Supporting Clients’ Choices:

Developing a Policy to Support Clients’ Choices and Support Our Staff

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Health Law Matters

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Outline

- Introduction to the Toronto Central CCAC
- Current Practice
- Rationale for a Client Choice Policy
- Policy Development Process
- Policy Statement and Supporting Tools
- Case Example
- Future Work
- Conclusion
Who is the Toronto Central CCAC?

Aging at Home

Rehab Services

School Programs

Chronic Disease Management

Mental Health & Addictions

End of Life Care
Policy and Practice Drivers

- Accreditation Canada standards
- Professional codes of ethics
- Tri-Council Policy Statement on Ethical Conduct in Research Involving Humans
- Relevant codes, policies, statutes and case law are founded on ethical considerations

Key Trends Affecting Health Care Ethics

• Increased pressures
  – (governments & payers) forces change in practice

• Increased caseload & complexity
  – of issues for community health care staff ➔ moral distress

• Changing demographics
  – elderly living at home, living in assisted living facilities,
    dependence on home care services, ➔ risk

Impact of medical technology
  – on people living longer with chronic conditions ➔ unease

Earlier hospital discharge
  – of non-compliant &/or complex cases - disagreement with choices
Laws Affecting Health Care Ethics

- *Health Care Consent Act:*
  - Defines “Capacity” to make treatment, admission decisions
  - Hierarchy of SDMs
  - Principles of substitute decision-making
  - Applications to Consent and Capacity Board:
    - To review capacity;
    - To appoint representative;
    - For directions;
    - To depart from wishes;
    - To challenge SDM’s decisions.
Laws Affecting Health Care Ethics

- **Substitute Decisions Act:**
  - Defines “capacity for personal care;”
  - Defines “capacity to manage property;”
  - Defines “capacity to execute Power of Attorney:”
    - For property;
    - For personal care (including treatment);
  - Assessments of capacity to manage property, personal care.
  - Guardianship Applications.
Laws Affecting Health Care Ethics

• *Mental Health Act*:
  – Defines who may be detained in a psychiatric facility;
  – Sets out grounds for detention;
  – Sets out process of detention;
  – Sets out protections for the rights of patients.
  – Statutory obligation to assess capacity to manage property.

• *Community Treatment Orders*:
  • May prescribe requirement to take treatment, requirement to live in a certain place.
“The law is the minimum ethic!”
CURRENT “CONTINUITY” OF CARE

MIND THE GAP

Patient Flows

Acute vs LTC Approaches

**Acute Care**
- Disease paradigm
- Cure oriented
- Short term/crisis
- Higher tech
- Medical services
- More predictable costs
- Passive patient
- Medical team

**Community Long Term Care**
- Disability paradigm
- Function oriented
- Longer term
- Lower tech
- Medical plus social services
- Less predictable costs
- Active patient/family
- Inter-professional team
Where Do Community Ethics Fit In?
What are Community Healthcare Ethics?

Endeavour to promote the sector’s philosophy of supporting clients' independence and ongoing integration or reintegration in their community

• *Unique view sensitive to how client’s self-determination may be affected by both distinct supports, and the different settings they are provided in.*
What are Community Health Care Ethics?

Critical reflection on ethical/moral issues in:
- Complex Continuing Care & Long Term Care
- Physical medicine
- Rehabilitation
- Mental Health
- Home Care
- Research
Key Ethical Issues in Community Health Care

- **Access to service**, limited resources, increased pressure for hospital discharge
- **Conflict over treatment decisions**, issues of autonomy, disagreement with client choice, relationship of client & family
- **Workplace demands**, employee safety
- **Client safety**, living at risk
- **Consent and decision-making capacity**
- **Moral distress**

**New Focus:**
- **Complex clinical relationships**, ‘difficult’ clients, ‘challenging’ family members, dysfunctional teams
- **Boundaries**, just like home, just like family?
- **Client sexuality**, conflicts in beliefs and values, lack of privacy, need for assistance, free and informed decisions?
Recurring Theme

- **Decision-Making Capacity**

  - Larger population incapable of informed decision-making.

  - Greater population with impaired cognitive and communication abilities.

  - Increased use of substitute decision makers.
Approaching Healthcare Ethics in Practice

• Bridge the gap between community and hospitals - create a vehicle for interprofessional communication and practice

• Address ethical dilemmas using a decision-making framework

• Build ethics capacity through strategic community engagement

• Formalize cooperation through development of a network
Who are some of our clients?

• Frail elderly couple with no family support. Want to remain in their home.

• 87-year-old with Alzheimer’s. Wanders.

• 65-year-old morbidly obese woman. Pays homeless people to help with activities of daily living.

• 53-year-old client with epilepsy and personality disorder. Non-compliant with medication.

• 26-year-old with paraplegia. Verbally abuses nurses when they don’t change his dressings the way he wants.
Why a policy to support client choice?

• We *respect* our clients' rights to make their own choices

• We *support* clients’ choices everyday

• We aim for *client-centred* care planning by:
  – Identifying what is important from the client’s perspective
  – Finding appropriate solutions

• Sometimes we *disagree* with clients’ choices

• When clients *choose to live at risk*...
Tensions, concerns, and questions...

- health
- well-being
- liability
- professional responsibility
- risks
- safety
- dignity
- decisional capacity
- duty to care
- client autonomy
Situations become even more complex…

• Practitioners of different disciplines can’t agree on what plans are best to support

• Client, family, healthcare and support service providers hold different and conflicting views

• Organizational conflicts related to contractual agreements

• Lack of consistent guidance or practice standards
Impact on staff

- Moral uncertainty
- Moral distress
- Interprofessional conflict
- Frustration
- Decrease in job satisfaction
- Burn-out
Impact on families and caregivers

- Moral uncertainty
- Moral distress
- Conflict
- Frustration
- Dissatisfaction with services
- Burn-out
Impact on clients

- Capacity questioned
- Wishes ignored
- Non-compliance
- Dissatisfaction with services
- Lack of support
- Withdrawal of services
Policy development overview

<table>
<thead>
<tr>
<th>Q1-4 08/09</th>
<th>Q1 09/10</th>
<th>Q2 09/10</th>
<th>Q3 09/10</th>
<th>Q4 09/10</th>
<th>Q1 10/11</th>
</tr>
</thead>
</table>

- Board Approval: Nov 24
Policy foundations and strengths

• Grounded in legislation:
  – *Health Care Consent Act, 1996*
  – *Long Term Care Act, 1994*
  – *Mental Health Act, 1990*
  – *Substitute Decisions Act, 1990*

• Consistent with:
  – Mission, Vision, Values, Code of Conduct
  – Codes of Ethics of Regulated Colleges
  – Community Ethics Network Code of Ethics

• Supported by Client Bill of Rights

• Incorporates stakeholders’ feedback
Policy statement

• Support our clients’ rights to make choices about:
  – How and where they live
  – Care or support services they may receive

• Clients have the right to live at risk as long as their choices do not pose imminent harm to others

• Risk must be “acceptable”

• Inform clients of actual or potential risks and likely consequences of choices

• Identify appropriate mitigation strategies where possible
What is “acceptable” risk?

- Acceptable risk determined by rigorous assessments, including risks of providing and not providing services
- Risk is uncertainty of outcome
- Risk is not always negative, but limits exist
- Limits include when:
  - Immediate and identifiable danger [to others only or also to client?]
  - Law or human rights violated
  - Resources beyond what we are mandated to provide
  - Serious concerns that client needs cannot be met
Policy tools

- Decision-making flow charts
- Community Ethics Toolkit
- Guiding Principles for Supporting Clients’ Choices
- Questions to Consider
- Risk assessment tools
  - RAI-HC
  - Ethical Decision-Making Worksheet
- Risk Support Plan
- Risk flag in Care Coordination Portal
Decision-making flow charts

For capable clients

For incapable clients
Community Ethics Toolkit

- Risk assessment and decision-making tool
- Forum for open and non-threatening discussion
- Assists in deciding what we should do, why and how we should do it
### Step 1: Identify the Facts - 4 Box Method

<table>
<thead>
<tr>
<th>Medical Indications:</th>
<th>Client Preferences:</th>
</tr>
</thead>
<tbody>
<tr>
<td>State the client’s medical problem, history, and diagnosis. Is it acute, chronic, critical, emergent, and reversible? Goals of treatment? Probabilities of success? Plans in case of therapeutic failure? Potential benefits of care? How can harm be avoided?</td>
<td>State the client’s preferences. Do they have the capacity to decide? If yes, are client’s wishes informed, understood, voluntary? If not, who is substitute decision maker? Does the client have prior, expressed wishes? Is client’s right to choose being respected?</td>
</tr>
</tbody>
</table>

- Client’s medical problem, history, and diagnosis
  - Acute, chronic, critical, emergent, and reversible?
  - Goals of treatment?
  - Probabilities of success?
- Plans in case of therapeutic failure?
- Potential benefits of care?
- How can harm be avoided?

<table>
<thead>
<tr>
<th>Quality of Life:</th>
<th>Contextual Features:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describe quality of life in client’s terms. Client’s subjective acceptance of likely quality of life, and views and concerns of care providers. Examine the emotional factors influencing each individual, such as existing feelings, values, biases and prior experiences.</td>
<td>Any other family involved or significant relationships? Any care plans put in place so far? Relevant social, legal, economic, and institutional circumstances? Other relevant features, e.g. religious &amp; cultural factors, limits on confidentiality, resource allocation issues, legal implications, research or teaching involved, provider conflict of interest?</td>
</tr>
</tbody>
</table>

- Quality of life in client’s terms
- Client’s subjective acceptance of likely quality of life
- Views and concerns of care providers

<table>
<thead>
<tr>
<th>Other family or relationships involved?</th>
<th>Other relevant features?</th>
</tr>
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<tbody>
<tr>
<td>Any care plans put in place so far?</td>
<td>Limits on confidentiality?</td>
</tr>
<tr>
<td>Relevant social, legal, economic, or institutional circumstances?</td>
<td>Resource allocation issues?</td>
</tr>
<tr>
<td>Other relevant features?</td>
<td>Legal implications</td>
</tr>
<tr>
<td>– Limits on confidentiality?</td>
<td>Research or teaching involved?</td>
</tr>
<tr>
<td>– Resource allocation issues?</td>
<td>Any provider conflict of interest?</td>
</tr>
</tbody>
</table>

**Step 2: Determine the Ethical Principles in Conflict**

**Identify ethical issues**
What ethical principles are in conflict? Refer to the Code of Ethics for the Community Health and Support Sector on page 16 for further details.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Explain the Issue</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>
Community Code of Ethics

- Advocacy
- Client and Employee Safety
- Commitment to Quality Service
- Confidentiality
- Conflict of Interest
- Dignity
- Fair and Equitable Access
- Health and Well-Being
- Informed Choice and Empowerment
- Relationship Among Community Agencies

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Code of Ethics for the Community Health and Support Sector

We, as employees of Community Health and Support Sector organizations, are committed to being an integral part of the communities we serve. We are responsible for: acting professionally and in a client-centered manner; upholding the dignity and honour of our clients; and practising in accordance with ethical principles. This Code of Ethics is intended to provide us with specific ethical principles to address situations that we may encounter, and to guide us in our relationships with clients, family members and others in the support team, other health care practitioners, and the public. This code is intended to complement laws, codes and standards of professional practice.

- **Advocacy**: We have the responsibility to help improve the awareness, the accessibility and the quality of our services by advocating on behalf of our clients. We will make available the means to ensure that the clients are aware of their rights and responsibilities. We will take steps to ensure that the clients are provided with the necessary information to enable them to make informed choices.

- **Dignity**: In all our interactions we will demonstrate professional respect for human dignity. We will be responsive and sensitive to the diversity among our clients and staff groups.

- **Client and Employee Safety**: We recognize that the community setting represents a unique environment for community and health sector employees. We will take available steps to assess and minimize risk to clients, while being sensitive to their wishes. We will also take necessary measures to ensure the personal safety of employees, and safety concerns of both clients and employees will be expected and addressed in a supportive and non-threatening way. After all options have been considered, we may withdraw services if employee safety is compromised.

- **Fair and Equitable Access**: We believe that each individual is entitled to an assessment. We will ensure that services are based on clients’ needs, regardless of their income, age, gender, ethnicity or race, physical or mental ability, and any other factors such as diverse behaviors or lifestyle.

- **Health and Well-Being**: We will use a holistic approach to clients’ health care needs by acknowledging all things important to them in their community.

- **Commitment to Quality Services**: We are committed to providing the highest quality services that will benefit our clients within available resources.

- **Confidentiality**: Client information is confidential; we will ensure that clients and their legal substitute are informed of their right to consent to the sharing of necessary information with individuals and organizations directly involved in the client’s case.

- **Conflict of Interest**: We will not compromise services to our clients for our own personal benefit.

- **Informed Choice and Empowerment**: We believe that most individuals have the ability and the right to make decisions about their health. We will assist clients to make care plans and life choices in keeping with the client’s values, beliefs and health care goals. We will ensure that clients are fully informed of their options and have all the information they need to make informed decisions about their health. Following due process, if the client is determined to be incapable of making these decisions, we will take directions from the client’s legal substitute.

- **Relationships Among Community Agencies**: We recognize there may be a competitive element in our work, and we agree to respect one another’s roles and to work together as the spirit of collaboration to maximize the effectiveness of client services.

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## Guiding Principles for Supporting Choice

- **Liberty**
- **Capacity**
- **Client-Centered Care**
- **Accountability**
- **Positive Approaches to Risk**
- **Empowerment**
- **Shared Decision-Making**

## Guiding Principles for Supporting Clients’ Choices

The following are the Toronto Central CCAC’s guiding principles for supporting clients’ choices. Included are questions to ask for critical thinking and reflection on cases of clients choosing to live at risk. These principles are intended to be incorporated within the Toronto Central CCAC’s Ethical Decision-Making Framework to guide decisions about supporting clients’ choices.

**Liberty:** People have the right to live their lives to the fullest as long as that does not stop others from doing the same—that is, does not pose imminent harm to others including Toronto Central CCAC staff.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Response</th>
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<tbody>
<tr>
<td>What are the consequences of the action taken and the likelihood of any harm to the client, staff, and/or caregivers from it?</td>
<td></td>
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<tr>
<td>What are the benefits (in terms of independence, well-being, and choice)?</td>
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</table>

**Capacity:** A capable client’s decision must be honored unless he or she poses imminent harm to others, or if the risk is too great to be supported by the Toronto Central CCAC.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Response</th>
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</thead>
<tbody>
<tr>
<td>Is the client capable?</td>
<td></td>
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<tr>
<td>Is the client able to appreciate the risk and possible consequences?</td>
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</tbody>
</table>

**Client-Centered Care:** Client-centered planning approaches identify what is important to a person from his or her own perspective and find appropriate solutions.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has what the client wants been considered?</td>
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</tbody>
</table>

**Accountability:** Ultimately, the Toronto Central CCAC has a statutory duty of care and a responsibility not to agree to support a care plan if there are serious concerns that it will not meet an individual’s needs or if it places an individual in immediate and identifiable danger.

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>How well the care plan meets the client’s needs?</td>
<td></td>
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<tr>
<td>What is the level of risk involved?</td>
<td></td>
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<tr>
<td>What procedure will be set by this decision?</td>
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</table>

**Positive Approaches to Risk:** The most effective organizations are those with good systems in place to support positive approaches to risk rather than defensive ones.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>What can be done (with reason and within the law) to best support the client?</td>
<td></td>
</tr>
<tr>
<td>Could things be done in a different way which might reduce risks?</td>
<td></td>
</tr>
<tr>
<td>What are the risks of not supporting the client?</td>
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</tr>
</tbody>
</table>

**Empowerment:** Enabling people to exercise choice and control over those lives, and therefore the management of risk, is central to achieving better outcomes for people.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the expected outcome?</td>
<td></td>
</tr>
<tr>
<td>What goals does the client want to achieve?</td>
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</tr>
</tbody>
</table>

**Shared Decision-Making:** Open and transparent decisions supported by senior leadership and shared across the care team shift from risk aversion to supported decision-making.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>What goals does the health care team want to achieve? Are there differences of opinion?</td>
<td></td>
</tr>
<tr>
<td>What would help resolve this case?</td>
<td></td>
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</tbody>
</table>
**Step 3: Explore Options**

Explore options and consider their strengths and weaknesses
Brainstorm and discuss options either alone or with peers. Be creative and use your imagination. Consider a compromise. Predict the outcomes for each alternative. Does the alternative fit with the client/family values? Question whether the alternative meets the company policies, directives and regulations.

<table>
<thead>
<tr>
<th>Option</th>
<th>Strengths</th>
<th>Weaknesses</th>
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<tbody>
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</table>
Step 4: Act on Your Decision and Evaluate

Develop an action plan (The actual plan should be documented in the chart.) Given all the information that you have, choose the best option available. Develop an action plan. Present your suggested alternative and action plan to the client and those involved in such a way that it allows them to accept the plan. Re-examine the alternatives if other factors come to light, if the situation changes, or if an agreement cannot be reached. Determine when to evaluate the plan. Document and communicate the plan.

Evaluate the plan
What was the outcome of the plan? Are changes necessary? Document the evaluation.

Self-evaluate your decision
How do you feel about the decision and the outcome? What would you do differently next time? What would you do the same? What have you learned about yourself? What have you learned about this decision-making process?
<table>
<thead>
<tr>
<th>Questions to Consider</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Is the client</strong> <strong>capable</strong> to make this decision?</td>
</tr>
<tr>
<td><strong>What are the likely consequences, benefits, risks</strong> of the client’s choice?</td>
</tr>
<tr>
<td><strong>What are the</strong> <strong>risks</strong> to client if service is removed?</td>
</tr>
<tr>
<td><strong>How will the client’s needs be met?</strong></td>
</tr>
<tr>
<td><strong>Has what the client</strong> <strong>wants</strong> been considered? What are the client’s goals?</td>
</tr>
<tr>
<td><strong>What are the</strong> <strong>options</strong> and <strong>expected outcomes</strong>? Could things be done</td>
</tr>
<tr>
<td><strong>What and who might help mitigate this case?</strong></td>
</tr>
<tr>
<td><strong>What precedents might help make a decision?</strong></td>
</tr>
<tr>
<td><strong>What precedent might be set?</strong></td>
</tr>
</tbody>
</table>
Risk Support Plan

- Summary of client’s current health status
- Support plan recommendations
- Risks (general and specific to not following recommendations)
- Staff and client signatures

Toronto Central CCAC Risk Support Plan Template

Summary of client’s current health status:

- 
- 
- 

Support plan recommendations:

- 
- 
- 

Risks (both general risks and those specific to not following above recommendations):

- 
- 
- 

I have read and understand the above information. I acknowledge that I am choosing to live at risk at my own free will, against the recommendations of my care team. I accept all associated risks resulting from this decision, including possible health complications. I understand that I can reverse this decision at any time and receive support from my care team to mitigate risks.

Client: (First name, last name)  Signature: ______________________  Date: ______________________

Staff: (First name, last name)  Signature: ______________________  Date: ______________________
Mrs. Jones is 82 and lives alone in a bungalow with her dog. Her CCAC case manager and service providers are very concerned for her safety. She has memory problems, poor vision, and an unstable gait. She sometimes forgets to turn the stove off. Her home is filthy, but she insists she’s fine and has always lived this way.

To make matters worse, she often drinks alcohol and refuses to stop saying, “so what if I fall and die, at least I’ll be in my own home!” When she drinks, she verbally harasses service providers.

Mrs. Jones was recently assessed as capable. Her case manager thinks we should respect her wishes to remain at home, but service providers don’t want to return and Mrs. Jones’ daughter is pressuring them to send her to Long-Term Care.
“How can we help someone when they choose to live at risk and won’t help themselves? Mrs. Jones needs our services, but she harasses the providers that are trying to help her! I want Mrs. Jones to be safe and well cared for, but she is capable, and we need to respect her wishes. I’m just not sure that leads to the best outcome.”

“I can’t take this anymore. I know Mrs. Jones needs my help, but every time I show up to see her, she is drinking and by the end of the visit she is screaming at me to get out of her house. Not to mention how dirty it is in there! I don’t want to go back and neither does anyone else that’s been there. They’ll just have to find someone else.”
Case analysis

Identify facts and risks

- Client at significant risk because of her drinking, memory loss, and state of her home.
- Service providers at potential risk – hazards in the home, verbal abuse.

Determine key principles

- Because of memory loss, client’s capacity was recently assessed. Client found capable. No reason to suspect client is now incapable.
- Client’s daughter is involved, but might not be appropriate substitute decision-making when client becomes incapable.

Explore options and develop Risk Support Plan

- Case conference to review the situation.
- Using Community Ethics Toolkit and Policy Tools, team reviews risks and options.
- Client has the right to decide where and how she lives. CCAC services will help to mitigate some risks.
- Continuing services without a plan puts providers at risk. Withdrawing services because of risks put Mrs. Jones at even greater risk.
What we did

• Client is capable so we:
  – Discussed options, risks, and likely consequences, and client’s future wishes.
  – Encouraged her to discuss these with SDM and/or daughter

• Risk Support Plan included:
  – Unplugging stove
  – Removing throw rugs
  – Assisting in housecleaning
  – Purchase of Life Line
  – Intensive Case Management from CCAC
  – Providers to visit in morning. If client has been or is drinking, service providers will leave.

• Document and upload plan into Client Record. Activate risk flag.
• Bi-weekly home visits to re-assess situation and plan.
• Re-evaluate plan as needed.
Value of the policy

- Organizational commitment to supporting client choice
- Common direction and tools
- Best-practice ethical decision-making framework
- Rigorous assessment of risks and options
- Team-based consultative model
- Client-focused plans
- Risk mitigation for client, staff and organization
Future work

- Implement policy across Toronto Central CCAC
- Communicate policy initiative to service providers and health care and community support partners
- Track and monitor clients choosing to live at risk
- Evaluate outcomes and impact
- Build capacity in hospital, community, and support services sectors to address these challenging cases
Conclusion

- These are challenging and complex cases
- Require an ethical and legal framework as a basis for these discussions
- Decision-making should be collaborative and not adversarial
- The stakes can be very high
- Even more difficult with the added challenge of the incapable client and navigating the hierarchy of substitute decision-makers
Thank You!
Questions

For more information or for copies of policy and tools, please contact:

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Toronto Central CCAC
kim.ibarra@toronto.ccac-ont.ca

Community Ethics Toolkit available from:
www.communityethicsnetwork.ca