

## **Human Rights and Persons with Intellectual Disabilities: An Action-Research Approach for Community-Based Organizational Self-Evaluation**

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### **Abstract**

*Persons with intellectual disabilities have historically been denied their rights or experienced severe rights restrictions. In recent decades there has been a shift towards the respect for the rights of persons with disabilities. However, there are still rights restrictions that may be in place in today's systems. Agencies supporting persons with intellectual disabilities are beginning to establish commissions on human rights to review restrictions when they occur and to ensure that such restrictions are either justified or removed. These restrictions may be in place to protect the individual, or they may represent restrictions or violations that have no justification. There has, however, been no systematic research into the nature of rights restrictions that exist in systems that support persons with intellectual disabilities. In this research, an agency that was initiating a rights review process asked the critical baseline question: What rights restrictions exist in the agency? Using staff questionnaires and interviews with individuals with disabilities, the more commonly rated rights restrictions were identified within the agency. The data, however, indicate that staff (primary and part-time) and the individuals identified different rights restrictions and had significantly different ratings of these restrictions.*

Historically, persons with intellectual disabilities have been denied the right to live in the community, marry, procreate, work, receive an education, and, in some cases, to receive life-saving medical treatment. They have been subjected to incarceration, sterilization, overmedication, and cruel or

unusual punishment (Scheerenburger, 1983). However, recent history has seen an increasing concern for the way in which people with intellectual disabilities have been treated. This article describes the results of a survey of human rights awareness that was conducted with individuals and their care providers in an Association for Community Living. This action research is part of an ongoing program focused on the implementation of an organization-wide human rights training program (see the article by Owen et al., this issue).

The word "rights" is used here in the sense of human (natural) rights, a term that implies entitlement to such things as food, shelter, a non-threatening physical environment, security, health, knowledge, work, freedom of conscience, freedom of expression, freedom of association, and self-determination (Bayles, 1981). These entitlements are considered to be independent of previous conduct or social position. They cannot be lost. They are not absolute, and they do not necessarily override other considerations (Bayles, 1981). Stratford (1991) explained:

*Each and every human life is equally sacred; each one of us is of infinite worth. To regard the life of a human with a mental or physical handicap as being less valuable than the life of a normal human being is to violate this fundamental notion of equality.(p. 11)*

In North America, rights and freedoms are guaranteed in many ways through vehicles such as the Canadian Charter of Rights and Freedoms, and the Declaration of Independence and the Americans with Disabilities Act (1973) in the United States. Rights are further protected through international agreements that Canada and the United States have signed, including the United Nations Universal Declaration of Human Rights (1948), the United Nations Declaration on the Rights of Mentally Retarded Persons (1971), and the Declaration on the Rights of Disabled Persons (1975) (see Rioux & Carbert, this issue for further details).

### **Rights restrictions**

Rights declared in law are inalienable and, as such, persons with intellectual disabilities should have access to them by virtue of their being. For example, the 1984 revisions to the Ontario Human Rights code declared the rights for all persons who had disabilities, and the Canadian Charter of Rights and Freedoms provides equal rights before and under the law regardless of disability (Neuman, 1984). Yet some of the rights outlined in the Declaration of Human Rights for Disabled Persons are routinely violated, ignored, or

restricted for persons with intellectual disabilities. Some examples include access to (Stratford, 1991):

- medical care, physical therapy, and other education, training rehabilitation and guidance that allow people to develop to maximum potential
- productive work, economic security, and a decent standard of living
- living with their own family, or other situations of their choice
- qualified guardians
- protection from exploitation and abuse

In law, no person can be physically detained, controlled, or restrained arbitrarily. However, this is often done in programs serving persons with disabilities. Examples include: a person with disabilities wishing to associate with others of his choice but not being allowed to do so; a person wishing to take part in religious practice but having no opportunity to do so; a person wishing to leave her/his home but is refused the right to do so; or a person who is physically or chemically restrained. From the perspective of the right to be free of cruel and unusual punishment, one might argue that aversive interventions to treat individuals who self injure is a violation of one's basic rights (Weagant & Griffiths, 1988). Yet, within services for persons with intellectual disabilities, rights restrictions that are imposed on organization members are not typically monitored.

In the literature, there are no documented studies to be found that examine system-wide human rights restrictions on persons with intellectual disabilities. In the present study, a review was conducted of the human rights restrictions that existed in Community Living - Welland/Pelham (CLWP). The review was initiated by the organization's Executive Director as a baseline for the development of a system-wide change that was designed to create increased empowerment and personal goal setting for all individuals.

## **Method**

### **Participants**

Individuals supported in the four types of residential settings operated by CLWP were given the opportunity to participate. The settings included Group Homes, Semi-Independent Living (SIL), Family Homes, and Specialized Group Homes. Group homes were described as locations with

maximum support and multi-bed settings (three or more). SIL consisted of minimum support settings where the individual lived alone or with others in the community with part-time staff support where needed. Family Home Programs involved placement of an individual within an existing family in the community. Specialized Homes were often individually designed residences of one or two individuals who experienced special needs. The supports in these Homes varied based on individual need.

At the time of this study, 120 persons were supported by CLWP in the four types of residential settings (56 lived in Group Homes, 22 in SIL, 33 in Family Homes, and 9 in Specialized Group Homes). Interviews were conducted with 74 out of a possible 120 individuals (32 lived in Group Homes, 15 in SIL, 20 in Family Homes and 7 in Specialized Homes). Forty-six were not interviewed for reasons including choosing not to participate, limitations in communication, providing over-compliant responses, or being away on vacation. In addition to the data gathered from individuals supported by CLWP, mail-in surveys were sent to 76 primary staff and 258 support staff.

### **The survey package**

A system-wide rights survey package (Gosse, et al., 2002) was developed specifically to examine the human rights of persons being supported in community living settings. This package was developed in collaboration with individuals supported by CLWP and their staff. The Human Rights Survey consists of 80 items. Participants rate each item using a 5-point Likert-type scale ranging from disagree (1) to agree (5). Lower scores are indicative of a greater perception of human rights restrictions.

Three parallel survey forms were designed to ask the same 80 questions to three different groups within an agency: the individual being supported, the primary staff person supporting that individual, and all support staff in residential services. Each survey form asked the same questions with slight wording changes to make the survey form appropriate to those completing it.

### **Procedure**

The survey questions were based on a literature search concerning rights of persons in the general population and specific rights for persons with disabilities. A committee of experienced agency staff developed the survey forms, and these were amended following focus group input from individuals served by CLWP, community participants, and staff and individuals who worked/lived in the settings.

All staff in the agency who were involved in residential support and all individuals receiving residential support were given the opportunity to take part in the survey. Written consent was obtained from all parties. All participants were advised that their participation was totally voluntary and that they could withdraw from the study without penalty.

Survey forms were sent to: 1) primary staff who had been approved by individuals to make comments about them, and 2) support staff in all residential settings. Of the 76 primary staff and 258 support staff, 53% of the primary staff and 29% of the support staff returned their surveys. The staff survey forms were returned by mail. Interviews regarding the survey forms were conducted with all individuals supported by the agency who consented and who were able to participate. Two interviewers conducted the interviews with the individuals supported by the agency. The purpose of this was to ensure improved monitoring for concerns such as constricted response sets (e.g., a yes or a no answer used repeatedly) or socially desirable answering (e.g., answering according to the way that they perceived the interviewer would prefer).

All data were coded for the individual and the setting, to protect participant confidentiality. After each individual was interviewed, his/her survey form was placed in an envelope and sealed. Staff survey forms were sent to a researcher at Brock University in self-addressed, stamped envelopes.

## **Results**

### **Human Rights Survey - Factor analysis**

The 80 questions on the survey forms assessed all aspects of a person's life and covered each area of CLWP's human rights statement. All items comprising the Human Rights Survey were subjected to a factor analysis with varimax rotation (Stevens, 2002). This analysis revealed four components with eigenvalues greater than 1.0, which accounted for 53.39% of the total variance. The majority of the intercorrelations of the factors had absolute values above .50 with a range of .40 through .79. The four factors that emerged from this analysis were *Access and Autonomy*, *Relationship and Community Support*, *Safety, Security and Privacy*, and *Control and Decision Making*.

The first factor, labelled *Access and Autonomy* (Eigenvalue=22.50), consisted of 24 items and accounted for 34.50% of the variance. The highest loadings were for "This individual can participate in any other religious

activity that he/she chooses" (e.g., praying, eating specific foods, fasting, wearing religious artifacts) (.79) and "This individual uses the phone in a private place whenever he/she chooses" (.76). The second factor *Relationship and Community Support* (Eigenvalue=4.81) consisted of 21 items and accounted for 7.28% of the variance. The highest loadings were for "A staff member has given this individual medication (meds) without his/her permission in the last 12 months" (.73) and "Everyone always rings the doorbell or knocks and waits for someone to answer before entering the home" (.71). The third factor was labelled *Safety, Security and Privacy* (Eigenvalue=4.27) and consisted of 7 items that accounted 6.47% of the variance. The highest loadings were for "This individual enjoys where he/she lives" (.65) and "This individual is worried about his/her things being stolen" (.64). Finally, the fourth factor was labelled *Control and Decision Making* (Eigenvalue=3.66) and consisted of 9 items that accounted for 5.55% of the variance. The highest loadings were for "This individual is able to decorate his/her room however he/she chooses" (.66), and "If this individual is unhappy, he/she has someone to talk to other than a staff member" (.61).

Five additional items were retained that did not load on any of the four factors but were considered to be conceptually valuable. These items were thought to measure important rights restrictions (e.g., "This individual has received sexual education or is scheduled to do so in the next six months"). Three qualitative, open-ended items, which were not included in the factor analysis, were included in the survey. These items invited the participants to comment openly and freely on any issues pertaining to human rights restrictions (e.g., "There is a human rights issue regarding this individual that needs to be addressed"). Eleven items were removed from the final analysis because they did not load statistically on any of the four factors nor did they fit conceptually with the other items on the survey (e.g., "This individual is required to inform someone else where he/she is going when he/she leaves"). Following the removal of these eleven items, the *Human Rights Survey* consisted of a total of 69 items, and each participant's score was subsequently recalculated (omitting these eleven items).

#### **Overall differences in rights restrictions: Percentage of rights restrictions reported by individuals, primary staff and support staff**

Overall percentages were examined for each of the final 69 items to determine the top seven human rights restrictions as reported by participants. Percentages were examined separately by type of rater including individuals, primary staff, and support staff and across each of the

four settings, that is, SIL, Specialized Group Homes, Group Homes, and Family Homes.

Table 1 presents the top seven rights restrictions as reported by individuals receiving services, for each of the four settings. The column labeled "overall" represents the top seven restrictions rated by the total group of individuals receiving services across the four settings. The top human rights restriction reported by the overall group of raters receiving services was "Worrying about their things being stolen" (46.6%). Some interesting differences are evident in the individuals' ratings across the four different settings. First, "Worrying about their things being stolen" appeared as a top seven restriction in three of the four settings: SIL (64.2%), Specialized Group Home (42.9%), and Group Home (46.9%). However, it did not appear in the top seven for Family Homes. Second, the individuals in Family Homes rated "Cannot be alone with boyfriend or girlfriend" as the number one restriction, but this did not appear on the top seven lists for any of the other settings.

*Table 1. The Top Seven Rights Restrictions Reported by Individuals Receiving Services*

<i>Top 7 Restrictions</i>	<i>Overall</i>	<i>Supported Independent Living</i>	<i>Specialized Home</i>	<i>Group Home</i>	<i>Family</i>
1	Worry about things being stolen (46.6%)	Worry about things being stolen (64.2%)	If sad, there is no one to talk to other than staff (50%)	Cannot decide to receive medical treatment (50%)	Cannot be alone with boy / girlfriend behind closed door (70%)
2	Cannot have children if I choose (44.4%)	There are things I want to do but can't (57.1%)	Worry about things being stolen (42.9%)	Worry about things being stolen (46.9%)	Cannot have children if I choose (70%)
3	There are things I want to do but can't (44.4%)	There are things I want to change but can't (57.1%)	Cannot decide to receive medical treatment (42.9%)	Cannot have a pet if I choose (46.9%)	Need to discuss a human rights issue (53%)

*cont'd*

*Table 1. (cont'd)*

<i>Top 7 Restrictions</i>	<i>Overall</i>	<i>Supported Independent Living</i>	<i>Specialized Home</i>	<i>Group Home</i>	<i>Family</i>
4	Cannot decide to receive medical treatment (42.3%)	Cannot choose primary worker (50%)	Something was removed as punishment (past 12 months) (42.9%)	If sad, there is no one to talk to other than staff (46.9%)	There are things I want to do but can't (45%)
5	If sad, there is no one to talk to other than staff (40.8%)	Worry about someone hurting me (42.9%)	Cannot choose primary support worker (42.9%)	Cannot choose where I live (43.7%)	Cannot live with girl/boyfriend if I choose (45%)
6	There are things I want to change but can't (40.3%)	Do not like where I live (35.7%)	Cannot get married if I choose (33.3%)	Cannot have children if I choose (40.6%)	Want to do something different during day (40%)
7	Cannot be with girl/boyfriend with door closed (38.9%)	Staff always tell me what to do (35.7%)	Cannot have children if I choose (33.3%)	Staff always tell me what to do (40.6%)	Cannot decide to receive medical treatment (40%)

Table 2 presents the top seven restrictions as reported by the primary staff across each of the four settings. Again, the column labeled "overall" represents the top seven restrictions rated by the total group of primary staff. The top two restrictions rated by the primary staff were: "Cannot choose primary support worker" (44.1%) and "There are things they wish to change" (40.3%). Some interesting differences were revealed when the top rights restrictions reported by the primary staff across the four settings were examined. For example, in Group Homes "People do not ring bell before entering the home" (45.5%) was rated as the second top rights restriction. This item did not appear in the top seven list for the other three settings.



Moreover, some notable findings were revealed in the overall magnitude of the top rights restrictions as reported by the primary staff across settings. Interestingly, all of the primary staff in SIL (100%) rated: "There are things the person wants to change but can't" as their top rights restriction. A total of 55.5% of primary staff in Group Homes reported: "There are things the person wants to change but can't" as their top rights restriction, and a total of 50% of primary staff in Family Homes reported "Cannot take a sexuality education course if I choose" as their top rights restriction. Finally, only 28.6% of the primary staff in SIL reported that "Cannot choose primary worker" as the top rights restriction.

*Table 2. The Top Seven Rights Restrictions Reported by Primary Staff*

<i>Top 7 Restrictions</i>	<i>Overall</i>	<i>Supported Independent Living</i>	<i>Specialized Home</i>	<i>Group Home</i>	<i>Family</i>
1	Cannot choose primary worker (44.1%)	Cannot choose primary worker (28.6%)	There are things the person wants to change but can't (100%)	There are things the person wants to change but can't (55.5%)	Cannot take a sexuality education course if chooses (50%)
2	There are things the person wants to change but can't (40.3%)	Staff are not helping find job person wants (28.6%)	Cannot have a pet if chooses (66.7%)	People do not ring bell before entering home (45.5%)	There are things the person wants to change (46.2%)
3	Cannot take a sexuality education course if chooses (36.4%)	Staff do not ask before helping person dress (16.7%)	Cannot take a sexuality education course if chooses (66.7%)	Worry about being hurt (45.5%)	Cannot choose primary worker (46.2%)
4	There are things the person wants to do but can't (38.4%)	Cannot choose friends (14.3%)	There are things the person wants to change (50%)	There are things the person wants to do but can't (40%)	Cannot decide to receive medical attention (38.5%)

*cont'd*

Table 2. (Cont'd)

<i>Top 7 Restric- tions</i>	<i>Overall</i>	<i>Supported Independent Living</i>	<i>Specialized Home</i>	<i>Group Home</i>	<i>Family</i>
5	Cannot decide to receive medical attention (20.6%)	Worry about being hurt (14.3%)	Do not like where living (50%)	Cannot choose where to keep money (36.4%)	There are things the person wants to do but can't (30.8%)
6	Cannot choose where to live (18.2%)	Worry about things being stolen (14.3%)	Cannot choose where to live (50%)	Staff always tell people what to do (33.3%)	Cannot talk on phone in a private place when chooses to (30.8%)
7	Cannot choose when to go out (18.2%)	Do not like what they do during day (14.3%)	Cannot take a sexuality education course if chooses (66.7%)	Worry about being hurt (45.5%)	Cannot choose primary worker (46.2%)

Table 3 presents the top seven restrictions as reported by the support staff across each of the four settings. As with Tables 1 and 2, the column labeled "overall" represents the top seven restrictions rated by the support staff. Overall, the support staff reported their top rights restriction to be "There are things they want to change but can't" (50.8%). This was also the top restriction for the raters in both the SIL (71.4%) and Family Home settings (83.3%). Overall, there were some differences in the types of rights restrictions reported by the support staff across settings. For example, the seventh rights restriction reported by support staff in Family Homes was "Cannot choose religious setting" (55.5%). Interestingly, this restriction was not reported as a top seven restriction by support staff in any of the other three settings.

*Table 3. The Top Seven Rights Restrictions Reported by Support Staff*

<i>Top 7 Restrictions</i>	<i>Overall</i>	<i>Supported Independent Living</i>	<i>Specialized Home</i>	<i>Group Home</i>	<i>Family</i>
1	There are things individuals want to change but can't (50.8%)	There are things individuals want to change but can't (71.4%)	People do not ring bell before entering home (69.2%)	Sent to room (past 12 months) (73.8%)	There are things individuals want to change but can't (83.3%)
2	Cannot choose where to keep money (48.7%)	There are things individuals want to do but can't (66.6%)	Not everyone knocks before entering bedroom (53.8%)	Cannot choose where to keep money (62.8%)	Chemically restrained (past 12 months) (77.7%)
3	Something was removed as punishment (past 12 months) (46.5%)	Cannot take part in sexuality education if choose (37.5%)	Chemically restrained (past 12 months) (53.8%)	People do not ring bell before entering home (64.5%)	Cannot choose when to go out (66.7%)
4	Cannot choose primary support worker (46.1%)	Need to discuss a human rights issue (25%)	Cannot decide to receive medical treatment (50%)	Cannot choose primary worker (60%)	Something was removed as punishment (past 12 months) (66.6%)
5	Given medications without permission (44.8%)	Staff is not helping find individual a job (22.2%)	Cannot choose where to keep money (46.2%)	Something was removed as punishment (past 12 months) (59.6%)	Sent to room (past 12 months) (66.6%)
6	When not at home other people go in room (43.4%)	Worry about being hurt (22.2%)	Given medications without permission (46.2%)	When not home other people go in room (57.7%)	There are things individuals want to do but can't (67.7%)

*cont'd*

Table 3. (Cont'd)

Top 7 Restrictions	Overall	Supported Independent Living	Specialized Home	Group Home	Family
7	There are things individuals want to change but can't (42.4%)	Cannot choose primary worker (22.2%)	Staff looked through person's things (38/5%)	There are things individuals want to change but can't (53.8%)	Cannot choose religious setting (55.5%)

### Mean differences in rights restrictions

Comparison of the means for each group of raters, across each of the four settings, revealed some interesting differences in terms of participants' reported top rights restrictions. In exploring the overall data set, a two-way ANOVA (Rater x Setting) revealed no significant interaction between type of rater and type of setting  $F(6,177)=1.768, p=.108$ ; however, a significant main effect for rater status was revealed  $F(2,177)=7.964, p=.000$ . Follow-up univariate tests revealed that primary staff ( $M=3.86, SD=.61$ ) and individuals ( $M=3.74, SD=.33$ ) reported significantly fewer restrictions than support staff ( $M=3.38, SD=.62$ ). There were no significant differences between the number of restrictions reported by primary staff and the individuals. A significant main effect was also found for setting  $F(3,177)=7.964, p=.000$ . Significantly more restrictions were reported in Group Homes ( $M=3.45, SD=.56$ ) than in Specialized Group Homes ( $M=3.81, SD=.40$ ) and SIL ( $M=4.05, SD=.27$ ). Significantly more restrictions were also reported in Family Homes ( $M=3.57, SD=.60$ ) than in SIL.

### Triangulated differences in rights restrictions: Percentage of rights restrictions reported by individuals, primary staff and support staff

Table 4 presents the top seven restrictions as reported by the individuals, primary, and support staff collapsed across the four settings. To obtain these percentages, only the responses provided by individuals, primary, and support staff that could be triangulated were examined. For example, data provided by an individual were included if data from their primary and support staff were also collected. Therefore, the comparisons made among the three raters would be expected to show more consistency than comparisons with all the staff.

*Table 4. The Top Seven Perceived Rights Restrictions Reported by a Matched (Triangulated) Group (Individuals, Primary Staff, and Support Staff)*

<i>Priority</i>	<i>Individual N=36</i>	<i>Primary Staff N=36</i>	<i>Support Staff N=43</i>
1	Cannot have children if choose (54.3%)	There are things the person wishes to change but can't (45.3%)	There are things the person wishes to change but can't (52.8%)
2	Want to do something different in the day (45.7%)	Cannot choose primary worker (44.4%)	Sent to room (past 12 months) (47.7%)
3	There are things I want to do but can't (42.3%)	The individual wants to do something different in the day (41.6%)	Something was removed as punishment (past 12 months) (45.3%)
4	Can't be alone with boy/girlfriend with door closed (42.9%)	There are things the person wants to do but can't (32.2%)	Cannot choose primary worker (44.2%)
5	If sad, I can't talk to people who are not staff (40%)	Cannot take sexuality education course if they choose (34.3%)	Cannot take a sexuality education course if they choose (42.8%)
6	Cannot decide to receive medical attention (38.9%)	Cannot choose where to live (22.3%)	Cannot choose when to go out (41.8%)
7	Worry about things being stolen (38.9%)	Cannot choose when to go out (22.3%)	Want to do something different in the day (41.5%)

Again, the data from individuals, primary staff, and support staff revealed some interesting differences in terms of the types of rights restrictions reported. For example, no individuals reported that they were "Sent to their

room as a punishment," but 47.7% of the support staff rated this as a restriction. Another important difference was the tendency for individuals to consistently report fewer rights restrictions overall, as compared with the primary and support staff.

The only question on which all three survey groups in the triangulated data agreed to be a priority for the individual was that the individual wants to do something different during the day. 45.7% of the individuals rated this as a priority, as did 41.6% of the primary staff and 41.5% of the support staff. These were rated as priority two, three, and seven respectively.

Individuals rated choice of medical attention (38.9%), worry over things being stolen (38.9%), and having no one to talk to but staff when they are sad (40%) as their priority items. These were not rated as highest priorities for the staff. Two of the top priority items for individuals were not identified as widespread issues by either staff group. Worry over things being stolen, although rated by 38.9% of the individuals, was identified by only 8.4% and 4.7% of primary and support staff respectively. Similarly, the fact that individuals had no one but staff to talk to when they were sad was noted by 40% of the individuals but only 5.8% of the primary staff and 12.2% of the support staff.

Staff members, on the other hand, prioritized two areas that were not highlighted by the individuals. First, the choice of primary workers was identified as an important rights restriction by 44.4% of primary staff and 44.2% of the support workers. This, however, was not a major priority for the individuals, being selected by only 25%. Of greater contrast was the rating of access to sexuality education. This was noted as priority #5 by both staff groups (34.3% and 42.8%) but noted by only 5.7% of the individuals. Of particular note was the identification by support staff of punitive measures taking place in their residential setting that were not identified by either the individuals or primary staff. This difference in perception may be an artifact of the fact that support staff members were reporting on general procedures and not individual-specific rights restrictions.

### **Mean differences in rights restrictions**

For the overall "triangulated" data set, a two-way ANOVA (Rater x Setting) revealed a significant main effect for setting in perceived rights restrictions  $F(3,105)=7.051, p=.000$ . Univariate follow-up tests revealed a significant difference between Group Homes ( $M=3.58, SD=.62$ ) and SIL ( $M=4.08, SD=.29$ ), and between Family Homes ( $M=3.55, SD=.64$ ) and SIL. The

greatest number of rights restrictions were reported by individuals in Family Homes, followed by Group Homes, then by Specialized Group Homes and SIL. A significant main effect was also found for rater status  $F(2, 105)=3.495, p=.034$ . Univariate follow-up tests revealed a significant difference between primary staff ( $M=3.87, SD=.62$ ) and support staff ( $M=3.43, SD=.70$ ). In this regard, the support staff reported the greatest number of rights restrictions, followed by the individuals and then the primary staff. The interaction between type of rater and type of setting was not significant  $F(6,105)=2.155, p=.053$ .

### Key findings

- Human rights restrictions in community living programs fall into four distinct categories: (i) access and autonomy, (ii) relationships and community supports, (iii) safety, security and privacy, and (iv) control and decision-making.
- The evaluation of the type and number of restrictions of rights differ significantly across different types of residential settings. In general, individuals in the SIL settings reported fewer restrictions, followed by Specialized Group Homes. The individuals in both the Family Homes and Group Homes reported the highest number of rights restrictions but were similar to one another.
- The type and number of rights restrictions also differed significantly between different groups within an organization (i.e., individuals supported by the agency, primary staff, and support staff). Individuals served by CLWP expressed concerns in all four rights domains. Primary staff placed greater emphasis generally on issues of *Control and Decision Making* and *Access and Autonomy*. Support staff also perceived the greatest rights restrictions to be focused around *Control and Decision Making* and *Access and Autonomy*, but saw issues of *Safety, Security and Privacy* as well. Interestingly, none of the staff rated issues of *Relationship and Community Support* as the top areas of rights concern, whereas these were paramount to the individuals themselves.

### Discussion

This survey provided an opportunity to examine the level of human rights awareness in individuals served by CLWP and their care providers prior to the establishment of a system-wide human rights training program. It represents a moment "frozen in time" from which the organization has now moved.

The above results may be accounted for by the fact that these data were not matched but represented global data. In 36 situations, however, the data for primary and support staff could be matched to the individual and/or location, although individuals reported more restrictions in the area of *Relationship and Community Support* as well as *Safety, Security and Privacy* than did the staff.

Surveys such as the one undertaken in this study provide a forum for open, dynamic, and ongoing dialogue about human rights issues. They also challenge organization members to examine the very nature of service delivery, including current practice, policy and procedures, and staff/individual training.

As a result of the survey, CLWP has established several mechanisms to reinforce and maintain a systemic emphasis on rights protection. First, it has established a Human Rights Commission to review existing rights restrictions. Second, it has initiated a system-wide Human Rights Training Program for Association staff, managers, members of the Association's Board of Directors, and the individuals who participate in the Association's services (see the article by Owen et al., this issue). Third, feedback from the Association's Human Rights Commission will be used to review Association policy and procedures, and to direct strategic planning decisions.

It is important to recognize that the number of infringements identified through a survey of this nature does not determine that an agency is providing poor service or that the people supported have a poor quality of life. The fact that agency staff, managers, and the individuals they serve have chosen to open them to scrutiny suggests an organizational culture of commitment to continuous improvement of services. Yet, the fact remains that rights restrictions do occur in agencies. Therefore, it is critical that each rights restriction be reviewed (e.g., ensuring people are offered an opportunity to vote).

Moreover, differential identification of rights restrictions across settings may not always be indicative of rights violations as much as the design of the setting. SIL and Specialized Group Homes have been designed more closely along an individualized planning mode, where the program has been designed to fit the individual. Group Homes and Family Homes are generally designed around congregate living in which the individual is placed. Still, in these settings, it is especially important to be aware that rights may be overlooked or ignored.



Individual outcomes planning must include an examination of issues of rights restrictions. If these factors are important for the quality of life the individual chooses, then individualized plans of support need to be developed to ensure that the aspects of rights that the person desires and values are respected and monitored for access. As service systems move toward more person-centered planning, evaluation of human rights and the protection of those rights become embedded in the culture of individualized agency support. At the conclusion of this survey, CLWP adopted a strategic plan to move the agency fully toward person-centred planning.

The goal of a system-wide survey such as this is to stimulate ongoing reflection, discussion, review and revision of Association policies and procedures, and to identify areas for training and staff support. The implications of the findings from this survey can be far-reaching, impacting all aspects of an organization's functioning. This survey is a tool to assist agencies to examine areas where improvement can be made to enhance the rights and the opportunities for individuals to assert their rights. If it is misused against staff or individuals within the agency, it can violate trust and damage important lines of communication. However, if it is used in a partnership with the Board, management, staff members, and individuals in the agency, it becomes a vehicle for powerful positive social change.

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