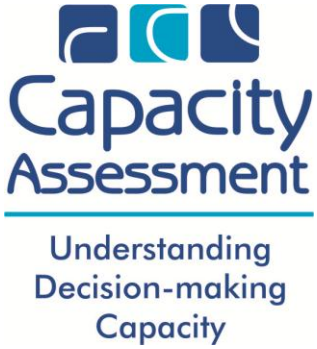

Assessment of Decision-Making Capacity in Adults with Diseases and Disabilities: Is the Decision-Making Capacity Assessment Model Appropriate for Alberta?

Final Report
February 2012 - March 2012

A Project Funded by

Alberta Health Services

UNIVERSITY OF ALBERTA

GLOSSARY OF TERMS

Attending teams
Attending teams are comprised of front line health care professionals who work directly with clients in various facilities to provide in-patient, out-patient, rehabilitation, and community-based health care services. Members of these teams may include physicians, nurses, social workers, psychologists, occupational therapists, physical therapists, speech-language pathologists, chaplains, recreation therapists, and therapy and nursing assistants. As attending team members work with clients on a regular basis and observe both their abilities and challenges, these front-line staff are often the first to identify issues related to decision making capacity in the clients they serve. While attending team members may or may not have specialized skills in the area of capacity assessment, they are often left to determine possible strategies to address challenges associated with a lack of capacity.

Mentoring teams
Mentoring teams are multi-disciplinary teams that have been established at each facility in Alberta that has adopted the DMCA Model. Members of these teams - physicians, nurses, social workers, occupational therapist, psychologist, and Designated Capacity Assessors (DCAs) - have a particular interest and expertise in the capacity assessment process. The purpose of the mentoring team is to educate facility staff on the capacity assessment model and process, provide support/answer questions/problem-solve during complex capacity assessment situations. Mentoring teams also champion the implementation of the DMCA Model at the sites, and facilitate training workshops as well as educational sessions (including the initial four-hour interactive workshop introducing staff to the model and its supporting materials, in-services, and continuing education "brown bag lunches" where they answer questions and discuss case studies or relevant topics).

Designated Capacity Assessors (DCAs)
DCAs are regulated health care professionals who have been appointed by the Government of Alberta to conduct formal capacity interviews and offer an opinion to the Office of the Public Guardian/Trustee regarding the decision making ability of an adult in question. Physicians and psychologists are designated as capacity assessors by regulation and therefore are not considered DCAs, while nurses, occupational therapists, and social workers may undergo a mandatory 3 day training module to become DCAs, and then complete at least three capacity assessments every two years to remain certified. Recommendations regarding capacity are made by a DCA based on opinions formed during a formal interview process. The DCA's opinion regarding co-decision making, guardianship or trusteeship applications is then submitted to the court, which makes the legal determination regarding capacity. Ideally, pre-assessment and problem-solving are done with front line staff and mentoring team members before DCAs are asked to conduct a formal capacity assessment.

EXECUTIVE SUMMARY

An evaluation was conducted of the Decision-Making Capacity Assessment Model (DMCA Model). The DMCA Model was developed in the Province of Alberta to provide guidance and support to health care professionals working with clients whose ability to make independent decisions regarding personal affairs (classified according to the domains of health care, place of residence, choice of friends and acquaintances, legal matters, and participation in social, educational or employment activities), and/or financial matters is in question as a result of disease or disability. The aim of the evaluation was to determine the strengths and limitations of the Model.

To evaluate the DMCA Model, feedback was collected from health care professionals (psychologists, social workers, nurse practitioners, nurses, occupational therapists, physicians), who have utilized the Model as it has been implemented in various health care sites in the Edmonton and Calgary areas. Staff feedback was collected through focus groups with mentoring team members and court-appointed Designated Capacity Assessors (DCAs), as well as through a survey administered to attending and mentoring team members, and DCAs at participating sites[1].

Evaluation results based on the 46 focus group participants and 123 survey respondents indicate that the DMCA Model currently utilized in the Calgary and Edmonton areas is effective and warrants being implemented - with adaptation specific to various sites - throughout the province of Alberta. While other models have been utilized elsewhere, the DMCA Model currently being utilized and implemented in Calgary and Edmonton offers an holistic inter-disciplinary approach to capacity assessment that maximizes client autonomy, offers the least restrictive and intrusive solutions, and facilitates collaboration between health care professionals within and among health care facilities/agencies.

RESEARCH OVERVIEW

OBJECTIVES

In this project, we evaluated the DMCA Model currently in use or being implemented at various sites in Edmonton and Calgary. The guiding questions of this quality assurance/program evaluation were:

1. Has the initial implementation of the DMCA Model been successful?
2. Do staff utilizing the DMCA Model consider it effective?

[1] Participating sites in the **Calgary zone** included Peter Lougheed Centre, Rockyview General Hospital, Foothills Medical Centre, Community/Rural; Participating sites in the **Edmonton zone** included: Royal Alexandra Hospital, Misericordia Community Hospital, Grey Nuns Community Hospital, Villa Caritas, Sturgeon General Hospital, Glenrose Rehabilitation Hospital, Westview Health Region, Good Samaritan Society Choice Program, Good Samaritan Society Seniors Clinic, Continuing Care Facility Living, Continuing Care Supportive Living, and Continuing Care Home Living.

Both focus groups with and a survey of mentoring team members and DCAs were utilized to collect feedback related to these two questions. Attending team members were also asked to complete the survey.

In the focus groups and survey, we examine the strengths and limitations of the DMCA Model, explore the extent of attending team involvement in the capacity assessment process and problem solving, identify reasons for consultation with mentoring teams (i.e., specific matters regarding capacity for which mentoring team members are being consulted), identify barriers/challenges to efficacy that mentoring team members and DCAs face when offering services, consider how to support their roles and responsibilities, and consider issues contributing to the sustainability of the DMCA Model.

BACKGROUND

Adults with diseases and disabilities contend with a number of barriers that can challenge their autonomy and ability to live independently. Such individuals are at increased risk in this regard. As the life expectancy of Canadians continues to rise, assessment of mental capacity (the ability to make decisions for oneself) emerges as an issue of increasing importance. A person's decision making ability – ranging from capable to incapable – is dependent on both the complexity of the decision making process, and one's ability to engage in that process. The degree of impairment regarding one's mental capacity can vary as a result of disease processes, cognitive impairment or decline, or brain injury.

The Adult Guardianship and Trusteeship Act (*AGTA*),[2] assented to December 2, 2008, and enforced on October 30, 2009, is legislation that outlines the capacity assessment process in the Province of Alberta, Canada. The *AGTA* is built on the four following guiding principles:

- The adult is presumed to have capacity and able to make decisions until the contrary is determined;
- The ability to communicate verbally is not a determination of capacity, the adult is entitled to communicate by any means that enables them to be understood;
- Focus on the autonomy of the adult with a less intrusive and less restrictive approach; and
- Decision-making that focuses on the best interests of the adult and how the adult would have made the decision if capable.

Adults with diseases and disabilities often require guidance and support in the area of decision-making. Caregivers (both formal and informal) who offer decision-making support often lack an adequate understanding of the extent of assistance and guidance a person may require. To support the capacity assessment process, the DMCA Model has been developed and implemented in the Edmonton zone, and is in the process of implementation in the Calgary zone with the support of steering committees[3] at participating sites.

[2] See Government of Alberta, Adult Guardian and Trusteeship: http://www.seniors.alberta.ca/opg/guardianship/

[3] **Steering committees** - with representation from medicine, psychology, nursing, occupational therapy, social work, as well as members from specialized services such as geriatric medicine, surgery, speech-language pathology, management and administration - are committees set up at sites intent on implementing the DMCA Model. Their purpose is to help support and

CAPACITY ASESSMENT PROGRAMS

The development of the currently used DMCA Model was the result of several years of dialogue, research and development among health care providers aimed at finding an appropriate process for assessing and addressing the loss of decision-making capacity in the adult population. What follows is a description of two existing capacity assessment programs that established a foundation for the development of the DMCA Model.

CALGARY REGIONAL CAPACITY ASSESSMENT TEAM

The Calgary Regional Capacity Assessment Team (RCAT) is the only multi-disciplinary team in Canada with the sole function of assessing and addressing capacity issues (Pachet et al., 2007, Pachet et al., 2012). RCAT was developed in 2005, with the purpose of educating other health care workers on capacity legalities and processes, and acting as a consultant in the more complex capacity assessments in the Calgary region. Most capacity assessments are done by family physicians, hospital programs and community mental health programs (Pachet et al., 2007).

The RCAT model for capacity assessment was developed after assessing five different capacity assessment models/approaches used in Canada (Baycrest Competency Clinic in Ontario, Ontario Capacity Assessors, Enquiry on Mental Competency (Ontario, 1990), Pepper-Smith Report (British Columbia, 1996), and the Yukon Capacity Assessment Model (Yukon Department of Justice, 2004)). Five key themes were selected to guide RCAT's approach to capacity assessments:

1. Capacity assessment is performed as a last resort, and only after a thorough pre-screening process[4];
2. Capacity assessment for complex cases is a multi-disciplinary process;
3. Capacity assessment is domain-specific and/or decision-specific;
4. Capacity assessment is multi-factorial and includes assessment of psychosocial, cognitive, functional, and medical factors, as well as assessment of the adult's decision-making processes; and
5. Capacity assessment takes into account an adult's culture, beliefs, values, and preferences. (Pachet et al., 2007)

If, after the pre-screening process, it is determined that a formal capacity assessment is needed, each team member assesses the client based on their discipline and offers a capacity score using a 7-point Likert scale. Team consensus regarding capacity for specific domains is then reached, and a recommendation to the treating physician is made by the RCAT team; the

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sustain implementation of the DMCA Model. Steering committees are tasked with developing a specific implementation plan for each site, identifying processes for selected staff to become DCAs, ensuring that training workshops and education sessions are delivered, developing site specific procedures for patients who require capacity assessment, ensuring staff have access to the provided capacity assessment resources, evaluating the model and the implementation process, and identifying resources needed for ongoing support and operational sustainability.

[4] Pre-screening is used to determine if the patient has a reversible medical or psychiatric condition that could be affecting capacity (for example, delirium or untreated depression), cases where there may be undue influence, or situations where there may be other solutions to solving the problem (Pachet et al., 2007).

treating physician makes the final recommendation and completes the required legal forms for capacity (Pachet et al., 2007). Stakeholders of RCATs services reported that they filled a gap in the systems of care and reported high confidence in recommendations made by the RCAT team (Pachet et al., 2007).

COVENANT HEALTH CAPACITY ASSESSMENT MODEL

Several years ago, it was recognized that capacity assessments at Covenant Health in Edmonton, Alberta were being provided with no particular format or organization of the process. Feedback from clinicians and hospital administrators suggested that the lack of clarity associated with this non-standardized approach resulted in inappropriate, unnecessary, or repeated capacity assessments. Concerns were expressed that unnecessary or repeated assessments can compromise both a patient's dignity and the integrity of the organization, generate additional costs and burden, delay service provision and discharge planning, tax health care staff resources, and lead to complaints, ethics consults, and unnecessary litigation.

To address the problems, an Interdisciplinary Capacity Assessment Working Group was created in January 2006 with representation from three Covenant Health sites (Misericordia Hospital, Edmonton General Continuing Care Centre, and Grey Nuns Hospital). The goal of the Working Group was to develop a model that would facilitate the performance of capacity assessments at Covenant Health, and be aligned with the organization's mission and ethical framework, as well as clinical best-practice. The Working Group determined that there was a need for the development of a systematic and well-organized approach to capacity assessment that would be most beneficial to the patient and staff.

A staged approach was taken to the project. First, a literature review was conducted. Second, knowledge from the literature review informed the development of a survey to determine the major issues of the staff at the three Covenant Health sites who are involved with capacity assessments. Third, information from the survey was used as a basis for the development of a Covenant Health Capacity Assessment Model. Finally, the Working Group developed and implemented an educational strategy to increase staff knowledge.

The following major problems/difficulties when conducting capacity assessments were identified:

- A lack of coordination of roles and responsibilities,
- A lack of time to complete assessments,
- Oversimplified notions of capacity,
- A lack of standardization,
- Conflicts in discharge planning,
- Varying degrees of knowledge among staff regarding assessment of capacity and legislation
- Teamwork required improved coordination, cohesiveness, and communication.

Suggestions for improvement included:

- Providing consistent capacity assessment methods and one model (that covered both legal and medical issues),
- Defining roles and responsibilities for each discipline,
- Providing widespread education on the model and process,
- Emphasizing front-end screening and problem solving (before a formal capacity assessment is required),
- Providing a more efficient process to provide better service to the patients (including better organization and documentation of information collected).

The Working Group used an iterative process to develop a Care Map for assessment of capacity. This was brought to several members of each of the major disciplines represented in the capacity assessment process (including geriatricians, social workers, occupational therapists, nurse practitioners and psychologists), who offered suggestions as to the role their respective disciplines should play in the process. Several versions of the Care Map were created before the Working Group decided by consensus on a finalized rendition.

After the Capacity Assessment Model was created, a Capacity Assessment Demonstration Project was implemented on medical units at each of the Caritas sites beginning in January 2007. During the project, the majority of cases were resolved through problem solving, thereby avoiding formal capacity assessment; only a few individuals were found to lack capacity. Social workers, nurse practitioners, occupational therapists and psychologists were most commonly involved in the inter-disciplinary assessment.

An education program was developed around the capacity assessment model and care map. This program included the creation and distribution of an education booklet, and the offering of educational workshops at each of three sites (Edmonton General Continuing Care Centre, Misericordia Community Hospital, and Grey Nuns Community Hospital). The education booklets consisted of background information on capacity and assessment of capacity, results of the staff survey, information on legislative acts pertinent to capacity assessment, and a copy of documents created to guide the team through assessments. These were distributed to staff members as pre-reading before attendance at the education session.

The education workshops were held between December 2006 and May 2007 with approximately 12-15 participants involved in each four hour session lead by mentoring team members. The participants in the workshop were health care professionals who worked on the teams/units selected for the initial demonstration project of the model (one team per site). These education sessions allowed staff to become familiar with the capacity assessment process, and gave them the tools necessary to implement the model.

THE DECISION-MAKING CAPACITY ASSESSMENT MODEL (DMCA Model)

A Provincial Working Group on decision-making capacity - comprised of representatives of all five zones of Alberta Health Services - was created within the Seniors Health Provincial Cognitive Impairment Strategic Committee in 2010. The group reviewed the Covenant Health model; revised the care map, worksheets and inventory of educational materials; and endorsed

the Decision-Making Capacity Assessment Model (DMCA Model) for provincial use. It is this model that is evaluated in this quality assurance/program evaluation project.

The DMCA Model attempts to implement a single province-wide approach to capacity assessments that is person-centered, consistent with the new Alberta AGTA legislation; comprehensive across professions, sectors and zones; and based on the core values of Alberta Health Services (respect, transparency, accountability, and engagement).

DMCA Model: Human resources

The DMCA Model relies on staff functioning in various capacities and supported by site-based steering committee members, who carry out distinct roles as is depicted in the following diagram.

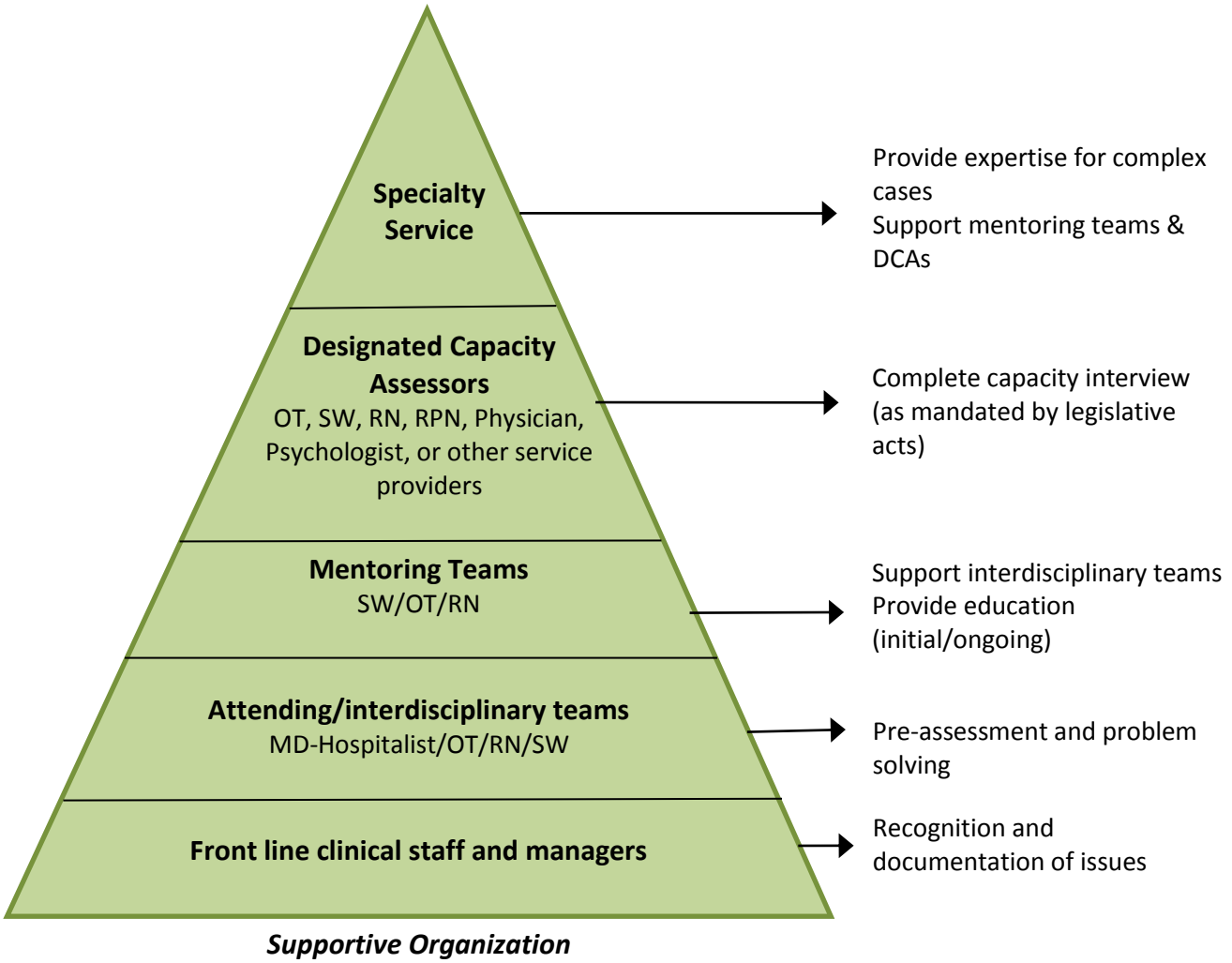


Figure 1: DMCA Model professional team roles & responsibilities

DMCA MODEL: TOOLS AND PROCESSES

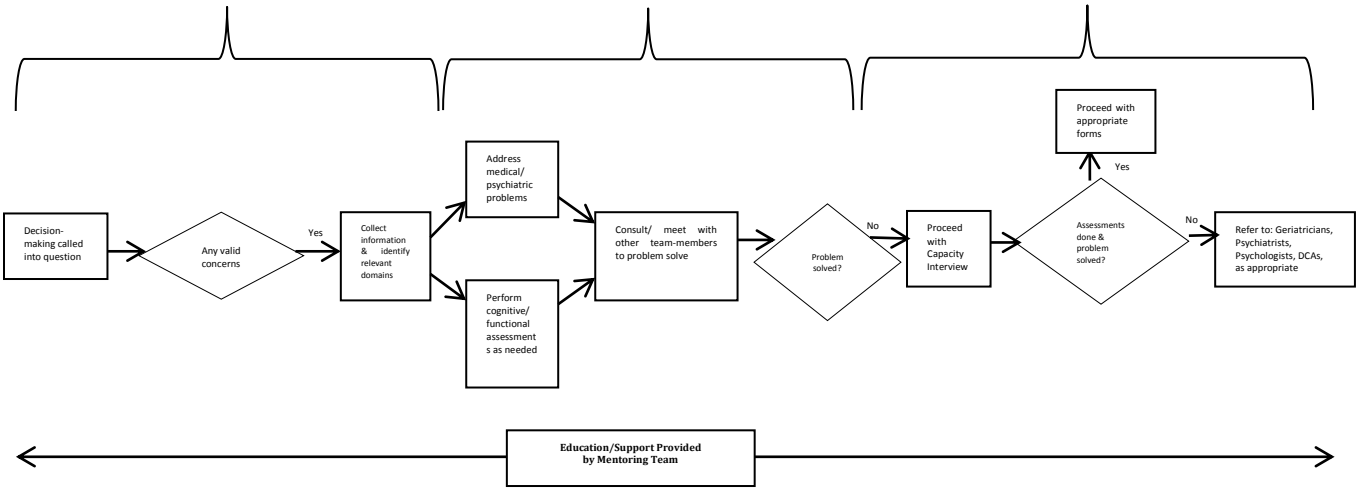
Inter-disciplinary teams who have adopted the DMCA Model follow a 3 phase assessment process, as outlined below in the *Care Map for the DMCA Model for Capacity Assessment*, with the formal capacity interview[5] (Step 3) being a last resort:

Figure 2: *Care Map for the DMCA Model for Capacity Assessment* (see Appendix 3)

Step 1: Initial Assessment: Identifying reasons for assessment (triggers), domains and risks.

Step 2: Pre-assessment: In-depth assessment and problem solving using cognitive and functional testing.

Step 3: Capacity Assessment: (Capacity Assessment Interview). When problems cannot be solved by less intrusive means.



The DMCA Model relies on health care professionals to identify valid reasons for conducting a capacity assessment with an individual, isolate domains needing to be assessed[6], perform appropriate cognitive and functional assessments, and problem-solve using an inter-disciplinary approach to determine the least intrusive and restrictive measures possible in support a person's decision making. Mentoring team members are available to support and educate frontline staff around the capacity assessment process, and respond to more complex cases. DCAs, who are often part of the mentoring teams, additionally conduct Capacity Assessment Interviews if all other avenues are exhausted and no less intrusive or restrictive alternative can be found.

Health care professionals have access to an education booklet, a brochure (see Appendix 4), worksheets (see Appendix 5), and additional documents in support of the Model and

[5] The Formal Capacity Assessment required under provincial legislation has evolved into the Capacity Assessment Interview. The Capacity Assessment Interview is conducted by a psychologist, physician, or DCA who then offers an opinion to the courts by way of a Capacity Assessment Report (CAR).

[6] Domains in which an adult may lack capacity include healthcare, social/leisure activities, legal matters, accommodation, education/vocational training/financial matters, choice of associates, and employment. An individual may be deemed to require support with decision making in one or more of these domains.

assessment process. The education booklet contains information such as general capacity theory, Legislative Acts, practice guidelines, details of documents, background literature and references. The brochure is a brief description of the capacity assessment process that is distributed to clients and family members as an education tool. The Capacity Assessment Process Worksheet and Capacity Assessment Interview Worksheet are currently in use to guide staff through the DMCA Model, facilitate this process, and facilitate collation of information gathered during the process.

DMCA Model: Goals

The Provincial Working group, when developing a vision of the DMCA Model, identified the following goals:

1. Development of a well-defined and systematic process which streamlines the capacity assessment process (Care Map).
2. Concentrate on front-end screening and problem solving to enhance the pre-assessment process in order to:
    a. Preserve autonomy for as long as possible (least restrictive/intrusive solutions proposed while still maintaining safety), and
    b. Reduce the number of unnecessary formal declarations of incapacity.
3. Definition of team member roles to distribute the responsibility of performing assessments across multiple regulated health care professionals (social workers, occupational therapists, and nurses in addition to physicians and psychologists).
4. Create well-defined systems for organization and documentation of information (worksheets).
5. Implement standardized assessment procedures at all sites (such as hospitals; continuing care including facility, supportive and home living; community health centers; and rural health centers), so decisions will be more reliable (less subjective or biased) between assessors and facilities in Alberta Health Services.
6. Widespread education to increase awareness of the legal acts and improve capacity assessing skill sets through workshops and information sessions.
7. Decrease in legal risk to the health facilities as capacity assessment is no longer arbitrary in the legislation, and minimization of legal quagmires.

DMCA MODEL EVALUATION:

Having provided background to the DMCA Model, both an overview and results of this program evaluation/quality assurance project will now be offered. The approach and methods utilized will be described, including ethical considerations, research questions, the evaluation process, and research findings. The implications for policy and practice will follow.

APPROACH AND METHODS

While the DMCA Model has been implemented in Calgary and Edmonton, neither an evaluation of the implementation of the Model, nor an examination of the experience of the team members, has yet been conducted. This study examined the experiences of healthcare providers implementing the Model in multiple healthcare settings across the province. The

perceptions of those implementing the model were then compared with the goals of the Model. While data analysis was limited by the focus of this study, data collected for this study may support future research and evaluation (e.g. indicators and performance measures to examine Model effectiveness) with additional analysis.

Ethical Considerations

Prior to beginning the project, an ethical review was completed by the University of Alberta's Health Research Ethics Board (Panel B) (see Appendix 6) and from the Conjoint Health Research Ethics Board, Office of Medical Ethics, University of Calgary (see Appendix 7). Both Boards determined that the project was a program evaluation/quality assurance project, and therefore did not specifically require Research Ethics Board review and approval. Operational approval was obtained from each participating site prior to commencement of evaluation activities. All participants of the DMCA Model Evaluation signed informed consent forms prior to participation in focus groups (Appendix 8); some participants also signed photo release forms (see Appendix 9).

Research Questions

Several key questions animated this program evaluation/quality assurance project. They were as follows:

1. Has the initial implementation of the DMCA Model been successful?
2. Do staff utilizing the DMCA Model consider it effective?

Program Evaluation

Evaluation Process

To evaluate the DMCA Model, attending team members, mentoring team members, and DCAs from various sites in Edmonton and Calgary in which the Model had been or is being implemented were invited to:

1. Participate in a DMCA Model Evaluation Workshop to review the Model and its tools (including participation in several focus groups), and
2. Complete a DMCA Model Evaluation Survey.

A brief description of both of these aspects of the evaluation follows. Invitations for participation in each of these activities were disseminated by steering group members to appropriate staff for attendance at a DMCA Model Evaluation Workshop.

DMCA Model Evaluation Workshops

Two day-long DMCA Model Evaluation Workshops were held - one in Calgary on March 26th, 2012 (with 16 participants and 3 focus group facilitators attending), and another in Edmonton on April 2, 2012 (with 33 participants and 11 focus group facilitators attending).

Participants in the evaluations completed questionnaires and surveys, and participated in focus groups. They were provided with a description of the purpose of the workshop, consent forms, and a survey sheet collecting anonymous demographic information (see Appendix 12). During the day, they were both given an opportunity to network, and invited to participate in 2-3 focus groups (2 for both non-DCAs and DCAs alike, and 1 specific to DCAs) each of 60-75 minutes

duration, and led by 1-2 facilitators. In the focus groups, the health care professionals were asked to offer feedback regarding the strengths and limitations of the DMCA Model, the role of mentoring teams, implementation of the Model in various sites, recommendations for further Model development, and suggested strategies for Model sustainability. DCAs also met separately to discuss their role in relation to the Model. The focus groups were audio-recorded, transcribed verbatim by a professional transcription service, coded and analyzed for common themes. (See Appendix 10 for an outline of the DMCA Model Workshop, and Appendix 11 for focus group questions).

DMCA Model Evaluation Survey

Following the evaluation workshop, a survey (see Appendix 13) was distributed via e-mail attachment and a Fluid Survey link to attending and mentoring teams, and DCAs at all of the participating sites in Calgary and Edmonton. 122 respondents completed and returned the survey within a 3 week timeframe.

Evaluation Participants

From a total N=171 (including both focus group participants and survey respondents), 60% (n=103) of the health care professionals were from the Edmonton zone[7] and 39% (n=67) from Calgary[8], with 1% unspecified. Of these, 57% (n=70) of the *survey respondents* were Edmonton-based, and 42% (n=51) were Calgary-based; 67% (n=33) of the *focus group attendees* were from Edmonton, and 33% (n=16) were from Calgary.

Focus Group Participants

Of the 16 health care professionals who participated in the focus groups in Calgary, 50% (n=8) were employed by the Foothills Medical Centre, 19% (n=3) were from Rockyview General Hospital, 19% (n=3) served community/rural sites, and 12% (n=2) worked at the Peter Lougheed Centre. Of the 33 health care professionals who participated in the focus groups in Edmonton, 27% (n=9) were affiliated with Continuing Care, 18% (n=6) with the Royal Alexandra Hospital, 18% (n=6) with the Good Samaritan Society, 9% (n=3) with the Glenrose Rehabilitation Hospital, 9% (n=3) with the Grey Nuns Community Hospital, 9% (n=3) with the Misericordia Community Hospital, 6% (n=2) with Villa Caritas, 3% (n=1) with the Sturgeon General Hospital, and 1% (n=1) with Westview Health Region. The chart below depicts the composition of focus group participants by age, gender, years of capacity assessment experience and professional designation.

[7] Participating sites in Calgary included Peter Lougheed Centre, Rockyview General Hospital, Foothills Medical Centre, Community/Rural representation.

[8] Participating Edmonton sites included Royal Alexandra Hospital Misericordia Community Hospital, Grey Nuns Community Hospital, Villa Caritas, Sturgeon General Hospital, Glenrose Rehabilitation Hospital, Westview Health Region, Good Samaritan Society Choice Program, Good Samaritan Society Seniors Clinic, Continuing Care Facility Living, Continuing Care Supportive Living, and Continuing Care Home Living.

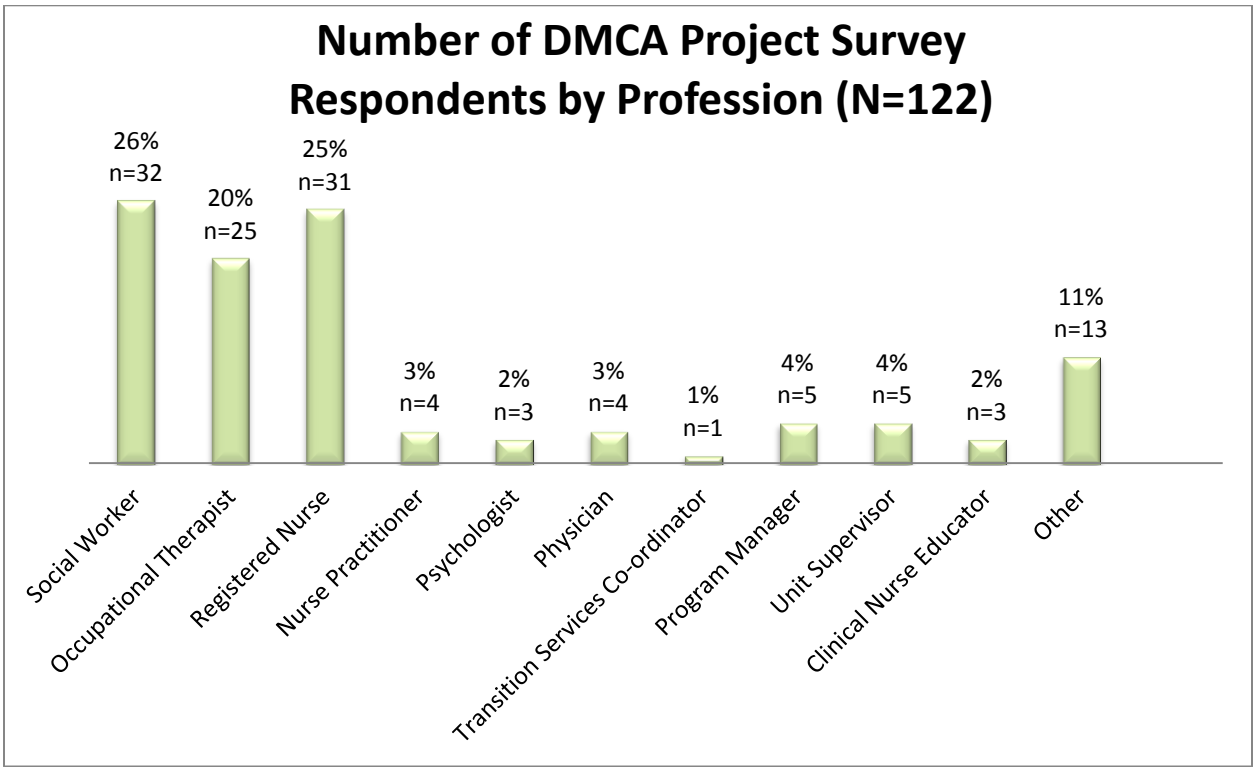
Table 1: Focus Group Participant Composition

	Calgary 33% (N=16)	Edmonton 67% (N=33)
Age distribution		
25-29	25% (n=4)	6% (n=2)
30-34	25% (n=4)	6% (n=2)
35-39	6% (n=1)	9% (n=3)
40-44	6% (n=1)	18% (n=6)
45-49	0% (n=0)	0% (n=0)
50-54	13% (n=2)	33% (n=11)
Gender		
Female	81% (n=13)	52% (n=17)
Male	6% (n=1)	12% (n=4)
Unspecified	13% (n=2)	36% (n=12)
Years of capacity assessment experience		
0-1 year	50% (n=8)	15% (n=5)
2-5 years	38% (n=6)	51% (n=17)
6-10 years	0% (n=0)	21% (n=7)
11-15 years	6% (n=1)	3% (n=1)
Unspecified	6% (n=1)	9% (n=3)
Professional designation		
Social Work	19% (n=3)	43% (n=14)
Occupational Therapy	50% (n=8)	12% (n=4)
Registered Nurse	13% (n=2)	15% (n=5)
Registered Psychiatric Nurse	0% (n=0)	3% (n=1)
Nurse practitioner	0% (n=0)	12% (n=4)
Physiotherapists & ethicists	0% (n=0)	6% (n=1)
Psychologists	13% (n=2)	3% (n=1)
Unspecified	6% (n=1)	6% (n=1)
Non-DCAs	69% (n=11)	36% (n=12)
DCAs	25% (n=4)	45% (n=15)
Unspecified DCAs	6% (n=1)	18% (n=6)

Survey Respondents

The graph below represents the survey respondents by professional designation:

Graph 1: DMCA Project Survey Respondent Composition by Profession



Evaluation Findings

Survey Findings

Results of the DMCA Model Survey together with the DMCA Model goal with which they are predominantly aligned (as outlined previously on page 11) are as follows:

- **85%** (n=102) agreed/strongly agreed with the statement, "The new DMCA model is followed in my workplace;" (13% (n=17) disagreed/strongly disagreed and 6% (n=8) did not know); (Goal 5)
- **90%** (n=113) agreed/strongly agreed with the statement, "I follow the guiding principles of DMCA when I am faced with concerns about a patient's decision-making capacity;" (5% (n=7) disagreed/strongly disagreed and 6% (n=7) did not know); (Goal 5)
- **72%** (n=89) agreed/strongly agreed with the statement, "I am confident in my knowledge about legislation as it applies to DMCA;" (25% (n=32) disagreed/strongly disagreed and 2% (n=3) did not know); (Goal 6)
- **71%** (n=90) agreed/strongly agreed with the statement, "When a capacity concern is identified in a patient, I and/ or my team member(s) will use the "Capacity Assessment Process Worksheet" to guide our work;" (20% (n=26) disagreed/strongly disagreed and 8% (n=10) did not know); (Goal 4)

- **87%** (n=110) agreed/strongly agreed with the statement, "I understand the role of my discipline in DMCA and the part I play in the interdisciplinary approach to assessment;" (11% (n=14) disagreed/strongly disagreed and 2% (n=3) did not know); (Goal 3)
- **92%** (n=114) agreed/strongly agreed with the statement, "I and/ or my team member(s) will explore problem solving opportunities in order to reduce the risk to the patient before suggesting a capacity interview;" (5% (n=7) disagreed/strongly disagreed and 5% (n=6) did not know); (Goal 2)
- **75%** (n=95) agreed/strongly agreed with the statement, "I am confident in my knowledge and skills regarding DMCA and comfortable being involved in these assessments;" (19% (n=24) disagreed/strongly disagreed and 6% (n=8) did not know); (Goal 3)
- **44%** (n=56) agreed/strongly agreed with the statement, "The capacity assessment model has reduced the angst/conflicts amongst staff, patients and families when dealing with issues related to DMCA;" (26% (n=32) disagreed/strongly disagreed and 30% (n=38) did not know);
- **88%** (n=110) agreed/strongly agreed with the statement, "A Capacity Assessment Mentoring Team is available to assist our team with questions and to provide support about DMCA;" (10% (n=13) disagreed/strongly disagreed and 4% (n=5) did not know); (Goal 1)
- **59%** (n=73) agreed/strongly agreed with the statement, "The standardized process for DMCA has improved the efficiency and effectiveness of capacity assessments performed by my team;" (16% (n=20) disagreed/strongly disagreed and 25% (n=31) did not know); (Goal 5)
- **74%** (n=91) agreed/strongly agreed with the statement, "I have had the opportunity to attend ongoing learning sessions that provide further information and support for the implementation of DMCA;" (24% (n=30) disagreed/strongly disagreed and 4% (n=5) did not know); Goal 6)
- **64%** (n=78) agreed/strongly agreed with the statement, "I and my team receive the necessary management support to implement the model for DMCA;" (23% (n=29) disagreed/strongly disagreed and 13% (n=16) did not know).

Focus Group Findings

Several main themes emerged in the focus groups with mentoring team members and DCAs during the DMCA Model Evaluation Days. Together with survey results, these data highlight themes that are useful for interpreting whether the DCMA Model goals have been implemented successfully. The following is a summary of these findings.

DMCA Model

Foundations in Alberta AGTA Legislation

Participants related the value of alignment of the DMCA Model with the Alberta Adult Guardianship and Trusteeship Act (Goal 7):

> *I think this model is beautiful in that it helps educate and advocate for the client, because it's guided under Alberta legislation. So what we say to our patients and families is not*

because we are bullies, it's because it's a patient's right. Autonomy should be maintained through the least intrusive measures, regardless if there's a capacity assessment, right. Regardless if even if you had a capacity assessment completed, you have to stick to those legislative standards that are legally bound. (01-14-00)

The DMCA Model was noted to provide greater clarity around ways to comply with the legislation, while alignment of the DMCA Model with the legislation offers endorsement for the process of capacity assessment outlined in the Model – a process that participants applauded.

Participants with DCA training felt that they had a greater understanding of the systems and legislation involved in capacity assessment. This training, which enhances their existing professional skill set, reportedly enables them to more comfortably address client and family concerns and questions.

I think the families were falling in cracks, into gaps. They weren't getting that information. I've helped redirect many of them so support groups to help them through the process. I've opened up their eyes, there's more to it than just five minute of declaration that their mom or their dad can't make the decision. And they're usually angry, they're overwhelmed to start with, but when I come in, by the time I've explained the process, they're wanting more information, they're wanting help. And they're glad that they finally found someone who can help navigate the system. (02-33-00)

A Client Focus

Focus group participants related that the DMCA Model clearly facilitates a client focus. Positive patient outcomes result due to an emphasis on the person's autonomy, best interests, and beliefs and values. In support of autonomy, the DMCA Model requires that staff, together with the client, consider a person's abilities in the various domains of decision making, and then problem solve to identify the least restrictive and intrusive solutions in each of the domains.

[P]eople are asking why more so now and then not just jumping to consult psych to come in. And it's more of a -- I find it -- it's more of the team working in a group to kind of work through the process and their patients, rather than it used to be, you know, get OT involved and do the assessments and then get psych to come in and then ... You know, and now it's there's more about, well, what's the purpose of doing a capacity? How is the patient going to benefit from this if we do go this route? So there's a lot more discussion. (01-12-00)

Focus group participants reflected on ways in which the DMCA Model places emphasis on patients' needs, rather than institutional issues or discipline-specific priorities. This emphasis reportedly helps health care professionals to consider the patient within the context of their social, cultural, institutional, and physical environments. It also fosters an awareness of the possible ramifications that a capacity assessment may have on a patient.

Instead of allowing external factors such as bed flow problems to guide the capacity assessment process, health-care professionals are reportedly encouraged to work collaboratively and consider the patients' best interests. Overall, the Model operates on the premise that health care professionals will utilize critical thinking to ensure positive patient outcomes.

> *Probably involving more families or clients in the process, you're going to get a better picture of actually what the issue is at hand or how it can be solved, possibly. And not just drop a bomb on someone all of a sudden, so and so lacks capacity, now you need to do this full legal process when it comes out of nowhere when they haven't been involved in the process. (01-13-00)*

> *[I]n my mind, the shift of the professional deciding what's in the best interests are really shifting that to the patient wherever possible, certainly to their caregivers and family is a slow -- it's -- but that's really where it needs to be. And really working with that worksheet I think is going to help that shift happen. Do you know what I mean? Because that's the whole thing, I think, of this worksheet is to empower patients and families and that, you know, I don't really care about the OT or social worker's judgment about the patient's best interests. I'm interested in the patient and the family placing a judgment on that risk, is that a tolerable level of risk for them or not. (01-12-00)*

> *I'm thinking that could often be things like if someone is... they've been moved and they have a delirium because of just having to move, but then that can... they can come back from that." (01-14-00)*

As a result, participants indicated that fewer capacity assessment interviews are required, more solutions are found that are less intrusive and restrictive, fewer outcomes are contested, and clients retain autonomy in the domains in which they are able to.

TOOLS: CARE MAP, WORKSHEETS, BROCHURE

Focus group participants appreciated the structures provided through the DMCA Model (e.g. care map, worksheets, etc.). They expressed support for how structural resources of the DMCA Model (Care Map, Worksheets, Brochure), help provide for effective and consistent clinical processes, inter-professional collaboration, and engagement with families. This is reflected in the following quote:

> *[T]he structure provided ensures that the inter-professional team does due diligence in taking at least invasive approach. (…) I think the other nice thing is that it's – we've been given the privilege to do part of the process. You don't have to declare that they lack capacity everywhere, and so I think there's been more clarification to the process itself. We're more educated and informed and that brings clarity to the process we're engaged in. (…) We're looking at the clients' domains individually as opposed to just throwing a blanket on everything. (02-12-00)*

Family involvement has reportedly also improved as a result use of the DMCA Model. Through the DMCA framework and the tools (the Care Map and brochure particularly), health care professionals indicated that they are better able to communicate the complexities of the capacity assessment process to families in an understandable way.

Participant discussions reflected numerous important opportunities that the DMCA Model affords. Most significant was the Model's ability to both highlight client needs and facilitate collaboration among health care providers. Regarding a client focus, participants noted that use of the worksheet was an effective way for multiple care providers to align capacity assessment with the needs of patients.

> *[I]n my mind, the shift of the professional deciding what's in the best interests are really shifting that to the patient wherever possible, certainly to their caregivers and family is slow, but that's really where it needs to be. And really, working with that worksheet I think is going to help that shift happen. Do you know what I mean? Because that's the whole thing I think of this worksheet is to empower patients and families and that, you know, I don't really care about the OT or social worker's judgment about the patient's best interests. I'm interested in the patient and the family placing a judgment on that risk - is that a tolerable level of risk for them or not? (01-12-00)*

Professionals felt strongly that the worksheets should be completed collaboratively, with each discipline being responsible for reporting their unique perspective. Professionals that were noted to be most involved in the capacity assessment process were social workers, and occupational therapists. Many participants indicated that greater collaboration with physicians and nurses would significantly strengthen the success of the process. (Physicians and psychologists, who are considered capacity assessors and are not required to undergo DCA training or the educational workshops, were frequently described as being less aware of the process of capacity assessment as outlined in the AGTA – a concern that was voiced consistently in the focus groups).

While the worksheet was seen as very valuable in supporting the capacity assessment process, workload and co-ordination challenges were identified. Of particular note was completion of the worksheet, especially given already heavy documentation requirements associated with their roles:

> *I already have so much charting and paperwork to do, I'm not really feeling comfortable. (01-14-00)*
> *And then it's a little awkward to have to go to a nursing colleague and say, you know, actually you could contribute to this too. (01-11-00)*

One of the biggest challenges participants identified in adopting the Model was clear accountability for the worksheet and related documents. A number of participants expressed concern over the "ownership of" and "responsibility for" the contents of the worksheet and related documents:

I've seen everyone be like, "that's your form, no that's your form, no I don't want to do that." (01-11-00).

Participants at some sites suggested that a lack of clarity regarding who ultimately is responsible for the forms was contributing to some apprehension on the part of health care professionals to use of the worksheets:

"Who's going to start it?" And it's almost like a hot potato in some sense that nobody wants to take" (01-24-04).

EDUCATION AND MENTORING

The majority of focus group participants stressed the importance of an investment of resources in the initial implementation of the DMCA Model through education and mentoring (by both mentoring team members and DCAs). These elements were considered to be effective vehicles for describing the DMCA Model and the legislation, as well as reviewing and trialing the worksheets.

Resources related to time that mentoring team members have invested in supporting workshops was a key issue identified and discussed by focus group participants – both in terms of that taken to deliver the workshops, as well as to tailor the content of the training sessions. This education and training role of the mentoring teams, though described as being critically important, was consistently noted to be a significant time investment when implementing the Model.

Yeah. And we were getting pulled, I think. Like, I was getting pulled from my unit day to day working as an OT you know, to do a lot of this work and ... I'm sure all of us are right, where you take a half a day to do four-hour presentations and it's half a day away from your caseload, and we were just managing, but barely.(01-12-00)

In addition to mentoring teams delivering education and training to staff at their respective sites, they also tailored and refined educational material based on workshop feedback. For example, when confusion for some staff arose between the pre-assessment portion (Steps 1-2 of the Care Map) and the formal capacity interview (Step 3 of the Care Map) of the assessment process, mentoring teams took time to adjust the training accordingly:

There was also some confusion, at least we experienced some of that in community and rural, some confusion around, you know, was actually doing the capacity assessment interview part of the model. And so it took us a fair bit of time to separate that out, but, no, this was just the pre-assessment piece. Actually, that is a critical piece. Because I know when we re-did the content of some of the slides, we had to spend a lot of time talking about this is actually the pre-assessment. (01-12-00)

In assessing the ongoing education and training needs of staff, many participants felt that the four hour sessions needed to include more than an explanation of the model. In response, some sites have included a stronger emphasis on case studies and practice using the worksheet.

> *One of the things that we ended up doing was we tightened up the presentation, we really tried to minimize the amount of didactic stuff so we had lots of time for case studies. And, personally, I would say that the purpose of this, the case studies, is to get practice at using the form. So I would make sure we had plenty of forms to say, "Here's one for this" … write on it, use it and get through several different kinds of case studies, so people … and if they say, "But we don't … what about this?" then you say, "That's a really good question," and flag that you would need to know that, keep going with the form and not get hung up on the right answer, because that's what happened. (01-24-04)*

A common recommendation across focus group participants was to make the Model structures and tools (such as the assessment worksheet), relevant by providing examples of how it applies to clinical practice.

> *And because there were very different levels of knowing (…) [I]f you actually take that capacity assessment worksheet and bring it to life, there's a fair degree of clinical skill involved in that risk assessment and that value piece that can be done at varying degrees of competency. (01-12-00)*

Following initial training and education with the implementation of the Model, focus group participants across multiple sites identified the need for a follow up process to support staff in getting additional information and addressing questions coming out of the 4 hour training sessions. Mentoring teams at a number of sites began offering Q&A or brown bag lunch sessions as an opportunity for staff to discuss difficult cases with mentoring team members.

> *We reviewed, like, the data group number to actually order the process worksheets. We did these FAQs. And then a couple people had come with cases, like active cases on their units. Let's sit around this table and talk about this, what do we do? And so we just had a conversation about a couple of those cases. (01-12-00)*

DMCA Model Implementation and Process

Reflecting on the implementation and application of the capacity assessment process as outlined in the 3 steps of the Care Map, focus group participants identified a number of key elements that have contributed to the success of the Model. This includes the contributions of both in-direct and direct service providers: steering committee members and management on a provincial and site level; front line health care professionals; mentoring team members; and DCAs.

Participants of the focus groups were very cognizant of the importance of the human resource component required to implement the DMCA Model. They noted that steering committees at both the provincial and site level were salient to the development, adoption and

implementation of the DMCA Model. Participants noted that, without the efforts, guidance and support of these committee members, the successful development, adoption and implementation of the Model within various sites would have been compromised or untenable.

Focus group participants also noted that the DMCA Model was best implemented in sites with

- Strong support from management regarding adoption of the DMCA Model
- Champions who made efforts to advocate for, guide others in, and oversee the implementation of the DMCA Model and its process
- Mentoring team members and DCAs who were available to champion, trial, implement, and both train staff in and support them regarding the Model,
- Attending team members who were willing to attend education and training sessions around the DMCA Model, and offer their professional knowledge and expertise to Steps 1 and 2 of the capacity assessment process
- DCAs, physicians and psychologist (who were well-acquainted with the AGTA legislation and Capacity Assessment process) available to conduct capacity assessment interviews (Step 3 of the Care Map) as needed (though the frequency of having to do so has reportedly decreased in light of staff problem-solving efforts in Steps 1 and 2 of the Care Map).

Participants further indicated that one of the key strengths of the DMCA Model is its ability to facilitate a strong sense of team collaboration.

> *I love that it's not just me. It's my team to bounce ideas off because I know my strengths and weakness as an OT and I know that social work brings so many other pieces to the table that I may miss… and psychology. I like knowing that my team's there behind me and we've come to a conclusion, we've went through it, we've picked through all the concerns we've had, and then we, as a team, we decide with the patient and family. That's the other piece. (01-13-00)*

With the implementation of the DMCA Model, healthcare professionals from a variety of disciplines reportedly recognized the valuable contribution they can make to the capacity assessment process. While the perspectives of all members of the inter-disciplinary team are essential to the capacity assessment process, some focus group participants emphasized that particular knowledge is also required.

> *You need more than just a few people out there with some awareness. You need people that are -- that feel like they -- they're -- it's their job to go back and make sure that this information gets to people and gets -- the process gets done properly and, you know, keeps people, if they're not doing it the way that it's sort of supposed to be done, keeping them doing it, right, or starting to question. (01-12-00)*

A number of participants felt that it would be preferable to have some staff – mentoring team members and DCAs – dedicated to the capacity assessment process:

It's better to have a few really trained people devoted to do this training, so you're consistently giving the training, versus having lots of different people… It's hard to maintain that kind of standardized. (01-23-03)

DCA expertise is particularly required if a Capacity Assessment Interview (Step 3 of the Care Map), together with completion of a Capacity Assessment Report (CAR), is indicated. DCAs, however, noted that they both feel they are not being adequately compensated for their involvement in capacity assessments, and are in a constant struggle to balance time dedicated to capacity assessments with that of their normal workloads.

The higher ups don't realize the extent of the work and the time that goes into all of that. And not only just doing the capacity piece, but educating staff, and educating family and going through all of those pieces. (02-31-00)

Some felt that a reclassification of their position would be indicated:

So, ideally a proper classification for the level of work you're providing….proper remuneration and acknowledgement of that. And then, even for the DCAs that are on the mentoring team, compensation for the rate of pay for when you are doing that. (02-34-00)

MODEL SUSTAINABILITY

Focus Group participants identified key components seen as necessary for sustainability of the DMCA Model. Most notably, they identified the need for increased resources in the form of time (e.g. dedicated time to apply toward DMCA Model implementation and capacity assessment related duties), finances (e.g. for offering/hosting training sessions, preparing handouts and materials), human resources (resource personnel, coordinators, administrative support), and education (particularly further training for mentoring team members and DCAs).

Some participants suggested that having a resource person may be very helpful, though at the same time, noted that this may take away from utilization of the expertise found on the mentoring teams, and/or compromise a sense of shared responsibility and contribution to the capacity assessment process by attending team and mentoring team members. In a similar way, participants suggested that a co-ordinator(s) may be helpful in organizing the staff training sessions, overseeing the process, being a point-of-contact person, and ensuring that the appropriate people were involved. They were concerned, however, that the loss of such people (resource personnel and coordinators) may negatively impact the process as the knowledge would go with them.

What follows are some salient comments made by participants regarding sustainability.

The time and resource required for mentoring and championing was stressed by participants:

In order to continue to have the people on the mentoring team finding the time to do that work, it's not just the DCA piece of it in terms of the assessment, it's organizing the workshops and doing the presentation and that kind of thing. It's very time consuming (01-11-00)

[T]he mentor group actually is supposed to create the roll out and the process and that small detailed stuff; so we were it. There's a lot of work that was done. That became my full time job. (01-13-00)

Participants expressed that having dedicated time to focus on implementation activities would be necessary for sustainability. Most professionals noted that they have taken on roles related to the implementation of the DMCA Model in addition to their already overfull caseloads and work demands. To do so, they have often worked on their own time to complete tasks required to make Model implementation successful. Many of these individuals, however, indicated that it would be unrealistic for them to continue to do so in the long term.

Participants also indicated that mentoring for mentoring team members would be needed for sustainability of the DMCA Model:

It's good to have that resource person to fall back on 'cause we were just saying in the other group where's the mentoring team for the mentoring team. (02-24-04)

The loss of a champion from a staff compliment was noted to be detrimental:

I think it's been very helpful for people to have someone to go to, like having the champions and feel like they're not alone. (…) [B]ut suddenly that champion leaves the position - is gone. Who's going to keep it going? If you actually have a coordinator position, that is critical. (01-11-00)

Having the right people, with the right time and resources in place appeared to be central to successful sustainability of the Model.

SUMMARY OF KEY FINDINGS

Strengths and Limitations of the DMCA Model

- In most cases, capacity assessment tools have been identified by frontline staff as **supporting more effective clinical processes**.
- Clinical processes supporting the DMCA Model suggest an overall **enhancement in the quality of care**; with **increased interdisciplinary collaboration** in the planning and delivery of more **patient centered** health care services
- Fewer client cases reportedly require capacity assessment interviews and involvement of the courts.
- Clients retain more independence and autonomy, and participate more actively in the assessment process
- Fewer cases require review as professionals from various backgrounds are involved in the assessment process making it more comprehensive and holistic.
- **Staff effectiveness** (a quality measure) seems to be increased with capacity assessment
- **System efficiency** and **service appropriateness** (quality measures) seem to be positively impacted
- Some responsibility and accountability issues described some risk of **increased role ambiguity** with the implementation of the Model for some health care providers
- Broadly applying **education and training programs increased the momentum** in implementation of the Model by increasing hospital staff awareness of capacity issues and introducing common terminology and processes. However, this greatly increased workloads across mentoring teams
- **DCAs and mentoring teams represented a specialized resource** and have played a key role in the implementation and continued coordinating of the model
- The Model has **increased support for health care provider awareness of and compliance with legislation** when managing capacity issues
- Risk in adopting and full implementation of the model exist if one person alone takes on the champion role
- While input from physicians and nurses was seen as invaluable, they were not always involved in, nor aware of, the process

Attending Team Involvement in the DMCA Model

Health care professionals on attending teams reportedly have

- Benefitted from the education sessions and are more aware of issues and legislation related to capacity assessment
- Become increasingly involved in the capacity assessment process
- Support the problem solving dimension (Step 1), and contribute to the assessment phase (Step 2) of the Care Map
- Have experienced improved communication and collaboration as a result of utilization of the Model and process

Consultation with Mentoring Teams

Mentoring teams are consulted for numerous reasons:

- During the implementation of the model, mentoring teams centralize site expertise that supports the translation and adoption of the Model into practical clinical practices and experiences
- Following the implementation of the Model, formally scheduled mentoring team consultations have been replaced or supplemented by education and training follow up sessions (e.g. Q&A and brown bag) at a number of sites.
- Mentoring team forums (Q&As and brownbag sessions) are both supporting staff education, and managing more complex and difficult assessment capacity cases
- Mentoring team members consult on more complex cases or respond to questions identified by attending team members

Barriers/Challenges to Mentoring Team and DCA Efficacy

- Increasing workload demands limit the time that mentoring team members and DCAs can be available for consultation on issues related to capacity, or for offering training sessions to staff on attending teams.
- Engaging in activities related to implementation of the Model on their own time, over and above their regular caseloads is unsustainable in the long term
- DCAs and mentoring team member turnover and burnout present potential risk to the sustainability of the Model
- Time limitations and a lack of human resource threaten the sustainability of the Model
- Continuing training and mentoring is not in place to address challenges facing DCAs and mentoring teams
- Format changes to the presentation should consider a stronger emphasis on case studies and practice using the worksheet as a guide

CONCLUSIONS

The results of this evaluation suggest that the implementation of the DMCA Model has been successful. Both the survey and qualitative data highlight how the goals of the DCMA Model – as identified by the Provincial Working Group – have been achieved with the implementation of the Model across piloting sites. An overall summary of evaluation themes highlights some of the impacts of the DMCA Model as experienced at various sites in the Edmonton and Calgary areas of Alberta. The evaluation found that the DMCA Model:

- Is appropriate and **recommended for implementation throughout the province** of Alberta, particularly if appropriate modifications to the Model are made based on site and zone specific resources, needs, and characteristics.
- Is effective in **supporting the capacity assessment process**
- **Eliminates confusion and ambiguity** regarding the purpose and process of capacity assessments
- **Ensures a client-centred approach** to the capacity assessment process and supports the least intrusive and least restrictive options regarding alternate decision making
- **Minimizes** the possibility of **medically unstable clients being unnecessarily declared** without decision-making capacity
- **Specifies domains** in which a client may lack capacity
- **Promotes inter-professional team-work, collaboration and communication**
- Has **valuable tools** that support the process (the Care Map, Worksheets, Brochure)
- Has an **integrated system of support and education** for attending teams offered by mentoring team members and DCAs
- **Distributes the responsibility for assessment of capacity** among all health care providers involved in a client's care
- **Reduces the need for formal capacity assessment interviews** as problem solving efforts often yields less restrictive and intrusive options.
- **Minimizes legal risk** for the client, health care professionals, and organizations
- **Facilitates dialogue with clients, families** and social supports
- **Supports the transmission of information** regarding a client's decision making capacity between and within organizations and sites.

Implementing the DMCA Model has created significant opportunities to increase staff awareness of capacity assessment issues. Evaluation results emphasize how using standard capacity assessment tools, a common approach and language, and consistent, clear processes can contribute to improved coordination, collaboration and communication across interdisciplinary care teams. The overall implication of this evaluation is that the DMCA Model supports enhanced discussion between care providers, patients and families, and contributes to a more patient-centered approach to care planning and delivery.

IMPLICATIONS FOR POLICY AND PRACTICE

Provincial Recommendations

- **Implementation of the Capacity Assessment Model on a provincial scale, with adaptation of the Model specific to various sites, service needs, and resource availability.**
- Develop a **provincial level implementation plan**
- Provincial supports and **training for mentoring team members and DCAs**
- Provincial Working Group **clearly identify the goals, objectives and intended outcomes** of the Model to support ongoing evaluation and research
- **Review processes and outcomes** given the experiences of those implementing the Model
- **Ongoing development and revision** of the DMCA Model tools
- Consideration of the **human resource requirements** for full adoption and implementation of the Model on a provincial level
- A **cost/benefit analysis** to determine the overt and covert costs and benefits of implementing the Model on a clients, health care providers, and health care systems
- Clarification of ways to more intentionally **integrate the client's values and beliefs** into the assessment process
- **Development of a strategic plan for model sustainability** at a provincial and site level
- Support **raising the awareness of physicians and psychologists regarding the AGTA and capacity assessment process** (particularly given that they are not required to undergo DCA training), as well as other health care providers.

Zone Recommendations

- Develop a zone level implementation plan that supports/resources the adoption of an inter-professional collaborative model for capacity assessment by building on existing resources
    - Support Local Priorities and Ownership
        - "*It's not necessarily a provincial model or an urban driven theme. It's got to be their thing that they helped to create and having a team of people to support them*" (01-11-00)
    - Reduce risk of turnover of program champions
        - "'*cause we have champions, but suddenly that champion leaves the position is gone. Who's going to keep it going? If you actually have a coordinator position, that is critical*." (01-11-00)
    - Support increased communication and collaboration with key partnerships
        - "*Rural is all about partnerships and getting to know the people who you're working with and trust big time. Oftentimes we're all, you're it. You're it for…you might have one OT and hardly any social workers and you're it for all things, so there's a lot more generalization in terms of roles*." (01-11-00)

- Identify and develop supports for a shared decision model that includes multiple providers and patients/families; increased communication and access to team resources; increasing understanding and awareness (e.g. education)
- Zone or provincial supports to mentoring teams; educational/competency; cross site communication/collaboration
- Identify quality of care and workload measures that consider the impacts and outcomes of implementing the model

Site Recommendations

- DCA role highlighted in building capacity for pre-assessment and overall site champion with regards to model implementation and sustainability
    - DCA role needs to be evaluated within the context of this model; not just as a resource for formal assessment capacity
    - Recommendation for dedicated model champion/coordinator/Quality Assurance role; required across settings (acute and non-acute) for model to be sustainable.
- Fully adopted Model must be supported by a site level steering committee with senior leader (including physician) representation and advocacy,; mentoring teams building capacity at the site level; unit level champions working with interdisciplinary team
- Model implementation needs to focus on interdisciplinary team capacity- rather than individual competencies regarding capacity assessment (DCA as a member of an existing team vs. DCA as new expertise)

DIRECTIONS FOR FURTHER RESEARCH

- Further and ongoing evaluation of the DMCA Model is essential to establishing a sound evidence base for provincial implementation of the Model.
- Further development and identification of performance measures and targeted outcomes focused on the Model will need to be considered to support any future evaluation or research.
- A cost-benefit analysis to:
    - capture the amount of time and resources currently being expended in the pre-formal capacity assessment phase (i.e. prior to a CAR needing to be completed);
    - the benefits to clients, provider and systems
- Pre- and post- implementation evaluations at sites which have not as yet integrated the Model to further examine Model effectiveness, impact and outcomes
- Evaluation of the DCA training program and role enactment

KNOWLEDGE DISSEMINATION AND TRANSLATION ACTIVITIES

We plan to submit various portions of our manuscript to peer-reviewed journals and present the results at various conferences in 2012 and 2013.

PUBLICATIONS AND PRESENTATIONS

Presentations to staff and at conferences, as well as peer-reviewed publications are anticipated and forthcoming.

PRINCIPAL APPLICANT (TEAM LEADERS)

Name	Position Title	Topics of interest
Name of Principal Applicants	Position title including organizational affiliation	Topics of interest
Suzette Brémault-Phillips, PhD	Assistant Professor, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Principal Investigator, Mental health, Seniors with Complex Needs, Rehabilitation, Community
Dr. Jasneet Parmar	Associate Professor, Department of Family Medicine, University of Alberta	Co-Principal Investigator, Seniors Health, Seniors with Complex Needs

PROJECT PARTNERS

Name	Position Title	Role
Lili Liu, PhD	Professor & Chair, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Co-Investigator, focus group facilitator, report writing
Elizabeth Taylor, PhD	Associate Professor, Department of Occupational Therapy, and Assistant Dean of the Faculty of Rehabilitation Medicine, University of Alberta	Co-investigator, policy impact, report writing
Steven Friesen	Adjunct Professor, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta, and Research Quality Practice Leader, Bethany Care Society	Collaborator, focus group facilitator, researcher, model evaluation, data analysis, policy impact, report writing
Jennifer Lee, MScOT	Occupational Therapist, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Research Assistant – model evaluation, data collection, focus group facilitation, data analysis, report writing
Anna Braslavaky, M.Sc.	Doctoral student, University of Victoria, and Research Assistant, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Research Assistant – model development, implementation and evaluation

Andrea Schertzer, MPH	Research Assistant, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Research assistant – literature review and report writing
Marlene Yaqub	MSc student, Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Research assistant – model evaluation, focus group facilitation, data collection, data analysis, report writing
Dayna Leskiw	MSc student, Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Research assistant – model evaluation, data collation and analysis, report writing
Jen Thai	MSc student, Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Research assistant – model evaluation, data collation and analysis, report writing
Mark Smith	MSc student, Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Research assistant – model evaluation, literature review, data analysis
Wendy Fothergill, RSW	Program Lead, Prevention & Promotion Community Addiction and Mental Health, Alberta Health Services	Research assistant – focus group facilitator & model evaluation
Sherrill Johnson, PhD	Principal, Colabora Consulting	Research assistant – focus Group facilitator
Cori Schmitz, MEd	Academic Coordinator of Clinical Education, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Research assistant – focus group facilitator
Andrew Phillips	Support Personnel, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta	Support personnel, data management and analysis

FINANCIAL STATEMENT

UNIVERSITY OF ALBERTA
Research Services Office
222 Campus Tower
8625 - 112 Street, Edmonton, AB T6G 2E1 Canada

Statement of Award & Expenditure

For the Period Ending - May 15, 2012

Name of Grantee - Project Role	Department	Project/Grant	
Bremault-Phillips,Suzette - Principal Investigator	340200 Occupational Therapy	Start Date : January 18, 2012	End Date : May 15, 2012
University Project Number RES0013657	Project/Grant Description AHS DMC Bremault-Phillips		

	Reporting Period January 1, 2012 to May 15, 2012	
OPENING BALANCE	**0.00**	
AWARD		
Direct Costs	25,000.00	cr
Total Funds Available	**25,000.00**	**cr**
EXPENDITURE		
Salaries & Benefits		
Undergrad Stu Salary & Benefit		
Grad Student Salary & Benefits		
Graduate Student Salaries		
Graduate Student Benefits		
Postdoctoral Salary & Benefits		
Postdoctoral Fellows Salaries		
Postdoctoral Fellows Benefits		
Other Sal & Adj (all benefits)		
Other Salaries	9,023.35	dr
Other Benefits	697.62	dr
Professional & Technical Svcs		
Equipment	119.94	dr
Materials Supplies & Other Exp	14,745.36	dr
Travel	413.73	dr
Transfers Out		
Total Funds Expended	**25,000.00**	**dr**
Indirect Cost Expenses		
Total EXPENDITURE	**25,000.00**	**dr**
PROJECT/GRANT BALANCE AS AT: May 15, 2012	**0.00**	

SIGNATURES

I hereby certify that the above statement is correct and that the expenditures shown were for the purpose for which the grant was made and disbursements conform to University policy and are in compliance with all terms and conditions imposed by the sponsoring agency.

Suzette Bremault-Phillips

Project Manager - Role: Bremault-Phillips,Suzette - Principal Investigator

30 MAY 2012

Date

I certify that the expenditures summarized above were incurred wholly by and paid on behalf of the grantee, and that the vouchers are available for audit purposes.

per Michael Walesiak
Assistant Director, Finance
RESEARCH SERVICES OFFICE
University of Alberta

Business Officer, Research Services Office

May 30, 2012

Date

ORGANIZATION RESPONSIBLE FOR HOLDING FUNDS

University of Alberta, Faculty of Rehabilitation Medicine

FUNDING

No external funding was received. In kind contributions were made by the Department of Occupational Therapy, Faculty of Rehabilitation Medicine, and the Department of Family Medicine, University of Alberta

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APPENDICES

Appendix 1: DMCA Model Evaluation Funding Request

Assessment of Decision Making Capacity in Adults with Diseases and Disabilities: Has the Decision-Making Capacity Assessment Model been effective?

Project Funding Proposal for the Alberta D-MC Model
(Submitted by: Suzette Brémault-Phillips, Assistant Professor, Department of Occupational Therapy, University of Alberta; Dr. Jasneet Parmar, Associate Professor, Department of Family Medicine, University of Alberta; Elizabeth Taylor, Associate Professor, Department of Occupational Therapy, and Assistant Dean of the Faculty of Rehabilitation Medicine, University of Alberta; Lili Liu, Professor and Chair, Department of Occupational Therapy, University of Alberta).

Background & Purpose
Adults with diseases and disabilities contend with a number of barriers that can challenge their autonomy and ability to live independently. One such barrier is an inability to make decisions on one's own regarding both personal affairs (health care, place of residence, choice of friends and acquaintances, legal matters, and participation in social, educational or employment activities), and financial matters. Adults with diseases and disabilities are at increased risk in this regard. As the life expectancy of Canadians continues to rise, assessment of mental capacity (the ability to make decisions for oneself) emerges as an issue of increasing importance. A person's decision making ability – ranging from capable to incapable – is dependent on both the complexity of the decision making process, and one's ability to engage in that process. The degree of impairment regarding one's mental capacity can vary as a result of disease processes, cognitive impairment or decline, or brain injury.

Adults with diseases and disabilities often require guidance and support in the area of decision-making. Caregivers (both formal and informal) who offer decision-making support often lack an adequate understanding of the extent of assistance and guidance a person may require. As a result, a range of support is seen – from highly intrusive, interfering or controlling interventions that compromise an individual's autonomy, to inadequate assistance that leaves the individual to his or her own insufficient devices and therefore at high risk. Support and guidance that employs the least intrusive and least restrictive measures possible, and that can facilitate independence and autonomy, has been determined to be the most ethical and desirable. Determination of the degree of support and guidance an individual may require is made using a capacity assessment.
The Adult Guardianship and Trusteeship Act (*AGTA*), ascented to December 2, 2008, outlines the capacity assessment process in the province of Alberta. The *AGTA* is built on four following guiding principles:
The adult is presumed to have capacity and able to make decisions until the contrary is determined;
The ability to communicate verbally is not a determination of capacity, the adult is entitled to communicate by any means that enables them to be understood;
Focus on the autonomy of the adult with a less intrusive and less restrictive approach; and
Decision-making that focuses on the best interests of the adult and how the adult would have made the decision if capable.
To support the capacity assessment process, a Capacity Assessment Model has been implemented in the Edmonton zone, and is in the process of implementation in the Calgary zone. This model outlines the assessment process, including validation of reasons for conducting a capacity assessment, identification of domains needing to be assessed, performance of appropriate cognitive and functional assessments,

and problem-solving using an inter-disciplinary approach. Under this model, a capacity interview and declaration of incapacity is suggested only as a last resort.
To facilitate both staff learning and implementation of the model, capacity assessment workshops have been offered to over 800 medical and allied health staff, and appropriate worksheets have been developed. Mentoring teams are comprised of health care professionals including physicians, nurses, social workers, occupational therapist, psychologist, and Designated Capacity Assessors(DCAs). These have also been put in place to support those educated through the workshops, and assist with problem solving.
To date, twelve mentoring teams are in place in a variety of settings in the Edmonton and Calgary zones. The role of the mentoring teams is to:
Be available as an expert resource to health professionals and attending medical teams for support and guidance in the Capacity Assessment Model
Plan and present interactive capacity assessment workshops for targeted staff
Organize and offer regular information sessions to front-line staff on capacity-related topics
Seek educational and promotional opportunities regarding the Capacity Assessment Model

While this model has been implemented across the zones in Calgary and Edmonton, neither an evaluation of the effectiveness of the model nor an examination of the experience of the team members has yet been conducted.

Objectives & Actions
The aim of this project is to:
Examine strengths and limitations of the Capacity Assessment Model
Explore the extent of attending team involvement in the provision of both capacity assessment process and problem solving.
Identify reasons for consultation with mentoring teams (i.e. specific matters regarding capacity for which mentoring team members are being consulted) and analyze for themes.
Identify barriers/challenges to efficacy that mentoring team members and designated capacity assessors face when offering services, as well as recommendations for change that might facilitate achievement of their roles and responsibilities.

These objectives will be met using a survey and focus groups of attending teams, mentoring teams and designated capacity assessors.

Budget (See appendix A below)
To support this project, we are requesting funds in the amount of $25,000.

Conclusion
Results of this project will help evaluate the effectiveness of this model, strengths of and gaps in services offered by mentoring teams and designated capacity assessors. Based on a review/analysis of information gathered from the survey future directions regarding mentoring teams and designated capacity assessors will be identified. In addition, after isolating challenges and barriers that attending team members have faced when offering services, recommendations and strategies to overcome barriers that compromise their effectiveness will be suggested.

Principal Applicants:
Suzette Carol Brémault-Phillips Dr. Jasneet Parmar

Assistant Professor
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Faculty of Rehabilitation Medicine
University of Alberta
2-64 Corbett Hall
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suzette.bremault-phillips@ualberta.ca

Associate Professor
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Department of Family Medicine
University of Alberta
Edmonton, Alberta, T6G 2C8
780-735-2048
jasneet.parmar@albertahealthservices.ca

Appendix A
Budget

Activity	Detail	Estimated total cost
Project Assistants (2)	$12,800 (2 x 30 hours/week for 8 weeks @ 25.00/hr)	$12,000.00
Research Assistants (4)	$8640 (4 x 15 hours/week for 8 weeks @ $20.00/hr)	$9,600.00
Mileage	Edmonton-Calgary ≈ 650 km x 3 = 1950 km Edmonton area ≈ 200 km	2150 x 0.45 = $967.50
Supplies, computer, software, paper, telephone	NVivo software, fluid surveys, computer equipment, general supplies	$1,092.50
Transcriptionist	≈ 8 – 75 minute transcripts ($2.04/min)	$1,340.00

Appendix 2: DMCA Model Evaluation Letter of Support

Alberta Health Services

January 25, 2012

Suzette Brémault-Phillips
2-64 Corbett Hall
Faculty of Rehabilitation Medicine
University of Alberta
Edmonton, AB, T6G 2G4

Jasneet Parmar
205 College Plaza
Dept. of Family Medicine
University of AB
Edmonton, AB,T6G 2C8

Dear Suzette/Jasneet;

This letter is to confirm our department, Seniors Health Provincial, Specialized Geriatric Services, Alberta Health Services will provide funding in support of the proposed quality improvement initiative to evaluate the Decision Making Capacity process that has been partially implemented in Alberta (Edmonton and Calgary focus). *This is a descriptive concurrent mixed methods evaluation using quantitative and qualitative data.*

We will provide up to $25,000 from the AHS, CI Strategy grant for use as outlined in the attached statement of work the budget, outlining deliverables, and outcomes. This funding supports the project's QI activity including human resource, focus group, data collection and analyses costs. This initiative will begin January 18, 2012 and be complete by March 31, 2012. These are project dollars from Alberta Health and Wellness and the term of grant also ends March 31, 2012.

As you have requested, these dollars require no:

1. Comingling of funds
2. ICR allowed, as its provincial funding, and
3. Agreement required.

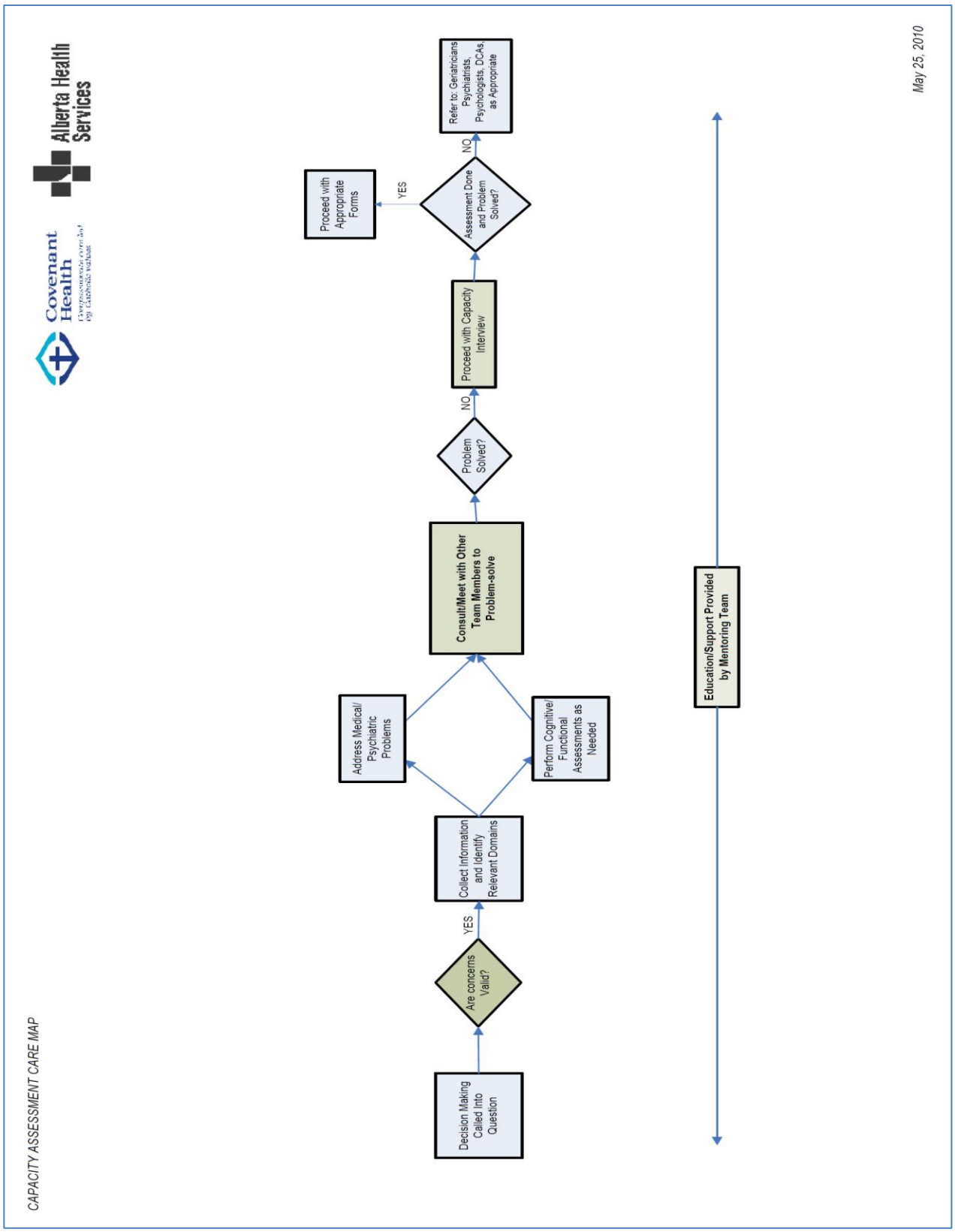
We look forward to working with you on this project.

Yours Sincerely,

Karen Gayman, RN, BScN
Executive Director,
Specialized Geriatrics and Palliative Care
Alberta Health Services
Seniors Health Provincial

Mollie Cole, RN, MN, GNC (C)
Lead,
Specialized Geriatric Services
Alberta Health Services
Seniors Health Provincial

Appendix 3: DMCA Model Care Map



Appendix 4: DMCA Model Brochure

What is Capacity?

It's all about making decisions!

Having capacity means you can understand information important for making a decision and can appreciate the consequences of that decision.

When making a decision, can an adult:

- **take in key information,**
- **think about the pros and cons, and**
- **make a decision, based on his/her values**

For more information, please contact the social worker caring for the adult.

For more information on the Legal Acts:

Personal Directive:
Office of the Public Guardian
http://www.seniors.alberta.ca/opg/PersonalDirectives/

Adult Guardianship:
Office of the Public Guardian
http://www.seniors.alberta.ca/opg/Guardianship/

Power of Attorney and Trusteeship:
Office of the Public Trustee
http://justice.alberta.ca/programs_services/public_trustee/Pages/default.aspx

Capacity Assessment

Understanding Decision-making Capacity

CAPACITY Dignity Respect decisions

Alberta Health Services | Covenant Health

Facts about capacity

It is assumed that all adults have capacity to make their own decisions.

Capacity assessment is a process used to determine whether an adult is still able to make his/her own decisions.

There must be proof that the capacity assessment is needed and the adult needs someone else to help make decisions.

Making a risky decision, or a decision others do not agree with, does not necessarily mean that the adult lacks capacity.

You can have capacity to make certain types of decisions but not others. For example, an adult may have capacity to choose where to live, but not have capacity to manage his/her money.

If an adult does not have capacity, steps can be taken to help them make decisions (see legal acts, below).

When should capacity be assessed?

Capacity should be assessed when:

- An adult makes choices or behaves differently than they usually do, which puts themselves, or others, at risk
- This change seems to be a result of impaired decision-making
- There is often conflict about the decision. For example, an adult does not want to give up driving when they should because of safety concerns

How is capacity assessed?

The assessment usually includes:

- Getting information on the risk caused by the adult's decisions from the adult/ caregivers
- Working with the adult to find out his/her strengths and limitations
- Problem-solving by the healthcare team to try and resolve the issue
- If the issue is not resolved, a staff member will formally interview the adult to determine his/ her capacity in a specific area
- The formal interview looks at whether the adult
  - Understands the facts about a decision, and
  - What might happen if they make one choice over another

Areas of Decision-making

The decision an adult has to make can be assessed in any of the following areas:

Health care	**Education/Training**
Accommodation	**Employment**
Choice of associates	**Legal Affairs**
Social Activities	**Finances**

Capacity assessments are only done in the area of concern. For example, if an adult is refusing much-needed surgery and appears to lack capacity, the capacity assessment will only be done for the area of health care.

Legal Acts that Cover the area of Capacity

Personal Directive Act

- Allows an adult to name a person he/she trusts (an agent) to make decisions on his/ her behalf
- Deals with personal decisions, including medical care, but not financial matters
- Set up by an adult when he/she has capacity and activated when the adult loses capacity

Powers of Attorney Act (Enduring Power of Attorney)

- Allows an adult to name a person to assist him/her with handling his/her finances and property
- Deals with financial matters or property only
- Set up by an adult when he/she has capacity and activated when the adult loses capacity

Adult Guardianship and Trusteeship Act

Co-decision-making

- Capacity is significantly impaired, but the adult can make personal decisions (not financial) with guidance and support
- The adult will be assisted by the co-decision-maker to make decisions together

Guardianship

- Legal process which gives an adult (called a guardian) the legal right to make or help make decisions about non-financial matters on behalf of another adult who lacks capacity
- Deals with Personal matters (i.e. healthcare, accommodation), but not finances

Trusteeship

- Legal process which gives an adult (called a trustee) the legal right to make or help make decisions about financial matters on behalf of another adult who lacks capacity
- Financial matters include personal property, realty, money, investments and income

	Decisions made by you in advance	**Decisions made for you by the Court**
Personal	Personal Directive	Co-decision-making / Guardianship
Financial	Enduring Power of Attorney	Trusteeship

Appendix 5: DMCA Model Worksheets

Alberta Health Services

Affix patient label within this box.

Capacity Assessment Process Worksheet

Do not complete this worksheet if the only concern of capacity is to drive. Consider a referral for driving assesment.

Date of referral *(yyyy-Mon-dd)*	Referred by	Date assessment began *(yyyy-Mon-dd)*

Is the adult making decisions *(or is unable to make decisions)* that are causing significant harm which makes you question his/her decision-making capacity? Does the adult need to be assessed for restoration of decision making capacity?

☐ No

☐ Yes, describe the reasons including risks, severity, conflicts, consequences of behaviours, etc.

Identify areas of authority *(domains)* in which the adult may lack capacity

☐ Healthcare	☐ Accommodation	☐ Choice of associates
☐ Social/leisure activities	☐ Education/vocational training	☐ Employment
☐ Legal matters	☐ Financial matters	

☐ Other *(specify)*_____

Collect and describe relevant domain-specific collateral information.

What are the adult's values and goals, cultural/religious beliefs, including any significant change recently, with regards to decision-making in relation to the domain(s) in question?

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Affix patient label within this box.

Capacity Assessment Process Worksheet

Has the adult's capacity been assessed on a previous occasion?
☐ No
☐ Yes, describe date of assessment, domain in question, assessment results etc.

Have any and all reversible medical conditions that are likely to impact capacity been ruled out?
☐ No
☐ Yes

Comments

Define the cognitive changes which may affect capacity

Test name	**Score**	**Date** *(yyyy-Mon-dd)*

Comments

Does the adult have functional limitations in relation to the domain(s) in question?
☐ No
☐ Yes

Comments

Alberta Health Services

Affix patient label within this box.

Capacity Assessment Process Worksheet

Have barriers to a valid assessment, such as language, literacy, vision and hearing, been addressed?
☐ No
☐ Yes
Comments

Can the problem be solved and the risks be managed by a less intrusive and restrictive form of support?
☐ No
☐ Yes, describe the solution *(consider meeting/consulting with other team members to problem-solve)*

Is a formal capacity interview required? *(Is the potential risk of harm to self, or others, high enough to justify the removal of the adult's rights i.e. appointment of an agent/ power of attorney, co-decision maker, guardian or trustee?)*
☐ No
☐ Yes
Comments

Has the adult given consent?	Is it in the best interest of the adult to conduct the assessment?
☐ No, complete this information ►	☐ No
☐ Yes	☐ Yes
	Has the adult has refused to participate in the assessment?
	☐ No
	☐ Yes

Comments

STOP **Conduct the Capacity Interview** *(adequately educate the adult regarding domain(s) in question and use the Capacity Interview Worksheet)* and then complete the following questions.

Identify the domain(s) in which the adult's capacity was assessed

☐ Healthcare	☐ Accommodation	☐ Choice of associates
☐ Social/leisure activities	☐ Education/vocational training	☐ Employment
☐ Legal matters	☐ Financial matters	
☐ Other *(specify)*		

Alberta Health Services

Affix patient label within this box.

Capacity Assessment Process Worksheet

How do you assess the decision-making capacity of this adult with respect to the following domains?
Check (✓) the appropriate box.

Domain	Has capacity	Significantly impaired	Lacks capacity

Plan of action *(depending on the results of assessment)*

☐ Invoke personal directive ☐ Invoke enduring power of attorney ☐ Specific decision making
☐ Apply for co-decision-making ☐ Apply for guardianship ☐ Apply for trusteeship
☐ Restoration of capacity ☐ Other *(specify)* _____

Comments _____

Outcomes

☐ Invoked personal directive ☐ Invoked enduring power of attorney
☐ Used specific decision making ☐ Applied for co-decision-making
☐ Applied for guardianship ☐ Applied for trusteeship
☐ Applied for restoration of capacity ☐ Discussed plan as above with referral source
☐ Informed patient of assessment findings and plan of action

Comments _____

Name *(print)*	Signature	Designation	Date *(yyyy-Mon-dd)*

Alberta Health Services

Affix patient label within this box

Capacity Interview Worksheet

Domain	
Health care	**Response to Query**
Medical conditions ▪ Able to identify medical condition(s) and treatment(s) ▪ Makes and keeps medical appointments ▪ Participates in own care and treatment ▪ Requests assistance, as needed ▪ Recognizes emergencies and uses EMR **Medication Regime** ▪ Aware of current medications and reasons for taking them ▪ Aware of potential side effects ▪ Takes medications as prescribed **Consent to Treatment** ▪ Aware of medical problem(s) ▪ Aware of proposed treatment and alternatives ▪ Aware of consequences of accepting or refusing treatment, when explained	**Opinion *(and rationale regarding opinion)* of the Adult's Capacity** ☐ Has capacity ☐ Significantly Impaired ☐ Lacks capacity
Accommodation	**Response to Query**
Suitability of Residence ▪ Describes current living situation & willing to accept help, if required ▪ Identifies current needs and assistance / services required ▪ Recognizes level of independence and able to organize assistance in areas such as Personal care, Basic Home Maintenance, Meal preparation, Mobility ▪ Aware of other suitable residential alternatives ▪ Can access transportation **Safety: evaluate risk and independence** ▪ Recognizes potential fire hazards ▪ Functions outside familiar environment ▪ Aware of environmental risks (icy conditions, traffic) ▪ Wandering	**Opinion *(and rationale regarding opinion)* of the Adult's Capacity** ☐ Has capacity ☐ Significantly Impaired ☐ Lacks capacity

Name of Assessor(s)	Signature

Alberta Health Services

Capacity Interview Worksheet

Affix patient label within this box

Choice of Associates	Response to Query
▪ Recognizes when others present a danger and takes precautions ▪ Able to choose companions who do not abuse or exploit the patient ▪ Recognizes frequently seen associates ▪ congruence with values and ability to express preferences **Sexuality/Intimacy** ▪ Consent ▪ Knowledge of relational concepts ▪ Social norms	**Opinion *(and rationale regarding opinion)* of the about Adult's Capacity** ☐ Has capacity ☐ Significantly Impaired ☐ Lacks capacity
Participation in social/leisure activities	**Response to Query**
▪ Able to choose social activities to suit interests ▪ Level of independence ▪ Engagement ▪ Ability to identify preferences	**Opinion *(and rationale regarding opinion)* of the about Adult's Capacity** ☐ Has capacity ☐ Significantly Impaired ☐ Lacks capacity
Legal matters *(e.g. PD, EPoA, Will)*	**Response to Query**
General ▪ Aware of legal rights ▪ Able to access counsel (formal and informal) ▪ Understands the implications of signing a legal document ▪ Understands reasons for legal proceedings (e.g. reason for charge, reason for suit, etc.) ▪ Permits / licences are relevant ▪ Able to apply for licences / permits	**Opinion *(and rationale regarding opinion)* of the about Adult's Capacity** ☐ Has capacity ☐ Significantly Impaired ☐ Lacks capacity

Name of Assessor(s)	Signature

Alberta Health Services

Capacity Interview Worksheet

Affix patient label within this box

Participation in employment activities	Response to Query
▪ Makes decisions re: type of work ▪ Able to find and maintain employment suitable to abilities ▪ Ability to identify preferences ▪ Awareness of skill level (strengths & weaknesses) ▪ Able to recognize and avoid workplace hazards ▪ Able to understand wages and benefits ▪ Aware of work alternatives and consequences of not working	**Opinion *(and rationale regarding opinion)* of the about Adult's Capacity** ☐ Has capacity ☐ Significantly Impaired ☐ Lacks capacity
Participation in educational, vocational or other training	**Response to Query**
▪ Education, vocation and / or training is relevant ▪ Ability to identify preferences ▪ Awareness of skill level (strengths & weaknesses) ▪ Awareness of options & able to choose a training program ▪ Initiates or terminates program independently	**Opinion *(and rationale regarding opinion)* of the about Adult's Capacity** ☐ Has capacity ☐ Significantly Impaired ☐ Lacks capacity

Name of Assessor(s)	Signature

Alberta Health Services

Affix patient label within this box

Capacity Interview Worksheet

Financial	Response to Query
Income/Assets ▪ Source(s) and amounts ▪ Bank information and signing authority on accounts ▪ Monitors account activity ▪ Knowledge of types and value of assets ▪ Manages investments ▪ Plans to acquire or dispose of asset(s) **Expenses/Debts** ▪ Types and amounts ▪ Method(s) of bill payment ▪ Gifts and donations ▪ Arranges for tax payments, does income tax return ▪ Debts **Financial Management** ▪ Maintains budget / accesses money ▪ Handles currency / issues cheques ▪ Able to ask for assistance ▪ Safeguards financial documents and information ▪ Manages business **Risks of Exploitation** ▪ Purchases from solicitors ▪ Recognizes abuse by caregivers ▪ Employs protective strategies **Other non-personal/financial legal matters** ▪ awareness of legal rights ▪ understanding the implications of signing legal documents ▪ understanding reasons for legal proceedings ▪ ability to access counsel	**Opinion *(and rationale regarding opinion)* of the about Adult's Capacity** ☐ Has capacity ☐ Significantly Impaired ☐ Lacks capacity

Name of Assessor(s)	Signature

Appendix 6: Ethics Letter – Edmonton

Health Research Ethics Board

308 Campus Tower
University of Alberta, Edmonton, Alberta T6G 1K8
p.780.492.9724 (Biomedical Panel)
p.780.492.0302 (Health Panel)
p.780.492.0459
p.780.492.0839
f.780.492.7808

February 23, 2012

Dr. Suzette Bremault-Phillips
Department of Occupational Therapy
Faculty of Rehabilitation Medicine
2-64 Corbett Hall

Re: Assessment of Decision-Making Capacity in Adults with Diseases and Disabilities: Has the Decision-Making Capacity Assessment Model Been Effective?

Dear Dr Bremault-Phillips;

Thank you for your email correspondence dated February 5, 2012, which contains a brief description of the above project. This project has been reviewed on behalf of the Research Ethics Board. It has been determined that the purpose of this project is for program evaluation/quality assurance purposes.

As indicated in Article 2.5 of the Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans, program evaluation/quality assurance studies are not subject to Research Ethics Board review and approval. On the basis of the information which has been provided, it seems clear that this project falls within this category.

Best wishes for your projects,

Charmaine N. Kabatoff
Senior REB Coordinator
Health Research Ethics Board (Health Panel)

UNIVERSITY OF ALBERTA Alberta Health Services Covenant Health

Appendix 7: Ethics Letter – Calgary

UNIVERSITY OF ALBERTA

Suzette Bremault-Phillips <suzette2@ualberta.ca>

RE: *****TIME SENSITIVE REQUEST - re confirmation e-mail of previously reviewed project - final report is due May 30,th

1 message

Glenys Godlovitch <ggodlovi@ucalgary.ca> Mon, May 28, 2012 at 3:41 PM
To: Suzette Brémault-Phillips <suzette.bremault-phillips@ualberta.ca>
Cc: Betty Brown <ebrow@ucalgary.ca>

Dear Dr Bremault-Phillips
This is to confirm that as chair of the Conjoint Health Research Ethics Board, University of Calgary, I reviewed the DCM project you described to me in March 2012 (and follow up emails with attachments) and I determined it to be quality assurance/program evaluation work not requiring an application for full review and approval by the CHREB. I considered the description you provided and identified no ethical concerns.
Please accept this comfort letter as equivalent to an ethics certificate from the CHREB and feel free to use it in conjunction with any submission for publication, presentation in a scholarly context, or for institutional performance reporting requirments.
Thank you for providing me with the opportunity to review your project.
A signed copy of this email will be sent you electronically for your records.
Best wishes

Glenys Godlovitch, BA (hons), LLB, PhD
Barrister and Solicitor
Chair, Conjoint Health Research Ethics Board
Associate Professor, Community Health Sciences
Phone:403-210-9757
Fax: 403-283-8524

Appendix 8: DMCA Model Evaluation Information Sheet and Consent Form

INFORMATION SHEET

Decision-Making Capacity Assessment Model

Title: Assessment of Decision Making Capacity in Adults with Diseases and Disabilities: Has the Decision-Making Capacity Assessment Model been effective?

Principal Investigator:

- Suzette Brémault-Phillips, PhD, Assistant Professor, Department of Occupational Therapy, University of Alberta
- Jasneet Parmar, MBBS, Dip. COE, Associate Professor of Family Medicine, Department of Family Medicine, University of Alberta; Misericordia Community Hospital, Alberta Health Services.

Co- Investigators:

- Lili Liu, PhD, Professor and Chair, Department of Occupational Therapy, University of Alberta.
- Elizabeth Taylor, PhD, Associate Professor Department of Occupational Therapy, University of Alberta.

Background:

Adults with diseases and disabilities contend with a number of barriers that can challenge their autonomy and ability to live independently. One such barrier is an inability to make decisions on one's own regarding both personal affairs, and financial matters. A person's decision making ability – ranging from capable to incapable – is dependent on both the complexity of the decision making process, and one's ability to engage in that process.

Adults with diseases and disabilities often require guidance and support in the area of decision-making. Support and guidance that employs the least intrusive and least restrictive measures possible, and that can facilitate independence and autonomy, has been determined to be the most ethical and desirable. Determination of the degree of support and guidance an individual may require is made using a capacity assessment.

To support the capacity assessment process, a Capacity Assessment Model has been implemented in the Edmonton zone. This model outlines the assessment process, including validation of reasons for conducting a capacity assessment, identification of domains needing to be assessed, performance of appropriate cognitive and functional assessments, and problem-solving using an inter-disciplinary approach. Under this model, a capacity interview and declaration of incapacity is suggested only as a last resort.

To facilitate both staff learning and implementation of the model, capacity assessment workshops have been offered to over 800 medical and allied health staff, and appropriate worksheets have been developed. Mentoring teams are comprised of health care professionals including physicians, nurses, social workers, occupational therapist, psychologist, and Designated Capacity Assessors (DCAs). These have also been put in place to support those educated through the workshops, and assist with problem solving.

Purpose:

The aim of this project is to:

1. Evaluate the effectiveness and efficacy of the DMCA model
2. Identify the strengths and limitations of the model
3. Explore barriers and facilitators faced by mentoring team members and designated capacity assessors
4. Identify strategies to overcome barriers and facilitate integration of the model

Procedure:

You are invited to participate in a series of focus groups on March 26th, 2012 (Calgary) or April 2nd, 2012 (Edmonton) from 8am-3pm. After a brief overview of the DMCA model, you will be asked to discuss your ideas, opinions, and experiences regarding the DMCA model and the capacity assessment process. There are 3 focus groups throughout the day, each taking no longer than 1 hour. These sessions will be audio-recorded and transcribed verbatim.

Possible Benefits:

Your participation will help researchers evaluate the DMCA model, understand its application in service delivery, and identify areas of improvement.

Possible Risks:

There are no identifiable risks to individuals participating in this study.

Confidentiality:

You will not be identified in any of the research and reports in this study. All audio recordings and transcripts will be stored on a password-protected computer at the University of Alberta. Transcripts will be stripped of ID information, and only research team members will have access. All records will be destroyed after seven years.

Voluntary Participation:

Your participation is voluntary and you can stop at any time.

Contact Names and Telephone Numbers:

If you have concerns about your rights as a study participant, you may contact Suzette Brémault-Phillips. Phone: 780-492-9503. Email: suzette.bremault-phillips@ualberta.ca

PARTICIPANT CONSENT FORM

Decision-Making Capacity Assessment Model Evaluation

PART 1

Assessment of Decision Making Capacity in Adults with Diseases and Disabilities: Has the Decision-Making Capacity Assessment Model been Effective?

Principal Investigator:

- Suzette Brémault-Phillips, PhD, Assistant Professor, Department of Occupational Therapy, University of Alberta
- Jasneet Parmar, MBBS, Dip. COE, Associate Professor of Family Medicine, Department of Family Medicine, University of Alberta; Misericordia Community Hospital, Alberta Health Services.

Co- Investigators:

- Lili Liu, PhD, Professor and Chair, Department of Occupational Therapy, University of Alberta.
- Elizabeth Taylor, PhD, Associate Professor Department of Occupational Therapy, University of Alberta.

PART 2	YES	NO
Do you understand that you have been asked to be in a research study?	□	□
Have you read and received a copy of the attached Information Sheet?	□	□
Do you understand the benefits and risks involved in taking part in this research study?	□	□
Have you had an opportunity to ask questions and discuss this study?	□	□
Do you understand that you are free to withdraw from the study at any time without having to give a reason?	□	□
Has the issues of confidentiality been explained to you?	□	□

I agree to take part in a focus group:	**YES**	**NO**
	□	□

Signature of research participant: _____

(Printed Name): _____

Date (D/M/Y): _____

Signature of Witness: _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _____

Date (D/M/Y): _____

Appendix 9: Photo/Audio release form

Consent for Disclosure of Personal Information
(Photographs, Videotapes and Audiotapes)

I authorize the	Decision Making Capacity Assessment Model Project
To use the designated photographs, videotapes or audiotapes	Listing of photographs, videotapes or audiotapes to be disclosed
Taken on	Date photograph taken or videotapes or audiotapes recorded
For the purpose of	Data collection and analysis
In the period	March 26-May 31, 2012

Full Name:	
Date:	

Signature: _____

Protection of Privacy - The personal information requested on this form is collected under the authority of Section 33 (c) of the *Alberta Freedom of Information and Protection of Privacy Act* and will be protected under Part 2 of that *Act*. It will be used for the purpose of managing the consent for disclosure of personal information process. Direct any questions about this collection to: [contact position, full address, and business telephone number].

This information will be retained and disposed in accordance with approved records retention and disposal schedules of the University.

Information and Privacy Office, January 2006

Appendix 10: Outline of the evaluation workshop days

Decision-Making Capacity Assessment – Focus Groups
Monday, March 26th, 2012
Rockyview General Hospital
7007 14 Street SW
Calgary, AB
08:00 - 15:00 Hrs

AGENDA

08:00 - 08:30	Breakfast
08:30 - 09:15	Welcome & Plenary (overview of model)
09:15 - 10:30	Mixed Mentoring Team Focus Groups (4 groups with representatives from each site)
10:30 - 10:45	Coffee break
10:45 - 12:00	Site specific Mentoring Team Focus Groups (FMC, RGH, PLC, Community/Rural)
12:00 - 13:00	Lunch*
13:00 - 15:00	DCA Focus Group

*Mentoring Teams are invited to join for lunch

Program Evaluation/Quality Assurance Research Day
of
The Decision- Making Capacity Assessment Model
Edmonton Zone

Monday, April 2nd, 2012
Alumni House - University of Alberta
11515 Saskatchewan Drive
Edmonton, AB T6G 2C4
Tel - 780.492.6057
08:00 - 15:00

AGENDA

8:00 - 8:30	Breakfast
8:30 - 9:00	Plenary (overview of model)
9:00 - 9:15	Discussion of the research component of the day
9:15 -10:15	Focus Groups aimed at evaluating the Capacity Assessment Model
10:15 -10:30	Coffee break
10:30 -11:30	Site-Specific Focus Groups aimed at evaluating the roll out of the Capacity Assessment Model and Mentoring Teams at various sites
11:30-12:00	Large Group Open Forum to discuss key themes and ideas raised in smaller focus groups
12:00 -1:00	Lunch
1:00 -3:00	DCA Focus Groups aimed at evaluating the role of DCAs including on Mentoring Teams, in the Capacity Assessment Model, and in regard to the roll out of the Model at various sites

Appendix 11: DMCA Model Evaluation Focus Group Questions

Mixed Focus Group (focus group members randomly selected for each group):

1. What are the strengths of the model?
2. What are the limitations of the model?
3. How has the model impacted the capacity assessment process?
4. Are the tools useful?
5. How has the model impacted the interactions/relationships between staff, family, and clients?
6. What is the value that the Mentoring Team brings to the model and the capacity assessment process?
7. What suggestions or improvements would you make regarding the Model or implementation of the Model?
8. What will help sustain the model?
9. What role do Mentoring Teams and DCAs play in sustaining the model?

Site Specific Focus Group (focus groups compromised as much as possible of participants from the same or similar sites):

1. How has the model been implemented at your site? What strategies were utilized in the roll out?
2. What factors helped/hindered the adaptation and integration of the model?
3. What is the composition of the Mentoring Team at your site?
4. How was the Mentoring Team created at your site?
5. What is the role of the Mentoring Team at your site? Are you able to fulfill the role? What do you need to fulfill this role?
6. Do you feel supported as a Mentoring Team member by your site? What do you need to feel supported?
7. What barriers or challenges, if any, have you faced as a Mentoring Team member?
8. What could be done to overcome challenges/barriers faced by Mentoring Team members at your site?

DCA Focus Group (participating DCAs randomly selected to each focus group):

1. To what extent have you been able to use your DCA training?
2. Do you feel comfortable in your role as a DCA?
3. Do you feel supported in your current role as a DCA? Please explain.
4. How has management supported/inhibited you as a DCA?
5. What value do you bring to the DMC model and to your site?
6. What role do you play in relation to the Mentoring Team?
7. What are the barriers to completing capacity assessments?
8. What are the facilitators to completing capacity assessments?
9. What would assist you to work to full scope of practice as a DCA?
10. Do you have any comments or suggestions on how to improve the current approach to the model for assessment of decision making capacity?

UNIVERSITY OF ALBERTA

Alberta Health Services

Decision Making Capacity Assessment Model Research Project

Capacity Assessment
Understanding Decision-making Capacity

Survey Identifier Number: _____

The purpose of this survey is to gather demographic data for a research project evaluating the effectiveness of the Decision Making Capacity Assessment Model. By completing this survey, you are acknowledging that you are aware that your answers will be analyzed and may be published. Please be assured that your anonymity will be protected, and that your identity will in no way be associated with any of the answers that you provide in this survey.

Please circle all that apply:

Gender	Male	Female										
Age	15-19	20-24	25-29	30-34	35-39	40-44	5-49	50-54	55-59	60-64	65-69	70-74
Facility Type	Public	Private										
Zone	Calgary	Edmonton										
Location	Urban	Rural	Combination									
Facility	Glenrose	Miscericordia	Grey Nuns	Continuing Care (home living, supported living & facility living)	Villa Caritas	Sturgeon	Good Sam.	Royal Alex	Foot-hills	Peter Lough-heed	Com-munity /rural	
Years of Prof. Experience	1-5	6-10	11-15	15+								
Profession	Physician	Geria-trician	Psychia-trist	Psycho-logist	OT	PT	NP	RPN	RN	LPN	SW	
DCA certified	Yes	No										
Years of capacity ass't experience	0-1	2-5	6-10	11-15	16+							
Prior capacity ass't training to DMCA training	Yes	No										
Prior capacity ass't experience to DMCA training	Yes	No										
% of work time conducting capacity ass'ts	0-25%	26-50%	51-75%	76-100%								

Appendix 13: DMCA Model Evaluation Survey Questions

According to the values of AHS, we strive to provide care that is respectful, accountable, and transparent, and that optimizes the engagement of our patients and others who are involved. Appropriate patient engagement may include assessment of a patient's decision-making capacity. Please complete the survey questions below to assist AHS to understand the current status of the implementation of the model for assessment of decision making capacity at your workplace. The survey will take about 10 minutes to complete. Participation in this survey is voluntary. Your responses will be confidential, and the results will only be reported in aggregate form. No individually identifying information will be used. Results will be used to guide future evolution of the DMCA model across AHS.

Please indicate your level of agreement with the following statements:

1. The new DMCA model is followed in my workplace.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

2. I follow the guiding principles of DMCA when I am faced with concerns about a patient's decision-making capacity.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

3. I am confident in my knowledge about legislation as it applies to DMCA.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

4. When a capacity concern is identified in a patient, I and/ or my team member(s) will use the "Capacity Assessment Process Worksheet" to guide our work.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

5. I understand the role of my discipline in DMCA and the part I play in the interdisciplinary approach to the assessment.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

6. I and/ or my team member(s) will explore problem solving opportunities in order to reduce the risk to the patient before suggesting a capacity interview.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

7. I am confident in my knowledge and skills regarding DMCA and comfortable being involved in these assessments.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

8. The capacity assessment model has reduced the angst/conflicts amongst staff, patients and families when dealing with issues related to DMCA.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

9. A Capacity Assessment Mentoring Team is available to assist our team with questions and to provide support about DMCA.

   □ Strongly Disagree
   □ Disagree
   □ Agree
   □ Strongly Agree
   □ Do not know

10. The standardized process for DMCA has improved the efficiency and effectiveness of capacity assessments performed by my team.

    □ Strongly Disagree
    □ Disagree
    □ Agree
    □ Strongly Agree
    □ Do not know

11. I have had the opportunity to attend ongoing learning sessions that provide further information and support for the implementation of DMCA.

    □ Strongly Disagree
    □ Disagree
    □ Agree
    □ Strongly Agree
    □ Do not know

12. I and my team receive the necessary management support to implement the model for DMCA.

    □ Strongly Disagree
    □ Disagree
    □ Agree
    □ Strongly Agree
    □ Do not know

13. Describe any barriers or challenges you have encountered to implementing the new Decision Making Capacity Assessment model.

14. Do you have any comments or suggestions on how to improve the current approach to the model for assessment of decision making capacity?