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Enhancing Independent Living within Community Services for People with Physical Disabilities in Ontario, Canada

Nathan Hauch

In recent years, policymakers in Ontario, Canada have recognized the value of the community sector attendant services in improving health outcomes and reducing costs to the healthcare system. In a context of fiscal restraint, elected officials have emphasized reducing avoidable emergency department admissions and limiting acute care beds to those consumers for whom they deem them most appropriate, as opposed to keeping them in acute care due to the lack of appropriate community discharge destinations. People with complex health conditions are disproportionately represented among consumers in hospital and it is noted that 1 % of Ontario's population accounts for 49 % of hospital and home care costs (Commission for the Reform of Ontario's Public Services, 2012; p. 161). While the province added an additional \$260 million to the community services sector in the 2013 provincial budget (Government of Ontario; p. 121) and also funded one million personal support worker hours for seniors (Government of Ontario, Action Plan for Health Care; p. 12), these investments prioritized seniors with short-term, non-complex needs, while non-seniors with complex needs faced significant access challenges to attendant services.

For non-seniors with disabilities, Community Care Access Centre (CCAC) personal support worker (PSW) services are particularly unequipped to provide consumer-centered services from an Independent Living (IL) framework. That is, with a mandate to control costs and a focus on common assessment measurements and standardization, I suggest that CCAC PSW services and professional services such as nursing and physiotherapy are rooted more in the *medical model* of disability. This

means that service provision tends to focus on specific clinical criteria, and not promote more integrated, community-based health for consumers. While more IL-based services, such as attendant outreach services and self-administered Direct Funding, may be cost-effective on a per capita basis for hours provided, recent governments have proven wary of expanding those services due to broad eligibility criteria. With limited services, consumers are left with paying out of pocket for attendant services, relying on family for caregiver support or are doing without (Spinal Cord Injury Ontario, 2014; p. 9).

Nonetheless, with a renewed focus on obtaining and analyzing consumer engagement results on an aggregate, province-wide scale, the potential exists to deliver CCAC services with more of an Independent Living approach. One could do this through a pilot project to determine eligibility criteria, the scope of services offered, and concurrent evaluation of outcomes. After gathering data, the pilot project could report back to the disability community, which could, in turn, suggest cost-efficient improvements via a public forum.

I begin by exploring the definition of the Independent Living philosophy is defined and then considering how attendant outreach and Direct Funding differ from personal support services provided by CCACs. From there, I examine the existing policy environment. I proceed with an alternative framework for providing CCAC services in a manner more conducive to consumer wishes and needs and the IL philosophy.

Nathan Hauch, M.A.

“Nothing About Us–Without Us!”

The above statement has been a rallying cry of the disability rights movement worldwide (Charlton, 1998; p. 3). At its core, the IL philosophy holds that people with disabilities should be granted control over their lives, including the physical assistance services that enable them to live in the community. This philosophy is not limited to the direction of services, but is also rooted in an advocacy and peer support model intended to remove attitudinal and other barriers to participation in broader society (Lord, 2010; pp. 15, 17). Under the *medical model* of disability, the consumer is relegated to the “sick role,” whereby he/she is denied the agency to determine the type and duration of the services he/she requires; instead, service delivery is contingent upon the approval of medical professionals (Dejong, 1979; 440-441). That is, a restrictive emphasis on diagnosis undermines the flexibility inherent for an integrated, Independent Living framework. As Morris notes:

“In order to determine eligibility for scarce resources, assessments commonly measure dependency levels: they thus often ask, ‘What is wrong *with* this person?’ rather than ‘What is wrong *for* this person?’ A medical model of disability therefore continues to underpin much of the contact between social services professionals and disabled people” [emphasis Morris’] (2004; 432).

Fortunately, social work professionals need not reinforce the medical model of disability with respect to attendant services. Indeed, they can support their clients by advocating for attendant services that are more rooted in the Independent Living model, including agency, self-determination, and access to services.

Attendant Outreach and Direct-Funding Models

Outside of the CCAC framework, both attendant outreach and Direct Funding provide services more rooted in the Independent Living philosophy. Recently, the province has made investments in Direct Funding (Government of Ontario, 20 January 2014) and attendant outreach

(Provincial Attendant Services Advisory Committee, 2014) whilst investing substantially more in services provided by CCACs. CCAC PSWs and attendant outreach and Direct Funding attendants all provide assistance with activities of daily living such as dressing, bathing and grooming, although the scope of services offered varies. In the case of attendant outreach, attendants are hired and trained by not-for-profit community support service agencies. Eligibility is broadly defined as those persons over the age of 16, who are able to “direct own personal and homemaking services” and “have a permanent physical disability and require physical assistance with [activities of daily living] in order to accomplish such tasks safely and within a reasonable time” (Government of Ontario, 1996; p. 12). According to policy guidelines, the contracted service provider must adhere to the following principles: (1) flexibility of services; (2) integration; (3) independence; and (4) consistency. That is, service plans must be open to changes in the consumer’s lifestyle over time. Furthermore, consumers should be able to live anywhere in the community. As well, flexibility in service routines and location of residence are intended to promote the consumer’s agency within the community. For this to occur, services must be dependable and provided with an appropriate level of skill on the part of the attendant (p. 7-8). Finally, service hours are capped at 90 hours a month, with up to 120 hours permitted in “exceptional circumstances” (p. 20).

With Direct Funding, consumers receive financial help from the Ministry of Health and Long-Term Care to hire, train, and administer attendant services. A local Centre for Independent Living (CIL) consisting of other, trained consumers or peers conducts an assessment via an interview process. The criteria is similar to attendant outreach, save for the greater human resources management responsibilities on the part of the consumer (Centre for Independent Living Toronto, 2001; p. 1-2). In terms of services offered, for both attendant outreach and Direct Funding, under Section 29.1 of the *Regulated*

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Health Professions Act, 1991, controlled acts such as bowel routines and catheterizations are permitted by trained attendants.¹ As noted below, the scope of PSW services offered by CCACs is, at best, a patchwork depending on the services provided by the contracted agency. Crucially, consumers report that flexibility is a core value of Direct Funding, with one consumer stating, “Direct Funding allows me the *freedom* to hire attendants and gives me the *flexibility* to modify my schedule, whether at home, work, medical, travel or play.” Another consumer notes, “I get to choose when I get up and go to bed. This allows me to plan ahead, schedule time with my friends and family, and attend events in my community—effectively allowing me to live a full and rewarding life” (Centre for Independent Living, “Testimonials”; n. pag.) [emphasis CILT].

Policy Drivers for Existing Personal Support Worker Services via CCACs

When elected in 1995, the Progressive Conservatives sought to encourage privatization in home-care and to drive down public costs (Aronson et. al., 2004; p. 121). Regional bodies funded by the Ministry of Health and Long-Term Care (now through Local Health Integration Networks, or LHINs), CCACs were initially supposed to provide “communities the flexibility to develop local models to their own needs” (Baranek, 2004; p. 231). They were to be responsible for service information and referral to LTC and community-based services, establish eligibility criteria, and oversee case management functions (p. 234). The services provided by each CCAC varies, but they range from professional services (such as nursing and physiotherapy) to personal support and homemaking (Kuluski, 2012; p. 439). By brokering services between private providers paid with public funds, the argument went, “competition between providers should, in principle, allow a single purchaser, exerting monopoly power, to drive down prices and demand higher quality leading to better, more accessible care” (Randall and Williams, 2006; p. 1596). As noted below, however, in recent years

access to services has been limited while demand has increased, despite overall funding increases.

As alluded to above, the policy focus has been on short-term, less complex needs seniors, and a large portion of CCAC dollars have been allocated accordingly. In his report to the Ministry of Health and Long-Term Care, Dr. David Walker emphasized that many consumers who are deemed Alternate Level of Care – that is, held in hospital due to the shortage of appropriate discharge destinations – could be served in the community with appropriate supports: “37 percent of ALC patients waiting for [a long-term care home] placement have care needs no more urgent or complex than those being cared for at home” (2011; p. 9). Eighty-three percent of ALC consumers are over the age of 65 (34). ALC costs are substantial: ALC acute (hospital) beds cost the health care system \$1,200 *per day*, while outreach attendant services cost \$1,200 *per month* (OCSA, 2010; 2). It is in this context of neoliberalism that “home care has moved from its former status in Ontario as a fully funded entitlement [...] to one in which availability of publicly funded services could be constrained by budget pressures” (Barenek, p. 17).

One example of CCAC’s focus on ALC seniors within homecare is *Home First*, part of the \$1.1 billion *Aging at Home Strategy* begun in the 2008/09 fiscal year (Auditor General, 2010; pp. 116, 118). If given assistance with daily living activities, those ALC patients with “short-stay” needs could be discharged into the community. The *Home First Implementation Guide* notes the following: “It is important to evaluate each patient based on their needs without any bias towards age” (LHIN Collaborative, 2011; p. 9). Nonetheless, access again varies by region, with the Toronto Central Local Health Integration Network having restricted access to those 65 years or older (Szabo, 2010; p. 9). Ultimately, consumers ineligible for programs like Home First have to make due with especially limited service caps, as outlined below. It is difficult to assess waitlists for PSW services specifically, although in 2010, there

¹For more information, please see: Centre for Independent Living. Regulated Health Professions Act, n. pag. Retrieved from <http://www.dfontario.ca/resources/regulations/regulated-health-professions-act.html>

was a global waitlist of more than 10,000 people for CCAC services “upwards of months” (Sinha; p. 74). As the Provincial Liaison Committee for Persons with a Physical Disability, consisting of attendant outreach and Direct Funding service providers, notes: “Inflexible service models and policies inhibit wider provision of services; for example, age related diseases affect people with disabilities sooner than non-disabled people, yet funding programs prioritize services for the aged who are 65+” (Jaglal et. al; p. 25).

In its *Action Plan for Health Care* released in 2011, the provincial government reiterated its policy focus on ALC patients: “Better serving these patients benefits the entire system, because it frees up hospital beds for those who need them, reduces pressure on emergency rooms and saves money” (p. 11). Nonetheless, the document focused largely on the perceived demographic challenges of an aging population in terms of healthcare costs (pp. 5-6). While it professed to “[empower] Local Health Integration Networks with greater flexibility to shift resources where need is greatest, such as home or community care” (p. 2), the government continued to direct the bulk of its 4% increase (2012; p. 28) to initiatives for senior populations, not non-seniors with chronic health conditions.

Challenges with the CCAC Model

Even for those eligible for CCAC services, from an IL perspective, there are two core challenges with the CCAC model: (1) Limited access to services; and (2) A more restrictive scope of services for personal support workers. With regard to funding, Ontario Regulation 386/99 placed strict limits on the number of personal support hours an individual can receive, which allows more people to be granted services, albeit with fewer hours per person (Jutan; p. 5). While these caps have varied over time, services are not provided on the basis of need, but on the basis of funds available, particularly for those consumers who do not meet the eligibility criteria for programs like *Home First*. With regards to personal support, these consumers are permitted up to 80 hours in the first 30 days following the first day of service; this is reduced to 60 hours for any 30-day period thereafter (CCAC, 2006; p. 8). This

is substantially less than the maximum offered under either attendant outreach or Direct Funding. While CCACs may “provide more than the maximum number of hours of homemaking and personal support services set out in that subsection for a period of up to 30 days if the [CCAC] determines that there exists extraordinary circumstances that justify the provision of additional services,” this does not mean that there are sufficient resources to do this (p. 8). Randall and Williams write:

“[Whether] or not the unit price of services decreased or increased, the managed competition reform, which placed responsibility for the provision of home care with CCACs as intermediary agencies, also provided the provincial government with a powerful tool for controlling costs [...] the provincial government now had a greater ability to shift blame: it contended that CCAC funding was sufficient to provide all required services, and that CCAC budget overruns, or subsequent to the 2001 funding cap, CCAC service cutbacks, stemmed from poor management or incomplete implementation of the reform” (p. 1603).

Such an approach may also have created perverse policy outcomes on however all costs, as Baranek writes: “[Limitations] on the number of publicly-funded hours of care that can be provided by CCACs are having the effect of moving those inadequately served in one of two directions: either back to hospitals and other institutions that will provide publicly-financed care (albeit often at higher cost), or towards private payment for the additional services” (p. 267).

While some investments have been made in recent years, in 2010 the Auditor General reported that all audited CCACs “regularly monitored the client services they ordered against the funds available to help ensure that a balanced budget was achieved, *which could also affect the level of services ordered from providers to meet clients’ needs*” (p. 123; emphasis added). More recently, despite concerns around CCAC PSWs providing “task-based care” that may not be “in line with the actual needs and wishes of the client,” the Province’s *Seniors Strategy* does not challenge the CCAC model directly, except to state that “service

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providers should broker and implement care plans with caution, understanding that not all clients fit into allocated service time provisions (e.g., the “15-minute bath”) and to recommend greater collaboration between the CCACs and CSS sectors” (pp. 74-75).

Turning now to the scope of services provided by CCACs, these include personal support workers and the aforementioned “professional services.” Unlike attendant outreach and Direct Funding attendants, however, they often do not perform more intimate services such as bowel routines and catheterizations (see Appendix 1). Some CCACs may contract out for professional services where there are limited or non-existent service providers from CSS agencies to perform these tasks. With some CCACs, some professional staff may train family members to do the tasks, which is not in keeping with the IL philosophy, whereby consumers are afforded greater choice in terms of who performs the services. This has led to higher costs in some circumstances for some professional services such as physiotherapy, as they are contracted separately from PSW supports (Randall and Williams; p. 1601). Not only are costs higher in the CCAC model, but consumers have to contend with multiple parties providing a range of services, which in turn result in inconsistent levels of service for consumers and poor quality of life for consumers (Spinal Cord Injury Ontario, p. 16). Furthermore, where consumers face challenges with specific PSWs or attendants, they often have to liaise with case managers rather than with the attendants and service providers directly (Appendix 1).

An Alternative IL-Based Evaluative Framework

With many of the CCAC services dedicated to shifting the “balance of care” from acute and LTC environments to hospitals, Kuluski notes that this is contingent on “(1) having a clear target population; (2) specifying a set of required services; and (3) determining the cost alternatives (p. 339). Conversely, in providing an alternative evaluative framework for CCAC PSW services more rooted in the IL philosophy, there are three components to consider: (1) consumer direction

of services; (2) flexibility of services offered; and (3) comprehensive, aggregated feedback on the quality of services provided, with public reports to stakeholders, including consumers themselves. The third piece empowers consumers to provide feedback on how to improve services to meet their needs. In essence, what is proposed here is the service flexibility of both attendant outreach and Direct Funding, albeit with more restrictive eligibility criteria.

Nonetheless, establishing clear criteria for eligibility of services is controversial. As Jutan notes, “Regardless of where the cut-off is made between those in need and those not in need, mistakes will be made and people who need services will be missed while others who do not need services will receive them” (p. 12). That is, any criteria established will, by design, disenfranchise some individuals. While Morris argues, “If the community care system was driven by assessments which were about needs and disabling barriers (rather than dependency levels and eligibility criteria), [...] authorities would also be able to identify what level of resources are required to meet the needs of their local populations, and to identify what types of service response will effectively meet those needs and represent good value for money” (p. 433), it is suggested that this degree of cost savings is not clear insofar as “need” is not clear. While the pilot may exclude many individuals, this does not mean that services should no longer be provided to those who fall outside of its criteria.

Criteria for service eligibility, then, may be best established through a pilot program. In this regard, it is helpful to point to the experience of the two-year Direct Funding pilot project. When Direct Funding was implemented, the Centre for Independent Living, the Canadian Association of Independent Living Centres (now Independent Living Canada) and other not-for-profit attendant service providers—all consisting of consumer representatives—established an alliance that pushed for self-administered Direct Funding. (Yoshida et. al., 2006; pp. 325-327). In this vein, CILs and other consumer-based entities could establish a consumer advisory body to develop potential eligibility criteria for more consumer-

directed CCAC PSW services. Once established, such a body could develop a profile of consumers who could benefit from hours of service over existing service caps. If, for example, policymakers wish to avoid long-term care placements for non-seniors with disabilities, they may ask which individuals are likely to be placed into LTC due to the lack of other options, and provide the required, community-based services. The same could apply to those at risk of emergency department admission due to escalations of secondary complications such as pressure sores that could increased attendant services could help prevent. Crucially, consumers could offer personal narratives or “vignettes” that could also provide a comprehensive understanding of their needs. While this eligibility criterion remains largely medical in its focus, it is not as stringent as existing standardized tools. This eligibility restriction provides the for “need”; admittedly, a reformed CCAC would exhibit less of an IL approach in eligibility criteria and potentially more of an IL approach in the flexibility and self-direction of services.

Removing the separation of some professional services from PSW services would fundamentally change the difference of the services CCACs offer. This is not to suggest that professional staff such as nurses and physiotherapists would not have a role in training attendants should consumers so wish. These staff could also provide services (especially for consumers facing the onset of secondary complications) that are beyond the scope of attendants; CCAC professional services complement attendant outreach and Direct Funding attendants in this way. Rather, PSWs would be expected to perform the wider range of services that are performed by attendant outreach and Direct Funding attendants. As well, with a more IL focus, consumers would be encouraged to self direct their services with attendants, and set their own routines to meet their needs, allowing consumers greater self determination. Furthermore, attendants would, to the extent possible, be attached to individual consumers, rather than to specific services. This would address the challenge of having multiple parties assisting along the continuum of services, and may provide for greater

scheduling flexibility. In the United Kingdom, prior to research funding ending, researchers studied a practice called experience-based design, which sought to encourage critical self-reflection on the part of staff with regards to how to improve the consumer’s experience (NHS Institute, 2013; pp. 52-54). Both attendants and case managers may potentially benefit from such a process, so as to determine, on a micro frontline level, how to improve services and the consumer’s experience.

The pilot nature of such an initiative would allow one to make aggregate comparisons as to how much increased hours of service would cost compared to other alternatives such as ALC designation or LTC placement. Yet simply measuring potential savings and individual consumer experiences is not enough to ensure a more IL-centered CCAC range of services. For this to happen, the advisory would develop a plan-language consumer survey that would ask IL-related questions such as these:

- Were consumers provided with choice in terms of attendants, particularly with respect to gender and language?
- Was there flexibility in the scheduling of attendants?
- Was there flexibility in the scope of services offered?
- Were consumers given the means to provide feedback to the attendants in terms of services offered?
- Did the case manager coordinate professional services where needed in a manner that did not unduly disrupt the day-to-day routine of the consumer?
- How might services be improved?

Such a survey would have to be trialed with focus groups and undergo academic ethics approval to ensure data integrity. The survey would also be administered anonymously to remove any consumer fear of reprisal. Once the results were aggregated and analyzed, a detailed report of findings could be provided to the public. It could list crucial information such as the age, gender, rural/urban residence, and economic profiles of consumers. Crucially, the report would also list

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themes that emerged in the surveys. From here, the advisory body could liaise with consumers and the Ministry to look for system improvements within set financial constraints. Such a process could be undertaken on an annual basis or other set period to ensure that processes are reviewed, evaluated, and revised. After a set period of time, the pilot could be evaluated on the three “balance of care” criteria listed above.

Conclusion

In the final analysis, it is clear that CCAC personal support workers and professional services are not provided in a manner conducive to the Independent Living philosophy. With restrictive eligibility criteria geared at seniors with less complex needs, non-seniors with complex health conditions face substantial barriers to receiving needed services. Furthermore, the services they do receive are often limited in scope and, with multiple service providers, the continuum of services is far from seamless. Both attendant outreach and Direct Funding deliver attendant services with a more IL-based approach, but with broader eligibility criteria, policymakers appear wary of expanding access to these services, lest consumers on waitlists – and those who previously have not bothered to apply – come on to service.

With the CCAC model receiving strong support from politicians in general, and with consumers facing substantial barriers in mobilizing its constituency, a reformed CCAC model may be possible. An advisory body of consumers and other stakeholders may wish to come together and determine those persons who may align with policy objectives of reducing LTC admissions and ALC designations. Such an approach would require granting CCAC PSWs a greater scope of responsibility, with case managers responsible for facilitating communication and greater scheduling flexibility for attendants.

Such a model, however, is not likely to be successful without consistent, detailed reporting of quality outcomes, which the current CCAC model lacks. With such reporting, consumers may suggest changes that may increase cost-

effectiveness and health outcomes for these consumers.

Of course, this model is not without its challenges. CCACs and contracted parties may resist change, and the political class is wary of expanding eligibility. Nonetheless, the social work profession could provide legitimacy to such a project. If social work professionals advocate greater consumer agency, self-determination, and self-direction of services, a shift in attitudes is more likely to take place. Consumers, too, may have concerns, particularly around excluding lower-needs members of their community from such a pilot. At this point we cannot predict the results of such a pilot, but the evidence may yield lessons for success moving forward.

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APPENDIX 1:

Outlined below are some high-level differences between CCAC Personal Support Workers and Attendant Outreach services and Direct Funding.

	CCAC PSWs	Attendant Outreach Services	Direct Funding
Compensation	May not be paid for travel time; varies by organization.	Generally paid for travel time between clients. A minority of agencies provide benefits, pensions to employees (not typical with CCAC PSWs). As with CCAC PSWs, attendant outreach attendants are often part-time, casual workers.	Attendants are paid an hourly wage for services rendered. Travel time is typically not paid, as the attendant residing in the local area is hired by the consumer. A travel allowance may be considered to cover one-way travel if the attendant lives far from the consumer.
Administration	CCAC does not provide service directly; third party agencies are contracted to achieve certain outcomes.	The agency is contracted directly to provide service through service accountability agreements with LHINs.	The consumer receives funding directly and hires, trains, and administers the funding to the attendant.
Consumer Protocols	Less flexible service plans; changes may require utilizing more protocols through case managers that may be more removed from day-to-day operations of service.	Hours that service can be provided within are greater in most areas than offered by CCAC. (e.g. in Toronto most CCAC agencies only provide up to 9:00 p.m., as compared to 6 a.m. to midnight for attendant outreach attendants). Consumers generally more empowered to direct the services of the attendant as outlined in the <i>Attendant Services Policy Guidelines and Operational Standards (1996)</i> .	The consumer establishes the service protocol in agreement with the attendant.
Scope of Services – Populations	Regional hourly maximums vary by LHIN. Recent initiatives (e.g., Home First) have been targeted to senior populations.	Service minimum is one hour of service. The Ministry guidelines are provincial and outline the maximum as 90 hours of direct service per month (for exceptional circumstances the area office may approve up to 120 hours per month). Many providers have opted to provide services to specifically senior populations for some programs (“following money”); the vast majority also serve non-senior populations (extensive waitlists exist for this cohort)	Services are available to eligible persons 16 years of age or older.

Enhancing Independent Living

APPENDIX 1 continued:

<p>Scope of Services – Activities of Daily Living</p>	<p>ADLs for most CCAC PSWs (there are some variations in some rural/northern areas) consist of bathing, dressing, grooming, etc.</p> <p>Controlled acts (e.g., bowel routines) are not often performed by PSWs, but through high cost professional services (e.g., nursing) – training may be provided to family/circle of care members.</p>	<p>Attendants receive more job specific training than CCAC PSWs (e.g. lifts and transfers, bowel and bladder care, CPI, abuse prevention, etc.)</p> <p>May perform client directed Passive Range of Motion exercises where the client specific routine was arranged and as outlined by a PT and approved by the AS manager.</p> <p>Services provided are specific to assistance with personal care. Some controlled acts may be performed, provided there is: (1) Client consent and the ability to self-direct service; and (2) Training of the attendant by nursing professionals.</p> <p>The client assumes the risk of any injury incurred as a result of this <u>self directed</u> task. Where a provider supports with passive range of motion, they may have different timing parameters (such as up to a maximum of 15 minutes only).</p>	<p>Attendants perform some routine activities of daily living such as showering, transferring, dressing and undressing. Some controlled acts may be performed under the same provisions as attendant outreach services.</p>
<p>Financial Accountability</p>	<p>Aggregate expenditures on specific services provided.</p> <p>May offer more restricted services provided they are applied equally.</p>	<p>Under Service Accountability Agreements, hourly breakdowns of service are provided, allowing for greater clarity of “per unit” costs. Actual service plan components change considerably, and may not be tracked to the same degree as CCACs.</p>	<p>Consumers have signed accountability agreements with the Direct Funding manager, in turn funded by the Ministry</p>