

Supporting Families through an Autism Assessment: After a Diagnosis of Autism – *What's Next?*

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AIM

To provide *early supports* to families after their child receives an ASD Diagnosis; *coaching* families in “next steps” using a format that is specific, timely, and sensitive to their needs.

CONTEXT

- More than 2000 children/youth receive an ASD assessments each year through the BC Autism Assessment Network (BCAAN).
- 70% receive a diagnosis of ASD.
- At Sunny Hill, families who's child receives an ASD diagnosis are provided with a “next steps” information package identifying what to do post assessment.

“What resources are available... how do we find them... who's good and reliable?”

PROBLEM – the “Why”

In 2016, feedback from a sample of 64 families was gathered 1 year after an ASD diagnosis. Parents indicated:

53% felt overwhelmed after receiving the diagnosis

65% found “next steps” package helpful

59% were unsure about aspects of organizing therapies for their child

“...so many things to process & steps to learn...”

... meet with a Social worker... figure out the funding... decide what therapies... hire and manage therapists... determine a home treatment plan... team meetings with the school...”

CHANGES MADE TO SUPPORT FAMILIES

Revised the “next steps” package

Parent input on the package helped reduce information overload & duplication of information related to other Autism services.

Provided in-service education for BCAAN Case Managers

Case Managers provide support to families after the assessment regarding funding processes and accessing appropriate community resources for their child.

Initiated a follow-up process

A Case Manager would make contact with all families post assessment to provide navigation support to ensure families are connected with resources in the community to support their child.

Repeat of survey

In 2019 we connected with 64 families to measure parents perceptions & need for further changes to our process to support families post assessment(s).

OUTCOMES: 2019 SURVEY

Parents reported they felt supported by:

Revised “next steps” package

97% of families contacted the appropriate Social Worker & Autism funding unit to access funding

Sunny Hill follow-up process

76% of families took advantage of the navigation support provided by Sunny Hill to assist them making connections to funding, community resources & strategies to help their child.

Community Collaboration

70% of parents were comfortable connecting with a community provider for advice and connecting with intervention services.

Parents continued to report feelings of being overwhelmed after receiving a diagnosis of ASD for their child but more indicated they felt supported.

WHAT WE LEARNED

- Families vary in needs, readiness and ability to process information & access supports/ therapies.
- Families want clear and simple step by step instructions regarding next steps.
- Families seek & appreciate collaboration across community partners regarding questions & strategies.
- Families need sustainable support through networking & collaboration to help connect the “puzzle pieces” of a complex health care system.

“Who is my go-to person?”

NEXT STEPS

Sunny Hill will continue to *partner* with Autism support agencies to facilitate their follow up with families – to help them navigate the Autism services community.

With increased resources, these Autism agencies have indicated they would like to provide support to families across the province.

Sunny Hill will continue to follow up with families who do not receive an ASD diagnosis and provide information about resources to support their children.