

Healthy Ageing - Adults with Intellectual Disabilities

Biobehavioural Issues

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1. Background

In nations with established market economies, most adults with intellectual disabilities who live past their third decade are likely to survive into old age, and experience the normal ageing process. As in the general elderly population, in spite of gradual declines in a variety of domains, they can still have active and varied lifestyles with an excellent quality of life. Age associated, functional declines must be separated from specific losses due to physical illness, dementia, depression, sensory loss, and social and environmental factors. The interaction between biological, psychological and social aspects of ageing remains the most important factor in the functional outcome of a person with intellectual disabilities.

Very little empirical data exists about normal psychological functioning developmental processes throughout the life-span in people with intellectual disabilities. Seltzer (1993) presents the best model, linking behavioural, cognitive and affective outcomes to the negotiation of developmental tasks of ageing in the context of a variety of interacting individual, social and environmental antecedent conditions, such as intellectual ability, social competence, personality, physical condition, environment and learning history. Every person has his/her own individual set of antecedent conditions, and has different opportunities to successfully negotiate the developmental tasks of ageing.

People with intellectual disabilities in general have restricted social roles and more limited social

Goal 1 To improve the understanding of normal psychological functioning throughout the life-span of people with intellectual disabilities

networks, and thus fewer opportunities to experience and learn from some of the tasks commonly experienced by those without intellectual disabilities, particularly those who have spent considerable time in more restricted institutional environments. Mid to older life changes such as bereavement may thus have a greater impact, and with a greater likelihood of adverse functional outcome. The acceptance of mortality for example, which is an integral part of ageing in people without intellectual disability, is often hindered by a lack of exposure to rituals such as funerals in an attempt to shield the person from unpleasant events.

Furthermore, the magnitude of individual adverse reactions to stressors may be accelerated because of cognitive impairment (pre-existing and/or degenerative, as in the dementias), poor self-esteem and poor perception of self-competence due to repeated adverse life experiences over the life-span, and poor social support.

Goal 2 To improve knowledge and awareness of age-related stressors and their impact on older people with intellectual disabilities

2. Mental and behavioural disorders

For the purpose of this paper we have defined mental disorders as disorders that can be classified into diagnostic systems such as the ICD10. Biological, psychological and social factors disorders may all contribute to their expression. Behavioural disorders on the other hand are patterns of maladaptive behaviors (usually as perceived by an informant) that interfere with typical life functioning. They may be related to another mental disorder in the individual, biological vulnerability, longstanding learned behaviors, or a mismatch between environmental expectations

and resources with the individual's capabilities and wishes: for example, a behavioural problem such as wandering in a demented person may be maladaptive if the individual lives in an open facility close to a busy highway, but contribute to the maintenance of physical abilities in a well-designed dementia unit due to regular exercise.

Major mental disorders, although less common than behavioural disorders, are still fairly frequent in elderly people with intellectual disabilities. Day and Jancar (1994) reviewed this topic and found an overall prevalence of about 10%. Some disorders such as dementia increase with age, which is particularly noticeable in those with Down Syndrome (DS). As in the general elderly population, psychotic disorders also increase with age, but are less frequent than mood and anxiety disorders. Interestingly, due to "differential mortality" or the tendency for healthier people to live longer, older cohorts may actually be healthier in many domains than younger cohorts (Janicki, Dalton, Davidson & Henderson, 1999), and show greater functional abilities than the young until the oldest ages.

Most studies find that, compared to the general population, behavioural disorders are more common in people with intellectual disabilities at all stages of the life span. There seems to be an association with age mostly in those individuals that have dementing disorders (Moss & Patel, 1995).

3. Etiology

Social, cultural, environmental and developmental factors and stressors have significant impact on the expression of both psychiatric and behavioural disorders in older people with intellectual disabilities (Day & Jancar, 1994). Stressors may be multiple, and include separation from or death of a parent, loneliness and sudden relocation. Unfortunately, little is known about quantifying these influences on age-related changes in persons with intellectual disabilities. However, the general consensus of clinicians in the field is that all perceived symptoms need to be evaluated in a broad context, and not necessarily attributed to one individualized factor but explored as part of a complex interaction of the individual with the environment.

Goal 3 To understand and appreciate the social, cultural environmental and developmental context of behaviors and their functions in older people with intellectual disabilities

Biological contributions to mental and behavioural disorders are also important, and often increase with age. Examples include sensory loss and dementia in DS, feeding abnormalities in those with cerebral palsy due to reflux, and a variety of other behavioural changes related to chronic medical illnesses (Lantman de Valk et al., 1998; Davidson et al., 1995). Of course, genetic risk factors for the major mental illnesses such as schizophrenia or bipolar disorders continue to be present in old age as in the general population, and specific behavioural clusters associated with developmental syndromes may persist from younger years into old age.

4. Detection and assessment of mental disorders

Major mental disorders in older people with intellectual disabilities may have considerable negative impact on cognitive, affective and general functioning as well as on the quality of life of the person. It is important therefore to detect and optimally treat these, especially treatable disorders such as depression. However, diagnosis is already more difficult in older people in general due to higher rates of comorbidity, polypharmacy and a reduced tendency to voice

psychological compared to physical complaints, and this is magnified in the intellectual disabilities group, particularly in the most disabled segment. The presence of seizure disorders and their treatments additionally complicates the assessment of mental functioning, although this may be more pronounced in younger age groups that tend to be more multiply disabled. Other challenges in the intellectual disabilities group include communication barriers, baseline behavioural abnormalities (secondary to brain abnormalities, learned maladaptive behaviors, and environmental deprivation) overlapping with core mental illness symptomatology, and more florid stress related decompensation.

Health care providers that are not familiar with intellectual disabilities have difficulty making accurate mental health assessments, yet carers that are most able to report changes in the usual functioning generally do not have the necessary knowledge of mental disorders. Unfortunately, in most parts of the world there are few specialists with both intellectual disabilities and psychogeriatric expertise that would be able to bridge that gap. Cultural perspectives on normative behavior may further color how seemingly "deviant" behavior, which may be attributable to intellectual disabilities, may be perceived. Tests and assessment instruments are often not available in local languages.

In many cases the combination of the above individual, environmental and care system difficulties leads to a lack of differentiation between mental illness and intellectual disability, with both over and under diagnosis of mental illness, each of which can lead to adverse consequences. Although florid and disruptive behaviors are likely to come to the attention of mental health services, milder symptoms such as early depression and cognitive impairment may be missed, whereas there may be an overdiagnosis of disorders like schizophrenia due to the diagnosticians' unfamiliarity with the presentation of older people with intellectual disabilities and stress decompensation, for example.

Ideally, assessment of biobehavioural issues involves interviewing the person as well as their carers, and exploring the environment as a potential contributor to the symptoms. Interactions between the older person's cognitive, affective and general functional abilities with the environment and care system must be explored. Frequencies of symptoms and possible correlation to other environmental events can be analyzed by charting identified behaviors and symptoms. A thorough medical evaluation, including visual and auditory assessments should precede a final mental health diagnosis.

Screening instruments exist for various mental disorders in intellectual disabilities, but must be developmentally and culturally appropriate. General instruments include the Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson), and the Reiss screen (Reiss, 1987). The Mini-PAS-ADD (Prosser et al., 1997) and the PASS-ADD Checklist (Moss et al., 1998) have been developed specifically to improve case recognition in this population. These instruments are not sufficiently specific or sensitive to make a diagnosis, but are useful to indicate the need to obtain further mental health assessment.

Instruments designed for specific disorders, such as the Beck Depression Inventory (Beck, Ward, Mendelson, 1961) and the Zung Self-Rating Depression Scale (Zung, 1965) have been adapted and simplified for use in intellectual disabilities by Kazdin and associates (Kazdin, Matson, Senatore, 1983). These, as well as others such as the Hamilton Rating Scale for Depression (Hamilton, 1960) have been used successfully to assess depression in people with intellectual disabilities and mental disorders.

The diagnosis of dementia in intellectual disabilities has been discussed at length, as people with DS are at very high risk of developing this. The instruments used in the general population are difficult to use due to floor effects, and furthermore, baseline abilities in intellectual disabilities are so varied that only repeated measures over time are likely to result in an accurate assessment of dementia. It is suggested that behavioural measures should be repeated at set intervals after age 40 in DS, and after age 50 in others with intellectual disabilities to detect functional changes, which can then be further evaluated clinically. The IASSID/AAMR practice guidelines give more detail on assessment and care management in dementia (Janicki et al, 1996).

Auxiliary diagnostic tools such as computerized tomography (CT), positron emission tomography (PET), single photon emission computerized tomography (SPECT) and magnetic resonance imaging (MRI) may be helpful diagnostically, and might eventually become more routinely used, at least in developed nations.

Goal 4 To improve the detection and holistic assessment of mental disorders such as depression, anxiety and dementia in older people with intellectual disabilities.

Goal 5 To increase mental health knowledge and skills in professionals, carers and families of older people with intellectual disabilities.

5. Interventions

Interventions in general must incorporate the best information from two separate bodies of evidence; the mental health-intellectual disability (dual-diagnosis) literature, and the psychogeriatric literature. Data from the psychogeriatric literature is important as it considers physical and mental changes developing longitudinally with the ageing process. Data from the mental health-intellectual disability literature is important because it identifies issues specific to or more prevalent in people with intellectual disabilities, and focuses on interventions that have particular use in this area. Both fields are now starting to address the role of autonomy and choice-making by adults in the development and treatment of mental health symptoms.

Ideally, interventions for behavioural and mental disorders should first consider prevention: primary, i.e., strategies implemented to prevent all occurrence of the problem; secondary, i.e., early treatment of a problem to prevent its full expression; and tertiary, i.e., strategies to minimize functional impairment due to the problem once firmly established. (It should be remembered that the "problem" referred to is not necessarily only directly related to the older person with an intellectual disability, but is really the interaction of multiple variables as described earlier, culminating in the perception of their being a "problem" by some person, usually in the care system or the community.)

Primary prevention strategies for behavioural and mental disorders are not comprehensively understood, but some issues are known to be associated with a reduced prevalence. Decreased use of large congregate care such as institutions reduces the frequency of a variety of maladaptive behaviors, infectious diseases as well as polypharmacy, which is responsible for many other secondary adverse effects. Increased work on communication skills and identification of sensory deficits often reduces the development of maladaptive behaviors such as aggression, and increases adaptive behavior. Increased availability of rewarding activities, and increased provision for autonomous choice making in various domains is also associated with positive

behavioural outcomes, although systematic studies are difficult to perform. Humane, non-abusive living environments sensitive to the needs of their older residents with intellectual disabilities are likely also to foster reduced development of maladaptive behaviors. Finally, staff that are trained to understand and deal with the emotional needs and stresses of their residents will better provide an emotionally supportive environment that will minimize the occurrence of challenging behaviors or the perception of the person as “a problem.”

Primary prevention of the major mental disorders such as schizophrenia is less likely, as there is a large biological and genetic component to most of these. However, the recurrence of individual episodes of illness can be minimized by reducing stressors if possible, providing sensitive support for those that do occur, and ensuring appropriate medication use.

Goal 6 To develop living environments that are responsive to the mental health needs of older people with intellectual disabilities.

Secondary prevention of mental and behavioural disorders involves appropriate early detection, assessment and treatment of the designated problem, by careful involvement of biological, psychological and social interventions. It is crucial to involve the persons themselves, staff, family and community in the holistic treatment planning process, and provide sufficient training to allow carers to continue therapeutic interventions after any professional involvement has ended. Modifications may need to be made to the home and work environment and/or staff approaches to the person. Needs that may be expressed in a maladaptive behavioural way must be met more productively, and alternate expressions taught. Supportive therapy, individual or group behavioural therapy, family therapy and social skills training might all be of help, as might be the involvement of spiritual elders or healers, depending on the cultural milieu. Unfortunately, there are too few clinicians, even in the developed world, who have the skills to undertake psychotherapy for individuals with intellectual disabilities. There are fewer still who are aware of the psychological issues related to functional decline, grief secondary to loss of family or friends, and other life changes that take place as people age.

Pharmacotherapy is most often used in the most severe, potentially harmful behavioural syndromes or in the more biologically driven mental disorders, and must be tailored to age related vulnerability. Medication pharmacokinetics, including drug volume of distribution, protein-binding, hepatic metabolism and renal clearance need to be considered in formulating psychotropic regimens. Treatment response time often lengthens with old age, and strange environments such as inpatient settings may result in significant stress that makes the assessment of change difficult. In addition, some older adults with intellectual disabilities may be receiving medications for chronic medical conditions, and the potential for drug interactions should be carefully considered. Thorough knowledge of the biomedical state of each older adult, as well as close coordination with primary health care providers, is necessary for the safe prescription of psychotropic medications. Adverse effects such as sedation, increased confusion, constipation, postural instability, falls, incontinence, weight gain, sex steroid dysregulation and other endocrinologic or metabolic effects, impairments of epilepsy management, and movement disorders must be minimized.

There must always be the awareness of risk and benefit calculations that require detailed knowledge of the specific adverse effects and drug interactions of each particular agent. The potential for acute and long term adverse effects should be determined and discussed with adults and carers at the time of initial prescription and during regularly scheduled psychotropic medication reviews.

Tertiary prevention, or the treatment of established disorders with the goal of minimizing further functional disabilities, becomes more important with the increasing age of the person. Although older people, as do young people, have the right to safe, effective treatment, at times the ageing process has brought about so many changes that a realistic goal becomes modified from cure to maximization of overall psychosocial outcomes. The maintenance of mobility, the preservation of meaningful social interaction, and the maximizing of cognitive and affective functioning becomes paramount. Possible hazards and unpleasant side effects of treatments must balance the reasonable likelihood of positive response, resulting in difficult end-of-life decision making for the person and significant caring others.

Goal 7 To promote mental health and minimize negative outcome of mental health problems in older people with intellectual disabilities

6. Service provision

Formal services that specifically provide mental health care to older people with intellectual disabilities are minimal to non-existent throughout the world. Service provision needs to be adapted to best deal with the local cultural and health care environment, and this is very variable.

In some areas basic life necessities, let alone mental health delivery to the general population are not yet available, and the disabled population is often last to benefit when this does come about. The primary need may be basic supports in these areas, whereas in other more privileged areas sophisticated education about the assessment and treatment of behavioural and mental disorders to care providers may be a reasonable goal. An overriding goal, however, in the development of any of these diverse services is to include the acceptance of basic principles. These include maintenance of respect for the individual and their families, involvement of the person's own needs and wishes in any treatment plan, and finally development of treatment plans that are minimally restrictive, culturally sensitive, and that foster the growth and autonomy of the person. All treatment programs should be broadly based with biological, psychological and social components.

Goal 8 To increase mental health services and supports in their own communities for older people with intellectual disabilities.

Goal 9 To collaborate with older people with intellectual disabilities and their support system in developing culturally sensitive, humane, and least restrictive mental health interventions with an integrated bio-psycho-social orientation.

7. Quality of life issues

During the past decade there has been increasing concern regarding the outcomes of treatment and involvement in intellectual disability services in the assessment of the social value of services. A similar shift has also occurred in other sectors, such as child and adult social services, public health, youth corrective activities, senior services and mental health. This type of reorientation in most sectors represents a substantial change in how the benefits of human services and other public or humane enterprises are gauged. The intended end result is tailoring of the services and supports to each individual in ways that encourage and promote the participation of that particular person with an intellectual disability in valued social roles. This is achieved by focusing the benchmarks for effective services upon outcomes with evident lifestyle impacts.

These desirable lifestyle impacts are usually embodied by the expression "quality of life," but are informed by philosophical implications of human and disability rights developments in many nations. From this standpoint, the value of professional services delivered in a high quality manner, the effects of those services, and the efforts of social groups, service groups, and advocates are ascertained with regard to impacts on lifestyle and related personal and social opportunity.

Valued outcomes that serve as a basis for demonstrating the social value of intellectual disability services, but which may vary in their particulars within different cultures, may include: (1) Increased practical, leisure, or life enhancing skills, such as those involved in making choices between alternative activities, and those which allow a person to access community opportunities (e.g., work or retirement activities), including enduring benefits; (2) Improved or maintained dietary and general health status that prevents physical health factors from becoming an untoward hindrance on typical activity; (3) A varied rhythm of life involving preferred activities and recognition that challenge and productivity must continue throughout old age; (4) Participation on a regular and full basis in the general life of their community and with friends and acquaintances of one's preference; and (5) An increased and well-established social network of acquaintances, friends and valued social amenities.

With increasing age, gerontological research has validated the expected belief that engagement and minimization of life stressors have preventive value and can lead to prolonged life and stable health status. Life factors that provide for sound nutrition, access to valued activities, safe and pleasant domicile, and intellectual challenge can minimize stress, organic or environmentally derived psychopathology and reactive behaviors. A quality old age among persons with intellectual disabilities will be based on the same factors that provides for a quality old age among other persons.

Goal 10 To improve the quality of life in older people with intellectual disabilities and mental health problems

8. Research

Most research in the area of mental or behavioural disorders or problems has had treatment as its focus. Much less has been done about the causes and risk factors of such disorders and their prevention. Almost all of the data available comes from populations of persons with intellectual disabilities from nations with established market economies, where research funding has been

most available and there has been a critical mass of workers who specialized in this field. For instance, prevalence data for psychiatric and behavioural disorders may differ between nations with established market economies and developing nations and treatment outcomes may vary where the cultural ethos may inhibit referrals and special resources or services are limited. Improved health status and prevention in developing nations, the principal goal of WHO, must depend on identification of special issues pertaining to developing nations and application of techniques that permit information to be gathered free of cultural or other restraints.

Well-controlled research in mental and behavioural disorders as they occur in persons with intellectual disabilities is limited. Most of the work over the past 30 years addresses treatment issues; fewer focused on diagnosis or etiologic factors, or prevention. Only a small number address basic mechanisms. These disappointing data probably reflect several things, including a well-known lack of a research focus or funding. As a consequence, there are limited numbers of scientists in the field and a lack of programmatic efforts in research centers addressing any relevant issue related to intellectual disabilities. Without specific attention from health planners and ministerial level policy makers, as well as a critical mass of investigators working on a common problem in programmatic ways, little converging data can emerge and, quite likely, few if any major discoveries will appear quickly.

Promising lines of inquiry relate to both treatment strategies and biological determination and regulation of behavior. Rigorous methodologies are available to undertake controlled or randomized clinical trials for behavioural and pharmacologic interventions. Recent advances in molecular genetics and neuropharmacology provide new opportunities for linking severe behavioural and psychiatric disorders to brain neurochemistry. The field must move toward a research focus that includes a better balance of studies of basic mechanisms, translational and clinical outcome studies.

Goal 11 To develop a research agenda that will provide evidence concerning each goal for all nations.

9. Conclusions

Ageing issues in older persons with intellectual disabilities still remain to be appropriately identified, assessed and resolved. The complex interaction between biological, psychological and social aspects is arguably the most important area of need at the start of the next millennium. Psychiatric and behavioural disorder prevalent among adults with intellectual disabilities may be both transnational and culture bound. The prevalent literature is based in the nations with established market economies where the longevity of adults with intellectual disability is more pronounced and has become a normative phenomenon. To what extent this same longevity and prevalence of psychiatric and behavioural disorders is shared among nations, other than those with established market economies is unknown.

The analyses in this paper rely heavily on research results from nations with established market economies. For developing countries, sufficient medical systems or well-trained physicians may be limited. Also, health care systems in developing countries often do not sharply distinguish between people with mental illness and people with intellectual disabilities. Thus, data from nations with established market economies may not be easily translated to social policy in other countries. From a policy perspective, developing nations may have to choose between allocating limited resources to such practices as diagnosis and treatment of mental and behavioural

disorders in persons with intellectual disabilities and improving the nutritional status of the general population, perhaps preventing some types of intellectual or developmental disabilities. Establishing reliable diagnostic practices that might permit effective treatment and tracking people with mental illness and people with intellectual disabilities may require resources beyond the indigenous capabilities of some developing nations.

Consistent with the Standard Rules of the United Nations, if recognition is to be given to the value of persons with intellectual disabilities and to the provision of resources to improve their general health status so that longevity becomes a norm, nations will also have to devote resources to aiding in treatment of mental and behavioural disorders that impede or distort normal ageing. However, first nations will need to internalize beliefs that value human life and the productivity of persons with intellectual disabilities. With valued status, resources will aid in promoting sound practices in ameliorating psycho-geriatric issues prevalent in the population. To this end, at minimum, there should be a core of professionals and clinicians with specialized training in intellectual disabilities and all mental health, psychiatric, or psycho-geriatric professionals or clinicians should also receive training in intellectual disabilities. Such training must stress the differentiation of intellectual disabilities from mental illnesses. Further, specialized resource centers need to be available to which clinicians, families and other carers can seek information and referral. Two main aspects to any new service focus on this subject are - information and the appropriate training of practitioners.

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10. Future goals developed at the 10th International Roundtable on Ageing and Intellectual Disabilities

1. To improve the understanding of normal psychological functioning throughout the life-span of people with intellectual disabilities.
2. To improve knowledge and awareness of age-related stressors and their impact on older people with intellectual disabilities.
3. To understand and appreciate the social, cultural environmental and developmental context of behaviors and their functions in older people with intellectual disabilities.
4. To improve the detection and holistic assessment of mental disorders such as depression, anxiety and dementia in older people with intellectual disabilities.
5. To increase mental health knowledge and skills in professionals, carers and families of older people with intellectual disabilities.
6. To develop living environments that are responsive to the mental health needs of older people with intellectual disabilities.
7. To promote mental health and minimize negative outcome of mental health problems in older people with intellectual disabilities.
8. To increase mental health services and supports in their own communities for older people with intellectual disabilities.
9. To collaborate with older people with intellectual disabilities and their support system in developing culturally sensitive, humane, and minimally restrictive mental health interventions with an integrated bio-psycho-social orientation.
10. To improve the quality of life in older people with intellectual disabilities and mental health problems.
11. To develop a research agenda that will provide evidence concerning each goal for all nations.