# BC Summit on Navigation for Children and Youth with Neurodevelopmental Differences, Disabilities, and Special Needs

#### PRESENTED BY:

Sunny Hill Health Centre at BC Children's Hospital and the BC Navigation Project's Provincial Advisory Group

January 18-19, 2021





## WELCOME & PROJECT OVERVIEW

On behalf of the BC Navigation Project 's Provincial Advisory Group, I warmly welcome everyone to our BC Summit on Navigation for Children and Youth with Neurodevelopmental Differences, Disabilities, and Special Needs.

The Project arose from a funding opportunity provided by Kids Brain Health Network aimed at improving the experience of families who have to navigate service and support systems for their child with neurodevelopmental special needs, and for their family. Our work has brought important voices in BC together to explore how we can ensure this kind of 'navigational' work is recognized as essential and well understood in BC and beyond, and to think about possibilities for the future.

This Summit, which you have generously taken the time to attend, is the long-planned embodiment of a vision of coming together now for a better future. We will hear and learn from families, researchers, service providers and decision-makers from various sectors. But beyond that, we want to hear from and learn from you. We want everyone to help the Project's Provincial Advisory Group shape a vision of how navigational supports for families might look and unfold in the coming years. In that sense, this Summit is just the beginning.

Thank you for joining this important effort, for your active participation, and for creating momentum going forward.

See you in one of the breakout chat rooms!

Anton Miller MD

Developmental Pediatrician, Sunny Hill Health Centre for Children Clinical Faculty, UBC Department of Pediatrics Clinician-Scientist, BC Children's Hospital Research Institute.

#### SCHEDULE OF EVENTS

# **MONDAY, JANUARY 18, 2021**

830 am - Zoom 'Doors' Open

900 am - Welcome and Opening Remarks
Anton Miller
Amanda Fenton (Event Facilitator)

#### 945 am - Learning from Families

Featured speakers: Ashley Seltenrich, Brenda Lenahan,

and Si Stainton

Moderator: Joshua Myers

1030 am - Well-being Break

#### 1045 am - Zoom Breakout Rooms

Explore what we're learning from our navigation practice and stories that can contribute to creating strategies for building a community of navigation in BC

1205 pm - Stretch Break

### 1215 pm - Learning from the Research

Featured speaker: Dr. Emily Gardiner Small group discussions to reflect together on the navigation research provided as a pre-Summit preparation video

1250 pm - Closing Day 1

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#### SCHEDULE OF EVENTS

# **TUESDAY, JANUARY 19, 2021**

830 am - Zoom 'Doors' Open

900 am - **Welcome to Day 2** Angela Clancy

925 am - Learning from Providers

Featured speakers:

Carly Owens, Autism Information Services BC (AIS BC) Angela Clancy, Family Support Institute of BC (FSI) Kimberlee Howland, Nanaimo Child Development Centre

955 am - Creating Strategies Together for Building a Community of Navigation and Related Services and Supports in BC Self-organized conversations

1150 am - Well-being Break

1205 pm - Cross-Pollinating + Illuminating Actions
Cross-pollinating the themes, patterns, and actionable insights
from the self-organized conversations.

1240 pm - **Next Steps and Closing Day 2**Jason Gordon

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## FEATURED FAMILY SPEAKERS

#### **Ashley Seltenrich**

Dawson Creek, BC

Ashley Seltenrich is an Indigenous woman living with her 4-year old son with ASD and family in a small community in the South Peace Region in Northern BC. She believes community inclusion helps benefit her son for awareness and acceptance. Being in a small community has required her and her family to do heaps of research on resources to navigate for support and services. Living in the north is a struggle with limited resources, but she is thankful for the ones they have found for her son's early intervention therapy.

#### Brenda Lenahan

Cumberland, BC

Brenda is a solo mom to 6-year old Cole who has a rare genetic condition that closely mimics cerebral palsy and affects him neurodevelopmentally. Cole thrives when he is included in his community and the community has embraced him. Together they have navigated rural and urban service delivery models for early intervention, interprovincial health systems, and now they are exploring BC's different education options as Cole is engaged in home learning through a Distributed Learning school. Cole has taught her the importance of advocacy, the beauty in diversity and the value of inclusion.

#### Si Stainton

Delta, BC

Si Stainton is a single Mum of three wonderful adult children. Her son, who is now 20, has a developmental disability. She immigrated to Canada when her son was one, so has a lot of experience navigating several ministries and is grateful for the help and advice she received on her way, particularly from the Family Support Institute. As a family they love to hike, eat out, play board games and watch movies. Si now works part time for the Delta Community Living Society as a Family Services Manger providing information and advice to families with a relative with a developmental disability in Surrey and Delta.

## **ACKNOWLEDGEMENTS**

The Summit would not have been possible without the time, efforts, and dedication of all those listed below. We would also like to thank all the families who have generously shared their experiences and stories with us.

With gratitude to our Provincial Advisory Group:

Angela Clancy (FSI)

Bobbi Taylor (Family representative; FSI)

Dulcie Mercado (AIS BC)

Emily Gardiner (BCCH Research Institute)

Jackie Watts (ASCD BC)

Jack Styan (CLBC)

Jason Gordon (BCACDI)

Joshua Myers (BC Centre for Ability)

Kasia Duggan (STADD)

Mandy Young (Family representative; FSI)

Shara Grice (Inclusion Supports and Services Policy Team, MCFD)

Sylvie Zebrov (CLBC)

Tracey Block (The Asante Centre)

We would like to acknowledge those who have contributed to the Project in the past:

Allison Pooley-Wong (The Asante Centre)

Anne Fuller (MCFD)

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Diana Elliott (AIDP BC)

Glenys Webster (MCFD)

Jaclyn Bates (STADD)

Karen Bopp (AIS BC)

Kiera Bailey (MCFD)

Lisa Woudzia (AIS BC)

Michelle Schmidt (Surrey School District)

Nadine Gagne-L'Hirondelle (Métis Nation BC)

Natalie Hagarty (AIS BC)

Shirley Meaning (MCFD)

Tamara Kulusic (MCFD)

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Sunny Hill Health Centre at BC Children's Hospital

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