Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities

Ideas Fund Final Report

Ensuring Quality of Life in Using Community Living Supports
Assistive Technology for Individuals with Complex Service Needs

January 25, 2013 - Joan Lee
EXECUTIVE SUMMARY
Assistive technologies, such as behavioural monitoring, telecare and telehealth, and home surveillance and security, are being considered in multiple sectors to aid individuals with complex service needs living in the community. These kinds of technologies have been thought to increase efficiencies and effectiveness (i.e., reduce staffing ratios and presence) in providing services and supports while ensuring safety and security of the individual and their service providers. However, potential use of such technologies creates challenges for government policy makers and service providers in providing more efficient and effective services and supports for the individual without sacrificing quality of life concepts, such as a sense of autonomy and self-determination.

This research study explored how assistive technology can be used ethically to ensure the safety and security of individuals with complex service needs and their service providers while promoting quality of life outcomes of the supported individuals. By reviewing the literature, past program evaluations, and organizational reports discussing the use of assistive technology for persons with complex service needs, and talking with experts in the field to gain additional insights, Vecova Centre for Disability Services and Research developed recommendations to policy makers and service providers on how to best use assistive technology to maximize the benefits they provide while minimizing the risks to individuals with complex service needs.

RESEARCH OVERVIEW
Objective(s)
The objective of this research is to collect information to inform:
- The use of assistive technology to enhance the quality of life of individuals with complex service needs.
- The maintenance of the safety and security of individuals with complex service needs in a community living setting.
- How service providers can meet the complex service needs of some individuals without sacrificing ethical practices.

Background
The resettlement of individuals with complex service needs from institutional to community living settings has provided the challenge of maximizing privacy and dignity while maintaining safety and security for the individual and their support staff (Linskill & Hill, 2010). With increasing demands for services resulting from an expansion of persons with complex service needs, government ministries and service providers have turned to a variety of assistive technologies to support communication, safety and security, mobility, and in-home supports. The research literature has indicated that assistive technologies have been beneficial for persons with developmental disabilities in that they enhance quality of life concepts such as independence and self-determination (Muselman, Woodruff, & Kellar-Guenther, 2010). Therefore, there is reason to believe that the benefits of assistive technology would also apply to individuals with complex service needs. However, it is unclear how to use assistive technology to ensure quality of life concepts without sacrificing ethical practices. Although it is expected that persons with complex service needs and their service providers will benefit from the use of assistive technology, we need to know how to use assistive technology to encourage multiple benefits.

When using surveillance and monitoring technologies to improve in-home support, it is important to
ensure that proper ethical protocols are being met (Welsh, Hassiotis, O'Mahoney, & Deahl, 2003). Without monitoring and alerting systems, many individuals cannot be guaranteed safety and security without having a support staff member present. Therefore, some elements of service delivery, such as ensuring client privacy, may need to be reviewed in order to best meet the support needs of the individual. It is important to develop a better understanding of these ethical considerations and implications in order to provide recommendations for appropriate use of assistive technologies to support individuals with complex service needs.

**Approach and Methods**

**Definition of Complex Needs**

In this initiative, individuals with complex needs are defined as: individuals with cognitive impairments (however caused- i.e., due to developmental disability, acquired brain injury or other factors) and co-existing challenges due to mental illness, behavioural or medical problems.

**Review of the Literature**

The literature review consisted of examining academic, peer-reviewed journals published in the last 10 years primarily from North America, the United Kingdom, Australia, and other countries with similar complex needs practices. In addition, the grey literature was reviewed, including but not limited to program evaluation reports, ministry reports, and organizational reports, discussing the use of assistive technology to support individuals with complex service needs in the community. The literature review focused on the:

- Use of assistive technology in community living settings and how this impacts quality of life for persons with complex service needs.
- Ethical implications and considerations of using assistive technology in community living settings to aid in the support of persons with complex service needs.
- Recommendations regarding how to use assistive technology to ensure quality of life while maintaining ethical practices.

**Field Methods**

The research team conducted a series of phone/email consultations with three experts in the field. Each expert was identified by the literature review and/or the Calgary Region Complex Needs Committee and the Calgary Region Community Board Persons with Developmental Disabilities Program. Experts were contacted directly by phone and email to inform them of the project and invite them to participate in a 1-hour, audio-recorded interview to share their opinions and provide guidance regarding this particular issue. Two interviews took place on the phone and one over email. The consultations gathered information on how:

- The benefits to the individual and the organization should be weighed against possible disadvantages for the individual in terms of the impact of surveillance/monitoring on privacy.
- To ensure that assistive technologies selected are in line with the needs and preferences of the individual.
- Clients are made aware of what information is collected, how that information is used, and how to gain informed consent.

**Key Findings**

Eight key recommendations resulted from the expert consultations and literature review:

- Professionals from multiple areas need to be included to ensure that assistive technology addresses multiple concerns of the individual and contributes to holistic service delivery.
- Individualized residential supports are strongly encouraged as each person with complex service needs will require various types of supports and differing kinds of assistive technology in the residence.
The group home model has not been found to be an effective model to support persons with complex service needs. Implementing new home designs and models is necessary to promote individualized residential supports for each individual to best address their unique needs.

- Assessing individual needs based on quality of life indicators will help guide the process in determining the unique needs of the individual and how their quality of life can be enhanced.
- Assessing the needs, wants, wishes, and experiences of the individual with complex needs is critical in matching the person to the technology.
- Assessing the priorities and needs of the organization, staff members, caregivers, family members, and government ministries (i.e., stakeholders involved in the care of the individual) will help balance the competing priorities of all the parties involved and contribute to holistic service delivery.
- The individual with complex service needs should be the person driving and guiding the process. Therefore, the person needs to be part of the process of selection, implementation, and evaluation of the assistive technology. This ensures informed consent of the individual throughout the entire process.
- Staff and client training is required when implementing the assistive technology devices or systems to ensure that all individuals using and adapting the technology is familiar with and utilizes it effectively. This fosters continued use of the technology, curbing abandonment.

Conclusions
Based on the information gathered from experts and the academic literature, recommendations for future practices in assistive technology use for individuals with complex service needs have been offered above to ensure that staff, organizations, and government ministries have guiding practices on how to select and implement assistive technology in community living settings. Involving the individual in decisions that will impact them is the best way to ensure that quality of life outcomes are promoted and ethical concerns and risks with respect to assistive technology are minimized. As gleaned from this review, the process of matching person to technology, while including the individual and relevant stakeholders in the decision-making, selection, training, implementation, and evaluation processes, is critical to the success of assistive technology in enhancing quality of life outcomes for persons with complex service needs.

Implications for Policy or Practice
Our findings provide policy-makers, decision-makers, service providers, and practitioners with a set of guiding principles for implementing community living supports assistive technology to enhance the quality of life of individuals with complex service needs. The key recommendations from the literature and experts have the potential to inform guidelines, policies, and service planning and delivery practices concerning the use of assistive technology to best meet the individuals’ needs and achieve quality of life outcomes, while maintaining ethical standards.

Directions for Further Research
There is limited research examining the quality of life of persons with complex service needs and further gaps exist in how to ethically obtain informed consent with this population. Future research on these topics is needed to improve our understanding of these individuals, their unique service needs and, in turn, how quality of life and consent procedures can be effectively applied to assistive technology use with this population.

Knowledge Dissemination and Translation Activities
We will make the results of our research available to the public through the Vecova website and circulate a research brief to interested stakeholders through an e-newsletter. We will also provide research summaries to the participating experts to inform future research and practices. This final report and a plain language summary will be submitted to the Alberta Addiction and Mental Health Research Partnership Program for dissemination through their knowledge exchange website. The findings from this
The report will also be shared at an upcoming Lunch and Learn event for the Calgary Complex Needs Collaborative. Future conferences are also currently being considered for further dissemination.

**Principal Applicant (Team Leader)**

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<th>Name</th>
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**Project Partners (Team Members)**

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**Publications and Presentations**

No publications were submitted or any oral or poster presentations conducted.

**About the Alberta Addiction and Mental Health Research Partnership Program**

The *Alberta Addiction and Mental Health Research Partnership Program* is comprised of a broad-based multi-sectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based addiction and mental health research in Alberta.

The mission of the Research Partnership Program is to improve addiction and mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into addiction and mental health promotion, prevention of mental illness, and innovative service delivery.

The Research Partnership Program sets out to increase Alberta’s excellence and output of addiction and mental health research findings, and to better translate of these findings into practice improvements.

**References**

