

Vulnerable Adults What are the Safety Checks?

Discussion Paper

October 2007

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VULNERABLE ADULTS – WHAT ARE THE SAFETY CHECKS?

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EXECUTIVE SUMMARY:

"Society has an obligation to afford its members, regardless of individual abilities or conditions, the opportunity to have security and the necessities of life".¹

The purpose of the discussion paper is to create increased awareness and discussion about the issues relating to safety mechanisms for adults who are vulnerable to abuse due to severe / multiple disabilities and potential life circumstances.

Over the past 50 years there have been very significant gains made in the life opportunities for people with disabilities. With the closures of institutions and increased focus on the rights and freedoms of individuals as equal citizens, there has also come increased community engagement, increased recognition of the value of and contributions of individuals with disabilities, and increased safety mechanisms available via informal supports of family and friends. However, the statistics of abuse of adults with disabilities continues to indicate an alarming rate of abuse even though abuse is commonly considered being highly underreported, thus indicating an even higher rate of potential abuse. Equally alarming is that there appears to be a relative limited awareness of the risks of abuse, the frequent barriers associated with disclosure, and of the course of action a family, community member, or service provider should take when concerned about the abuse of an adult who is vulnerable who is unable to advocate for themselves.

A brief overview of various formal and informal avenues of potential safeguarding for vulnerable adults is provided as well as a brief snapshot of how other provinces are responding to this issue. It is essential that a balanced approach be considered. **In the attempt to provide protection of vulnerable individuals, great care must be taken to ensure that the possible attempts to help do not infringe on individual's rights under the Canadian Charter of Rights and Freedoms.**

This discussion paper raises far more questions than it does answers. However, it is in these questions and the working through of discussions, that some answers can be found which will both provide an increased ability to provide protection when needed for adults who are vulnerable and at the same time allow for and encourage the continued autonomy, rights, and freedoms that individuals with disabilities have worked so hard at achieving over the years. Throughout all of the discussions it will be important that focus be kept on a balance of (1) Informal Supports Emphasis, (2) Public and Service Sector Education and Awareness, and (3) Systems Improvements if and only if required.

While some of the issues raised will require careful thought and consultation, it is important that we not avoid the task for reasons of not immediately knowing how to find the balance of protection and rights. Many adults with significant disabilities are being abused and neglected and some have died. We need to struggle with the issues to find this balance. We must not avoid the hard work for fear of the issues it raises, even if some of these issues may involve discussions around topics which are unpopular due to "political correctness". With careful thought and discussion a balanced approach can be found. The individuals who are at risk deserve the best we can bring to them in discussion, thought, consultation, and support.

¹ Nova Scotia Health. Adult Protection Act Discussion Paper. Pg 3.

PURPOSE:

The purpose of this paper is to create awareness and discussion about the issues relating to safety mechanisms for vulnerable adults in Ontario. It is important to note that this paper is not meant to critique current systems or individuals. The sole purpose is to generate an honest transparent discussion amongst those who care about adults who have severe disabilities and have difficulty advocating for themselves. The aim is to increase awareness of the risks these individuals face and as such continue to improve the safety checks for vulnerable adults both at a system level as well as at an informal community level. It is expected that this paper may raise some tough questions that may cause discomfort. It is hoped that we can collectively rise to the challenge of having open frank discussions to improve safety checks for adults with significant disabilities in our communities. The individuals who are vulnerable deserve the best we can bring to them to ensure we collectively are supporting them in the best ways we know how.

CONTEXT:

This paper has arisen out of a number of recent situations where adults with significant disabilities have been at risk of abuse and/or death and as such the need for increased awareness and discussion around these issues. For the most part, the issues raised are ones relating to those who have significant developmental disabilities which impacts on their ability to communicate and advocate for themselves, oftentimes with severe cognitive impairments and multiple disabilities. These situations have caused many to ask questions as to the process for raising safety concerns for vulnerable adults. What has become apparent as a result of these questions is perhaps equally alarming. In raising questions about how one can report and raise concerns for an individual who cannot advocate for themselves, it has become apparent that there is very little awareness of the issues, the supports available, what is required, or who to call. This lack of awareness and understanding of proper processes is at all levels of our community and service system, from families, front line workers, managers, senior management, police, and government officials.

The following provides brief examples of situations where concerns have been present and yet repeatedly there is not an awareness or clarity of how we should be responding. These examples below are ones which have come to the writer's attention within a span of 6 months within a very small scope, thus providing an indication of how wide span the problem may be.

- Family with an adult with significant disabilities, whose parents are deceased and the family withdraw from the support services, becoming totally withdrawn from all support services at a time of family stress and need. While there is no reason to believe the person is at risk, there are concerns about the family's coping ability and as such ability to support the young adult without support.
- Family with a young man with significant disabilities where the mother kills herself and following this the father withdraws from all support services including informal supports such as previously very active involvement in an informal parent support group
- Family with a son with autism and significant behavioural challenges is having difficulty coping to the point where they as a last resort, tie the young man to a chair.
- A young woman with autism is kept in the basement and not provided with adequate personal care support, supervision, or food and drink, eventually resulting in her death.

- A young woman with developmental disabilities and mental health disabilities finds herself in a relationship with a gentleman who is clearly abusing her financially, sexually, and emotionally. The gentleman is very controlling and the young woman's disabilities are such that she is not able to adequately understand the risk, the injustice, and that there are ways to leave the relationship.
- A young man with autism is locked in his bedroom by his caregivers.
- A gentleman with significant developmental disability is taken to a hotel by his caregivers who sexually abuse him.
- A young man with autism is involved in bestiality. He is meeting people on the internet and going to their homes to have sex with their animals. Due to his autism he does not understand the risks involved in going into the homes of people who does not know. When agency staff asked a community police liaison for guidance, he indicated that agency staff could call the Humane Society to report the abuse on the dogs. However, legally there was nothing that could be done about the risks for the young man with autism because he was of consenting age. While the agency is trying to educate the young man, it is a concern that he is putting himself at great risk with the lifestyle and people he is meeting up with who are previously unknown to him.
- A young man lives with his sister who is using his ODSP (Ontario Disability Support Program) funding to fund her own use of alcohol and illicit drugs and has the gentlemen stay home to provide free household chore work. A family friend tries to talk with the sister to no avail and then tries to report the situation to the ODSP office but is told there is nothing that can be done.

WHAT ARE THE ISSUES?

The statistics on abuse of people with disabilities is alarming as are the barriers individuals face in the disclosing of abuse. Studies indicate that of women with disabilities surveyed, 73% had been victims of violence and adults with intellectual disability are 2.9 times more likely to be victims of a physical assault and 10.7 times more likely to be victims of sexual assault than adults without a disability.² One must also remember that most abuse goes unreported and as such these alarming statistics on the rate of abuse must be taken with the consideration that the actual rate is much higher.

Abuse most often occurs at the hands of someone who the individual knows well such as caregiver, service providers, or family. Vulnerability is increased for individuals with disabilities both directly due to the nature of the disability (ie. limited communication and/or ability to fend off the abuse) and indirectly (ie. as a result of societal views of people with disabilities). Types of abuse include; physical abuse, emotional abuse, sexual abuse, financial abuse, neglect, systematic abuse, and institutional abuse. Quite frequently abuse occurs when there is an imbalance of power, albeit not necessarily intended (ie. caregiver and recipient of support). Some of the barriers to disclosure are fear, economic dependence, isolation, limited access to alternative support, communication challenges, and the reality that due to their disability and often accompanying communication challenges individuals with disabilities are sometimes not viewed as reliable witnesses in courts.

² Sobsey, D., Wells, D., Lucardie, R., & Mansell, S. Violence and Disability: An Annotated Bibliography, 1995

The issues relating to abuse prevention and protection are multifaceted but for the sake of this document we will be examining the informal and formal safety nets for vulnerable adults. **It is important to note that a balance is required. These issues must be considered within the context that the individuals are adults and absolutely deserve the respect, dignity, autonomy, and rights that come along with being full citizens in our society.**

While we want to be sure to be doing “due diligence”, we also must be careful to whenever possible maintain individual’s rights and freedoms. It will be a delicate balance to look at these issues and possible improvements and yet ensure we are not violating these inherent rights and respect afforded to all citizens in our society. One does not want to cross the line into being overbearing or “big brotherish” in the attempt to provide protection. **As such it is absolutely critical that informal safety nets also be considered, as when the rubber hits the road it is often these informal networks of friends, family, neighbours, and community members that provide the real safety net for individuals, as is the case with all of us.**

One comparison to examine, albeit one with many differences, is that of safety nets for children in Ontario. If a child were to be locked in a room, tied to a chair, or to be involved in going to a stranger’s house for sexuality reasons, it is clear that there would be uproar of concern. Immediately the local Children’s Aid Society would be called and would intervene for each of these reasons. Courts would intervene when required. Additionally, family and friends would rally around the child to provide safety, love, care, and support. At a societal level, if the situation is public knowledge, it is quite likely that it would result in media attention.

While a horrible comparison, it is also telling to note the chronological history of “protection” in our society. World wide, the history of “protection” involves first the protection of animals and then the protection of children.

- In 1833 the first Society for the Prevention of Cruelty to Animals was formed in England
- Between 1866 and 1880, the Society for the Prevention of Cruelty to Animals was founded, with Illinois being one of the first states to found this society.
- In 1853 The Children’s Aid Society was started in the United States by Charles Loring Brace in New York City.

In Canada the history is similar.

- In 1869 the first Society for the Prevention of Cruelty to Animals was formed in Montreal
- In 1887 the Toronto Humane Society was founded with a mandate towards the protection of both animals and children with “its mission to be broadly educational – better laws, better methods and development of the humane spirit in all affairs of life”³
- In 1891 the first Children’s Aid Society in Ontario was founded by John J. Kelso.
- In 1893 the Act for the Prevention of Cruelty to and Better Protection of Children was passed.
- Currently in Ontario the Child and Family Services Act provides for the protection and welfare of children who are at risk of abuse or neglect.

Very recently there has also been an increased focus on the issue of elder abuse. In recent years there has been a great deal of work to increase awareness of elder abuse along with development of mechanisms to deal with this issue. In Ontario there exists the ONPEA (Ontario Network for the Prevention of Elder Abuse), which works in partnership with the Ministry of the Attorney General,

³ Kelso, John. Early History of the Humane and Children’s Aid Movement in Ontario, 1911.

Ontario Victim Services Secretariat, and the Ontario Seniors' Secretariat surrounding The Ontario Strategy to Combat Elder Abuse. The Canadian Network for the Prevention of Elder Abuse outlines an extremely thorough prevention and education strategy being used to protect older adults who are vulnerable.⁴ Today throughout Ontario in all Retirement and Long Term Care Homes, there is a highly visible focus on the prevention of elder abuse. Each home has openly displayed public awareness posters which also highlight a Victims Hotline which can be called whenever a staff person, visitor, or elder is concerned about potential abuse.

FINDING THE BALANCE: WHY ARE ADULTS WITH SIGNIFICANT DISABILITIES AT INCREASED RISK & WHAT IS HELPFUL?

The answer to the question of why adults with significant disabilities are at increased risk of abuse and neglect is one which is not popular and will cause discomfort for most people. However, as the purpose of this paper is to take a hard honest look at the issues with an aim for potential improvements, then it is also necessary that we honestly look at the root causes of the issues. These issues can generally be categorized into the areas of (1) societal trends which place all individuals who are vulnerable at increased risk, and (2) life circumstances which individuals with significant developmental disabilities are more prone to which also increase their vulnerabilities.

Some societal trends, while initially seen as positive in nature, over time can also have an impact of increasing the vulnerability of some people with significant disabilities. As our society is increasingly individualistic and materialistic and focused on these areas as defining success, there is less value placed on the more inherent gifts those with disabilities bring to humanity; such as gentleness, friendship, and often simple but profound wisdom. As a society and as a disability advocacy group, a great deal of emphasis has been placed on the value of independence and rights over the past 50 years. Clearly this has been important and a powerful movement which has resulted in people having increased access to housing, education, employment, and freedom of speech. The benefits of this movement are significant and not to be discounted. However, in some situations it has also resulted in people being afraid to speak up in concern for someone who is clearly making poor decisions (or is not involved in the decision making at all) having extremely negative repercussions on their welfare and safety. Sometimes we have forgotten how to offer help in the name of wanting to respect another's rights (and assumed wishes without having ever asked them). Sadly, a new terminology has cropped up titled "to die with one's rights one". Focus on radical independence has sometimes caused great isolation and loneliness. Radical independence also has us forgetting that we ALL are interdependent on each other, regardless of ability or disability. Often as a society we become muddled as how to tease out when independence is good and when we need to look to our families and neighbours to grow together. Given these societal trends it has now become unpopular to either ask for help or to offer help, for fear of interfering with independence or offending someone's rights.

People with significant developmental disabilities are generally more prone to some life circumstances which increase their vulnerabilities. Additional vulnerabilities that adults with significant developmental disabilities may face are:

- Dual diagnosis of having a mental health condition in addition to a developmental disability
- Experiencing physical poverty (limited work options / low rate of disability pensions / higher rate of medical and care assistance required etc.)

⁴ Canadian Network for the Prevention of Elder Abuse. <http://www.cnpea.ca/prevention.htm>.

- Accompanying difficulties in communication and as such decreased ability in advocating for oneself
- Social isolation particularly over a lifetime
- Higher risk of being prescribed psychotropic medications (often in higher doses and in combination) and suffering the often serious side effects of these
- Some disabilities, such as autism, by nature involve difficulties in social interactions and as such place the person at increased risk due to a higher level of behaviours that others may not understand and inaccurately view as deliberate or provoking in nature.
- Decreased education and as such less resources to draw on in decision making

It is also noted that when a person has a significant disability and also experiences another of these life circumstances, the chances of additional situations listed above will be that much higher, thus the vulnerabilities stacking on top of each other.⁵

General “best practices” to increase safety are supports which assist individuals to:

1. gain communication skills to have a clear voice in their wishes and to have the ability to speak up when they are not being treated fairly
2. learning to do as much as possible for oneself, thus decreasing dependency on others particularly in areas of personal care
3. building strong relationships with family and extended family
4. building relationships with a network of friends who care about the person and will speak up for them if required
5. being involved in the community alongside others who get to know the individual and build relationships
6. having a valued role in society where they are accepted as a valued contributing member of society
7. supported in living arrangements that are not isolating
8. living in a home where the individual has some aspect of tenure
9. being informed about rights to safety, supports, and legal assistance
10. having some autonomy over the direction of their supports and finances
11. where required the use of a “supported decision making” model whereby the individual is assisted in decisions with the support of people whom the individual has chosen to assist them in this area

WHAT IS THE CURRENT SITUATION IN ONTARIO?

Progress Made and Areas to Improve On:

One would be remiss if we did not acknowledge the tremendous improvements that have occurred over the years in the lives of individuals with disabilities. Clearly as a society we have made improvements from the days when individuals with developmental disabilities were institutionalized often in rural settings far from the sight and protection of family and friends. Families are generally offered an increased level of support in the family home than would have been available in past generations. Individuals with disabilities are more accepted as contributing members of society and for the most part

⁵ Emerson, Eric, Dr. “The Wider Picture: The Importance of Taking a ‘Public Health Perspective on the Mental Health of People with Intellectual Disabilities’”. March 2007.

go to school, participate in social and recreation activities, and work alongside their peers without disabilities. Individuals with disabilities are recognized as having the same rights, responsibilities, and freedoms as do all members of our society. It is more widely accepted that we have a duty to make the necessary accommodations for individuals with disabilities to allow them the full range of freedoms and community involvement that are available to all citizens. Most importantly, individuals with disabilities are generally more often accurately viewed as valued contributing citizens. **These gains are very significant as with increased recognition of the value all individuals have regardless of abilities and the increased community presence and engagement, comes increased safety for all of us individually and collectively.**

However all that said, currently there continues to be limited awareness of the issues of risk to adults with significant disabilities. It is true that for the most part families, caregivers, and service providers provide very loving, compassionate, and competent support and guidance with individuals with disabilities. However, this does not dispel the reality that there are increased risks for adults with significant disabilities and that some situations do arise where the individuals' caregivers are not able to provide the required level of support either due to abuse, neglect, basic inability or lack of personal or physical resources. To ignore this reality would be akin to saying that Children's Aid Societies are not required because most parents and childcare providers provide competent care.

There appears to be two primary issues relating to the current situation in Ontario, perhaps being closely intertwined. One issue is that of **awareness of the risks and prevalence of abuse**. The other issue is the **limited awareness of and understanding of what one can and is obligated to do when individuals with significant disabilities are at risk**, of serious harm. It is important that both of these realities be examined and addressed in order to move forward in potential improvements in the service system. **Beyond this, it is critical that the issues relating to informal safety nets be also examined and addressed.** Both formal and informal supports will be discussed in light of the issues of (1) awareness of risks, and (2) understandings of what one can do when a person is at risk.

Formal Systems of Protection: Awareness of Risks & Understanding of What to Do

While it is true that staff and management in the developmental services sector are generally caring people who are concerned about the welfare of those we support, when faced repeatedly with very difficult situations with limited resources, often people become accustomed to the challenges many individuals and families face. The result of this repeated barrage of very difficult situations is that often situations which would normally be alarming are at risk of now being seen as a new norm. The heightened awareness of the scarcity of resources is often so prevalent that workers in the field, while recognizing the risks, are limited in their ability to respond. There is a risk of a sense of apathy as workers are faced repeatedly with difficult situations yet the limitation of resources often becomes a barrier in responding. Examples of this are situations where staff and senior managers have been aware of situations of desperation and high risk and yet have not appeared to react with the urgency or seriousness in the manner one would if the individual were a child. This is despite the fact that some adults with a severe disability are at times more vulnerable than a child, due to limited communication and mobility.

Similarly, it can be a very confusing system in identifying what one should do when there is a concern for the welfare of an adult with a significant disability. There does not appear to be one consistent method of accessing assistance when concerned for the welfare of an adult who is vulnerable and unable to advocate for themselves.

Theoretically the safety net process is the same for those with a disability as it is for all of us. However, given the added vulnerabilities of people with disabilities, one must consider that the status quo may not always work for this population. Current potential avenues of asking for assistance when concerned about an adult who is vulnerable in Ontario are listed below. However, as one looks closer, most of these have very little mandate or resources to provide actual concrete assistance in serious and urgent situations, particularly if the concern relates to the care from a primary caregiver or substitute decision maker.

Police: If a situation is of crisis nature and the abuse is obvious, then local police can intervene. However if the abuse or neglect is not obvious, if the person with a disability is not able to communicate the abuse or neglect, and if the abuse/neglect is not witnessed by another person able to clearly advocate on the individual's behalf, the police are limited in their capacity to respond. Many times the individual with a significant disability has trouble in communicating the abuse, even if they had the confidence and advocacy skills to do so. Also, often people with a disability are not viewed as credible witnesses by the court systems. Isolation is often a key factor in others not seeing the abuse and/or not being willing to speak up. As such, it is only in rare and extreme situations where the police are able to intervene. Sadly, this at times happens when it is too late when a death has occurred.

Office of the Public Guardian and Trustee: The OPGT is perhaps the closest mechanism within the service system which has the authority to conduct investigations into situations where there is a concern for the welfare of a vulnerable adult. "The OPGT will conduct an investigation when it receives information that an individual may be incapable and at risk of suffering serious financial or personal harm and no alternative solution is available. An investigation may result in the OPGT asking the court for permission to make decisions on the person's behalf on a temporary basis."⁶ However, this ability of the OPGT to intervene is not a well known fact either in the public or within the developmental services sector. Very few in the public would even be aware of the OPGT in order to know to call them. Also surprisingly, very few workers and even managers in the developmental services sector are aware of this mandate of the OPGT and as such do not know to call this office when faced with difficult situations needing guidance.

Substitute Decisions Act: The Substitute Decisions Act is the Ontario legislation which governs how decisions are made when "someone is not mentally capable of making certain decisions about their own property or personal care. The SDA describes how a decision-maker may be appointed for a mentally incapable person. The procedures to be followed depend on the type of decision the person is unable to make. One set of procedures and rules applies when a person is incapable of making decisions about their property or finances; another applies if the incapacity relates to personal matters such as health care or housing."⁷

⁶ The Office of the Public Guardian and Trustee. The Role of the Public Guardian and Trustee, 2005.

⁷ The Office of the Public Guardian and Trustee. A Guide to the Substitute Decisions Act, 2000.

Health Care Consent Act: The Health Care Consent Act provides for the decision making hierarchy in regards to medical decision making when an individual is deemed to be not capable of making that specific decision. The definition of capacity is a legal definition, not a clinical definition, and is not based on a diagnosis. According to the Health Care Consent Act a person is deemed capable with respect to treatment “if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision”.⁸ A person may be capable of making a decision about one treatment but not another. A person may be capable of making a decision about a treatment at one time but be deemed to be incapable of making the same decision at a different time. It all depends on the complexity of the particular treatment and the person’s level of capacity at the time.⁹ Under the HCCS the hierarchy for substitute decision makers occurs as follows; guardian appointed by court, person with a “power of attorney for personal care”, representative appointed by the Consent and Capacity Board, spouse or partner, child or parent, parent who has access rights (if person is a minor), brother or sister, other relative, the OPGT.

Adult Protective Services Workers: Adult Protective Services Workers (APSW) are often employed by Transfer Payment Agencies such as a Family Services / Family Counseling Agency or a Community Living Association. While the name for these workers would imply that they have a mandate to provide protective services, currently there is not a legal mandate or obligation associated with these roles in Ontario. When the APSW Program was first initiated the goal was that these workers would have the ability to intervene in situations where adults who are vulnerable were at risk or being abused / neglected. Throughout the years there has continued to be some interest and advocacy in pursuing this mandate for APSWs but without success. Currently Adult Protective Services Workers perform excellent key work in providing community support and informal advocacy for adults with disabilities, most often with adults who are residing on their own in the community. For many adults these APSW workers are key links in their ability to live independently in the community. Unfortunately they do not have the mandate or legal ability to either investigate or intervene when the welfare of a vulnerable adult is in question, where the adult is not able to ask for the help themselves or where the caregiver is restricting access.

Transfer Payment Agencies funded by the Ministry of Community and Social Services: Most Transfer Payment Agencies (TPAs) funded by the Ministry of Community and Social Services provide some elements of individual and group advocacy. However, these agencies do not have any legal mandates and are voluntary services. As such, if a TPA raises concerns about the safety or welfare of an adult, there is the risk that the individual’s caregiver may withdraw them from services. The adult is legally his/her own entity and not under any guardianship limitations, unless having gone through a court process identifying incapacity and having a guardian appointed. However, many individuals with disabilities are strongly influenced by the wishes of others, particularly of family members and support providers whom a sense of loyalty is often felt.

Office of Child and Family Services Advocacy: The Office of the Child and Family Services Advocacy provides advocacy for children and youth in the province of Ontario, with recent movement to establish a more independent provincial advocacy role as an officer of the legislature, removed from the previous role of being directly funded by the Ministry of Children and Youth Services. While this advocacy

⁸ Health Care Consent Act – Section 4-1, 1996.

⁹ Office of the Public Guardian and Trustee. Making Substitute Health Care Decisions. Pg. 5

office performs excellent work, it is restricted in mandate to serving children and youth, thus limiting its ability to intervene in the care of an adult.

ARCH Disability Law Centre: The ARCH Disability Law Centre provides a great deal of legal advocacy and education regarding the rights and welfare of individuals with disabilities. ARCH does provide some direct legal advocacy but primarily in situations which are precedent setting.

Bill 230 – Adult Protection Bill¹⁰: In December 2002 Rick Bartolucci, MPP of Sudbury, brought forward the Private Members Bill 230 titled the Adult Protection Bill to the Legislative Assembly of Ontario in it's first reading. The Bill would provide for the appointment of the Director of the Adult Protection Office to provide protection for abused and neglected adults who are unable to protect themselves. Additionally the bill would provide for mandatory reporting of adult abuse or neglect. This bill did not move forward.

Community Based Networks for Protection of Elders: Many communities have developed networks to provide for the reporting of and response to abuse of people who are elderly. Theoretically if an individual with a developmental disability was an elder, they would be able to receive support through these networks.

Informal Systems of Protection: Awareness of Risks & Understanding of What to Do

Ironically, it is usually the informal supports that are the most effective in providing more effective safeguards for individuals who are vulnerable. Informal supports are identified as those whereby the support relationships are freely provided and more based on mutual relationships. Usually these informal supports are based on freely given unpaid mutual relationships and/or connections with unpaid community groups of mutual interest. Examples of informal supports are; family, friends, faith communities, neighbours, peer support, and acquaintances. **Informal supports, when they are present, are often most effective as these are the people who care deeply about the person with the disability and as such have a vested interest in watching out for their wellbeing as most friends and family do.**

It is also quite often the informal supports of family members who are most acutely attuned to the potential risks their vulnerable family member faces. When parents are asked what their greatest fears are for their child with a disability, the consistent response of the top three concerns are:

1. Fear of abuse – emotional, physical, neglect, financial
2. Fear of sexual abuse
3. What happens to their child after they as the parent die? / Who will look out for their family member when they are gone?

While some parents have been able to join with other parent groups or community groups to develop creative and practical responses to these fears and risks, many others become overwhelmed with the concerns and place reassurances of safety in service systems. Unfortunately, compared to other types of supports, there is relatively very little assistance available to families to assist them in the difficult, time

¹⁰ Bartolucci, Rick, Bill 230 Adult Protection Bill. Legislative Assembly of Ontario, Dec. 11, 2002.

consuming, and often lifelong work of building informal supports around their son or daughter. There are a few services which attempt to do this but these resources are relatively scarce, often time limited, and some require family fees that not all families can afford. These are approaches which systematically focus on building in desired informal supports as identified by the individual and their family. Examples of service supports which attempt to build on informal supports are:

- Wraparound Approach
- Circles of Support / Support Circles
- Networks of Support
- Extend A Family
- PLAN (Planned Life Advocacy Network in British Columbia)
- Supportive Care in the Congregation
- Citizen Advocacy
- Supported Decision Making

The aim of the building in of these informal supports is to assist the person in increasing their quality of life through relationships and active community involvement and to build in safeguards to protect people in the natural ways that we all receive support and protection from those who love us. **Time and time again, it is noted that people are at increased risk for abuse as their level of isolation increases.** As more people who care know the person well and see the person on a regular basis, the potential for abuse decreases. This is particularly true if the unpaid relationships are with people who themselves have strong advocacy skills and a strong standing in society. The Citizen Advocacy movement deliberately recruits for citizen advocates who are well known socially to stand beside those who are the most vulnerable and most at risk. While perhaps a sad statement on our societal values, it is a truth that people are more vulnerable if they do not have any family or friends who have the resources (ie. People connections or financial) to help advocate.

Informal Supports – Extremely Valuable but a Growing Scarcity:

However, the increasing limitations of informal supports much be recognized. Sadly, as our society and culture becomes increasingly individualistic, materialistic, and fast paced, the availability of and effectiveness of informal supports is decreasing rapidly. While families with children with disabilities may be at increased risk to the negative effects of societal trends, one must recognize that the level of commitment between individuals is also often much lower than it was in previous generations. Divorce and family breakup rates are at an all time high. Abuse, whether it be sexual, physical, or emotional also is at the highest rate in recent years. Most two parent families require both parents to work to meet financial obligations of our lifestyles today. There is a higher rate of single parent families than ever before. Geographically we are living in cities rather than smaller more tight knit communities as was in the past. There simply is not the level of neighbourly connections and shared support that occurred in past generations in smaller communities where neighbours relied on each other for practical assistance and social support.

The implications of these societal trends are significant when considering the safety of vulnerable adults. The implications of these trends on informal supports can in some situations result in:

- Adults with disabilities being less connected with their neighbours than in past generations potentially resulting in increased isolation.
- With the increased focus on technology, there are fewer avenues for employment in traditional labour fields (ie. Agriculture, carpentry, etc.) which require less academics. As a result, fewer

adults with disabilities are engaged in regular work alongside co-workers who would come to know them and build relationships and as such potentially experience increased isolation.

- More families with children & adult children with disabilities are led by a single parent who is also working. This potentially increases the risk of stress due to the multiple demands on the single parent and the increased isolation for both the parent and the child with a disability, due to less time being available for connecting with local community members.
- As couples are having less children, families are smaller, thus decreasing the amount of sibling support (and support from the nieces and nephews) than in past years.
- As our society is more mobile, families are more likely to be spread out across provinces and countries, thus decreasing the ability to stay in regular close direct contact with the adult with the disability (who often requires extra support to travel etc.), thus potentially resulting in increased isolation compared to past generations.

As such, while it is critical to examine the issues in light of the need to build on informal supports, one needs to recognize that our societal trends are potentially resulting in individuals and families being more isolated from each other and from their communities as a whole. As this level of isolation increases, it is more difficult to identify the informal supports which may be of assistance in any given situation but also increasingly difficult to engage these informal supports in manners that involve longer term commitments and safety. Therefore, while it is important to continue to emphasize and invest in informal supports at an increased level, it is also critical to consider the informal supports as one piece of the larger puzzle.

WHAT ARE OTHER COMMUNITIES DOING?

Communities across Canada and the USA appear to be taking a variety of approaches in addressing this need of finding a balance of safeguards for adults with disabilities who may be at increased risk to abuse. Nova Scotia, New Brunswick, Prince Edward Island, and Newfoundland each have special adult protection laws.¹¹ Some of these laws have mandatory reporting, others rely on voluntary reporting. While these protection laws are helpful in some situations, there are also many criticisms and potential challenges raised regarding such protection laws;

- Adult protection laws are limited in scope
- Adult protection laws can be paternalistic
- Some adult protection laws may lack procedural safeguards (criticized as taking away people's rights without due process)
- Adult guardianship laws often strip incapable people of all their rights (as such both intrusive and stigmatizing)
- Often there are inadequate resources at all levels¹²

These are all very valid concerns and must be taken into consideration. **In the attempt to provide protection of vulnerable individuals, great care must be taken to ensure that the possible attempts to help do not infringe on individual's rights under the Canadian Charter of Rights and Freedoms. This simply reinforces the need to find that careful balance both systematically as well as on an individual support level.**

¹¹ Canadian Network for the Prevention of Elder Abuse, Canadian Laws on Abuse and Neglect, http://www.cnpea.ca/canadian_laws_on_abuse_and_negle.htm , October 8, 2007.

¹² Canadian Network for the Prevention of Elder Abuse, Canadian Laws on Abuse and Neglect, http://www.cnpea.ca/canadian_laws_on_abuse_and_negle.htm , October 8, 2007.

A CHALLENGE – WHAT CAN BE DONE AS NEXT STEPS?

Understandably this discussion paper raises far more questions than it does answers. However, it is in these questions and the working through of discussions, that some answers can be found which will both provide an increased ability to provide protection when needed for adults who are vulnerable and at the same time allow for and encourage the continued autonomy, rights, and freedoms that individuals with disabilities have worked so hard at achieving over the years. It is recommended that priority focus be given to (1) increasing awareness of abuse of adults who are vulnerable due to severe disability and unable to advocate for themselves and the processes in Ontario to report abuse, and (2) building on supports and practices which are deemed to be preventative in nature.

It is recommended that a very thorough and serious examination occur in the area of best practices relating to the development and enhancing of informal supports. As discussed, it is in these informal supports of friends/family/community acquaintances, that true increased safety and community involvement can be found. There are many groups and models of helping individuals increasing these informal supports which can be more thoroughly examined for potential best practices and methods of building on these ideas and models.

If it is determined that the PGTO is the formal systems mechanism which should be contacted when concerned about abuse of an individual who is vulnerable and whom has difficulty advocating for themselves, then consideration should be given to finding ways to increase the public and service system awareness of this mechanism.

Consideration may be given to the bringing together of key stakeholders for facilitated discussion with clear mandate of identifying next steps which focus on:

- a) Identifying and confirming the current systems processes for protection of vulnerable adults
- b) Identifying current legislation and agency / government mandates which cover the protection of vulnerable adults
- c) If adequate current legislations and/or mandates are in place, explore the possibilities of increasing community and service worker awareness of the options available when concerned about the welfare of a vulnerable adult.
- d) If required (and only if required), initial recommendations regarding potential legislative or systems changes which would enable well trained, compassionate, and competent workers to have the mandate to investigate and respond to potential risk situations where less intrusive means of advocacy and support have been first attempted.
- e) A “next steps” plan in regard to the development of a comprehensive public and systems awareness campaign regarding the issues and reporting mechanisms
- f) Initial recommendations on potential methods to identify and build on best practices which are supportive of informal supports of protection of vulnerable adults

Simultaneously it may be helpful to learn from what other groups are doing in protection of individuals who are at risk of abuse.

Throughout all of the discussions it will be important that focus be kept on a balance of (1) Informal Supports Emphasis, (2) Public and Service Sector Education and Awareness, and (3) Systems Improvements if and only if required.

While some of the issues raised will require careful thought and consultation, it is important that we not avoid the task for reasons of not immediately knowing how to find the balance of protection and rights. Many adults with significant disabilities are being abused and neglected and some have died. We need to struggle with the issues to find this balance. We must not avoid the hard work for fear of the issues it raises, even if some of these issues may involve discussions around topics which are unpopular due to “political correctness”. With careful thought and discussion a balanced approach can be found. **The individuals who are at risk deserve the best we can bring to them in discussion, thought, consultation, and support.**

*Respectfully submitted by Gail Jones
October 2007*

GLOSSARY OF TERMS/ACRONYMS:

APSW	Adult Protective Services Worker
ARCH	ARCH Disability Law Centre
Bill 230	Adult Protection Bill – proposed by Rick Bartolucci, MPP but did not proceed
CAS	Children’s Aid Society
Citizen Advocacy	Establishing and supporting one to one freely given unpaid relationships between valued members of society and those at risk of being devalued and abused with an aim of advocacy for the individual with a disability
HCCA	Health Care Consent Act
ODSP	Ontario Disability Support Program
ONPEA	Ontario Network for the Prevention of Elder Abuse
OPGT	The Office of the Public Guardian and Trustee
PLAN	Planned Life Advocacy Network
SDA	Substitute Decisions Act
Supportive Care in the Congregation	A method for congregations to offer supportive care to families and individuals with disabilities in their congregation.
TPA	Transfer Payment Agency (funded through the Ministry of Community and Social Services)
Wraparound	A strength based approach in working with families with complex needs.

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