THE EDINBURGH PRINCIPLES

with Accompanying Guidelines and Recommendations

These principles and guidelines were developed by the Edinburgh Working Group on Dementia Care Practices at a special meeting held in Edinburgh, Scotland (February 5-7, 2001) and called by the University of Stirling (Scotland), the University at Albany (USA), and the University of Illinois at Chicago (USA) to define internationally applicable working practices for the community supports of adults with intellectual disabilities affected by Alzheimer disease and related dementias.

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Alzheimer Disease and Related Dementias and Intellectual Disabilities

Dementias resulting from Alzheimer's disease and other related conditions are age-associated, that is, they primarily affect older adults and their prevalence increases significantly with advancing age. The consequences of such dementias are memory loss, personality changes, and diminished self-care abilities and the eventual impairment of cognitive and adaptive skills necessary for successful personal, occupational, and community functioning. Dementias generally affect people with intellectual disabilities in the same manner as they do other older people, save for some differential effects on persons with Down syndrome. Adults with Down syndrome are at greater overall risk of being affected by dementia, are often affected at an earlier age, and may be affected by precipitous decline and loss of skills within a shorter period of time.

In many jurisdictions, practices have been inconsistent with regard to how to provide services and supports to persons with intellectual disabilities affected by dementia. Many providers have not defined workable responses to the increasing presentation of dementia among people with intellectual disabilities. Care providers become increasingly challenged to avoid institutionaliza- tion or the referral of affected individuals to inappropriate settings. Notwithstanding the insidious effects of dementia, there is agreement that adults with intellectual disabilities, as they are affected by Alzheimer disease or related dementias, should be treated with respect and given the opportunity to remain in their community with sufficient and appropriate supports and services to compensate for personal losses in function and decline. There is further agreement that the prevailing practices and policies of service provision need to be examined with an eye to adopting universally applicable guidelines that promote continued community care and supports of persons with intellectual disabilities affected by dementia.

Therefore, the Edinburgh Working Group on Dementia Care Practices has adopted the following principles with relation to continued community supports and services for people with intellectual disabilities affected by dementia. It proposes that governments, organizations, and providers adopt these and promote their use in aiding those adults with intellectual disabilities affected by Alzheimer disease and other similar conditions resulting in dementia.

The Edinburgh Principles

1. Adopt an operational philosophy that promotes the utmost quality of life of persons with intellectual disabilities affected by dementia and, whenever possible, base services and support practices on a person-centred approach.

2. Affirm that individual strengths, capabilities, skills, and wishes should be the overriding consideration in any decision-making for and by persons with intellectual disabilities affected by dementia.

3. Involve the individual, her or his family, and other close supports in all phases of assessment and services planning and provision for the person with an intellectual disability affected with dementia.

4. Ensure that appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs, and support healthy ageing, of persons with intellectual disabilities affected by dementia.

5. Plan and provide supports and services that optimize remaining in the chosen home and community of adults with intellectual disabilities affected by dementia.

6. Ensure that persons with intellectual disabilities affected by dementia have the same access to appropriate services and supports as afforded to other persons in the general population affected by dementia.

7. Ensure that generic, cooperative, and proactive strategic planning across relevant policy, provider and advocacy groups involves consideration of the current and future needs of adults with intellectual disabilities affected by dementia.

Background of Effort

The development of these principles and accompanying guidelines originated from questions raised by various service providers organizations across the world and in a series of meetings held during the past several years involving key international researchers and service providers in the field of ageing and intellectual disabilities (ID).

The basis for the Principles was an international consensus meeting, underwritten by the National Institute on Aging in the United States, and held in July 1994. The meeting, the Minneapolis Invitational Colloquium on Alzheimer's Disease and Developmental Disabilities, was an international gathering of experts held to address three key issues involving people with intellectual disabilities: a) diagnosis and assessment of dementia; b) epidemiology of dementia; and c) care and management practices. Subsequent related meetings in Manchester (UK) and Chicago (USA), both in 1994, and New York (USA) in 1995 lead to the publication of three reports detailing the key issues mentioned above under the auspices of the American Association on Mental Retardation (AAMR) and the International Association for the Scientific Study of Intellectual Disability (IASSID) (*see www.aamr.org and www. iassid.org for copies of the reports*)

As of yet, the varied national associations furthering the needs of persons affected by Alzheimer disease and related dementia have yet to define specific and consistent strategies in support of persons with ID affected by dementia. Many have looked to the ID systems in their nations for guidance and direction as to how best advise families and providers on avenues for care and supports. Some national ID groups have developed guidance documents on the basics of dementia, but these have not been generally circulated within the Alzheimer provider community (*see www.uic.edu/orgs/rrtcamr/dementia for a bibliography of these documents*).

In general, the documents produced dealt primarily with the challenges of diagnostics and general care practices related to people with ID and dementia and have only touched on specific services or support practices or principles. In activating the working group that developed the original AAMR/IASSID documents, it was determined that there was a need for agreement on a set of principles underlying the provision of supports and services to people with ID once they are identified as affected by dementia. The underlying belief for this agreement was that although dementia is an insidious condition, the people affected should continue to get the full benefits of continued community care and supports drawing from the best practices in the intellectual disabilities system and the Alzheimer disease and related dementias network.

The aims of the Edinburgh Working Group on Dementia Care Practices were to:

- build on the expertise and relationships created during previous meetings and develop new multidisciplinary relationships and networks;

- extend expertise, knowledge and skills in the specific area of provision of care for people with intellectual disabilities who are affected by dementia; and

- produce a set of principles outlining the rights and needs of people with intellectual disabilities affected by dementia.

This document details the outcomes of discussions held over a three-day meeting where participants focussed on several key questions and worked toward developing the Edinburgh Principles. The document is structured toward a four-point approach: adopting a workable philosophy of care, adapting practices at the point of service delivery, working out coordination of diverse systems, and promoting relevant research.

The recommendations embedded in this document are designed to influence care in existing service systems and to influence the development of care in the future. Efforts were made to use language that cuts across national systems of care provision.

A. Adopting a Workable Philosophy of Care

The members of the Edinburgh Working Group on Dementia Care Practices agreed that a number of key notions were important considerations in defining a workable philosophy of care with considering service provision to persons with ID affected by dementia. *First*, that such support philosophy adopted should be consistent with a belief that all individuals have a right to live their lives to their fullest potential based on their own values, beliefs and needs with a continuity of care reflecting changing individual needs. *Second*, that any provision of services should be proffered in a person-centred manner.

Third, that in adopting a philosophy, providers should achieve a balance between protection of function and a flexible, proactive and imaginative approach to developing quality of life. *Fourth*, that providers should avoid any inconsistency or tension between philosophies that may promote learning and growing and those for people living with decline. *Fifth*, that providers should strive to resolve any friction between regulatory standards and overall service philosophy, and the changing needs of individuals. *Lastly*, that in adopting a fundamental philosophy of care, providers should think long term about dementia rather than

engaging in a reactive process, but also provide hour-to-hour flexibility and the opportunity to maintain human interaction.

B. Adapting Services at the Point of Delivery

Persons with ID affected by dementia reside in a variety of settings, including with their families, on their own or with spouse or friends, in group living residences, and in institutions. There is a need to respond to needs across groups and include a family perspective and recognize that individuals needing services may often be unidentified. Therefore, providers need to be cognizant of the funding issues attached to where the individual is living. It is also important to consider that there are particular "at risk" groups such as people with ID who are semi-independent and capable of self care, as there are also individuals living on their own or with their own families.

Therefore, how to organize services and attend to meeting individual needs is a key consideration. Specific attention should be paid to future planning, with consideration of legal and financial issues, and that practices should be instituted that attend both to the physical needs of the individual and which promote healthy ageing. Such practices should also improve the awareness and attitudes of people who are involved in diagnosis, service planning and service provision. Issues need to be defined that relate quality of diagnosis and policies set as whether to share the diagnosis with the individual.

With regard to diagnostics, there is a need to develop and use a standardized assessment instrument with reliable thresholds and to ensure that the assessment process reviews a range of conditions and circumstances that otherwise mimic or distort symptoms. Clinicians need to recognize the variability of courses that the disease could take and that diagnosis of dementia is time consuming and difficult. It is recognized that there are few diagnostic facilities and, generally, a lack of trained personnel to do accurate and reliable diagnostic work-ups.

Carers need to be trained and other otherwise assisted to become more adept with their skills and the ways in which they can assist in the diagnosis process. Using a proactive approach to assessment where issues of registration and monitoring also involve family and other carers is important. The process of assessment is facilitated when there are standard tools and uniform ways of assessing for dementia. Planning should involve a lifelong approach based on typical patterns of change, but clinicians need to build in mechanisms to adjust for care changes.

Assessments, using a baseline for each individual, should be able to compare behavior presentations and thus indicate decline. However, information-gathering should be sensitive and should avoid being overly intrusive. Any information-gathering should include the knowledge and views of the people who are closest to the person. A biography-focussed approach, for example, can be used to complement any assessment. In the end, an impression should be built on what the individual wants that are based upon history and past choices.

Internal organizational relationships need to be thought out and instituting a clear line of referral into primary system established. Being clear to define "whose responsibility" and "which branch" is important. Bringing diverse branches of a provider system together is a goal to strive for and thinking compartmentally across and between services is something to avoid. Being aware of other possible causes and the possibilities of differential diagnosis is a major consideration (e.g., psychiatric issues, misdiagnosis, over diagnosis).

People with ID may lose skills and benefit from assessments that can highlight correctable conditions (such as, hearing, sight, pain, etc.). It is important to ensure that culturally sensitive supports are provided – moving away from the bias and stigma that there is no need to assess people with ID where dementia is suspected just because there are no services available. Establishing a register of people with ID affected by dementia – this often needs to be government-led with a national database of need especially for planning services – is a sound strategy. However, more work on predictive factors and dementia especially in people with Down syndrome is needed, as is more basic science information and more culturally sensitive supports. There is also a need to work with peers and being aware of how peers can contribute to the care of each other.

Any model of comprehensive services/supports has to have the goal of enhanced quality of life for the person. This means that an effective model may require legislative or regulatory changes; meaningful evaluation and oversight of the process; carer supports for those in the home; cultural sensitivity; an approach that meets the needs of the workforce and the medical professions; and encouragement of a partnership approach between and among a variety of providers and agencies.

A number of staffing issues require consideration. One is job descriptions – for example, there is a need for clarity around defining what is a nursing job and what is a social care job/role? The other area is the differentiation between health and social work – who gets to do what? There are obvious issues with transfer of money and resources to pay for staff and other

adaptations, so there is a need to look at coordination of different funding resources. The requirement for continued "active treatment" (found in some countries) is very much goal-driven – so there is a need to look at interpretation or impression of the regulations which underpin this practice. Generally, there is a need for a mix of paid and unpaid support. In addition, there is a problem with current cohorts of older people as their natural support systems have been removed or destroyed in the past.

C. Working Out Coordination of Diverse Systems

System coordination issues focus on who does what and under what statutes or agreements. For example, in the area of ID and dementia care, the penultimate question is which system has responsibility? Is it the ID system or the services developed to provide for older people? Further is the well-elderly support system or the long-term care system for impaired elderly persons? Being clear to define "whose responsibility?" and "which system?" is important. Bringing diverse systems together is a goal to strive for and thinking compartmentally across and between services something to avoid. Establishing a register of people with ID affected by dementia can be a useful first step in determining and defining care needs and practices.

Fundamental to system coordination is the issue of common terminology. The diverse systems (e.g., the ID, well-elderly aging, long-term care, Alzheimer support) all have their own terms and concepts in use. One significant challenge is overcoming the language and terminology differences between and within ID and older adult systems. Even in such primary areas as assessment effort needs to be given to how to best promote standards for diagnosis. Ethical issues, especially questions such as "who makes the decision(s)" need to be addressed (that is, is it the funder, the direct care provider, the family carers, and/or the individual affected by dementia?).

One area of cross-system coordination is the provision of end stage supports and the question of how can "end of life" care be improved by more effective use of generic resources -- such as home-nursing assistance and hospice? Drawing upon diverse systems' resources and how to make better use of such resources in flexible, reliable and consistent ways are major system coordination issues.

Coordination also involves delving into payment schemes and determining how to best use governmental support systems that pay for in-home supports and care. While the need for such coordination is universal, much of what can be resourced or accessed is contingent on country-specific

schemes. Important to coordination is the process of financing and time-scales for releasing funds and recognizing that additional funds are often needed for stage-related supports.

Attaining system coordination often involves complexities that require strategic planning to be effective and can involve such issues as "Are existing services comprehensive enough?" Thus, to be effective in coordinating diverse care systems, questions related to "What are effective strategies for maximizing cooperation between systems and are there ways of using historical/traditional connections" needs to be addressed. Further, issues of valuation or devaluation of pre-dementia disability conditions will affect how diverse systems choose to interrelate. For example, "How can the stigma associated with ID and dementia be reduced at an individual and service/system level?" needs to be addressed before attempting to build bridges across systems, knowing that such stigmata often will impede inter-system communication and willingness to cooperate or share resources.

System coordination can also involve issues of personnel. Questions related to such issues as "In what ways can training be delivered in robust and effective manners, especially where there is a high turnover of staff and where it might be dependent upon individual professional interest?" need to be addressed. Training can be targeted and delivered in flexible ways taking account of delivery, outcomes, core competencies and still be either specialized and/or generic, but this needs careful consideration of factors that often transcend the ID system. To maintain community supports for people with ID affected by dementia, workforce issues (such as staff retention and preparation) are important internal and external management challenges. Following on these challenges are several others, such as: "How can the general public concern for relatively 'small' numbers be effectively cultivated?" and "Can the use of 'advocacy services' or increased political awareness and power be effectively channeled to this end?"

A number of key policy issues are recognized as fundamental to change and for moving forward and can be outlined as follows:

- All individuals have a right to live their life to its full potential based on their own values, beliefs and needs with a continuity of care reflecting changing individual needs. Service provision should be person-centered to achieve this goal.

- There needs to be a balance between protection of function and a flexible, proactive and imaginative approach to developing quality of life. Funding is key to achieving this balance.

- Dementia registers are important – but there are difficulties in developing such registers. Governmental leadership is required to develop such national data bases of need, especially for planning services.

- Staff roles and job descriptions require greater clarification, minimizing conflicts between nursing and social care jobs/roles. Universities and regulators need to affect proper coordination between health and social care training.

D. Promoting Relevant Research

Research issues involving community supports and care are myriad, mainly because this is an area that has received scant attention in the medical and social services research literature. For example, there is a need to evaluate different models of care (including those that are person-centred) and conduct evaluations that take account of different perspectives (including type of living area, ageing in place, and supported living arrangements). Such evaluation studies should take account of the different people involved such as direct care providers, volunteers, paid staff and clinicians.

Research is also needed in examining the possible conflicts occurring between the differing philosophies of care that exist in ID services and those that are prevalent in dementia services. Traditionally, the prevailing care philosophy in ID services has focused on autonomy and developing skills, whereas dementia care philosophies focus on maintenance of skills. Research also is needed in examining the conflicts of "need" around specialist services for ID and older adults, as well as focusing on the commonalties across the ID and older adult service provision fields. Studies are needed that examine the nature and degree of cooperation between the ID systems and the aging network or elder care system. Greater investment is needed in conducting research on the epidemiology of dementia in the ID population with particular questions on the needs and stages in a person's life, very early intervention, and preventive measures.

Another research area is health needs, with an emphasis on how to maintain physical well being and cognitive functioning, as well as how to meet social needs and come to terms with congenital conditions and environmental factors. Further, research is needed on the effects of alcohol and substance use, oestrogen replacement, risk factors, nutrition (including vitamin supplementation), lipid profiles and life experiences and their effects on dementia. Research is required on the possible patterns of disease variation, including aetiology and duration and research is required on social needs (such as activities, education, employment, and stimulation).

System factors and ecological research are also needed, examining such broader topics as social care outcomes, quality of life, and life expectations. Research questions around the theme of family caregiving (included culture and values, constituents of support, expectations), age related differences of carers (especially younger carers and parents who provide care) and the characteristics of both carers and care recipients require exploration. Also needed is research on the impact of caring for an individual on other people in the home and the impact of the dementia on peers and family members.

Finally, research is needed to explore a range of social policy and financing questions and issues, including cost of care, efficiency, expertise consultation, multiple agencies and systems, accessibility, cross disciplinary work/research, service values and principles, shared or common service delivery and changing needs. Cost of care research needs to examine questions related to ageing in place versus ageing with dignity and those around the timing of care in relation to stages of illness/process.

Lastly, the research agenda needs to include questions on how to measure and research these issues, such as the fundamental question of "How can we evaluate the different models of care?" Another relevant issue deals with ethical and consent challenges faced by researchers, such as "legal prohibition" of participation in research, the use of protocols for consent, and ethical questions raised around participation in medication research.

Dissemination Program

Dissemination of the Edinburgh Principles and discussion points includes distribution to a variety of international and national intellectual disability associations, Alzheimer's disease organizations and disability-related non-governmental organizations (NGOs) throughout the world. Dissemination also includes posting on the Internet at key websites (such as, www.uic.edu/orgs/rrtcamr/dementia, www.iassid.org, www.inclusion-international.org, www.Alz.co.uk).

Acknowledgments

This document was produced by the Edinburgh Working Group on Dementia Care Practices, a group specially convened to discuss and produce this document. The initial draft was broadly circulated within the group and to external reviewers and experts for comment. The final document was accepted by consensus of the members of the Working Group. Special appreciation is extended to all those persons who commented and added to the document.

Summary

A panel of experts attending a three-day meeting held in Edinburgh in February 2001 was charged to produce a set of principles outlining the rights and needs of people with intellectual disabilities and dementia and defining service practices that would enhance the supports available to them. The Edinburgh Principles – seven statements identifying a foundation for the design and support of services to people with intellectual disabilities affected by dementia and their carers – was the outcome of this meeting. The accompanying guidelines and recommendations document provides elaboration of the key points associated with the Principles and is structured toward a four-point approach: adopting a workable philosophy of care, adapting practices at the point of service delivery, working out coordination of diverse systems, and promoting relevant research. It is expected that the Principles will be adopted by service organizations worldwide and the accompanying document will provide a useful and detailed baseline from which further discussions, research efforts, and practice development can progress.

Appendices

Available upon request from the University of Stirling, Dementia Services Development Centre, Department of Applied Social Science, Faculty of Human Sciences, University of Stirling, Stirling, Scotland FH9 4LA (via internet at h.a.wilkinson@stirling.ac.uk).

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