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Defining the problem

2.1 Making decisions is an important part of human life. The decisions that an individual makes impact upon his or her personal well-being and financial position. They can involve issues relating to, for instance, accommodation, health care, education, employment, social contacts and financial arrangements. The exercise of choice in such matters is one of the ways in which people express their individuality, and having decisions acknowledged and acted upon by others is one of the ways in which people exert control over their own lives.[14] As will be shown in Chapter 4, one of the major disabling consequences of mental incapacity is the inability or limited ability to make legally effective decisions.[15] Diminished decision-making capacity may in turn reduce a person's ability to control his or her life. It may unfairly lower the esteem in which a person is held by others and may also diminish such person's sense of self-respect and dignity.[16]

2.2 Although we take it for granted that "adults" (persons of 21 years and above)[17] can make decisions about their personal welfare, financial affairs and medical treatment, some adults cannot make such decisions for themselves. They may have diminished capacity as a result of mental illness[18] (including acquired

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[14] Ashton and Ward 3-7; Queensland Law Reform Commission **Draft Report** 1995 1.

[15] Cf also Cooper and Vernon 213 et seq.

[16] Ibid.

[17] International law and the Constitution 108 of 1996 (the Constitution) define a "child" as a person below the age of 18 years (sec 28(3)). In law there is an 'instantaneous transformation' from childhood to adulthood at a specified age. In South Africa "majority" (i e when the law confers full capacity to act and to litigate on an individual) is attained at age 21 years (sec 1 of the Age of Majority Act 57 of 1972; SARLC **Discussion Paper 103: Review of the Child Care Act** 2001 52 et seq). The Commission under its investigation on the review of the Child Care Act addressed this discrepancy and recommended that the age of majority should, with certain exceptions, be lowered to 18 years (SALRC **Report on Review of the Child Care Act** 2002 29 et seq). These recommendations have been included in clause 17 of the Children's Bill, 2003 which states that "(A) child, whether male or female, reaches the age of majority and becomes a major upon reaching the age of 18 years".

[18] "Mental illness" can take many forms but can be distinguished from "mental handicap" (or "intellectual disability" - see footnote 20) in that treatment is appropriate and a cure may be possible

organic brain syndromes such as dementia of which the most common form is Alzheimer's disease)[19]; intellectual disability (sometimes also referred to as mental handicap or mental retardation);[20] physical disability; or their incapacity may be related to ageing in general.[21] Note that physical disability may or may not be associated with intellectual disability. The law is however concerned with *capacity* of an individual, and this may in practice depend upon *ability* (eg an

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(although not in all circumstances). The term covers both neurosis (a functional derangement due to disorders of the nervous system eg depression and obsessive behaviour) and psychosis (a severe mental derangement involving the whole personality eg schizophrenia and bipolar disorder [also known as manic depression]). According to medical criteria "mental illness" is an acquired condition (i e the person has previously been normal), and the condition must satisfy the diagnostic criteria of one or more particular groups.

For purposes of the Mental Health Care Act, 2002 "mental illness" is defined as "a positive diagnosis of a mental health related illness in terms of accepted diagnostic criteria made by a mental health care practitioner authorised to make such diagnosis" (sec 1).

19 Medically, people who acquired a normal ability and then subsequently lose it are classified as having *acquired organic brain syndrome* which constitutes a mental illness (even though treatment may not be possible). Dementia is an acquired organic brain syndrome. It has been described as a clinical syndrome characterised by generalised cognitive impairment where the primary deficits occur in the areas of orientation, memory, and reasoning. About 5% of persons over 65 and 20% of persons over 80 are affected by dementia. The single most common cause of dementia is Alzheimer's disease, a progressive degenerative disorder of multiple neuronal systems in the brain. Forgetfulness is usually the first symptom, followed by difficulty with language and difficulty carrying out complex motor behaviours such as dressing and eating with utensils. Currently the definitive cause of Alzheimer's is still unknown and there is no cure although certain drugs are modestly effective. Other causes of dementia include multiple strokes (known as multi-infarct dementia); other neurological conditions (eg multiple sclerosis and Huntington's disease); various systemic medical disorders; and drug toxicity. Severe depression may also cause a dementia syndrome. Most dementing conditions are not reversible (Ashton and Ward 13-15; Roca in **Aging and the Law** 216 et seq).

20 "Intellectual disability" may have a biological, genetic, or environmental basis, and should be distinguished from mental illness. It is generally accepted that "intellectual disability" encompasses any set of conditions resulting from genetic, neurological, nutritional, social, traumatic or other factors occurring prior to birth, at birth or during childhood up to the age of brain maturity (normally taken as 18 years), that affect intellectual development. These conditions result in a lifetime of lower than average overall capability for self-determination and general independent functioning and performance in vocational, social and personal functions. In some instances these conditions may occur in conjunction with physical, sensory or psychiatric impairments of varying degree. Such conditions have variable impact on the individual, from minimal to severe. Persons with intellectual disabilities include for instance persons with Down's syndrome (WHO **Report on Aging and Intellectual Disabilities** 2000 1-2).

The Mental Health Care Act, 2002 defines "severe or profound intellectual disability" (in contradistinction with "mental illness" [see fn 18 above]) as "a range of intellectual functioning extending from partial self-maintenance under close supervision, together with limited self-protection skills in a controlled environment through limited self care and requiring constant aid and supervision, to severely restricted sensory and motor functioning and requiring nursing care" (sec 1).

21 Roca in **Aging and the Law** 216 et seq; Ashton and Ward 10-15.

individual who cannot communicate may not be permitted to open a bank account notwithstanding that his or her mental capacity is unaffected).[22]

2.3 In some cases incapacity is relatively short-term; in others mental capacity is lost and may never be recovered; some people have never had the capacity to make decisions about their own affairs because of congenital conditions or conditions which developed early in their lives.[23] In the case of older persons or persons with diseases such as Alzheimer's, incapacity develops gradually and unpredictably and depends not only on the specific patterns of cognitive impairment characteristic to the individual's condition, but also on the specific decisions he or she is facing.[24] Since incapacitation can result from unexpected acute illness or injury as well as long-term degenerative conditions, every competent individual is to some degree vulnerable to the possibility of becoming incapable. The probability of incapacitation however increases with age – while actual life expectancy has increased, the expectancy of life without disability has not. Furthermore, current medical science holds out little hope that the chronic, non-lethal degenerative diseases of old age can be significantly prevented or delayed.[25]

2.4 From a medical point of view the problems presented by the variety of conditions referred to above appear to differ. There may for instance be real differences between intellectual disability and the effects on a mature person of a head injury: The method of care, education, training and assistance adopted for the former person may be inappropriate for the latter and different services may be needed.[26] It may also be uncertain, for instance, whether "mental illness" as defined in traditional mental health care legislation covers persons suffering from

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22 Ashton and Ward 13.

23 Whitton 1996 **University of Cincinnati Law Review** 881-882.

24 Ibid.

25 Ibid; Khaw **BMJ** 1999 1350-1352; Kirkwood 2003 **BMJ** 1297.

26 Brain damage, for instance, appears to fall rather uncomfortably between mental illness and mental handicap (Ashton and Ward 15-19).

incapacity related to organic diseases such as Alzheimer's disease.[27] Hoggett explains these difficulties thus:[28]

> "Defining mental disorder is not a simple matter, either for doctors of for lawyers. With a physical disease or disability, the doctor can presuppose a state of perfect or 'normal' bodily health (however unusual that may be) and point to the ways in which the patient's condition falls short of that. A state of perfect mental health is probably unattainable and certainly cannot be defined. The doctor has instead to presuppose some average standard for normal intellectual, social, or emotional functions, and it is not enough that the patient deviates from this, for some deviations will be in the better-than-average direction; even if it is clear that the patient's capacities are below that supposed average, the problem still arises of how far below is sufficiently abnormal, among the vast range of possible variations, to be labeled a disorder".

It is clear that it is problematic to find an all-encompassing definition for the individuals with conditions as described above. The law is however concerned with capacity[29] and from a legal point of view similarity may be found between these medically different disabilities in the common inability to make all necessary decisions.[30] In accordance with this, the Commission's investigation deals with decision-making incapacity however it was caused. What must be borne in mind however is that the person with intellectual disability will never have had a greater degree of understanding than that now displayed, whereas those who have developed normally and then suffered an illness or accident causing the disability will at an earlier stage have enjoyed a greater level of ability.[31] This difference is relevant when developing legal solutions that will cater for the needs of both these groups.

2.5 A legitimate expectation of the law is that is should establish a structure within which appropriate autonomy and self-determination is recognised and protected. Such a structure should provide appropriate substitute decision-making devices

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27 On doubt whether the Mental Health Act, 1973 applies to persons with dementia see SALRC **Report on Enduring Powers of Attorney and the Appointment of Curators to Mentally Incapacitated Persons** 1988 13, 22 and 24. The medical fraternity however seems to accept that dementia can be classified as a "mental illness" (see fn 19 above).

28 Hoggett 59.

29 Cf the discussion on capacity in Chapter 4 below.

30 Ashton and Ward 15-19.

31 Ibid. See also fn 20 and 18 above.

and the necessary protection from abuse, neglect and exploitation.[32] At present the legal solution to the problem of persons who cannot manage their own affairs takes the form of curatorships.[33] An individual can also allow another to act on his or her behalf through a power of attorney. A power of attorney however terminates on incapacity of the person who granted the power.[34] The existing system of curatorships has been criticised on the ground that it suffers from a number of serious and frustrating difficulties mainly relating to its high cost, prolonged procedure, paternalistic nature and potential for abuse.[35] The problem of a power of attorney ceasing on incapacity is also a major cause for concern: Frequently caregivers are under the impression that the power of attorney granted by a person in their care will be effective until that person dies, even in cases where the person had severely diminished mental capacity and is therefore incompetent in the eyes of the law.[36] This is an unsatisfactory position as caregivers acting in good faith are putting themselves at risk of performing unauthorised acts for which they could be held personally liable. Even if such caregivers are aware of the legal position, it can be very difficult to determine whether or not they may continue to act as loss of mental capacity may be gradual or erratic.[37] The present state of affairs is complicated by the fact that South Africa has no specific statutory provisions dealing with adults with impaired decision-making capacity. The law has to be found mainly in a combination of the Constitution, the common law as extended by the Courts, mental health legislation, legislation pertaining to the administration of estates, and the rules of the High Court. In many cases incapacitated persons are cared for by persons who are ignorant of the law and who appear to be unaware that their acts, done in kindness and good faith on behalf of such person, may have serious and adverse legal implications. There is further no formal assisted decision-making

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32 See the discussion on constitutional considerations in par 3.13 et seq below. Cf also Cooper and Vernon 213; Ashton and Ward 3-9.

33 See the discussion in par 6.3 et seq below.

34 See the discussion on the current legal position regarding powers of attorney in par 7.6 et seq below.

35 See eg Neumann **De Rebus** June 1998 61-64; Barker **De Rebus** April 1996 259-260; Van Dokkum 1997 **Southern African Journal of Gerontology** 17-20.

36 Van Dokkum 1997 **Southern African Journal of Gerontology** 18.

37 Ibid.

device that clearly provides for mild, fluctuating or temporary impairment. There is also no provision for some default arrangement to deal with situations where incapacitated persons have no family or carers to act on their behalf or where the existing formal measures have not been utilised.

2.6 The above problems are discussed and solutions are suggested in the chapters which follow. This is done against the wider context which influences the need for reform and the public response on Issue Paper 18.