Recommendations for Nursing Support Services (PHSA) in British Columbia

May 2019

(Report prepared by a collective of families that access Nursing Support Services)

Introduction

This report and the subsequent recommendations are a compilation of the deep concerns and huge challenges faced by families that access Nursing Support Services (NSS) through the Provincial Health Services Association (PHSA) in British Columbia. NSS provides assessment, planning and monitoring of care for children with very complex medical needs.

We are aware that there is a current focus on Children and Youth with Special Needs (CYSN) as the BC Ministry of Children and Families (MCFD) is doing research to better understand family experiences. The Select Standing Committee for Children and Youth are embarking on a special project in this area as well. Although this particular program is delivered through the Ministry of Health, there is a lot of overlap as our medical supplies, medical equipment and under some circumstances, direct nursing care hours come from MCFD.

Nursing Support Services was created in 1996, about seven years after the At Home Program was created. The program has eroded over the years and not kept up with medical advancements. Only in recent years, have children with medical interventions such as ventilators and tracheostomies, been able to leave the hospital to live at home. However the program has not changed significantly to reflect the increased need for supports that comes with caring for children with those life-sustaining interventions.

The population of children that access Nursing Support Services is small but highly vulnerable and susceptible to a wide variety of challenges with regards to their health and quality of life. Children who qualify for NSS are diverse in their needs and family situations, but they all share medical complexities that present enormous challenges and overwhelming needs. As families, we struggle to meet the needs of our medically fragile children while at the same time navigating the system of support and dealing with a significant number of ministries, programs and health professionals.

Because our families experience very unique and particularly difficult circumstances, we know that it is hard for people to understand our situations. We have come together to create this report and share our invaluable knowledge and experience. We hope that our suggestions for improvement will raise awareness and be considered in the process as decisions are made to change how services are delivered. We see the global shift towards family centred care models and desperately want to see our system of support move in this direction.

The children that access Nursing Support Services are extremely vulnerable and we want to ensure that we are not left out of this important process of evaluation that is happening. We thank you in advance for listening to our collective voices and considering our input.

Nursing Support Services – An Overview

One of the central services in this program is to provide contracted, in-home, direct nursing care when the knowledge, skill and judgement of a nurse is required to provide complex care such as home dialysis, tracheostomy, ventilator, end of life care and a multitude of other supports. Families who qualify for direct nursing supports will be approved for a certain number of hours per week dependant on the assessed needs of the child and family. In-home nursing is absolutely critical for many families because medical complexities can mean a child needs to be monitored 24/7 including while they sleep. They need to be monitored so closely that a nurse (or second parent) is needed to watch a child while they are riding as a passenger in a vehicle. This requirement can dramatically complicate traveling to school, medical appointments, therapies and opportunities for social connection.

Access to quality and dependable nursing services is absolutely crucial for the whole family's quality of life. It is the difference between medically fragile children being able to live in their homes and communities and attend school instead of living in a hospital. At home, this support is critical and allows parents to sleep at night, and leave the home for work or errands.

There are NSS Coordinators across the province that are assigned to families to help them navigate this service as well as connecting families to other community based care and resources. The NSS Coordinators collaborate with families and other community service providers such as social workers, physiotherapists and teachers to facilitate provision of appropriate services and supports.

Understanding Our Families

Children who qualify for Nursing Support Services are diverse in their needs and family situations but they all share common challenges and experiences. Some of our children also have palliative conditions and are receiving end of life care. Regardless of the reason for needing nursing support, there is an immense amount of emotional stress for our families as we navigate a world that we never expected to find ourselves in. We work hard to maintain balance for the rest of the family relationships as we navigate challenging life circumstances with our fragile children.

Financial stress and hardship is a reality for many of us. We have become nurses ourselves and spend countless hours taking care of our children’s daily medical needs. Even with direct nursing support, many of us need to stay at home to care for our children because the support offered is unreliable and inadequate. We are often only allotted enough hours to cover basic needs such as watching our child while we sleep and a few daytime hours to run errands. One of our main challenges is actually getting those allotted hours covered from week to week. When nurses call in sick, the agencies do not have a contingency plan to provide a replacement nurse. This has a tremendous impact on families being able to maintain any sort of routine including employment.

Our families strive to provide a healthy home environment for the whole family. This includes the enormous weight of protecting immune compromised children from contracting any viral or bacterial illness. We try to avoid unnecessary hospital visits, as the hospital can be a very dangerous environment for an immune compromised child. Having properly trained nurses as well as adequate medical supplies and back up biomedical equipment readily available is critical for reducing hospital visits. Currently, if a child's gastrostomy tube is displaced while in the care of a nurse, the child will need to be admitted to a nearby hospital or BC Children's Hospital for placement because nurses are not trained to do this. We would like to see the health system be more responsive to the needs of our immune compromised children. Providing nurses with training for gastrostomy tube placement is just one of several missing links in providing adequate care for our medically fragile children.

Like all parents, we love our children and want to provide the very best quality of life we can for our families. Because of circumstances, this can be extremely challenging. On top of the obvious challenges of having a medically complex child, we also expend enormous amounts of energy navigating the health, social services, and education system. We desperately need the system to be more responsive to our needs so that we can be healthy, both physically and emotionally for our kids and maintain the capacity to care for them at home.

The Current Situation

A great number of our families are struggling to keep their heads above water. Our best efforts are made to navigate the system but it can be so extremely challenging. We are frequently left feeling physically and emotionally exhausted as we navigate the system and attempt to secure the supports and services we need.

Assessment and Eligibility

The need for a family to enter the Nursing Support Services program is very often preceded by a hospital stay or procedure. It is important that the health system identifies this need for nursing in a timely manner and ensures that adequate supports are in place before a child is discharged from the hospital. The responsibility for identification, assessment and planning needs to be shared by the child's medical team, the BC Children's Hospital social worker and Nursing Support Services. Too often this need goes unnoticed and if a family is overwhelmed they may not know how to access these services. Nursing support must be in place before leaving the hospital in order to provide a safe environment for the child and ensure adequate and appropriate supports are available for the family. Timely eligibility assessments are essential to ensure that families are not waiting unnecessarily in the hospital while these supports are organized.

Once this need is initially identified the family should be connected with an NSS Coordinator in their local area. The role of the NSS Coordinator is to assess whether there is a need for direct nursing supports, dependant on the medical complexities of the child. If it is determined that direct nursing supports are appropriate then the assessor will determine the number of hours per week the family is eligible for and will also distinguish between night nursing and other nursing needs. This assessment will then go to PHSA and a decision will be made on how many hours will actually be approved. This decision was previously decided by a panel but is now decided by one person at PHSA.

We feel it is important to note that the current system of assessment and determination of eligibility is inadequate and often leaves children and families without the support they need because they didn't "tick" the right boxes. Individual assessments that take into consideration the needs of the whole child and family situation would provide the best information to make an appropriate determination. We also feel that the return to a panel of professionals would be prudent.

Barriers to service exist when a child needs more than the maximum hours provided by NSS. For school age children this is 91 hours per week (13 hours per day) and previous to being school age the maximum is 66 hours (9 hours per day). This is a frequent problem as these maximums are inadequate in many situations when you consider the need for night nursing. Beyond that threshold, families need to look to MCFD for additional hours however this is not widely shared or known. Families find themselves exhausted by the process of navigating across ministries to secure this vital funding and are frustrated when even their MCFD social workers don't always know how to access this funding or easily navigate the system on their behalf. Unfortunately, we are aware of multiple situations where a social worker has suggested placing a child in care before exploring the possibility of the family accessing NSS. We urgently need seamless solutions that are transparent and easy to access for families.

Hiring and Training

Once the assessment and eligibility variables are determined, a local nursing company will be given the contract by NSS and create a job posting for this specific family. It can take months for the agency to hire an appropriate nurse and then there is often a subsequent need for the nurse to acquire some specific medical skills through training in order to meet the child's needs. These can include tracheostomy and ventilator training in order to be capable of managing these lifesaving interventions. These trainings are offered through PHSA at Sunny Hill Health Centre for Children but usually only about once a month. Sometimes nurses from rural areas are unable or unwilling to commit to spending a day or two in Vancouver for the training. Often families are left waiting for more than six weeks before nursing supports are in place. This is inadequate and leaves gaps in the critical care of our children. We would like to see the system of hiring and training become more reflective of the urgency of the needs they are meeting.

Currently there is no training program in place for nurses to replace gastrostomy tubes. A large percentage of our children do have gastrostomy tubes and this is a simple enough procedure that families are trained in this practice. Introducing this training would help ensure that medically fragile children do not need to visit the hospital unnecessarily.

There are many other specific specialized paediatric procedures that we need nurses to be trained for in order to support our families adequately. Collaboration with the nursing colleges to identify and erase these gaps in the training of nurses would be a step forward and better support families.

Agency Accountability

One of the biggest challenges for NSS families is securing nursing support that is dependable. Current estimates from families suggest that anywhere from 25-75% of their scheduled shifts are cancelled and the shifts are not filled with a back up nurse. We find this completely unacceptable and can suggest multiple solutions for this problem. Families need dependable direct nursing support in order to maintain any sense of health for themselves and for the safety of their children. The lack of dependability also drastically affects a parent's ability to be employed. Agencies need to be made accountable for delivering this service to families. A potential solution would be for the contracting ministries to mandate that 95% of shifts will be covered. This would ensure that the agency had a system in place to provide back up nurses.

Another accountability measure needs to be put in place to deal with complaints from families. There have been multiple reports of unprofessional nurse conduct (eg. falling asleep on shift) followed up by inappropriate responses from the agencies such as simply reassigning the nurse to another family. We need to know that there are systems and procedures in place to ensure that complaints and concerns are investigated in a timely and appropriate manner.

Direct Funding

A number of families receive direct funding from MCFD and hire their own nursing staff. It is empowering for families to hire, train and retain their own nurses. Although it is a lot of extra administration work for families, many of them report that it is worthwhile to ensure they have a dependable and reliable nursing team.

Direct funding is not an option through NSS but we would like to see this as an option for families. This would help to bridge the gaps in regions where agency options are limited or an agency is proving to be challenging to work with. Robust direct funding agreements for families would mean that we are able to offer competitive wages and benefits to attract nurses to our in-home nursing team.

NSS Coordinators and the Lower Mainland Pilot Project

PHSA is currently trialling a pilot project in the Lower Mainland that sees the elimination of regional NSS Coordinators being involved directly with families. Services for these families, including coordination of their direct nursing supports, are now centralized at Sunny Hill Health Centre in Vancouver.

Two Nurse Clinician/ Case Managers at Sunny Hill have a combined caseload of about 150 families. Most of these families are reporting serious difficulties and a lack of support with this new model of service even on a basic level. There are delays in the Nurse Clinician/ Case Managers' ability to respond to emails and phone calls from families, likely due to their high caseloads. This is resulting in delays of delivery of critical medical supplies, equipment and services. NSS Coordinators are able to request and provide medical justification for new medical supplies and biomedical equipment as needed for each child through the At Home Program (MCFD). This has been one of the supports the regional coordinators have provided for years. What should be a simple process is now becoming a lengthy and burdensome one as families wait to connect with one of the two Case Managers at Sunny Hill. Alternatively, families in the pilot project region are now taking matters into their own hands by making appointments with their family doctor for the sole purpose of acquiring these medical supply requests. Doctors have not routinely dealt with these requests and so there are further delays as they work through learning the system and process for justifications. It seems like an inappropriate use of our doctors' time and also creates a new set of challenges for families who cannot easily get themselves and their children to appointments.

The pilot project has also demonstrated the impact and significant loss of team collaboration, previously facilitated by the NSS Coordinators, with families and other community service providers such as social workers and physiotherapists to ensure provision of appropriate services and supports. Families in the Lower Mainland have also lost the valuable connection their NSS Coordinators provided to other community based care and resources including the regional hospitals and schools.

There are other significant downsides of centralizing this service. There is a loss of the knowledge, skill and judgement that the NSS Coordinators routinely bring to families. NSS Coordinators are in a unique role with a very specific set of experiences provided by years of working with medically complex children and their families. The benefit that this provides for families and the system as a whole cannot be underestimated. They have intimate knowledge and experience with the critical care of complex children and routinely make life sustaining, health care suggestions and recommendations to families.

The pilot project has been in place for approximately one year now. We question whether our families will be a part of the evaluation process. Some doctor's have had an opportunity to provide feedback regarding this pilot project despite the fact that, unlike our families, they are on the periphery and not deeply affected by the changes.

We are deeply concerned that we will see this new centralized model continue in the Lower Mainland and eventually be implemented in other areas of the province. This would be a devastating mistake with potentially serious consequences for vulnerable families. In contrast, we would like to see a return of the regional NSS Coordinators in the Lower Mainland with the family centred care model and array of services they provide.

We support the recommendations made in the recent Representative for Children and Youth report “Alone and Afraid” with regards to the need for cross ministry case coordinators. NSS Coordinators have been providing a model of this for years and we would like to see an expansion and enhancement of this role, not an elimination process. Consistently being connected with the families on their caseloads puts them in a position to be responsive to emergent needs and changes in a child’s health condition over time. They provide a safeguard for vulnerable families whose challenges go unseen by schools, social workers and doctors. Our NSS Coordinators are extremely vital for families with medically fragile children.

Communication

As mentioned, many of our children are on the At Home Program (MCFD) and require timely access through the program for medical supplies and biomedical equipment. Our NSS coordinators are able to put in requests to the AHP for new supplies and biomedical equipment for our children. It is so important that these requests are dealt with in a timely manner but we also need a system of communication that keeps parents informed about the status of new requests and monthly orders, supply limits, out of stock items etc. As an example, if a child’s formula is out of stock or recalled, the family needs this communicated to them immediately so they can plan accordingly. Another example is that a new product requested may be part of a critical medical intervention and parents need to know when the product is approved and ready to be ordered and supplied.

A family centered system of communication would empower families, validate their role as part of the medical team and relieve the anxiety associated with not having this critical information communicated to them in a timely manner.

Parent Representation

We feel that there is a strong need for a system of parent representation that would allow for communication between families and PHSA regarding the delivery of this program.

Some families have taken their concerns about NSS to PHSA's Patient Care Quality Office. Unfortunately, this has not resulted in any meaningful moves towards change or improvements, and the families have been left feeling unheard and disempowered.

Knowledge of family experience is essential for ensuring that resources and systems are meeting the needs of the families that rely on them. We recommend creating a Parent Engagement Group with province wide representation that meets regularly with PHSA to share information, ideas, knowledge, successes and challenges with the program.

Conclusion

Our families face immense challenges as we navigate multiple ministries and programs in an effort to secure the resources that our complex children need to be able to continue living in their homes and communities and to receive the care they require.

We hope that by sharing our experiences we can help shed some light on the critical nature of this program and the gaps that exist for us as the families on the receiving end of the program.

We are deeply concerned that these gaps are putting children and families in a state of imminent risk. Major risk factors from lack of support include (but are not limited to) sleep deprivation, PTSD from dealing with critical health situations, and complete isolation from social life for both parents and children. We are concerned about the resulting mental health challenges and also the possibility of a tragic incident or accident occurring. These risks are very real for all of our families and even more so for our most vulnerable families.

As we have shared throughout this report, there are multiple barriers to accessing adequate and appropriate supports and this is leaving families at their emotional, physical and financial capacities. This is undermining our ability to care for our children at home and has pushed some of our families to feel like they have no other option than to place their children in care. The Representative for Children and Youth has estimated that it can cost up to $80,000 per month to support a medically complex child in care. More importantly, there is the extraordinary emotional cost to families when they find themselves unsupported and making this excruciating decision.

Thank you for allowing us to be heard. We are small in numbers and feel virtually invisible as a demographic of the social health system. We are often isolated in our communities but have managed to connect as a group through social media. It has taken a ground swell of energy and collaboration to create this document of our shared experiences.

Please note that this is our best collective summary of the most pressing concerns we have but it does not necessarily cover all of the challenges we face with the program. Most of our children also receive funding through the At Home Program and we support the recommendations made in their recent report.

We strongly believe that it is possible to improve the current system of nursing support and bring dependability and efficiency to the quality of services available through this program. Implementing a family centred care model at the heart of the program would ensure that NSS was meeting the needs of the families it serves.

RECOMMENDATIONS

1. **Ensure all families have nursing supports in place when they need them.** Create a system for eligibility and assessments that is efficient, responsive and ensure supports are in place prior to discharge.

2. **Review the funding model for the maximum number of nursing hours that NSS will provide.** The program needs to be updated to reflect the changing and higher complexity of care needs that children are being discharged home with. Also provide a transparent, simplified process for navigating the cross ministry aspect of the program when different ministries will be topping up hours.

3. **Improve agency accountability.** Ensure they provide an efficient and thorough system for hiring nurses so that families have the timely access to this service they desperately need. Set strict mandates for agencies with regards to fulfilling contracted nursing hours for families.

4. **Improve paediatric specialized training for nurses.** Work across ministries and with the nursing colleges to ensure appropriate and timely training options are available to fill the urgent needs of families.

5. **Provide the option of direct funding.** This will help to empower families and fill gaps in services.

6. **Discontinue the Pilot Project.** Halt the elimination and centralization of NSS and instead work to expand and enhance this valuable program.

7. **Improve communication with families.** We need better systems of communication that bridge the gaps across ministries, medical teams, our BCCH and CYSN social workers, At Home Program Medical Benefits and the provincial Product Distribution Center.

8. **Create a Parent Engagement Group.** This will give a voice to families and open a collaborative discussion with all stakeholders and service providers.