Services to People with Developmental Disabilities

Contemporary Challenges and Necessary Solutions

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Political and Economic Context

Most social services – health, education, welfare and child care – were developed throughout the world based on charitable institutions that provided care for the most vulnerable in society. Churches, clubs, fraternities and community groups would see a human need in societies and develop a response that was created by volunteers or paid staff, depending on time and place. Many of these efforts were funded by philanthropists or well-off citizens who believed it was their duty to contribute to the welfare of others, based on the norms of their day. These types of arrangements were part of the culture of ancient Rome, feudal societies and in the developing New World. In many ways, they continue to this day.

The Enlightenment of the 1700's brought with it a secular response to assisting humans in need. The works of John Locke, Voltaire, Diderot and Rousseau introduced ideas about the equality of human beings in an era when kings and churches controlled which rights were granted to which individuals. The Enlightenment philosophers believed in natural rights – to life, liberty and property – and many of these rights were incorporated by the American Thomas Jefferson in the Declaration of Independence. As churches and kings lost power after a series of political revolutions, countries became more democratic and tolerant of other viewpoints. It was now possible for people who were not part of the elite classes to enjoy freedom, ambition and the pursuit of happiness – but they also had a civic duty to support children, spouses, extended family and the most vulnerable through charitable good works.

As democracies developed and governments began taxing citizens, people demanded more from those who were taxing them. Public education systems were developed to cooperatively teach everyone's children to a standardized curriculum that ensured countries had the human resources to seek out prosperity. Health care was primitive, but people wanted doctors to help them get well during times of illness. Social supports to the needy – including orphans and widows -continued to be provided by charities and churches.

As Western governments evolved over the past 300 years, an increasing share of social responsibility was accepted as public responsibility. Not only were governments there to collect taxes to provide common goods and services with which to build commerce (roads, law courts, customs houses), but they also accepted increasing responsibility for the welfare of their people. By the 1960's, Canada, the USA, Europe, Australia, New Zealand and the British Isles all had major programs to support the health, education and well-being of their businesses and citizens. Some of these programs came with legislated ‘entitlements’ – that is, they needed to be provided to all who qualified while others were ‘voluntary’ – available to citizens at the governments’ discretion.

By the late 1970’s and early 1980’s, governments began to question the idea of the ‘embedded Liberalism’ that had impacted governance since the times of the Enlightenment. The world was changing. In 1978, Deng Xiaoping began to liberalize the Chinese economy by allowing foreign trade and building infrastructure that would provide the foundation for a huge manufacturing sector. In 1979, Paul Volker was placed in charge of the Federal Reserve Board in the US. He dramatically changed monetary policy but more importantly in 1979, Margaret Thatcher was also elected in Britain with a mandate to curb trade union power. In 1980, Ronald Reagan was elected president in the U.S. and immediately set about deregulating industry, agriculture and resource extraction while liberating the powers of the financial community internally and internationally. The ‘Neo-Liberal’ doctrine had become the guiding principle of economic thought in the West and was about to go global.

Neoliberalism is a “theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets and free trade.” (A Brief History of Neoliberalism, ©David Harvey 2005, Oxford University Press, p.2). In this view, the role of the state is to:

Ensure the quality and integrity of money

- Establish military, police, legal structures and systems required to secure private property rights
- Guarantee the functioning of markets
- Help create new markets (e.g. privatize public functions, build trade relations)
- Avoid interfering in markets and de-regulate, privatize and withdraw from direct service provision – “Let the markets decide”
- Regulate the labour market as much as possible to ensure wages remain at levels that ensure greater affordability

Almost all countries – from old communist-bloc to new democracies – have embraced neoliberalism in one form or another. Since neoliberal advocates now occupy influential positions in universities, think tanks, the corporate media, boardrooms, banks, government, supreme courts, the IMF, World Bank and World Trade Organization, it is likely that this political and economic ideology will continue to dominate global ideology for many years to come. Rather than focussing on the rights of the individual, as was the case in most democracies up to the 1980’s, neoliberalism assumes that individual freedoms are guaranteed by freedom of the market and free trade.

In old school “Keynesian” economics, the role of government was to focus on full employment, economic growth, and the welfare of its citizens. Under this model, government intervention in markets was encouraged to achieve its primary aims. A class compromise between capital and labour was generally advocated as the key guarantor of domestic peace and tranquility. This 'embedded liberalism' provided a regulatory environment that included environmental and social policies, but by the end of the 1960's, Keynesian policies stopped working. There was a long period of stagnating economic growth, inflation and unemployment that was impacting the welfare of all citizens in the democratic capitalist world. For this reason, based on the work of the American philosopher Friedrich von Hayek and economist Milton Friedman, neoliberal policies began to be adopted by Western governments by the beginning of the 1980's

Margaret Thatcher was the first and perhaps most strident government proponent of neoliberalism. She confronted all trade unions and "broke the backs" of a few. She attacked all forms of uncooperative social solidarity movements and rolled back or dismantled welfare state commitments. She privatized public enterprises, including social housing, reduced taxes, encouraged entrepreneurialism and created a business climate to attract foreign investments. Thatcher was all about individualism, private property, personal responsibility and family values: "Economics are the method, but the object is to change the soul".

Thatcher was very successful in turning around the economy in Britain and hailed by the neoliberal community as a guiding light. In this view, the role of government was to create a good business climate rather than look to the needs and well-being of the population at large who were or should be responsible enough to take care of themselves. Legislation pertaining to business de-regulated their operating environment to increase profits and expansion while unions were regulated and disempowered. Reduced union influence bred reduced wages for everyone, including foreign competitors. Corporate welfare programs increased dramatically while funding for social welfare decreased dramatically, and continues to do so.

Eventually, corruption, influence-peddling and widespread speculation resulted in the global financial crisis that started in 2008 because all governments had de-regulated their financial sectors. At the same time, government withdrawal from social welfare provision combined with technologically induced shifts in job structures rendered large segments of the labour force redundant and workers were laid off. Workers were viewed as a factor of production and if machines or cheaper labour elsewhere created more efficient production, then local workers were no longer required.

In this new world, rights are enforced by the courts, but access to legal recourse to enforce rights is expensive. Since governments do not confer rights – they are inalienable – then governments do not have to pay or subsidize citizens to enjoy their rights. It is the responsibility of the individual to exercise their rights and the government really should have little to do with it. Since most needy people can't afford to enforce their own rights, advocacy groups form to take up their cause and non-government organizations step in to fill the void left by the withdrawal of the government from social support functions. This has been called 'privatization by NGO' and some academics argue that this has helped to accelerate government withdrawal from social service provision.

President Roosevelt made his view clear that excessive market freedoms lay at the root of the economic problems of the 1930's Great Depression. He believed the primary obligation of the government was to use its powers and allocate its resources to eradicate poverty and hunger in addition to assuring the security of livelihood against major hazards. With the advent of the economic collapse of the late 2000's, many earlier neoliberal enthusiasts are now critical and the U.S. government has reverted to a modified Keynesian approach. The crisis is now in political philosophy – although the financial, manufacturing and housing sectors have been bailed out in a Keynesian-style intervention of major consequence, neoliberal principles continue to dominate discussions about the responsibility of governments to those citizens who may be prevented from participation in production or free enterprise because they are not valued economic units, either temporarily or permanently. There is some talk of instituting regulatory structures of global governance to monitor the kind of reckless financial speculation that led to the last economic collapse, but the withdrawal of governments from social service provision – including health care, education and public welfare – has accelerated.

The widening gap between neoliberal rhetoric and reality is now all too obvious. The market has never purported to be about fairness and charity – it is about profit. To bridge this gap between magical thinking and reality, we must identify feasible alternatives by introducing local experiments with new technologies and styles of governance. We must also record true instances of best practices that can be generalized throughout service delivery systems, based on empirical data rather than anecdotes.

The Local Situation

Before the election of the B.C. Liberal Party in 2001, social services had gone through a consolidation process whereby all sectors were brought together for the purposes of collective bargaining through the Public Sector Employer's Act, which recognized social service employees as a part of the broad public sector. Agencies had been quickly unionized in the aftermath of institutional service transfers to the community and their collective bargaining rights were assumed by government through an Employer's Association (CSSEA). Since social services employers were now represented at the Public Sector Employers Council (PSEC) table along with more sophisticated sectors such as health care, education, crown corporations, advanced education, and so on, their low wage rates and lack of other government benefits were recognized. A 'low wage redress' project was launched in the 1990's so that minimum wage rates in social services could be increased to the predominantly female employees in the sector.

Major gains were made during this time, but parity between social services and other public sector workers remained elusive.

This consolidation of the sector ultimately concluded with a 'master' collective agreement bargained by CSSEA, each agency's collective bargaining agent, so that wage rates could be equitable throughout the social services sector and government, who funded community agencies could also control wage costs through representation on the CSSEA and PSEC boards.

With the election of the Liberals in 2001 the goal was to improve the B.C. economy, which had stagnated over the previous decade in comparison to other provinces and the United States. The goal of the new provincial government was now to ensure that public services were modernized and 'transformed' for greater efficiency and effectiveness. The PSEC and CSSEA funding and bargaining structures were now used to roll back wages in the sector which, during the intense economic activity of the 2010 Whistler/Vancouver Olympics made recruitment very challenging due to the higher wages paid in the construction, transportation, retail and service industries.

The plan for community living seems to have been hatched before 2001, but by the time the new government settled in, great activity was taking place in the community living sector based on discussions of individualized funding and new legislation that would establish a provincial crown corporation to fund and support people with developmental disabilities. The plan originally included children, but after a few years of implementation government decided that children with special needs had more in common with other children than they did with adults who had developmental disabilities. At the time, they were the only children excluded from services offered by the Ministry of Children and Families so it made sense that their services would revert back to this Ministry while adult community living services under the auspices of Community Living B.C. were transferred to the Ministry of Social Development, also responsible for other adult services such as housing, employment, social welfare, and so on.

CLBC did not have an easy start. The idea of such a crown corporation focused on individualized funding was based on a similar devolution of services in Alberta and Western Australia, the two jurisdictions that were touted as the most progressive in the world, in spite of the fact that there was no empirical evidence that these models had met their objectives and were producing superior efficiencies or quality of life for the people they supported. Government liked the idea because they were promised by their selected community representatives that such a transformation would reduce costs and provide more individualized, community 'supports' and would allow families to 'become more involved in the lives of their [adult] children.' Rather than funding going to agencies in block funded contracts, each individual would be asked to dream their dreams and CLBC would be able to make sure those dreams came true through more ‘flexibility’ in funding and individualization of budgets. At the time, in no place in the world was it evidenced that individualized funding actually reduced costs and in some cases, it was known that this funding model indeed increased costs due to the loss of economies of scale and allocation of staff to individuals rather than groups. Several studies were commissioned by the government to improve the functioning of CLBC and these resulted in some changes, but the major challenge of increasing service demand and decreasing funding has never been fully articulated or overcome.

Analysis of Funding by Government of Adult Community Living Services from 2001-2002 until 2011-2012

	Projected	*Actual*	*Actual*	*Data Source*	*Actual*
	2011-12	2010-11	2002-03		2001-02
Population of BC	**4,655,400**	**4,530,960**	**4,098,178**	BC Stats	**4,076,264**
Revenue (millions)	$41,337	$39,893	$24,975	Ministry of Finance Budget Documents	$22,853
BC Gov. Expenditures	$41,912,000,000	$41,008,000,000	$28,475,000,000	Ministry of Finance Budget Documents	$25,637,000,000
MCFD Expenditure or Ministry Transfers to CLBC	$680,977,000	$680,977,000	$630,800,000	MCFD and CLBC Service Plans + Reports	$640,988,000
	Projected	*Reported*	*Reported*		*Estimated*
Adult Community Living Expense	**$639,200,000**	**$641,300,000**	**$555,700,000**	MCFD and CLBC Service Plans + Reports	**$565,888,000**
Adult CL Services as a % of Total BC Gov. Expense for the fiscal year	1.53%	1.56%	1.95%	Calculated Amount	2.21%
Population Increase Since 2002	13.6%	10.6%		Calculated Amount	
Inflationary Increase Since 2002	20.4%	16.6%		From Bank of Canada Inflation Calculator	
Combined Population and Inflationary Increase % Since 2002	**34.0%**	**27.1%**		Calculated Amount	
Actual Adult CL (ACL)Budget Increase Since 2002	**15.0%**	**15.4%**		**Calculated Amount**	
BC Gov. Expense Increase Since 2002, total expenditures	**47.2%**	**44.0%**		Calculated Amount	
CLBC Adult Caseload Increase Since 2002	57.7%	50.1%		Calculated Amount	
No. of Adults Receiving CL Services	14,104	13,416	8,941	MCFD and CLBC Service Plans + Reports	8,657
Funding Per Adult Receiving CLBC Services	**$45,320**	**$47,801**	**$62,152**	Calculated Amount	**$65,368**
Funding Per Adult in 2002 Dollars	**$37,642**	**$41,003**	**$62,152**	Calculated Amount	
ACL Community Living Funding Shortfall using population increase since 2002 and inflation since 2002 (34%).	**$105,420,344**			Calculated Amount	
ACL Shortfall if funding had remained at 1.95% of Provincial Expenditures (2002)	**$178,727,951**			Calculated Amount	
ACL Shortfall Using Inflation (20.4%) and Caseload Increase (57.7%) Since 2002	**$350,752,980**			Calculated Amount	
ACL Community Living Funding Shortfall using population increase since 2001 and inflation since 2001 (36.7%).	**$134,354,859**				
ACL Shortfall if funding had remained at 2.21% of Provincial Gov. Expenditures (2001)	**$285,927,661**				
ACL Shortfall Using Inflation (22.5%) and Caseload Increase (62.9%) Since 2001-02	**$410,013,961**				

CLBC is projecting a 6% compounding increase in demand for supports over the next 20 years, which is likely a conservative estimate, particularly since we know that a large number of aging people will be needing extraordinary services as their care-giving parents pass on and there are also major increases in the number of children with autism spectrum disorders who will be entering the adult system starting in about 2015.

British Columbians with developmental disabilities now face a future of escalating demand and diminishing funding with no public plan regarding how this problem will be addressed other than creation of a perpetual wait list for those entering the system. This problem is not unique to British Columbia. An October, 2010 KPMG report to the Minister of Seniors and Community Supports in Alberta reviewed issues similar to those currently being experienced locally and recommended a move of service responsibility back to government from the board governance structure that was copied by B.C. The main recommendation was: "… a new organization model, a new governance approach and a more efficient network of service providers for the PDD Program." The government's goal is to ensure the program is sustainable into the future "to make it even better." (http://www.seniors.alberta.ca/pdd/adminreview/PDDAdminReviewSummaryReport.pdf)

Lessons from Alberta

Over the past 5 years, total funding for Alberta's PDD program has steadily increased – from less than $500 million in 2005-2006 to almost $600 million in 2009-2010 when the program supported about 9,300 individuals at a cost of $592 million. Of this, administration cost $142 million because of the costs associated with contracts with 257 service providers, 935 family managed administrators and 3 direct operations. 32% or $46 million was spent on internal administration of 6 Community Boards and their bureaucracies while 68% or $96 million was spent on external administration, paid to contracted agencies and family administrators. The actual administration costs were 31% of direct support costs, compared to B.C., Western Australia and Massachusetts where administration rates were between 6% and 20%. The administration amount paid per individual served in Alberta ranged from $3,000 to $31,000 per year, depending on region. This indicates the higher cost of administering individualized budgets due to duplication of corporate services. Service providers who supported over 100 people and offered multiple services had the lowest administration costs, but they comprised only 17% of the total. KPMG noted significant overlap in responsibilities and duplication across all levels.

Problems common to British Columbia included:

- Huge caseloads for PDD Coordinators, who had responsibility for between 57 and 290 individuals

- Roles and responsibilities of PDD staff were unclear and differed between regions, particularly the different roles of Coordinators (Facilitators) and Contract Managers (Analysts)
- Skills and capacities in finance, analytics, forecasting, budgeting and Information Technology varied between regions
- The PDD program has not defined what standards and performance indicators should be monitored, how often or by whom
- PDD staff have big challenges clearly conveying how their mandate and core businesses translate into individual funding decisions – information about what the PDD program funds and how individual funding is determined is not available
- Many stakeholders are unclear about the boundaries or limits of the PDD program – the lack of equity and transparency needs to be addressed by establishing clear accountabilities, a common understanding of the mandate, priorities, risks and a sound communication strategy
- For individuals, families and advocates, navigating through the system is difficult and confusing
- There is no common communication strategy but rather confusion, mistrust and increased costs
- Although family-managed supports are the least expensive, only 10% of services are provided this way because there has been little uptake of this option by families
- There is no case management system – just a payment system introduced in 1998. This is missing key functionalities, stores client information in many locations (so it is hard to retrieve), provides no economic commerce system, and is too sophisticated for the level of IT proficiency amongst service providers. Because of this, about 15,000 invoices generated from providers need to be manually entered into various records and systems each year. KPMG stated: "It is difficult to manage and monitor the achievement of client outcomes without an effective use of technology".

KPMG's recommendations were:

1. Dissolve the 6 Community Boards and create one organization under the direct authority of the government, which eliminates the need for a separate agency with a Board of Directors: "A governance board structure is generally not appropriate where the mandate or business of the agency cannot be clearly defined". The PDD's business is to fund, monitor and evaluate supports for individuals with developmental disabilities.
2. Establish an Advisory Council with no fiduciary duties that reports directly to the Minister.
3. Adopt a matrix organizational model where staff have direct reporting relationships to functional leaders.
4. Implement a new procurement strategy to optimize the size and efficiency of service providers.
5. Implement additional resources to support the family-managed option.
6. Introduce an integrated case management system that will allow a common view of the individual between providers and funders.

KPMG also recommended that the future organization be created within government and designed along the following functions: Client support services; contract management; client case management and support – in order to achieve the following key outcomes:

1. Enhanced role clarity between case management and service procurement
2. Improved client experiences accessing information and acquiring supports
3. Increased portability and flexibility
4. Improved relationships between case managers, individuals and families.

The Ontario Experience

In a “Partnerships that Build Quality” Business Plan released for 2010/2011, (http://www.communitylivingontario.ca/sites/default/files/PNDS%20Business%20Plan%202010.pdf) the Ontario Provincial Network on Developmental Services (a group of non-profit service providers who provide support to over 36,000 people with developmental disabilities) iterated the top priorities for their sector:

- Address the waitlist of 19,000 Ontarians waiting for supports at an approximate cost of $36 million;
- Focus on the increasing need due to transitioning youth and aging demographics of both people with developmental disabilities and their parents;
- Develop operating budgets that reflect current expense levels;
- Provide competitive wages for sector employees across the province.

Their recommended HR Strategy for the sector focussed on:

- Recruiting qualified and motivated staff
- Strengthening HR practices across Ontario
- Providing effective training with measurable results
- Developing collaborations with colleges
- Developing clear career paths for employees
- Identifying core competencies for 6 key positions

The base funding situation in Ontario is bleak – the sector is unable to trim costs further as they are already operating with no capacity to respond to growing demand, changing needs or additional accountability requirements and there are serious shortages in services since the system is overloaded.

The recommendation from the Ontario Provincial Network was a minimum salary target of $24.60 per hour plus 26% benefits for a mid-level support worker. In a September, 2009 benchmarking survey, support worker wages ranged from $20.50 per hour with 10% of agencies below $17.06 and 10% above $24.60.

According to a report issued by the Metro Toronto Agencies Representatives Council released in February 2005: "Beyond Numbers: The Implications of Financial Restraints and Changing Needs on Developmental Services" (http://lynneakin.com/frameset/images/LE_DOCS/Reports/FinancingtheNonprofitSector/beyond-numbers.pdf), the sector faced the effect of a 5% across-the-board budget cut in 1994-1995 and was frozen at 0% increases for the next 10 years. This occurred during a period where inflation was 28%. The system was over capacity and financially unstable. Since 74% to 83% of budgets accounted for staffing costs, agencies had already used the following strategies to meet accelerating demand in the face of reduced funding:

1. Adjusting shifts to achieve reductions in front-line staff hours
2. Clustering people to allow for more efficient staff coverage
3. Delaying filling staff positions
4. Reorganizing and reducing management
5. Reducing supervisory positions and increasing responsibilities of remaining supervisory staff
6. Trimming administration staff and reassigning responsibilities to others
7. Reducing access to specialist consultants
8. Limiting salary increases
9. Reducing or deferring maintenance and replacements
10. Limiting client travel and outings
11. Reducing food and household budgets
12. Passing on more responsibilities and costs to families and the faith community

The results of these strategies included:

- Increased reliance on untrained, part-time staff
- Great difficulties recruiting and high turnover due to stagnating salaries
- Decreased retention due to limited advancement opportunities
- Compression between line and management salaries
- Increased workload for all remaining staff, so service enhancements were not possible
- Supervisors taking on roles for which they are not qualified
- People not receiving the specialist services they needed.

In spite of these efforts, the following challenges remained:

- Increasing demands for awake overnight staff due to high client needs
- Increased need for at-home day coverage as people aged out of day programs
- Increased need for 1:1 staff to attend doctor's appointments and assist hospitalized clients
- Increased need for staff training re: Alzheimer's, lifting, medications and so on
- High support residential spaces never becoming available to those waiting
- Agency reluctance to accept people with high needs as they are already too stretched
- Increasing numbers of Baby Boomers with developmental disabilities who are flooding the system
- Increasing numbers of families who can no longer provide care
- Diminished capacity for agencies to provide care.

Recommendations included:

1. Restore system capacity:
- Fund agencies
- Increase capacity through flexibility
- Support development of elder care services
- Strengthen staffing
2. Restore financial health to developmental disability services:
- Provide competitive compensation
- Improve service contracts
- Provide predictable funding
- Provide flexible funding for changing needs
3. Strengthen planning capacity and develop a multi-year plan based on sound information
4. Support and promote inter-system planning with other sectors such as social housing, community health and long term care
5. Streamline and simplify accountability measures and reporting required from agencies

Canadian Realities

The National Report Card on the Inclusion of Canadians with Intellectual Disabilities issued by the Canadian Association for Community Living in December, 2010 (http://www.cacl.ca/sites/default/files/uploads/docs/REPORT_CARD_2010_ENG_web.pdf)

CACL offered the following statistical results reflecting the reality of community inclusion in Canada:

- 30% of children with an intellectual disability had to leave their community in the past to receive services

- Only 33% of children with intellectual disabilities are in inclusive high school settings
- 41% of children with intellectual disabilities felt threatened at school and 36% had been assaulted
- 52% of young adults (20-29) with intellectual disabilities are neither working nor attending school – compared to 12% without a disability
- 25% of families with children with intellectual disabilities report financial difficulties meeting expenses
- 66% of parents reported having to leave their job, forego promotions or work fewer hours, decreasing their income
- 73% of parents who lack the support they need report cost as the barrier
- 37% of parents report the services they need are not available locally
- 45% of people with intellectual disabilities report needing more help than they are currently receiving
- The refundable Disability Tax Credit provides no benefit for those without a taxable income
- Adults with intellectual disabilities are 3 times more likely than others to live in poverty
- Almost 50% of working age people with intellectual disabilities are in receipt of welfare

The Irish Review

Report of the National Disability Authority: "Developing Services for People with Disabilities: A Synthesis Paper summarizing the key learning of experiences in selected jurisdictions as at October 2010" - The National Disability Authority's advice paper to the *Value for Money and Policy Review of Disability Services in Ireland* (http://www.nda.ie/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/F1D157570980DF218025778100507AD0?OpenDocument)

The National Disability Authority in Ireland is the independent statutory organization supporting the implementation of a National Disability Strategy. "The goal is to replace historical and inefficient financing systems with higher performing systems that control costs better while delivering on defined outcomes for individuals and populations".

This report delivered the findings of NDA research on health, social care and specialist services for people with disabilities in England, Scotland, New Zealand, Norway, the Netherlands and Victoria, Australia. It considered the challenges that have arisen in these jurisdictions and incorporated learning from NDA visits to the United States. Results included:

- The disability service systems in all jurisdictions are in transition and some are undergoing rapid redevelopment

- A clear vision and articulated service model design were absent in many areas
- Although the goal was to implement a vision through strategic commissioning, service provision, maintenance through monitoring outcome measurement and building partnerships, these objectives were very rarely met
- Models that were emerging in various contexts were intended to be person centered, self-directed, individualized, and to promote community/independent living
- Increased coordination between health, social care and community services that utilize assistive and information technology to reach into home settings was required
- Priorities for public services internationally include cost-effectiveness, cost-containment and sustainability. These policies necessitate building expertise in resource allocation and costing; determining appropriate needs assessment tools; developing person-centered and self-directed plans; administering individualized funding; and developing community support systems with suitable, affordable accommodation and housing
- In reality, however, virtually all systems in all jurisdictions were crisis-driven

Efforts being made across jurisdictions included:

- Operationalizing policies, strategies and incorporating new concepts and principles into service planning
- Formulating clear implementation plans to ensure delivery of new services
- Developing integrated public service frameworks and systems to support new services
- Developing accessible environments in transportation, housing, employment and technology
- Determining outcomes for people based on variables such as individual characteristics, service design and staff activities
- Targeting attention to “natural” versus paid supports
- Developing outcome measures that monitor the long-term changes that have occurred in the lives of people with disabilities as a result of policies, services and programs
- Introducing market values into public services with the evolution of some responsibilities for the provision of services from governments to the market, community and citizenry
- Strategic commissioning, assessing, forecasting needs, defining outcomes, considering options and planning services
- Promoting direct funding – so far the uptake internationally is only about 10% where they are offered and the old systems are still doing the bulk of the work
- Developing better resource allocation strategies – in Australia, there is no strategy, in England, crisis service contracting to the lowest bidder has had bad results like placement problems, out of area placements, re-institutionalization, loss of service choice, poorer efficiency and public criticism
- Consideration of an insurance system for social care as the best way of funding future services (if carriers would in fact provide such insurance)

- Addressing geographic disparities in service provision, the lack of comprehensive data collection systems anywhere, the increase in service inflexibility and parent risk-aversion and developing some explicit models or frameworks for integrating health, disability and social services

Outstanding problems in the systems change to more cost-effective, individualized services common to all jurisdictions studied included:

- New systems, without coordinator support, are difficult for service users to understand and navigate
- Insufficient staff training
- Under-financing of assessment systems
- Insufficient resources allocated to accommodation
- Segregated day programs with less funding are discouraging the development of individualized, community-based services
- High levels of unmet need are creating crisis-driven systems
- Inappropriate placements due to lack of suitable services for people with developmental disabilities and challenging behaviours
- Confusion between “rights” and access to funding (that is, government funding is not a right)
- The market is increasingly operating to maximize the number of placements over quality of placements
- The new competitive environment undermines a culture of collaboration, shared ideas and innovation
- Many senior personnel have resigned, so professionalism and institutional memory of the sector is disappearing
- Continued resource allocation to old models because of the lack of uptake for direct funding is leaving fewer resources for individualized solutions
- Scarce financial resources
- Conflict between individualization and regulations, standards and accountability mechanisms
- Risk management problems in human and financial areas
- The complexity of developing services for people with high behavioural needs
- The lack of clarity, honesty and trusting communications from government on the realities and limitations of new services
- The lack of utilization of ‘natural supports’ in the community
- The need for robust systems for costing and funding of services
- Increased unmet need for those with the most complex challenges
- Required persistence in keeping an outcome versus output focus
- Lack of data that supports the effectiveness of any of these new theoretical models – there is no robust outcomes knowledge base

The United States in Transition

Report from the National Association of State Directors of Developmental Disability Services, Community Reporter, Volume 18, Number 6, June, 2011

In the United States, the vast majority of individuals with developmental disabilities depend on families as their primary source of support. Service systems are currently having to make incredibly difficult budget decisions due to the high-debt situation both federally and state-wide. Professionals in the US are focussing on supporting families, including those from all backgrounds, to maximize their capacity, strengths and abilities so they can facilitate inclusion in all facets of community life for their family members. There have been unhealthy, unrealistic expectations on the role of services, with “too much entitlement thinking versus the use of natural supports and a philosophy of a self-determined life.” The goal is to mentor family capacity building. “To build a sustainable service system into the future, states must find ways to fully support families whose adult sons and daughters are living at home with them.”

Understanding Medicaid Home and Community Services 2010 Edition from the U.S. department of Health and Human Services, Office of the Assistant Secretary of Planning and Evaluation (http://aspe.hhs.gov/daltcp/reports/2010/primer10.pdf)

Medicaid is the major source of public funding for all long-term care services and supports in the U.S. Medicaid was enacted in 1965 as a joint Federal/State entitlement program providing primary medical care to low-income Americans. In the past, Medicaid funded institutional services but has increasingly funded home and community based services through the HCBS Waiver program. By 2009, HCBS waivers accounted for 45% of Medicaid long-term care funding. The Center for Medicaid and Medicare Services cites the increased numbers of people with congenital and acquired disabilities who survive and live longer lives and those who are over age 85 as rapidly driving up costs for long term care services. The age 85 group alone is estimated to grow from 5.3 million in 2006 to nearly 21 million by 2050 – including people who have developmental disabilities and those who are currently providing their care. Most long term care is provided by women, but since women are now necessarily in the work force, there are fewer people available to provide this care.

Medicaid is a means-tested entitlement program. The individual’s income and assets cannot exceed state thresholds, which are usually at or slightly above the poverty line. To qualify under the disability category, the individual must have a “long-lasting, severe, medically determinable physical or mental impairment” and earn less than $1,000 monthly. Most people who qualify come to Medicaid through social insurance benefits that are $674/month for individuals or $1,011 per couple per month. Maximum ‘countable assets’ must not exceed $2,000. States can further limit HCBS waiver funding and create their own eligibility standards. State funding for family support programs is about $3,000 to $4,000 per family per year. The average annual expenditures for all HCBS waivers was $43,464 per person but in institutions and nursing homes, the annual funding was up to $175,000 per person.

State-regulated foster care homes serve from 6 to 8 people, but states generally prefer groups of 1 to 3. Individuals or corporations can own and operate settings licensed as foster homes, which provide assistance with daily living and community access. Residential facilities also exist that provide housing services and supervision to from 2 to 3 to over 100 adults. “Special populations” training and certification must also be acquired by people who provide foster care to people with developmental disabilities. State licensing rules set the minimum requirements for Medicaid adult foster care providers. These include such policies as minimum staff to resident ratios, specific needs for awake overnights, mandatory training and so on.

Participant-directed services emerged in 1995 as “an essential element of self-determination” after the Robert Woods Johnson Foundation and the U.S. Department of Health and Human Services launched the National Cash and Counselling Evaluation Demonstration Project. Rather than funding programs, cash allowances were advanced to clients so they could purchase their own services and supports. This was followed in 2002 with the “Independence Plus” initiative. In 2005, the HCBS waiver was modified to include a participant-direction option, which has been adopted by 37 states. Use of this option must include the following elements:

- The individual must also be presented with a service provider option so there is a choice
- Participants must be able to opt in or out of directing their services and a traditional service delivery alternative must be available
- Participants must have authority to select their services and supports
- Participants must be allowed to select, hire, supervise and manage their workers since they have “Employer Authority”
- Participants must determine how and when services are delivered, including scheduling
- Participants may have an individual budget and exercise decision making over expenditures
- States must provide supports such as financial management, information and assistance services including counselling, teaching skills to manage and create a budget, assistance in locating workers and help accessing other community resources
- States are also expected to provide safeguards during transitions, in cases of premature depletion of funding, and must develop a back-up plan in case things go wrong

Medicaid dollars may only be used for personal care. All other necessities must be covered by social insurance benefits or through the generosity of others.

The U.S. is also investigating the use of Managed Care in the developmental disabilities field. The key feature of managed care is that it that the contractor bears the financial risks for services that are provided across settings and over time. The contractor is paid a capitation rate per enrollee and is expected to provide all contracted benefits at a cost under this rate. The theory is that ‘cheaper’ clients will balance the more expensive and since the profit motive is at play, more cost-effective services will result. The main challenges with implementing a managed care option are that the infrastructure is currently lacking in state and service delivery systems and rate setting is very complex – at what rate should capitation be set?

Overall, disability services in the US are at a critical crossroads, impacted by external circumstances that will determine the future of virtually every American. The aging of the population is already testing the limits of social programs that were established when the bulk of the citizenry was young and costs of supporting those in need were reasonably borne by the majority of workers. Today, the ratio of old to young is reversing precisely at the time the US has come to a major financial reckoning and needs to make difficult decisions to maintain an economic revival that has yet to appear. There is no longer any money to fund social services without a significant increase to taxes, a course that is politically unpalatable for many elected officials. The US debate will undoubtedly influence future policies in Canada as well.

Lessons from Australia

In 2009, the Victorian Department of Human Services, a secretariat of the Disability Policy and Research Working Group, engaged KPMG to analyze the "elements of contemporary disability service systems that enhance sustainability, innovation and maximize opportunities for equity, access and effectiveness of service delivery". The Summary Report was issued in May, 2009 under the title: "The Contemporary Disability Service System" (http://www.dprwg.gov.au/sites/default/files/attachments/Contemporary%20Disability%20Service%20System%20Summary%20Report.pdf)

The strengths of Australia's system were defined as:

- A strong human rights emphasis
- A focus on individual and person-centered approaches
- Robust quality management systems
- Good local response structures

Significant challenges were also noted:

- Limited resources
- The perception that disability services should be the sole or main source of support for people with disabilities, their families and carers has increased stress on the system
- Measuring effectiveness and the achievement of outcomes at the individual level is difficult or non-existent
- Work force limitations must be addressed
- There are severe services system constraints, including consideration of alternative sources of funding
- Increasing client complexity
- Decreasing capacity of the sector to implement reforms or improve service quality

The key reform goal in Australia is to move away from reliance on specialist disability service systems by establishing greater "connections and pathways between a broader range of human services". This requires significantly enhancing all (generic) human services to meet disability-related needs. There is consideration of an alternate funding mechanism to increase capacity through insurance, taxation or income support mechanisms. KPMG sees the disability system as part of a broader system that includes health, education, housing, employment and income support. In order to reach their goals, there needs to be a shift to "more inclusive informal supports" and "progressive thinking that is at an early stage internationally".

Victoria and Western Australia are implementing many elements of this new "best practice" system, although there is no data that has determined that these are best practices. New South Wales implemented Individualized Funding while Queensland, Tasmania and the rest of Australia are implementing service system changes and focusing on improving outcomes. The KPMG report recommended the following "high priority areas for attention":

- Rejecting the idea of 'specialist' disability supports in favour of a generic model – "reframing the support system" to focus on generic, unpaid and informal supports that are supplemented by the disability service system as required
- Discovering alternative funding 'levers' to boost private sector contributions, taxation and income support measures
- Increasing persons with developmental disabilities participation in employment
- Individualized funding and "strengthening individual support networks"
- Increasing investments in early intervention
- Improving the evidence-base for new services
- Developing greater consumer involvement in the delivery of supports and advocacy services
- Building industry and workforce capacity
- Developing a research-base for contemporary services because the current base is 'patchy'
- Encouraging family service provision by developing flexible funding tailored to the needs of the family as a whole, developing family centers so they know what is and is not available, better targeting of disability services and mutual self-help or families helping families

The only available evidence-based research cited was provided by the National Disability Strategy 2010-2020 in a report published by the Commonwealth of Australia in 2011 (http://www.fahcsia.gov.au).

By 2003, almost 4 million Australians or 20% of the population had a disability. This prevalence increased with age, with 55.7% of adults over age 65 reporting disabilities. From 1981 to 2003, the number of people with disabilities in Australia more than doubled from 1.9 million to 3.9 million. The number of people with a profound or severe core limitation increased by 173% to 1.2 million during this period because of increased life expectancy, an increase in the 65+ age group and an increase in disabling conditions in children, particularly ADHD and autism spectrum disorders. The most common disabling conditions are physical – 83.9% and mental – 16.1%, which included all people with psychiatric and developmental disabilities. 61.5% of people with disabilities needed ongoing assistance and most people relied on a mix of formal and informal (family) care. People with restrictions in core activities had a lower level of social attachment and were more likely to have difficulties accessing services, including assistance to participate in life outside the home. This group was also 1.8 times more likely than their disabled peers to have fallen victim to physical or threatened violence. In 79.5% of cases where care arrangements existed, parents provided the care. Of these parents, 51.8% were over the age of 45 and 13% were over the age of 65. When diminished health or loss of life terminated these relationships, the individual was usually supported by a sibling or other relative until emergency services could be coordinated, but only if they were available.

Overall Impressions

The Neoliberal goals of low taxes and privatized services have resulted in significant decreases in funding supports to people with developmental and other disabilities throughout the world. Since there is minimal profit in developmental disability services, high risk, labour intensity, and relatively a relatively high level of dependence on government, most service provision is being offloaded back onto families. This is an extremely frustrating situation because families cannot purchase insurance or otherwise predict that they will have a child with a disability that will need 24 hour care for the rest of their lives. Families rarely bear responsibility or fault for the disabling condition – having a child with a disability is typically unpredictable - but there is increasing suspicion that some disabling conditions are triggered by toxins and pollutants in our water, air, earth and food – impossible to avoid.

According to the Neoliberal ethic, there is a “moral hazard” in helping someone because it will prevent them from learning from their behaviours and improving themselves. Although this did not apply to multi-national banks and American car companies during the global financial crisis, this credo is being applied to people born with insurmountable challenges to self-help and daily living. Other relevant jargon to note in the neoliberal lexicon is: “starving the beast” (reducing human service government budget lines so they can provide only the most critical supports), “personal responsibility” (which generally means self-pay), “community [family] care”, “de-unionization”, “de-collectivization”, “employment first”, “community first” and “choice”. These one- or two-word policy directions are not supported by any empirical data regarding effectiveness or risk to the individual and are demonstrating their ineffectiveness in virtually every jurisdiction where they have been applied. The solution in most situations has not been to recognize the folly of these policies but to rather accelerate reliance on the flawed systems that are struggling against the realities of implementation.

People cannot work their way out of having a severe developmental disability and most families do not have the income to pay for services on the open market. The “community” is not volunteering to step up and provide free services. De-unionization is interfering with the rights of workers to bargain collectively, reducing the wages and qualifications of caregivers, increasing risk, creating increased turnover and exploiting an unprepared lay workforce. De-collectivisation is increasing costs, reducing the advantages of bulk buying, efficiencies of scale, and the benefits of sophisticated service infrastructure. Private companies can only profit from services by diluting care and accepting often unacceptable levels of risk. Individualized budgets and funding are increasing costs and/or de-professionalizing services. Funding is being capped and rationed in spite of the intensification of client needs. The lack of group advocacy is increasingly pitting individuals against governments, placing them in a “no win” situation. “Employment First” is very difficult for people who need 24/7 care because they have high behavioural or health care needs, particularly in an economy of high unemployment for everyone. “Community First” only works when there are paid staff to provide support and “choice” still means that funders and service providers provide the choices (if any) unless individuals can activate their choices with their own money.

It would be difficult if not impossible to fight the global trend toward “Families First”. The best it appears we can do is continue to advocate for the highest quality supports for people with developmental disabilities while we begin to envision a public service delivery system with far fewer services. In order to do this, however, we must work to move past the jargon, idealistic rhetoric and unfounded theories that have characterized so much of the “new thinking” in developmental disability service planning and see the reality of the “service transformations” of the early 21st century for what they are – a demonstration of how desperately governments are trying to reduce their responsibilities to care for their most vulnerable citizens.

The KPMG reports from Alberta and Australia demonstrate the first reckoning with the failures of the “new world order” in disability services. The “old” system was inefficient. The “new” system increased inefficiencies. The time has come to face reality and implement better, more modern modes of operation while we simultaneously respect the dignity of people with disabilities, have compassion for their families and value the people who work to maximize their potential. It can be done, but only if we recognize that current practices are intolerable and change is immediately required. Too many lives are at stake for us to hesitate any longer.