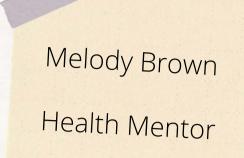
## Better Together

Group 43

Communication: patientcentered, collaborative, intentional, and relational



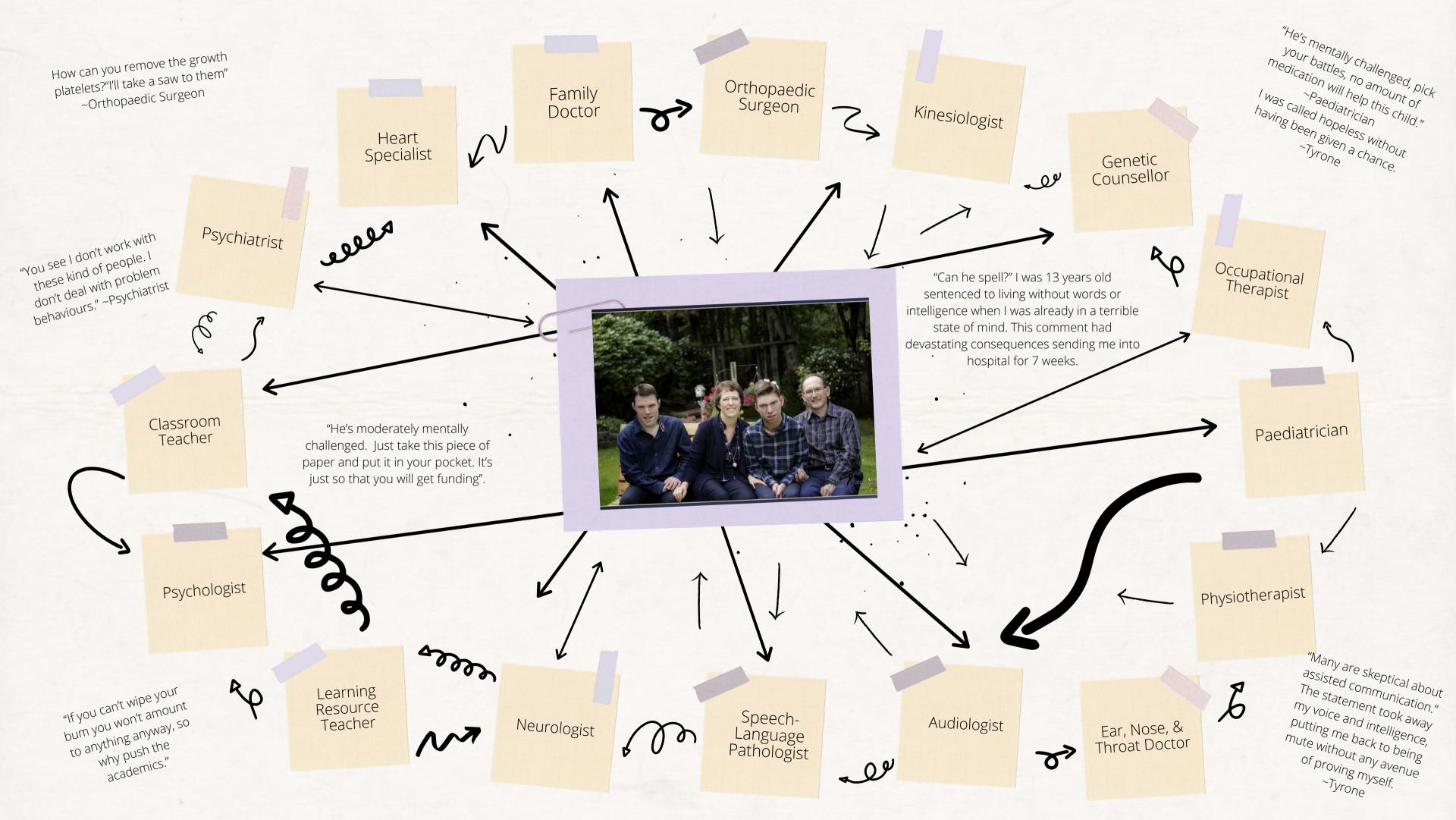
Julia Vander Heiden : Medicine . . . . .

> Manraj Randhawa

Genetics Counselling Cheyenne Ghag Occupational Therapy

> Nicole Schmidt

Speech-Language Pathology



The phone call from my family doctor to tell us that the ultrasound showed our baby would be born with clubfeet

Sitting in the paediatrician's office and him asking me "Do you think your baby is funny looking?"

Going weekly to the
Royal Columbian
Hospital to have
Tyrone's feet recasted
for 8 months and the
comment so often from
the doctor "Why is this
child not growing?"

My family doctor
handing me a tissue
as I cried in his office
when he told me that
the ultra-sound
showed our second
child also would be
born with clubfeet

Tyrone being called to the front at his Grade 12 graduation to give the Valedictorian speech

I remember

The impact on family

The many times of going into the operating room and holding my child/boys as they went out under anesthetic

Being devastated when the orthopedic doctor said as fact that the boys had a syndrome, which genetics were looking into and in fact was not the case at all

The visit with the boys' psychiatrist, and for the first time having a doctor address Tyrone and Lyndon as intelligent individuals

The phone call from the teacher to tell us that both boys had won a prize for their essays entered in the Royal Commonwealth Essay Competition

Sitting in the child psychiatry unit for at BC Children's Hospital for 7 weeks while they tried medications to help Tyrone's difficult behaviours

The paediatrician telling me "He's mentally challenged. Pick your battles; there is no medication that will help this child."

Being called into the school by Tyrone's assistant in grade 3 to be handed a letter to Santa, the very first writing of Tyrone's. I cried.

Taking the boys to assessments prior to kindergarten and being told "He is mentally challenged. Just take this paper and tuck it into your pocket. Really it's just for funding."

### About our family

At 19 weeks pregnant we received a call from our doctor "your baby has clubfeet", and so our journey began. Both Tyrone and Lyndon were born with severe clubfeet, both were small at birth and both had slow development. As time passed it also became apparent that they were motor impaired and non-verbal. The psych-ed assessment for both labelled them "moderately mentally challenged"; however Tyrone graduated as the valedictorian of his class at the Abbotsford Virtual School and Lyndon graduated with a 98% average. Consequently, there were many misunderstandings along our journey, and a lack of understanding of Tyrone and Lyndon's communication issues caused untold anxiety and frustration. It is because of this, that our goal as a family is to share our story and experiences in the hope of advocating for those without a voice and to give up and coming healthcare professionals a knowledge of the difficulties faced by those who are nonverbal.



# Lives More Than Can Be Understood By Tyrone Brown

The blinds are closed. No one is home. Who makes a peep? That gives the clue. What lives inside that empty house? That seems so abandoned and alone? Behind those covered window shades Lives more than can be understood.

The covered awning shades the porch
With accents of colour the flowers close in
The path to the door is hardly worn
Who visits a house where no one is home?
Behind the door can be so lonely
When lives more than can be understood.

With paint that is faded with passing of time
The building still stands; the foundation is firm.
Gutters don't leak when storms pour down rain
Heat of the sun warms the house within
Life on the inside has shut out the storms
Inside lives more than can be understood.

There lives behind that covered house
Beneath the weathered roof, still good
What others think, an empty shell
Aging with time but still growing strong
The one who's still silent, wishing each day
The house to be opened; to be understood.

# The Seed By Lyndon Brown

The seed was planted in the garden of time Planted as a child being read nursery rhymes There it lay buried, covered and still No gardener coming to hoe and to till Dormant and silent the seed in the ground Yet there was life waiting just to be found Gathering weeds kept growing on top Wasting good land that should have been crop Then one day the plough removed all the weeds Giving hope to the silent, buried, young seed The gardener began watering the ground where it lay The earth was warmed with the sun's bright ray Out of the earth the silent seed grew As a beautiful flower with all that it knew It blossomed with flowers others never had seen The plant growing strong that dormant had been The gard'ner had taught so much to this flower It bloomed with life and belief gave it power

**Lyndon Brown** 

#### **Having a Voice**

Voicing ones opinion opens up forum for dialogue. Hearing the psychiatrist call me "these kind of people" and call my actions "problem behaviours" and then finding excuse not to provide me with professional help was discrimination. Having the affliction of not being able to speak is difficult when facing indiscriminate comments but it is imperative that one does not remain silent concerning the biased judgement. Personal advocacy is personal victory over hurt and humiliation. Writing a letter expressing my frustration and concern regarding his attitude and misunderstanding of my disability, has given me internal satisfaction that my voice has been heard and consideration for my case has been made. He wrote a letter of apology which made me realize he had listened to my comments and that reading my letter was no different than listening to me speak. Though one may look different or may seem disabled according to social standards, does not mean he should remain silent when faced with unfair treatment or social discrimination. Having power over discrimination comes by action with speaking out against it and beginning dialogue so that there is understanding of our feelings as ones who find life a challenge and often lonely. This power will have a positive impact on one's life and on the lives of others.

### **Tyrone Brown**

Perhaps my journey may have been, and continues to be, a path running alongside of the general population, but it is not without purpose. Finding advocacy as worthwhile, as an avenue to helping others who struggle with continual social understanding in our communities, my desire is to champion the cause with using my abilities to demonstrate the potential found in each one. Present in who you are is the God-given gift, which is yours to share in whatever sphere you find yourself in. My utmost hope is having opportunity to dispel the idea, reflected in my difficult journey, that being non-verbal assimilates me as one having no intelligent thought. There is really another person inside me who people fail to recognize, and redeeming my self-worth beckons me on to work, advocating for myself and others like me. There is more cause in advocacy than just my situation, without doubt, and I sincerely hope collectively we can make a difference in our society for all who live with disabilities.

### **Tyrone Brown**