



Transforming DS Services Response to Preliminary Discussion Paper

Introduction

The Bob Rumball Associations for the Deaf¹ enthusiastically embraces the concept of transforming developmental services in Ontario. Ontario has a proud tradition of supporting individuals with developmental disabilities it is necessary from time-to-time to review what we do and how we do it.

Since making the decision, as a province, to move away from institutional service delivery to community based service a network of agencies and supports have been set up in many areas across the province. Community expectations have also shifted away from fear and separation towards acceptance and belonging. This is true to varying degrees depending on communities, schools and individual attitudes, however, we have come a long way.

There is still much to do for the developmental services system as a whole and for the move towards full citizenship in Ontario for individuals with a developmental disability. The Bob Rumball Associations for the Deaf would like to see this transformation give voice to the often overlooked and marginalized population of Deaf children and adults who have a developmental disability and their families and care givers.

We are supportive of other submissions that have gone forward and are members of OASIS, MARC and the Faith & Cultural Group. We also feel that the needs and characteristics of the Deaf need to be highlighted and distinct. With this in mind we respectfully submit the following.

Current Services

When a family has a Deaf child in Ontario there is no pre-determined path to follow. The challenging stories of families and individuals are as varying as they are numerous. A consistent theme that emerges is one of frustration; frustration

¹ For the purposes of this document the Bob Rumball Associations is inclusive of the services provided by the Bob Rumball Centre for the Deaf. Although two separate agencies with two transfer payment relationships in Toronto and Central West Region, the developmental services programs are integrated between the agencies.

of being given vastly differing advice from equally credible sources and the frustration of being alone on a journey.

Language selection is one of the first choices a parent has to make, whether a child has a developmental disability or not. Unlike other jurisdictions in North America families are forced to choose a particular communication mode and follow it to the exclusion of others. It is believed, in Ontario, that children who are to have a Cochlear implant should not be given training in sign language. While children wait for surgery they are not permitted to learn sign language or they put their implants at risk. Steps have been made in recent years to move away from this, however, progress is slow.

This lack of early exposure to language is a cause of concern. Although not the topic of this submission, lack of early exposure to language for Deaf children can mean that developmental milestones are missed or, if delays are present, they may be overlooked.

Studies at Gallaudet University in Washington and OISE in Toronto have shown that Deaf children of Deaf parents develop intellectually, socially and emotionally healthier than their peers of hearing parents. Early immersion in a full and complete language and culture is vital to the healthy development of Deaf children.

When a developmental disability is diagnosed the situation becomes even more complex and frustrating. Local early years centres', schools, case management organizations and other community supports - both funded and non-funded - have limited or no knowledge or experience working with Deaf children with developmental disabilities. This leads to difficulty in diagnosis as well as providing practical and emotional support to families. While parents of children with developmental disabilities often have very difficult early years this is significantly compounded for parents of Deaf children who now must choose a language, learn a language and be supported by services that may have never worked with a Deaf child before or met a Deaf adult. There is very little literature and few role models for parents to follow.

Families have reported since we began providing services that the early years are the most frustrating and isolated time of their lives. They receive conflicting messages, are faced with decisions that have a life long impact and have few role models to follow. Where as in the hearing community a parent is able to meet and talk and be supported and encouraged by families who have children with a developmental delay parents of Deaf children are often not afforded this benefit. Generic services for the Deaf are often contacted but, being unfamiliar with the developmental services system, are unable to offer much support.

Services for Deaf individuals with a developmental delay are also often contacted by families, especially as children age, for support ranging from finding SSAH

workers, summer programs, respite, planning, etc. Although there is knowledge and understanding there are no funded case management services, family support workers or other supports beyond the day to day activities of supporting individuals already in care. Agencies are available for the occasional consultation but unable to provide meaningful ongoing support and planning to families.

School programs in local school boards have different policies for working with Deaf students. Being a Deaf student in a local school can be very isolating as you are often the only one or one of a few who communicate in sign language. Friendships are difficult to develop and often lack the depth and commonality of hearing peers. Again, adding a developmental disability to the situation only compounds the sense of isolation. In some situations this early isolation leads to frustration which manifests itself in behavioural problems.

Accessing SSAH funding is helpful for families, however, locating staff who are Deaf or sign is a challenge. The nature of the Deaf community is to live in a few communities throughout Ontario. If a family is not close to one of these communities, is not connected to the Deaf community or a Deaf service provider finding staff is difficult. Often staff who have a few signs are used as temporary care givers to provide families with a break, however, they are unable to fully connect to the Deaf person they are supporting.

Provincial schools for the Deaf are the choice of some families, however, they are set up to educate Deaf students and have been overwhelmed with the influx of special needs students. The supports, teachers and educational assistants and curriculum are lacking.

Issues & Recommendations

Geographic Boundaries, Planning & Support

Current MCSS policy emphasizes ones geographic home community for the planning and provision of services. Deaf culture and community values emphasize proximity to others who are Deaf. In countries all around the world individuals who are culturally Deaf tend to live in a few geographic communities and often move to these communities when they are of age. These communities are often located around schools for the Deaf. The cultural norm is at odds with MCSS policy of service provision in ones geographic home community.

Specialized services for the Deaf are located in a few communities in Ontario. Accessing these services from other regions is challenging.

In Ontario different regions have responded differently to their Deaf members. Some Deaf specialized transfer payment agencies have been able to accept

individuals from out of region; others have had separate more cumbersome processes which may include special funding. It should be noted that despite a number of individuals in crisis in several regions of Ontario there have been no new funded residential programs for Deaf individuals with the new funds MCSS has allocated over the past several years.

Program funding that has been provided is restricted to the funded community. A family in a neighboring community will be denied access to the most suitable service because they live on the wrong side of a street. Boundary restrictions mean that families who may transport their children up to 70 minutes by bus to a school for the Deaf are not allowed to access an MCSS program that may be 20 minutes away.

These geographic boundaries also eliminate effective planning. Although there may be Deaf individuals with similar needs but in different regions local planning tables would not be aware of these opportunities. This type of planning in a vacuum leads to missed opportunities for effective programs and economies of scale.

Recommendation 1

MCSS & MCYS support the development of a Resource Centre for Deaf children and adults with developmental disabilities. The role of this centre would be to provide leadership in the area of Deafness and developmental disability in Ontario. A Resource Centre will:

- **Support agencies within local communities to enhance their existing knowledge of Deaf needs and culture through creating partnerships and providing information and knowledge regarding evidence-based approaches to service delivery and best practices.**
- **Provide a range of specialized supports including: day programs, residential programs, parent relief and respite and crisis.**
- **Provide families with access to planners who are knowledgeable of the DS system and the Deaf community and services in Ontario.**
- **Increase the service system's capacity to engage the specialized resources necessary to effectively plan for Deaf individuals, thus alleviating some of the pressure that is currently placed upon the Developmental Services system**
- **Provide specialized mental health and behavioural supports**
- **Ensure seamless supports for identified students during their transition from the school system, as well as supporting students and families as they navigate the service system through community integration planning.**
- **Engage in needs identification and cross regional planning, especially during transitional periods**

Recommendation 2

MCSS & MCYS implement a policy allowing for cross regional planning for services for Deaf individuals with a developmental delay and that current MCSS & MCYS barriers to accessing specialized services in different regions be removed.

Staffing and Staff Training

There are no full or part-time Developmental Services Worker programs for Deaf students in Ontario colleges.

Our experience shows that Deaf staff are often the most able to connect with Deaf individuals in care. They provide role models and are best able to relate to the challenges and richness of being Deaf. There are growing employment opportunities in the developmental services field for individuals who are Deaf. Approximately 95% of the Bob Rumball Associations' front line staff are Deaf.

Unemployment and underemployment rates for the Deaf community are much higher than in the hearing community, however, agencies serving the Deaf are not able to find educated staff to fill positions. There is an opportunity for meaningful employment in a community that would greatly benefit.

Much of our training is done in-house or with other agencies creating increased initial training and on-going expenses for interpreting and related costs. Providing educational opportunities for staff and other Deaf adults would be beneficial to individuals in care as well as individuals and families in the community.

Various training programs have been attempted by Deaf service agencies in the past and their success rates are high. This has not translated into consistent support from training agencies or various levels of government.

Recommendation 3

The Ministry of Training, Colleges and Universities develop full-time programs for Deaf students wanting to enter the human services field from high school.

Recommendation 4

That the Ministry of Training, Colleges and Universities develop part-time and apprenticeship programs for Deaf adults currently in the human services field or those wanting a career change.

Community Inclusion

Deaf providers view community inclusion in a slightly different way than hearing providers. Although involvement, presence and belonging in the broader hearing community are important true inclusion is targeted for the Deaf community.

The Deaf community struggles with the same issues of acceptance for individuals with a developmental disability as the hearing community, however, they are further ahead in many respects.

Where as in the hearing community most people do not know an individual with a developmental disability the opposite is true in the Deaf community. At the major Deaf events and festivals there are undoubtedly individuals present who have developmental disabilities. These may be individuals involved in a service supported by staff or simply there on their own to enjoy the event.

The Deaf community is world wide and has a rich history, culture and shared values. Deafness as a disability disappears when Deaf people are together. A cultural view of Deafness where a person is seen as whole and complete and not simply a broken hearing person who must be signed at occasionally is what we aspire to with Deaf individuals with a developmental disability.

True belonging and involvement in the community is possible with the elimination of the language barrier.

Recommendation 5

Developmental services agencies recognize the value of the Deaf community and take steps to involve and include deaf individuals with developmental disabilities within their service in the local Deaf community.

Recommendation 6

A Resource Centre for the Deaf take the lead in reaching out to the Deaf community to increase the opportunities for inclusion. This would involve education and awareness with Deaf services providers, Deaf clubs, schools for the Deaf, local boards of education, Deaf churches, etc.

Recommendation 7

A Resource Centre for the Deaf take the lead in reaching out to hearing agencies to provide support, training and accommodation supports for Deaf individuals in their care.

Sign Training for Families

Many motivated families will take sign language classes through local agencies or boards of education; however, these follow a particular curriculum and are often not focused on language parents would use with children.

Easily accessible one-on-one family sign language classes should be made available to all families who are diagnosed with a Deaf child. This should be done in conjunction with other strategies that are being undertaken. This type of support will greatly lead to early intervention and identification of Deaf children with a developmental disability.

Recommendation 8

The Ministry of Community & Social Services and the Ministry of Children & Youth and The Ministry of Education – Provincial Schools Branch work together to ensure all families of Deaf children have access to suitable sign language training and support from early years staff around child development and language.

Sign Language Services and Deaf Interpreters

Deaf individuals cannot access community services without the support of an interpreter.

Despite progress in recent years accessing interpreters is time consuming, costly and frustrating. Often many weeks notice is needed to book an interpreter. Community services do not have interpreting costs included as part of their budgets and will normally not pay for them. Individuals with a developmental delay require support to navigate this system.

This lack of access to communication supports means that even the simplest of interactions in the community is difficult. Issues that are challenging for many with a developmental delay living in the community such as doctors appointments, getting subscriptions filled, going to the bank, traveling, etc. are that much more difficult when language is a barrier.

Deaf individuals with a developmental disability living in the community should have easier access to interpreters, communicators and community workers who are able to provide hands-on support.

Recommendation 9

Existing services for the Deaf establish a roster of communicators that can be accessed by individuals with developmental disabilities

to assist with community integration and that this become part of the mandate of existing funded interpreting services.

Importance of Language and Culture

Language needs to be recognized as a key component in supporting individuals who are Deaf and have a developmental disability.

Decisions should be made about language capacity and potential by individuals who are trained in language development and are either Deaf or fluent in sign language.

Recognition needs to be given to the fact that Deaf individuals cannot hear. If an individual is Deaf and has limited signed communication that circumstance needs to be seen as beneficial and not as justification to arrange placements where there will be even less access to sign language. Having full immersion in a visual language environment and having only a few signs is preferable to having no access to oral language and having a few signs. A Deaf person will never learn to hear, however, they can learn to sign.

Using a Deaf cultural model for Deaf individuals with a developmental delay is preferable and more effective than using a pathological model. Given a choice Deaf individuals tend to socialize, live and even work around others who are Deaf. This cultural norm and personal preference needs to be recognized and advocated for on behalf of individuals who have limited ability to make their needs known.

Not all Deaf individuals with a developmental delay are or could be supported by agencies serving the Deaf. Many individuals who have left institutions or have not desired to leave their home communities are supported throughout the province with local agencies. There are currently no standards with regards to access to language, ASL training for staff, access to the Deaf community, and employment of Deaf staff.

Recommendation 10

Mainstream DS agencies partner with Deaf consumers, service providers and families to develop a set of best practices to support individuals residing in hearing programs which include involvement with Deaf culture and community and exposure to sign language as part of each individual planning process.

Recommendation 11

A Resource Centre for the Deaf will recruit and provide training for Deaf students and adults who wish to provide in-home support and

respite to families is different areas around the province. Once trained, workers can link with local DS providers, Deaf services or be registered with the Resource Centre and be available to families in communities around Ontario. Workers would provide access to language and culture as well as providing parent relief and effective support to individuals.

Planning for People Leaving Institutions and Deaf individuals in Local Community Agencies

The Ministry's current policy of focusing on reintegration to home communities does not give enough emphasis for individual who are Deaf and the importance of providing services that are culturally and linguistically appropriate. No one policy can meet the needs of the many individuals living in provincial institutions, however, we believe that during this round of planning greater emphasis needs to be given to cultural and especially linguistic needs of Deaf, Deafened and hard-of-hearing residents.

Recommendation 12

MCSS engage a planner who is knowledgeable in Deafness and developmental disability that will be involved in the planning process for individuals leaving institutions who are Deaf.