

# Building a System of Service for BC's Children and Youth with Special Needs and Their Families:

### The BCACDI Survey - what did we learn?

### Maureen O'Donnell MD MSc FRCPC

on behalf of



Anton Miller
Bruce Sandy
Bill McKee
Fran Boyd
Maureen O'Donnell
BCACDI







### **Outline**

- Introduction what are the issues
- Why did the Ministry and the BCACDI work together to do this survey?
- Survey goals and methods
- Findings
- Key Messages and what it means to Sunny Hill?



# Introduction



# Who are Children and Youth with Special Needs?

Children and youth between birth and 19 years of age who require additional educational, medical/health and social/environmental support, beyond that required by children in general, to enhance or improve their health, development, quality of life, and community integration.

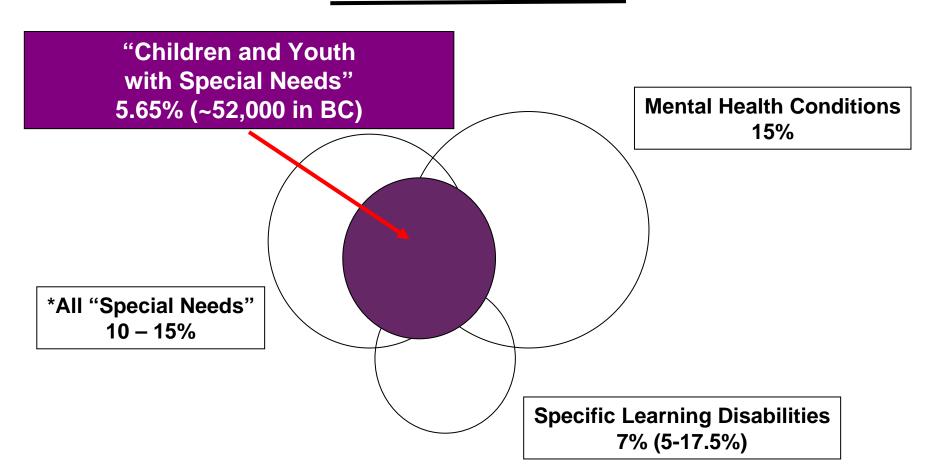
# Cyss Who are Children and Youth with Special Needs?

They have significant limitations in age-appropriate daily activities at home, school and in their communities in one or more of the following domains:

- Cognition and learning
- Communication
- Sensory domains (vision and hearing)
- Movement and mobility
- Interpersonal interaction and relationships (social, emotional, behavioural)
- Community, social and civic life
- General tasks and demands (including developmentally appropriate self-care)



### **Prevalence**



<sup>\*</sup>The literature states that 10-15% of children have a special need which, in this definition, might mean that the child has a disability or has a chronic health condition



# Services for Children With Special Needs

- Over 90 identified programs delivered primarily by three ministries:
  - Ministry of Children & Family Development
  - Ministry of Education
  - Ministry of Health Services
- Total spending over \$550 Million annually



### Pressure on children and families

Who is my team?

Am I alone or are there other parents out there?

What will happen when he goes to school?



Where do I go for help?

How do I find out about new supports and treatments?

What can we expect next?

Where can I go to get a break?

Is my child getting the right care and support?



### System Challenges Identified

- Waits, Gaps and Overlaps
  - Multiple points of access, intakes, waits
  - A need for better access to program information and to providers
  - Limited service provider continuity over age ranges
- Inconsistent Standards and Service Quality
  - Limited knowledge of effectiveness
  - Limited systematic evaluation of services
  - Inadequate sharing and use of new evidence
  - A need for more research
  - Different quality standards across the sectors
- Complex and Disjointed Service System
  - Parts of the service system have different mandates, values, priorities, definitions, funding models...



### Goals: Where do we want to be?



### Improved Access

The right services at the right time

### Effective Services

High quality services with strong evaluation

### Coherent Systems

Improved integration and coordination



## **Organizing Service Delivery**

### **Tier Four:**

Provincial Sub-specialized Special Needs Services

#### Tier Three:

Regional Specialized Special Needs Services

#### **Tier Two:**

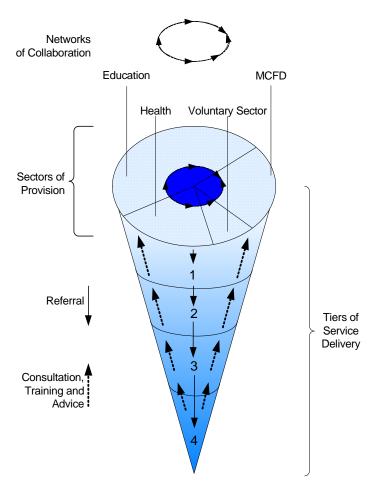
Community Special Needs Services

#### Tier One:

"Broad-reaching" Service Providers



### **Conceptualizing Service Integration**



Tier 1: Broad reaching Services

**Tier 2: Community Services** 

**Tier 3: Regional Services** 

Tier 4: Province-wide Services



### **About the BCACDI:**



Is a provincial non-profit organization which provides advocacy, communication networking, research and education services to its member agencies







Without a comprehensive sense of who is providing service, we can't track or improve our efforts to coordinate the complex array of CYSN services



### Goals of the province wide survey:



- Determine services provided across BC across the three sectors
- Determine providers and profession involved
- Determine the populations served by each service and the tier of service offered
- Map services and link to population distributation as a means of modeling how well the systems if meeting CYSN population needs



# 1. Establishment of project steering committee:

- 17 members from across the three sectors and across the province
- Multi-disciplinary
- Different roles: clinicians, educators, researchers, administrators, policy makers etc
- They made a very significant contribution over a long period
- Small "executive group" evolved as well





# 2. Confirmation of Scope and Sampling Frame

- A critical step! Some animated discussions!
- Agreed to use CYSN Definition needed to further delineate sub groups of the population for the purposes of agency response
- Agreed to use Tier definitions with explicit definitions
- Re sampling frame: Agreed to describe and find all agencies or organizations receiving funding from the three ministries in support of CYSN.



# 3. Creation of the Survey tool and process

- Another critical, time consuming but very collaborative process including working through issues with:
- Definitions that work for all three sectors
- Common language around the definitions
- Optimal time to survey
- Paper vs online
- Length of survey vs quality of information





## 4. Finding Respondents





# 4. Finding respondents was the most significant serious challenge

- Significant effort to identify potential respondents
- Initially more than 600 potential respondents agencies and organization were identified
- Final mailing list for the survey numbered 480 organizations/agencies (after removing duplicates and inappropriate organizations)



## 5. So - in summary re the process

- Goals and objectives and scope were framed by the CYSN Framework
- Survey methodology and content was agreed to.
   Then...
- Paper-based survey developed with Steering Committee guidance
- Providers contacted by mail and email, survey package enclosed
- Online version developed
- Deadlines extended
- Followup by phone and support for completion



### **Results**





### **Survey Response Rate**

Table 1 below provides further detail on adjusted response rates by sector and region (excluding independent schools).

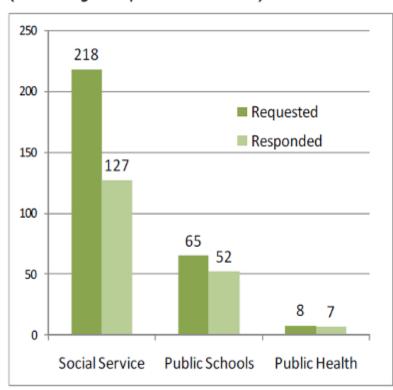


Figure 4: Requested and actual respondents by organization type



### **Survey Response Rates**

- Reporting jurisdictions and agencies vary greatly in size and number of reporting units
- Data combined for social and health services for a two main reasons
- Independent schools removed from analysis
- Overall completion rate of 64%



## **Organizing Service Delivery**

### **Tier Four:**

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Sub-specialized Special Needs
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#### Tier Three:

Regional Specialized Special Needs Services

#### **Tier Two:**

Community Special Needs Services

#### Tier One:

"Broad-reaching" Service Providers



### What kinds of service are offered?

Service Type	Includes
I. Diagnosis/ Initial Assessment	<ul> <li>Activities aimed at arriving at a diagnosis that explains medically the basis of a child's developmental difficulties (etiologic);</li> <li>Activities aimed at arriving at a "developmental" or "functional" diagnosis that characterizes a child's developmental difficulties without accounting for the medical cause (functional – developmental); and</li> <li>Activities aimed primarily at describing a child's functional profile of strengths and weaknesses, without necessarily arriving at a summary diagnosis or label (assessment/identification in schools).</li> </ul>
II. Assessment of Function/ Progress Monitoring	Activities aimed primarily at describing a child's functional profile of strengths and weaknesses, without necessarily arriving at a summary diagnosis or label.
III. Intervention	Therapeutic, instructional, counselling, health and equipment/ technology services in four sub-groups:  Therapeutic interventions for the child or youth Special education for the child or youth Transition planning for youth Family intervention and support (e.g. parenting courses, respite, family advocacy and training)
IV. Service Coordination	A formal role that involves coordinating services between different providers and/or agencies and organizations
V. Consultation to Outside Providers	Involves consultations to providers outside the agency/organization for specific children not seen directly by agency/organization providing consultation.

Table 5: Analytic Framework for Service Sub-Types

Tier 2: Community Special Needs Services									
Organization Type/Region	Coastal	Fraser	Interior	Island	Northern	Total			
Social Services/Public Health	21	24	37	20	25	127			
Public Education*	8	9	11	11	9	48			
Tier subtotal	29	33	48	31	34	175			
Share of agencies by region	16.6%	18.9%	27.4%	17.7%	19.4%	100.0%			
Tier 3: Regional Specialized Nee	ds Services								
Organization Type/Region	Coastal	Fraser	Interior	Island	Northern	Total			
Social Services/Public Health	3	3	3	2	2	13			
Public Education*	0	0	1	2	2	5			
Tier subtotal	3	3	4	4	4	18			
Share of agencies by region	16.7%	16.7%	22.2%	22.2%	22.2%	100.0%			
Tier 4: Provincial Sub-specialized	Special Ne	eeds Serv	ices						
Organization Type/Region	Coastal	Fraser	Interior	Island	Northern	Total			
Social Services/Public Health	2	2	1	2	0	7			
Public Education*	4	2	0	1	1	8			
Tier subtotal	6	4	1	3	1	15			
Share of agencies by region	40.0%	26.7%	6.7%	20.0%	6.7%	100.0%			
All Tiers									
Organization Type/Region	Coastal	Fraser	Interior	Island	Northern	Total			
Social Services/Public Health	26	29	41	24	27	147			
Public Education*	12	11	12	14	12	61			
Tier subtotal	38	40	53	38	39	208			
Share of agencies by region	18.3%	19.2%	25.5%	18.3%	18.8%	100.0%			

<sup>\*</sup> Excludes independent schools

Table 4: Adjusted responses by region, tier and sector (number and percent)

Service Type	Tier 2 - Community Special Needs Services (N=175)	Tier 3 - Regional Specialized Special Needs Services (N=18)	Tier 4 - Provincial Sub-specialized Special Needs Services (N=15)	
I. Diagnosis/Initial Assessment	143	15	13	
II. Assessment of Function/Progress Monitoring	148	15	13	
III. Intervention	168	15	15	
IV. Formal Service Coordination	96	11	10	
V. Consultation to Outside Provider	116	14	11	

Table 6: Agencies and organizations by service type and tier (number)



# Tiers of Service and provincial distribution

- Number of agencies for Tier 2 within each region is larger than those providing Tier 3 and 4
- Higher concentration of Tier 4 in the lower mainland
- Tier 3 distributed except in Coastal where Tier 4 may also deliver Tier 3



### Tiers 2 agencies

- Tier 2 agencies are the major providers in the system with 175 agencies responding
- While they provide most types of service, Tier 2 agencies are predominantly involved with intervention. In addition,
  - Some provide diagnostic assessment
  - 55% provide formal service coordination
  - Nearly all public education provide a range
  - Health and social service focus more on intervention



### Tiers 3 agencies

- 18 agencies reported
- Report providing a range of all types of service
  - more likely to provide more formal service coordination and consultation to outside providers than Tier 2
  - also more likely than Tier 2 t provide dx/initial assessment



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### Tiers 4 agencies

- 15 agencies reported providing provincial one of a kind services (8 in education and 7 in social/health services)
- All provide intervention
- More than ½ also provide all types
- Opportunities exist to share information across this tier.



### **Service Distribution**

- Three sub-groups defined:
  - Primary sensory impairments
  - Primary neuromotor conditions/physical disabilities
  - Primary developmental=behavioural conditions
- A great deal of expertise to serve all these groups
- No statistical difference between regions



### **Service Distribution**

Primary Condition Population Group	Tier 2	Tier 3	Tier 4
Primary Sensory Impairments	139 (78%)	13 (72%)	15 (80%)
Primary Neuromotor Conditions/Physical Disabilities	154 (80%	18 (89%)	12 (80%)
Primary Developmental - Behavioural Conditions and/or General Developmental Delay	186 (94%)	20 (83%)	14 (87%)
No response given	16 (9%)	10 (42%)	7 (37%)
Total agencies	198	24	19

Table 8: Agencies providing services, by primary condition population and tier



## Service Distribution Trends by population?

- Tier 2 serves a higher proportion of CYSN with developmental behavioural conditions or developmental delay
- Tier 3 less likely to serve children with sensory impairments
- Tier 4 serves all groups with subspecialty services



## What about evidence based practice and training?





Organization Activity	Tier 2	Tier 3	Tier 4
Program evaluation and quality Improvement	91	100	93
Promoting the use of new research evidence	78	94	100
Participation in formal research projects	36	61	93
Initiation of formal research projects	16	33	60
Staff development within agency	95	100	100
Staff development in other agencies	75	83	87
Education of University/College students	79	83	87

Table 16: Involvement in Organizational Activities by Tier



#### What about evidence based practice?

- 91-100% across all sectors and all tiers involved in program evaluation and quality improvement
- Positive findings regarding participation in research, use of research evidence and KT
- Strong overall committment to creation and dissemination of new knowledge
- All committed to trainees

System Tier	% of responding agencies involved in post-secondary training
Tier 2: Community Special Needs Services	79%
Tier 3: Regional Specialized Needs Services	83%
Tier 4: Provincial Sub-specialized Special Needs Services	87%

Table 15: Agencies involved in post-secondary training for CYSN service providers, by tier



#### Human resources to support the system?







#### Human resources to support the system?

- More than 22,000 FTE's identified!
  - Range from 8000 teachers to those very specialized

 Significant variation in job titles acorss sectors and regions with more than 90 different role descriptors and professional classifications

Position/Role	Filled FTEs reported (all tiers)
Mainstream Teacher	8,770.30
Teaching/Special Education Assistant	4,176.73
Teacher's Assistant	1,386.83
Learning Support Teacher	932.33
Counsellor – School Counsellor	562.41
Coordinator Special Programs – MST, Resource Room	456.30
Resource Room Teacher	418.89
Special Needs Teacher	393.66
Child and Youth Care Worker	386.86
Speech Language Pathologist	362.93
Alternative Program Worker	356.60
Supported Child Development Worker	240.51
	18,444.35

Profession/Position	Filled FTEs reported (all tiers)
Child Care Worker	176.66
Occupational Therapist	176.05
Child and Youth Workers	161.85
Community Link Worker	146.17
Supported Child Development Consultant	143.94
Physiotherapist	129.21
Certified School Psychologist	118.00
Behaviour Interventionist	111.12
Family Support Worker	108.95
Infant Development Program Consultant	106.64
Aboriginal Infant Development Program Consultant	105.25
	1,483.84

Table 12: Provider Positions Reported 100 to 199 FTEs

	(all tiers)
Counselling	9.64
Augmentative Communication	8.90
Recreation Therapist	8.80
Assistive and augmented communication consultant	8.80
Aboriginal Supported Child Development Program Coordinator	8.00
Seating technician	6.20
Deaf Blind Specialist	4.40
Dietician	4.15
Orthotist	4.00
Aboriginal Wellness Coordinator	3.80
Neuropsychologist	3.60
Social Work Aide	3.00
Orientation and Mobility Instructor	2.90
Nurse Clinician	2.86
Rehabilitation engineer/technician	2.30
Teacher of the Deafblind	2.30
Mental Health Clinician	2.00
Occupational Therapy Assistant	2.00
Family Practitioner	1.50
Infant Mental Health Clinician	1.00
Home Maker Support Worker	1.00
Psychiatrist	0.84
Child Life Therapist	0.20
	92.19

Table 13: Provider Positions Reported <10 FTEs

Tier 2 Positions	Vacancy rate (%)	# Positions vacant for >6 months
Auditory – Verbal Therapist	27%	2
Seating Technician	19%	-
Speech Language Pathologist Assistants	17%	2
Mental Health Support Worker	14%	-
Aboriginal Supported Child Development Consultant	12%	5
Aboriginal Infant Development Program Consultant	11%	4
Tier 3 Positions	Vacancy rate (%)	# Positions vacant for >6 months
Registered Nurse	72%	1
Supported Child Development Worker	19%	1
Tier 4 Positions	Vacancy rate (%)	# Positions vacant for >6 months
Registered Psychologist	18%	2

Table 14: Positions Reported Vacant >Six Months by Tier



#### Human resources to support the system?

- Challenges in maintaining appropriate numbers and mix of providers
- Significant long term vacancies (> six months)
  - Physiotherpasits (27 positions)
  - SLP's (14 positions)
  - OT's (14 positions)
- Presumably vacancies = waiting time increases



#### **Funding Mechanisms**

- Diversity of funding mechanisms
- Services provider contracts
  - 87% of respondents did not receive direct funding
  - 75% had a contract from another agencies
  - 26 agencies hold 10 or more contracts!
- Related to workload/admin load and accountability risk



#### **Key Learnings?**

- Tiers of service language
  - Need more communication
- This cross- sectoral task was more complex than ever imagined... why..?
- Timing of work with across sectors important!



#### **Key Learnings?**

- Little common language
- System complexity but there is some evidnec eof tiers
- Chronic vacancies why?
- Commitment to evidence, quality and training



#### **Key Learnings?**

- What do we need?
  - Prospective data collection with common definitions
  - Data systems
  - Increased communication
  - To use this information, though limited, in working with others.







#### **Comments? Clarifications?**



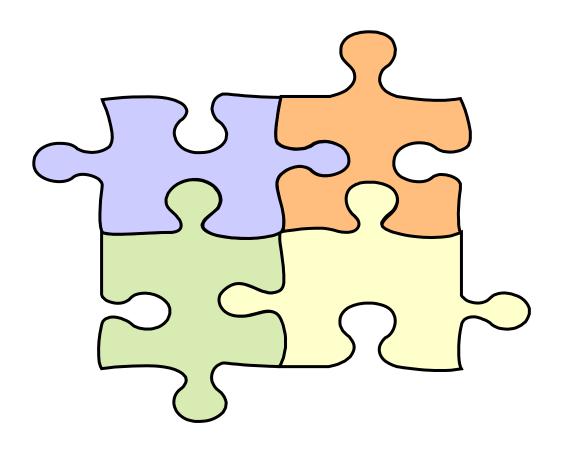


# Strategies and Action: How do we get there?





### In summary...





#### **Challenges and Opportunities**

cross-ministry work



