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

Tracy Conley, MHA, Cathy Parent, RN, MEd., Sunny Hill Health Centre for Children, Vancouver, BC, Canada

**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...”

**OUTCOMES: 2019 SURVEY**
Parents reported they felt supported by:

<table>
<thead>
<tr>
<th>change</th>
<th>percentage</th>
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<tbody>
<tr>
<td>Revised “next steps” package</td>
<td>97%</td>
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<tr>
<td>Sunny Hill follow-up process</td>
<td>76%</td>
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<tr>
<td>Community Collaboration</td>
<td>70%</td>
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**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).

**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.