issues are two of the most discriminated and isolated groups in society. They may be subject to discrimination, broad stigmatization, prejudice, and human rights violations preventing social inclusion to a considerable degree. It is particularly concerned with the long-term placement of people in institutions which apparently occurs in Central and Eastern Europe rather frequently.

However, the document states that, besides those similarities, there are significant differences between the two concepts which have to be acknowledged in order to provide adequate services for each group. It explains the terms 'intellectual disability' and 'mental health problems' in a very concise and illustrative way as well as the respective services needed to ameliorate symptoms and conditions. With regard to intellectual disabilities the emphasis lies on assistance aiming at best possible independence, self-autonomy, and self-advocacy as well as optimal individual development trough early intervention. In relation to mental health issues the brochure stresses the necessity of services without stigmatization to help people coping with those problems and re-building a satisfying life. Of utmost significance it considers appropriate information for the patient and treatment plans that are aimed at the earliest possible re-integration into the community.

Although intellectually disabled people - because of some extra risk factors, such as multiple prescribed medications and drug interactions or a childhood spent outside a family home - are more likely to suffer from mental disorders than the general population, it seems extremely important to distinguish both aspects to decide for adequate treatment.

Particularly useful for The booklet can help carers, social workers as well as families and friends to achieve the abovementioned distinction.

Dörte Herrmann

2. Educators

Field, Martin, Miller, Ward, Wehmeyer, "Self-Determination for Persons with Disabilities: A Position Statement of the Division on Career Development and Transition," available at: http://www.dcdt.org/pdf/self_deter.pdf

Keywords Teachers, School, Disabilities, Self-determination, Education Activities, Legislation, Teacher Training.

Abstract The Division on Career Development and Transition was established in 1978 under the Council for Exceptional Children. It consists mainly of teachers and parents of children with disabilities. The main focus of their work is on post school outcomes of children with disabilities.

Research shows that self-determination is fundamental to a successful transition from secondary education to adult life and once it is established students have been shown to achieve more positive outcomes. However these studies also show that students with disabilities often have difficulties developing the necessary skills to take control of their adult life and to be self-determined. Students with disabilities need to be taught these skills in school and it is imperative that it becomes part of their curriculum. The article provides many examples as to how promotion of self-determination can be incorporated into the education of children with disabilities through various educational activities, legislative changes and teacher training.

Particularly useful for Anyone working in the education sector, especially those teaching children with intellectual disabilities.

Aoife Maeve Clarke

3. Lawyers

Green, "'I'm OK- You're OK': Educating Lawyers to 'Maintain a Normal Client-Lawyer Relationship' with a Client with a Mental Disability," (2003-2004) 28 *Journal of the Legal Profession* 65

Keywords Lawyer, Client, Disabilities, Capacity, Effective Representation, Discrimination, Stigma, Autonomy, Self-Determination.

Abstract Under the American Bar Association Model Rules of Professional Conduct lawyers ought to maintain a "normal client-lawyer relationship" with clients who have disabilities. These rules provide no guidance as to how this should be established and lawyers are often as uninformed about the needs and capacities of people with disabilities as the rest of society. This article highlights the importance of effective representation to clients with disabilities and the adverse consequences which can occur when either the client or the lawyer are uninformed. Clients with disabilities are often not forthcoming about their mental disability for fear of the stigma which is often attached to such illnesses. Lawyers therefore ought to seek advice from experts in the field when working with such a client so as to more fully understand their client's situation and needs. Once this fundamental information has been established the lawyer is then more fully equip to represent their client effectively and communicate in a way which the client can fully understand. The legal system and legal representatives are often quite daunting to clients with mental disabilities and are often reluctant to seek their advice or help. In recent years the courts have overcome societal stigma of mental disabilities and have strived to eliminate discrimination in this area. Lawyers now need to be properly educated as to how to effectively represent clients with mental disabilities to allow them to be autonomous and fully self determined in making important legal decisions.

Particularly useful for Lawyers looking for a practical discussion on how to treat and represent clients with intellectual disabilities.

Aoife Maeve Clarke

Homepage of Intellectual Disability Rights Service Australia, http://www.idrs.org.au

Keywords Lawyers' Information, Communication Strategies, Violence.

This webpage is provided by the Intellectual Disability Rights Service (IDRS) which is a community legal centre in New South Wales. It aims at working with people with an intellectual disability to "exercise and advance their rights."

Inter alia, the well-structured website offers a 'Lawyers' Information Kit' explaining what an intellectual disability is and which rules to follow to communicate successfully with the respective person. These suggestions are also available in the form of a pdf-factsheet 'Acting for Clients with an Intellectual Disability.' In accordance with a functional approach to capacity, the authors stress the importance of making own decisions as far as possible. In this regard the webpage includes a comprehensive fact-sheet describing simple communication strategies for carers to enable persons to actually do so. Further helpful fact-sheets concern producing information for people with an intellectual disability, discrimination (partly with regard to the local laws), and wills and trusts. The webpage also contains a section concerning violence and victim information.

Particularly useful for Therefore, the webpage provides a broad range of information, partly addressed to disabled persons themselves, partly addressed to carers, families, and lawyers.

Dörte Herrmann

VIII. Overview of Human Rights Instruments Relevant to People with Intellectual Disabilities[1]

Gostin, "Human Rights of Persons with Mental Disabilities," (2000) 23 *International Journal of Law and Psychiatry* 125

Keywords Human Rights, United Nations Instruments, European Instruments, European Convention on Human Rights and Fundamental Freedoms, European Court of Human Rights, Involuntary Detention.

This article gives an overview of the human rights instruments that are concerned in the context of mental disabilities besides the UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities adopted by the General Assembly in 2006.

It begins by describing the relationship between mental health law and human rights and continues by focusing on the system of protection under the UN human rights instruments, the European instruments, in particular the ECHR. The author explains the different levels of state obligations, for example depending of the instrument being an international treaty or a "soft" General Assembly Resolution. He also discusses the adjudication of the European Court of Human Rights with regard to issues such as involuntary detention, treatment of residents as well as aspects of access to adjudication, privacy, family life, marriage and procreation.

Particularly useful for The article provides the non-legal reader with a sound overview of the relevant human rights instruments and their level of enforcement without an excessive body

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[1] An overview of the relevant Human Rights Documents can be found in the appendix to the research sample.

of footnotes. At the same time, it solidly indicates sources of information to track down particular issues of interest.

Dörte Herrmann

Inclusion Europe, "Children with Intellectual Disabilities and their Families - A Position Paper of Inclusion Europe,"available at: http://www.inclusion-europe.org/documents/ChildrenfamiliesEN.pdf

Keywords Children with Intellectual Disabilities, UN Convention on the Rights of Persons with Disabilities, Education, Participation of Children.

In this position paper *Inclusion Europe* specifically addresses the position of vulnerable children with intellectual disabilities. It refers to Article 7 of the UN Convention on the Rights of Persons with Disabilities which states the special obligation of states to provide intellectually disabled children with full enjoyment of human rights and equal treatment compared to other children.

The paper considers of utmost importance respect for family and home, access to health care as well as access to mainstream education, and participation in cultural life, leisure, recreation, and sports. It demands from all member states to the Disability Convention effective and clear actions to implement those aims in their respective legal orders and politics. For this purpose, the position paper elaborates shortly on each of the demands under a separate subheading. It thereby provides a very concise overview of the scope of obligation stipulated in Article 7.

Particularly useful for It may be highly recommendable for people engaged in policy issues as well as advocates and family members who wish to clarify rights under the Convention.

Dörte Herrmann

Inclusion Europe, "Your Rights as Citizens - Access to Rights and Justice for People with Intellectual Disabilities," available at: http://www.inclusion-europe.org/Justice/EN/EN_ETR_justice.pdf

Keywords Citizenship, Access to Public Administration, Adjudication, Role of Lawyers.

The booklet is designed to guide people with an intellectual disability on their rights as citizens. After explaining the concept of rights and duties in a state it particularly emphasizes the right to accessible public administration. It further describes the general system of adjudication, occurrences when people can find themselves before courts, proceedings, participants and their respective rights. A special emphasis is put on the disabled person's lawyer and his connecting and supporting role.

Particularly useful for Similarly to "Your Rights as Citizens - Being a Person before the Law," the booklet addresses the reader directly, is written in an easy-to-read style and contains a number of auxiliary pictures.

Dörte Herrmann

Appendix - Human Rights Instruments

Universal Declaration of Human Rights

General Assembly Resolution 217A (III), 10 December 1948, available at http://www.un.org/Overview/rights.html

International Covenant on Civil and Political Rights

General Assembly Resolution 2200 A (XXI), 16 December 1966, available at http://www.unhchr.ch/html/menu3/b/a_ccpr.htm

International Covenant on Economic Social and Cultural Rights

General Assembly Resolution 2200 A (XXI), 16 December 1966, available at http://www.unhchr.ch/html/menu3/b/a_cescr.htm

United Nations Declaration on the Rights of Mentally Retarded Persons

General Assembly Resolution 2956 (XXVI), 20 December 1971, available at http://www.unhchr.ch/html/menu3/b/m_mental.htm

United Nations Declaration on the Rights of Disabled Persons

General Assembly Resolution 3447 (XXX), 9 December 1975, available at http://www.unhchr.ch/html/menu3/b/72.htm

Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care

General Assembly Resolution 46/119, 17 December 1991, available at http://www.unhchr.ch/html/menu3/b/68.htm

European Convention on Human Rights

ETS No. 5, 4 November 1950, available at http://www.echr.coe.int/ECHR/EN/Header/Basic+Texts/Basic+Texts/The+European+Convention+on+Human+Rights+and+its+Protocols/

Convention on the Rights of Persons with Disabilities

General Assembly Resolution 61/106, 13 December 2006, available at http://www.un.org/disabilities/default.asp?navid=12&pid=150