short communication

The Edinburgh Principles with accompanying guidelines and recommendations

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Abstract

A panel of experts attending a 3-day meeting held in Edinburgh, UK, in February 2001 was charged with producing a set of principles outlining the rights and needs of people with intellectual disability (ID) and dementia, and defining service practices which 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 ID affected by dementia, and their carers, were the outcome of this meeting. The accompanying guidelines and recommendations document provides an elaboration of the key points associated with the Principles and is structured toward a four-point approach: (1) adopting a workable philosophy of care; (2) adapting practices at the point of service delivery; (3) working out the coordination of diverse systems; and (4) promoting relevant research. It is expected that the Principles will be adopted by service organizations world-wide, and that the accompanying document will provide a useful and detailed baseline from which further discussions, research efforts and practice development can progress.

Keywords dementia, Edinburgh Principles, needs, rights, services

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Introduction

The following principles and guidelines were developed by the Edinburgh Working Group on Dementia Care Practices (EWGDCP) at a special meeting held in Edinburgh, UK, on 5–7 February 2001. The meeting was called by the University of Stirling, Stirling, UK, the University at Albany, Albany, NY, USA, and the University of Illinois at Chicago, Chicago, IL, USA, to define internationally applicable working practices for the community supports of adults with intellectual disability (ID) who are affected by Alzheimer disease (AD) and related dementias. The Edinburgh Principles were adopted by the International Association for the Scientific Study of Intellectual Disability (IASSID) Council on 27 September 2001. This document is sourced at the Centre for Social Research on Dementia, University of Stirling.

Alzheimer disease and related dementias and intellectual disabilities

Dementias resulting from AD and other related conditions are age-associated, i.e. they primarily affect older adults and their prevalence increases significantly with advancing age. The consequences of such dementias are memory loss, personality changes, diminished self-care abilities, and the eventual impairment of the cognitive and adaptive skills necessary for successful personal, occupational and community functioning. Dementias generally affect people with ID in the same manner as they do other older people, apart from some differential effects on individuals with Down's syndrome (DS). Adults with DS 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 people with ID affected by dementia. Many providers have not defined workable responses to the increasing presentation of dementia among people with ID. Care providers are becoming increasingly challenged to avoid institutionalization or the referral of affected individuals to inappropriate settings. Notwithstanding the insidious effects of dementia, there is agreement that adults with ID, as they are affected by AD 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 which promote continued community care and support of people with ID who are affected by dementia.

Therefore, EWGDCP has adopted the following principles with relation to continued community supports and services for people with ID affected by dementia. It proposes that governments, organizations and providers adopt these Principles and promote their use in aiding those adults with ID affected by AD and other similar conditions resulting in dementia.

The Edinburgh Principles

1 Adopt an operational philosophy that promotes the utmost quality of life of people with ID 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 people with ID 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 ID affected with dementia.
4 Ensure that appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs and support the healthy ageing of people with ID affected by dementia.

5 Plan and provide supports and services which optimize remaining in the chosen home and community of adults with ID affected by dementia.
6 Ensure that people with ID affected by dementia have the same access to appropriate services and supports as afforded to other people 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 ID 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 ID.

The basis for the Principles was an international consensus meeting, underwritten by the National Institute on Aging in the United States, that was held in July 1994. This 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 ID: (1) the diagnosis and assessment of dementia; (2) the epidemiology of dementia; and (3) care and management practices. Subsequent related meetings in Manchester, UK, and Chicago, IL, USA, both in 1994, and New York, NY, USA, in 1995 led 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 IASSID. (For copies of the above reports, see <www.aamr.org> and <www.iassid.org>.)

As of yet, the varied national associations furthering the needs of people affected by AD and related dementia have yet to define specific and consistent strategies in support of people with ID affected by dementia. Many have looked to the ID systems in their home 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 AD provider community. (For a bibliography of these documents, see <www.uic.edu/orgs/rrtcamr/dementia>.)

In general, the documents produced have primarily dealt 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 an 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 individuals affected should continue to get the full benefits of continued community care and supports drawing from the best practices in the ID system, and the AD and related dementias network.

The aims of EWGDCP were to:

• build on the expertise and relationships created during previous meetings, and develop new multi-disciplinary relationships and networks;

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

• produce a set of principles outlining the rights and needs of people with ID affected by dementia.

This document details the outcomes of discussions held over a 3-day meeting at which participants focused on several key questions and worked toward developing the Edinburgh Principles. The document is structured toward a four-point approach: (1) adopting a workable philosophy of care; (2) adapting practices at the point of service delivery; (3) working out the coordination of diverse systems; and (4) 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.

Adopting a workable philosophy of care

The members of EWGDCP agreed that a number of key notions were important considerations in defining a workable philosophy of care considering service provision to people with ID affected by dementia:

1 Any such support philosophy that was adopted should be consistent with the 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.

2 Any provision of services should be proffered in a person-centred manner.

3 In adopting a philosophy, providers should achieve a balance between the protection of function, and a flexible, proactive and imaginative approach to developing quality of life.

4 Providers should avoid any inconsistency or tension between philosophies which may promote learning and growing, and those for people living with decline.

5 Providers should strive to resolve any friction between regulatory standards and overall service philosophy, and the changing needs of individuals.

6 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.

Adapting services at the point of delivery

People with ID affected by dementia reside in a variety of settings, including with their families, on their own, with a 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, recognizing 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, because there are also individuals living on their own or with their own families.

Therefore, the question of 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 practices should be instituted which both attend to the physical needs of the individual and 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 which relate quality of diagnosis and policies set, such 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 which otherwise mimic or distort symptoms. Clinicians need to recognize the variability of

courses which 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 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 behaviour presentations, and thus, indicate decline. However, information-gathering should be sensitive and avoid being overly intrusive. Any information-gathering should include the knowledge and views of the people who are closest to the person. For example, a biography-focused approach can be used to complement any assessment. In the end, an impression should be formed of what the individual wants that is based upon history and past choices.

Internal organizational relationships need to be thought out and a clear line of referral into the primary system must be established. It is important to define clearly who is responsible and which branch is accountable. 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 and over diagnosis).

People with ID may lose skills, and they benefit from assessments which can highlight correctable conditions (e.g. hearing, sight or pain). 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. The establishment of a register of people with ID affected by dementia often needs to be government-led and a national database of need, especially one for planning services, is a sound strategy. However, more work on predictive factors and dementias needed, especially in people with DS, as is more basic science information

and more culturally sensitive supports. There is also a need to work with peers and to be 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 individual concerned. 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 the 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 to define clearly nursing jobs and social care jobs/roles. Another area is the differentiation between health and social work: Who gets to do what? There are obvious issues about the transfer of money, and resources to pay for staff and other adaptations, so there is a need to look at the coordination of different funding resources. The requirement for continued 'active treatment' (found in some countries) is very much goal-driven, and therefore, there is a need to look at the 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 because their natural support systems have been removed or destroyed in the past.

Working out the coordination of diverse systems

System coordination issues focus on who does what under which statutes or agreements. For example, the penultimate question in the area of ID and dementia care is the matter of which system has responsibility. Is it the ID system or the services developed to provide for older people? Furthermore, is it the well-elderly support system or the long-term care system for impaired elderly people? It is important to define clearly who is responsible and which system is accountable. 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. ID,

well-elderly ageing, long-term care and AD 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, an effort needs to be made to establish how to best promote standards for diagnosis. Ethical issues, especially questions such as the issue of who makes the decision(s), need to be addressed: Is it the funder, the direct care provider, the family carers and/or the individual affected by dementia who makes the decision(s)?

One area of cross-system coordination is the provision of end-stage supports and the question of how 'end of life' care can be improved by the more effective use of generic resources, such as home-nursing assistance and hospice care. Drawing upon diverse systems' resources and knowledge of 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 best to use the governmental support systems which 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. The process of financing is important to coordination, as are time-scales for releasing funds and recognizing that additional funds are often needed for stage-related supports.

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

System coordination can also involve issues of personnel. Questions related to such issues as the ways in which training can 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 and core competencies, and still be either specialized and/or generic, but this needs careful consideration of factors which often transcend the ID system. To maintain community supports for people with ID affected by dementia, workforce issues (e.g. staff retention and preparation) are important internal and external management challenges. Following on these challenges are several others, such as how the concern of the general public for relatively 'small' numbers can be effectively cultivated, and how the use of 'advocacy services', or increased political awareness and power can be channelled to this end effectively. A number of key policy issues are recognized as fundamental to change and for moving forward, and these 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-centred 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 to minimize conflicts between nursing and social care jobs/roles. Universities and regulators need to ensure proper coordination between health and social care training.

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 to date. For example, there is a need to evaluate different models of care (e.g. those which are person-centred) and conduct evaluations which take account of different perspectives (e.g. the type of living area, ageing in place and supported living arrangements). These evaluation studies should take account of the different people involved such as direct care providers, volunteers, paid staff and clinicians.

Research is also needed that examines the possible conflicts which could occur between the differing philosophies of care which exist in ID services and 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 is also needed that examines the conflicts of 'need' around specialist services for ID and older adults, as well as work that focuses on the commonalties across the ID and older adult service provision fields. Studies are needed which examine the nature and degree of cooperation between the ID systems, and the ageing network or elder care system. Greater investment is needed in research on the epidemiology of dementia in the population with ID with particular regard to the needs and stages in a person's life, very early intervention, and preventive measures.

Another potential 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. Furthermore, 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. Work is required on the possible patterns of disease variation, including aetiology and duration, and on social needs (e.g. activities, education, employment and stimulation).

System factors and ecological research are also needed that examines such broader topics as social care outcomes, quality of life and life expectations. Research questions around the theme of family caregiving (e.g. culture and values, constituents of support, and expectations), age-related differences of carers (especially younger carers and parents who provide care), and the characteristics of both carers and care recipients all require exploration. Work is also needed 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 that explores 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 about how to measure and research these issues; for example, the fundamental question of how we can evaluate the different models of care. Another relevant issue deals with the ethical and consent challenges faced by researchers, such as 'legal prohibition' of participation in research, the use of protocols for consent, and the ethical questions raised about participation in medication research.

Dissemination programme

Dissemination of the Edinburgh Principles and discussion points includes distribution to a variety of international and national ID associations, AD organizations and disability-related non-governmental organizations throughout the world. The dissemination also includes posting on the Internet at key websites; for example, <www.uic.edu/orgs/rrtcamr/dementia>, <www.iassid.org> and <www.Alz.co.uk>.

Appendices

Appendices are available upon request from the corresponding author (H.W.).

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