

Training, Recruitment and Retention in the field of

Developmental Disabilities and Dual Diagnosis

A Review of the Literature

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Prepared by:

**Task Group of the NADD Ontario Chapter**

Susan Morris, MSW., RSW Chair

Contributors:

Shelley Bishop,

Maria Gitta MA Psychology

Yona Lunsky Ph.D., C.Psych.

Jo Anne Nugent MA, EdD (candidate)

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On Behalf of: **National Association for the Dual Diagnosed, Ontario Chapter**  
(Formerly Habilitative Mental Health Resource Network)

## EXECUTIVE SUMMARY

In the field of developmental disabilities<sup>1</sup>, our most fundamental current issue is the education, training, recruitment, and retention of staff.

NADD (National Association for the Dually Diagnosed) Ontario is an organization which has a particular focus on individuals with developmental disabilities and mental health needs. In keeping with its mandate, NADD Ontario has produced a literature review to identify successful strategies used in other jurisdictions such as the United Kingdom, the United States, and Australia that contribute to sustainable training and education models. These models are applicable for staff working in developmental and mental health services, as well as in generic services that support people with developmental disabilities.

The report has concluded, based upon the literature, that there are 11 key elements for success:

1. Developmental disability policy includes health and mental health needs and recognizes the skills, training, and qualifications required to address these needs.
2. Funding policy is established that is specific to the needs of individuals with developmental disabilities and becomes a powerful tool to effect change.
3. The structure to oversee the implementation of policy and to evaluate outcomes is integrated within other policy and program level initiatives (e.g., primary health, mental health, income support, education)
4. Career pathways, developed through policy as well as program/practice level initiatives, support recruitment, retention, and advancement.
5. When access to care occurs through the generic health care system, training and continuing education in developmental disabilities and dual diagnosis are required aspects of curricula, practicum, and practice standards
6. Training sanctioned within professional practice standards and/or certification criteria supports the implementation of best practice.
7. Early exposure to developmental disabilities and dual diagnosis within training and clinical or practicum experiences increases a sense of competence to serve this population
8. A variety of creative models, approaches and strategies can be utilized to achieve success in training
9. Teaching clients and caregivers about primary care improves quality of care.
10. Existence of local, regional or national interest groups contributes to enhanced practice.
11. Standardized procedures or templates assist practitioners in the implementation of quality care.

The NADD Ontario report concludes that there are 3 fundamental keys to success of education, training, recruitment and retention of staff in the field of developmental disabilities in Ontario:

- ❖ Government policy that incorporates human resource principles, strategies and structure to address training, education, recruitment and retention.
- ❖ Training, education, recruitment and retention policy and practices that take a population health perspective, integrating health and community living needs.
- ❖ Education curricula and practice standards that are developed upon and follow policy intent

NADD Ontario recommends that the current discussion occurring within Ontario incorporate a population health perspective. That is, training, education, recruitment and retention initiatives in the field of

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<sup>1</sup> In Ontario the term Developmental Disabilities is most often used to refer to individuals who have an intellectual disability (significant limitations in cognitive and adaptive functioning prior to age 18 years of age). Dual Diagnosis refers to developmental disabilities and mental health needs. Other jurisdictions use the terms intellectual disability, mental retardation or learning disabilities. These terms are used in the paper when quoting a specific reference from those jurisdictions.

developmental disabilities reach across and include the mainstream systems within which individuals with developmental disabilities live their lives and from whom they obtain their supports (e.g., health, education, mental health and justice sectors as well as social, recreational and housing).

NADD Ontario's focus will now be to coordinate our efforts with other organizations that share similar concerns and objectives. We would like to become a partner in the provincial discussions that are occurring, with the goal of bringing the population health perspective to the dialogue and supporting as necessary cross sector communication. To achieve this, the paper has been distributed to key system stakeholders to invite their feedback and request to join the efforts of those stakeholders. Recipients of the paper include the Provincial Network on Developmental Disabilities, the leads of the Community Networks of Specialized Network Care for Individuals with a Dual Diagnosis and/or Challenging Behaviours, Directors within the Ministries of Health, Community and Social Services, and Training Colleges and Universities, and the Academic Health Science Centres Task Force.

## **Preamble**

NADD (National Association for the Dually Diagnosed) Ontario has long been engaged in education and training initiatives to build the skills of Ontario providers who serve individuals with developmental disabilities and mental health needs. A current goal of the association is to ***support the establishment of sustainable education and training related to dual diagnosis in Ontario.***

This goal has taken on greater urgency over the last few years as several stakeholder groups in addition to NADD Ontario have increasingly identified education, training, recruitment and retention of staff to work in the field of developmental disabilities as the most fundamental issues facing us in the new millennium. For example:

- A policy forum on Dual Diagnosis held by MCSS (Ministry of Community & Social Services) in 2004 identified training, recruitment and retention as major issues to be addressed at a system level.
- The response from OASIS (Ontario Agencies Supporting Individuals with Special Needs) to the MCSS Transformation of Developmental Services (2004) identified specific concerns regarding recruitment, training and salary levels, building on work undertaken by OASIS some years earlier looking at human resource issues and salary levels in particular.
- MCSS recently completed a significant human resources study on "Improving recruitment, training and retention in Ontario's DS (Developmental Services) sector". The study involved a literature review, a jurisdictional scan, a survey of current employees and employers, in depth interviews and focusgroups. The draft report contains a gap analysis that compares the current state of the DS sector with the leading practices for recruitment, retention, and training. Gaps have been prioritized based on their prevalence and recommendations for improvements are provided.
- The Human Resource Development Symposium sponsored by MCSS, Queen's University and Ongwanada in November 2006 discussed a number of recruitment and retention ideas. Included were the need to establish additional university-agency affiliations and a major human resources initiative that would identify current availability of professional staff, "benchmarks" for staffing from other jurisdictions, application of technology such as website listing of practicum settings and career opportunities.
- In the spring of 2007, the Ontario Association on Developmental Disabilities (OADD) surveyed 173 people working in the developmental services field. In response to the questions on training, the priority needs identified by respondents were, team work, information on specific disabilities, stress management, leadership, and relationship management. The emphasis on the development of general employment related skills rather than solely specific knowledge related to disabilities is noteworthy, as these are broader skills that enable longevity and advancement within a field of practice.

One of NADD Ontario's most notable achievements in the area of education was the publication of *An Introduction to the Mental Health Needs of Persons with Developmental Disabilities* (June 2002). This publication (available in hard copy and on the web at <http://www.naddontario.org/>), supported by grants from the Ministries of Community and Social Services and Health and Long Term Care, has been used in whole or part in various communities and academic institutions as a training manual and source book. While the book has provided a 'minimum' standard of information for front line staff, the training initiatives undertaken have historically been uneven across the province, often occurring as "one-off's" related to one time year end funding as opposed to tied to a longer term strategy.

NADD Ontario, as an organization, has a particular focus on individuals with a dual diagnosis. However, with an estimated 38% of Ontario's individuals with developmental disabilities experiencing mental health issues (approximately 104,000 Ontario residents) (Yu & Atkinson, 1993), the reality is that many individuals with a dual diagnosis currently are and will continue to be served by 'generic' developmental, social service, health and mental health providers. The specialized resources for individuals with a dual diagnosis and/or challenging behavior that are taking shape within the coordinating structure of the newly formed Networks of Specialized Care for Individuals with a Dual Diagnosis and/or Challenging Behaviour will support a portion of these clients. However, Network services will be an adjunct to the continuum of services and not a replacement for generic services. As a result we believe that while tertiary-level specialized services and training are required, NADD Ontario's goal regarding education and training is synonymous with that of other stakeholders involved in supporting individuals with developmental disabilities. Further, NADD Ontario supports a population health perspective that would suggest that training and education needs to be incorporated into all the mainstream systems (e.g., community living including social, recreational and housing sectors, health, education, mental health, justice) that support and promote the health and well being of persons with a developmental disability. Therefore training and education related to dual diagnosis should be incorporated with training and education related to developmental disabilities. Making headway in an organized way in the area of education, training, recruitment and retention has been a challenge as there have been numerous and not necessarily connected activities undertaken at different levels both within and outside of government. NADD Ontario's efforts in this area need to be coordinated with other organizations that share similar concerns and objectives.

From a NADD Ontario position, our role, reflective of our membership and knowledge base, is to provide the cross sector perspective and experience of the mental health and developmental systems. That includes the experience of families, the knowledge of providers, our specific focus and expertise on dual diagnosis and our knowledge and experience of other jurisdictions. This role is also consistent with other papers that have been developed by NADD Ontario, the most recent having been a response to the MCSS Transformation Agenda "*Meeting the Health and Mental Health Needs of Individuals with Developmental Disabilities*" (December 2004). (<http://www.naddontario.org/>)

NADD Ontario determined that its' most meaningful contribution to the discussion of these issues at this stage was to develop a brief paper that would provide a summary of strategies undertaken by other jurisdictions that appear to be contributing to sustainable training and education models. What follows is a summary of a literature review of policies, structures and practices in other jurisdictions related to training, recruitment and retention in the field of developmental disabilities. One area that this review does not address is the issue of compensation, as there have been other very well documented and thorough reports that enumerated the issues and solutions to this key issue.

For the reasons stated above, the paper examines the literature on developmental disabilities rather than limiting our review to only the area of dual diagnosis. Literature for the United States, United Kingdom and Australia were the primary sources as they have more well-developed training systems. While it appears that no jurisdiction has a comprehensive model addressing all the various issues for all staff, there were elements within the various strategies that seemed to point to a greater likelihood of success. Some challenges to

implementation experienced within jurisdictions are also identified.

While the jurisdictions reviewed have different political structures, the actual strategies seem to cluster in two groups: those that impact at a system level (state or federal depending on where the legal authority is vested for the jurisdiction) and those that impact at a program, practice or operational/delivery level. For the purposes of this paper, system level should be interpreted as a provincial level as the province of Ontario has the primary authority for funding, policies and programs in this area.

It is our hope that the paper will be useful in advancing the discussion on these very important issues.

## **Summary of Common Strategies or Key Elements from a Review of Literature**

What follows is a summary of the common strategies undertaken by other jurisdictions that appear to be contributing to sustainable training and education approaches in those locales. They have been grouped into two broad categories: system level strategies that have broad impact - including policy, funding and related supporting structures; and program/practice delivery level strategies – including practice standards, education and training approaches and related supporting structures. Strategies that overlapped between the two categories were placed within one category based on the best judgment of the authors.

### **At a System Level**

#### **1. Developmental disability policy includes health and mental health needs and recognizes the skills, training, and qualifications required to address these needs**

The literature clearly indicates that in jurisdictions where significant and comprehensive reform has occurred, there are two key elements: an integrated health and social services approach to policy, and expectations regarding knowledge and skills which are anchored within policy in ways that are most likely to result in implementation of strategies and changes in behaviors.

#### **Specifics from the Literature**

In the U.K., *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, published by the Department of Health in 2001, established a series of Government objectives that fell into 2 categories: goals for people with disabilities, and goals for the systems needed to deliver better outcomes for people. This policy paper has led the way for reform in all aspects of the service system for people with developmental disabilities. Two goals in *Valuing People* are of particular note:

- Goal 9 is to ensure all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value; and,
- Goal 10 is to ensure that social and health care staff working with people who have learning disabilities are appropriately skilled and trained to be qualified to meet the needs of people with learning disabilities.

Both of these objectives were strengthened by the inclusion of specific commitments/outcomes. For the service provision objective, legislation was enacted that defined minimum care standards. For the skills objective, new programs at the individual, regional and systems level were created to provide the opportunity for skill development and qualification enhancement.

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The U.S. has a long history of policy commitment to the field of developmental disabilities, dating back to President Kennedy and the early 1960s with a comprehensive federal legislative initiative to establish programs in research, diagnosis, and treatment of mental retardation, and to educate and train professionals in the field. The result was the creation of a national network of *University Centers of Excellence in Developmental Disabilities* (UCEDD), formerly known as University Affiliated Programs (UAPs). Currently 61 UCEDDs exist with at least one found in every state and territory in the U.S. and each UCEDD is affiliated with a major research university. Some examples are the Nisonger Center at

Ohio State University and the Shriver Center, part of the University of Massachusetts Medical School since 2001. The Shriver Center has one of the oldest UCEDDs in the country and has led the way in developing undergraduate, graduate and post-graduate training programs for professionals in medical and allied health fields. The Administration on Developmental Disabilities (ADD) is the federal government organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and for designating UCEDDs. This structure remains linked to the political agenda through the President's Committee for People with Intellectual Disabilities and has, over the 44 years since its inception, been a key point in the system for research, treatment and education and training.

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More recently, the U.S. Surgeon General published *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, 2002*. Similar to the U.K., the 4th goal focuses on "training health care providers in the care of adults and children with mental retardation". (National Institute of Child Health and Human Development (NICHD), 2006). This report identified both the challenge and the potential solution as follows: "The challenges and rewards of treating individuals with MR are rarely addressed in the training of physicians and other health care professionals". This report provides anecdotal evidence and some data indicating that opportunities for clinical experiences with these patients, early in medical and other health professions training, increase the capacity of providers to value and accept these patients into their practices. As with the U.K. strategy, this broad intention is given focus through specific strategies in the report related to training, certification, accreditation and curriculum.

*In summary, a comprehensive policy is one that integrates a population health approach and the systems of care that affect individuals with developmental disabilities (e.g., community living, health, mental health), and also incorporates clear statements of expectations and outcomes regarding workforce knowledge and skills.*

## **2. Funding policy is established that is specific to the needs of individuals with developmental disabilities and becomes a powerful tool to effect change**

The literature indicates effective funding policy is structured to address the service system from a consumer/provider perspective and also includes specific funding to change the behaviours and skill levels of those working in the system. Expectations for outcomes regarding the functioning of the system and wellbeing of those served must be accompanied by an investment in the workforce on whom these expectations rest.

### **Specifics from the Literature**

At its' inception, participation in the UCEDDs was stimulated by federal funds for campus facilities to conduct research and provide training and clinical services. This established an infrastructure within which the goals of policy would be achieved. Annualized funding commitment also needs to be considered, as within the UCEDD example, some of these centres have recently experienced difficulties due to successive funding cuts.

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Similar to the UCEDDs in the U.S., there are now 4 academic state-funded centres in Australia, which combine clinical, research, and education aims through partnerships with teaching hospitals, universities, and Intellectual Disability services. (Centre for Developmental Disability Health Victoria (CDDH),2004)

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In the U.K., the achievement of Goal 10 in *Valuing People* was supported through a *Learning Disability Awards Framework*. This strategy invested approximately 20 million pounds (approximately 45 million CDN) to provide a new recognized route to qualification, and career progression (career paths) for care staff, in order to create more qualified staff in the field. As reported in *Valuing People – 4 Year Review, Valuing People Support Team 2005*, this fund also paid for leadership programs for managers, families,

health professionals, self-advocates, and tool kits to support work within specialist health services. Additionally, the Framework provided for a four year research fund of approximately 2 million pounds (approximately 4.5 million CDN) to examine effectiveness of health and social service delivery including elements of good practice, social inclusion re: access to good health care, and partnerships (e.g., ‘green light protocols’ to assist partnerships across generic, secondary and specialist providers).

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Training is one component of a successful strategy; the second is application of the knowledge and skill within a profession by providing incentives and/or infrastructure to support people to use their skills to better the lives of individuals with a developmental disability. In Australia the government announced a new *Medicare rebate* for an annual health assessment, to be available by July 2007. (Department of Health and Ageing. (n.d.)) This rebate to primary care physicians recognizes the fact that people with an intellectual disability have complex health needs that are difficult to adequately assess because of the patient’s inability to recognize and communicate symptoms. The Minister introducing this initiative estimated that there are 80,000 Australians with an intellectual disability who would be eligible, at a cost of around \$11 million (approximately 12 million CDN) over four years. “Current GP items available under Medicare do not allow sufficient time for the complex needs of people with an intellectual disability,” Minister Pyne said. “As a result, evidence suggests that around 40 per cent of medical conditions remain undiagnosed and that only half of the diagnosed conditions are appropriately treated. The new Medicare item will provide a structured clinical framework for GPs to assess a patient’s overall health and plan for their long-term care. The item will allow GPs to spend extra time with intellectually disabled patients that will result in a more comprehensive care plan involving the GP and other allied health professionals to prevent the onset of chronic disease.” (Ibid)

*In summary, to effect change ‘on the ground’, funding policy must be linked to the original policy intent and implementation strategies, particularly in relation to addressing knowledge and skill gaps of persons working in the field.*

### **3. The structure to oversee implementation of policy and to evaluate outcomes is integrated within other policy and program level initiatives (e.g., primary health, mental health, income support, education)**

The literature suggests that implementation strategies are more likely to be effective when they are supported by a policy framework that links the policy intentions of different parts of government in an integrated way as it relates to a specific population whose needs cross traditional boundaries. Complex strategies therefore require “vertical and horizontal” structures that cross traditional boundaries and silos. These structures are also clearly mandated to require collective action to address issues and needs.

#### **Specifics from the Literature**

The *President’s Committee for People with Intellectual Disabilities* (PCPID), formerly The President’s Committee on Mental Retardation (PCMR), is a federal advisory committee established by presidential executive order to advise the President of the United States and the Secretary of The Department of Health and Human Services on issues concerning citizens with intellectual disabilities. The PCPID has both vertical and horizontal impact in relation to its’ responsibilities to coordinate activities between different federal agencies and to assess the impact of their policies upon the lives of citizens with intellectual disabilities and their families. The Committee’s goals include assurance of full citizen rights, provision of all necessary supports to individuals and families, reduction of occurrence and severity of intellectual disability, and promotion and dissemination of information models, programs and services within the field.

The 2004 annual report of the PCPID “*A Charge We Have To Keep: A Roadmap To Personal And Economic Freedom For Persons With Intellectual Disabilities*” provides an example of this vertical and horizontal strategy. (Administration for Children & Families (ACF), 2004). The PCPID

recommends:

- The President participate in a public awareness campaign to change employers' attitudes.
- Federally funded programs are held accountable to advance personal and economic freedom for persons with ID through the introduction of House and Senate oversight hearings to assess performance of agencies – such hearings should extend beyond traditional lines of authority to embrace a holistic view of individuals and family support that analyzes relationships among tax, finance, economic, education, health care and workforce policies.
- Guidance to States is provided on standards and assessment for students with intellectual disability to improve post secondary outcomes for intellectual disability through “Job” initiatives – forums with business leaders, enhance teacher training skills.
- Individuals with intellectual disability are allowed to accumulate assets without losing benefits.
- Establishment of an Interagency Task Force on Developmental Health within the Center for Disease Control with representation from Bureau of Health Professions, Agency for Health Research and Quality, Administration on Developmental Disabilities.
- Establishment of a network of ‘Research Centres of Excellence in Technology and Intellectual Disability’.

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In the U.K., implementation of the Valuing People policy is occurring across different government departments, also demonstrating this ‘vertical and horizontal’ approach to policy implementation. For example:

- Implementation Support Teams focus on strengthening advocacy, person centred planning and partnership, and promote the changes outlined in Valuing People at the regional and local levels.
- A National Learning Disability Task Force includes people with disabilities and their supports to monitor, support and advise government.

Following the initial outcomes from **Valuing People**, additional horizontal and vertical initiatives and indicators have been identified:

- A government promise to consider introducing health checks for people with learning disabilities.
- The start of a ‘formal investigation’ by the Disability Rights Commission into the health inequalities facing people with learning disabilities, which will help to raise awareness of peoples’ poor health.
- Work starting on the ‘confidential inquiry into the deaths of people with learning disabilities’ promised in Valuing People. This will help to understand why people die much earlier than the general population.
- Two new learning disability ‘performance indicators’ include - checking that all GPs know which of their patients has a learning disability and that the NHS (National Health Service) is not spending too much time and money on old-fashioned bed based services.
- A promise by the Healthcare Commission to consider the health of people with learning disabilities across all their work by a learning disability specialist.
- A new Department of Health plan for NHS information collection called ‘Better Metrics’ that includes 12 learning disability standards.
- The new Disability Discrimination Bill requires that the NHS show that it is taking positive action to address the health inequalities facing people with learning disabilities. This means that, even if people with learning disabilities are not listed as a top NHS priority, the NHS will be required to pay more attention to them. (Valuing People Support Team, 2005).

Although there remain some implementation issues, the same report noted that the federal structures put into place are successfully supporting implementation of the intent of the original policy, and noted as an “important weapon in helping to win arguments with people who still do not see why they should include people with LD. (Ibid)

*In summary, the principle of an integrated health and social service approach to policy is continued within the implementation strategies and structures. ‘Vertical and horizontal’ links occur between policy and program level initiatives across the systems and sectors, thus having a more consistent impact on the daily lives of individuals with developmental disabilities. This can include links between areas such as primary health care, mental health, income support, education, or justice.*

#### **4. Career pathways, developed through policy as well as program/practice level initiatives, support recruitment, retention and advancement**

The literature suggests that defining and supporting meaningful career development options and standards for training (particularly through policy) contributes to a skilled and committed workforce able to operate effectively in the system.

##### **Specifics from the Literature**

An example of policy defining a career pathway is from the previously mentioned U.K. ***Learning Disability Awards Framework*** (LDAF). It established that all new entrants to learning disability services would be registered for the new awards. The LDAF is intended to improve the skill level of care workers in the field and create the path through which people could seek career advancement through improved qualifications. Of note is that it established two new vocational qualifications:

- A level 2 Certificate in working with people with learning (ID) disabilities;
- A level 3 Advanced Certificate in working with people with learning (ID) disabilities.

The Government targets set an expectation that 50% of front line staff should have achieved at least Level 2 by 2005. In a review of progress it is noted that training is one of the highest areas of achievement as a result of the Valuing People policy. (Ibid)

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A practice level example is the National Leadership Consortium on Developmental Disabilities established at the University of Delaware. In response to significant concern about training and support for the next generation of leaders in the developmental disabilities field, the Consortium offers undergraduate and

graduate level campus-based programs, distance learning opportunities, continuing education programs, and a resource-rich website. The Consortium serves both current executive-level leaders and those who will fill these roles in the future. The Institute supports the development of skilled leaders who are passionate about quality, have the management and financial skills needed to run solid not-for-profit businesses and government agencies, are capable of assembling top-notch teams of caring staff, and have a solid commitment to progressive values that assure lives of meaning and impact for the individuals receiving support.

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Another practice example is the AAIDD (formerly AAMR) Ad Hoc Committee on Student/Junior Member Recruitment and Retention. They offer a Young Professionals web site that synthesizes and organizes information relevant to young researchers and professionals working in the field of intellectual and developmental disabilities. The new AAIDD Guide Program matches experienced AAIDD fellows with students and new members based on member interests or locality to encourage participation in the association and the field. (American Association on Intellectual and Developmental

Disabilities, AAIDD).

*In summary, an intentional and focused strategy of establishing career paths, supporting recruitment and retention, is part of both policy and practice initiatives.*

### **5. When access to care occurs through the generic health care system, training and continuing education in developmental disabilities and dual diagnosis are required aspects of curricula, practicum and practice standards**

The literature demonstrates that when access to care is through the generic health care system then trainees require core curriculum training (augmented with actual clinical experience) in assessing and supporting the needs of individuals with a developmental disability. The health statistic for people with developmental disabilities would appear to indicate that when training and clinical experience in developmental disabilities is discretionary the diagnosis and treatment of co-morbid conditions is less than optimal.

#### **Specifics from the Literature**

From *Valuing People - The Story so Far 2005* in the U.K., one can observe the impact of policy requiring training of all generic providers. Service recipients note that they feel they are being listened to more, have more choice and control and they are more involved in their community (e.g., participating on Partnership Boards). The review also indicated that the government was planning to release a white paper looking specifically at access to health care and the role of the NHS (National Health Service). It was also noted that some GP practices include Learning Disabilities in their screening and prevention interventions. Additionally a national network of Learning Disability nurses and another one for staff working in acute care hospitals are examples of continuing education structures.

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The *Australian Association of Developmental Disability Medicine* (AADDM) has focused on improving the health of people with intellectual and developmental disabilities across the lifespan by establishing national standards for health management of people with disability. They are actively providing continuing professional development/tools/resources for doctors and related clinical providers.

*In summary, education curricula and practice standards must follow policy intent. Many jurisdictions similar to Canada have established access to services through the generic system as a basic human right. It follows therefore, that providers of such services be appropriately trained, based on best and/or informed practice.*

## **At a Program/Practice Delivery Level**

### **6. Training sanctioned within professional practice standards and/or certification criteria supports the implementation of best practice**

While this element overlaps somewhat with point 5 above, it bears separate acknowledgement. The literature indicates that professional and licensing bodies play a key role in supporting implementation of best or informed practice and therefore broader policy intentions.

#### **Specifics from the Literature**

The Australian Association of Developmental Disability Medicine (AADDM) has established principles consistent with the European Manifesto on Basic Standards of Health Care for People with Intellectual Disabilities. The AADDM is actively:

- developing standards for service provision;
- identifying outcomes/evaluative measures (through establishment of Adult Intellectual Disability Health Evidence Collaborative); and
- advocating at regional and national levels on many issues for example, changes to the

funding formulas and putting healthcare issues for people with disabilities on the national agenda.

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In Ontario in 2006, under the leadership of Dr. Bill Sullivan, and jointly funded by Surrey Place Centre and the Ministries of Community and Social Services and Health and Long Term Care, the first ***Primary Health Care Guidelines for Adults with Intellectual Disabilities*** were peer-reviewed and published in the Canadian Family Physician. (Sullivan et al, 2006) The guidelines were also distributed to all family physicians and general practitioners in Ontario and have been presented and discussed in a series of workshops in key Ontario sites. Briefly described, the 24 guidelines fall into three groups: general issues (1-7), physical health guidelines (8-17), and behavioral and mental health guidelines (18-24).

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In a related vein, within psychiatry, training standards are under revision by the Specialty Committee for Psychiatry of the Canadian Royal College of Physicians and Surgeons to “strengthen the training in dual diagnosis and recommend that residents have experience assessing and treating persons with developmental delay across the life span. A selective in developmental disabilities of three to six months duration is included in the menu of rotations that are intended to address societal needs”. (Elliot, 2006) These proposed revised standards if accepted, would apply to residents starting a program in 2008.

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Other professional practice groups have provided leadership in this regard. In a joint report by the American Academy of Developmental Medicine and Dentistry and Special Olympics regarding health disparities for individuals with developmental disabilities, three interacting factors were identified as responsible for the current push for better training:

1. the trend towards deinstitutionalization
2. the increasing life span of the population and the resultant rise in health care access problems; and
3. the scientific evidence for the importance of oral-systemic health interactions. (McCreary & Stanton, 2006)

The first two of these factors obviously apply across the spectrum of providers. In the U.S. there are a few dentistry schools that have actually developed mandatory undergraduate curricula on the care of special patients, including those with developmental disabilities. Efforts are also underway within the U.S. to develop a nationally consistent curriculum for undergraduate or graduate programs. (Ibid)

With regard to nursing the U.S. has a Developmental Disabilities Nursing Association (DDNA) and the AAIDD has a nursing division. The U.K. model incorporates a training curriculum for learning disability for community nurses. (Ibid) In the U.K. and Australia graduate training in intellectual disabilities is a requirement for clinical psychology degrees. Additionally, in 2004 the British Psychological Society’s Division of Clinical Psychology developed accreditation guidelines outlining core competencies, academic teaching and supervision requirements within post doctoral courses.

*In summary, professional practice bodies play a significant and key role in ensuring coherence with best and/or informed practice. The challenge for the developmental disability/dual diagnosis field is to obtain recognition of this need against the many other competing areas for recognition within such groups.*

## **7. Early exposure to developmental disabilities and dual diagnosis within training and clinical or practicum experiences increases a sense of competence to serve this population**

The literature indicates that creating opportunities for caregivers (in particular physicians) to be educated in the area of developmental disabilities through a period of sustained contact with individuals with developmental disabilities can increase competence.

### Specifics from the Literature

***Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, U.S. Department of Health and Human Services, 2002*** provides anecdotal evidence suggesting that clinical experiences early in medical and other health professional training increases capacity of providers to value and accept patients in practice. (National Institute of Child Health and Human Development (NICHD), 2006) In light of this understanding, a series of action steps was proposed to strengthen skills and knowledge in the field:

- Professional Education – integrate didactic and clinical training in health care of individuals with MR into basic and specialized education and training for all health care providers. This is to be done by: evaluating existing training curricula that address health and MR and disseminate those that are efficacious, partnering with families and individuals with MR to develop and implement modules, using provider experience to mentor health profession students, developing and implementing accreditation and certification criteria.
- Interdisciplinary education and training – develop and disseminate effective training modules in interdisciplinary practice. Design modules to include social workers, family members, individuals with MR and others.
- Continuing education – develop, evaluate and disseminate continuing education curricula for health care providers at all levels of practice.

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Burge et al recently examined medical training in the field of intellectual disabilities from the perspective of clinical clerks (undergraduate medical students) during their psychiatry rotation at the Universities of Queen's and Toronto. (Burge et al, In Press) The majority of clerks (93.3%) reported a need to enhance the coverage of intellectual disability in medical training particularly through more time in the curriculum and more clinical contact with clients. Additionally 88.8% believed that their future practice would likely include patients with intellectual disability, that all physicians should be trained in the care of individuals with intellectual disability (96.4%), and that training in the field is good preparation for other areas of medicine (90.7%), such as working with individuals who do not speak the same language, or have learning disabilities or communications difficulties related to a range of common medical problems including hearing impairments, brain injury or stroke. Of note within this study, however, is that over two-thirds of the clerks believed that specialists in intellectual disability should provide primary care to persons with ID. The interpretation by the authors is that while there is an understanding that as future doctors they will be expected to provide care to this population, they would rather not.

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Related to the training experience is the possible impact of early exposure on career choice. In a 2006 survey by the Ontario Association on Developmental Disabilities, 590 students in the Developmental Services Worker Programs across community colleges in Ontario were asked why they entered the DSW Program. Almost one third of respondents reported a range of early experiences: 70 students had a family member with a developmental disability, 13 had previous work or volunteer experience, 49 had co-op experience with students who had special needs, and 49 knew someone already working or volunteering in the field. Therefore, previous knowledge of developmental disabilities in some capacity certainly contributed to entering the field.

*In summary, exposure during training appears to contribute to greater competence and confidence in the provision of care. We only know anecdotally, from those of us who chose to make this our life's career, that our choice was usually the result of accidental early personal or academic exposure. The question remains, how much and what kind of exposure 'by design' will lead to more frequent selection of this career by design.*

## **8. A variety of creative models, approaches and strategies can be utilized to achieve success in training**

The literature notes many different strategies that appear to be effective. The value of a range of approaches is that it allows for variation and adaptation to meet the needs of a particular group within a community (both professionally and geographically). The following strategies were noted as being effective models for education and training of health care professionals and support workers:

- continuing education credits,
- peer supervision,
- learning directly from families and people with developmental disabilities,
- multidisciplinary / cross sector environment,
- knowledge transfer / capacity building – e.g., specialist consultation and support to generic providers (e.g., dental hygienist with specialist knowledge supporting dentists who have clients with developmental disabilities; nurse educator / advanced practice clinician consulting with health providers),
- Specialist providers (e.g., University Affiliated Programs) serve as training centres for multi-disciplinary community providers or students to work in generic systems, or for training of specialists.

### **Specifics from the Literature**

#### ***Cross System Training to Improve Services for Children and Adolescents with Dual Diagnosis***

provides seminars and monthly peer supervision groups to support specialists in developmental disability, education, homeless services, mental health, family support, respite and case management. Peer supervision is open to families and service providers. (Georgetown National Technical Assistance Center for Children's Mental Health, May 2005) A Planning Advisory Group is established to address the system issues identified in the supervision and seminars.

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The ***New Mexico Continuum of Care Project*** is a statewide program that trains health care professionals in the care of deinstitutionalized individuals and trains direct care staff and case managers to provide medical support for clients. (National Institute of Child Health and Human Development (NICHD), 2006). The program also includes specialty consultation clinics; specialized clinics at several primary care sites; consultations for physicians, nurses, caregivers, case managers, interdisciplinary teams, and families; and consultations on policy for State agencies. Mediation is also provided for team or agency conflicts affecting delivery of services.

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The ***Dual Diagnosis Community of Practice Videoconference Rounds*** lead by the Royal Ottawa Dual Diagnosis Consultation Outreach Team in Ontario links 20 dual diagnosis specialized team sites in Ontario, Quebec, Nova Scotia and Manitoba. (NADD Ontario Chapter Bulletin, Spring 2006). A case presentation format highlights multidisciplinary clinical practice, encourages sharing of informed practices and case level problems.

*In summary, the literature demonstrates the need for planned and sustained commitment to training and continuing education. This includes training that is integrated within services, as well as the use of approaches that are based on adult learning and client and provider realities.*

## **9. Teaching clients and caregivers about primary care improves quality of care**

The literature indicates that informed consumers are partners in bringing higher quality to the health care relationship. Efforts directed at improving the ability of individuals to advocate for themselves appears to be producing better results in both the quality of care and the person's self-perception.

### Specifics from the Literature

Health care professionals and others working with people with developmental disabilities lack in-depth knowledge about the specific health care needs of this population. Health promotion is also an issue. The *Health Care Quality Unit Program in Pennsylvania* was created to respond to these problems and to help people with disabilities become better consumers of health care, to expand their choice of health care providers, and to help deliver a higher quality of care to people with disabilities. (National Institute of Child Health and Human Development (NICHD), 2006) The Program targets individuals with developmental disabilities and their families, providers of developmental services, community medical providers, and county staff (including “support coordinators” who serve as case managers). The emphasis is on providing support but not direct care services. The Office of the Medical Director in the State’s Office of Mental Retardation coordinates the Program’s activities. The activities are implemented by a consortium of counties and are staffed by different clinicians and data personnel. To reach its’ goals, staff members identify gaps in health care services and health care knowledge and then develop professional training and technical assistance programs to address these needs. Staff members also identify systemic problems and work closely with other offices and agencies to address these issues. The Program has been effective at the individual and community levels.

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The *Oregon Lifestyles for Persons with Developmental Disabilities* was developed to address the issues that persons with disabilities often experience poorer health status and narrower margins of health, may be more susceptible to illness, have limited access to treatments, and may be excluded from health promotion opportunities. (Ibid) The Program is currently developing two new intervention efforts. The first project is the Healthy Lifestyles Workshop for adults with developmental disabilities. The two-and-a-half-day workshop uses a peer training model that emphasizes empowerment training. This training includes understanding the importance of assessing one’s own health and establishing personal health goals. The workshop also targets self-determination and motivation and describes wellness as a lifelong journey that encompasses balance across life activities. To ensure continued success, each participant is paired with a mentor who works with the individual for up to six months following the workshop. In the past, the workshops were presented in six locations across Oregon, and have included 33 participants with cognitive limitations. Feedback on the project shows that follow-up is very difficult, but participants report increased awareness of healthy lifestyle choices and of self-empowerment.

*In summary, with the appropriate supports and mediators, individuals with developmental disabilities can become more informed recipients of care. Emphasis in this area would be similar to health care delivery directions within the general population and is also consistent with the principles of community living.*

### **10. Existence of local, regional or national interest groups contributes to enhanced practice**

The literature repeatedly notes the invaluable role of peer organizations or interest groups, organized by professional practice, common interest or advocacy goals. A few of these have been referenced throughout this document e.g., Special Olympics collaborating with American Academy of Developmental Medicine and Dentistry, Developmental Disabilities Nursing Association, and the genesis group of the Primary Health Care Guidelines in Ontario.

*In summary, whether they are groups of consumers, family members, primary care workers, professionals, or a mix thereof, interest groups are an important vehicle for political advocacy and action, peer support and education.*

## 11. Standardized procedures or templates assist practitioners in the implementation of quality care

The literature demonstrates practical assistance that is derived through templates or tools that can be used within the care process to support implementation of best/informed practices by providers and to achieve better intervention outcomes. *Valuing People, Closing the Gap*, and the Australian Association of Developmental Disability Medicine all identified the creation of tools to support practitioners as a key strategy for creating change on the ground.

### Specifics from the Literature

The *Vermont Rural Medical Home Program* is based in a primary care physician's office, for children with developmental disabilities and their families. (Ibid) A steering committee composed of the physician, head nurse, and three families designed special office procedures based on a survey of the parents. Procedures include a script for the receptionist to identify patients with special needs, parking and other special accommodations for office visits, and queries during visits about non-medical needs. Other elements are a resource parent/care coordinator position and a family network that advocates on medical and educational concerns.

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The START Program in Massachusetts, a multidisciplinary specialized dual diagnosis service, developed a Crisis Prevention and Management Tool. (Beasley & Kroll, 1999) The tool maps out a strategy for individuals, families, and care providers to follow during the crisis (identifying trigger events and intervention choices) as well as clarifies roles and responsibilities within the service system to ensure ready access to needed services (e.g., crisis supports, emergency rooms, police). This approach has been adopted by some dual diagnosis specialized teams and crisis network providers in Ontario.

*In summary, tools or toolkits are a very effective means of translating research and evaluation outcomes into informed/best practice.*

## Conclusion

The literature clearly demonstrates a range of effective strategies and approaches that establish sustainable education and training and which also enhance recruitment and retention within the field of developmental disabilities and dual diagnosis. Of the eleven key elements for success described in this discussion paper, three appear fundamental to progress in Ontario:

1. Government policy that incorporates human resource principles, strategies and structure to address training, education, recruitment and retention challenges.
2. Training, education, recruitment and retention policy and practices that take a population health perspective, integrating health and community living.
3. Education curricula and practice standards that are developed upon and follow policy intent.

In this review of the policy and practice literature we have found an encouraging breadth of knowledge and experience in many jurisdictions, including Ontario. Some of these jurisdictions use strategies that are very creative and progressive. It is exciting to note that they can be implemented by building on existing initiatives within the Ontario environment.

As a next step NADD Ontario recommends that the current discussion occurring within Ontario incorporate a population health perspective. That is, training, education, recruitment and retention initiatives in the field of developmental disabilities reach across and include the mainstream systems within which individuals with developmental disabilities live their lives and from whom they obtain their supports (e.g., health, education, mental health and justice sectors as well as social, recreational and housing). As an example, training and education initiatives for front line staff would reach both developmental and health and mental health workers, or dual diagnosis would be incorporated in training and education related to developmental disabilities and mental health.

Making headway in an organized way in this area and with a broad cross sector approach will be very challenging particularly as the issue is so complex, touching on so many elements of our government, education and training systems. However the literature has demonstrated that other jurisdictions, having chosen the population health approach, have over time achieved some successes. As a result, NADD Ontario's focus will now be to coordinate our efforts with other organizations that share similar concerns and objectives.

NADD Ontario would like to become a partner in the provincial discussions that are occurring, with the goal of bringing the population health perspective to the dialogue and supporting as necessary cross sector communication e.g. reaching out to the other systems involved. To achieve this, the paper has been distributed to key system stakeholders to invite their feedback and request to join the efforts of those stakeholders. Recipients of the paper include the Provincial Network on Developmental Disabilities, the leads of the Community Networks of Specialized Network Care for Individuals with a Dual Diagnosis and/or Challenging Behaviours, Directors within the Ministries of Health, Community and Social Services, and Training Colleges and Universities, and the Academic Health Science Centres Task Force.

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