Beyond Numbers

The Implications of Financial Restraints and Changing Needs on Developmental Services

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Executive Summary

Metro Agencies Representatives Council (MARC) agencies are having significant difficulty balancing their budgets while maintaining service levels. This review was undertaken to explore factors contributing to the financial pressures, what agencies have done to mitigate these factors and what next steps need to be taken to ensure the agencies' financial health.

Research indicates there is no single factor, but rather a convergence of financial, service and client-related factors that result in the current pressures faced by the sector. Strategies agencies employed to balance their budgets have eroded any flexibility they had to accommodate the changing and increasing service needs of aging residents. The sector faces pressure to meet urgent need for residential care from elderly parents who find themselves no longer able to care for their adult children at home.

Financial Pressures

Changing Needs:
The first generation of individuals with developmental disabilities to live in community are facing aging issues. Throughout their lives, community services have been developed to meet their needs as they transitioned from children to adolescents to adults. Now however, as they experience accelerated aging and declining health, agencies are faced with the costs of putting the necessary elder services in place.

Inflation and Funding:
Financially, the sector has faced the combined effect of the 5% across the board cut to budgets in 1994-95 and the subsequent ten years of 0% increases to base budgets while absorbing rising costs (e.g. in utilities, transportation, insurance, staff benefits) during the same period.

Strategies used by Agencies

Agencies have employed a variety of strategies to address the funding shortfall, inflation and changing services needs. Many of these strategies could only be sustained temporarily while others resulted in a permanent reduction in agency response capability. Agencies have no more capacity to find additional strategies to address an on-going growth in the funding gap.

Summary

The agencies have been "trimming from within" to balance the budget. Front line, administrative and management staff have all been trimmed as far as possible. At the same, time individuals in care are aging and requiring increased levels of supervision and support to ensure their continued well-being and safety. In the community, many long time community residents are living with family members. These caregivers are now elderly and increasingly unable to provide for their adult children who are undergoing their own aging difficulties. Simultaneously, compliance, planning and accountability expectations for developmental service organizations have continued to increase.

A squeeze is on: the sector has reached capacity, the service system is overloaded, and there are serious shortages in services. The capacity of the sector to manage current and future risk is of concern as service pressures continue to challenge the seriously depleted and stretched service system. The organizations do not have the resiliency they need to meet the service challenges ahead.

Moving Forward: Recommendations

In order to restore financial and service capacity to the sector, the developmental service organizations and their MCSS Developmental Service funders must work collaboratively to plan, design and fund system capacity to meet the demand now and in the future. To move forward there is an urgent need to address two recommendations:

First, **system capacity must be increased**; especially urgent is the need to develop responsive models of elder care and add flexibility to existing residential care systems so they can respond effectively to resident's changing needs while negotiating partnerships with other service sectors to deliver coordinated health, well-being and end of life services.

Second, **financial stability must be restored to the sector** through annual cost of living increases, flexibility in managing budgets to increase agency capacity to respond to changing needs, and funding that reflects the true cost for the individual.

Conclusion

The years of cost trimming by agencies to balance their budgets have resulted in reduced front line and lean management staff. The sector is unable to trim its operations further and is currently operating with no capacity to respond to changing needs, growing demand for services, or additional compliance and accountability requirements. At the same time, the developmental service sector faces unprecedented challenges. As elderly parents reach the end of their capacity to care for their adult children and the early aging of individuals with developmental disabilities curtails their independence, more individuals will require specialized coordinated care from developmental service provider organizations. The need to address this impending crisis in care is urgent.

Introduction

Metro Agencies Representative Council (MARC) agencies find themselves having increasing difficulty balancing their budgets and maintaining service levels even though the adult developmental services sector has received some funding increases in recent years. To understand this conundrum, MARC engaged Lynn Eakin and Mary Thelander to undertake a review to determine what the financial and service pressures are, the source of the pressures, and why additional funding has not mitigated them.

This report describes the study's method, presents the findings, provides the analysis and implications of the findings, and suggests steps necessary to resolve problems and strengthen services for people with developmental disabilities.

Study Focus

Research into financial pressures in the non-profit sector is complicated by the fact that non-profit organizations are not permitted to show operating deficits in their budget submissions to MCSS. While the intent of this practice is to encourage agencies to operate within the funds allocated, as revenues fall behind expenditures this practice masks the revenue shortfall and its impact on the organization. To understand the financial pressures and the impact on services the researchers looked beyond the numbers to figure out how agencies managed to present balanced budgets and what the effect of balancing had on services. The research questions were:

- How do agencies manage their budgets to avoid deficit?
- What is the effect of the strategies agencies employ to balance budgets?
- What demands for service create financial pressures?

The study objectives were to:

1. Identify, analyze and present the factors that put agencies under financial pressure.

2. Identify, analyze and present the factors that contribute to service pressure.

3. Identify and describe the commonly employed financial and service strategies agencies use to avoid deficit and mitigate service pressure.

4. Identify future financial and service challenges facing the developmental services sector and providers and the individuals they serve.

Study Methodology

Study Sample

Five agencies participated in the study. They reflect the range of service providers providing residential services and day supports where the majority of funding for developmental services is invested. A brief description of the participating agencies follows.

All of the developmental service organizations participating provide residential and day support services to individuals who require moderate to high support. Two also provide other community supports. The agencies report serving people with complex needs including medical and psychiatric, physical disability, behavioural challenges, and conditions associated with aging who require special support.

The five organizations together receive funding of over $66M and serve 2165 people in the residential and day services.[1] The five organizations receive funding of $2M, $5M, $7M, $15M & $37M..

The organizations differ from one another. Some began operations supported by faith communities, others have roots with parent groups that wanted services for their children, while others developed from the commitment of service providers to provide services for individuals with especially challenging needs, many coming from institutions.

All the organizations have been providing services for considerable lengths of time. The agencies in the sample reflect the different periods of service development in the sector beginning with the demand for community based supports for children with developmental disabilities dating from the 1950's and continuing with the growth in the 1960's and 1970's as children grew and their needs changed. Additional service organizations were formed in the 1980's to help respond to the more specialized and complex needs of those individuals being brought out of the institution and to assist those with more challenging needs in the community. In the sample, the youngest of the agencies is 17 years old, two are 21 and 22 years respectively, a fourth is 32 years and the oldest has been providing services for 56 years.

The differences between agencies in the study sample allowed us to identify similarities and differences among the participating organizations, enriching the information gathered, and permitting us to explore if differences among agencies create differences in financial and service circumstances.

Study Approach

Several large group meetings were held with study participants. Initially these large group meetings were used to identify common data definitions and data sources. After the data was gathered the meeting was used to clarify and confirm findings across agencies.

[1] Other less intensive community support services serve many more individuals, often for shorter periods of time. These services, while vitally important are more discretionary than the residential and day programs,

The following data was collected from agencies:

- 2003-2004 operating budgets, salaries, benefits and operating costs.
- current demographic information on individuals in residential and day programs
- data on operating expenditure increases and the history of revenue increases received

Every agency also participated in an agency specific interview. Those attending the organization interviews included agency director and /or program director, financial directors and/or accountants. The purpose of the interviews was to identify the factors that place the agency under financial pressure, identify any shifting or changing demands on services and the factors underlying them, and to document the strategies used to mitigate financial and service pressures and the impact these measures have had on the organization. Perceived future challenges and new strategies were also explored with each organization.

Wait list information was provided from the centralized database kept and compiled by the Service Provider Committee of the Residential Services Sector. An individual interview with the staff person managing the data base provided additional information about the manner in which the wait list data is collected and used by providers to place those on the waiting list into services. A sample of the monthly statistics report is in Appendix A.

Study Findings

I. The origins of shortfall

Operating expenditure increases and revenue constraint

- The agencies all provide similar descriptions of their financial difficulties and how they arose. They described a gradual erosion of their financial capacity as expenditures far outstripped revenues. The major difficulties began with:
- 5% base budget cut imposed across the board by the government implemented in 1994-95
- followed by ten years of 0% budget increases. In 2004-2005 agencies received a .5% increase to base budgets.
- Between 2001-2004, $75M was made available province wide, to the sector for augmenting staff salaries. Depending on their salary levels agencies received different amounts of this funding.
- Some agencies received pay equity payments of 1% for salaries during some of these years.

During this period there were uncontrollable increases in operating expenses that agencies absorbed. The cost of utilities, insurance, food, clothing, personal hygiene, medicines, dental care etc. is largely non discretionary and the cost is outside the agency's control. Between 1990 and 2003 utilities have risen more than 69%, food 28% transportation 47%. Overall inflation from 1990 to 2003 was 28%.

Agency operating costs for those in the sample range from a low of 17% to a high of 26% of their budget.[2] Operating costs include all non-staff costs and include such items as costs to operate residential and day program premises, program costs, living expenses and transportation costs. Salary and related benefits account for the largest portion of the budget; on average 80% of expenditures is for staffing.

Expansion funding
During the 1990's and continuing to the present, new funding to expand service capacity was provided to the sector. The new funding, however, did not address the shortfall in existing budgets but only provided for the expansion of services. The expansion dollars available were based on provincial average costs of care for an individual. Expansion funding sometimes fell short of actual program costs if the individuals admitted required above average levels of care and/or local living costs were above the provincial average, further contributing to agencies' financial difficulties. Additionally, in each year subsequent to expansion, with the lack of COLA, agencies fell further behind.

Analysis
The base budgets of developmental service agencies have eroded consistently and steadily for more than a decade. Though many agencies participated in the service expansions to accommodate individuals in urgent need of care, this expansion funding, restricted as it was did not address the ongoing funding shortfall, but only additional service capacity. Moreover agencies reported the expansion activity actually placed additional demands on their organization as the increased funding often failed to provide adequately for the service and administrative supports required. Agencies found they were further stretched as they attempted to absorb additional operating costs. The organizations in the study have focused on balancing their books, in the face of rising costs, by "trimming from within" to produce balanced budgets.

II. Strategies employed to avoid operating deficits

Staffing strategies
Approximately 80% of an agency's budget is in salaries and benefits. In our sample the range is from a low of 74% to a high of 83% of the agency budget dedicated to salaries and benefits. All agencies report that managing their staffing and staffing structures are their primary strategy in creating economies and avoiding shortfalls. The strategies employed are:

[2] Many variables influence the amount agencies spend in operating costs such as the equipment required for different programs, the age of the physical plant and equipment, whether premises are rented or owned.

1. *Adjusting shift schedules to achieve reductions in frontline staff hours.*
   Where possible, full-time shifts have been cut back to 3-4 hour shifts at key demand periods. This often results in a reduction of full time positions and an increase in part-time staff to cover the part-time shifts. These reductions also achieved salary and benefit savings.

2. *Clustering people to allow for more efficient and flexible staff coverage.*
   Demands for increased staff time are managed by congregating or clustering people served in an effort to maintain or increase service levels without increasing costs.

3. *Gapping (delay in filling vacancies) of staff positions.*
   By delaying filling staffing vacancies, one time cost savings are achieved

4. *Reorganizing and reducing management to achieve cost savings.*
   All agencies described how they had cut back, and reorganized management to the point where management staff span of control has reached its maximum and cannot be expanded further.

5. *Reducing supervisory positions by increasing supervisory responsibilities*.
   The remaining supervisors are now responsible for multiple programs and program locations.

6. *Trimming administrative staff and reassigning responsibilities.*
   Administrative functions have been automated where possible e.g. telephone reception. Staff cutbacks have resulted in a reassignment of duties to other administrative, supervisory or management staff.

7. *Cutting back on in-house specialized services, moving to external contracts for delivery of specialized services, reducing and controlling access to specialized consultants.*
   Agencies cut back on specialized program supports and implemented controlled access to external consultants.

8. *Limiting salary increases,*
   Agencies have held the line on management and supervisory increases to the point where they now report compression problems and difficulty hiring.

Analysis

Staffing reduction strategies have been an important component of agency efforts to avoid deficits. However, the impact of these economies on agencies and the sector has had unintended, far reaching negative implications for the sector that seem to be compounding.

- Use of part-time staff creates a reliance on employees with little related education or direct experience; they are less well trained, often temporary without commitment to the sector. Training part time staff creates additional costs.
- Stagnating salaries makes it difficult to hire and retain full-time staff. There is already a shortage of trained developmental service workers as colleges have reduced the programs offered due to declining enrollment. Salaries in the sector are also no longer competitive with those offered by other sector employers.
- Limited advancement within the agency or sector; limited number of supervisory and managerial positions and the higher levels of responsibility assigned makes it difficult for front-line staff to transition into management. Staff that want to advance their career move on and are lost to the organization and the sector.
- Lack of salary increases for supervisors has created a compression in salaries between front-line and supervisory staff reducing the incentive to take on the added responsibility.
- Managers and supervisors are spread thin making it impossible to consider expanding or enhancing services. The agencies do not have the depth in management or supervision to take on initiatives and expansions.
- Reduced administrative staff increases the responsibility of supervisors to undertake more responsibility and different roles.
- The purchase of specialized services has been cutback and this has meant individuals do not receive the specialized services they did in the past.

The impact of staffing economies is a loss in the sector's capacity to respond flexibly to new situations and demands. The sector is weakened and its capacity diminished. Management and supervisory capacity is insufficient to support enhancing or extending services. Front line staff reductions have resulted in a dilution of trained staff in the sector. With fewer specialized service staff working in the sector, specialized individual programming has been reduced. As safety and immediate care of the residents is a priority and staffing levels have decreased, out of home activities and community outings have decreased. These findings applied to all five agencies regardless of size or situation.

Strategies to manage operational costs

As reported above, the 17-26% of agency budgets that are in operational costs are largely beyond the control of the organizations. The agencies have put strategies into place to contain and mitigate the impact of rising operational costs.

Strategies to manage operational costs include:

1. *Reducing or deferring expenditures on replacements, repairs and maintenance.* Agencies described cutting back on repairs and maintenance. Some have shifted to outside contracts for maintenance. Any replacement or repair that can be deferred is put off as long as possible. As a result the agencies have deteriorating

housing stock and household furnishings. This problem is most acute for agencies with older infrastructure.

2. *Limiting travel and outings to reduce transportation costs.*
   Some agencies have restricted outings to local destinations to save on travel costs. In others, volunteers no longer have taxi vouchers to take people out. Each agency described constraints they had placed on travel to contain transportation costs. Agencies have also undertaken strategies to reduce and contain the costs of operating agency vehicles.

3. *Reducing or not increasing food and household supplies budgets*
   Agencies describe holding the line on household budgets and the added pressure this places on supervisors and front-line staff to manage within ever decreasing household and day program budgets. This is particularly problematic as more and more individuals have specialized diets that can be quite costly.

4. *Passing on more responsibilities for clothing and personal needs of individuals to family members.*
   Where family members are involved, agencies have encouraged them to take more responsibility for clothing and other personal needs. Where families are not involved clothing replacement has been delayed as long as possible.

In addition to cost containment strategies the agencies have undertaken proactive measures in and attempt to maintain operational levels:

1. *Working with Government and Others to keep expenses down.*
   Faced with large increases in WSIB premiums, agencies worked with WSIB to have sector workers properly classified into a lower rate group, thus mitigating, but not eliminating the increases. Agencies lobbied for incontinence supplies to be included under the Assistive Devices Program. Agencies benefited from changes in the calculation of the Employer Health Levy that reduced the impact of the increase for multiple site settings. They were unable, however, to stem increases in statutory payroll deductions, extended health and dental coverage, insurance, utilities, food, transportation and supplies, all driven by market forces beyond their control.

2. *Seeking alternate sources of funding.*
   While all agencies have tried to bring in alternate sources of revenue to augment their government funding, the capacity of organizations to raise additional funds or obtain other gifts varies considerably from organization to organization. In our sample the organizations affiliated with faith communities had the greatest capacity, while those organizations established primarily to serve individuals with complex needs, have fewer individuals with family involvement and have the least capacity. Regardless of capacity, all organizations have found fundraising insufficient to bridge the growing gap between program expenditures and

revenues. Organizations have found fundraising cannot subsidize operating expenses on an ongoing basis.

Analysis
Agencies have cut back, deferred and passed on as much of their operating costs as possible. In fact some of the strategies agencies undertook in order to achieve immediate savings have not in the longer term proved sustainable. The agencies hoped that circumstances would change before the cost deferral caught up with them, however, the situation has not improved and those organizations are now dealing with the deferred costs. At least one organization is facing serious maintenance and replacement costs of vehicles, equipment and buildings and another increased care needs of individuals as aging parents are no longer able to share care. Rising operating costs continue to place pressure on the organizations that have no further capacity to trim staffing. All agencies reported that they have exhausted all economies and deferred expenses are now impossible to put off further.

III. Countervailing Pressures To Increase Services

The agencies identify the needs of people in service and increased accountability demands as the major countervailing pressures.

Table I shows the age of individuals in residential and day programs for the 5 agencies.

- Individuals in residential care are split 50/50 between those under 44 and those over 45 with 7% over 65 years of age.
- The age distribution is slightly older (over 45 years) in the more independent SIL and Associate Care homes (52%) than in the higher care group homes (48%).The over 65 age group is 5% of the SIL population.
- In the day programs the age distribution is younger with 67% 44 years of age or less and 33% over 45 years of age with 2% over 65years of age
- Of the 66 individuals over 65 years of age, 66% are in group homes, 26% in SIL residences and 11% in day programs.

Needs of People in Service

Table 1. **Ages of People in Residential Care and Day Programs**

		0-20	21-44	45-64	65+	Total
Group Home	Number of Individuals	5	303	239	42	589
	Percentage	.8%	51%	41%	7%	66% of Residents live in Group Homes
SIL and Associate Care	Number of Individuals	0	147	143	17	307
	Percentage	0	48%	47%	5%	34% of residents live in SIL
Total Residential	Number of Individuals	5	450	382	59	896
	Percentage	.05%	50%	43%	7%	
Day Program	Number of Individuals	4	835	401	7	1269
	Percentage	.03%	66%	32%	2%	

Analysis

The current large cohort of individuals over 45 years are the "early aging" baby boom generation. Forty-five years was selected as the age break for the study because the organizations identified this age as the time in which they begin to see substantial declines in the health and well being of individuals with developmental disability. Recent research[3] has reported accelerated aging among individuals with developmental disability including earlier onset of and higher risk of dementia related diseases. Other health problems such as diabetes, heart and cancer are also reported by agencies.

While the numbers of older individuals (over 65) is relatively low in the community system their placements indicate the likely trend for those now over 45 years of age and aging early. As individuals age they need higher levels of care which is why few of the over 65 individuals are still able to make use of a day program (11%), the majority are in higher support group homes (66%). The seventeen individuals over age 65 in SIL

[3] Janicki,M.;Dalton,A (eds) *Dementia, aging ,and intellectual disabilities: a handbook. Philadelphia, PA: Brunner/Mazel, 1999*

residences are in *modified SIL arrangements.* While still in their SIL residences, they are receiving extensive staff support, (e.g. 30 hours a week and CCAC health care), making them SIL residences in name only.[4] For some older residents maintaining them in their apartments with higher levels of support is the best service option, for others they require the higher support provided by more structured group care.

Service Needs

All agencies reported experiencing the following service pressures:

1. *Increasing demands for overnight awake staff to respond to changing residents needs e.g. awake and wandering, disruptive nighttime behavior.*
   In organizations that had been funded to operate homes with asleep overnight staff or, in the case of semi-independent living accommodation (SIL) no overnight staff, this presented a major staffing challenge.

2. *Increased need for in home daytime coverage for people who can no longer attend day programs, e.g. deterioration in health and physical condition, aging, behaviours*
   People in residences traditionally attended a day program but when failing health necessitated them staying home, agencies were faced with a staff coverage problem. One agency reorganized their day program and brought staff into the homes however this was not always possible, especially when the individual attended another agency's day program or where staff/participant ratios in the day program made redeploying staff impossible.

3. *Increased demand for incidental daytime coverage, e.g. medical appointments,*
   As residents age and develop more chronic illness the number of medical and other appointments has risen. These day appointments were not originally anticipated in the funding formula and have placed stress on group home staffing especially with the move to shorter part-time shifts. Agencies describe trying to support residents through cancer treatments, provide palliative care and generally cope with the illnesses that are becoming more common with age.

4. *Increased staffing support to hospitalized residents or residents newly transferred to long term care settings.*
   People with a developmental disability present unique challenges to hospital and long term care personnel. Often staff in those settings know little about people with developmental disabilities and are cautious about admitting them unless the developmental service agency provides transitional staffing support. As people age, agencies face increased demand for this kind of support.

[4] The basic SIL is funded for 10 hours a week. There is no process in the funding of developmental services to negotiate the conversion of existing services as individual's needs change.

5. *Increased need for additional staff training as resident's health deteriorates e.g. lifting due to reduced physical mobility, or medications, or care needs for those with Alzheimer's disease.*
   Lifts are being installed in houses and staff require training to use them. More frequent and complicated medical care is being asked of staff. Managing behavior resulting from dementia also requires training.

Analysis

The increase in demand for staffing, while at the same time the number of available staff is declining, has created pressures on agencies to find additional ways to spread staff further. Agencies report they have increased congregate living (more residents in a home) or increased hours of coverage by clustering residents in independent living situations close together to provide improved staff availability. Agencies, in some cases have redeployed day program staff to provide coverage for groups of residents during the day in group homes.

Creative problem solving is limited when the agencies do not have the resources to effectively implement the strategies. Agencies report they have run out of ways to accommodate residents needing higher levels of care. There are no more accommodations that can be made in the sector with the existing staff complement and residential housing stock. The turnover rate in higher support group homes is not sufficient to accommodate the aging individuals in lower support settings.

The age distribution means that an escalation in the demand for more staffing hours can be anticipated in the immediate future. In the SIL locations of the study sample, over half the residents, (150 individuals) are over 45 years of age and 17 are over 65 years. Meeting an individual's changing needs is currently the responsibility of the service provider, yet none of the five agencies has the resource capacity going forward to accommodate the increasing service needs of individuals within their existing services. There is currently no mechanism to renegotiate, with MCSS Developmental Services, increases in support levels for in-service individuals as they age.

Waiting for Service

The Toronto Service Provider Committee collects and analyzes waitlist data to assist in the placement of individuals when vacancies occur. The data reported in Table 4 and Table 5 is from the monthly statistical report for November 2004. [5]

[5] *The waitlist database collects profile data on waiting list individuals including for example diagnosis, dual diagnosis, other conditions, aggression, self-injurious behavior (see Appendix for sample Statistical Report, November 2004).*

Table 4. Ages of individuals waiting for day and residential care in November 2004

Years	0-21	21-30	31-40	41-50	51-60	60+	Total
Number of Individuals	360	781	605	333	138	30	2247
Percentage of Total	16%	35%	27%	15%	6%	1%	100%

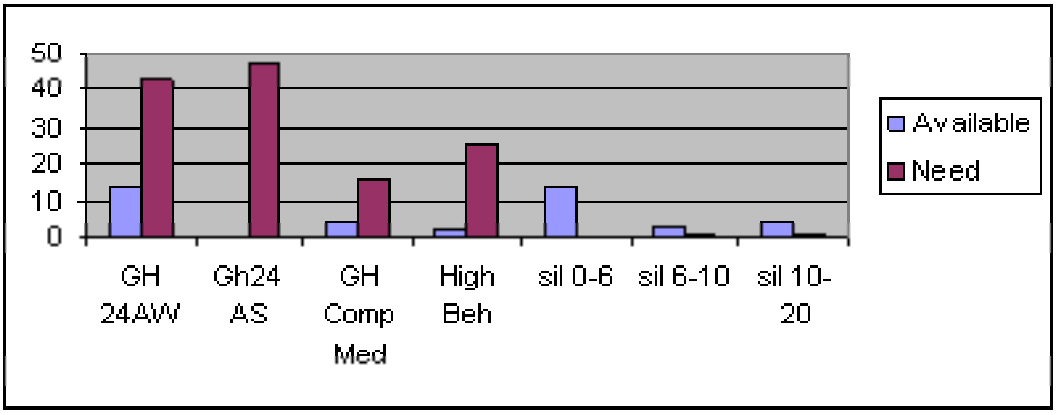
Table 5. Ages of parents waiting for care for their dependant adults, Nov 2004

Years	0-21	21-30	31-40	41-50	51-60	60+	Total
Number of Parents	0	6	17	134	343	489	989
Percentage of Total	0	.6%	1.7%	13.5%	34.6%	49.4%	100%

The number of adults and children waiting for placement is 2247. Of those adults waiting, 62% are between the ages of 21 and 40, while 22% are over the age of 41. The age on the waiting list is on average younger than the individuals in service particularly because so many young adults are waiting for day programs. Of those waiting for service, 1106 are over 40.

The waiting list system cannot breakout the day and residential wait lists but it does collect the age of parents waiting for service particularly if they are requesting residential service for their family member. Of the 989 parents who provided data on their ages, half (489) are over the age of 60, and 84% are over 50 years of age. Clearly there is a substantial population of individuals waiting for service with elderly parents and the individuals themselves are aging. This finding is confirmed by the data of the Toronto Service Provider Committee that documents the pressure for residential spaces for individuals who have increasingly high and urgent needs.

Figure 1. Availability of resources relative to the identified needs of the individuals.



Legend
GH, 24AW - Group Home with 24 hour awake staffing
GH, 24AS - Group Home with overnight asleep staff
GH, Comp Med – Group Home providing comprehensive medical care
High Beh – Group Home for individuals with high behavioural needs
SIL 0-6 - Semi-Independent living with 0-6 hours of care a week
SIL 6-10 - Semi-independent living with 6-10 hours of care a week
SIL 10-20 – Semi Independent living with 10-20 hours of care a week.

Figure I shows the availability of resources relative to the identified needs of the individuals[6] **:**

- Over the course of the year only 42 residential spaces (a vacancy rate of 4%) became available, 21 of these were high support homes and 21 were SIL residences (14 were low support SIL).

- In November the priority list of individuals waiting for urgent placement had 132 waiting for high support homes, and 2 waiting for higher support SIL placements.

Analysis
The graph visually illustrates the discrepancy between the services available and the services needed for people identified as priorities for placement. It also gives a sense of the gap between resources and need in the sector: 42 beds becoming vacant over the course of a year and 132 urgently waiting at one point in time.

[6] The availability data is based on turnover over a one year timeline; the need data is the waiting list as at November 2004

Given the internal care pressures faced by agencies, many high support residential care spaces never become available to those waiting for service. The lower support settings are not appropriate for most waitlist priorities as they too are aging individuals with aging parents. The agencies moreover are cautious about admitting individuals who are likely to require higher levels of care in the near future as they are already overwhelmed by their existing internal pressures.

Individuals on the waiting lists are waiting for services that will not become available in sufficient quantity. Agencies providing community and family support services are supporting increasing numbers of aging caregivers without adequate and timely access to day and residential service for their adult family member.

IV. Increase in Compliance, Reporting and Planning

The organizations described three main areas of increased accountability and management. They are: service system coordination and planning, increasing accountability, compliance standards and expectations, and cross-regional differences for those organizations that cross MCSS Regional boundaries.

System Planning and Service Coordination.
Ministry Program Supervisors in the province use local committees of service providers to assist with the coordination of service priorities and to problem-solve service difficulties. These committees require the active participation of senior agency staff. Depending on their service portfolio, developmental service agencies can be on some or all of the residential, day, respite, crisis, community support or service resolution groups. Major service and planning challenges confront each of these groups and system wide policy development takes time (e.g. the risk assessment tool for determining the priorities for residential service referral). Participation in these planning and coordination groups, while valuable, requires significant senior staff time when agencies have reduced management.

Increased Compliance Requirements.
The compliance requirements identified by agencies including health inspections, fire inspections, workplace health and safety requirements, staff training requirements, residential standards, serious occurrence reporting, and financial reporting, are reported as becoming more rigorous. Agencies describe the impact of cumulative new regulations, directives and legislative requirements. Senior staff spend increasing amounts of time coordinating and reporting on compliance requirements.

Recent examples of the proliferation of regulation include:

- requirements for staff training (staff now must have first aid, CPR, medication training, crisis prevention intervention, health and safety training, fire safety, vehicle training);

- physical plant standards including water safety regulations, fire and health regulations;
- incident reporting directives and most recently, the new monitoring requirements for persons in service; and
- increased detail in financial reporting.

These multiple accountabilities challenge managers who are already stretched. Complying with increased requirements has not generally been funded and in instances where funding has been provided agencies report it did not cover the full costs nor was provision made for the management time required for implementation.

Cross Region Jurisdictions
The organizations in the sample that provide services in more than one MCSS Region describe the "double burden" of two sets of different expectations, and double reporting. They describe being caught in the middle of differing expectations from one region to another. For example, policies that were approved in one region were not accepted by another. Planning meetings in two regions placed an additional burden on their staff. There is currently no easy method of resolving these differing expectations or easing the double burden.

Analysis
Coordinated planning and service delivery has added considerably to the workload of senior managers and expectations for agencies to participate is high. While agencies have held in check or reduced administrative and management staffing levels, demands on management and administrative staff time have escalated.

Two of the agencies in the sample had reduced administrative costs below the 10% benchmark to maintain services. The remainder operated at the 10% level, however, they all found it difficult to navigate the multiple and sometimes conflicting compliance expectations. They reported being overloaded with reporting, and expressed frustration that much of the information they provided (particularly financial) was never used. Another frustration was the differences in interpretation between individual MCSS Program Supervisors, and between Regional Offices. There is no way of easily resolving these differences and they consume inordinate amounts of agency staff time trying to resolve the problems that arise.

All agencies reported they felt they had too little management and administrative capacity and questioned the effectiveness of the 10% administrative cap imposed by MCSS. Several senior managers felt additional administrative capacity would result in improved management systems and would provide greater organizational and service efficiencies. They felt the arbitrary limit was unnecessarily confining and prevented them from making optimum use of their resources.

Conclusions

MARC agencies find themselves having increasing difficulty balancing their budgets and maintaining service levels even though the adult developmental services sector has received increases in funding in the past five years. This research identified four key findings hidden behind the agencies balanced budgets. The agencies have been "trimming from within" to balance the budget. Front line, administrative and management staff have all been trimmed as far as possible. At the same, time individuals in care are aging and requiring increased levels of supervision and support to ensure their continued well-being and safety. In the community, many long time community residents are living with family members. These Caregivers are now elderly and increasingly unable to provide for their adult children who are undergoing their own aging difficulties. Simultaneously compliance, planning and accountability expectations for developmental service organizations have continued to increase.

A squeeze is on: the sector has reached capacity, the service system is overloaded, and there are serious shortages in services. The capacity of the sector to manage current and future risk is of concern as service pressures continue to challenge the seriously depleted and stretched service system.

The conclusions are interrelated. They are discussed below.

1. Flexibility to respond is gone.

The sector as it is now has reached its capacity. Through its own efforts to manage shortfalls it has used up the flexibility it previously had:

- ***Limits of "trimming from within" to balance the budget***
  The staffing economies employed by the organizations in the study allowed them to balance their budgets but it has been at the expense of their service capacity. Agencies report they have made every accommodation they can to respond to changing individual needs – whether for more supervision, night time staffing, daytime care for those who could no longer go out, or increased support for those in failing physical health and neurological decline. There is no more flexibility left in agencies to make the accommodations for changing individual needs. The staff reduction efforts to balance the budget have far reaching negative impacts on services.

- ***No organizational resiliency remains in the organizations. Administrative and management staffing is "bare bones" so any additional service pressure or demand places stress on the whole organization.***
  To manage more, to add or enhance – whether new people in service, new spaces, new residences or new programs, all require administrative and management capacity. To do more means that more administrative responsibility has to be taken on by supervisors (human resource responsibilities) or delayed or deferred until there is time (e.g. takes longer for new admissions). Not one organization interviewed has

any extra capacity to cope with change and the unexpected. Staff, at all levels, are stretched and cannot assume more responsibilities**.**

2. Shortages – looming crisis in care and capacity

- ***Aging baby boomers with developmental disabilities***
  Individuals with developmental disabilities experience a higher incidence, and earlier onset of cognitive impairment and other related health problems**.** This means the pressures of the "Baby Boom" adults are occurring in developmental services now rather than ten years from now. These "early aging" Baby Boomers are also the first generation of individuals with developmental disabilities who are reaching old age while living in their communities. All their lives, they have been the generation that fueled the development of community-based developmental services as they grew – first the school programs, then the day and residential options. Now, as they enter their later years they need services that can provide for their changing needs as they and their parents age. The last service component – elder services has not yet been fully developed in the developmental service system. This combination of early aging and the lack of elder services in developmental services has created a crisis of capacity in the sector that will build significantly over the next several years.

- ***Service Shortages - The number of older people with developmental disabilities and their elderly parents living in community will require more not less service in the coming years at the same time as those currently receiving care also need more service.***
  Agency efforts to meet the escalating needs of people in service means very few resources can be freed up to meet the needs of those waiting for service. This is extremely problematic since the elder care needs of those still living in community are urgent as their parents, their life long caregivers, can no longer provide the necessary support. The system is unavailable to those needing support.

- ***Diminished capacity to cope with escalating service demand - Agencies do not have the care capacity to internally manage their existing residents as they age nor do they have capacity to respond to people living in community, unless they receive additional government support to convert, augment and redesign services.***
  The demand for residential group care with overnight awake staff has outstripped the capacity of the system to provide it. The demand for residences with supervised 24 hour care is growing and will continue to grow. Agencies need to work with government to adapt their services to meet the changing needs of residents. Adding staff, changing programs, increasing service options, renovating existing residences to accommodate people with complex needs, purchasing or building new residences, all require additional government support and planning.

- ***Improved service planning and a rebuilding of agency and system management capacity are needed.***
  Developmental service providers are well known for their willingness to extend themselves to help individuals with developmental disabilities, so it was startling to

hear them, one after the other, explain how they are at their limit, cannot do more, and in fact feel they are currently not able to do all they need to do. Longer term, collaborative planning by government and the sector is needed to ensure the organizational and system capacity is there to respond to current and future service demands.

Moving Forward

The system is at a turning point. At the same time as capacity of developmental service organizations is diminished, the pressures are escalating for more responsive and accessible residential care for individuals both receiving and not receiving services.

To address the service challenges in the sector requires the developmental service organizations and their MCSS Developmental Service funders to collaborate in planning, designing and funding system capacity to meet the demand.

There are two overriding recommendations:

1. **Restore system capacity**
   - *Fund agency organizational capacity* sufficiently to ensure the service system has response capability. Agencies are currently in the position where their management capacity needs to make a quantum increase to improve long term capacity.

   - *Increase organizational resiliency* by allowing agencies maximum flexibility within and between their budgets to reconfigure services and better support people in service.

   - *Support the development of elder care services* that show promise for cost effective, quality care.

   - *Strengthen Staff* - Support and encourage promising and innovative agency staff training, recruitment and retention strategies.

2. **Restore financial health to developmental services**
   - *Competitive Compensation* - Enable developmental services to compete for staff with other sectors by pegging their annual increase to those in the MUSH sector (municipalities, schools and hospitals.)

   - *Improve Service Contracts* - Global budgeting across program codes; allow retention of small surpluses to rebuild flexibility and service response capacity into the system.

- *Predictable Funding* - Provide multi-year predictable funding and provide agencies flexibility in managing their budgets and negotiating partnerships to deliver innovative service models.

- *Flexible Funding for Changing Needs* - Take measures to pay actual cost of service delivery for individuals rather than using a formula "average' to fund expansion of services to new individuals.

Three other recommendations support the restoration of system capacity and financial health:

3. **Strengthen planning capacity and develop a multi year plan based on sound information.**
   - *Streamline Planning and System Management*- Evaluate existing planning structures with a view to streamlining and strengthening Ministry /agency joint planning and system management capacities.

   - *Build on and improve existing planning* data to provide improved service and individual need information for planning and resource allocation. The current data base needs to be on a relational data base, be extended to individuals in service, and have enough staff time allocated to produce timely reports.

   - *Develop multi-year plans* that include cost increases for service delivery and salary enhancement in addition to plans for existing service redevelopment and expansion.

4. **Support and promote inter-system planning with other sectors such as social housing, community health and long term care.**
   - *Fund transitional support*s - Support the developmental service sector to be an enabling participant with other sectors by ensuring developmental service agencies have capacity to provide transitional support to other sectors as needed. Other systems vary in their willingness to serve people with developmental disabilities. Often this is due to a lack of experience and knowledge.

   - *Improve access to other services* - Assist individuals with development disabilities access other service systems by working to change regulations, policies and practices that exclude them.

6. **Undertake a concerted initiative to streamline and simplify the accountability measures required by agencies.**
   - *Designate one Regional Office "lead"* when agencies cross regions to eliminate dual reporting for all but service planning and delivery objectives.

   - *Risk management protocols* - Encourage the development of risk management protocols for management of developmental services to prevent overloading agencies with burdensome obligations that do not contribute to service

provision. Serious events will occur when supporting vulnerable individuals in communities. Agencies and government need to develop risk protocols not paper trail overload.

- *Process to resolve differences* - Compliance measures are sometimes differently enforced between ministry staff and ministry offices. In addition, from time to time the Ministry expects accountability measures from the field organizations that are impractical, costly, or ineffective. MCSS needs to establish a conflict resolution process to settle these issues efficiently and fairly. Developmental service providers currently have no easy method of seeking resolution to accountability reporting problems.

Appendix A

Toronto Res/day & Day Applicant Statistics Report November 7th 2004

DEMOGRAPHICS

Applicant Counts

Waiting Applicants	2248
Total Applicants	2248

Gender

Female	900
Male	1348
No entry	0
Total for Gender	2248

Ages

0-21	360
21-30	781
31-40	605
41-50	333
51-60	138
over 60	30
Total for Age	*2247*

Language

English	1390
Others	858
Total for Language	2248

Dual Diagnosis (multi-select)

Anorexia/Bulimia	*44*
Anxiety Disorder	54
Bipolar Disorder	26
Borderline Personality Disorder	15
Depressive Disorder	73
Obsessive Compulsive Disorder	41
Other	77
Phobia	7
Schizophrenia	58
Sexual Deviance	6
Unknown	42
Total for Dual Diagnosis	443

Other Conditions (multi-select)

Hearing	128
Medically Complex	79
Non-Ambulatory	157
Non-verbal	233
Seizures Disorder/Epilepsy	270
Unknown	251
Visual Impairment	163
Total for Other Conditions	1281

Aggression

Mild	151
Moderate	128
Severe	45
No entry	1924
Total for Aggression	2248

Self-Injurious

Mild	91
Moderate	62
Severe	22
No entry	2073
Total for Self-Injurious	2248

Age of Caregiver

0-21	0
21-30	6
31-40	17
41-50	134
51-60	343
over 60	489
No entry	1259

Total for Age of Caregiver	2248

Diagnosis (multi-select)

Alzheimer/Dementia	6
Autism/PDD/Asperger's	301
Cerebral Palsy	164
Developmental Disability	1228
Down Syndrome	217
Fetal Alcohol Syndrome	11
Fragile X	14
Other	121
Prader-Willi	9
Rett's Syndrome	18
Tourette's	15
William Syndrome	4
Total for Diagnosis	2108

Behaviour

No	1112
Yes	484
Unknown	652
No entry	0
Total for Behaviour	2248

Location

East	598
No Preference	827
North	236
Out of Area	80
South	268
West	239
Total for Location	2248

Current Living Situation (multi-select)

Crisis/Hospital Bed	39
Group Home	79
Home of Caregiver	1120
Hostel	11
On own	63
SIL	12
Temp. Living Arrangement	190
Total for Living Situation	1514

SERVICE REQUESTS

Day Support Needs (multi-select)

Individualized Programming	216
Life Skills	529
Literacy Academics	252
Prevocational	250
Psychotherapy	42
Recreation and Leisure	491
Sensory/OT/PT	98
Work Experience	387
Yes	502
Total for Day Support Needs	2767

Residential Support Needs (multi-select)

Associate Family Home/SHS	115
Group Home	1336
Individualized Living	48
Supported Independent Living (SIL)	575
Total for Residential Support Needs	2074