

Excerpt from a Formal Proposal for an Evaluation Study

PROPOSAL FOR AN EVALUATION STUDY

This evaluation study will examine three aspects of the project in order to address important immediate questions pertaining to implementation:

1. Program Rationale: Is the project justified? Do the objectives and goals make sense?

Questions pertaining to need have been addressed during the feasibility study. The size of the population is known. However there has not been a formal consideration of the rationale within which the project is situated. The rationale provides the perspective from which to view the program and to develop methods most appropriate to achieve defined program objectives. The rationale acts as an anchor to avoid mandate drift and ensures that the evaluative data is an effective tool for decision-makers. In short, the rationale is the means to effective evaluation design including selection of appropriate variables for measurement. This proposal will examine the theory that supports the project in order to clarify and support the work that is being done and provide a framework within which the evaluation must be designed.

2. Program Alternatives: What are the services and activities that could be used to produce the desired changes?

The feasibility study identified several key activities. However the project relies on a developmental process involving almost 50 agencies, two disparate funding Ministries, hundreds of clients and their families, thousands of employees and several planning bodies. It is important that the proposed activities be analysed to determine whether they include key stakeholders in appropriate and meaningful ways. An analysis of the project goals relative to stakeholders and their needs will serve to identify which activities should be included in the project and will provide a basis for development of a logic model of the project. The logic model will provide a schematic outline of the various components that go into the program and their logical connection to one another. These connections are central to establishing support for one input or activity over another and measuring their influence relative to program success.

3. Program Inputs: What are the required contributions that will ensure program success? Are these inputs available? How well are they being provided?

The partners committed to building a self-sustaining, cross sector planning process that relied on resources already within the system rather than new funding. The Ontario Trillium Foundation is funding the developmental phase of the project over 20 months from February 2003 to September 2004. The partners need to know what inputs are required in the long-term and whether they have the capacity to sustain these within their current operating budgets and the willingness to support them within their respective mandates when developmental funding is exhausted. The process evaluation will identify and measure inputs of participating organizations so they can make this determination. It will also serve to guide implementation over the long run. Methods for collecting and evaluating data will be defined.

The results of the proposed evaluation are important not only for informing implementation but also to lay the groundwork for an outcome evaluation. The Ontario Trillium funding requires that the project evaluate outcomes prior to the completion of the developmental funding phase in September 2004. The current proposal, while it focuses on a process evaluation of inputs, will lay the groundwork for the outcomes evaluation. Consequently the proposal includes some discussion of outcome related issues.

PROGRAM RATIONALE

The rationale for the Huron Trillium Partnerships project rests on a five part foundation. First, the practical necessity of the two sectors to pool knowledge and resources in order to deal responsibly with the aging boom. Second, the trend towards coordinated access to services. Third, a theory of community development that supports community strengthening through participation and collaboration. Fourth, the similarities and differences in mandate and culture between long-term care and developmental services. These five areas provide a solid footing for clarifying project activities and building the logic model.

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Practical Necessity

There is a history of disassociation between the long-term care and developmental services sectors maintained by factors such as separation of education programs for each sector, funding from different provincial Ministries and the shorter life span experienced by people with a developmental disability. There has not been a logical link between the two service systems.¹ Instances of cross sector planning and collaboration have been isolated and exceptional.

The boundaries between long-term care and developmental disabilities are changing into an exciting new frontier where exploration is a practical necessity. When the aging boom was first described in the 1970's it was not considered relevant to the developmental disabilities sector. The prevailing experience was that persons with a developmental disability did not live into old age and if they did, they would be adequately cared for in the provincial institutions where they were housed. However four factors changed that.

First, during the 1970's, parents of persons with a developmental disability secured Ontario government funding for a system of support programs for their sons and daughters. These programs, with their roots in advocacy and community development have contributed to higher expectations about what is possible for persons with a developmental disability. Programs have strengthened the skills of persons with a developmental disability to participate with others, to live interesting lives and to make contributions to their communities. The higher expectations include being treated like anyone else. The community living movement calls this inclusion. It extends to having access to long-term care services in the same way as anyone else.

Second, advances in pharmacology have improved treatments for conditions such as diabetes, hypertension, and cardiovascular diseases. Consequently these are no longer fatal for persons with or without a developmental disability. Third, a universal medicare program in Canada opened healthcare access to all persons regardless of income. Improved healthcare contributed to the longevity of not only persons with a developmental disability but also their parents. Fourth, the longer life span of parents stretches the time during which most persons with a developmental disability can remain living in their own home or a home shared with their families.

This fourth factor deserves closer examination because of the important role that parents play in the lives of a son or daughter with a developmental disability. Research indicates that the majority of persons with a developmental disability still live with their parents.² Researchers estimate that 60% of older adults with a developmental disability live with family.³ Moreover, 80% of adults with a developmental disability rely on family as their primary caregiver.⁴

This holds true for Huron County. Data gathered by the Huron Trillium Partnerships Project reveals that the total population of persons with a developmental disability being supported by developmental service agencies in Huron County is 278 persons. This represents 16% of the total estimated population of 1790 Huron residents with a developmental disability. The data also reveals that approximately 3% of persons with a developmental disability are currently in a long-term care facility. This leaves 81% in the care of family. It is also worth noting that 39% of those supported by agencies are living with family who provide a significant portion of the total care giving.⁵ It is clear that parents play a significant role in the support available and when they are no longer able to do so, the pressure on the system will be several times

¹ Edward F. Ansello. "Seeking Common Ground." Aging and Disabilities. (Winter 1992) 9

² Ibid. 9

³ T. Rose and E.F. Ansello, Aging and Developmental Disabilities: Research and Planning. (Final Report to the Maryland State Planning Council on Developmental Disabilities), College Park: The University of Maryland Center on Aging. 1987,

⁴ Tamar Heller, "Current Trends in Providing Support for Families of Adults with Mental Retardation," IDHD Forum, Washington: Institute on Disability and Human Development, 1997, 6

⁵ Huron Trillium Partnership Demographic Survey, February 2002

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greater than it is now. This is not only a factor in creating a practical necessity for collaboration between the sectors, it also has significant implications for program design and required inputs.

Increased longevity of persons with a developmental disability has been documented in several studies.⁶ However the effects of aging are often exacerbated in this population. While 65 is the typical age to be considered an older adult, many researchers have selected the mid 50's as that point for persons with a developmental disability based on observations of changes in functional ability. People with a developmental disability exhibit earlier onset of age-related conditions such as loss of vision, hearing impairment, increased thresholds for taste and smell, decline in sensory detection, loss of flexibility and muscle strength, decreased vertebrae strength, diminished capacity to maintain balance and gait, loss of lung capacity and coronary artery disease.⁷ Some syndromes associated with developmental disabilities also exhibit a higher incidence of age-related conditions. For example, most adults with Downs Syndrome over the age of 35 years, develop Alzheimer's disease.⁸ The nature of aging in this population adds to the learning challenges for the sectors and the complexity of transition planning.

The overlay of aging parents supporting aging adult children underlines the practical necessity of cross sector collaboration that includes families in the process. Many parents now in their 60's, 70's and 80's are faced with their own aging while caring for adult children in their 40's, 50's and 60's. The majority of persons with a developmental disability are receiving their primary care from family. These parental caregivers are looking to developmental service or long-term care agencies, both of which have diminished capacity due to years of funding constraint and mounting service demand.

The end result of this chain is that a serious illness, long-term care placement or death of a care-giving parent generally precipitates an emergency situation. The adult child is likely to end up in an unnecessary and more costly long-term care placement themselves or a hastily contrived support situation that lacks suitability.

The developmental services sector is experiencing the aging of people already receiving service. Consequently, the sector has identified its need for education and training related to aging.⁹ However the sector is also receiving increased requests for service from aging families with older adult children. This adds to the challenges of devising cooperative planning strategies with the long-term care sector and negotiating service access agreements with long-term care providers in order to support aging care giving families.¹⁰

Meanwhile the long-term care sector is experiencing an increase in requests for residential placement of persons with a developmental disability. Their capacity to respond is constrained by staffing levels, the emergency nature of many requests and their lack of understanding of developmental disabilities.¹¹ During the feasibility study for the Huron Trillium Partnerships, long-term care representatives reported their need for training in developmental disabilities.¹² Each sector recognizes that the other has knowledge it needs.

The key points, which emerge from this discussion, are summarized in Chart 1 below.

⁶ Barbara H. Connolly, "General Effects of Aging on Persons with Developmental Disabilities," Topics in Geriatric Rehabilitation, Aspen: Aspen Publishers Inc. 1998; 13(3): 3

⁷ Ibid. 4-11

⁸ Ibid. 2

⁹ Grey Bruce Huron Perth District Health Council, Survey of Learning Needs for Workers Supporting Aging Developmentally Disabled Adults, (August 6 2002)

¹⁰ Wingham and District Community Living Association, Report of the Task Force on Aging, (May 2001)

¹¹ Ontario Federation on Aging and Developmental Disabilities, Aging and Developmental Disabilities Regional Workshops Summaries, (2000)

¹² Huron Trillium Partnerships, Phase 1 Final Report, (October 11 2002)

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Chart 1: Practical Necessity: Factors and Implications

PRACTICAL NECESSITY KEY FACTORS	IMPLICATIONS FOR PROGRAM DESIGN
No history of collaboration	Learning curve; cross sector learning (jargon, methods, legislation)
Aging of persons with a developmental disability: longevity, early onset, greater severity of some chronic conditions such as dementia	Need for extended support during old age Planning that acknowledges complexity of the aging process and uniqueness of each individual
Expectations of inclusion	Equal access to long-term care
Parental caregivers: - 60% in home - 80 % primary	Pending pressure on service system - > cross sector collaborative process that includes families
Recognition by each sector that the other has knowledge it needs	Cross sector training curriculum

Coordinated Access to Services

The literature on aging and developmental disabilities supports coordinated effort as the means to success with the aging boom among the population of persons with a developmental disability.¹³ Janicki (2001) describes coordinating systems, interagency agreements and coalition building as necessary approaches to deal with issues that cross system boundaries.¹⁴ Sir Sanford Fleming College and several retirement residences have collaborated in the development of a modern replacement facility and the establishment of an Institute on Health Aging.

The Government of Ontario has been encouraging coordination of services for several years as a means to improve service delivery and efficiency. This trend is evidenced in several planning documents prepared and distributed by the Ministry of Community and Social Services (now re-named Ministry of Community, Families and Children). The Ministry framework for people with developmental disabilities requires coordination of information and assessments and a single point of access for services.¹⁵ The Ministry document prescribing individual support agreements for persons with a developmental disability requires "that individuals and families receive a coordinated set of services and supports in the right sequence..."¹⁶ The Southwest Regional Office of the Ministry document, "Coordinated Access to Services Model" not only encouraged coordination but assigned a coordinating function for service access to a regional planning body, the Community Services Coordinating Network¹⁷

The long-term care sector has experienced similar shaping. District Health Councils were formed to plan implementation of a balanced and integrated health care system including long-term care. Community

¹³ Tamar Heller. Aging and Developmental Disabilities: Emerging Models of Support, Aging and Developmental Disabilities Symposium (June 21 1999), 5

¹⁴ Matthew P. Janicki. Coordinating Systems Serving Carers of Children and Adults with Developmental Disabilities, Albany: Center on Intellectual Disabilities (November 25 2001) 2

¹⁵ Ministry of Community and Social Services, Making Services Work for People, Toronto: Queen's Printer for Ontario, 1997 26-31

¹⁶ Ministry of Community and Social Services, Individual Support Agreements for people with Developmental Disabilities, Toronto: Queen's Printer for Ontario, 1998, 5

¹⁷ Ministry of Community and Social Services, Coordinated Access to Services Model, London: Ministry of Community and Social Services Southwest Regional Office, 1999, 8

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Care Access Centres were created to provide a simplified point of access to long-term care for more than 400,000 people each year.

Coordination has also been an important approach within Huron County. The Huron Respite Network is a consortium of ten agencies that provide respite services for families. Community Support for Families is a county-wide agency serving all children with developmental disabilities, jointly established and governed by the three associations for community living. All long-term care facilities are participants in a Facilities Operations Group that meets regularly to consider systemic planning issues. Coordination has been tested and found to work.

Government encouragement and the traditions of collaboration within the county are positive forces for the Huron Trillium Partnerships Project. The involvement of both the District Health Council and the Community Services Coordinating Network bring important planning knowledge to the partnership process.

Community Development

Community Development work is based on two premises:

- a. Analysis and understanding of the causes of structural or systemic problems
- b. Identifying and achieving practical alternatives to ameliorate the problems so that the situation of people will improve.¹⁸

Community development theory also relies on the concept of systems. A system is a set of elements that has something in common. This can include any grouping with any sort of identifiable relationship. Organizations, groups of organizations with the same mandate and families may be thought of as systems. Moreover there can be smaller systems within larger systems as well as relatively equal systems that share some portion of their respective boundaries. Systems may be more or less open to one another depending on what they have in common, how much they communicate and what degree of influence they may have on one another. The nesting of systems within larger systems also raises issues about what is public knowledge between the systems and what may be hidden from one or both.

Systems tend to a dynamic balance or homeostasis. This is achieved if the system has access to the resources it needs to maintain itself. If a system experiences a loss of its balanced state, it will seek out the resources it needs. In doing so it must engage in boundary management such as opening its boundary to new resources.¹⁹

The systems concept is reflected in the Huron Trillium Partnerships Project. Two service sectors (systems) are experiencing a loss of homeostasis through service pressures that lie outside the expertise of their respective staff. A third system (families) is also experiencing disequilibrium due to the pressures related to aging. The loss of homeostasis in each of the three systems is resulting in the opening of their respective boundaries to one another in various ways. Families seek support from the service systems. The service systems seek support from one another. There is an intersection among the three that may be deeper and more open under the present circumstances.

Community Change Theory includes a branch known as Locality Development. Locality Development involves experts and community members working together as equals. This is the approach being taken by the partners. Implementation of this model requires that community (system) members:

¹⁸ "Community Development." Saskatchewan Community Resources and Employment, (2003) 2 pp. Online. Internet. April 30 2003

Available <http://www.gov.sk.ca/socserv/regional/comdev/commdeve.html>

¹⁹ Andy Tamas. "System Theory in Community Development." (2000) 8 pp. Online. Internet March 15 2003.

Available <http://www.tamas.com/samples/source%>

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- a. Participate in each phase of the change program
- b. Receive training as required to gain knowledge and skills necessary to achieve the change agenda.

This has implications for involvement in planning and training, of not only sector staff but also families.

Mandate and Culture

The fourth part of the rationale relies on an understanding of the mandate and culture of the two sectors. Differences can be stimulating but their acceptance and understanding may take some effort and education. Differences can also contribute to tension that can be detrimental or dynamic. Collaboration will not go far on unresolved tension. Success requires the maintenance of a dynamic tension that respects differences and allows for resolution of disagreements. The project must be able to mediate such tension if the collaborative is to be maintained.

The long-term care system provides quality care over the long-term. In some cases this care is interim until a person can return home. The point to be taken here is that it is not “end-of-the-road” care. The persons working in the system see themselves as misunderstood in this regard and work to correct this mistaken image of their sector. Long-term care providers expressed concern during the feasibility study that the developmental service system might be looking for a dumping ground.

Long-term care is currently oversubscribed. Despite the development of additional beds, there are more stringent regulations pertaining to waiting lists which pressure clients on the waiting list accept placement offers within 24 hours or risk being put to the end of the line. This pressure and funding formulae require operators to keep beds occupied to tighter tolerances than in the past. Moreover staff client ratios are significantly lower in long term care than in the developmental service sector. These factors contribute to a systemic pressure to avoid difficult client placements if possible.

Long-term care is home to older adults of all ages. Residents range from the 50's to the 90's. Long-term care providers must ensure different levels of support and protect the frail from interference by the active. Developmental service providers encourage clients to express their needs in ways that are possible for them. Consequently a loud vocal sound or wave of an arm may signal a request for a cup of coffee. These friendly signals in the developmental services sector can be interpreted as threats of aggression by staff concerned for frail elderly.

Many people with a developmental disability depend on others for ongoing support. Service providers have worked to accommodate this dependency by providing support options throughout the life cycle. Consequently there is a tendency for service providers to focus on how to support a person as they age. This focus sometimes results in a service provider trying to maintain a client beyond the capacity of the agency to do so. It is exacerbated by the general belief that there are no options since the entire human service delivery system has been under funding constraints for some time. Some service providers are also heavily influenced by volunteer board members who have remained on boards for many years and bring an outdated maternal approach to service delivery that says, “These are our people and we shall always look after them.” These factors within developmental services delay transition planning to long-term care supports such as day programs and residential placement. Delays compromise the capacity to plan adequately with the long term care sector.

What becomes clear from this comparison of the sectors is that there are points of tension. Unresolved tension will result in disagreement. This has implications for the sectors learning about one another, learning communication and negotiation skills and having recourse to some resolution process in case of disagreements. These points of tension have implications for program design and are illustrated in Chart 2.