

**Developing the OASIS Response to “*Transforming Services in Ontario for People who have a Developmental Disability*”**

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**Summary Proceedings of  
November 8, 2004 Consultation**

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## **Context**

In order to develop a formal response to the Joint Developmental Services Sector Partnership Table document, “*Transforming Services in Ontario for People who have a Developmental Disability*”, OASIS has undertaken a process of gathering information and opinions on the future of the service system in Ontario. The process involves a number of inputs including a consultation session on November 8, 2004, gathering of information from individual member agencies prior to November 22, 2004 and a Board review of information gathered on November 25. The outcome of these activities will be a formal OASIS response developed by the Board of Directors. OASIS members are encouraged to submit their individual responses directly to the Ministry in addition to copying OASIS to ensure that all perspectives are heard.

## **November 8, 2004 Consultation Session Process**

About 80 people attended the session representing about 50 member organizations. Attendees had previously received the Preliminary Discussion Paper from the Partnership Table. The participants were divided into 3 groups and each group considered 3 or 4 of the 7 questions posed in the discussion paper. Each group provided feedback to the broader group and there was discussion of common themes and points of transformation that might be considered in the response. The following represents the major themes identified along with discussion points, identified issues, points needing clarification by the OASIS board and items requiring further conversation. Attached as appendices are the detailed notes from the 3 groups, thereby ensuring that no specific details of the consultation are lost (these notes have not been modified and are presented as they were developed on the 8th).

## **Major Themes**

### **Vision**

Throughout the day, there were many references to the need for a clear vision for the developmental services system shared by the Ministry, the transfer payment system and the families involved. In this way, any decisions regarding transformation of the system will be based on agreed upon values and principles. This will allow the various partners to develop clarity regarding roles and responsibilities and will guide the change process.

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## **Resources**

There were many references to the notion of entitlement and mandatory services. Many people were supportive of the idea of moving forward with this but others cautioned that a move in this direction might result in a move to the lowest common denominator. Related to this, there was also some discussion of needs testing and whether this would be appropriate, especially if the system moves to an entitlement basis.

Regardless of the model of funding, there was general agreement that the system needs to be equitable and fair and generally, there was agreement that that means some sort of assessment of need to ensure that resources are matched with needs of the individuals and families. There were a number of different thoughts on what that assessment should look like including some form of levels of support, ongoing quality of life assessments, personal outcome measures, etc. and there were a number of participants that expressed concern that this type of tool might focus on the physical requirements of daily living but miss out completely on quality of life issues.

The idea of individualized funding was raised by all of the groups and although there seemed to be general support for exploring this idea, this was balanced with a concern with the impact of this on the stability of the transfer payment system. There were also many differing views expressed of what individualized funding means and how it might be implemented including control of the resources by families, guarantee of a specific level of resources for an individual (which could create issues if the needs of the person change) and the ability to purchase services from a range of providers and to change providers as desired. Experience with SSAH has indicated that the majority of families have appreciated having some control over services but have not wanted to move into self-administration. Any move towards individualized funding will require a healthy discussion of underlying principles, definitions and methodology.

There were several discussions regarding creative financing of services and the need to make some taxation changes to allow families to plan for the future – one example given was the RESP approach which would allow families to save funds and receive tax breaks and possibly, matching funding to provide for their family members in the future. Other suggestions included the provision of tax credits for families who are primary caregivers for their family member.

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## **Service System Characteristics**

All of the groups discussed the necessity of having a seamless system of support for individuals and families. Creation of a seamless system will require a number of changes including a recognition that there will be life-long support required for individuals with developmental disabilities, a different way of dealing with transition points in the system, consideration for a life planning system which would begin as soon as the diagnosis is made and the development of services which are not age specific (early years to school, school to life, ODSP, etc. are all examples of age specific services).

There was some discussion of the role of private for profit providers particularly given their role in the Long Term Care system. Generally, there was agreement that the transfer payment system is working well and that the not for profit system is the preferred delivery system.

It was acknowledged that there are now a significant number of seniors in the developmental services system and the sector has the opportunity to provide some leadership and vision in terms of how we as a society work with, respect and provide services to seniors generally.

The availability of specialized resources is quite limited in many communities. There was some discussion of the success of having the specialized resources and expertise which may be housed in existing facilities preserved within the community after the facilities close. There were also many comments made about the availability of resources that are generally available to the public such as doctors, dentists, psychiatrists, etc. and the difficulty in accessing these resources for individuals with developmental disabilities.

In some communities, third party planning and coordinated access mechanisms have worked very well to assist in individualizing services for people and creating a more fair and equitable system. In other communities, these mechanisms have not been viewed as very helpful. The value and role of access mechanisms needs to be addressed across the Province.

Concern was expressed regarding the impact and changes that will occur within the system as the result of the Facilities Initiative and the fear that this initiative might overshadow any other planning. There were strong opinions expressed that community pressures also need to be addressed within the next couple of years.

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## **Accountability**

Accountability was acknowledged as an area that needs further discussion and attention. In the past, accountability concerns have often only related to agency actions, e.g. filing of reports, accounting for increases in service to individuals, etc. There was general agreement that there are accountability issues for agencies but also for the government and that accountability goes both directions – up and down. The government’s accountability relates to appropriate funding of the system, development of policies which result in a system that is more seamless to families, cooperation and planning among different Ministries, etc.

Again, the issue of levels of service or some other assessment tool was discussed in all groups. There is a general agreement that something formal has to be in place to ensure that there is accountability for funds spent but there are several different views of what that tool or approach should be.

One thought that came up several times related to accountability was the relationship between the government and the transfer payment agencies and the need for the government to stop micro-managing the service delivery sector. Related to this was the notion of a more global budget for agencies and a move away from specific line items and program delineations. The notes from the day don’t reflect any discussion of how a global budget approach might be reconciled with individualized funding, greater accountability for funds and a more equitable and fair system of funding so that will be a conversation that will need to take place.

## **Cross Ministry/Sector Planning**

There were many references to the need for collaboration and cross-sector policy development among the various Provincial Ministries including Health and Long Term Care, Housing, Transportation, Corrections, etc. There was clearly a feeling that this is not happening in a coordinated way at present and needs some fairly immediate attention from the government.

## **Community Capacity**

There were many comments regarding the current state of the community system including references to the many years of absorbing community pressures while not having additional financial resources. Many people described the current infrastructure as being under

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overwhelming pressure or being in crisis and concern was expressed regarding the additional strain that will be created by the 1,000 people moving into communities from the remaining facilities.

The current infrastructure issues are creating staffing concerns in the areas of recruitment and retention and, in many cases, staff working in the sector do not feel valued. Solutions to infrastructure issues do have financial implications for the system and there was agreement that these issues cannot be resolved without additional investment by the government. There was concern expressed that the existing infrastructure issues will get lost during the facilities initiative but that they need to be addressed in order to have a successful facilities closure process.

Participants expressed an interest in developing a more cohesive network which would allow for the sharing of best practices across the Province and which would also facilitate discussions of the changing roles of transfer payment agencies and the system in general.

## **Data Gathering/Research/Information**

There was general agreement that good data can assist greatly with good planning and the participants agreed that appropriate data should be available currently but isn't routinely being accessed and analyzed. This data should be available through a number of sources including the access mechanisms across the Province, the transfer payment system, the school system and general research regarding incidences of disability and other demographic trends.

The series of forums that are being hosted by the Developmental Services Branch are seen as a positive step in accessing and learning from other jurisdictions. Additional subject areas were suggested and there was some discussion of OASIS being more proactive and taking a lead in hosting some of them.

## **Public Education**

Throughout the day, there were many different references to the need for various forms of education. These included general attitudinal changes regarding the contributions of people with disabilities to society, views regarding inclusion, education of professionals i.e. medical,

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dental, etc., regarding the specialized needs of people with disabilities, and education of families about what to expect at different transition periods.

### **Next Steps**

This summary document will be distributed to all members of OASIS for their review and consideration as they develop their individual responses to the Preliminary Discussion Paper. Comments and suggestions on this summary and on the Discussion Paper are welcomed and may be forwarded to the attention of Dave Ferguson, Doug Anderson or George Braithwaite. In order for comments to be considered by the OASIS Board in the development of the official position, they should be received no later than November 22, 2004. On November 25, 2004, the Board of OASIS will be convening to review all input received and to develop the official response which will be provided to the Ministry.

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**APPENDICES**



# Appendix A - Notes from Group A

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## 1. What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability?

### **GOVERNMENT:**

Provincial: Advocate for mandatory funding

Federal: Tax Credits

Municipal: Access to services

Agency system needs to have a range of supports and types of services in place

Government should step away from management of agencies and set the tone

To the extent you can, provide as much local autonomy as you can on an individual basis

Starts with recognition of Human Rights

Core services along with mandatory funding

Role of health at provincial level – medical supports needed

Liaison between Ministries

Reduce funding silos

Public education and cross-sector collaboration

Ministry needs to begin setting standards

Re: mandatory funding – elimination of rules

Re: mandatory funding – role of family to choose - their role needs to be considered

Ministry of Education – collaboration between Ministries

Align government districts – across Ministries – artificial boundaries

Need to have a status declared by the Minister

Individuals and families decide what they want – get to buy supports not services – licensed providers – criteria – range of services

Wrap services around the individuals

More active role of the court system in our system

### **FAMILY:**

Individuals and families decide what they want – get to buy supports not services - licensed providers – criteria – range of services

Should the government expect them to have their sons/daughters at home?

Should look at RESP's – should be able to look at them for their disabled children (more at the Federal level)

Take more of a role in planning for their future

### **SERVICE PROVIDERS:**

Obligation to act as a network – give up autonomy as an individual agency

Accountability

Educational responsibility to present needs – community has responsibility to respond – then work together

Who can best provide within the network

Strategic plans – not done in isolation

Accountable to whom  
OPR – private service  
Lack of legislation re: work stoppages  
Catastrophic levels of service/support  
Connecting to waiting lists – should agencies have the right to say no  
Number of agencies – what is the rationale  
Future planning – understanding other services  
Seamless services

### **PRIORITY POINTS - #1:**

Range of Services – that are responsive, accountable, and portable  
Mandatory funding – including funding for families and service providers  
Agencies work in networks – need community capacity building so all stakeholders work together to provide an optimum level of service based on what those agencies do best -  
Inter-ministerial collaboration - Enhanced cross-sector  
Governmental support  
Government role in cost of living increases – where's the mandate

### **2. What strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?**

Portable –  
Strategy – building legislation around this  
Remove age limits  
Resources –  
ODSP –  
Seniors – be a leader to demonstrate how to serve seniors - project  
Nursing Homes??  
Sustainable funding  
Cross-sectoral planning  
Seamless supports – challenges with transitions – challenges across sectors/across ministries  
Third independent party planning to bring all potential supports into place - look across sectors to support seamless supports  
Facilitation, as well as planning. Important for it to be outside of the service provider  
How are transfer payment agencies set up to specifically support an individual  
Individuals we don't support – resources – outreach component not funded by the ministry – left up to individual agencies to do so

For those who wish it that individualized funding is available.  
What does individualized funding mean  
Individualized Funding – what will make it workable?  
Scale  
How to make individualized funding fair for all to get the services they need?  
Create equitable and fair funding, which includes individualized funding.  
Support of a funding formula with an appeal mechanism

## **PRIORITY POINTS #2:**

Seamless support

Leadership and support for seniors – we would illustrate best practices

Life planning – to create a seamless service – revise plan as move through various levels of need  
option of third party planning

Create equitable and fair funding, which includes individualized funding.

Support of a funding formula with an appeal mechanism

### **3. What supports and services that are currently available work well and should be built on for the future?**

Regional Support Agency – provides professional support services

Special Services at Home – good individualized funding – but short changes families.

Family Support Program without the age limitations

Case coordination

Respite – works well, needs to be expanded – ranges/types of respite options

Develop Best practices

Move away from services that target specific populations – good approach, too limited – ..  
expanded longer

Personal Outcome Measures – works well as a process of accountability

Transfer Payment Agencies – work well – need to recognize in this document – system working  
within difficult funding

Base funding arrangements also work – expanded – give us multi-year contracts and ability to plan

Range of residential options/day supports

Individualized funding

SSAH supports – employees – quality issues

## **PRIORITY POINTS #3:**

Transfer payment agencies

Supports and coordination of supports that are not age specific

Individualized funding which includes SSAH

### **7. Is there anything else you would like to say about the ideas in this discussion paper, or ideas not included in the paper that you feel are important?**

1. Legislation re: work stoppages
2. Accounting methodology
3. Service contracts need to be renegotiated at a macro level
4. Service planning –
5. Number of organizations - duplication/justification
6. Innovation/new program/ new initiatives – not near the local level
7. Clarity on the role of Single point of access
8. Involvement in planning re: closing institutions

**CENTRAL THEME(S):**

**Questions 1,2,3**

Funding  
Seamless life cycle service  
Coordination/cooperation  
System that encourages organizations to be creative

## Appendix B - Notes from Group B

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### 2. What strategies and resources would help individuals receive seamless supports throughout their lives, including points of transition?

- If want seamless transition what strategies do we want?
- Lifelong support plan – not ODSP here, old age there – level of funding once a person has been identified – doesn't change throughout life of person – is this what we want? No – but it is not filling in all the paper work – may require more funding, but not the paper work – not agency support, but financial support – an amount carries through their life.
- Respite care – help along that seamlessness – family and resources are there when they are needed.
- Improved communication with government/community
- Want cake and eat it – see transition and additional support – but not substantiate the need – need template – formula – method of evaluation – when a significant transition happens – if want support from government have means to prove – would rather rely on data/method; expect seamless transition – don't see it.
- How do we make those transition points more smooth – i.e. know how many kids graduating – how ensure resources there in community. Recreation services – ensure ready to receive – if believe in inclusion and community playing role – comes to planning and ensuring resources available – reduce transition points – only key transition points – individualized support – follow person through the system/life. Age 2-5; 5-18 etc. The biggest is age 18 – in terms of funding and change of ministries and what people received prior to age 18 – planning while kids in school important.
- Education of family as to what is available – many families don't have idea what is available and how system works – more time to adjust and lobby – by knowing what to expect. Ask Ministry why different worlds and different standards. Why is that transition different – valid support – why (child to adult).
- Research and planning – resource decision based on those plans.
- Are we as a system good at planning? Yes. Are we good at collecting data and then planning? Not great, but can identify number of people receiving supports – arrive with list, but no money, or other way around. Big problem is resource allocation.
- System will reach point of saturation/maturity – look at population – people are dying and making spaces for new people. Openings - physical location – no one can manage physical location – fill spot.
- Strategies and resources – we don't have this information – if it becomes fully funded system – it will eventually stand on its own – we will not be “sucking” it up.
- Interesting opportunity – now have seen the services that are required lifelong – through history – what does it cost – what do we need – developed group homes etc., but no time to look at – is this a complete system? We have good prospective – now determine how to use this data ourselves – collectively/provincially – observe what that system looks like – if small town doesn't have component, review. No time or thought, what does the system look like now – what/where are the gaps.

- ODSP – individual gets employment – one month get money/next no money. If make too much money, no payment for dental appointments – too complicated if they would like to work – penalized – completing forms etc. Government needs to visit this issue. Confusing
- Moving from agency to long term care facility – Down Syndrome - at what point do they move from care of agency to long term – government needs to look at.
- Strategy – government develop in partnership – proactive strategy, instead of reactive.

### 3. **What supports and services that are currently available work well and should be built on for the future?**

#### **What doesn't work well?**

- Micro management of agencies – let us do our jobs
- Inconsistency of funding that ministry provides
- Inconsistency of messages
- Absence of adult protection legislation. If can't get person in group home because of funding – they remain in abusive situation

#### **What does work well?**

- Residential support – long term
- Respite services – enable families to support family members longer in community
- Personal planning/life planning – continual life plans – long term
- Employment – main stream – job coaching
- Special Services At Home – with some review – some misuse with it. Too many people on wait list
- Regional Support Associates – unique to southwest – expanded across the province – group of professionals – facility based – transferred to community – non-profit
- Community support to individuals living independently in community – should be expanded. Criterion is that they can stay overnight alone. Component – life skills trainer – highly successful in some areas – need to do more. Independent – not a large advocacy group.
- Developmental Disabilities program – community outreach workers – stationed in various jurisdictions – works well. Funded by Ministry of Health – Access? Yes, dually diagnosed – ACT team? Yes, but for developmental disabilities.
- Associate Family Home Model
- Principle – supporting mainstream services – i.e. recreation, volunteerism with support – inclusive communities – need extra support.
- Mediator model – where folks working front line – utilize consultation services – professional – through front line workers.
- Transitional services – leaving CAS system – money travels with them – a lot of work. Variety of Day Supports.
- Trustee System – for those who can't manage finances alone – no longer used – government pulled funding – didn't do everywhere – consistency issue.
- Change in terminology – broadened what is available. Alter rules for Special Services At Home? Yes.
- APSW – some parts of province have – very flexible advocates – hands on or case management – good working model.

#### 4. How should a reasonable level of government funding for an individual be determined?

- Funding based on individual needs and adjusted as those needs change. Is that reasonable – what are the supports that the government has identified – they have obligation to provide i.e. residential support – what is a reasonable amount. If state based on individual – open flood gates, but state these are services government must provide (core services) – may provide form of measurement.
- If move to levels of support, it should be broad categories like A, B, C etc. We know more or less what people cost to support – particular service types versus individual costs. More work required to determine levels of support. One fear, that the C levels i.e. those with lesser needs will translate to lesser importance in funding scheme of things. Focus on residential and day programs – support level, but equally vulnerable population receiving minimal supports – without funding some levels will crash.
- Other jurisdictions where institutions are not the major sector anymore – where is that information – research for this. Are we outspending, under spending or in line with other jurisdictions?
- Responsibility of other partners – families, individuals etc. Determining reasonable funding from families – should they pay part of the costs if they have the means? What is a reasonable parental contribution? Parents with child under the age 18 – should have some responsibility – to contribute child support. Does government have responsibility to fund supports/services to enjoy quality of life equal to peer in community? We don't say what we feel the government is responsible for funding. Do people have funding to enjoy community supports i.e. recreation, involvement in community. Is it reasonable for government to fund beyond basic needs - how to achieve and measurement? Peer comparator in community possibility. Outcomes model – outcome oriented in what we do now? The government would have to address the resourcing issue. Some service providers are very outcome oriented, some are not. Adult re: family contribution – get 2 tier system. If family minimal funds, then 2 possibility 2 tier. We need to move away from total entitlement to shared responsibility – various means – if family can provide contribution – great, if not service provider to assist – something in between to stop 2 tier system. Flip side to having government fund more than basic funding – have community partners share responsibility i.e Trillium Funding – to partner and leverage what is out in community – why doesn't govt assist with this – incentives i.e. Teen Camp – the community centers open, but not fund fully – need incentive from government to spearhead this – not a major issue, but an incentive from the government would be great. Cautionary feature from shared funding – board governance – who owns the organization – the parents or government? Stakeholder model – implications.
- Government funding – local – what is their responsibility – zoning, fire, health, education (spec ed), government funding – think more broadly. Applying to Trillium/Citizenship – all government money – if valid need, why fill out different forms – when all government funding – time/waste.
- ODSP – community supports based on that – affordability of independent living and SIL living – can't afford bussing etc.

- Person with disability or currently in service – some people have more than they need – some don't have enough – cap on services? How are people being served with tax payers money? Some people being supported in group homes that maybe shouldn't be there?
- How are we going to assist Ministry without them being intrusive with us as service providers?

**5. Services are changing in Ontario for people who have a developmental disability. What would you like to see happen?**

- More dollars for technology
- Linkages between other ministries i.e. health; education
- Services changing for people with developmental disability? Yes. 30 years ago people with developmental disability not living in community. Services changing? Expectations? Changing year to year. Service system always changing. Philosophy/Principals/kind of models/inclusion/
- Better mechanisms to deal with change/transition; change is valued at government; more usual/expected; orientate government that changes are happening and more often. Flexible funding? Yes. Resolution teams – give authority to resolve. Accreditation fit in here? Accountability tool possibility. Globalization of budget as well.
- Celebration of what we have achieved in DS – what we have achieved in 30 years – institutionalized and now community based. Health should listen to COMSOC. Invest more in people we support – financially and emotionally – investment different. Maintenance of strong not for profit sector – safety net. Advocacy of group of people.
- Top of list or out of running – have to be in critical need to receive support. We have to do this ourselves – create a crisis around areas that will affect government. We as a sector have to stop being nice – how do we achieve this? System is there – don't use it i.e. pay equity – go to court – difficult role – agency receiving funding from government. Maybe role for OASIS – to take system wide view – increase its role/profile.
- Not enough money in system to meet current needs or future. What can we do differently? Our system is not short term – drum up more support? how are we going to support the people coming up in the system.
- Should people with developmental disability be entitled to supports? Mandatory? That is where court situation comes in. Familiarity with Health – mandated services – making equal, quality of service may be low.
- We are the business arm of government – families might say we get no service/poor service – what mechanism is in place to report to government. Families not always happy/more knowledgeable. Are we the “new institutions”?
- If we move to individualized funding, we need data/performance evaluation – look at the business factor – we need solid data/solid stats.
- More creative with tax system. i.e who pays for own day program. If kept individual at home – tax break?
- Review of ODSP
- If take everyone in to services – history is you can get “stuck” with huge cost if their needs increase through time. Appeal system needed or some mechanism to go back when circumstances changed – reassessed.



- Dual Diagnosis – behaviour services are needed.
- Multi year funding approach – agencies would have more stability – 5 year plan. These are not budgets – allocations – get into proper budgeting theory as needs arise – no budgeting process currently.
- Waiting lists are getting longer – no movement – persons most in need gets service before person on waiting list. People on waiting lists are not happy – agencies have all money, why don't I get service? Two groups – some very happy, others not.
- Ministry message needs to be consistent.

## 6. What do you think are the priorities the government should address?

### Finance:

- HR planning – staff training and development – for next 10 years; APSW
- Salaries – correct wage disparity within and outside
- Flexible funding models, enhanced SIL and individual funding models for hard to serve individual - within agencies – transitional hard to serve individuals; some transition to get through times; aging or illness transitions; funding for transitional problems. Moving funds from one service area to another, funding from one area to another – okay as a system? No. Difficult to move whenever people want.
- Best Practices at internal Ministry level – good starting point.
- Opportunity to look at things provincially – we don't have data – need to take a business approach – system that is workable/affordable – need handle on stats before we have a system/common language – data analysis – we can't ask for more money without understanding performance levels and how we are going to manage funds
- Globalized budgeting – some agencies have many budgets
- Funding for research – best models of services
- Pay Equity
- Infusion of new money – over 5 year period – need government to make this sector a priority. This could address existing infrastructure and new services
- Present information to government regarding staffing needs and impact on future employment in Province – make case regarding the need for DSW's; and do some research on how many graduates will be needed and what their level of training requirements will be so that the college system can make necessary adjustments.
- Discord between corporate and regional level of Ministry – don't cooperate – frustrating; OASIS has asked for data – not there on corporate level.

### Administration

- Dual Diagnosis
- Education – Legislation: Childcare has to be re-amended for childcare and nursery school; a fair housing act for Ontario – following US; government needs to create clarity around fire code, implementation from one year to the next can change in same jurisdiction; our sector should be an essential service; DSA?

### Legislation

- Other pieces of legislation put in place with understanding of our sector. Government needs to look at transition – seamless transition

## Key Areas

- Waiting lists
- Infrastructure of community and capacity
- Accreditation
- Aging individuals. Receiving services and transition
- Equitable services
- More linkages between ministries – health, transportation
- Additional services for those not in services – balance
- Hard to serve – high needs
- More linkages between the Ministry and service providers such as ongoing consultation;
- More performance related – what is working/what isn't – across the system; should OASIS be involved? In terms of priorities – best practice?
- Clear direction of pay equity
- Levels of support – better defined for particular range – a lot of disparity; formalized assessment tool/document. Lays out some formulas – within a range – a way of getting at disparity within our sector; live with these days? No, depends on how tool deployed; we may be vulnerable if we utilize this method;
- What is mechanism used that is in place for levels of support – case resolution; consider flexibility; has to be some ranges; ranges of services – disparity; no objective/transparent method; where are cutoffs; criteria – some framework/guide needed
- If don't use levels of service – what is there? Accreditation; why have waiting lists? Why some receiving more services than needed? How are we going to justify where at? Levels of support can include case resolution. Too many factors for one level of support. We can't leave the system that open ended - having one level of support will not advance us at all. Need system i.e. mild, moderate etc. Perhaps look at factors instead of levels? Value audits – done by people who are knowledgeable. People based system versus tool based system. What is working well – supporting wide range of people with high needs – service provider know needs/supports best.
- Ministry needs to look at their definitions of most in need. Often ignored are the individuals living in community with minimal supports. They need to be acknowledged as well because for some of them, without the small amount of support, they can crash. Person by person process. Flexibility still needs to be built in.
- Life planning – need permission from government every time there is a change in need – need flexibility – time frame
- Government has to ensure they have a consistent message with each regional office stating the same thing.
- Base Budgets
- If additional funding becomes available, how to allocate?
- With a separate children's ministry, we need to do better to create a smooth transition – tie into education – children have 1:1 support when go into services
- Children and adults – differentiate
- Regional offices – more authority – more accountability – more decision making – rather than dump responsibilities on them
- Community and capacity – cost of living
- Housing

- Day Supports
- Special Services At Home
- Creating linkages to other ministries
- Funding for community capacity building
- Funding and support for innovation

### **5 main areas:**

#### Finance

- Variety of services currently available and maintained
- Longer term and internal flexibility – ability to move money around
- global funding and value audits – form of accreditation – part of accountability
- Multi year funding
- Aper – move away from (input/output) – no longer utilize this

#### Human Resources

- Valued Staff: trained, ongoing training, reasonable wage for job being done.
- All Agencies negotiate separately – negotiate act as one unit
- Sector – valued sector
- Recruitment and retention
- If pay people enough will stay – a lot of competition (education/long term)

#### Research and Communication

- Data collection/analysis
- Strategic planning/multi year planning
- Authority between regional/corporate and service provider

#### Transition Planning

- Early intervention
- ODSP
- Adults to retirement
- Waiting list
- Aging issue
- Duplication of services

#### Inter-ministerial Collaboration

- Direction to other ministries – education/health/longterm
- Legislation
- Philosophy/principals

## Appendix C - Notes from Group C

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### 4. How should a reasonable level of government funding for an individual be determined?

- must start by acknowledging that supports for people will be lifelong, ongoing and ever changing - cost-benefit analysis may be a way to capture this
- variables such as cost of living, evolving lives, changing individual needs, changing social needs - impacts all of this
- the old way of doing things will no longer be acceptable in the future
- the current standard process to allocate funding (base funding) must be reconsidered
- base funding needed as well as some sort of measurement of individual needs - equitable distribution of funds
- need a way to determine the cost of support for each person - individualized funding approach that is portable - needs to recognize quality of life issues
- base funding must be sustainable, accountable and objectively determined to support the continuation of a system infrastructure and respecting individual needs
- need an objective way to determine needs and costs - we need to define what we want - what is quality? - a cost-benefit analysis may be a starting point - an accreditation process may help to measure this
- needs to be an accountability mechanism throughout the system to ensure that the funds allocated for each person are being spent in a reasonable manner
- "reasonable funding" so hard to define
- government must recognize mandated requirements of agencies - more people have come into the system without additional dollars
- we currently have a "squeaky wheel" system
- measurement tool needed and system integrity
- "iso-funding" used by the Ministry of Education - learn from this model
- need to bring our community on side
- need to acknowledge realities of today - inter ministry communication/partnerships, societal pressures, rising community costs - need to bring community on side - partner with community
- objective assessment tool needs to be developed to determine a person's needs and quality of life issues as well as requirements for service is needed
- there is a need to "flag" individuals from time of birth and track people throughout the system to plan effectively for the future - results in the integration of service sectors
- if regular inflationary costs were built into the system and funded by government, agencies would be prepared to address people's needs as their requirements change

### 5. Services are changing in Ontario for people who have a developmental disability. What would you like to see happen?

- legislation required to make us a mandated service - would create a seamless system - supports and money would flow with people
- multi ministry coordination and accountability for life long support
- system validation with regular assessment of needs and changes to maintain the integrity of the infrastructure

- inter ministry coordination exercise - proactive approach - MCSS must engage all ministries that may impact on a person's quality of life i.e. Health, education, employment, citizenship etc.
- perhaps a piece of legislation needs to be developed to support this cooperative approach
- MCSS needs to be legitimized - recognition that it is valuable, worthy and seen as an essential service
- individual quality of life factors must drive the approach
- a system of value driven/outcome based principles should be embedded into the approach (i.e. What has happened in Central East)
- standards must be established to guide the approach still providing reasonable flexibility by each agency
- accountability mechanisms to guide agencies and the Ministry would be helpful
- systems changes that would be helpful - more flexibility in systems and individual funding - opportunity to maintain surplus beyond the fiscal year - funding beyond the single year
- recommend some changes in regulations i.e. fire codes, not being able to house people in walk-out basements, locking medications etc. - those practices that do not support quality of life

**1. What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability?**

- government must adopt a holistic approach - be a catalyst - support a collaborative approach which includes all stakeholders (individual, family and community)
- government has a responsibility to pass legislation that would mandate developmental services - there needs to be a timeliness to the families' requests for service - there must be a proactive/preventative approach
- there should be supports/resources for families to enable them to support their family for as long as they can - at that point, the system needs to be able to respond to the needs of the individual
- this requires that people with disabilities need to be identified at very early stages and information about supports must be readily available to people - requires that communities become better informed about resources/services available for people with disabilities - public awareness campaign to address two key issues: knowledge about our field and greater community acceptance
- must build community capacity - helping community to understand that there must be acceptance of all members and acknowledgment that everyone has value and can contribute to the betterment of that community

## **6. What are the priorities the government should address?**

- revitalization input - retention of employees is a huge, important issue - appropriate salaries and benefits are required - need to value the work that people are doing - appropriate pay and benefits - address pay equity obligations
- recognize the link between appropriate pay and value and understand how this impacts on society perceptions of the field
- need to develop social capital - community awareness - building community capacity
- changing needs of an aging population - flexible funding
- inter ministry collaboration
- professionalization of our sector at the education level - professional standards in our field - ongoing training - again adds respect and value to the field - cautious of balancing this with the view that "an expert is required"
- work with colleges to enhance the training
- government should hold private services accountable to the same extent they do TPA
- the term "developmental disability" is not well known
- more preventative programs e.g. respite services - keeping our families well is critical and impacts on the future needs of services - more proactive approaches - responding to crisis in a timely manner so as not to react to situations
- tap into existing community services i.e. Alzheimer supports
- pay equity
- creating joint ventures with other ministries to provide a variety of opportunities to a full range of supports including: supports for housing options, day supports, SSAH, and unique options within the community
- develop effective clinical supports for people with developmental disabilities

## **SUMMARY - THEMES**

- mandated services - entitlement of funding for individuals
- sustainable funding for individuals and agencies
- accountability mechanism - cost-benefit analysis
- professionalization of staff and the sector - better salary and benefits
- funding decisions driven by a strong set of values - flexible funding
- strong clinical supports
- acknowledging that supports should be lifelong (cradle to grave), ongoing, seamless and ever changing
- building community capacity