Retrospective Exploration of the 3Rs Education Program: Systemic Facilitators and Barriers to Implementation

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Abstract

Individuals with intellectual disabilities (ID) have historically been denied basic rights and thus have been subjected to abuse. The *3Rs: Rights, Respect and Responsibility* Human Rights Education Program was implemented and researched through a partnership with Community Living Welland Pelham and Brock University initially and then cascade training on the program was provided to five developmental service sector agencies from across the Niagara Region. This research evaluated the role of the 3Rs education program on the shift to a rights-based service agenda across those five agencies. Interviews were conducted with the Executive Director and Liaison staff from each of the agencies and a thematic analysis was used to describe factors that facilitated organizational changes and a cultural shift. Systemic barriers to the change were also explored. The results indicated that the 3Rs education program provides the catalyst necessary for the shift to a rights-based service agenda and that the resultant changes in practices now embedded in the organizations are reflective of a shift to a rights-based service agenda.

Key words: organizational change, intellectual disability, rights

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Introduction

For many years, one's right to live in the community, attend school where one wants, access appropriate medical services, choose one's place of employment, marry and have children has been taken for granted by the majority of citizens in Canada. However, the same cannot be said for persons with disabilities, who historically have been seen as not being of value to society and hence denied basic human rights (Watson, Stainton, & Sobsey, 2011). The declaration of the UN Convention on Rights of Persons with Disabilities in 2006 highlighted the shift in direction towards the provision of rights for persons with disabilities, including those with Intellectual Disabilities (ID) (http://www.un.org/disabilities). However, while the UN Convention delineated the rights of persons with disabilities, to ensure day-to-day enactment of its provisions it is necessary to shift the service delivery model from a paternalistic focus to a rights-based orientation. In this context, the *3Rs: Rights, Respect and Responsibility* rights education program has been identified as a systemic approach that could facilitate the change to a rights-based service agenda within developmental service sector agencies (Owen et al., 2003). Previous research has indicated that the *3Rs* educational program affected the organizational policies and procedures in a community service agency, which would likely facilitate the sustainability of the rights-based service agenda (Mullins, 2009).

The present study is a retrospective exploration examining the implementation of the *3Rs* educational program within five developmental service agencies all of which were involved in *3Rs* educational program for staff and persons with ID. The study focuses on determining

whether the *3Rs* program had an impact on organizational policies and procedures in those

agencies and whether the resulting shift to a rights-based service agenda, if achieved, has

been sustained. For this study, changes in policies and procedures will be demonstrated by

modifications made in day to day practices including hiring processes, staff training,

development of planning documents and hiring practices.   Executive Directors and Liaison

staff from the identified organizations were invited to participate in the study. Through a

focus group and individual interviews with Executive Directors and each of the Liaison staff

members, data were collected and analyzed both inductively and deductively to identify key

themes. Furthermore, a member checking document that highlights the themes identified in

the focus group and individual interviews was distributed to all participants to verify the

accuracy of the analysis.

Review of Literature

The declaration of the UN Convention on Rights of Persons with Disabilities on

December 13, 2006, and its subsequent ratification by 100 countries, including Canada, heralded

the proclamation that individuals with disabilities, including those with intellectual disabilities

(ID), were entitled to the same rights as all other citizens (Griffiths, Owen, & Watson, 2011).

Historically, individuals with disabilities had systemically been denied basic rights, including the

right to live, the right to supports and services through the justice system, the right to education

and health care, and the right to be free from exploitation and abuse, to highlight a few examples

(Griffiths et al., 2011). The historic denial of rights for persons with ID was predicated on the

fact that others in power in a hegemonic society had determined that the lives of people with ID

were not of value (Watson, Stainton, & Sobsey, 2011).

Historically, the medical model of disability was the accepted discourse and it was presumed that the individual with a disability was not able to perform activities considered normal for a human being (Barnes, 2010). Within the past century, there has been a shift to the social model of disability which locates the individual's disability in the environment, including social attitudes, structures, and physical and/or communication barriers (Davidson, 2010) rather than in the individual him/herself. With the theoretical paradigm shift from the medical model of disability to the social model of disability, the time was ripe for the ratification and implementation of rights for individuals with ID in society.   In addition, as with other marginalized groups, acknowledging that historically the rights of the individuals had been denied was not enough; the change in the discourse to a rights-based agenda had to reflect the internal changes needed in organizations:

> It ought to respect the dignity and individual autonomy of all those it claims to help; including the poorest and most excluded, including minorities or other vulnerable groups, often discriminated against; it ought to create opportunities for their participation – opportunities that are not dependent on the whim of a benevolent outsider, but rooted in institutions and procedures. (Uvin, 2007, p. 603)

Human Rights of Persons with Disabilities

Initially, it is important to be cognizant of the overarching principles that underlie the UN Convention on Rights of Person with Disabilities. These are:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

- Equality of opportunity;
- Accessibility;
- Equality between men and women;
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (http://www.un.org/disabilities, article 3).

Historically it is important to note that persons without identified disabilities have been in the position of determining whether persons with ID were of value and deserved to be included in society with all the basic rights afforded to all other members of society. The belief that persons with ID were not of value to society perpetuated the practice of eugenics including prenatal testing and termination of pregnancies of "undesirable" fetuses and the refusal of life sustaining treatment to people with disabilities (Stein, 2007;Watson, Stainton, & Sobsey, 2011). Further, it resulted in many children and adults with ID being removed from their families of origin and being relocated to institutions far away from their homes (Perry, Shervington, Mungur, Marston, Martin, & Brown, 2007). The devaluing and dehumanizing of people with ID resulted in significant abuse histories for many children and adults (Ryan, 1994; Sobsey, 1994).

Any discussion of the importance of the provision of rights for people with ID must include the fact that it is not enough to just protect vulnerable individuals from inequitable treatment and abuse; it is also necessary to provide opportunities for those same individuals to have the chance to make personal choices about where they live, who they live with, and where they work, to name just a few examples, and so to enjoy enhancements in their quality of life (Young & Quibell, 2000). As the aforementioned idea is also included in the principles on which the Convention on Rights for Persons with Disabilities was based, a discussion with respect to first generation (or negative) rights and second generation (or positive) rights as they apply to the enactment of a rights-based service agenda must be included.

Though themselves critical of the rights discourse, Young and Quibell (2000) have highlighted several important issues that are significant to this dialogue. Young and Quibell (2000) note that, most recently, the rights that have been afforded to persons with ID are the ones that are necessary to ensure that basic material needs for food and shelter are met and to ensure protection from injustice. As the provision of these types of rights protects the individual from inequalities and abuse and thereby ameliorate negative circumstances in their lives, these are referred to as "negative" or first generation rights. "Positive" or second generation rights are dependent on first generation rights being ensured for all so that a supportive environment that fosters true involvement in choice making is available for people with ID, thereby providing the opportunity for positive experiences and enhanced self-determination (Young & Quibell, 2000). Some examples of "positive" or second generation rights include choosing where you will live in the community, where you will work, who you will date or marry and whether or not you will have children. While many of these examples may seem basic, they provide illustrations of the choices that historically have been denied to people with ID.

Furthermore, as many individuals with ID receive supports and services from community agencies, the theoretical paradigm shift from the medical model of disability to the social model of disability needs to be replicated in these agencies. Enactment of this conceptual commitment necessitates a shift from a paternalistic approach to service delivery (Stainton, 2005) to providing safe environments where people with ID can develop enhanced self-determination and learn to gain control over their lives (Wehmeyer & Bolding, 2001). Therefore, it becomes an additional focus of the agencies involved in the provision of supports and services for people with ID to provide an environment that facilitates a systemic process to address concerns related to the rights of people with ID. The aforementioned approach must not only provide for an

environment that ensures basic rights are met but also fosters a shift in supports that provides for enhanced self-efficacy and self-determination (Owen & MacKinnon, 2011). One additional point to consider when establishing a rights-based service agenda is that each individual who is in receipt of services from the agency may require different supports to achieve the outcome he/she desires (Stainton, 2005; Stein, 2007; Young & Quibell, 2000). As discussed by Ward and Stewart (2008), "scaffolding" of individualized supports for persons with ID is required to ensure that each person has the services necessary to facilitate decision making based on his/her right to do so. Hence, for the present research study, an organization with a rights-based service agenda would be described as being driven by guiding principles that include "willingness to take direction from the person with ID and his/her advocates with respect to lifestyle preferences, use of natural supports, enhanced opportunities for choice and valued and respected roles, enhanced personal competencies, promotion of social relationships and community inclusion" (Richie et al. cited in Ward & Stewart, 2008, p.304).

Organizational Change

There is a vast amount of literature available on the processes involved in organizational change and development. Specific to the present research project is the comprehensive literature on change processes, at an organizational level, as well as the roles of "change agents" in social service agencies, specifically those related to adopting a rights-based service agenda (Owen, Julien, Sales, Tardif-Williams, Vyrostko, & Stoner, 2009; Owen & MacKinnon, 2011, Stainton, 2005; Wagner, 2000; Ward & Stewart, 2008).

Readiness for change.

First, the reviewed literature highlights the significance of an organization's readiness for change. Austin and Claassen (2008) note that evaluating the change readiness of both individuals and organizations may help to ensure that the proposed change in practice is well-received, implemented, and supported. Building momentum and true interest in the organizational change could result in a change in beliefs and attitudes of stakeholders which results in the stakeholders seeing that the changes are necessary (Eby, Adams, Russell & Gaby, 2000). The former is similar to the concept of "unfreezing" of a system described by Lewin that must occur before change (transitioning) and eventually refreezing into a new system can occur (Lewin cited in Eby, Adams, Russell & Gaby, 2000). It is important to note that readiness for change may be unique to each individual and that some resistance to change is inevitable, especially in those stakeholders who believe the proposed change to be not in the best interest of the agency, or who were part of the original culture of the agency or who feel threatened by the change. An enhanced level of readiness for change can be facilitated by ensuring that the organization's policies and procedures are supportive of the change, and that skills training on the new processes and procedures involved with the change are conducted. Further, involvement of all stakeholders on task forces that increase their participation in the decision-making process will facilitate an increased state of readiness for change within an organization (Eby et al., 2000). Thus it can be seen that the level of readiness for change demonstrated both by individuals and by the organization as a whole can mitigate the successful implementation of an organizational change.

Learning organization.

The development of a "learning organization" that is committed to an ongoing culture of learning that could provide support for the desired organizational change is the second important factor delineated in the organizational change literature.   It has been noted that learning a new process and accepting the "risk" inherent in the organizational change needed for the new process is fostered by a learning organization that is based on trust and the provision of support through the change for all involved (Dubrow, Wocher, & Austin, 2008). Furthermore, a learning organization demonstrates a continuous commitment to the process of ongoing change and provides a feedback loop and support for the staff and stakeholders so that the desired change can become a permanent part of the organization's culture (Callaly & Anya, 2005). It is important to note that the term "feedback loop" is used to describe the mechanisms that are introduced so as to ensure ongoing communication among all stakeholders within the organization who are involved in the change process. In addition, the role of the leadership team within a learning organization should include developing an environment where learning is supported and taking the "risk" necessary to implement a change is provided (Austin & Claassen, 2008). Hence, organizational change can be facilitated by the agency becoming a learning organization whereby learning and acceptance of change fostered through the learning process become integral components of the agency culture.

Role of change agent.

Throughout the literature on organizational change in social service agencies, the role of the change agent or change leader in the process is presented. In fact, Dubrow, Wocher, and Austin (2001) propose that designated staff serving the role of change agent would be beneficial

to the change process in a social service agency as they are historically "closed systems." To this

end, an internal change agent would be tasked with the roles of introducing structure to new

ideas that the agency wants to implement, assisting communication between staff and

management, helping to provide a frame of reference for difficult issues and supporting staff

members who are initially resistant to the change (Dubrow et al., 2001). Moreover, change

agents must be able to communicate and work across several environments while serving as the

bridge between stakeholders and those initially desiring the change in process. Finally, it is a

significant role of the change agent to implement and help to sustain the feedback loop among all

stakeholders so as to ensure success of the change in service protocols. Thus, the role of the

change agent within the social service agency would be to champion the proposed change in

service delivery through the introduction and implementation until the new practices have

become part of the agency culture (Hemmelgarn, Glisson, & James, 2006).

Barriers to change.

The review of literature on organizational change within a social service agency also

includes some of the known barriers to the implementation of change in organizational practice -

for example, barriers to a rights-based service agenda. The most dominant barrier identified in

the literature is the perception that there is no need for the agency to make changes in practice.

This barrier was noted especially in agencies with a strong organizational culture and was

expressed especially by staff members who had long employment relationships with the agency

(Austen & Claassen, 2008; Callaly & Arya, 2005). The potential risks associated with the

change in organizational practice that could potentially result in uncertainty for the staff and a

perceived loss of personal status and identity were highlighted as the primary reasons why staff

believed that the change in practice was not needed (Kotter & Schlesinger cited in Callaly &

Arya, 2005; Lawler & Bilson, 2004). Finally, Callaly and Arya (2005) state that there could be resistance to the implementation of an organizational change in practice if the additional work necessary to implement the change is an addition to the duties already assigned to the staff members. In all the research discussed in this review, there is consistent reference to the fact that the culture of the organization must change to reflect the change in practice adopted to sustain the change within the organization.

Thus far, the concept that people with ID are entitled to the same rights as all other people and that agencies that provide supports and services for people with ID may need to engage in an organizational change process to facilitate a rights-based service agenda have been discussed.   To provide a more in-depth analysis of the systemic change process that may facilitate the implementation of a rights-based agenda within actual social service agencies, the *3Rs Project: Rights Respect and Responsibility* will be examined.

3Rs Project: Rights, Respect and Responsibility

The 3Rs: Rights Respect and Responsibility Project is one example of a process that could facilitate the change to a rights-based service agenda within a developmental service sector agency. The *3Rs* project was developed through a collaborative process between the management and staff of Community Living Welland/Pelham, a developmental service sector agency located in the Niagara Region that has been providing supports and services for persons with ID since 1953, and researchers and students at Brock University. The impetus for the project was initially two-fold: the felt need to implement a prevention program aimed against potential abuse for the individuals supported by the agency and to address specific standards delineated in the accreditation process the agency was involved in. The felt need for basic rights

training became a priority when the results of a human rights' awareness survey conducted by

the original 3Rs research team indicated that the individuals supported by the agency did not

realize they had the right say to "no" to someone in authority (Owen et al., 2003; http//www.cl-

wellandpelham.ca/3RsProject.aspx).

   One of the challenges faced by the agency in the development of this project was the

need to define and address the fine balance between respecting the rights of the people with ID

who received supports from the agency versus protecting people who are seen as vulnerable,

especially from the perspective of the front-line staff. To this end, it was determined that a

systemic training program both for the people receiving support from the agency and for the staff

who are involved in maintaining the rights of people with ID was necessary. As noted by

Sobsey (1994), human rights training must occur in the context in which the support for the

application of rights will occur. In addition, the need for familiarization with human rights

mandates and the courage for all stakeholders to engage in organizational self-examination of

current practices are of paramount importance in the development of a human rights statement

for the agency (Owen et al., 2003). Finally, the transformative shift to a rights-based agenda

would "require risking the shift from encouraging compliance to fostering self-determination in

those served by the organization, and shifting from the security of protecting individuals to

working in partnership with them" (Owen et al, 2003, p.52). This section will describe these

steps in the implementation of the *3Rs* approach.

   The first step in the process for the founding agency in this project, Community Living

Welland Pelham, was the development of their Human Rights Statement based on the work of

the agency by the Executive Director, the Board of Directors and management staff in

conjunction with researchers and students from Brock University. The resulting list of 21 rights

focused on the people supported by the agency and all other stakeholders involved with the organization. The first eleven rights' principles were based on the Canadian Charter of Rights and Freedoms and are stated below:

1. Right to equal treatment without discrimination because of race, ancestry, origin, colour, ethnicity, citizenship, creed, sex, sexual orientation, age, marital status, family status, disability, or other analogous ground

   - With regard to services, goods, facilities, and accommodations.

2. Freedom of conscience and religion

   - Develop own set of values and beliefs.

   - If needed, this includes the assistance to discover various religions/values/beliefs and assistance to participate as much as possible.

3. Freedom of opinion and expression

   - Have feelings and communicate those feelings.

   - Express one's thoughts while respecting the thoughts of others.

   - Advocate for oneself and for others.

   - If needed, this includes the assistance to learn ways to advocate as well as to contact someone to advocate on one's behalf.

4. Freedom of peaceful assembly and association

   - Choose with whom, when, where to communicate or spend time, whether formally or informally.

   - This includes the participation in deciding where to live and work or from whom to receive support.

5. Right to vote

- Has the right to vote in any or every election.

- If needed, this includes the assistance to learn of and about the candidates, transportation to the voting location, and assistance with the actual voting process.

6. Right to enter, remain in, or leave Canada or any Province

- To live, work, or receive service without discrimination because of disability.

7. Right to life, liberty, and security

- Life- receiving necessary and life-sustaining medical or surgical treatment.

- Liberty – making one's owns decisions about any matter that affects his/her life.

- Security – individual physical, emotional, and psychological security as well as the security of personal property.

8. Right not to be deprived of one's life, liberty, or security except in accordance with the principles of fundamental justice

- Restrictive measures can be justified only in situations where the individual is at risk of harming himself/herself, others or property and not without clear reasoning, an adequate hearing upholding all legal rights of the citizen, and substantial plans for the removal of the restriction with the best interest of the individual always in the forefront.

9. Right not to be subjected to any cruel and/or unusual treatment or punishment

- Physical, emotional, psychological, financial, or sexual abuse or neglect are never acceptable.

- In situations where an individual is at risk of harming himself/herself or others, treatment and/or punishment that is not regularly used may be utilized for the protection of that individual and/or others only.

- A review of each unusual treatment or punishment involving an individual or staff will take place following the procedure explained in (the Association's) Human Rights' Handbook.

- If any treatment or punishment continues to be used, the situation must be strictly monitored.

- Plans for the elimination of the infringement must be established directly following the incident.

10. Right to be secure against unreasonable search and seizure

- Each individual and his/her possessions should not be examined or seized without his/her permission for any reason unless legal authorities have ordered so by law.

11. Right to equal protection and equal benefit of the law

- Equality does not always mean being treated the same, but with appropriate accommodations to fully respect and allow for the rights of the individual to be upheld (Stoner et al. cited in Owen et al., 2003, p.48-51).

As well, in recognition that their commitment to human rights for people with ID must extend beyond their own supports and services, the Association developed the following principles to advocate for the rights of individuals with ID in the community at large:

1. Right to equal treatment under the law

2. Right to participate in affirmative action programs designed to ameliorate the conditions of individuals or groups that are disadvantaged

3. Right to contract for, possess, and dispose of property

4. Right to income support

5. Right to an education

6. Right to sexual expression, marriage, procreation, and the raising of children

7. Right to privacy

8. Right to adequate health care

9. Right to equal employment opportunities

10. Right to appropriate support services of the individual's own choosing (Stoner et al. cited

    in Owen et al., 2003, p.48-51).

The next step in the overall shift to a rights-based service agenda at Community Living

Welland Pelham was the development of a systemic multi-level human rights training

program that would identify and provide the forum to address human rights issues in the

Association and ensure the maintenance of the rights-based service agenda. The forum was

the development of a Human Rights Committee.

The focus of the training component of the *3Rs* education program was on providing

training to the staff and management team of the organization prior to implementing the

training for the persons with ID who were supported by the agency. It was important to

ensure that the staff had the training first so that they would know how to support the

individuals with which they were working to make choices based on rights, know how to

identify and address rights' concerns as well as to reinforce to the individuals' understanding

of the relationship among rights, respect, and responsibility. As well, it is important to note

that the training program was developed in the spirit of adult education as empowerment

(Owen et al., 2003). The former decision reinforces the shift in supports that promotes

enhanced self-efficacy and self-determination in persons with ID (Owen & MacKinnon,

2009).

A Human Rights Commission (later renamed Human Rights Committee) was formed to address rights concerns that could potentially arise as all individuals supported by the agency and their caregivers became more aware of rights. It was determined that the Commission would have the power to influence policy and procedural changes that could be required to address rights concerns. Ongoing feedback between the management team and the individuals receiving services from the Association could also result in changes to both the training program and the organization's human rights statement in response to the changing needs. The Human Rights Committee was comprised of voting community and non-voting elected agency staff member representatives in addition to the Association's Executive Director and an agency manager. The first step in receiving rights concerns was a review by the organization's Executive Director who then brought the concerns forward to the Committee for final determination of whether a rights' restriction was present and how it should be addressed. All stakeholders in the Association, who for the purposes of this study, include front-line staff, managers, board members and the individuals with ID who received supports and services from the Association, were trained in the processes involved in making a rights complaint and were also provided with information about the appeals process in the event that the decision made by the Executive Director or the Human Rights Committee was unacceptable to them (Owen et al., 2003).

All Board members, Association managers and front-line staff were involved in the compulsory *3Rs* training that was developed to provide information and tools to heighten awareness of human rights in Associations that provide services to persons with ID. During this training, staff members learned about the Association's Human Rights Statement, about the interplay of respect and responsibility with rights, the role of the Association's Human

Rights Committee and about positive ways in which to advocate for the review of organizational policies and procedures related to rights protection and promotion (Owen et al., 2003).

The training program for individuals with ID who received supports and services from the association included presentations, scenarios and role-playing and was conducted by two facilitators. Sessions were geared at explaining the concepts of rights, respect and responsibility and then the interplay among these concepts was rehearsed. In the original version of the training (Owen et al., 2003) 22 lessons dealing with each of the principles delineated in the Human Rights Statement were prepared as well as a lesson on the agency's Human rights Commission. In order to avoid overloading the individuals with too much information and to encourage ongoing Human rights training that would embed the practice into the association's culture, it was recommended that the facilitators conduct 8 – 10 sessions followed by a break before continuing (Owen et al., 2003). In subsequent versions of the training an interactive training CD was used (Tardif-Williams et al., 2007) and, later, video taped scenarios in a game-based training format were introduced (Agnew et al., 2010).

Initially, it is important to note, that the original research partnership received a Social Sciences and Humanities Research Council of Canada Community University Research (SSHRC-CURA) grant in 2004 that was focused on researching and developing an education program on the rights of persons with ID thereby continuing the work that the partnership had begun in the 1990s (http://www.brocku.ca/news/11004). As the *3Rs Project* grew from its initial training project (Griffiths et al., 2003; Owen et al., 2003) other organizations including several development service sector agencies from across the Niagara Region, the Niagara Regional Police Service and the Adult Protective Service Worker Program were

invited to join the research partnership.   A cascade training system was initiated that

involved core *3Rs* trainers in training managers and staff in participating organizations,

thereby ensuring that the education program could be conducted throughout the partner

organizations on an ongoing basis. Five direct service agencies for persons with ID in

Niagara chose to partner with two of the original partners, Community Living Welland

Pelham and Brock University, to become involved directly in the *3Rs Rights in Everyday Life*

training program. To this end, there were then a total of six organizations that provided

direct supports and services to individuals with ID who were involved in the research

partnership with Brock University. Each organization agreed to develop a Human Rights

Statement for their agency and to ensure that they would have access to a Human Rights

Committee. They also agreed to appoint a liaison staff person or persons who would be

trained in the train- the- trainer program provided by *3Rs* project staff so that the Liaisons

could then provide training within their home agency.

Systemic issues research.

The effects of the training were researched by Mullins in 2009 who examined the

systemic aspects of rights training for people with ID who received supports and services,

specifically from Community Living Welland Pelham (CLWP) during the introduction and

implementation of the *3Rs* educational program in that agency. The research conducted by

Mullins (2009) involved interviews with a stratified sample of front-line staff, managers and

directors who were all employees of CLWP and a subsequent questionnaire involving staff

from all three levels who would have been eligible to participate in the interviews.

Mullins' (2009) results indicated that there were many changes in behaviour noted in the front-line staff, management and individuals receiving support from the Association after the *3Rs* training was provided. Initially, a change in management style was identified by informants that reflected the need to lead by example and to provide the educational influence for staff in supporting rights. This change also included reminding staff of the need to question the Association's policies and procedures so as to identify possible sources of rights concerns. The front-line staff noted the importance of relinquishing control in their relationship with the individuals with which they were working so as to support each person in exercising his/her rights even if there was a potential risk in doing so. The staff noted that there are times when they believed that a choice made by an individual is not in his/her best interest but that, as explained by Perske's (1972) concept, they have the same "dignity of risk" that any other person has and so they cannot prevent the person from making that choice. The staff noted that a process to identify and address rights concerns was also formulated. The front-line staff also noted a more balanced relationship with their supervisors in that they could check in with them to discuss rights concerns even when the concern was the result of the supervisor's behaviour. Also, it was noted that initially some of the individuals supported by the agency were unsure of their rights and how to respond to rights concerns but that the change in staff behaviour encouraged self-advocacy in the individuals (Mullins, 2009).

The importance of establishing a feedback loop during the process of the shift to a rights-based service agenda was also identified in this study. The feedback included praise from a supervisor for advocating and supporting the rights of a specific individual, changes that were made in policies and procedures in order to prevent potential rights concerns and

reports from the Human Rights Committee as well as from the *3Rs* research team (Mullins, 2009). Furthermore, Owen et al. (2003) explained the role of the Human Rights Committee in the feedback loop whereby the Committee would have the power to recommend changes to agency policies and procedures as well as the human rights training program based on learning arising from the review or a rights concern that had been submitted. As well, feedback from the training and from the Human Rights Committee could be brought to the organization's managers to address changes that could be needed in the human rights statement over time (Owen et al., 2003).

There were also some barriers identified in the study that impacted on the implementation of a rights-based service agenda even after the *3Rs* educational program had been conducted. First, it was noted that there was some preliminary concern about the fact that submitting rights concern forms to the Human Rights Committee could reflect badly on staff, especially if the concern involved the immediate supervisor of the staff member submitting the form. This preliminary concern was ameliorated by positive responses to submitted rights concern forms and changes that occurred because of them. A second barrier to the initial implementation of the rights-based agenda was the perception that there would be more initial work necessary when providing supports based on the rights of each individual than when using the more traditional protection- oriented approach to care provision (Mullins, 2009). This second preliminary barrier was addressed as staff became more familiar with this new role and acknowledged that supporting the rights of persons with ID was an important measure of their performance especially as their job descriptions and annual performance appraisal processes had been changed to reflect the organization's shift to a rights-based service agenda during the initial implementation of the 3Rs program.

There were also some systemic barriers to the implementation of the rights-based agenda that were identified in the study. The nature of congregate settings, such as group homes and day programs, in which many services are provided to individuals with ID, inherently makes it more difficult to provide individualized rights-based supports and services as the rights of one person may interfere with the rights of another. The need for the Association to provide services that are aligned with the compliance standards established by the Ministry of Community and Social Services (MCSS) also has an impact on the ability to provide rights-based services in that these standards are arranged around programs rather than the needs and goals of individuals supported in the programs. In addition, it was identified that there appeared to be a need for additional funding to support the choices some individuals made based on their rights as additional staffing and changes to the built environment were required to address them (Mullins, 2009).

Finally, participants in Mullins' (2009) study indicated the need for ongoing training on rights, enhanced feedback from managers, co-workers, the research team, and the members of the Human Rights Committee about the process of identifying and eliminating expressed rights concerns. They also discussed the need for support to balance the concerns from staff who were worried about infringing on the rights of an individual versus their responsibility to ensure his/her safety. These issues were all presented as factors that could become barriers to implementing and sustaining a rights-based service agenda in the Association (Mullins, 2009).

Overall, the results of the study conducted by Mullins (2009) indicated that the *3Rs* education program had affected the organizational policies and procedures and that the

reported behavioural changes would likely facilitate the sustainability of the rights-based service agenda.

As illustrated in Mullins (2009), the change to a rights-based service agenda can be facilitated through the implementation of the *3Rs* education program in conjunction with the organizational changes that were discussed. The focus of the present research is to investigate the perspectives of the Executive Directors and Liaison staff of each organization involved with the *3Rs* Project concerning the introduction of the rights education program in their agency, and the factors that acted as facilitators and barriers to the implementation of a rights-based service agenda.

Researcher's Perspective

The researcher's perspective is an important factor to consider when conducting a study as the inherent biases that may arise from this perspective could potentially have an effect on the manner in which the study is formulated, the data that are collected, how the analysis of the data is conducted and the conclusions that are drawn from the study. To this end, it is important to initially be aware that I worked in excess of 25 years for an agency that provided supports and services to people with ID.

I began my career working at a group home for children and youth who had been institutionalized at a very young age and who had been repatriated back to their home community. While this repatriation back to the community was seen as progressive at the time, this congregate living situation was home to eight children with complex developmental and physical needs. Furthermore, all decisions were based on the group, not on individuals, and the driving force behind decisions was the safety of the children and youth in the home, not on individual choices. As well, as I reflect on my career working with people with ID, I have come

to realize that I had been involved in the implementation of behaviour management programs that I now know were clear examples of significant rights concerns.

As discussed by Davidson (2010), with the paradigm shift from the medical model to the social model of disability that was ongoing during the tenure of my career in the developmental service sector, I became acutely aware of the need for person-centred planning and the need to advocate for the rights of the people with ID for whom I provided supports and services. However, at that time, there was some reluctance in the agency for which I worked to shift the service delivery model from the traditional "care giving" model to a rights-based model, so the scope of my advocacy was limited to my sphere of influence as a front-line staff member and then as the manager of two residential programs within a larger agency.

I changed career paths and, shortly thereafter, many of the developmental service sector agencies in the Region became involved in the 3Rs education program. While no longer involved directly in the provision of service to people with ID, I celebrated the potential change in service agenda that this training could herald and the opportunities it could bring for people with ID.

Due to my lengthy tenure in the developmental service sector field in the Niagara Region, it is important to be aware that I personally know the majority of the Executive Directors and liaison staff in the Region, including the agency with which I was associated for more than 25 years. It has been 4.5 years since I have worked for the agency and have maintained contact with only one person from the agency who was peripherally involved with the 3Rs project. I also know another person in this Executive Director/Liaison staff group in a different context. Provisions were made in the design of this study to ensure that the aforementioned individuals did not feel undue pressure to participate in the study as a result of their relationships with me.

Finally, as both a graduate student in Applied Disability Studies and as a Senior Manager in a children's mental health agency, I am keenly interested in the systems in which service delivery for people with ID, dual diagnosis, and mental health concerns occur. As this is a retrospective study, I am especially interested in the process of implementation of a rights-based service agenda within each of the agencies and whether or not this process helped to sustain the organizational change. The threat to sustaining the former change is especially significant during times of fiscal restraint and due to changes in funding allocation for service providers and individuals. Furthermore, the potential risk to individuals and the organizations supporting a person with ID to make individual choices in conjunction with uncertain financial times is of special interest to this researcher.

Method

Purpose of the Research

The purpose of this research was to examine, through a retrospective exploration, the perceived impact on organizations of the *3Rs: Rights, Respect and Responsibility* educational programs for persons with ID and their care providers, and the barriers and facilitating factors to the implementation of a rights-based service agenda. The study focused on what, if any, changes to organizational policies and procedures have been tried following *3Rs* training, how the changes were implemented and with what effect, and what recommendations Executive Directors of the participating organizations and members of their staff who acted as *3Rs* Agency Liaisons would make to other organizations undertaking this process.

The research questions that have arisen from the review of literature are:

1. How do Executive Directors and Agency Liaisons describe their role in the *3Rs* human rights educational program?

2. How do the Executive Directors and Agency Liaisons describe the process and
   outcomes of the *3Rs* human rights educational program?

3. How do Executive Directors and Agency Liaisons describe barriers to, and
   facilitating factors for, the implementation of a rights-based service agenda?

4. What recommendations do Executive Directors and Agency Liaisons have for
   other organizations considering adopting a rights-based service agenda?

Two specific sets of interview questions (one for the Executive Directors and one for the Liaison staff) were developed based on the research questions which examined the research participants' perspectives on the *3Rs* education program and the implementation of a rights-based service agenda within their agency. As there were a significant number of potential participants in this research project, it was decided to interview the Executive Directors as a focus group, as they meet regularly in a group forum, and to conduct individual interviews with the Liaison staff since they do not have access to a similar regular meeting structure. However, to facilitate maximum participation from all invited, the Executive Directors who wanted to participate but were not available for the focus group were offered individual interviews.

Participant recruitment – Executive Directors.

Letters of invitation to participate in a research project and consent forms, for review, were emailed by the student investigator to each of the Executive Directors of the six developmental service sector agencies in the Niagara Region of Ontario who had been involved in the *3Rs* education program (please see appendices C and D). Upon receipt of an email confirming interest in being involved in the research study, the date for the focus group was established with the participants. Individual interviews with Executive Directors who wanted to

participate in the research but were not available to attend the focus group were also arranged at that time via email.

Participant recruitment – Liaison Staff.

After consent that their respective organizations could be involved in the research study had been received by the student investigator from the Executive Directors, a letter of invitation to participate in a research study and a consent form, for review, were emailed to the seven Liaison staff (please see appendices E and F). Upon receipt of confirmation via email that they were interested in participating in the research study, individual interviews were arranged with the time, date and location of the interview being selected by the participant.

Focus group.

A focus group is an interview conducted with a number of participants in which the answer to a question by one participant to the question posed by the researcher may result in additional responses from another group member. The fundamental purpose of a focus group is to get data in a social setting where individuals in the group have the opportunity to consider their own answers in the context of the views and opinions of others (Patton, 2002).

Focus group participants.

The Executive Directors of the six developmental service sector agencies that participated in the *3Rs* staff training and the rights in everyday life education program were invited to participate in the focus group. The focus group was conducted at a time that was mutually agreeable to the majority of the Executive Directors who agree to participate in the study and lunch was provided for those who chose to participate. Semi-structured open-ended questions with probes were asked in order to generate discussion with respect to the research questions (please see Appendix A for a complete list of the focus group/individual interview

questions). The responses to the questions were recorded by two note-takers. Two note-takers

were used for inter-observer reliability purposes (Martin & Pear, 2007). Two Executive

Directors participated in the focus group though four had initially indicated that they would be

present. Two participants were unable to attend at the last moment due to other matters. The two

Executive Directors who participated in the focus group have worked in the developmental

service sector for many years (specific number of years withheld to maintain confidentiality).

Both of these participants were the Executive Director of their respective agencies when the *3Rs*

education program was implemented.   The focus group was conducted in a meeting room of an

agency that was not in the developmental service sector so that the confidentiality of participants

in the group was protected.

Interviews – Executive directors.

Individual interviews using semi-structured open-ended questions with probes were

offered to any Executive Director who indicated that they were interested in participating in the

research but were not available to attend the focus group. The individual interviews were

audiotaped and then transcribed. Three Executive Directors were interviewed individually

including one who had originally indicated that she/he would like to attend the focus group.

Each of the Executive Directors chose the location of their individual interviews – one at the

administrative offices of her/his agency and two at an outside agency. The Executive Directors

who were interviewed have worked in the developmental service sector for many years. All of

the participants were the Executive Directors of their respective agencies when the *3Rs* education

program was implemented.

Interviews – Liaison staff.

Seven Liaison staff members, who were involved in the *3Rs* rights in everyday life education training program, were invited to participate in the study after the Executive Director of their agency had granted permission for their agency to participate in the study. The Liaison staff were selected to be involved in this study because of their enhanced involvement in the *3Rs* education program. The Liaison staff members who were involved in the *3Rs* education program were selected by the Executive Management of each of their respective organizations and were either supervisory staff or staff who were not directly involved in the provision of direct supports and service for persons with ID. Five of the identified seven Liaison staff chose to be involved in this research project.

Individual interviews using semi-structured questions with probes were conducted with each of the Liaison staff and were audiotaped and transcribed.   The Liaison staff were interviewed individually at their respective agencies as was requested by them. The Liaison staff who were participants in the research project have worked for their respective agencies in excess of 10 years and have all been employed as front-line staff at one time.   All of the Liaison staff are either managers or provide consultative supports to individuals in services within their respective agencies. Four of the five identified Liaison staff were provided with *3Rs* training by the *3Rs* research team and have conducted between 4 and 10 training groups each for staff and/or for individuals supported by their agency. (Please see Appendix B for a complete list of the interview questions that were asked of the Liaison staff who chose to participate in the study).

Member checking document.

Member checking, which allows for a different type of data source than individual interviews or a focus group, also serves as a form of triangulation that demonstrates strength

and/or robustness of the data in a qualitative research study (Patton, 2002). Two member

checking documents (one for the Executive Directors and one for the Liaison staff) were

developed to check the validity of the themes that were derived from data gathered during the

focus group and individual interviews. Both inductive and deductive analyses of the data were

conducted to identify themes related to organizational change that were related to the *3Rs Rights*

in Everyday Life education program, and the facilitators and barriers to the implementation of a

rights-based service agenda. After the thematic analyses were completed, each of the Executive

Directors and Liaison staff who participated in the study was given the opportunity to review a

summary of the themes that were identified in the data. They were asked to identify whether they

agreed or disagreed with the themes that were delineated and to provide additional input into the

research, if desired, as a means of member checking. Four completed member checking

documents were returned to the researcher; two from the Executive Director participants and two

from the Liaison participants. (Please see Appendices H and I for the respective member

checking documents).

Analysis of Interviews

Thematic analysis, a rigorous method for identifying, analyzing and reporting on both

deductive and inductive themes, was conducted on all of the transcribed interviews as well as the

noted from the focus group (Braun & Clarke, 2006, p.77). Deductive themes are primarily

theoretically driven and reflect patterns identified in the literature reviewed prior to the research

being conducted. Inductive themes are discovered by the researcher during the analysis and may

not be linked to the literature but capture a pattern that is important to the research (Braun &

Clarke, 2006).

Coding process.

A multi-stage process, enhanced by the use of NVIVO 10 ™ to organize the data, was conducted during the analysis of the data (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006). After the verbatim transcription and subsequent review of the transcriptions and notes from the focus group by the researcher, heretofore described as an integral part of the analysis by Braun & Clarke (2006), overall topics were generated and then a subsequent review was conducted to aggregate the topics. This review included reading all of transcriptions initially to identify themes at the member level. During this review process, patterns were identified from the data that were used to generate codes. Multiple readings of the transcripts were conducted within participants, within groups, across participants and across groups to identify patterns (Patton, 2002).

From the codes and sub-codes generated by the patterns in the data, deductive themes were identified and developed that were driven by the research questions and the review of the literature. These themes were identified first within case and then across case and which led to the within group analysis. Due to the high level of agreement between the two groups, the cross group themes will be presented in this research paper with the perspectives of each group described and between group differences included where they are present. Furthermore, inductive themes, which were identified during the analysis process as significant to the research, were identified (Fereday & Cochrane-Muir, 2006). The reciprocal relationship between deductive and inductive themes was highlighted during this analysis process.

Member checking.

At this stage in the thematic analysis process, the two member checking documents were developed: one for the Executive Directors and one for the Liaison staff as discussed above. The

documents summarized the themes and sub-themes that had been identified and developed from

the data and the participants were asked to agree or disagree with the identified theme and make

comments if they desired. The function of member checking within this analysis process was to

"validate participants' responses to a researcher's conclusions about them" (Fereday & Muir-

Cochrane, 2006, p.82).

> **Use of quotations**.

One final consideration in the analysis process was the use of direct quotations from the

participants in the writing of the final report. Fereday and Muir-Cochrane (2006) stressed the

importance of illustrating the findings that are reported with quotations from the participants.

This point was emphasized by Patton (2002) who reiterated that reflections in the participants'

own words add both credibility and validity to the report. Within this report, quotations from

Executive Director participants were labelled with ED followed by the number assigned to the

specific participant so as to ensure confidentiality. Quotations from Liaison staff participants

were labelled with L followed by the number assigned to the specific participant so as to ensure

confidentiality. In cases where labelling the participants in this manner could potentially identify

the organizations with which these participants are affiliated, the label was not included.

<center>**Results**</center>

Organizational Change

The results of this research project focus on the organizational changes needed to

introduce and sustain a rights-based service agenda in five organizations that provide community

to persons with ID. The key deductive themes from the cross group analysis are presented with

inductive themes, where evidenced, highlighted in the summary paragraphs following each

section. The reason for the inclusion of the inductive themes as described is the reciprocal nature

of the deductive and inductive themes in this research project. However, there is one key

inductive theme from the cross group analysis: Self-Advocates – their role in the change process.

This theme has an individual results section due to its significance.

To this end, the key deductive themes from the cross group analysis presented in this

section are as follows: the *3Rs* Education Program as a Catalyst for Change, the Culture of

Continuous Learning, the Liaison Staff as Change Agent, Barriers to Change and

Recommendations.

3Rs Education Program as a Catalyst for Change

A shift in service philosophy from a "traditional" service agenda to a rights-based service

agenda can be a significant shift in all aspects of the organization including hiring practices, staff

orientation, training, and evaluation, and the very manner in which services are delivered to the

individuals the agency supports. The Executive Director and Liaison staff participants described

the *3Rs* program and other factors that played an important role in the organizations'

development of a rights-based service agenda. As previously noted in the review of literature,

there are many processes that an organization should undertake to successfully shift their service

agenda (Owen et al., 2003). One of the processes noted was the need to prepare an agency for

any organizational change.

Readiness for change.

The "felt need" for a change from a traditional model of service delivery to a rights-based

service agenda was identified as the primary factor that led to the involvement of all of

organizations involved in the cascade training of the *3Rs* education program that was developed

and piloted by Brock University researchers and Community Living Welland Pelham as the lead

agency partner in the community-university research alliance. All of the Executive Directors of

the five developmental sector service agencies involved in the research noted that their

respective agency's involvement or interest in a formal accreditation process was one of the

factors that spurred the "felt need" for change. However, while all of the agencies identified that

they were "moving along the rights journey," the *3Rs* education program was described as

providing the catalyst for the shift from a more traditional service agenda to a rights-based

service agenda. As one participant described it:

> And I think as I was exposed more broadly to more focus across the agency, or to
>
> agencies across the province, that was one area I thought – my agency was – I won't say
>
> was lacking – but wasn't demonstrating the kind of leadership and direction it probably
>
> could (to its staff, people supported, all that kind of thing) and ... so knowing that it was
>
> coming along and knowing that somebody else was going to be doing the lion's share of
>
> the lifting - I was all about joining in because I knew it was the direction we wanted to
>
> head but was comfortable with having somebody else kind of... carve out that path
>
> (ED3).

The *3Rs* education program was described by all participants as providing the catalyst for

change to a rights-based service agenda after the "felt need" for change had been identified. It is

important to note that during this initial cross group analysis, an overarching inductive theme

was identified. This inductive theme could best be described as the difference in perspective of

the rights-based service agenda between the Executive Director participants and the Liaison staff

participants. To this end, it emerged that the Executive Director participants' perspective of the

shift to a rights-based service agenda was from a more philosophical and governance focus while

the Liaison staff participants' perspective was from the authentic enactment of rights in everyday

life. The former provides the perspective from which to view certain findings in this research

paper especially during discussions of the initial resistance to change experienced by the Liaison staff and the importance of support during the initial implementation process.

Understanding the 3Rs educational model.

It was noted by all participants that the *3Rs* educational program was a comprehensive educational model designed for all stakeholders involved in the process. One participant stressed that the *3Rs* program provided an "excellent framework" for the shift to a rights-based service agenda as "it accounts for all of the resources and materials needed to train everyone in the agency and it has the research to back it" (ED1).

In addition, several of the participants highlighted the fact that the *3Rs* education program identified and stressed the importance of the interplay of all of the *"Rs" – Rights, Respect and Responsibility* – while previous rights initiatives had primarily focused on an individual's right to make choices without acknowledging the significance of the other two social context factors. One participant stressed that the focus on the *3Rs* both ameliorated some of the "push back" from staff who were reluctant to espouse the change and "enhanced the choice making process for the individuals" supported by the agency (L1). Another participant stressed the importance of the concept of rights in relation to respect and responsibility and the context in which the person resides as being integral parts of the *3Rs* training for all.

> I think I would be focusing on the fact that the *3Rs* is not just, not just dealing
> with rights – that it is taking in a much more … comprehensive view of it in
> terms of getting people to understand that – yes you have rights but the
> responsibility of those rights and the respect of other people's rights is also very
> important so I think too many times when we have looked at other … training or
> educational programs it was only about the individual and it was taking into

account that rights can - the implementation of your rights - can vary based on

your living arrangements, … what's going on in your life at that time and that not

all rights are as important that they, that they vary in terms of the individual so it

it's much more, I felt, comprehensive and it gave – in some ways – more

flexibility … many of the things that came out of the rights programs that we had

been involved in was that people just saw their rights and it became a very strong

struggle between the individual and the support staff or the parent. … someone

saying 'well I have the right I don't have to do that' – well, yes you do but the

bottom line is the circumstances do not allow you without harming other people's

rights to continue to do that activity (ED2).

As well, this participant highlighted the impact of the *3Rs* education program on staff

both in providing guidance for the individuals they supported while they learned about making

choices based on rights and on the staff's own education about rights.

It gave staff or families a better place to help the person walk through the rights where

rather than saying "no, no, no, I was told I have this right and you can't stop me" … and it

gave the staff – staff were very threatened at the beginning and it allowed the staff to

learn along with the individuals about the complexity of rights so that would be my

description as compared to another program (ED2).

Hence, the participants in the project stated that the *3Rs* education program, with the

focus on the interplay of rights, respect, and responsibility, provided the framework needed to

ensure their respective organizations were ready for the shift to a rights-based service agenda.

The *3Rs* education program also had a direct impact on the service delivery model as it moved

from program based to being based on choices made by individuals, on change in the role of staff

from caregiver to advocate and educator and for individuals supported by the agency who

learned to make choices and advocate for their rights.

The process of initiating the 3Rs training.

All Executive Director and Liaison participants in the study identified that the decision to

become involved in the *3Rs* education program was made by their Executive Director, often in

conjunction with the Board of Directors of the organization. Two agencies noted that their

respective management teams were also included in the initial discussion about the education

program although the final decision was made by their Executive Director.

All of the participants stated, as well, that the decision about who would be chosen as the

Liaison staff for the agency was decided by the Executive Director of the organization. The

Liaison staff were chosen as they were "positive, engaged and comfortable training both staff

and individuals supported [by the agency]" (ED3), "committed to the rights philosophy" (ED2)

and "because the role fit in with their current job description" (ED4). In addition, the

significance of choosing the right person as the Liaison staff so as to ensure the shift to a rights-

based agenda was highlighted:

> And you need to have a lead – the Executive Director can't do it - it needs to be
>
> somebody [who] had that philosophy and really has a commitment to people to make that
>
> happen because certainly our managers most of them, all of them have come up through
>
> the front-line ranks and some of them are more focused on certain issues within the
>
> agency than others so I was very fortunate to have (person's name removed for
>
> anonymity purposes) and – if you don't have an ____ on staff – yea – that's gonna be
>
> hard – you've got to find them and I think anybody within an agency has that person – it
>
> might not be like I was lucky that I had a manager and I just added it to her already

overburdened job description and she willingly took it on – … you need to maybe

sometimes make some changes within your agency structure to make it happen (ED1).

All of the participants identified that their organizations had developed a Human Rights

Statement when they agreed to become involved in the *3Rs* research project. The majority of the

participants stated that they adopted the statement developed by CLWP though one noted that

there were "several versions of the statement before we settled on one" (L2). Two of the

participants noted that their original statement has been changed since the *3Rs* project to embrace

plain language versions, for instance, but that the key elements have remained intact.

The development and introduction of a Human Rights Committee and the processes for

identifying and addressing rights concerns identified by the individuals supported by the

organization and/or their staff or family members was another key component of the *3Rs*

program that was discussed by all participants. All of the participants noted that their Human

Rights Committees had evolved since they were first introduced. Eight participants indicated

that their committees no longer had external members, such as police officers or lawyers, as it

was very difficult to maintain their involvement in the process due to the irregularity of the

meeting schedule. Two participants noted that their existing Rights Committee had blended with

other committees that review the quality of services and well-being of individuals supported by

their organizations as the staff identified that they believed the process of bringing a rights

concern to the committee was seen as punitive by some and so it became a stumbling block for

the process (L4). By blending the committees, the process of bringing rights concerns forward

was identified as being one more function of an existing committee, which served to demystify

the process of addressing rights concerns and integrate it into ongoing organizational processes.

Six of the participants stated that their internal processes for addressing rights concerns have

remained the same since the *3Rs* training program was introduced, though a few of the

participants indicated that the name of their committees had changed.

All of the participants indicated that their front-line staff, Managers and Directors from

their respective organizations were all involved in rights education training prior to the

individuals with ID chosen to be involved in the *3Rs* education program began their program.

While some Liaison staff were involved in the staff training component for their agency, one

participant explained:

> We found the staff responded better to an outsider coming in if that makes sense -
>
> otherwise they would say 'oh there goes ____ again'...so we found somebody else coming
>
> in seemed to make it more receptive to some extent with some people (L2).

One key point that was made by several participants was the importance of the training

for all staff so as to ensure that they were aware of the shift in service philosophy and they had

the information that would be provided to the individuals they support during the training, thus

preparing the staff with the tools to support individuals to make choices based on their rights.

> ...you have to have the staff understanding and on-board. Training individuals without
>
> doing that – I believe – [is] pretty much a waste of time. Other than, other than people
>
> maybe living in their own apartments and, you know, you give them some understanding
>
> of it - that that would be of some value to them...but to be training people who are, are
>
> dependent on people for pretty much everything in their lives...if you don't change the
>
> attitude of those people … giving this information to someone living in that home and no,
>
> no support to exercise that information to me is just a waste of time... so any organization
>
> that is going to start it...they need to start with their staff (ED2).

Five of the Liaison staff stated that they had been involved in the *3Rs* education program with the individuals supported by their agency after receiving the training in the education program themselves and after shadowing the training provided by the *3Rs* project staff. This factor was extremely important in order to sustain the training component within each agency after the *3Rs* research team was completed their work as well as to enhance the skill set of the internal champions of the rights-based service agenda, the Liaison staff, within each organization.

All of the participants noted that their respective organizations had engaged in the processes outlined by the lead agency in conjunction with the research team from Brock University when they became involved in the *3Rs* educational program. These processes included the development of a Human Rights Statement, access to a Human Rights Committee and the appointment and training of a Liaison staff member within their organization.

Initial outcomes of the training.

There were many initial outcomes of the *3Rs* education program that were highlighted by the participants in this research project. As has been mentioned earlier, all of the participants stated that they were in various stages along the "rights journey," but six participants identified that prior to the introduction of the *3Rs* program, their agencies did not have a formalized rights training program for staff or for the individuals being supported by their organizations.

The importance of the Human Rights Committee and the processes developed to identify and address rights concerns were highlighted by all of the participants. One participant noted that the feedback from the Human Rights Committee provided the opportunity to "operationalize the policies and procedures" that had been developed as part of their agency's Accreditation process (ED3). Other participants noted that their organization's policies and procedures had to

be changed during the process of implementing the *3Rs* education program to reflect the shift to a rights-based agenda.

The introduction of the processes to address rights concerns, as proposed by the *3Rs* program, provided an ongoing opportunity for Liaison staff to educate staff members on potential rights restrictions. One participant gave the example of an in-depth discussion with staff about their rationale for locking up someone's personal belongings. While the staff person acknowledged it had "always been that way" and "thought there was a safety reason behind the practice," the Liaison staff member was able to describe the rights concern and provide education to the staff (L2). The indentified individual's possessions are no longer locked up.

Hence, the initial outcomes in all organizations that were identified as being a direct result their involvement in the *3Rs* education program were presented. These outcomes included the establishment of the mechanism for examining rights concerns and the processes to examine potential rights concerns that could arise regarding the safety of individuals related to choices made. Another interesting outcome was the internal discussions that challenged the staff to examine the way they had previously provided supports to individuals and the rationale for doing so.

Culture of Continuous Learning

As previously discussed, all of the participants in the study reported that the *3Rs* education program was the catalyst for the shift to a rights-based service agenda within their respective agencies. Furthermore, the participants articulated several processes and practices that began with and/or were enhanced by the *3Rs* educational program that have helped to sustain the shift to a rights-based service agenda within their organizations.

Feedback loop(s).

Initially, all of the participants stressed the importance of feedback loops, both formal and informal, within their organizations. The Human Rights Committee was highlighted by the majority of participants as an ongoing example of a mechanism that provides for the review of rights concerns brought forward by stakeholders and facilitates the sharing of the resulting feedback to the management team of the agency for appropriate action. The participants identified that this mechanism had advanced the shift to a rights-based service agenda within their agency. Several participants noted that the process of bringing rights concerns to the committee, though very slow at first, had helped to identify and address rights concerns within each specific program, and across their agencies, as well to implement a process to review rights restrictions when they were deemed necessary. One example shared by a participant noted that the feedback loop inherent in the process to review the identified restriction of locking up an individual's food

> ...was awesome because now I even have staff that come back and say 'yea we just
>
> unlocked everything and it's going good now.' We just wanted you to unlock the crackers
>
> and bread - cool....like and that's not a total example but umm now I've looked at that
>
> other manager and said...see –it's starting to unravel now...it is starting to come'... If we
>
> hadn't have started it that way and had just given up we'd still be ...these staff would still
>
> be going – 'yea we lock it up, that's how we support people' (L2).

Further, one participant noted a change in an organizational policy that was a direct result of an individual supported by the agency asking to exercise his right to attend an event in the community. The former request was presented as a rights infringement to the Human Rights

Committee and was reviewed and addressed by the members of the committee, the Executive

Director and the Board of Directors thereby resulting in a change to an organizational policy.

Three of the Liaison staff participants noted that staff meetings afforded the opportunity

for an informal feedback loop with respect to the rights of the individuals supported by the

organization. One further advance in the informal feedback mechanism process was that these

participants also identified that front-line staff from their agencies are now more comfortable

discussing potential rights concerns and how to address them when planning with the individuals

they support during ad hoc meetings rather than waiting for more formal venues to discuss them.

The importance of both formal and more informal feedback loops within the system

introduced during the implementation of the *3Rs e*ducation program were identified as important

so as to ensure the sustainability of the shift from training to an embedded rights-based service

agenda.

Outcome measures.

Three participants identified that training front-line staff in Personal Outcome Measures®

has now been added to their portfolio of responsibilities within their respective agencies.

Personal Outcomes Measures ® as defined by the Council on Quality and Leadership shifted the

focus from program compliance to measuring an individual's quality of life (http//www.the

council.org). The twenty-one Personal Outcomes Measures ® are divided into three categories,

My Self, My World, My Dreams and include:

- People are connected to natural support networks

- People have intimate relationships

- People are safe

- People have the best possible health

- People exercise rights

- People are treated fairly

- People are free from abuse and neglect

- People experience continuity and security

- People decide when to share personal information

- People choose where and with whom they live

- People choose where they work

- People use their environments

- People live in integrated environments

- People interact with other members of the community

- People perform different social roles

- People choose services

- People choose personal goals

- People realize personal goals

- People participate in the life of the community

- People have friends

- People are respected (http://www.thecouncil.org/Personal_Outcomes_Measures.aspx).

  These participants identified that as, within the scope of Personal Outcome Measures ®, an

individual's freedom to exercise his/her rights is one of the outcomes. Hence, within these three

organizations, rights training for all staff is now embedded in their outcome measures training.

Quality assurance committee.

The role of the Quality Assurance Committee is to review practices of an organization

within the framework of their accreditation standards and to examine best practices as a measure

of internal quality control (Kinney, 2000). Four participants indicated that the work of their

organizations' Quality Assurance Committees has furthered the shift to a rights-based service

agenda. One participant noted that the committee, which is comprised of the Executive Director,

managers and front-line staff, reviews issues that may impact on an individual's quality of life

which may pre-empt a discussion with respect to a rights concern (L4). Another participant

reiterated that the Quality Assurance Committee within his/her agency addresses the same issues

as the former organization's committee but that there is also a person supported by the agency on

the committee which adds the authentic perspective of an individual with the lived experience of

having an intellectual disability to the committee..

   Innovative practices.

   Several participants discussed innovative practices and/or processes that had been started

within their agency to foster learning and to promote practices to support individuals to exercise

their human rights. These innovative practices reflect a wide range of activities including

involving individuals supported by the agency in the development of rights-based materials and

the practices whereby staff incorporate rights promotion strategies within various aspects of their

work.

   Two participants, who are Non-Violent Crisis Intervention (NVCI) trainers for their

organization, stated that all components of the training are now given through a " rights lens" so

that the view and rights of the individual requiring emergency behavioural intervention are

considered and respected and the impact of the staff's behaviour on the individual is highlighted

(L1; L3).

   One participant described the involvement of the individuals supported by the

organization in the development and presentation of a revised Human Rights Code for their

agency that reflects their lived experience since the *3Rs* training (ED5). These individuals, with

the support of staff, had reviewed the Human Rights Statement that the agency had developed

prior to the implementation of the *3Rs* education program and rewrote it using phrases and terms

that reflect how they felt about their rights.

Another participant described a dedicated phone extension within their organization that

individuals supported by the agency can use to discuss rights concerns with the Liaison staff for

that agency. This phone extension is included in their organization's plain language brochures as

well as in the policies and procedures manual for staff (L4).

Finally, a participant described a proposal that had been submitted to the Ministry of

Community and Social Services (MCSS) Innovation Fund. The request for proposals called for

innovative ideas from developmental service sector agencies to enhance the organization's

supports and services for persons with ID. This participant highlighted that the proposal

submitted by his/her organization was based on the individual and not on the agency, something

that would never have happened prior to the organization's shift to a rights-based service agenda.

He/she stated:

> We submitted an Innovations Fund proposal to develop a web-based app to do one-page
>
> profiles... I love the idea. [And] imagine the application, as a free app to the world,
>
> whether it's for folks in long-term care hospitals, children, people with and without
>
> disabilities – you name it. And it's just, but it's because it, it is about the person. And it
>
> does boil down to a one-page profile. It's your cover sheet, it's your dashboard –
>
> however you want to look at it – It's about the person. I would think if we were putting
>
> together [an] Innovations Fund proposal... five years ago, it wouldn't have crossed our
>
> mind almost – it would have been an agency-based thing ...what can we get (ED3)?

Changes in individual planning processes.

All of the participants stated that each individual's support plans (which are called various names across the Region) now contain statements of the individual's rights to pursue his/her goals, hope and dreams, not just what his/her family or support staff want for him/her. As well, more consideration is given to how each individual will be supported in meeting his/her goals not how the existing agency program fits that individual's needs (ED3). One participant noted that even the format of planning meetings had changed from the past when the individual being supported might not even be invited to his/her own planning meeting. Now the individual determines who will be attending the meeting and chooses the goals him/herself (L3).

These changes in service delivery and planning processes reflect the shift to a rights-based service agenda in these organizations. Further, these changes reflect the shift to "understanding" individuals with ID through narratives from the person so that the staff learn about who the person is, where he/she has come from, and what they need (Young & Quibell, 2000). As such, these changes are indicative of a change in culture within the organization. An important inductive theme was identified during the discussion with the participants about the culture of continuous learning within their organizations. It was noted that, since the implementation of the *3Rs* education program, the practices and processes have evolved to reflect the existing practices within each organization thereby ensuring that the rights-based service agenda becomes embedded within each organization's distinctive culture. To this end, all of the participants described changes within their respective organizations that were indicative of the shift to a rights-based service agenda.

Changes in the culture of the organization.

There was significant discussion by participants from both groups with respect to the changes in culture within the organizations that have occurred since the *3Rs* training. As one participant noted, the dialogue around rights has been completely transformed within his/her agency with the individuals supported by the agency, with the staff and with the community as his/her agency has become more rights-based.

> I think the difference is we're trying not to be as parental and as recognizing people as individuals [who] need to be respected and that the rights are really their rights not ours to give, and I think that kind of change in your mind is essential because really... and you know, I'm looking at, at what we did before and it would be well, of course, so and so has the right to do this because they've earned it because they're capable because we have given them that right and we can take it away where now, it is even though at times we do have to, you know, intervene around a safety issue but now, it's much more thought you, you think that through – it's not ours to take away – it's not ours to give – it is belonging to the individual ... (ED3).

At a broad organizational level, two participants reported that the rights of individuals supported by their respective agencies are now included in their strategic planning processes for the upcoming year (ED2; ED3). All participants reported that all of their new staff, new members of the Board of Directors, and new volunteers are given rights training when they begin their work with the organization. As well, all participants noted that all of their existing staff, including management, have mandatory rights training on an annual basis; three noted that this now includes the training on reporting abuse as required by the MCSS. One participant noted

that existing staff in his/her agency are required by his/her agency's policies and procedures to be involved in a rights interview on an annual basis (ED5).

In addition to changes in agency policies and procedures, four participants noted that individuals supported by their organizations play an active role in the interviewing process for new staff. One example given was:

> ... we do have a person supported that is part of our orientation and our ... interview process, ... not the same person but ... anyways the person [who] sits on interviews ... you know, has come forth in the past and said, you know, ...I was not happy with the person we were interviewing because they never spoke with me during the interview and, you know, rarely even looked at me and we didn't hire them... (L4).

All of the participants reported more active involvement of the individuals supported by the agency on decision-making committees within their respective agencies. Noted examples were that individuals supported by the organization were now on the Human Rights Committees, Quality Assurance Committees and Orientation Committees.

Though all of the participants reported a change in the culture of the agencies since the *3Rs* education program, three identified that the shift was very gradual. One participant described his/her experience with the shift to a rights-based service agenda as "ripples" of change but that she/he felt was still an ongoing change despite her/his initial concern that the change process would end after the research component of the *3Rs* project was complete (L1).

Though slight in one instance, all participants reported a change in the culture of their organizations towards a rights-based service agenda since the implementation of the *3Rs* education program. As well, the participants reported that the shift was ongoing.

Evaluation of cultural change.

There were discussions with respect to the evaluation of the perceived cultural shift to a right-based service agenda with all of the participants. Several of the participants noted that their respective organizations distributed satisfaction surveys to all stakeholders in conjunction with their quality assurance and/or accreditation processes and that these surveys track many quality of life indicators that demonstrated the shift to a rights-based agenda. The stakeholders who receive these surveys include individuals who receive supports and services from the organization, family members and advocates, and community agencies that partner with the organization. Further, one participant noted that while there is not a formal process within his/her organization, the Rights Committee regularly discussed, through anecdotes, the changes that have been made in respecting an individual's rights since the inception of the *3Rs* education program. However, two participants noted that while their respective organizations have evaluative processes, these did not really measure the cultural change within their organization. As stated by one participant when discussing evaluation:

> I think... things you can implement and do ...doesn't necessarily... it could just mean staff compliance, not a culture shift. And that's great... but are they actually considering... the impact of their actions on another human being every time they engage (ED3)?

Hence, it was noted that the evaluation processes that exist within the organizations are informal and/or based on the satisfaction of the stakeholders with the services that they or their

family member is receiving. A need for a more formal evaluation of the cultural shift and not just compliance with a process was identified.

Liaison Staff as Change Agents

The integral role that the Liaison staff played throughout the implementation of the *3Rs* education program within their respective agencies and with the ongoing shift to a rights-based service agenda was well documented within the responses from all of the Executive Director and Liaison staff participants. As was previously noted, the Liaison staff, who had all been selected for the role by the Executive Directors of their organizations, have over 10 and less than 40 years of experience within their respective agencies and/or with other developmental service sector agencies across the province.

Given the breadth of knowledge and experience found within this group of participants, their descriptions of how services have shifted from traditional to rights-based within their tenure was noteworthy.

Descriptions of the shift.

All of the Liaison staff noted that traditional services were based on a program model that ensured the safety of all the individuals. As one participant stated:

> It was group home or ... day program and that was pretty much it. When I started I was
>
> working in a group home and ... it was, you know, you were there and you helped them to
>
> learn new skills and become independent (L3).

One participant noted that the services were driven by the organization which at that time had very traditional values. He/she stated:

...obviously very controlling in the way that the agency is making the decisions about

how services are provided.... People who are receiving the services have very limited

choices and ... empowerment within their own ... lifestyles and decision making. ... very

oppressive I think for the people in services(L2).

Furthermore, all Liaison staff described that front-line staff in an agency with a more

traditional service delivery model saw their roles as parental. One participant noted:

...staff so much took the role of caregiver and because of that they 'took care of people'

and not really taking into consideration that people do have rights and they do have

choices that they can make on their own(L5).

With the shift to a rights-based service agenda, all of the Liaison staff reported a change

in their agencies to services made with each individual's goals, hopes and dreams being given

priority. As one participant noted:

..more rights based one I think is more flexible more open minded ... and, again, because

you're gearing towards the people in services making decisions and having their input on

how services should run and ... less systemized than the traditional. It's very, you know,

this is the system (L2).

As well, all Liaison staff noted that the staff who have embraced the shift to a rights-

based service agenda now see the mutuality of their roles whereby carer and caregiver can

explore and realize potentials for being. As one participant stated:

I don't think the staff look at themselves as caregivers they look at themselves more like

... promoting peoples' lives now and ...asking them about the things that they want to do

and letting them know that they have choices and giving them those choices so I don't

see us in that traditional role anymore (L5).

However, it was also noted by all Liaison staff that there are still front-line staff who struggle

with this change in their role although the prevalence of this has decreased over the years since

the implementation of the *3Rs* education program.

Skills and qualities needed in a good liaison staff.

The Executive Director participants in the research project were forthright about what

skills and qualities were required in a Liaison staff. Several noted that they were fortunate to

find this person within their existing human resources as it would be a difficult position for

which to recruit. Many of the responses from the Executive Directors spoke to specific qualities

in a successful Liaison staff which included being well respected by their colleagues, being

positive, well-engaged and a champion of the rights agenda. One participant noted that "in

hindsight, [Liaison staff] had to communicate without offending, people took a lot personally,

had to listen and play it back so it taken in the right context" (ED5). Another participant added

to this description:

> ... that person in that role has to be able to have those values...but they also have to be
>
> able to present and talk to people without implying that what you're doing is wrong...
>
> whoever is your Liaison has to be understanding of the "bigger picture" ... and present in
>
> a way that's supportive and constructive rather than being ... demeaning (ED2).

Finally, from a sustainability perspective, one participant noted that it was beneficial that

the Liaison staff was a member of the management team as "she would recognize or see when

there was a bump in the road, bring it back to the managers to our meetings and we would work

through it that way" (ED1). Another participant noted that there would be no additional cost that

could be incurred by hiring additional staff with the choice of Liaison staff that had been made

for his/her organization and that this was always a consideration when planning for

sustainability.

How the Liaison staff saw their role.

All five of the Liaison staff participants described their formal role within their respective

organizations as actively involved with their agencies' rights review committees[1], often as Chair

or Co-Chair, although they also shared their individual perspectives on how they view their roles

within their own agencies. Initially, all of the Liaison staff described themselves as strong

advocates for the individuals who are supported by their organizations. Three Liaison staff

highlighted their ongoing role as trainers for both the staff and the individuals supported by their

organizations. One clearly defined his/her role as the "go to person" (L5). Finally, one

participant described his/her role as:

> ...was definitely a trainer in the initial stages...now it's more of an educator role and I am
>
> the ... resource or the supervisor... I don't know how you would describe it but I guide the
>
> staff reps [who] are doing the training within the organization so when they run into any
>
> stumbling blocks they come to me (L4).

Within the scope of the roles that each participant described, several identified specific

functions as the identified Liaison staff who helped to assist the shift to a rights-based service

agenda. Initially, one participant stated that it was her/his role to "keep things going – especially

at the rights committee meetings" (L2). This same participant noted that the processes put in

place in his/her organization have made staff realize that they "will be held accountable for their

practices" (L2).

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[1] This committee name was selected to represent all committees with the same function as described across all organizations by the participants in this research project.

Two of the Liaison staff identified that since the rights concerns processes have been put in place within their organizations front-line staff will now come to them to discuss solutions when they identify a potential rights concern for an individual with whom they are working prior to initiating the need for a review by the rights committee (L2; L5).

Finally, one Liaison participant in the study stated that his/her role permitted him/her to truly evaluate many of the ongoing practices within his/her organization, both at the management and front-line levels:

> ... but when you're starting off and then you're saying okay let's really take a snapshot of what we do and ... we worked with the management team initially and are saying okay – let's really look at ourselves – are we respecting people's rights – and what is in place that really doesn't need to be in place like you know years ago – locked cupboards on everything – it was easier that way – why are we doing that – is it because it is easier that way or because we are really, you know, we've exhausted looking at every other possibility before we put the lock on the cupboard ... and we've, in probably 90% of the situations, we've come to find that we really didn't explore enough...(L4).

Negative reactions to the Liaison staff.

While all of the Liaison participants in the research project stated they were willing participants in the *3Rs* education program as it espoused their own personal values, many reported negative reactions from their colleagues during the initial phases of the implementation which created a challenge for them. One participant identified that "there's a lot [who] just think I'm making their job harder or I think they're not good enough or they get very defensive about the whole thing" (L2). One participant stated that some of the staff acted differently around him/her initially and noted "oh I shouldn't have said that in front of you ....as if there could be

ramifications" (L3). Another participant identified the negative reaction but also explained it by

saying "oddly enough, when it first started there was a lot of 'hoopla' over the whole transition

and the initiative and I think a lot of it, you know looking back now, was fear" (L4). Finally, one

participant summed it all up by saying "yea...there has been push back ...and, and ... not...I don't

feel it quite as much now as in the beginning but there definitely was a lot of push back in the

beginning" (L1).

The Liaison staff participants involved in this research study were chosen for their role by

the Executive Directors from their respective organizations as they had demonstrated a

commitment to the rights of persons with ID. By accepting the responsibility of being the

Liaison staff , they assumed the role of change agent during their respective organization's shift

to a rights-based service agenda that included additional duties as trainer and advocate which

sometimes resulted in challenges from their colleagues. The integral role played by the Liaison

staff in the shift to a rights-based service agenda was described by all of the participants in the

research project.

Self -Advocates – Their role in the change process

One recurring pattern in the data that was noted during this research project was the role

that the Self - Advocates group [2] within each respective organization played in the shift to a

rights-based service agenda. Some participants stated that their Self-Advocates group was in

existence prior to the introduction of the *3Rs* education program within their organization while

others noted that it was introduced in conjunction with the initiative. One participant stated that:

> ... The development of our self-advocacy group is a huge step yea....and it's pretty much
>
> self-directed so the topics of discussion are things that they've decided that they want to

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[2] Self-Advocates group was the generic term selected for this project to represent the variety of specifically indentified names of the group that function within this framework in each organization.

talk about... there is still that learning piece too like we do go through the rights, respect

and responsibility... (L3).

Another participant emphasized the importance of his/her Self-Advocates group's

presence as a cogent group with influence within his/her organization by stating:

Our self advocates group up and you know they're very...very strong now ... they've just

gone through their second election ... for their executive members... so they're in their

third year and they meet regularly. Their roles are reviewed ... well I shouldn't say well

their roles, but the terms of reference they've developed are reviewed regularly and in the

terms of reference it clearly indicates their role as one of being an assistant to the

organization in the development and review of policies and procedures pertaining to...

you know, rights being one of the them (L4).

One participant stressed the power of rights-based activities with which the Self-

Advocates group within his/her organization is involved by explaining:

...it's like People First – but they call themselves [name removed for anonymity

purposes] - that's very focused on rights there and truth be told I think that group was

just starting as the *3Rs* so, you know, it just all come together – and they really focus on a

lot of rights issues - they did the burying of the "R" word activity and created the march

for social inclusion...(ED 1).

Another participant noted that the individuals supported by his/her agency, some of

whom are members of the Self-Advocates' group, provide regular feedback to the staff on their

rights within the organization.

"Name removed for anonymity" will point out to us when we are stepping on people's

rights they'll question us about that.... it, it gives staff, I really do believe, it gives staff a

better understanding of when they need to say yes or no...and that they are going to have

to justify it...could come under scrutiny which makes people be a little more cognizant of

when they say "oh no you can't do that" as to why they are saying that (ED3).

Finally, one participant highlighted the unique and powerful role the Self-Advocates'

group within his/her organization plays in the shift to a rights-based service agenda when he/she

referenced a conversation he/she had with the Chair of the group.

...and just having her explain, sort of, in terms of 'what they do'... and one of the things

central to one or two of their meeting was, you know, discussions about rights and, why

it's important and the rights type of thing beyond... and ... what was neat about that... in

terms of the... somewhere on the empowerment/self-determination spectrum... was as

fundamentally, well it's not fundamentally different... we create an environment where

it's able to thrive (ED3).

Hence, the important role that the Self-Advocates' groups can play within an

organization in the shift to a rights-based service agenda was identified as an important inductive

theme within this study. As highlighted by the Liaison staff, the members of the Self-

Advocates' groups remind the front-line staff and management of rights concerns on a regular

basis and challenge them to think of ways to respect choices made by individuals. The

Executive Director participants reflected that the members of the Self-Advocates' groups, as

self-directed entities that participate actively at all levels of the agency and within the

community, demonstrate empowerment and self-determination within an environment that

provides the support necessary to do so.

Barriers to Change

The previous discussions have focused primarily on factors that have facilitated the shift to a rights-based service agenda in the organizations represented in this study since the implementation of the *3Rs* educational program. However, the participants also clearly identified barriers that have affected the shift.

Perception of risk.

There was considerable discussion by Executive Directors and Liaison staff with respect to the risks associated with undertaking the shift to a rights-based service agenda. Several of the participants noted that their respective organizations discuss risk in relation to choices made by individuals but, while some have a clear process including a risk assessment protocol (L4), many stated that they still "struggle with this issue" (ED3) and when there is any question that an individual making a request might not understand the inherent risks of his/her choice, or cannot demonstrate that he/she understands the risk, then the individual's choice cannot be respected and the organization must defer to keep the individual safe until an alternate solution is found.

Another tangible consideration was the risk to an organization's reputation and, therefore, its ability to provide supports to individuals with ID when community members or the funding sources question the organization's decision to support an individual's right to make a choice. One participant described the delicate balance of respecting an individual's right to choose versus the funder's expectations that an individual can make a choice as long as "there is no risk or injury" (ED5). Two participants discussed the community's reaction to situations when an individual who is making an informed choice about engaging in an activity with an element of risk, and the need for enhanced rights education for the community to facilitate broader understanding and respect for rights. As one participant stated:

... Community response to agency when it is a perceived risk to someone....... if, you

know, the individuals if you're part of their lives there's much more understanding –

people just get it...but we – I think the community is growing - it is better ... oh we have

such a long way to go (ED3).

Therefore, the individual's ability to make choices and be afforded the "dignity of risk"

(Perske, 1972) can present as a barrier to the implementation and sustainability of a rights-based

service agenda. The former is especially true given the pressure on organizations to demonstrate

to community members, other stakeholders, and potentially to the MCSS that the individual who

has made a choice has the skills to stay safe.

Financial barriers.

All of the Executive Director participants indicated that the initial implementation

of the *3Rs* education program did not present any financial barriers as the majority of the

costs associated with the training, including the cost of replacement staff while the

permanent staff participated in training, was covered by the SSHRC- CURA grant

obtained by Brock University and Community Living Welland Pelham. Three of the

participants from that group indicated that, without this additional funding, the cost of the

training would have been prohibitive for their organization.

None of the Executive Directors indicated that they were directly questioned by their

major funder, the Ministry of Community and Social Services (MCSS), about expenditures made

within their overall budget to facilitate a choice an individual is making. In fact, one participant

noted that the MCSS was very receptive to providing funds to address accessibility issues that

could be tied into a rights issue (ED1). However, several of the participants spoke to the funding

pressures that affect their ability to provide adequate staffing at times to address individual

choice. As one participant stated:

> We are working toward the outcome - it's when we don't have any supports and those
>
> things go to the Board – ... and quite often that happens around some rights issues – it's
>
> not so much that we want to infringe on the right – it's just that we don't have the support
>
> in place to ensure that people have a reasonable safety in exercising that right (ED3).

Therefore, while the funding is available to implement the shift to a rights-based service agenda,

it often requires creativity and support from stakeholders to sustain the shift.

Ministry directives.

All of the organizations involved in this research project received funding from the

MCSS as transfer payment agencies to operate their services for persons with ID with

governance, policies and procedures, and staffing levels directed by the Management and Board

of Directors of the agency. Many participants noted that, while understandable, the

accountability pieces attached to the funding can present as a barrier to a rights-based service

agenda. One of the participants highlighted the residential compliance inspections that require

front-line staff to complete house inspections which could be in direct contravention of an

individual's right to privacy (ED5). Furthermore, another participant spoke of the formal written

agency acknowledgement required for specific directives from the Ministry and the ethical

conundrum this has presented for him/her in recent years (ED2). The directives forwarded by

the MCSS are frequently related to Health and Safety concerns which have included, for

example, installing water temperature regulators on all systems after an incident in one program.

The funding to the agencies provided by the MCSS is often tied into compliance with these

directives.

Hence, this indicates that while the MCSS is supportive of the rights-based service agenda within community organizations, and now has a specific directive related to that basic human right to a life free of all from types of abuse, the accountability framework for some Ministry directives presents as a barrier to the shift.

Issues with communication.

The significance of the integrity of the feedback loop to sustain the shift to a rights-based service agenda was acknowledged by all participants in the research project. Hence, any break in this feedback loop could affect the sustainability of this shift. A few of the Liaison staff participants presented their concern with respecting the rights of individuals who do not use words to communicate and the need to provide appropriate education to this group. As an example, one participant, after discussing significant push back from staff who indicated that they knew what "was best" for the individuals in their program, elected not to involve that staff group in the first cohort of training rather than engaging in a power struggle with that staff group - a difficult choice for him/her (L2). Without this necessary training, this staff group would not know the process for addressing rights concerns within their organization thereby demonstrating a complete lack of awareness of the supports necessary to facilitate the rights of the people whom they support.

One participant explained the difficulty with changing the perspective of one particular staffing group within his/her organization, especially during the initial implementation of the *3Rs* education program. This participant noted that it would likely have been easier, though not morally or fiscally responsible, to acknowledge the strengths that this staffing group had but to help them "leave the organization" and replace them with others who had "championed" the rights-based service agenda (ED2).

It was noted that any breaks in the feedback loop, whether from staff members'

reluctance or inability to embrace the fundamental shift in perspective needed, can impact the

sustainability of the right-based service agenda.

Recommendations

The final question posed to each participant asked for recommendations that they would

have for another organization contemplating adopting a rights-based service agenda.

All of the participants focused on the need for all staff – Executive Director, Directors,

Managers, Supervisors and front-line support staff – to make a full investment in and to support

the shift to a rights-based service agenda. One participant noted that this point was key even if it

required the Executive Director to say "We all need to be on board with... something like... this

is what WE do. Not – this is a new initiative that we have to complete; this is how our agency

rolls" (ED3).

As all participants described it as a "top down" implementation process, it was stated that

"well you know you need to... have the commitment of the board" (ED1). Full support of the

shift from the Board of Directors and Executive Director was emphasized by one participant

when he/she stated:

> Again I feel it has to start from the top and move down and it has to be....the top has to
>
> have the leadership skills to move it forward and the communication skills to get it out
>
> there... of what the expectations are and the courage to lead the path ....that it's not easy –
>
> that there is resistance and there [are] difficulties with family members and with some
>
> staff and to be able to manage those bumps in the road and still be determined that we are
>
> still moving forward with this (L2).

Many of the participants stressed the importance of training for all of the staff prior to the individuals supported by the agency receiving the *3Rs* education program. One participant noted that he/she was of the belief that "training individuals without doing that – I believe – is pretty much a waste of time" (ED2).

A few participants offered suggestions that could enhance the training package for the staff. One participant stated:

...well certainly you know the education ...you can't go without in the initial stages – it's big – make sure your senior managers and your boards are committed to it ...really take...the managers...the direct support managers ...evaluate what you think are going to be some of the biggest stumbling blocks and problem-solve around those so come up with concrete examples of how to overcome some of the issues (L4).

Another participant proposed that the training includes time for the direct support staff to play the game that was developed as part of the education for the individuals who receive supports from the organizations. He/she believed this opportunity to play the game could help the staff learn how to support the individuals with which they are working when they receive the training (L1).

One participant stated that the biggest recommendation he/she would make would be to "Listen to the people ... ...allow them to experience – allow them to make choices – allow them to fail...because everybody learns from failing – right so ..yea...but the biggest thing is listen – don't make judgements – it's their life – their choice" (L3)!

Finally, one participant stated that his/her words of advice would be:

...rejoice when you get a rights concern come forward because that means that people are

getting it ...don't take it personally... be open – definitely be open to the fact that people

will question what you're doing and why... but it's a journey – it's not like one education

– one training is going to make a difference – it's a journey and you've got to "walk the

walk".... (ED2).

Member Checking Documents

As described in the methodology section, member checking documents that delineated

the themes developed during the thematic analysis process for this study were emailed to the five

Executive Director and five Liaison staff participants. These member checking documents were

slightly different for the Executive Director participants and the Liaison participants as the

themes identified were not identical. The member checking documents asked the participant to

agree or disagree with each theme statement and to make additional comments about each one.

Four completed member checking documents were returned by email – two from Executive

Director participants and two from Liaison staff participants. The completed member checking

documents provided 91 percent agreement with the key themes identified during the thematic

analysis of the data. Comments included the role of the *3Rs* education program as a catalyst for

change within their organization (L1; L3) and the significance of putting the training learned

during the *3Rs* education program into practice to sustain the shift to a rights-based service

agenda (ED5). Additional comments highlighted the importance of the Liaison staff member

being well- respected by his/her colleagues (ED5) and the importance of the inclusion of rights

initiatives at the Board level within an organization (ED1; ED5). Finally, two participants stated

that the *3Rs* education program "sparked the interest in rights" in staff who were having

difficulty shifting their perspective from the traditional protection-oriented service agenda to a

rights-based service agenda (L1; L3).

Therefore, the validity of the themes developed during the thematic analysis of the

transcripts of the individual interviews and focus group meeting was supported by the results of

these completed member checking documents. Of course, the perspective of those who did not

respond to the call for member checking cannot be assumed. As well, the information provided

by the completed member checking documents afforded an additional source of triangulation that

enhanced the robustness of the data (Patton, 2002).

Discussion

The increasing international focus on rights protection and promotion for persons with

disabilities, especially since the declaration of the UN Convention on the Rights of Persons with

Disabilities in 2006, and, in part, due to the theoretical shift in philosophy from the medical

model of disability to the social model of disability, has challenged organizations providing

supports and services for persons with ID to evaluate the model of service provision that has

existed within their organizations. Upon reflection, many of the participants in the current study

were struck by the fact that the services that had been provided by their organizations were

program based and so did not necessarily adequately respect the individual rights of the persons

with ID who were supported by them to make choices or to follow their goals and dreams.

To this end, the purpose of this research project was to explore the role, if any, the *3Rs*

educational program played in the shift from a traditional protection-oriented service agenda to a

rights-based service agenda in six developmental service sector agencies across the Niagara

Region in Ontario. Initially, it is important to note that all of the organizations identified that,

historically, they had provided services in a traditional protection-oriented fashion but that some

were already farther along on the trajectory to a rights-based service agenda within their

organization than others during the initial implementation of the *3Rs* education program within

their respective organizations. At this juncture, it is important to note that five of the six

developmental direct service agencies that were involved in the *3Rs* research partnership

supported by the 3Rs SSHRC-CURA grant, elected to participate in this research project. The

nature of the shift within each of these five organizations and how it has evolved over time were

the main foci of the present research. Factors that facilitated the shift to a rights-based service

agenda, especially the replication of the implementation processes necessary to introduce the *3Rs*

education program (Owen et al., 2003), and barriers to the implementation of the rights-based

service agenda were examined.

3Rs Education Program

Initially, the significance of the cascade training system developed in conjunction with

the research team from Brock University and the lead agency, Community Living Welland

Pelham, was identified as a major facilitating factor in the shift to a rights-based service agenda

in the participating agencies. Participants described how the processes involved in the

implementation of the *3Rs* program to introduce and/or enhance an ongoing rights initiative

within their agencies was not instant; it is transformational and continues to evolve. Hence, the

importance of initially replicating the factors that constituted the existing framework was

emphasized by all participants. These elements included introducing the processes needed for

the provision for the double feedback loop between the Committee and the training evaluation

process to the organization's policy development and training functions, and the ongoing review

of the Human Rights statement (Owen et al., 2003).

The overarching theme of the discussions with both Executive Directors and Liaison staff with respect to the role of the *3Rs* education program was that it provided a specific framework for the implementation of the program as well as the processes necessary to enhance the shift to a rights-based agenda within each organization. Ensuring the sustainability of the shift required the incorporation of both the elements of the *3Rs* education process as well as the evolution of the principles inherent in the *3Rs* program into existing practices and processes within each respective organization so that the rights focus became broadly embedded in their organizational culture. As described by Owen et al. (2003), these processes included the development of a Human Rights statement for their agency and access to a Human Rights Committee; the latter became especially important when the staff and individuals supported by the agency became more aware of rights concerns and required a venue to address these concerns. As well, all participants discussed the importance of the identified Liaison staff being trained as *3Rs* trainers for their agency staff and persons supported by their agencies. However, while useful, this was not sufficient to ensure the shift to a rights-based service philosophy that informs all aspects of the organization's work. The present research indicates that while all organizations reported a shift towards a rights-based service agenda, the nature and depth of this shift within each organization since the implementation of the *3Rs* education program was reflective of each agency's prior involvement in a rights initiative and the overall culture of each organization. Hence, the organizations that described themselves as always being strong proponents of the rights initiative, even prior to the implementation of the *3Rs* education program, described a more embedded rights-based service agenda within their organizations. Within these organizations, initial steps had already been taken to include the discussion of individual rights within planning processes and the shift toward individualized supports based on choice had

begun. The organizations that identified that they were newer to the journey towards a rights-based service agenda described a slower though ongoing shift in the service agenda within their organizations. For these organizations, supports and services that focused primarily just on the provision of safety and caregiving within a program-based environment was still the norm when the *3Rs* educational program was implemented.

The evolutionary processes involved in the shift to and then sustaining the rights-based service agenda within each organization were also highlighted in this research. During the initial research stage of the implementation of the *3Rs* education program, all of the organizations directly replicated the training, factors and processes as described by the *3Rs* research team. However, over the years since the research project ended in 2010, all of the organizations have refined their internal processes to reflect their culture in order to enhance the sustainability of the rights-based service agenda. For instance, while all of the organizations still have a committee that addresses human rights concerns that are brought forward by the staff and/or individuals supported by the organization this function does not necessarily remain as a free standing and specific rights committee. Instead, some organizations have embedded this function within another committee while others have multiple committees to address the concerns and the process of feeding back these concerns to management. As well, while all of the participants stated that all of their volunteers, staff, management, and people supported by the agency receive ongoing rights training, this training may be "stand alone" rights training or it may be incorporated with other training modules such as Outcome Measures and/or Risk Management. However, the feedback loop from the Human Rights Committee to the training program and the processes needed to address required changes to the organization's policies and procedures

remain intact though the structure and/or name of the committee has evolved over the course of time to reflect the issues within each organization.

As described by the participants in the research project, the *3Rs* education program served as a catalyst for change to a rights-based service agenda within the five participating developmental service sector agencies across the Niagara Region. Further, it is important to note that the agency-specific evolution of the processes that were initially introduced through the *3Rs* education process are reflective of the culture of each agency therefore indicating that the shift to the rights-based agenda is being embedded in the culture of the organizations.

As described previously, the shift to a rights-based service agenda within an organization is transformational and revolutionary (Owen et al., 2003). The *3Rs* education program, and the associated cascade training system, was designed to include factors that were necessary to facilitate a cultural shift toward a rights-based service agenda. To this end, certain elements described in the literature on organizational change and transformational leadership are reflective of factors in the framework. The role of these elements in the implementation of a rights-based service agenda within an organization must be acknowledged in this research. The three elements that will be discussed are readiness for change, the nature of learning organizations and the role of the change agent.

Readiness for Change

The decision for each of the organizations to become involved in the *3Rs* education program was made by the Executive Director. This "top down" implementation also often involved the organization's Board of Directors and the management team. As discussed previously, the "felt need" for change within each organization, predicated on the organization's

interest or full participation in an accreditation process, lead to the "unfreezing" of the system

thus affording the opportunity for change needed to implement the *3Rs* education program

(Lewin cited in Eby, Adams, Russell, & Gaby, 2000).

Through the presentations on the *3Rs* education program to the organizations' Executive

Directors and Boards of Directors by the Brock University research team as well as through the

rights training for staff and management, interest in this proposed organizational change,

including the implementation of the 3Rs education program was fostered. This enhanced interest

in the *3Rs* education program could result in a change in the attitudes and beliefs of all

stakeholders which could result in the stakeholders feeling the change was necessary (Eby,

Adams, Russell, & Gaby, 2000). The former factor was very important as the change in attitude

and beliefs was necessary to ensure that front-line staff acknowledged the significance of the

rights of persons with ID so that they could accept the change in their role from caregiver to

advocate and educator.   All of the participants in this research project stated that their respective

organization's policies and procedures had been revised to reflect the shift to a rights-based

service agenda, some immediately before the implementation of the *3Rs* education program and

some during an earlier accreditation process. In addition, training on the new policies and

procedures was provided to all stakeholders and this continues to be undertaken on an annual

basis and/or when new policies and procedures are introduced. As described by Eby et al.

(2000), both of the aforementioned practices can help to facilitate an organization's readiness for

change.

Finally, all of the participants in this research project described various committees that

had been introduced to address rights concerns that arise within their respective agencies initially

during the implementation of the *3Rs* education program as well as after as more in-depth

processes were needed to address rights concerns. As well, several participants described

additional committees that serve to enhance individual planning processes for individuals

supported by the organization. It was noted that membership on these various committees

included the individuals supported by the agency, the Executive Director, Management team

members, front-line staff and sometimes members of the community.   Therefore, as posited by

Eby, Adams, Russell and Gaby (2000), stakeholders' involvement on committees that increase

their participation in decision-making processes such as demonstrated by internal committees

within each organization will facilitate an increased readiness for change within an organization.

However, while all of the organizations involved in the present research participated fully

in the processes to facilitate readiness for change within their respective organizations as

proposed by the *3Rs* research group, there was reported "push back" with respect to the rights

initiative from certain staff within each organization. Hence, it appears that further evaluation of

each individual's readiness for change, especially those who are threatened by the change and/or

do not see the need for the change, prior to the implementation of the *3Rs* education program,

would be beneficial during the organizational change process (Austin & Claassen, 2008). The

former idea is reflected by one of the recommendations made by many of the participants when

they underscored the need for all stakeholders to be invested in the shift prior to the

implementation of the program and that additional education might ameliorate this issue.

Learning Organization

All of the participants in this research project noted that since the implementation of the

3Rs education program within their respective organizations that there has been ongoing

commitment to learning by the Executive Director and Management team that supports the

sustainability of the shift to a rights-based service agenda. The participants discussed formal

opportunities for learning such as training in Outcome Measures, Person-Centred Planning and

annual rights training as well as informal opportunities such as discussions at staff meetings that

are ongoing within their respective organizations. This ongoing commitment to training and

educational opportunities in a supportive environment is fostered by a learning organization

(Dubrow, Wocher, & Austin, 2008).

The significance of a feedback loop in an organization's commitment to ongoing change

that is required to sustain a rights-based service agenda resonates both in the literature and in the

discussions with the participants in this research project. Several examples of formal and

informal feedback loops were discussed by the participants in this study. The most referenced

feedback loop was the one that was incorporated in the processes that had been instituted within

each organization with the introduction of the Human Rights Committee prior to the

implementation of the *3Rs* education program. All of the participants discussed the significant

role that this identification, discussion, and formulation of suggestions to ameliorate potential

rights concerns within their respective organizations had in the shift to a rights-based service

agenda. Furthermore, the scheduled check-in processes for all involved in a temporary rights

restriction, based on a legitimate safety concern, served to reinforce the need to review the

process and provided for an additional feedback loop. The participants noted that the feedback

from the Human Rights Committee was used to inform policies and procedures, provide input

for ongoing staff training and encourage innovative practices and thinking within their

organizations.

There were also examples of more "informal" feedback loops that supported the rights

initiative described that were seen to be a direct result of the *3Rs* education program. Several of

the Liaison staff stated that front-line staff will now approach them proactively to discuss

proposed plans for an individual they are working with so as to ensure that there are no rights

concerns apparent. Several of the participants noted that rights concerns are frequently an

agenda item at staff meetings now and that rights training may be offered at meetings too.

Finally, a few of the participants noted that after Human Rights Committee meetings there is

often the opportunity to debrief and reflect on the concerns that were discussed at the meeting.

These discussions serve as another type of informal feedback on the shift to a rights-based

service agenda.

These mechanisms reinforce the findings in the literature that indicate that a learning

organization provides a feedback loop and support for staff so that the desired change, in this

case the shift to a rights-based service agenda, becomes a permanent part of the agency culture

(Callaly & Anya, 2005).

The former examples of feedback loops were driven by processes that were instituted

during the implementation of the *3Rs* education program. However, an additional noteworthy

contribution to the feedback loops and, therefore, the shift to a rights-based service agenda, was

the introduction of and/or strengthening of the role of Self-Advocates' groups in each of the

organizations involved in the research. All of the participants noted that the members of the

Self-Advocates' groups regularly provide ongoing reminders to the organization itself of the

rights of the individuals supported by their agencies whether through their work on advisory

committees and hiring panels or on a one-to-one basis when a concern arises.   As well, as a self-

directed entity with activities planned and facilitated through its own actions, the Self-

Advocates' groups afford the opportunity to experience self-determination and empowerment for

many individuals who may not have experienced this before. Hence, as noted in the literature,

these organizations have provided an environment where the staff, initially through the training

provided, now support the individuals with ID who receive services from them to make informed

choices based on their rights which has resulted in an increase in their autonomy and self-

determination (Wehmeyer & Bolding, 2001). This supports the findings in the literature that

training being developed in the spirit of adult education as empowerment would reinforce the

shift to a rights-based service agenda due to enhanced self-efficacy and self-determination in

persons with ID (Owen & MacKinnon, 2009). As well, the participants noted that for the

individuals supported by their respective organizations who require additional supports to enact

their rights, the processes introduced by the 3Rs education process affords the opportunity to

discuss the scaffolding of supports required to ensure that all people with ID, even those who

cannot use spoken or symbolic communication, can gain greater control over their own lives and

experience enhanced self-determination (Stainton, 2005; Ward & Stewart, 2008).

It is important to note that this discussion with respect to the feedback from the Self-

Advocates' groups is also indicative of a gradual shift from the provision of first generation or

"negative" rights for the individuals supported by the agencies involved in this study to the

support necessary for these individuals to experience second generation or "positive" rights as

previously described in the literature by Young and Quibell (2000). The addition of the feedback

provided by the members of the Self-Advocates' groups served to further reinforce the shift to a

rights-based service agenda within each of the organizations as well as to reflect the "voice" of

individuals with the lived experience of having ID to the process.

These changes illustrate that each of the organizations involved in this research study,

through the processes introduced prior to, during and following the implementation of the *3Rs*

education program, have demonstrated elements identified in the organizational change

literature that are indicative of the commitment to ongoing learning that is needed to support the

change to a rights-based service agenda.

Change Agent

The selection and appointment of a Liaison staff, who would be trained in the educational

program, shadow training provided by the *3Rs* project staff at their agency and then be available

to provide training within their own organization, was an integral component of the initial

implementation of the *3Rs* education program. As noted through the interview process with all

of the Executive Director participants in this research project, the significance of selecting the

right person(s) for this role and the importance of the ongoing role that this person(s) continue to

play in the shift to a rights-based service agenda within their respective organizations could not

be overemphasized. The Liaison staff served as change agents and were tasked with the role of

introducing new concepts to the agency, assisting communication between the staff and

management, helping to provide a frame of reference for difficult issues and supporting staff

some of whom were initially resistant to the change (Dubrow, Wocher, & Austin, 2008).

The Liaison staff described their role during the implementation of the *3Rs* education

program and moving forward, as a trainer of the *3Rs* training groups for persons with ID and/or

staff groups, as a member of their respective organization's Human Rights Committee and as a

facilitator during the ongoing training on various rights initiatives that they continue to provide

and/or support within their respective agencies. The fact that the Liaison staff serve these

various roles across different environments, such as at staff meetings, various group homes and

day programs, within their organizations further supports their role as change agents (Dubrow,

Wocher, & Austin, 2008). The specific role that the Liaison staff, as change agents, played as

the primary facilitators of the identified formal feedback loop within their organizations was

identified during the interview process within this research study. Such a responsive feedback

loop has been described as being integral to the successful facilitation of a shift, such as the one

to a rights-based service agenda, and the eventual change in culture within an organization that is

required to sustain such a rights-based service agenda (Hemmelgarn, Glisson & James, 2006;

Mullins, 2009; Owen et al., 2003). Therefore, an important facilitating factor to the

implementation and sustainability of a rights-based service agenda within an organization, as

described by the Liaison staff in this study, was the ongoing support and commitment by the

leadership team of the agency to the organizational feedback process. The ongoing support for

the feedback mechanism is of paramount importance so that the changes needed in the rights

training and processes within the agency, as well as changes identified in the policies and

procedures to address rights concerns brought forward by the Human Rights Committee and by

the Self-Advocates' groups, would continue to be addressed.

Thus far, this retrospective exploration has illustrated that the *3Rs* education program,

including the organizational change elements incorporated in the process, has provided both the

catalyst and the framework for the processes needed to facilitate and/or enhance the shift to a

rights-based service agenda within the five developmental service sector agencies that

participated in the present study. This finding was echoed in the recommendations that the

participants stated that they would have for other organizations that may choose to embark on a

similar journey.

The examination of individual readiness for change.

Through this exploration, one noticeable area of concern that could impede the implementation of the shift to a rights-based service strategy was the perceived lack of thoroughness within each agency to evaluate each individual staff member's readiness for change prior to the implementation. As was highlighted by several of the Liaison staff participants (L4; L2; L5), and described in the literature, additional staff training on the historical perspective of the infringement of the rights of persons with ID, concrete examples of rights concerns in everyday life within their organization and, perhaps, the opportunity to explore the rights games that the individuals would use in their training, prior to the introduction of a program such as the *3Rs,* may be beneficial to promote this individual readiness for change and to address concerns these staff members may have with respect to the impending change in their role within the agency (Kotter & Schlesinger cited in Callaly & Arya, 2005).

One of the initial research questions for this study asked the participants to identify barriers to the facilitation of a rights-based service agenda within their organizations. To this end, the barriers to the organizational change needed for the shift to a rights-based service agenda, as well as some practices that have been introduced to mitigate the effect of these barriers, will be discussed.

Barriers to Change

The participants in this study identified barriers that impacted on their respective organization's ability to shift to a rights-based service agenda. It is important to note that many of these barriers had been previously identified in the literature (Mullins, 2009; Owen et al., 2003). Some of the initial barriers that were identified had been at least partially addressed over

time since the implementation of the *3Rs* project while others continue to present an ongoing

challenge.

Risk.

Risk presents as a significant barrier to the implementation of a rights-based service

agenda on many levels. As noted by some of the participants, the internal processes to assess the

level of risk for individuals when they are making choices based on their rights and whether they

understand the risk inherent in these choices demand further discussion by all stakeholders

involved in the provision of supports and services to persons with ID. As mentioned by one

participant (ED3), a planning process to develop best practices across the developmental service

sector agencies in the Niagara Region has been suggested so that all service provider agencies

would be consistent in their approach to rights-based decision making. One participant (ED5)

noted that while the MCSS states that services should be rights-based, it is implied that there can

be no risk or chance of injury when an individual is supported in making a choice. In addition,

the risk to the reputation of an agency after a reported mishap related to an individual supported

by the agency and therefore, their ability to provide supports to persons with ID, was presented

as a serious barrier. The former risk is related to rights-based decision making when the

possibility of risk or injury may be involved for a person with ID being supported to make a

choice. All participants noted that from the perspective of a rights-based service agenda, safety

considerations remain of paramount importance during the planning process with individuals

who are making a choice based on their rights.

On a positive note, some of the participants discussed internal processes that are in place

within their organizations to identify and address risk so that an individual can make informed

choices. It was noted that these processes have been reviewed by staff, management, and the

Executive Director so the staff feel supported when reviewing the choice made by an individual.

As well, a few of the participants identified that the processes introduced with the

implementation of the *3Rs* education program and the Human Rights Committee that require

ongoing review of all rights concerns to ensure that rights restrictions are temporary, and based

on safety only, were beneficial to the shift to a rights-based service agenda. These processes

challenge the organization to find solutions to situations that could lead to a rights concern and

have ended the old pattern of denying choices made by an individual if there was any risk

involved to him/her.

Hence, while risk, both for the agency and the individuals supported by the agency,

remains a potential barrier to the implementation of a rights-based agenda, there are now

processes in place to identify and address the concern at both individual and organizational

levels.

Financial barriers.

There were two primary financial barriers that were presented by the participants in this

research study that could affect the implementation of the *3Rs* education program and the shift to

a rights-based service agenda. First, the Executive Director participants noted that the cost of

training all of the staff, including the cost of backfilling all of their original shifts during *3Rs*

training, could be prohibitive for an agency. These participants noted they were all appreciative

of the funding provided by the SSHRC-CURA grant as they believed in the benefits of this

training for all. Second, and potentially more concerning, is the effect that fiscal restraint is

having on the ability of organizations to provide additional staffing when an individual requires

enhanced supports to exercise his/her right to make a choice, especially in congregate settings

when staffing is based on a "unit cost" of doing service - i.e., the aggregate cost of the service

divided by the number of individuals involved with no consideration given for individual

differences (ED3) and there are waiting lists for even basic services for many persons with ID.

As described in the literature, this funding shortfall could affect the scaffolding of

supports required by some individuals with ID who require additional supports to achieve self-

determination (Owen et al., 2003;Ward & Stewart, 2008) thus resulting in a deleterious effect on

the shift to a rights-based service agenda across an organization.

Ministry directives.

The primary barrier identified as being related to Ministry directives is the accountability

framework requirements that are attached to the funding provided by the MCSS. The annual

residential compliance review was the most significant example given of this type of barrier as

the review is based on compliance with Ministry standards rather than on the rights of

individuals to make choices within their own home-even if it is a group home. One of the

participants noted, however, that the Ministry representatives who complete the compliance

reviews within his/her organization are now more willing to engage in conversations about

meeting the standards with a "rights lens" rather than through absolute compliance as previously

defined by the Ministry representative (ED5). This increased willingness to discuss the

standards with a "rights lens" may be due to the enhanced importance of the rights of individuals

with ID being more in the forefront of Ministry directives.

Break in the feedback loop.

As previously described, the ongoing role of communication feedback loops was of paramount importance to the successful implementation of rights-based service agendas.   The most significant break in the feedback loop discussed primarily by the Liaison staff participants in this study was a result of staff resistance to the change in their role, often identified during the initial implementation of the *3Rs* education program. This issue highlights the importance of organizations thoroughly preparing prior to the implementation of the *3Rs* education program. This includes identifying individual external motivating factors that have valence or significance for each staff member who is resistant to the change so that they are fully engaged in the change process (Issac, Zerbe, & Pitt, 2001).

Implications of this Research Study

The stated purpose of this research was to engage in a retrospective exploration of the perceived impact of the *3Rs: Rights, Respect and Responsibility* educational program for persons with ID and their care providers on participating organizations; this included a focus on the barriers and facilitating factors to the implementation of a rights-based service agenda. At this juncture, it is important to note that the *3Rs* education program was developed with organizational change elements embedded, as delineated in the literature, that are consistent with processes needed to facilitate the organizational shift from a more traditional protection-oriented service agenda to a rights-based agenda and so it is with this perspective that the present research was conducted.

Through this research project, it has been identified that the implementation of the *3Rs* education program served as a catalyst for the shift to a rights-based service agenda within these

five developmental service sector agencies. While some agencies identified that they were already strong advocates for the rights of persons with ID prior to the *3Rs* project, and that their services had been somewhat reflective of this, the *3Rs* education program provided the framework and processes needed to further this rights initiative and ensure the practices were in place to sustain the change. Conversely, other organizations identified that they were newer to the philosophy of rights-based services and that their experience with accreditation processes had highlighted the need for this organizational change. For these agencies, the 3Rs education program, with the research component inherent in the initial training process, was described as a "turning point" for the shift to a rights-based service agenda (ED3).

Further, it is important to note that, although very gradual in some organizations, the shift to a rights-based service agenda is ongoing within all five organizations. This would indicate that the processes that address the organizational change elements introduced with the *3Rs* education program, including readiness for change, the need for a learning organization, and the role of the change agent, may have helped to sustain this shift to a rights-based service agenda (Mullins, 2009; Owen et al., 2003).

As well, it is important to be cognizant of the fact that, as this is a retrospective exploration, many of the barriers to the shift to a rights-based service agenda remain consistent with those described previously in the literature (Austin & Claussen, 2008; Mullins, 2009; Owen et al., 2003). However, internal processes have developed over time within each organization to address many of the potential barriers– even if the initial result of the process is the identification of the rights concern and the organization's commitment to address it and/or advocate for the changes necessary to deal with the identified barrier.

Limitations of the Study and Recommendations for Future Research

In interpreting the results of this study, it is important to be aware of the limitations of the research and to make recommendations for future research that could address these limitations. Initially, while ten of the possible thirteen invited participants who were involved in the *3Rs* education program participated in the study, there was no input from one of the six developmental service sector agencies that participated in the original *3Rs* project. As each of these organizations has unique geographic and cultural perspectives, the data from this agency may have afforded a different perspective of the role of the *3Rs* education program in the shift to a rights-based service agenda. To this end, future research with this population could include an addition to the methodology to include a questionnaire about the role of the *3Rs* education program in the shift to a rights-based service agenda that would be sent to all invited participants as another source of data that would be used to further triangulate the results and to ensure maximum participation in the study even for those participants who are not available for an individual interview (Patton, 2002).

The second limitation in this research study is related to the selection process for participants for the study in that only the Executive Directors and Liaison staff from each of the organizations were invited to participate. The rationale for the decision to invite participants from the Executive Directors and Liaison staff groups only was because of the focused and significant role that each of these participant groups played in the implementation of the *3Rs* education program within their respective organizations. Given this limited focus, the depth of penetration of the shift to a rights-based service agenda within and across the participant organizations could not be ascertained as other members of the management team, front-line staff, volunteers and individuals supported by the organizations were not involved in the study.

This limitation could be addressed through future research by replicating the model of this research project with stratified samples of participants from the individuals supported by the agency, front-line staff, volunteers and management across the six organizations. This research may provide additional insight into strategies to identify and address each stakeholder's individual readiness for change that has been described as a barrier in the literature and this study.

Finally, the nature of the interview questions can be considered a limitation to the application of the findings of this research study. All of the research questions were framed around the *3Rs* education program and the role that the program played in the shift to a rights-based service agenda within the organizations involved in the study. While all of the questions were weighted equally to describe facilitators and barriers to the shift to a rights-based service agenda, the questions may have appeared leading to some participants. As well, as this study was a retrospective analysis, some of successes attributed to the *3Rs* education program may have been over reported. To this end, future research on the shift to a rights-based service agenda and the role of the *3Rs* education program, could include the development and implementation of an evaluation framework that could assess the organizational culture prior to the implementation of the *3Rs* education program and one year after.

There were also several strengths that can be associated with this research study. Initially, there was an excellent response to the invitation to participate in the study as 10 out of the 13 people invited chose to participate in the research. As well, as there were several sources of data including the focus group, individual interviews and the member checking document, triangulation of the data was inherent in the design of the study and the reliability of the thematic analysis was enhanced (Patton, 2002).

In conclusion, this research study has provided a broader, though not as in-depth perspective as that originally investigated by Mullins (2009), of the role of the *3Rs* education program in the shift to a rights-based service agenda. However, this study has demonstrated how the processes inherent in the design of the *3Rs* education program have been implemented across five organizations and how they have evolved to be incorporated into existing practices and thus have become embedded during the cultural shift to a broader, rights-based service agenda.

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Appendix A

Focus Group Questions (with sample probes)

1. Why did your organization become involved with the 3Rs rights training?

2. Who decided to get involved in rights training?

     a) What role, if any, did the Board of Directors play in this organizational change?

3. For someone who knew nothing about the 3Rs Project how would you describe it for them?
   Did your organization use regular rights training for staff and persons you support before the 3Rs project?

4. What impact, negative or positive, did the 3Rs Project have on your organization?
   What challenges did your agency experience during the 3Rs educational training program? Did these challenges make you question your involvement in the training?

5. How would you describe the difference between a traditional approach to community services in your field and an approach that is based on Human rights?

     a. What, if anything, changed in your agency during or after the 3Rs rights training?
     b. Did the 3Rs Project and the rights training have any impact on how your agency operates on a day-to-day basis (i.e., policies, procedures)?

6. How would you describe the approach to rights issues in your organization?

     a. Do you have a rights committee or access to a rights committee? How does it work?
     b. How did or does the rights training impact staff hiring, evaluation, the day to day work of the organization?
     c. How are rights reflected in individual support plans? (Do support plans include identification of his/her choices based on his/her right to choose?)
     d. Are new staff and board members provided with the 3Rs educational program training or an alternative rights-based training program?
     e. Have your staff had the opportunity to develop innovative practices that have enhanced the rights-based training within your organization?

7. Please describe the roles, if any, that your senior management team and Board of Directors played in the 3Rs rights process and the role they play in the continued promotion a rights-based service agenda?

    a) How were they involved in developing your organization's rights statement for your agency?
    b) How were they involved in rights related changes in policies and procedures?
    c) Did they determine or have input into who the liaison staff for the agency would be?
    d) What was their role in providing support and guidance to front-line supervisors and/or front line staff in promoting a rights-based service approach? (prompt: i.e. training, extra supervision, open discussions with respect to the challenges they were experiencing?)
    e) Who secured the extra funding needed to ensure that the staff could attend the 3Rs training and how was that accomplished?

8. Implementing a rights-based service agenda within an agency is a rewarding but challenging task. What factors facilitated the shift to a rights-based service agenda?

    a) What, if any, role did the 3Rs training play?
    b) Please describe whether and what type of impact the 3Rs training had on your managers and staff. (Did the 3Rs educational training help staff to identify potential rights restrictions in their own work? Did they revise how they provide support to people?)
    c) Please describe what, if any, impact the 3Rs training had on the individuals supported by your agency. (Did the 3Rs educational training for the people supported by the agency make them aware that they have choices based on their rights thereby increasing the awareness of the rights-based service agenda?)
    d) Was there additional funding available to support the training for individuals (How was it obtained?)
    e) What factors assisted in the "cultural" shift that is needed to adopt a rights-based service agenda (e.g. buy-in from the Board of Directors and staff)? Have you been able to sustain this shift within your agency and, if so, how have you done this?

9. What are the challenges/barriers to implementing and promoting a rights-based service agenda?

    a) How do you manage questions from the Ministry about funding expenditures based on choices made by individuals your support?
    b) How do you manage funding based on individual rather than program needs?

     c) Respecting a choice made by an individual can sometimes include recognizing the "dignity of risk". How does your agency address the risk factor?

10. What do you do to evaluate the impact of implementing the change to a rights-based service agenda?

     a) Is this evaluation ongoing?
     b) Are formal tools, e.g. satisfaction surveys, used as part of the evaluation process?
     c) Have there been any changes in your rights agenda given changes in government policies and procedures and funding allocations?

11. What recommendations do you have for other agencies that are contemplating a shift to a rights-based service agenda?

Appendix A.1

Demographic Information Sheet for Executive Directors

1. How long have you worked as the Executive Director/Chief Executive Officer for the agency you are representing?

   _____

2. How long have you worked for a developmental service sector agency?

   _____

3. Were you in the same position as you are now when the 3Rs rights training program was introduced to your agency?

   □ Yes   □ No

4. What other positions have you been employed in at a developmental service sector agency? e.g. front-line support staff, Manager

   _____

   _____

   _____

   Thank you for your willingness to participate in this research study. It is hoped that the information gathered will help the reader to understand the process of implementing a rights-based service agenda and inform others who are contemplating the adoption of a rights-based service agenda within the organizations they work for.

Appendix B

Interview Questions for Liaison Staff (with sample probes)

1. How long have you worked for this organization?

2. Are you in the same position now as you were in when you were chosen as the Liaison staff for the 3Rs educational training program?

3. How long have you been involved with the 3Rs educational program?

4. How were you chosen to be a Liaison for the 3Rs project in your agency?

5. How many training groups did you run and when was the last one you offered for:

    a. Staff?
    b. People supported by your agency?

6. Why did your organization become involved with the 3Rs rights training? (Who was involved in deciding that you're your organization would be involved?)

7. Please describe your involvement in the development of the rights statement for your agency.

8. How would you describe how services work in an agency that has a traditional approach to community services in your field?

9. How would you describe an agency that has a rights-based approach to services?

10. For someone who knew nothing about the 3Rs Project how would you describe it for them?

    a. Please provide some examples of the changes within an organization that are needed to implement the rights-based service approach that the 3Rs project describes.

11. How would you describe the approach to rights used in your organization?

     a. Do you have a rights committee or access to a rights committee? How does it work?

    b. How did or does the rights training impact staff hiring, evaluation, the day to day work of the organization?

    c. How are rights reflected in individual support plans? (Do support plans include identification of his/her choices based on his/her right to choose?)

12. Are new staff and Board members provided with the 3Rs educational program training or an alternative rights-based training program?

13. What impact, negative or positive, did the 3Rs Project have on your organization? What challenges did your agency experience during the 3Rs educational training program? Did these challenges make you question your involvement in the training?

    a. Please describe any changes to your organization's policies and procedures since your involvement with the 3Rs.

    b. Do you believe the 3Rs training and the proposed shift to a rights-based service agency resulted in a positive change within your agency? If so, please give some examples. If not, why not?

14. How would you describe your role as a Liaison staff for the agency?

    a) As a trainer for staff and the people we support?

    b) As an advocate for the rights of people with ID?

    c) Have there ever been any negative reactions to you because of your role as a liaison staff? Please give me an example?

    d) Have there ever been any positive reactions to you because of your role as a Liaison staff? Please give an example.

15. How would you, as the Liaison staff, describe your relationship with other staff and the people you support?

    a) Has your relationship with staff colleagues changed since you became a 3Rs Liaison staff? Please give examples.

    b) Have there ever been any negative reactions to you because of your role as a liaison staff? Can you give me an example?

c) Can you give me examples of positive feedback you have been given by colleagues because of your role as the Liaison staff?

d) Have you had the opportunity to develop innovative practices that have enhanced the rights-based training within your organization?

16. Please describe any changes to your thinking with respect to a rights-based service agenda from the beginning of the organizational shift to now.

a) Did you become more concerned with infringements on the rights of the people supported by the agency?
b) Were you less concerned about rights' infringements as others were now becoming aware of them?

17. Can you tell me about some practices within your agency that fostered the shift to a rights-based service agenda?

a) How was a focus on rights promoted in your agency?
b) What was the role of senior management and Board members?
c) Did the family members and friends of people supported by the agency identify changes in their member's choice-making? If so, how did they describe the change and where it came from? (Was this connected to the 3Rs educational program?)
d) What, if anything, was the role of the 3Rs educational training program in supporting or hindering the change to a rights-based service agenda within your agency? Please describe and give examples.
e) Do the processes introduced to address rights infringements help to facilitate or did they hinder the change? Please describe and give examples.

18. Please describe the challenges associated with adopting a rights-based service agenda in your agency.

a) What were the major barriers?
b) What was the role of front line staff in promoting rights in the agency?
c) Have funding cutbacks or changes affected your ability to offer choices to the people you support? How is this addressed within your agency?
d) Respecting a choice made by an individual can sometimes include recognizing the "dignity of risk". How does your agency address the risk factor?

19. What additional factors have facilitated the adoption of a rights-based service agenda in your agency? e.g. increased awareness of rights, support of management staff in the process,

20. Without identifying anyone, please describe any changes you have seen in persons you support in the way they will make a request or a choice since the introduction of the 3Rs educational program.

    a) Do you believe the people you support are more or less aware of their rights and the rights of others since the 3Rs training? Please give examples without identifying anyone.
    b) Do the people you support identify when someone has infringed on their rights?
    c) How do the persons you support typically deal with rights infringements that they identify?
    d) Do the people you support share anecdotes about the impact the training has had on their lives?

21. On an organizational level, how do you evaluate the impact of the 3Rs training on the agency?

    a) How would you describe your role as a trainer and advocate on the impact of the 3Rs training in your agency?
    b) Is there the opportunity for ongoing discussions with respect to the 3Rs educational program within the agency?
    c) Do you use formal tools, e.g., satisfaction surveys, to evaluate the impact of 3Rs training?

22. What recommendations do you have for other agencies that are contemplating a shift to a rights-based service agenda?

Appendix C

BROCK UNIVERSITY

Invitation to Participate in a Focus Group

Retrospective exploration of the impact of the 3Rs education program: Systemic facilitators and barriers to the implementation of a rights-based service agenda

Researchers: Linda Morrice, Centre for Applied Disability Studies & Frances Owen, Child & Youth Studies and Centre for Applied Disability Studies

The purpose of this research project is to provide a retrospective exploration of the perceived impact of the 3Rs educational programs and the barriers and facilitating factors involved, on both personal and organizational levels, in the implementation of a rights-based service agenda in community agencies. The study will focus on what, if any, changes to organizational policies and procedures have been tried, how the changes were implemented and with what effect and what recommendations could be made to other organizations undertaking and implementing a rights-based service agenda. It is important to note that to fully examine the perceived impact of the 3Rs educational program, challenges to the implementation of a rights-based agenda as well as innovative ideas that would facilitate the cultural change needed within an agency to sustain this change will be examined.

Participating in this study includes involvement in a focus group (approximately 1 hour) and completing a questionnaire that will be emailed to you after the focus group is completed. The focus group will be conducted immediately after the monthly meeting of the DSSF table that is scheduled, once ethics approval has been received, to be held at the administrative offices of

Bethesda.   Lunch will be provided for all who choose to participate in the focus group. The

questions will focus on the perceived impact on you, your agency and the persons you support

since the 3Rs education program was implemented. If you are not able to attend the focus group

meeting but would still like to participate in the research study, the student investigator will

interview you individually. As well, immediately after the focus group and/or interview, the

student investigator will be requesting your consent for your agency to participate in the research

project and for permission to invite the staff from your agency who acted as 3Rs Liaisons to

participate in this project through an interview process and the completion of an emailed

questionnaire.

Your participation will be voluntary and will occur immediately after a monthly meeting

of the DSSF table or as per your schedule in the case of an individual interview. Please be aware

that you may withdraw from the study at any time without penalty. All personal data will be

kept strictly confidential. Only the researchers named above, and a note taker for the focus

group, will have access to the information you give throughout your participation in the study.

Your name will not be associated with any comments provided when the results of the study are

reported, used for educational purposes and published however you may be identifiable through

your organizational position or title. Your involvement in the study involves only minimal risk

(e.g., possibly feeling uncomfortable disclosing some information). However, all information

disclosed will remain completely confidential. This study has been reviewed and received

clearance through the Research Ethics Board at Brock University (REB file # 12-026).

The information gathered during this study will help to inform other agencies that are

considering implementing a rights-based service agenda and could be utilized by the agencies to

inform their decision-making processes in relation to implementing a rights agenda in their

agencies. The participants in the study may also find the opportunity to reflect on the process

beneficial to the work in their own agencies. If you would like to participate in this research

project, please contact Linda Morrice, at lm76cu@brocku.ca . Thank you for your consideration.

Appendix D

BROCK UNIVERSITY

Consent for Focus Group Participants

Retrospective exploration of the impact of the 3Rs education program: Systemic

facilitators and barriers to the implementation of a rights-based service agenda

Researchers: Linda Morrice, CADS   Frances Owen, CHYS/CADS

Name of Participant: (Please print) _____

I understand that the purpose of the research project is to provide a retrospective

exploration of the perceived impact of the 3Rs educational programs and the barriers and

facilitating factors involved in the implementation of a rights-based service agenda. The study

will focus on what, if any, organizational policies and procedures have been developed to

promote a rights-based service agenda in my agency, how the changes were implemented, and

with what effect, and what recommendations could be made to other organizations undertaking

this process**.** I understand that my participation in this study is voluntary and that my refusal to

participate in this study will not affect my relationship with my colleagues or the researchers. I

understand that I may withdraw from the study at any time and for any reason without penalty. I

understand that this research project is being conducted as partial fulfillment of the degree

requirements for a Master of Arts degree in the Centre for Applied Disability Studies at Brock

University.

I understand that this focus group will take approximately 1 hour.

I understand that this research could benefit agencies that provide support and services to people with intellectual disabilities who are thinking of adopting a rights-based service agenda. In addition, this research could potentially benefit the agencies in the region who have already adopted a rights-based service agenda by reinforcing their decision to do so and by providing the opportunity to define the challenges and highlight their successes.

I understand that the risks involved in participating in this study are only minimal (e.g., possibly feeling uncomfortable disclosing some information). However, I am also aware that all information I provide will not be associated with me by name. I understand that quotations may be included in presentations and/or publications but they will not be identified other than as coming from a focus group of Executive Directors whose organizations participated in the 3Rs Project. The exception to this is that those who participate in the focus group and a note taker associated with the researchers will hear my responses. I understand that I and all other focus group members will be asked to keep the focus group discussion confidential. In addition, while I understand that you will not use my name, I may be identifiable through my organizational position or title since the names of organizations that have been partners in the 3Rs project is public information. I understand that as the focus group will be held immediately after a regularly scheduled DSSF meeting that others from the forum may be aware that I am a participant but that the researchers will keep individual responses confidential.

I understand that all my personal data will be kept strictly confidential. I understand that only the researchers named above and a note taker for the focus group will have access to the information I give throughout my participation in the study. I understand that the researchers may publish articles, books and/or book chapters and make professional and public presentations

using information from the data provided in this study but my name will not be associated with the published or presented research results.

[   ] Yes, I understand the nature of this study and my involvement in it. I agree to participate in this study and I understand that I may withdraw from this study at any time without penalty.

[   ] Yes, I also give you permission to involve my agency in your research project and to invite the Liaison staff from my agency to participate in this project.

Participant Signature_____ Date: _____

This study has been reviewed and approved by the Brock Research Ethics Board (File #12-026). If I have any questions or concerns about my participation in the study, I may contact Linda Morrice (lm76cu@brocku.ca) or Frances Owen (fowen@brocku.ca) or (905) 688-5550 ext. 4807) or the Brock University Research Ethics Officer (905) 688-5550, 3035.

Thank you for your help! Please take one copy of this form with you for further reference.

Researcher Signature_____ Date: _____

Appendix E

BROCK UNIVERSITY

Invitation to Participate in Interviews

Retrospective exploration of the impact of the 3Rs education program: Systemic

facilitators and barriers to the implementation of a rights-based service agenda

Researchers: Linda Morrice, Centre for Applied Disability Studies & Frances Owen, Child &

Youth Studies and Centre for Applied Disability Studies

The purpose of this research project is to provide a retrospective exploration of the perceived impact of the 3Rs educational programs and the barriers and facilitating factors involved, on both personal and organizational levels, in the implementation of a rights-based service agenda. The study will focus on what, if any, rights-based changes to organizational policies and procedures have been implemented in your agency, how the changes were implemented and with what effect, and what recommendations could be made to other organizations undertaking and implementing a rights-based service agenda. It is important to note that to fully examine the perceived impact of the 3Rs educational program, that challenges to the implementation of a rights-based agenda as well as innovative ideas that would facilitate the cultural change needed within an agency to sustain this change will be examined.

Participating in this study includes being interviewed by the student researcher (approximately 1-1.5 hours) and completing a questionnaire that will be emailed to you after the interview is completed. The questions will focus on the perceived impact on yourself, your agency and the persons you support since the 3Rs education program was implemented.

Your participation will be voluntary and refusal to participate will not affect your relationship with your employer or the researchers. The interview with you will be scheduled at a time that is convenient for you. Please be aware that you may withdraw from the study at any time without penalty. All personal data will be kept strictly confidential. Only the researchers named above will have access to the information you give throughout your participation in the study. Your name will not be associated with any comments provided when the results of the study are reported, used for educational purposes and published. Your involvement in the study involves only minimal risk (e.g., possibly feeling uncomfortable disclosing some information). However, while your name will not be associated with the information you provide when the results of the study are presented and/or published you may be identifiable through your organizational position or title since the names of organizations that have been partners in the 3Rs project is public information. This study has been reviewed and received clearance through the Research Ethics Board at Brock University (REB file # 12-026).

The information gathered during this study will help to inform other agencies that are considering implementing a rights-based service agenda and could be utilized by the agencies to inform their decision-making processes especially during times of fiscal restraint, government restructuring and/or challenges to the rights of the persons they support. The participants in the study may also find the opportunity to reflect on the process beneficial to the work in their own agencies. If you would like to participate in this research project, please contact Linda Morrice, at lm76cu@brocku.ca or Frances Owen at fowen@brocku.ca or (905 688-5550, ext. 4807).

Thank you for your consideration.

Appendix F

BROCK UNIVERSITY

Consent for Participation in Interviews

Retrospective exploration of the impact of the 3Rs education program: Systemic

facilitators and barriers to the implementation of a rights-based service agenda

Researchers: Linda Morrice, CADS   Frances Owen, CHYS/CADS

Name of Participant: (Please print) _____

I understand that the purpose of the research project is to provide a retrospective exploration of the perceived impact of the 3Rs educational programs and the barriers and facilitating factors involved in the implementation of a rights-based service agenda. The study will focus on what, if any, organizational policies and procedures have been implemented in my agency, how the changes were implemented, and with what effect, and what recommendations could be made to other organizations undertaking this process**. I** understand that this research project is being conducted as partial fulfillment of the degree requirements for a Master of Arts degree in the Centre for Applied Disability Studies at Brock University

I understand that my participation in this study is voluntary and that I may withdraw from the study at any time and for any reason without penalty from my employer or the researchers.

I understand that the interview I am agreeing to will take 1-1.5 hours and will be audiotaped. The audio recording will be transcribed and erased. Transcriptions will be retained in a secure location at Brock University for five years after the study.

I understand that this research could benefit agencies that provide support and services to people with intellectual disabilities who are thinking of adopting a rights-based service agenda. In addition, this research could potentially benefit the agencies in the region who have already adopted a rights-based service agenda by reinforcing their decision to do so and by providing the opportunity to define the challenges and highlight their successes.

I understand that the risks involved in participating in this study are only minimal (e.g., possibly feeling uncomfortable disclosing some information). However, I am also aware that all information disclosed will remain completely anonymous.

I understand that all my personal data will be kept strictly confidential. I understand that only the researchers named above will have access to the information I give throughout my participation in the study. I understand that the researchers may publish articles, books and/or book chapters and make professional and public presentations using aggregated information from study participants. While I understand that you will not use my name I may be identifiable through my organizational position or title since the names of organizations that are partners in the 3Rs project is public information.

[   ] Yes, I understand the general nature of this study and my involvement in it. I agree to participate in this study and I understand that I may withdraw from this study at any time without penalty. I also give you permission, should it be deemed necessary, to contact me after my interview has been transcribed so that I can review the transcription for accuracy and to add additional details that I may have thought of.

Participant Signature_____ Date: _____

This study has been reviewed and approved by the Brock Research Ethics Board (File #12-026). If I have any questions or concerns about my participation in the study, I may contact Linda Morrice (lm76cu@brocku.ca) or Frances Owen (fowen@brocku.ca) or (905) 688-5550, ext. 4807 or the Brock University Research Ethics Officer (905) 688-5550, ext. 3035.

Appendix G

BROCK UNIVERSITY

Note -Taker Confidentiality Agreement

Title of Project: Retrospective exploration of the impact of the 3Rs education program:

Systemic facilitators and barriers to the implementation of a rights-based service agenda

Researchers: Linda Morrice, CADS   Frances Owen, CHYS/CADS

I, _____, agree to:

a) keep all of the research information shared with me confidential by not discussing or sharing the research information in any form or format, including flash drives, transcripts, notes or any other medium, with anyone other than the researchers.

b) keep all research information in any form or format secure while it is in my possession. This may include keeping all transcript documents confidential, closing any transcription programs and documents when temporarily away from the computer, keeping any printed notes or transcripts in a secure location such as a locked file cabinet in the lab at Brock University; and permanently deleting any e-mail communication containing the data.

c) return all research information in any form or format to the researchers when I have completed the research tasks.

d) after consulting with the researchers, erase or destroy all research information in any form or format regarding this research project that is not returnable to the researchers.

Name of Note taker: _____

Signature of Note Taker   _____

Date: _____

Witness: _____

Appendix H

Member Checking of Themes – Executive Directors

Title of Project: <u>Retrospective exploration of the impact of the 3Rs education program:</u>

<u>Systemic facilitators and barriers to the implementation of a rights based service agenda</u>

Researchers: Linda Morrice, CADS   Frances Owen, CHYS/CADS

An integral part of qualitative research that includes thematic analysis is the review of the

themes derived by the researcher from the transcribed audiotapes of the participants in the study.

The consent you signed prior to your interview indicated that you were willing to review a

summary of themes for accuracy and to add any additional details you may have thought of.

Delineated below is a compilation of overarching themes derived from the information provided

by the Executive Director(s)/Chief Operating Officer(s) who chose to be involved in the study.

For each theme noted below, please feel free to agree or disagree and to add comments

that could enhance accuracy and add robustness to the research.

1. The Executive Director/CEO, in conjunction with the Board of Directors, served as the

   lead for the introduction of the 3Rs program into the organization.

   Agree □   Disagree □

   Comments:

2. During the introduction of the 3Rs program, the "push" came from the top down and was carried by "champions" from among the management team and front-line staff.

   Agree □   Disagree □

   Comments:

3. The Liaison staff member, who was chosen by the Executive Director/Chief Executive Officer, played a key role in the successful implementation of the 3Rs program and a rights-based service agenda within the organization.

   Agree □   Disagree □

   Comments:

4. The demonstrated qualities important in a Liaison staff include, but are not limited to: being a champion of rights-based causes, being positive and respected by their colleagues, having the ability to communicate without offending anyone during "difficult conversations" and being seen as non-threatening by all members of the organization.

   Agree ☐   Disagree ☐

   Comments:

5. The Liaison staff member serves an integral role in facilitating the "feedback" loop between the concerns raised at the rights committee and the changes made to the organization's rights statement and operational policies and procedures based on the discussions at the rights committee meetings.

   Agree ☐   Disagree ☐

   Comments:

6. The 3Rs program provided the resources, training and structured framework needed to facilitate the change to a rights-based service agenda within the organization to augment the organization's ongoing rights work.

Agree □   Disagree □

Comments:

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7. Our organization's involvement in an accreditation process, in conjunction with the 3Rs program, helped to ensure a shift to a rights-based service agenda.

Agree □   Disagree □

Comments:

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8. Our organization's involvement in person-centred planning, in conjunction with the 3Rs program, helped to ensure a shift to a rights-based service agenda.

    Agree □   Disagree □

    Comments:

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9. Our organization's involvement in outcome measures, in conjunction with the 3Rs program, helped to ensure a shift to a rights-based service agenda.

    Agree □   Disagree □

    Comments:

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10. The rights committee, though reconfigured since the introduction of the 3Rs program, continues to provide a venue for staff and the individuals supported to address rights concerns and challenges so that all involved continue to be accountable when infringements are necessary for safety reasons.

Agree □   Disagree □

Comments:

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11. The cultural shift necessary to sustain a rights-based service agenda within an organization was enhanced by the 3Rs program in that the staff were challenged to review existing practices through a "rights-based" lens.

Agree □   Disagree □

Comments:

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12. Rights-based services have become part of our organization's strategic planning

processes and/or are regularly discussed at Board meetings.

Agree □   Disagree □

Comments:

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13. Our organization's self-advocates' group plays a key role in ongoing rights education for

their peers thereby providing an opportunity for empowering individuals and increasing

their self-determination abilities.

Agree □   Disagree □

Comments:

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14. The 3Rs education program provided the training necessary for all staff and individuals supported to understand the balance among rights, respect and responsibility in an agency with a rights-based service agenda.

Agree □   Disagree □

Comments:

15. Services based on an individual's rights and choices may be negatively affected by Ministry policies and procedures such as the residential compliance standards.

Agree □   Disagree □

Comments:

16. Some staff of the organization still "struggle" with accepting the individual's right to the

 risk inherent in making individual choices and prefer to keep the person safe by limiting

 their choices.

 Agree □   Disagree □

 Comments:

17. The fear of litigation should an individual be harmed when exercising his/her rights

 could affect an organization's decision on whether or not to support a specific request

 from an individual.

 Agree □   Disagree □

 Comments:

18. The cost of backfill staff to cover shifts while the regular full-time staff are attending the

    3Rs education program could prove to be a barrier to the implementation of this program

    for other agencies during this time of fiscal restraint and increased mandatory training for

    staff.

    Agree □   Disagree □

    Comments:

    _____

19. An increased waitlist for services and a prioritization tool to determine access to services

    could affect an agency's ability to deliver services based, at least in part, on an

    individual's rights to make choices.

    Agree □   Disagree □

    Comments:

    _____

20. Innovative practices such as embedding the concept of rights into Non-Violent Crisis

 Intervention training and/or Outcomes training for staff helps to sustain the shift to a

 rights-based service agenda.

 Agree □ Disagree □

 Comments:

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21. All stakeholders of the organization including the individuals served, the front-line staff,

 managers, directors, the executive director and the board of directors must be "on board"

 with the rights-based service agenda during the implementation process and on an

 ongoing basis to ensure the sustainability of the shift.

 Agree □ Disagree □

 Comments:

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22. All levels of staff (front-line, management and executive) need to be involved in the development, implementation and refining of all facets of the rights-based service agenda within an organization so as to ensure that the cultural shift is sustained thereby facilitating a process whereby the rights of the most vulnerable individuals receiving support from the organization are heard, reflected upon and respected.

Agree ☐   Disagree ☐

Comments:

23. Enhanced community awareness, involved representatives from the Ministry and a change in curriculum at community colleges and universities to reflect and support the rights of people with intellectual disabilities to make choices may assist with the shift to the rights-based service agenda as has been demonstrated in the identified developmental service sector agencies within the Niagara Region.

Agree ☐   Disagree ☐

Comments:

Thank you for completing this survey.

This document can be completed on-line, saved and emailed back to the student investigator of the research project at lm76cu@brocku.ca or you can write on the printed template, scan it and email it back to lm76cu@brocku.ca.

This study has been reviewed and approved by the Brock Research Ethics Board (File #12-026). If you have any questions or concerns about this study, please contact Linda Morrice (lm76cu@brocku.ca) or Frances Owen (fowen@brocku.ca) or (905) 688-5550 ext. 4807) or the Brock University Research Ethics Officer (905) 688-5550, ext. 3035.

Appendix I

Member Checking of Themes – Liaison Staff

Title of Project: Retrospective exploration of the impact of the 3Rs education program:

Systemic facilitators and barriers to the implementation of a rights based service agenda

Researchers: Linda Morrice, CADS   Frances Owen, CHYS/CADS

A usual part of qualitative research is a review of the themes interpreted by the researcher from the transcribed audiotapes of the participants in the study. The consent you signed prior to your interview indicated that you were willing to review a summary of themes for accuracy and to add any additional details you may have thought of.

Listed below are some themes derived from the information provided by the Liaison staff member(s) who chose to be involved in the study. For each theme please feel free to agree or disagree and to add comments that could enhance accuracy and add robustness to the research.

1. The Executive Director/CEO, in conjunction with the Board of Directors, served as the lead for the introduction of the 3Rs program into the organization.

   Agree □   Disagree □

   Comments:

2. During the introduction of the 3Rs program, the "push" came from the top down and was carried by "champions" from among the management team and front-line staff.

    Agree □   Disagree □

    Comments:

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3. The Liaison staff member, who was chosen by the Executive Director/Chief Executive Officer, played a key role in the successful implementation of the 3Rs program and a rights-based service agenda within the organization.

    Agree □   Disagree □

    Comments:

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4. The Liaison staff member's role during the implementation of the 3RS program (and

    ongoing) is as an advocate for the rights of individuals with ID who were supported by

    the organization.

    Agree □   Disagree □

    Comments:

5. The Liaison staff member's role during the implementation of the 3Rs program (and

    ongoing) is as a trainer or educator for the staff and/or for the individuals with ID

    supported by the organization.

    Agree □   Disagree □

    Comments:

6. The Liaison staff member's role in the 3Rs program (and ongoing) is as a resource for individuals with ID to assist them in ensuring their rights are listened to and respected when decisions that affect them are being made.

Agree □   Disagree □

Comments:

7. The Liaison staff member serves an integral role in facilitating the "feedback" loop between the concerns raised at the rights committee and the changes made to the organization's rights statement and operational policies and procedures based on the discussions at the rights committee meetings.

Agree □   Disagree □

Comments:

8. The 3Rs program provided the resources, training and structured framework needed to

    facilitate the change to a rights-based service agenda within the organization to augment

    the organization's ongoing rights work.

    Agree □   Disagree □

    Comments:

9. Our organization's involvement in an accreditation process, in conjunction with the 3Rs

    program, helped to ensure a shift to a rights-based service agenda.

    Agree □   Disagree □

    Comments:

10. Our organization's involvement in person-centred planning, in conjunction with the 3Rs program, helped to ensure the shift to a rights-based service agenda.

Agree □   Disagree □

Comments:

11. Our organization's involvement with outcome measures, in conjunction with the 3Rs program, helped to ensure the shift to a rights-based service agenda.

Agree □   Disagree □

Comments:

12. The rights committee, though reconfigured since the introduction of the 3Rs program, continues to provide a venue for staff and the individuals supported to address rights concerns and challenges so that all involved continue to be accountable when infringements are necessary for safety reasons.

Agree □   Disagree □

Comments:

13. The cultural shift necessary to sustain a rights-based service agenda within our organization was enhanced by the 3Rs program in that the staff were challenged to review existing practices through a "rights-based" lens.

Agree □   Disagree □

Comments:

14. The meetings of the rights/quality assurance committee provide the opportunity for

ongoing rights education for both the staff of and the individuals supported by the

organization.

Agree □   Disagree □

Comments:

15. Our organization's self-advocates' group plays a key role in ongoing rights education for

their peers thereby providing an opportunity for empowering individuals and increasing

their self-determination abilities.

Agree □   Disagree □

Comments:

16. The 3Rs education program provided the training necessary for all staff and individuals supported to understand the balance among rights, respect and responsibility in an agency with a rights-based service agenda.

Agree □   Disagree □

Comments:

17. A comprehensive education program on the 3Rs program for all staff members should include concrete examples to make the program more relevant. This comprehensive education program prior to the education program for the individuals who receive support from the agency could enhance the "buy in" for the change in roles for the support staff.

Agree □   Disagree □

Comments:

18. Services based on an individual's rights and choices may be negatively affected by

Ministry policies and procedures such as the residential compliance standards.

Agree □   Disagree □

Comments:

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19. Some staff of the organization still "struggle" with accepting the individual's right to the

risk inherent in making individual choices and prefer to keep the person safe by limiting

their choices.

Agree □   Disagree □

Comments:

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20. Some of the initial "push back" the Liaison staff members experienced from their

    colleagues may have been due to change in role for the staff (from caregiver to advocate)

    and the fact that some of the staff felt threatened by this change in role.

    Agree □   Disagree □

    Comments:

21. Professional support from the Liaison staff member's direct supervisor and colleagues is

    imperative during the implementation of a new program such as the 3Rs so as to facilitate

    and sustain the change to a rights-based service agenda.

    Agree □   Disagree □

    Comments:

22. The fear of litigation should an individual be harmed when exercising his/her rights

could affect an organization's decision about whether or not to support a specific request

from an individual.

Agree □   Disagree □

Comments:

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23. The cost of backfill staff to cover shifts while the regular full-time staff are attending the

3Rs education program could prove to be a barrier to the implementation of this program

for other agencies during this time of fiscal restraint and increased mandatory training for

staff.

Agree □   Disagree □

Comments:

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24. An increased waitlist for services and a prioritization tool to determine access to services could affect an agency's ability to deliver services based, at least in part, on an individual's rights to make choices.

Agree □   Disagree □

Comments:

25. Innovative practices such as embedding the concept of rights into Non-Violent Crisis Intervention training and/or Outcomes training for staff helps to sustain the shift to a rights-based service agenda.

Agree □   Disagree □

Comments:

26. The shift from a service-based agenda to a rights-based agenda has been a gradual

process within my organization but is still moving forward.

Agree □   Disagree □

Comments:

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27. All stakeholders of the organization including the individuals served, the front-line staff,

managers, directors, the executive director and the board of directors must be "on board"

with the rights-based service agenda during the implementation process and on an

ongoing basis to ensure the sustainability of the shift.

Agree □   Disagree □

Comments:

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28. All levels of staff (front-line, management and executive) need to be involved in the development, implementation and refining of all facets of the rights-based service agenda within an organization to ensure that the cultural shift is sustained to facilitate a process whereby the rights of the most vulnerable individuals receiving support from the organization are heard, reflected upon and respected.

   Agree ☐   Disagree ☐

   Comments:

29. Enhanced community awareness, involved representatives from the Ministry and a change in curriculum at community colleges and universities to reflect and support the rights of people with intellectual disabilities to make choices may assist with the shift to the rights-based service agenda as has been demonstrated in the identified developmental service sector agencies within the Niagara Region.

   Agree ☐   Disagree ☐

   Comments:

Thank you for completing this survey.

This document can be completed on-line, saved and emailed back to the student

investigator of the research project at lm76cu@brocku.ca or you can write on the printed

template, scan it and email it back to lm76cu@brocku.ca.

This study has been reviewed and approved by the Brock Research Ethics Board (File

#12-026). If you have any questions or concerns about this study, please contact Linda

Morrice (lm76cu@brocku.ca) or Frances Owen (fowen@brocku.ca or (905) 688-5550

ext. 4807) or the Brock University Research Ethics Officer (905) 688-5550, ext. 3035.