

Use of Routinely Collected Early Intervention Data for Deaf and Hard-of-Hearing Children for Outcome Monitoring: A Case from British Columbia, Canada

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PURPOSE

- ▶ Can quality, routinely collected data from early intervention programs contribute to critical information to develop a coordinated database infrastructure for monitoring outcomes of children with hearing loss?

METHOD

A case study design

- ▶ Data was collected from [BC Family Hearing Resource Society](#). The agency enrolls approximately 80% of the children referred from the province's universal early hearing detection (newborn hearing screening) and intervention programme and is the largest provider of outreach services to young deaf and hard-of-hearing children in the province
- ▶ In-depth file reviews was conducted of the types of data collected and methods of data management used to identify types of individual-level child and family demographic and outcome data that the agency collected
- ▶ Issues with the data set that may influence the agency's ability to utilize it for local outcome monitoring purposes
- ▶ The usability of early intervention agency data as potential inputs for a population level outcome monitoring system

Data Analysis

- ▶ Review of the early intervention data set involved extensive consultation with programme staff as well as in-depth file reviews over a 5-month period
- ▶ All case files for children born between 2000 and 2007 were reviewed
- ▶ Formats for these data were paper based or electronic
- ▶ Existing data related to children's hearing status and developmental outcomes in auditory, speech, language, and pragmatic abilities were reviewed
- ▶ In total 267 file records were reviewed

FINDINGS

Table 2 Availability and types of early intervention data in the agency files

Types of data	Proportion of 267 cases with data available				
	None (0%)	1-25%	26-50%	51-75%	76-100%
Child and family demographics					
Date of birth					✓
Place of residence					✓
Client record number (health number)				✓	
Gender					✓
Family household socio-economic status	✓				
Family primary language spoken in home					✓
Parent hearing status			✓		
Sibling data (number of siblings, hearing status)		✓			
Child's hearing characteristics/audiology					
Type of hearing loss					✓
Date of diagnosis of hearing loss				✓	
Hearing loss laterality					✓
Degree of hearing loss by ear				✓	
Date of first audiological testing					✓
Recipient of cochlear implant(s)					✓
Date received cochlear implant(s)					✓
Aetiology					
Presumable timing of hearing loss			✓		
Known risk factors for hearing loss		✓			
Presumable cause of hearing loss			✓		
Other conditions/disorders/anomalies/syndromes					✓
Amplification and early intervention					
Date of receiving amplification				✓	
Date of enrolment in the early intervention programme					✓
Types of assessments					✓
Outcomes of assessments					✓
Early intervention goals					✓
Communication diagnosis					✓

FINDINGS

▶ Sampling and measurement issues:

- Self-selected group of individuals seeking intervention
- Data from one early intervention agency
- Intervention determined based on the child/family's need and not controlled; intervention judgement in choosing assessments and intervention strategies
- Variations in descriptors and definitions

▶ Missing data

- E.g., Mothers and father's hearing status, aetiology of hearing loss/deafness, date first received amplification device, type of intervention

▶ Reliability

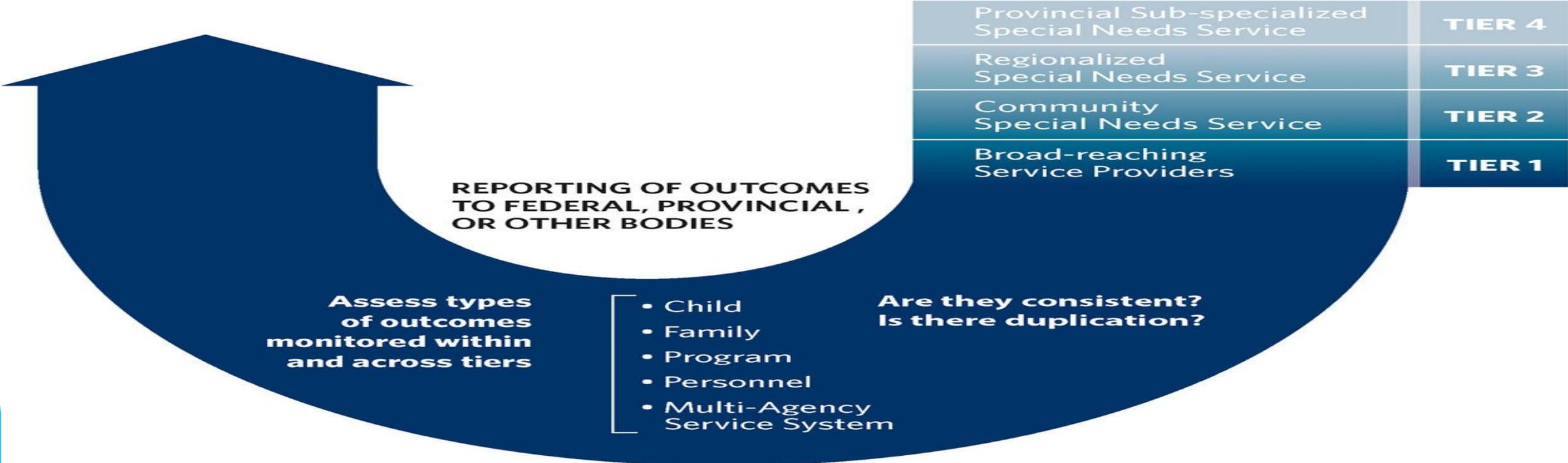
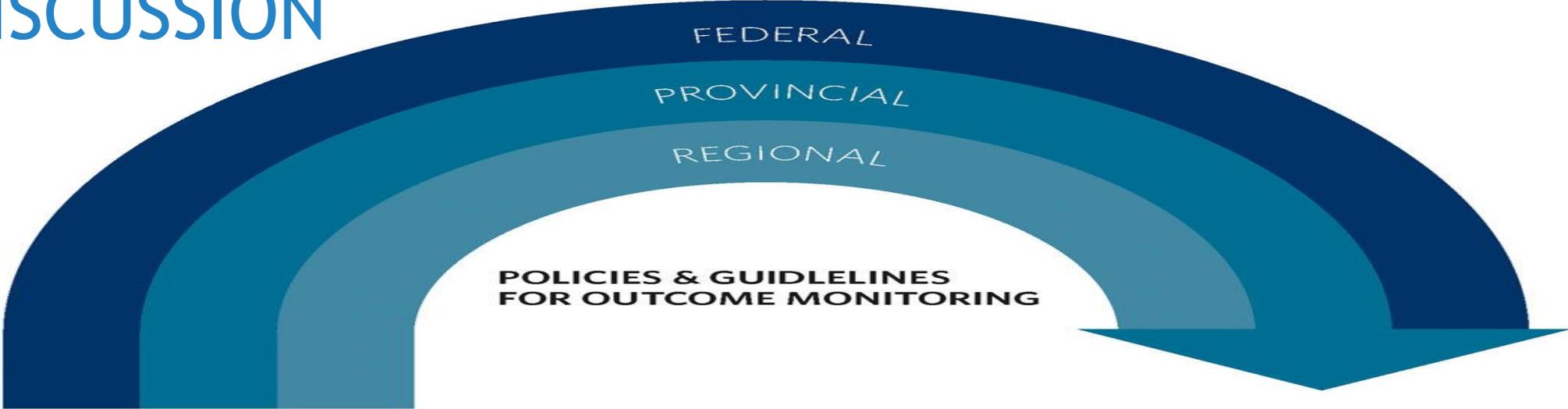
- Data entered by multiple personnel over time
- Different format - paper and electronic
- Diverse assessment and intervention strategies made it difficult to analyse and synthesize information

DISCUSSION

Considerations for developing an outcome monitoring network for Deaf and Hard of Hearing children

- ▶ Accountability framework: Lack of provincial consensus about the types of child-, family-, and programme-level outcomes that should be measured as part of an accountability
- ▶ Consistent outcome measures: Uncertainty about the utility of specifying a common set of outcomes when there is diversity not only in the needs and backgrounds of the children and families served, but also, in the interventions implemented, which may have been tailored to individual children and families
- ▶ Practical issues: Despite the information gathered by a combination of electronic and paper-based format not in a format readily useable for statistical analysis
- ▶ As a result, the capacity for the early intervention agency to use the routinely collected data for outcome monitoring purposes was very limited

DISCUSSION



DISCUSSION

- ▶ The early intervention system is not closed and predictable; but involves multiple providers, changes over time (e.g., in assessments, providers, diagnostic outcomes), and great variability in child, family, and service provider backgrounds
- ▶ Development of a coordinated, long-term population-based longitudinal outcome monitoring approach requires further consideration and examination of the complex systems in which early intervention services are embedded

DISCUSSION

- ▶ These types of data have been underutilized in studies of the hearing loss characteristics, amplification, and intervention services and outcomes for children with permanent hearing losses and/or deafness in Canada
- ▶ If standardized and collated into database format, such data would provide a data resource that could inform not only programme planning, practice, and evaluation, but also population-based prevalence and historical-prospective studies related to the health and developmental trajectories of deaf or hard-of hearing-children
- ▶ A broader, multi-level, systems based strategy is needed to develop a population level outcome monitoring framework that is coherent, useful, and reflective of the complexity of the service systems for children with special needs. Such a strategy for outcome monitoring, which is yet to be implemented in Canada, would require in-depth review of existing legislation, guidelines, and policies for monitoring outcomes of children

REFERENCE AND CONTACT INFORMATION

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Reference:

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