A Working Document to Inform the Development of an Individualized Funding Model in Newfoundland and Labrador

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Table of Contents

Executive Summary

Background

This literature review provides an analysis of the individualized funding (IF) model, which refers to the provision of funds directly to individuals with disabilities to allow for the purchase of disability-related goods and services deemed necessary. As stated in the "The Way Forward: A Vision for Sustainability and Growth in Newfoundland and Labrador", the IF model is among the community support services initiatives envisioned to be implemented in the second phase of this strategic plan with the goals to provide better and more cost-efficient services with better outcomes.

The Biopsychosocial Model of Disability

Combining the principles of the biopsychosocial model of disability and the Rights-Based Social Policy, the underlying inter-correlations among the medical model of disability, the social model of disability and the social and physical environment were revealed. The biopsychosocial model provides a comprehensive foundation to support individuals with disabilities to realize full citizenship.

Jurisdictional Scan and Literature Review

The Provincial Home Support Program is a community support service intended to sustain community living and improve the wellbeing of clients. The performance of the Provincial Home Support Program in terms of its prudence, user-friendliness and procedural efficiency and appropriateness was demonstrated by a comprehensive review conducted by Deloitte. To better inform the implementation of the IF model in the province of Newfoundland and Labrador, both qualitative and quantitative studies of existing IF programs in other jurisdictions are also examined.

Recommendations and Conclusion

In accordance with both the initiatives to provide better services in "The Way Forward” and evidence derived the review of the Provincial Home Support Program, the streamlining of financial assessment is recommended. Based on the underlying philosophy of IF models successfully implemented in other jurisdictions, the use of the Individual Support Plan as a needs assessment tool was recommended. In the context of the IF model, case management generally consists of planning, assessment, service linkage, coordination and monitoring. The four elements of a Rights-Based Social Policy suggested that case managers (planning facilitators) who are not linked directly to the funders or service providers were more suitable to be responsible for service planning, linkage, coordination and monitoring of both clients and services.

Introduction

A Vision for Sustainability and Growth

In November 2016, the Premier of Newfoundland and Labrador launched "The Way Forward: A Vision for Sustainability and Growth in Newfoundland and Labrador”, which contains a series of initiatives derived from 26 provincial-wide public consultations (GNL, 2016). The initiatives are to be rolled out in three phases to achieve four objectives: a more efficient public sector, a stronger economic foundation, better services and better outcomes. Among the second phase of initiatives, better Community Support Services will be carried out to provide client-centered service delivery to seniors and individuals with disabilities. An individualized funding (IF) model will be introduced as a new funding model to clients availing of provincial social programs and services (see Table 1 for stakeholder analysis). By taking a client-centered approach, clients of the IF model will develop personalized support plans, ideally with the help from case managers (planning facilitators), and receive funds to carry out those plans. Keeping in line with the Convention on the Rights of Persons with Disabilities, the IF model espouses the rights of individuals with disabilities to not only live in the community, but also to have access to a range of support services which are responsive to needs and promotes community inclusion (United Nations, 2006). With the underlying principles of a single point of access, portability and flexibility across departments, agencies, regions and clients’ life spans, the IF model aims at increasing clients’ independent-living skill development, community integration and capacity building for clients while reducing service duplication and administrative costs (GNL, 2016).

Disability in Canada

According to the 2012 Canadian Survey on Disability (CSD), approximately 3.8 million Canadians aged 15 or older reported limited daily activities due to a disability (Statistic Canada, 2013). All participants of the 2012 CSD were living in private dwellings and more than 80% of participants required assistive devices to carry out daily activities. Due to the co-occurrence of multiple disabilities, help was required for a wide range of daily activities including transportation, housework, personal finances, personal care and health care among 94% of the 160,500 individuals (approximately 4.25% of the current sample) with a developmental disability. Sixty-five percent of individuals with a developmental disability who also identified as having complex personal conditions reported some level of unmet needs for at least one of the daily activities (Statistics Canada, 2015).

Besides the unmet needs reported by individuals with a developmental disability, another concern is associated with the rapidly aging Canadian populations. By 2030, 25% of the Canadian population is expected to be over 65 years of age (Torjman, 2015; Statistic Canada, 2015). The prevalence of reported disability increased from 4.4% for Canadians aged between 15 and 24 to 42.5% for Canadians over 75 years of age. While three types of disabilities, pain, flexibility and mobility, were reported most commonly by Canadians over 45 years of age. A positive correlation between age and prevalence of disability emerged from the 2012 CSD (Statistic Canada, 2013). Corresponding with the Canadian findings, a study conducted on Australians with disabilities suggested that the intensity of medical and physical support needs is positively correlated with age (Riches, 2009).

The Biopsychosocial Model of Disability

According to the Federal Disability Reference Guide composed by Human Resources and Skills Development Canada (2013), the definition of disability in the context of Government of Canada programs and services should refer to both the definition of disability provided by the World Health Organization (WHO) and the Convention on the Rights of Persons with Disabilities presented by the United Nations. Developed from the integration of medical and social models, a disability is defined by the WHO as a dynamic state of restricted functioning resulting from the inter-correlation among impairments in body functions or structures, activity limitations of tasks execution and participation restrictions due to environmental barriers and life situations (Human Resources and Skills Development Canada, 2013; World Health Organization, 2011). Based on the biopsychosocial model, the definition of disability reflects an integration of both the medical model and the social model of disability. On the one hand, the medical model views disability as a problem of the individual which requires medical or other treatment interventions provided by professionals. On the other hand, the social model recognizes that disability is neither a mere feature of the individual nor is it simply the result of a health condition but it is a socially-created problem due to unaccommodating physical and social environments. Emphasizing the social model, the Convention on the Rights of Persons with Disabilities recognizes disability as the result of an interaction between individuals with long-term physical, mental, intellectual or sensory impairments and attitudinal and environmental barriers which hinders the full and effective social participation of individuals with impairments (United Nations, 2006). The biopsychosocial model takes the two models further by synthesizing the two models, so that disability is acknowledged as an inter-correlation among health conditions, external environmental factors and internal personal factors (WHO, 2002). Evident from the biopsychosocial model of disability, while there is certain overlap between disabilities and support needs, a model of service delivery based solely on deficit is oversimplified (WHO, 2011).

For individuals with disabilities, physical stress can be derived from inaccessible environments and unwieldy service delivery systems; social stress can be derived from discriminatory behaviors and social exclusion; psychological stress is likely to result from both the actual experiences with the former two sources and the mere anticipation of them. As demonstrated by the biopsychosocial model, medical, social and psychological factors not only interact with each other, but also feed into each other. The chronic stress derived from physical and social conditions is likely to suppress an individual's immune system, which in turn exacerbates their physical and mental illnesses and forms a vicious cycle of distress (WHO, 2011).

Shared Decision-Making

In the medical encounter, patients' treatment decisions have been largely determined by physicians due to prevalence of the expert role assumed by physicians. The adoption of the expert role formed a paternalistic model in which physicians have professional dominance over patients' treatment selection (Charles, Gafni & Whelan, 1997). Similar to the provision of disability-related services, individuals with disabilities are also deprived of basic citizenship rights due to the traditional "worthy poor" perspective of disability policy. According to this perspective, individuals with disabilities are incapacitated due to physical or medical conditions rather than due to laziness or unwillingness to be productive and are thus regarded as the "objects of charity". Systems of segregation such as asylums, special schools and sheltered workshops were established based on this imposed incompetence to function in society. As a result, social aids are provided to individuals with disabilities at the cost of basic citizenship rights such as equity, equality, social participation and self-determination (Prince, 2009).

Patients' self-determination, especially individuals with long-term or chronic conditions, started to become more pronounced in the 1980s due to an increasing emphasis on patients' informed-consent and preferences. The shared decision-making process instead combines professionals' technical knowledge with patients' preferences by information sharing and encouraging patients to become autonomous decision makers, which reduced the informational and power asymmetry between professionals and patients (Charles, Gafni & Whelan, 1997). Social liberalism perceives individuals with disabilities as consumers of services instead of victims of biomedical conditions. A new approach to service provision is to increasingly promote self-determination and personal choice by advocating consumers to control over which services to access, to monitor the quality of service provision and to change services if necessary (Prince, 2009).

According to Stainton (2005), Canadian disability policy and practice should progressively move away from the assumption that individuals with disabilities are incapable of making choices. Instead, policy structures and instruments should progress towards supporting individuals with disabilities to exercise rights and citizenship by supporting the articulation of choices and building the capacity to act on choices. Prince (2009) also advocated that disability budget decisions should not only be disability-responsive, but should also enable Canadians with disabilities to realize full citizenship.

Moving Towards a Rights-Based Social Policy

Four Elements of a Rights-Based Social Policy

First, by recognizing independent personal representation in law, not only are individuals with disabilities encouraged to develop self-advocacy skills but the option of managing health care, services, financial and legal affairs through representatives is also available. As suggested by the Convention on the Rights of Persons with Disabilities, instead of being an inherent trait of individuals with disabilities, communication incapacity is likely due to the lack of support from the social and physical environment. The second and equally important element is to devise support plans for the implementation of needs identified by individuals. Ideally, the personal planning of support needs and service funding and delivery should be separated in order to rule out conflict of interest. Third, a potential solution is to transfer the control over resources and purchasing power to individuals with disabilities in the form of individualized funding (Stainton, 2005). Individualized funding refers to the provision of funds directly to individuals with disabilities to allow for the purchase of disability-related goods and services deemed necessary by those individuals (Torjman, 1996). Last but not least, in order for this Rights-Based Social Policy to be successfully implemented, the previous three elements need to be introduced simultaneously in the governance of disability policies. While governance monitors the prudent and reasonable use of funds, the ultimate decision of how the funds are used should rest with the recipients of the funds (Stainton, 2005).

Position Statement on Disability-Related Supports

Approved by the Newfoundland and Labrador Provincial Advisory Council of the Inclusion of Persons with Disabilities (2012), the position statement on disability-related supports suggested that all policies, programs and services should be guided by the following principles: accessibility, accountability, community inclusion, comprehensiveness, fairness, flexibility, individualization, portability, transparency, self-determination and universality. Revolving around rights of individuals with disabilities, the rights of choosing locations to live, work and study are ensured by the principle of community inclusion; the right to require any accommodation or supports to gain access to programs and services is ensured by delivering programs and services in a fair manner which is free from bias or discrimination. Individuals' rights to control and direct decisions about their own lives and disability-related supports are ensured by the principle of self-determination. The principles of accessibility and universality ensure that not only are programs and services universally provided based on needs, but accurate and consistent information on programs and services are also made easily available in accessible formats to the public. The design and delivery of programs and services should follow the principles of comprehensiveness, flexibility, individualization and portability, so that individuals could receive supports that cover enough depth of needs to ensure independent living and are responsive to changes in their needs. Such programs are specifically designed to meet individuals' needs and are continuously available across age groups, geographical locations and delivery agencies. The monitoring and evaluation of program and service delivery should follow the principle of accountability to ensure consistent, timely, responsive and effective service delivery. In order to ensure equality, fairness and accountability, all decisions and information regarding program and service delivery must be made publicly available.

Provincial Home Support Program

Deloitte (2016) was appointed by the Department of Health and Community Services (HCS) to conduct a comprehensive review of the performance of the PHSP and other jurisdictions in Canada to examine its effectiveness and efficiency and to suggest improvements that could be made. Operating since the 1980s by the HCS, the Provincial Home Support Program (PHSP) is funded by the Government of Newfoundland and Labrador. An increase in demand by approximately 14% for services and funding over the next five years was anticipated (Deloitte, 2016).

According to the Department of Health and Community Services (2012), the philosophy underlying the PHSP operation is to provide individuals across the province of Newfoundland and Labrador with accessible and equitable supports and services under the person-centered model of care in order to foster independent living within the community. In addition to six roundtable consultations hosted by the Minister of Health and Community Services with different stakeholder groups, province-wide public consultations to obtain feedback on how to improve the long-term care and community support services system were also held in 19 communities during August and September 2010. Clear desires to prolong independent living in the community and to increase quality of life of service users emerged from those discussions. In terms of areas for improvements, service users and stakeholders mentioned the need for better guidance when navigating the system for services, the need for access to specialized equipment and support with fewer restrictions, as well as the need for well-trained multidisciplinary teams to meet the growing demand for services (GNL, 2012). By 2015, there were 7197 clients across the province enrolled in the PHSP. Among the 7197 clients, 3752 clients were seniors (over 65 years old), 3219 clients were adults with disabilities and 226 clients were children with disabilities. The annual cost of both eligibility assessments of and service provision to this client population of over 7100 individuals from the Eastern, Central, Western and Labrador-Grenfell regions was projected at 199.2 million dollars for 2015 (Deloitte, 2016).

According to data collected from Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland and Labrador, Nova Scotia, Ontario, Prince Edward Island, Quebec and Saskatchewan, the average per capita spending on home care and support services across the ten provinces as of 2013 was 182 dollars per year. Among the ten provinces, Newfoundland and Labrador was found to have the highest per capita spending of 302 dollars per year on home care and support services. While the proportion of the senior population (over 65 years old) in Newfoundland and Labrador (15.8%) was similar compared to the national average (14.9%), the percentage of seniors receiving home care was the lowest in Newfoundland and Labrador (4.2%) compared to the national average of 14.6%. Since each province has different demographic and geographical features, differences in service expenditure may be due to different reasons. However, when compared to Alberta and Saskatchewan with comparable geographical challenges, the per capita home care expenditures in Newfoundland and Labrador is still significantly higher. Both with 1.4% of population receiving home care and 15.8% of population aged 65 and over, the per capita home care expenditure in Prince Edward Island was only one-third of Newfoundland and Labrador. In terms of future demands of Newfoundland and Labrador, the anticipated 14% increase in caseloads translates to an increase of 53 million dollars in funding (Deloitte, 2016).

The three main goals of the PHSP are, to provide individuals who meet program admission criteria with support services in order to foster independent living within the community; to let individuals have choice in how they live; and to ensure that the PHSP is equitable for all eligible individuals across the province. According to program utilization data of the Eastern, Central, Western and Labrador-Grenfell regions, program usage rate was moderated by the availability of Personal Care Home (PCH) and Long Term Care (LTC) facilities. Higher usage of the PHSP was found in regions with less PCH and LTC vacancies, whereas lower usage of the PHSP was found in regions with more PCH and LTC vacancies. In order to improve the usage rate of the PHSP and decrease institutionalization, better promotion of the program can be achieved by advertising it across the province, implementing a provincial centralized intake and referral process and increasing community and physician referrals. Besides lack of referral and intake, another potential barrier to the uptake of the PHSP is the complex eligibility assessment process (Deloitte, 2016).

In order to examine individuals’ need for services and eligibility to the PHSP, financial and clinical assessments and reassessments were conducted by the Regional Health Authorities (RHAs). More specifically, program eligibility is contingent upon the presence of a formal diagnosis and financial assessments of liquid assets, income and living expenses. The complicated financial assessment process is manual and paper-based, which requires a large amount of paper correspondence between the RHAs and service users. Other jurisdictions in Canada have either streamlined their financial assessments for eligibility to be based on net household income (Nova Scotia), or do not require an income-test in order to receive publically funded home support (Alberta except for Calgary). Clinical assessments for seniors were generally completed by community health nurses, whereas social workers were generally responsible for assessments of the adult with disabilities and children with disabilities. The assessment tool employed by the PHSP was the interRAI Home Care Assessment System (RAI-HC), a well-established tool which measures individuals' clinical status. However, due to inconsistencies in community health nurses' and social workers' familiarity with the tool, the validity and reliability of the tool might be compromised. In order to ensure the consistent delivery of the tool, cross-professional training is required for community health nurses and social workers. Approximately 3.9 million dollars were invested in the implementation of the RAI-HC between 2006 and 2012. Besides threats to the validity and reliability of the tool due to inconsistencies in its implementation, another concern is related to the appropriateness of it as a determinant of service needs (Deloitte, 2016).

Modified from the nursing home Resident Assessment Instrument (RAI), the RAI-HC comprises of two parts and the on site assessment process takes approximately three hours. The first part, referred to as the Minimum Data Set-Home Care, is designed to collect standardized information on a range of physiological and psychosocial functioning. The second part, referred to as the Clinical Assessment Protocol Areas, is composed of algorithms which help clinicians to focus on risk factors in physiological and psychosocial functioning and identify treatable conditions. Similar to the RAI, the RAI-HC has good validity and reliability in measuring physical function and cognitive status but again due to potential implementation problems, there is no guaranteed accuracy of the data collected from the real world of day-to-day care. Although the RAI-HC is clinically relevant and focuses on measuring key deficits of individuals, it does not seek individuals' inputs of their subjective values or their unmet needs (Hawes, Fries, James & Guihan, 2007). In the absence of provincial standards and guidelines on how to translate the clinical assessment findings into service plans pertaining to individuals' unmet service needs, not only is it hard to develop objective service plans but also the approval of service hours was largely based on subjective estimation of community health nurses and social workers (Deloitte, 2016).

While the RAI-HC was used to assess eligibility and support needs of seniors and adults with physical disabilities, other clinical instruments were used for adults with intellectual disabilities and children with disabilities. The Adult Needs Assessment is used to assess adults with intellectual disabilities, whereas clinical documentations from professionals and other regional methods are used to assess children with disabilities. In addition to this inconsistency in the use of assessment tools on different client populations across the provinces, IQ scores have also been used to determine eligibility for some services (Deloitte, 2016). According to the mandate letter of the minister of Health and Community Services, the use of IQ testing to determine autism-related services is to be progressively eliminated (GNL Office of the Premier, 2015).

An analysis of case files of an anonymous sample of 46 service users was carried out by clinical subject matter experts. Evident from the examination of completed clinical assessment, corresponding service plan, clinical documentation and activity notes, more than half (12 out of 23) of the senior case files indicated an excess of service hours approved relative to actual client needs. Even though some of the adults with disabilities (4 out of 20) and children with disabilities (1 out of 3) case files failed to provide sufficient information for reliable assessments, it was still evident that the approval of service hours by community health nurses and social workers was subjective due to a lack of standardized assessment protocols. Both the lack of consistent measurements across client groups and the absence of cross-professional training of community health nurses and social workers to ensure reliable administration of the measurements resulted in inappropriate provision of service hours. In order to improve the effectiveness and efficiency of service provision, it was recommended that funding arrangements should be based on the achievement of pre-determined client outcomes instead of hours worked (Deloitte, 2016).

As emphasized in the strategy for long-term care and community support services, family members as informal caregivers accounted for a large proportion of support provided to service users in addition to formal care provided by the PHSP. In order to support informal care givers who act as the front line of support for many service users, the Paid Family Caregiving Option was introduced in 2014 to compensate for home support services provided by family members (excluding spouses and common law partners) residing in the same home as service users (GNL, 2012). According to McIntyre and colleagues (2016), informal caregivers can effectively prevent individuals with disabilities from premature entry into residential aged care.

Individualized Funding

As a rights-based social policy the individualized funding (IF) model not only espouses the Convention on the Rights of Persons with Disabilities, but it also agrees with the position statement on disability-related supports (Provincial Advisory

Council of the Inclusion of Persons with Disabilities, 2012; Stainton, 2005; United Nations, 2006). The idea of IF began in British Columbia in the 1970s, as the Woodlands Parents Group advocated for full participation of their children in the community. Although the vision of receiving funding for support needs directly from the government by presenting personal support plans was not realized, this vision nonetheless inspired the actual development of IF around the world (North Shore Disability Resource Centre, 2005). IF, now established in Canada, the United States, United Kingdom, Australia and New Zealand, is a service funding mechanism based on the principles of self-determination and person-centered control (Field, McGechie, King, 2015; Ontario Round Table for People with Disabilities, 2000). Existing IF programs tend to fall on a continuum with direct funding programs on the one end and ideal IF programs on the other end. When programs directly pay a fixed amount of funding set by government to consumers, they are more properly classified as direct funding programs because they do not consult individual needs. Ideally, in order to qualify as IF, programs are required to not only directly fund consumers but the amount of funding should also be determined by support needs derived from personal support plans of consumers (North Shore Disability Resource Centre, 2005). Besides increasing consumer control for individuals with disabilities, IF also emphasizes increasing consumer community participation and increasing the emergence of new services over time from both formal and informal support networks (Lord & Hutchison, 2003; Torjman, 1996).

In addition to formal support provided by disability support systems, individuals with disabilities often times receive extensive informal support provided by family members. While contributing significantly to the functioning of individuals with disabilities in the context of community and avoiding institutionalization, informal care givers are susceptible to financial hardship, social isolation and physical and emotional strain. Without adequate advice and assistance from the formal disability support system, a family care giver's paid employment may be interrupted in order to keep up with demand for informal care. In order to address care givers' burden, financial compensation should be provided to this type of self-directed caring work (McIntyre, Fleming, Foster & Tweedy, 2016). Besides family care givers, other supply of services can also be generated in the market place when individuals have greater purchasing power (Torjman, 1996). The effectiveness of disability services can be enhanced through implementing an Individualized Funding model which is portable, flexible, equitable and individualized to support self-determination and capacity building among service users (see Appendix A).

As of 2011, IF has been adopted by six Canadian provinces including British Columbia, Alberta, Manitoba, Ontario, New Brunswick and Prince Edward Island (National Individualized Funding Discussion Group, 2011). Inspired by the Ontario Round Table for People with Disabilities initiated in early 2000, a Canadian study investigated three promising IF projects (see Appendix B) from Canada, Australia and the United States (Lord & Hutchison, 2003). Across these three jurisdictions, the planning of services and provision of services are typically performed by separate agencies to prevent conflict of interest. In 1997, with support from the Ministry of Community and Social Services and through the Individualized Quality of Life Project, the Family Service Association was responsible for both allocating funds and planning services for individuals with disabilities in Toronto. By aiding in planning services, building personal networks and providing support, community resource facilitators efficiently increased the quality of life, accountability and community involvement of consumers and their family members. Aiming to support individuals with intellectual disabilities in rural parts of Western Australia, the Disability Service Commission was established in 1993. By receiving direct funding and Local Area Coordination from the Disability Service Commission, consumers were enabled to purchase support services with the planning and support provided by local area coordinators. The success of direct consumer funding and effective coordination was evident from case studies and surveys conducted in 1996. Consumers reported increased quality and quantity of supports and enhanced capacity and well-being (Lord & Hutchison, 2003). With the introduction of the *National Disability Insurance Scheme* in 2013, disability service provision shifted further away from government block funding and closer towards the IF model in Australia (Dew et al., 2016). Funded by the Robert Wood Johnston Foundation in 1995, the New Hampshire Division of Mental Health and Developmental Services implemented a self-determination project. The project management team focused on an ongoing leadership development for groups of stakeholders including consumers, family members, service staff, advocacy organizations, the University of New Hampshire's Institute on Disability and the community. In order to produce systemic change, not only were case managers (planning facilitators) trained on planning and budget development, but all stake holders were also trained on collaborative problem solving and communication skills. Different from the two previous jurisdictions, funds of the self-determination project were managed by independent agencies called fiscal intermediaries. By fostering open communication involving different stakeholder groups, the project created a responsive service system (Lord & Hutchison, 2003).

Quantitative evidence for the efficacy of IF can be derived from cost-effectiveness analyses of IF programs (see Appendix B) in the United Kingdom, Canada and New Zealand (Field, McGechie, King; 2015, Stainton, Asgarova, Feduck, 2013; Stainton, Boyce & Phillips, 2009). In April of 1997, the *UK Community Care (Direct Payment) Act 1996* enabled individuals with disabilities to receive direct cash payment to purchase services. Qualitative studies involving Direct Payment users demonstrated a range of positive outcomes in terms of flexibility, self-esteem, control over lives, interpersonal relationships and vocational and lifestyle opportunities. Building on these initial positive qualitative findings, a cost and resource analysis was conducted in two Welsh local authorities between April 1999 and June 2001on the cost and resource implications of Direct Payments compared with traditional services. The two local authorities (LA1 and LA2) were the first and most fully developed schemes in Wales and they jointly funded an Independent Living Support (ILS) scheme which assisted people in using Direct Payments. Officially launched in 1998, the ILS enabled individuals with disabilities to develop and manage support services using the funding from local authorities. With help from the coordinator, advisor and administrative support, 40 Direct Payment users (all under the age of 65 and majority had physical disability) were given information and advice about direct payments, becoming an employer, employing personal assistants, and payroll services. According to comparison of cost of Direct Payments compared with the cost of traditional service provision, Direct Payments were clearly less costly compared to in-house services and were roughly equivalent to average independent sector rates. In addition, evident from qualitative interviews with users, both users and family members reported extreme satisfaction due to the flexibility permitted by Direct Payments. By employing neighbors or friends who had direct contractual obligation to the users and could flexibly respond to needs at short notice, some users achieved cost effectiveness due to the efficient use of staff time. In contrast, formal support workers generally worked according to fixed schedules which did not respond to consumers' fluctuating needs and resulted in waste of service hours. When a system of accountability was in place and appropriate support was provided to users, resources allocated to case managers were also reduced. By putting users in a position of trust and partnership, case managers were expected to shift from the traditional paternalistic model of care management to a trusting partnership with users (Stainton, Boyce & Phillips, 2009).

Mandated under the *Community Living Authority Act*, Community Living British Columbia (CLBC) is a provincial crown agency which has been developing traditional block funding, direct contract with individual home care providers and IF funding options for adults with developmental disabilities since 2005 (Stainton, Asgarova & Feduck, 2013). Before the introduction of IF in 2005, ministry social workers were responsible for both the allocation of funds and the planning of services in the traditional case management model. Faced with high caseloads and resource scarcity, social workers typically prioritized the gatekeeping of funds instead of assisting clients with planning and accessing supports and services. By separating service planning functions from funding allocating functions, the entire service system was shifted towards a rights-based system (Bigby, Fyffe, Ozanne, 2007). The three IF funding options available across the province of British Colombia were direct funding, host agency funding and microboard funding. Services commonly provided across the three IF funding options and the traditional block funding are: outreach support, live-in support, employment services, skill development, individual services, community based services and homemaker services. Except for microboard funding, the two other IF funding options costed lower than traditional block funding. Support needs were determined by the Guide to Support Allocation (GSA), which has five levels indicating ascending need for support. While more than half of the users of IF models were between 19 and 30 years old, IF utilization rate was the lowest among users older than 61years old. Typically, IF users tended to have higher levels of assessed disability-related needs as measured by the GSA compared to non-IF users (Stainton, Asgarova & Feduck, 2013). As mentioned by Schulman (2014), if an intervention is effective for the extreme users, then it is highly likely to also be effective for the average users. Similar age compositions and patterns of high support needs were also demonstrated by users of an IF funding program in New Zealand (Field, McGechie, King, 2015).

Managed by Manawanui InCharge (MIC), the Home and Community Support Services (HCSS) was funded and monitored by the New Zealand Ministry of Health. Two kinds of HCSS service users, IF users and non-IF users, were compared against each other in terms of demographics and patterns of expenditures. While the MIC was responsible for assisting clients in using funds, the eligibility assessment and funding allocation were administered by government’s Needs Assessment and Service Coordination agencies. The adoption of the IF program was often accompanied by significant life changes such as transitioning to independent living from the education system and significant changes in needs which are no longer satisfied by the traditional service environment. As a result, IF users typically entered the program with higher support needs compared to non-IF users as measured by the Support Package Allocation (SPA), which translates to higher costs required by service provision. Even though the school leavers to 65 years age group comprised 69% of total users in both IF users and non-IF users in 2014, IF users (68% aged under 35 years) were significantly younger than non-IF users (74% aged over 35 years). Between 2009 and 2014, the number of IF users increased from 246 to 1343 while the number of non-IF users decreased from 5237 to 4988. An expenditure analysis was performed on the annual spending of school leavers to 65 years age IF and non-IF users. For non-IF users, the HCSS spending has fluctuated between 88 million and 98 million between 2009 and 2014. The HCSS spending on IF users grew from 9.6 million dollars to 39.2 million dollars between 2009 and 2014, which reflected both the increase in uptake of IF and IF users’ high SPA ratings. However, some degree of cost controlling was indicated by the decline in annual cost by 28% for every IF user from $28,035 in 2009 to $20,212 in 2014. Cost controlling was also evident from the lower growth of IF spending in relation to growth in the uptake of the IF program, especially for IF users who entered the program with complex needs. Another cost containment feature of the IF users is that IF users with complex needs were less likely to transition to higher-cost residential care than non-IF users with complex needs (Field, McGechie, King, 2015).

Implementing Individualized Funding

Better Services in "The Way Forward"

Among the second phase of initiatives to provide better services in "The Way Forward", in addition to the implementation of the IF model, the streamlining of Financial Assessment Process for Community Support Services is also an integral component (GNL, 2016). As mentioned earlier, the financial assessment and reassessments of liquid assets, income and living expenses for the Provincial Home Support Program (PHSP) were conducted by the Regional Health Authorities (RHAs). The manual and paper-based financial assessment process is complicated, requires a large amount of paper correspondence between the RHAs and service users (Deloitte, 2016). For the streamlining of the financial assessment process for community support services to make the application and eligibility process more client-friendly, a single income-based financial assessment tool will be employed (GNL, 2016). Besides changes to be made to the financial assessment process, the assessment of service needs also indicated the absence of provincial standards and guidelines on how to translate the clinical assessment findings from the RAI-HC into service hours (Deloitte, 2016). For the implementation of the IF model, a tool different from the RAI-HC will be recommended.

Recommendation of an Individualized Planning Tool

The creation of personal support plans with clear indications of personal goals is at the heart of individualized planning not only because it helps to clarify individuals' support needs but it also monitors the effectiveness of services received and informs outcomes (North Shore Disability Resource Centre, 2005). As mentioned in the review of the PHSP, there were no provincial standards and guidelines on how to translate the RAI-HC clinical assessment findings into service plans pertaining to individuals’ unmet service needs. Therefore, not only was it hard to develop objective service plans but the approval of service hours was also at the subjective discretion of community health nurses and social workers. It was recommended that funding arrangements should be based on the achievement of pre-determined client outcomes instead of hours worked (Deloitte, 2016). In order to improve the effectiveness and efficiency of service provision, pre-determined outcomes need to be underpinned by quantifiable activities and behaviors (Schulman, 2014).

Instead of measuring hours of service utilization, underpinning quantifiable change mechanisms better informs service effectiveness. The processes of creating and acting on change mechanisms pertaining to service users’ needs permit more interactions between service delivers and service users which will shift the traditional top-down implementation of service programs to a bottom-up implementation of service programs. Different from the non-mutual relationships created by the top-down implementation of service programs where service users passively receive assessments and services from service providers, bottom-up implementation of service programs enables reciprocating relationships. By co-producing individualized support plans and monitoring change mechanisms, not only is service users’ sense of control enhanced, but users’ are also motivated to take ownerships of the co-produced individualized support plans. Besides the co-production of individualized support plans, the participation of service users in the continuous monitoring of outcomes is also recommended (Schulman, 2014).

Generally, the data collected from all service users were aggregated into an accountability indicator of a program's effectiveness rather than kept at a disaggregated level as a behavior change tool. However, in order to recognize and foster positive behaviors, service users also need to gain access to the directly recorded changes and be informed of both their achievements and areas of improvement. By making data available at both aggregated and disaggregated levels, not only are decision-makers informed of the efficacy of a program, but service users are also informed of their progress (Schulman, 2014).

As indicated in “Close to home: A Strategy for Long-Term Care and Community Support Services”, the philosophy underlying the PHSP operation is to foster independent living within the community among individuals across the province of Newfoundland and Labrador (GNL, 2012). Nevertheless, providing individuals with accessible and equitable supports and services only contributes partially to the realization of prolonged community living. Besides service provision, the creation and strengthening of both bonding and bridging social capital are also fundamental change mechanisms. Bonding social capital refers to relationships between individuals of similar backgrounds and resources, whereas bridging social capital refers to connections with individuals of distinct backgrounds and resources. While bonding social capital provides safe opportunities for learning and experimentation, bridging social capital promotes intentional change by widening possibilities individuals envision. By linking individuals with disabilities to local business owners and organization members, bridging not only enables broader experiences in the community but it also functions as a network expander (Schulman, 2014).

In order to organize client progress in both aggregated and disaggregated forms using both top-down and bottom-up implementation methods, a needs assessment tool has to involve the active participation of both clients and assessors (Schulman, 2014). The Individual Support Plan (ISP) developed by Alberta Human Service (2013) not only examines clients from a holistic approach but it also constantly solicits clients' inputs. An ISP is a written tool that can be used as a step-by-step framework to describe a client's desired personal outcomes and the methods to achieve these outcomes by involving a range of services and supports. By acknowledging clients' strengths and planning services around their existing natural supports, the ISP differs from traditional deficit-based assessment tools in that it endorses a glass-half-full perspective instead of a glass-half-empty perspective.

Since each client has different strengths and personal aspirations, a planning tool needs to be highly fluid to accommodate individual differences from the bottom-up inputs yet still have certain fixed components to allow for systematic top-down monitoring. The ISP achieves fluidity in devising plans and encompasses diverse individual goals in its first two components, the eight quality of life domains (see Appendix C) and the Supports Intensity Scale (SIS). The SIS outlines a wide range of detailed support needs organized under eight quality of life domains including emotional well-being, interpersonal relations, social inclusion, personal development, self-determination, physical well-being, material well-being and rights (see Appendix D). Not only is the SIS referred to by clients to identify and articulate what is important to them but it is also used by assessors to recommend what is important for the clients. After clients articulate what is important to them in terms of their needs and goals, their needs and goals are classified under certain quality of life domains. Detailed support needs listed in the SIS can then be identified by assessors as what is important for the clients and communicated back to clients. After clients and assessors reached consensus on translating goals to support needs, relevant services which address those support needs can be chosen from the list of Exemplary Support Strategies organized under eleven broad System of Support Elements (see Appendix E). The last part of the tool monitors outcomes achieved within certain time frames, which functions as a system of accountability. Progress reviews need to be conducted periodically to see if clients are having their needs met and their goals achieved. Taking all the components together (see Appendix F), the ISP is a flexible framework which systematically tracks progress and evaluates outcomes (Alberta Human Services, 2013). Besides building a program where clients take ownerships of the plans co-created with assessors and clients gain capacity along that process, the ISP also serves as a source for both aggregated and disaggregated data. At the disaggregated level, it provides continuous disaggregated feedbacks to clients and assessors to enable performance calibration. At the aggregated level, it allows service funders to pay for the outcomes achieved by clients, instead of paying for the hours submitted by support providers.

Recommendation of Case Management

With the introduction of the ISP, not only can clients actively participate in the bottom-up assessment process but performance data at the disaggregated level are also readily available as a mechanism of accountability for ensuring efficient allocation of funding (Schulman, 2014). According to the four elements of a Rights-Based Social Policy, for the purposes of ensuring objectivity and ruling out conflict of interest, the creation of support plans should be performed by agencies who are in a neutral position in relevance to funders and service providers (Bigby, Fyffe, Ozanne, 2007; Stainton, 2005). A solution to this potential problem of conflict of interest is to employ case managers who are not linked directly to the funders or service providers to deliver needs assessments. Case management (planning facilitation) in the context of IF refers to the processes of providing clients with control over resources, supporting clients to articulate wants and needs, assisting clients to identify, obtain and manage supports which meets their needs. In addition, by separating the roles of service planning and fund allocation, the autonomy of case managers (planning facilitators) to defend the rights and to support self-determination of clients also increases. However, in order to separate planning functions from fund gatekeeping, macro-level system change has to happen. As demonstrated by the Community Living British Columbia example, the governance of the system was altered so that two vice presidents were separately responsible for the management of planning facilitators and the approval of funding, each vice president then reported directly to the chief executive officer (Bigby, Fyffe, Ozanne, 2007).

Limitations and Future Directions

While the realization of full citizenship is enhanced by increasing purchasing power and by the movement towards rights-based social policies and initiatives, not every individual will be comfortable with assuming the responsibility and stress associated with the decision-making processes of service planning and purchasing (Charles, Gafni & Whelan, 1997; Torjman, 2015). Without a provincial-wide education of the IF model and consultations on individuals’ opinions about it, it is impossible to find out how receptive individuals are to this new model. The consultation will involve stakeholders from both the community and the government. A stakeholder analysis template can be found in Table 1.

It is also important to note that a new IF model often takes time to be established and achieve outcomes because not only do individuals need to go through the learning process of decision making and direct purchasing of goods and services but potential new services in the market place also need time to emerge. With regards to private service arrangements, attention also needs to be paid to the controlling of quality of services provided by the marketplace and monitoring of accountability of money spent. Valuable lessons can be drawn from the Choice in Supports for Independent Living (CSIL) program, which fosters clients to assume the responsibilities of being their own employers by providing extensive training and support on recruiting and hiring workers (North Shore Disability Resource Centre, 2005).

Conclusion

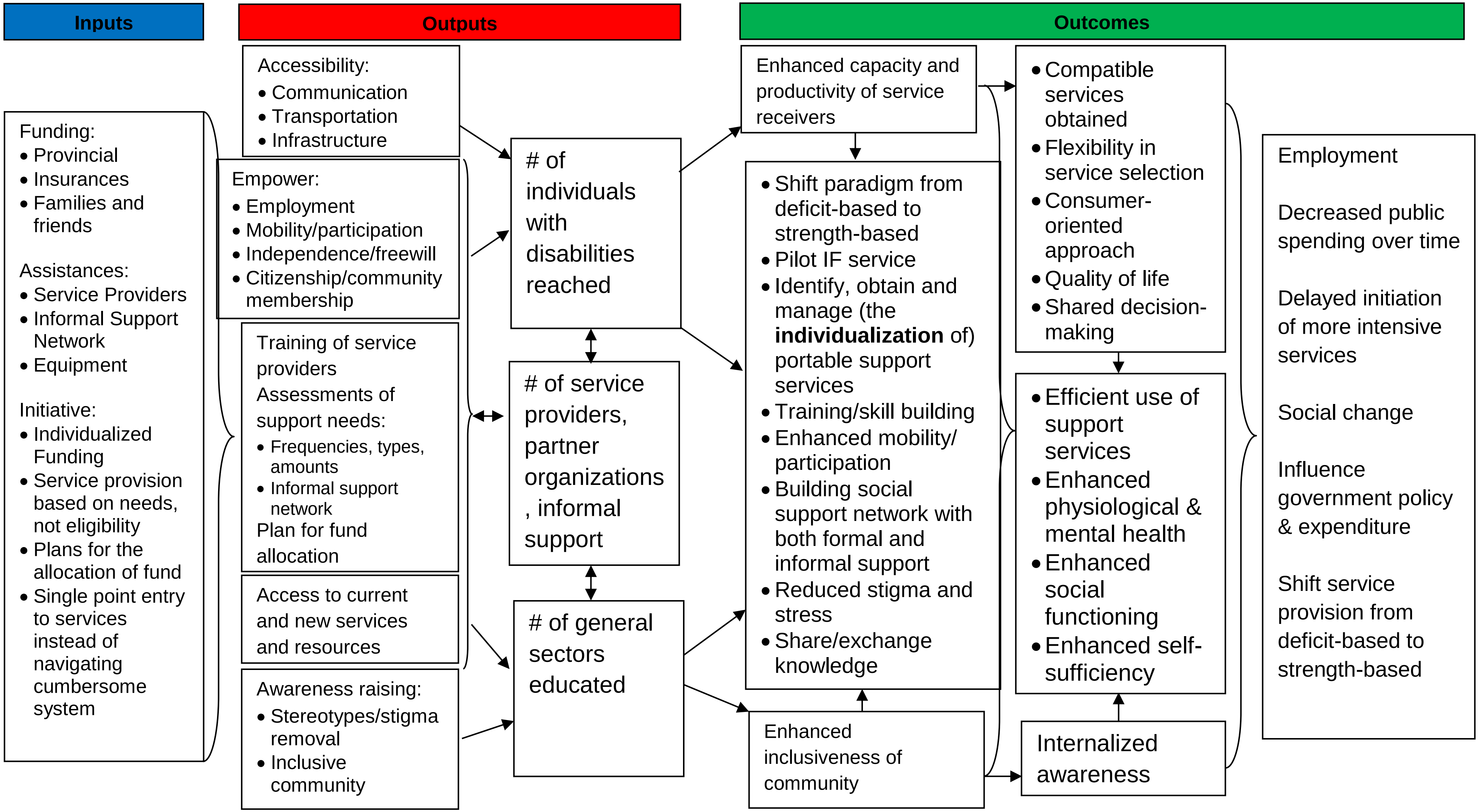
As a rights-based social policy, the IF model not only espouses the Convention on the Rights of Persons with Disabilities and the biopsychosocial model of disability, but it also corresponds with the feedbacks obtained from roundtable consultations with the community. Responding to service users' desire to prolong independent living in the community with enhanced quality of life and the need for easier access to support and services, "The Way Forward" scheduled the implementation of the IF model and the streamlining of financial eligibility assessments in its second phase. In order for the implementation of the IF model to approach the idealized version of IF, the functions of fund allocation, service planning and service delivery must be separated, which means that macro-level changes need to take place in the governance of disability policies. The employment of case managers (planning facilitators) who are equipped with the appropriate type of outcome-tracking planning tool and who operate on a client-centered bases are crucial to the successful implementation of IF.

Table 1

Stakeholder Analysis

	Interest	
Power	**Low**	**High**
High	Involve/engage • Office of the Chief Information Officer • Central agency • Division of Income Support • Advanced Education, Skills and Labor	Partner • Disability Policy Office/ Department of Children, Seniors and Social Development • Health and Community Services • Policy Innovation and Accountability Office/Policy NL • Individualized Funding design team
Low	Inform • General public • Community organizations • Social workers • Academia	Consult • Support team for the design of Individualized Funding • Human Rights Commission • Network of Disability Organizations • Other jurisdictions • Clients • Informal care givers

Appendix A



Inputs

Funding:
- Provincial
- Insurances
- Families and friends

Assistances:
- Service Providers
- Informal Support Network
- Equipment

Initiative:
- Individualized Funding
- Service provision based on needs, not eligibility
- Plans for the allocation of fund
- Single point entry to services instead of navigating cumbersome system

Outputs

Accessibility:
- Communication
- Transportation
- Infrastructure

Empower:
- Employment
- Mobility/participation
- Independence/freewill
- Citizenship/community membership

Training of service providers

Assessments of support needs:
- Frequencies, types, amounts
- Informal support network

Plan for fund allocation

Access to current and new services and resources

Awareness raising:
- Stereotypes/stigma removal
- Inclusive community

# of individuals with disabilities reached

# of service providers, partner organizations, informal support

# of general sectors educated

Outcomes

Enhanced capacity and productivity of service receivers

- Shift paradigm from deficit-based to strength-based
- Pilot IF service
- Identify, obtain and manage (the **individualization** of) portable support services
- Training/skill building
- Enhanced mobility/ participation
- Building social support network with both formal and informal support
- Reduced stigma and stress
- Share/exchange knowledge

Enhanced inclusiveness of community

- Compatible services obtained
- Flexibility in service selection
- Consumer-oriented approach
- Quality of life
- Shared decision-making

- Efficient use of support services
- Enhanced physiological & mental health
- Enhanced social functioning
- Enhanced self-sufficiency

Internalized awareness

Employment

Decreased public spending over time

Delayed initiation of more intensive services

Social change

Influence government policy & expenditure

Shift service provision from deficit-based to strength-based

Assumptions
- Coordination of components
- Articulation of support needs and communication with service providers
- Careful planning and implementation of support services

Risks
- Lack of separation between service planning and funding responsibilities
- Delay in service delivery

External Factors
- Cooperation of the general public
- Cooperation of individuals with disabilities and their informal support network
- Sufficient funding
- Inter-professional collaboration

Appendix B

Individualized Funding Jurisdictional Scan

Program and Delivery Agency	Source of Funding	Activities	Separation of Functions	Outcomes (qualitative and quantitative)
Individualized Quality of Life Project (1997) by Family Service Association, Toronto, Canada	Ministry of Community and social Services	- allocate fund - plan services - build personal networks - community involvement	service planning is separated from service provision	- enhanced quality of life - cost-effective
Local Area Coordination (1993) by Disability Service Commission, Perth, Australia	Disability Services Act	- approve grants - identify needs - plan services - identify informal supports - build capacity	service planning is separated from service provision	- enhanced wellbeing - improved quality and quantity of supports
Self-Determination Project (1995) by New Hampshire Division of Mental Health, New Hampshire, the United States	Robert Wood Johnston Foundation	- leadership development - collaborative problem solving - communication skills - service brokerage	service planning is separated from service provision	- fostered open communication - identified creative approaches - created a responsive service system
Independent Living Support Scheme (1999) by Welsh local authorities, Welsh, England	The UK community Care Act 1996	- direct payments - assist in the use of direct payments - develop and manage support services	service planning is separated from service provision	- client satisfaction - flexibility - efficient use of fund - cost saving or neutral
Individualized Funding (2005) by Community Living British Columbia, British Columbia, Canada	Community Living Authority Act	- employment services -skill development - individual services - community based services -homemaker services	- service planning is separated from both service provision and fund allocation	- satisfied high-levels of service needs - cost saving demonstrated by two IF options out of three
Home and Community Support Services (2009) by Manawanui InCharge, Auckland, New Zealand	New Zealand Ministry of Health	- direct payments - assist in the use of direct payments - develop and manage support services	- service planning is separated from both service provision and fund allocation	- satisfied high-levels of service needs - cost saving

Appendix C

Quality of Life Domains

Well-Being	**Physical Well-Being**: energy levels, being able to get medical help, health and lifestyle
	Emotional Well-Being: happiness and safety, and how individuals feel about their lives
	Material Well-Being: personal possessions that are important to individuals, how much individuals can use money for things they want or need
Independence	**Personal Development**: the things that individuals are interested in learning and things that they enjoy and are important to them
	Self-Determination: the choices and decisions individuals make about areas that matter to them in their life
Social Participation	**Interpersonal Relations**: type of support and help individuals get, relationships with family and friends, and the types of activities that individuals do with people in their life
	Social Inclusion: the activities and things individuals do and would like to do in the community, the people they do things with and places they go in their community
	Rights: individuals' right to privacy, how individuals are treated by people, how much they are listened to

(Alberta Human Services, 2013)

Appendix D

Supports Intensity Scale (SIS) organized by Quality of Life Domains

Quality of Life Domains	**SIS Support Areas**
Physical Well-Being	Learning health and physical education skills Taking medications Avoiding health and safety hazards Obtaining health care services Ambulating and moving about Learning how to access emergency services Maintaining a nutritious diet Maintaining physical health and fitness Exceptional medical support needs
Emotional Well-Being	Learning self-management strategies Maintains emotional well-being Exceptional behavioral support needs
Material Well-Being	Accessing/receiving job/task accommodation Learning and using specific job skills Completing work-related tasks with acceptable speed Completing work-related tasks with acceptable quality Changing job assignments Seeking information and assistance from an employer
Personal Development	Toileting; Bathing-person hygiene Eating food; Preparing food Dressing; Taking care of clothes Housekeeping and cleaning; Operating home appliances Interacting with others in learning activities Participating in training/education decisions Learning and using problem solving strategies Using technology for learning Accessing training/educational settings Managing money and personal finances

Self-Determination	Learning self-determination skills Advocating for self Participating in self-advocacy group Making choices and decisions
Interpersonal Relations	Going to visit family and friends Interacting with community members Interacting with co-workers Interacting with supervisors/job coaches Socializing within the household Participating in recreation/leisure activities w/others Socializing outside the household Making and keeping friends Communicating about personal needs Using appropriate social skills Engaging in loving and intimate relationships
Social Inclusion	Transportation Participation in recreation/leisure activities in the community Using public services in the community Participating-preferred community activities Shopping and purchasing goods and services Accessing public buildings/settings Engaging in volunteer work
Rights	Protecting self from exploitation Exercising legal responsibilities Obtaining legal services Advocating for others

(Alberta Human Services, 2013)

Appendix E

Support Strategies organized by Support Elements

Support Elements	Exemplary Support Strategies
Professional Services	Physical Therapy, Occupational Therapy, Speech Therapy, Medical, Psychological, Psychiatric, Nursing
Prosthetics	Sensory aides and mobility assistance devices
Cognitive	Assistive and information technology (e.g. communication devices, cell phones, iPads, medication dispensing devices, med alert monitors, speech recognition devices
Skills and Knowledge	Task analysis (i.e. step-by-step guide to learning) applied behavior analysis, information availability, situational learning opportunities, education and training strategies such as Universal Design for Learning
Environmental Accommodation	Ramps, Braille, push buttons, modified counters and work spaces, modified transportation, secure and predictable environments, adapted texts and signs, environments that are conducive to learning, matching tasks to an individual's relative strengths and interests
Incentives	Role status involvement, recognition, appreciation, money, personal goal setting, empowerment, self-directed ISP, community participation
Personal Assets	Attitudes, interests, adaptive strengths (conceptual, social, practical), and natural supports
Positive Behavior Supports	Functional assessment of problem behavior and focusing on altering the environment before a problem behavior occurs and teaching appropriate behaviors

Natural Supports	Support networks (e.g. family, friends, colleagues, generic agencies), advocacy, befriending, community involvement, social engagement, and interactions
Policies and Practices (organizational)	Aligning staff and professionals' work, increasing staff involvement, providing needed transportation, reducing turnover and continual change of direct support staff, establishing a reference person for each client, partnering with universities and other research and training centers
Policies and Practices (societal)	Resource allocation patterns, interagency networks, public relations campaigns, information services

(Alberta Human Services, 2013)

Appendix F

Individual Support Plan (ISP) Template

Client Name:

Date:

Identify Personal Goal (What is important to/for the client?)	Quality of Life Domains	Support Objectives (SIS/What needs to be done?)	Support Strategies (How will support workers assist?)	Timeline (Keeping track of the time spent on each stage of approaching the goal.)	Progress Review and Comments

First let a client **Identify Personal Goal**, and then categorize the goal under one out of the eight **Quality of Life Domains** (Appendix C.). After identifying a domain, refer to the **Supports Intensity Scale** (SIS, Appendix D.) to determine the service needs pertaining to the goal. The **System of Support Elements** with corresponding Exemplary Support Strategies (Appendix E.) provides a list of **Exemplary Support Strategies**. The client's progress towards the goal should be monitored periodically (at least four times per year) in the last two columns (Alberta Human Services, 2013).

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