

Our Journey Forward: Mapping TBFN's Path to Supporting Family Voices

An Exploration in Planning with The Thunder Bay Family Network

With Families, People with Disabilities, Professional Allies and the TBFN Board



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Realizations Training & Resources

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Table of Contents

Introduction	Page One
Some Initial Thoughts From the Facilitator	Page Four
Board Thoughts on TBFN Legacy	Page Five
Connections/Relationships	Page Six
Summary of Suggestions on Connections/ Relationships	Page Twelve
Communication	Page Fourteen
Summary of Suggestions on TBFN and Communication	Page Seventeen
Information/Learning	Page Nineteen
Summary of Suggestions: Information/Learning with TBFN	Page Twenty-Two
Advocacy	Page Twenty-Three
Summary of Suggestions on Advocacy Through TBFN	Page Twenty-Five
Sustainability	Page Twenty-Six
Summary of Suggestions on Sustainability	Page Thirty
Gifts of the Network	Page Thirty-Two
Facilitator Suggestion Gifts/Talents	Page Thirty-Four
Challenges for TBFN	Page Thirty-Four
Facilitator Suggestion on Challenges	Page Thirty-Seven
ICAN	Page Thirty-Seven
Facilitator Suggestions on ICAN	Page Thirty-Nine
Conclusion	Page Forty
Appendix: Summary of All Suggestions	Page Forty-One

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Findings from Conversations with Families, People with Disabilities, Professional Allies, and TBFN Board Members

Introduction

For the latter part of 2021 and the first part of 2022 I have been involved with the Thunder Bay Family Network in an exploration of the experiences and suggestions of people who use their supports....Family members and people who have a disability...and professional allies to learn what will be needed to take the next steps along this journey.

The overall aims of the Network have been articulated through the following image:

The Three Pillars

Family Empowerment

Community Engagement

Professional Capacity

These are interconnected, as are the approaches chosen by TBFN to accomplish the above Goals ... developing and offering opportunities for Connections and Relationships, Information and Opportunities for Learning and Increased Awareness, Strategies, Tools and Resources to Support for Advocacy, and being part of a Mutual Community...a Network.

In the spirit of openness and learning the Board invited me to interview a number of people who are connected to TBFN through using the supports they offer or supporting their efforts, or both.

Over the course of this exploration I interviewed or had conversations with people in the following roles:

TBFN Board: We conducted three group interviews as well as individual conversations with most members.

Ad Hoc Planning Working Group: We had several conversations as well as additional communication through various social media platforms.

I also attended part of the 2021 virtual AGM to speak about the Planning Process and to introduce myself to other TBFN members.

Staff: I had various Zoom and email conversations with two part-time staff regarding various aspects of this planning process. Unfortunately no staff were available to be interviewed for their perspectives.

Families: I did in-depth interviews **with seven** individual Family Members, one Family Group of four members, and asked Family related questions of several Board members in our one to one conversations. The parents I spoke to individually has children who were adults, several just recently transitioning from late teens, and the Family Group are younger parents. One of the individual interviews was with a member of another Family Network. Two Family Members were also former Board Members.

ICAN Participants

I attended two virtual ICAN meetings ...one to talk to people about interviewing them and the other to do a group interview.

At the second ICAN conversation I interviewed 5 participants and one volunteer. Most were long time members of ICAN, attending between seven and ten years, while two others had been coming respectively, for four and five years.

Professionals

The Professionals I spoke with were primarily ones associated with the Partnership agreement held with TBFN. I interviewed seven people in this role, and one consultant who had done some work with the Board. Two Families interviewed also work in the disability field.

Referral and Interview Process

Two approaches were used to put me in touch with people to speak with. One was a letter that went out to people who have had a connection to TBFN. They were invited to contact a Network staff member, who then passed on their information to me. The second was through direct referrals from Board members who reached out to some people and then put me in touch with them. All interviews were virtual, either by phone or Zoom, and scheduled at the convenience of those participating.

Documents Read

TBFN Strategi Plan, 2016-2019 with Updates Nov., 2017 Aug. 2, 2018 Feb. 2020

Logic Model of the Three Pillars

Thunder Bay Family Network Partnership Agreement

ICAN Procedures Updated December, 2018

Community Development Coordinator Goals, August 2018

TBFN Website and Facebook Posts

Limitations of the Process

Covid didn't really present much of challenge in conducting interviews or collaborating with Board and Staff around this process. However, the findings were certainly influenced by the fact that for the past two years, like everyone else, TBFN could not operate as usual. Consequently, these circumstances need to be taken into consideration regarding everyone's experiences of the Network.

The number of Families interviewed was fewer than we had hoped for. Again, Covid is a factor, but as the Board was already aware, finding ways to increase Family involvement with TBFN is an important priority.

It is also unfortunate that no Staff members could be interviewed. My limited interactions with the two part-time people were always positive and helpful.

With only limited time, interviews with Professionals were primarily with those involved in the Partnership agreement with TBFN. Connecting with more organizations over time will be helpful in many ways.

Structure of the Report

The Three Pillars of the Network: ***Family Empowerment; Community Engagement; and Professional Capacity***, remain the primary Goals ...the Vision ...the "What". The responses to the conversations with Families, ICAN Participants, Professionals, and Board Members focus to a large extent on the "How's" ... the ways in which these Goals can be achieved through building Connections and Relationships, effective Communication, sharing Information and Learning Opportunities, supporting Advocacy, and exploring creative approaches to ICAN. And to help in these ways TBFN also needs to be aware of both the Challenges they face, utilize fully all of the Gifts/Strengths and Resources available to them and ensure that they are growing and preserving the Sustainability of the Network.

The Report is therefore structured around these topics and further broken down by people's roles as Family members, Professionals, Board, and under the ICAN section, Participants in that support. Following those responses I have also added some of my own suggestions at the end of each section.

A Summary of Suggestions is also included as an Appendix.

It has been a real pleasure working with this Board and getting to know some of the people connected to TBFN in various capacities. It is easy to see that the Network cares deeply about the experiences of Family members and their relatives and to continue finding ways to create a more inclusive community. I hope the responses and ideas people have shared here will be a support to TBFN as they continue to do this important work.

Some Initial Thoughts From the Facilitator

I will offer a few specific Suggestions under individual topics but I also wanted to share several more general ideas here, that I hope will be helpful to the TBFN Board as they continue this process.

There is much of value that can be borrowed from the process of person-centered/person-directed individual planning, when an organization or group is exploring how they move forward. Two thirds of that process of ***Describing, Dreaming, and Doing*** is gathering information, which initially has been my role in seeking feedback and ideas from people who are invested in your Network. I encourage you to take the time as you move forward on this journey to keep gathering more specific information, that will allow you to continue with more ease and certainty.

We have already incorporated several features of individual planning into this processidentifying Gifts/Talents and looking at Challenges. There are also other exercises that would be helpful, which can be done one at a time, to gather information that will assist you in identifying all of the potential resources within the Board and among the wider community as well.

One of the first things I learned from a mentor in this field, John O'Brien, who is known, I think, to a few of you, is to consider the roles of both Effectiveness and Efficiency in anything we want to accomplish. As John explained it, Effectiveness is doing the right thing and Efficiency is doing things right. By the right thing he didn't mean morally, though hopefully that is understood...he meant doing what makes sense, choosing well. Once that is decided on, we can then determine the best way to do it, but Effectiveness needs to come before Efficiency. His analogy was wanting to dig a hole and that a backhoe is a better tool than a teaspoon, but if we don't know where we want to dig, the backhoe will only get us where we don't want to go, faster.

So, I encourage you to take the time (especially since Summer is somewhat of a slowdown season anyway) to balance some immediate actions that seem really clear and manageable, with building on the information gathered here, to clarify some of the other directions you are considering. Perhaps one of the suggested exercises could be done each time you meet? They are enjoyable, not very time consuming, and result in a lot of practical information that can make a real difference.

I will list them here and then explain each briefly under the topic in this Report that it pertains to.

- A collective ***Community Map*** of other Families that you know/are aware of and who specifically has some connection to each
- A collective ***Community Map*** of Family Groups that you know/are aware of and who, specifically has a connection to each

- A collective **Community Map** of Organizations in the disability or related fields that you know/are aware of and who, specifically, has a connection to each
- A collective **Community Map** of ordinary Community Groups that might be helpful to Families and People with Disabilities, that you know/are aware of and who, specifically has a connection to each
- Honouring and Identifying each Board Member's **Gifts/and Talents**
- Using a simple **Brainstorming Process** to keep exploring possibilities

One of the Suggestions from the Board under Sustainability is to continue this planning as an ongoing function of the Network. As with personal planning I have found over the years that breaking things down to understand the components and taking action in manageable, clear "chunks" always increases success. And as you continue to reflect and act on steps along the way, you will go farther in this journey.

Moving Forward: Past...Present ... Future

As people look toward new ideas and directions it is also important to celebrate and value what they "hold dear". Throughout this Report people speak of what they value about TBFN ...what is important to honour, celebrate, and preserve as well as what may need refining and updating, and what new endeavours will enhance the foundation of what is already in place.

When asked about what Legacy they felt was important for the Network to uphold and continue, Board members said the following:

"We need to keep our legacy of being compassionate, resourceful, and showing how much we genuinely care. We are still there to help!"

"We need to ask some hard questions, but the Board is open and flexible and we work amazingly well together. We are different but we always have the Families at the forefront of our thoughts and efforts. We need to keep looking at what Families need."

"We've created a safe space to have conversations; we can grow and change but we always need to have that safe space!"

"We are in the process of shedding our old skin and looking for new ways to build on our roots. We want to keep a relaxed atmosphere but have more structure. This is about Families coming together!"

Connections/Relationships

In the spirit of these comments, and because at the heart of TBFN is the vision of and commitment to a Network, people's experiences and perceptions about the web of Connections and Relationships within it and around it, offered the most responses to the questions asked. Initiatives of the Network around sharing information, supporting advocacy, and other meaningful activities, are all closely entwined with and depend on the connections and relationships among people who wish to be there for one another. These days the first definitions of "Network" listed relate to computers, but down the list a bit is, "a group of inter-connected people" ... "inter" being, as we know, "between or among". TBFN cares deeply about Families and community, and taking the time to foster that interdependence will secure a strong foundation for sharing so much!

Families' Experiences & Impressions of Connections/Relationships with TBFN

Individual relationships have been an important means for Families to become involved with the Network... knowing a former staff member, a current or previous Board member, or another family or friend with a child or sibling who has a disability. Several found out about TBFN from a professional in the field with whom they were acquainted personally.

Connections with people already involved with TBFN have also taken place through Network events, as well as related ones such as an OIFN Forum, and through other Family Networks in the province. These one to one encounters was mentioned more frequently than meeting through events.

Regarding TBFN's community connections, the Partnership agreement was mentioned most frequently.

"They seem to be well connected with the Partnership model ...their community is behind them ... they get invited to do presentations. "

"Their relationships are unbiased, professional, and try to include all voices ...they are well connected and have formed some lasting partnerships."

Provincial connections such those with the Ontario Independent Facilitation Network (OIFN) and Partners for Planning (P4P) were also mentioned.

Professionals' Experiences & Impressions of Connections/Relationships with TBFN

People interviewed all felt that that TBFN has a good base of relationships in the community, outside of the district and in the province.

Board Question: “What do our Partners see as benefits to them?”

People interviewed are eager to continue in the Partnership model, both to help Families in general and also to assist in people with disabilities getting the support they need. Their relationships with the Network are thus seen as a benefit to them in fulfilling their purpose as organizations. One professional mentioned that they routinely redirect families to the Network. Another said that they value the ongoing communication and the ability to make use of the Network as a resource for families when needed, and appreciate referrals from the Network to their organization. Another person said that they inform families about the Network as part of their organization’s Intake process.

Several remarked that there seem to be very healthy, stable relationships within TBFN as well.

“They are in the game of relationship building”

Board Members’ Experiences & Impressions of Connections/Relationships

Internal: Board to Board

People became Board members for various reasons:

- Wanting to learn from Families
- To get more information about advocacy and support: ***“I need to be part of this!”***
- Connections and outreach from current and former Staff and Board members

Board members have a positive experience of their involvement:

- There is a positive, safe atmosphere
- Feelings of lots of accomplishments
- Members are consistent in attendance
- There is a cooperative culture of collaboration
- They experience a friendly, collegial environment
- There is flexibility and adaptability among members

“Everyone has a link...being a parent or working with people who have a disability or a desire to contribute...sometimes at Board meetings we chat about so many things.”

Internal: Board and Staff

Most Board members have been connected to Staff only virtually since Covid.

Not everyone on the Board has much contact with Staff; there was more connection Pre-Covid and Staff would sometimes come to a Board meeting.

Some Members have been part of hiring or other HR interactions.

Most of the interactions with Staff in the recent past have been with the Board President. She would like to have some reduction in these responsibilities, but she also appreciates other Board members as offering her good support, including help with interviews, and hopes to have other ways to explore meeting staff needs in the future.

“I feel like I have a back-up system”

External: Local

Below are some of the connections the Board mentioned that TBFN has in the Thunder Bay area. This is not a complete list, just some that were identified.

- The three organizations involved in the Partnership agreement: Community Living Thunder Bay, Lutheran Community Care, and Options Northwest
- Communities Together for Children
- March of Dimes
- Autism Ontario, local chapter
- The DSO
- OPSEU
- Participation in The Community Links event (virtual during Covid)

District

TBFN has made progress in connecting with more families in the larger Thunder Bay district over the past two years.

Provincial

There have been connections and collaborations with other Family Networks and Provincial organizations in Ontario, such as Ontario Independent Facilitation Network, Inclusion Press, and others, resulting in additional information, resources, and new contacts. Again, this is not a complete list.

Moving Forward on Connections/ Relationships

What Families Would Like

“When my child was diagnosed I didn’t want any contact with groups but after a few months I knew, ‘I need help!’”

A desire to meet and speak with like-minded Families was mentioned various times.

“It’s all about relationships!”

“It’s good that they (TBFN) are reaching out to people through this planning, who aren’t deeply involved with the Network at this time”

Board Question: Do Families feel part of the Network?

There is a feeling that there is not enough family involvement right now. Something to consider, based on this question from the Board as well as their question regarding people seeing the Network primarily as ICAN, is what really defines, or could define, the Network? Is there a formal or informal membership, etc., that could contribute to this? Involvement on a working, group, committee, etc? Additional conversation on this topic could be very productive.

One parent mentioned that she would like a Network that prioritizes networking and building connections. She feels, “only a little bit part of the Network” and hopes TBFN will find ways to include Families more. *“I do want to be part of the Network!”*

“I really want to meet other families and include a wider range of disability ... not just autism!”

Families’ Suggestions/Ideas To Increase Connections/Relationships with Families

A major suggestion was to connect the Goals of helping families become better acquainted and sharing information with them...when planning events to build in both opportunities for them.

“Families often don’t realize they need connections or information...they don’t know to ask for what they don’t know.”

“You only find out about certain things from other parents... i.e. special funding.”

An important question people had was, “Who is first contact when a family reaches out?

“Can it be a Board Member or a Family Network volunteer?”

People mentioned a need for more 1-1 opportunities for Families.

Several people said they would like to know more about what is happening in other Family Networks and have ways to be in touch with them.

People who have a family member with a disability other than autism would like more connection with others around that specific disability.

People would also like to be more connected to Families outside of Thunder Bay and to Families connected to various service organizations.

Professionals' Suggestions/Ideas To Increase Connections/Relationships

Most suggestions from the Partners pertained to other professional or community contacts but it was raised by several people that more family peer support is needed.

"Families are so frequently in silos and not connected to each other."

"Families want to know there are people they can talk to!"

Partners look forward to continued interaction with TBFN, especially now that Covid is hopefully less of a challenge. These connections could be in person, virtual, or a combination.

"One way to develop alliances is through education."

There were suggestions about contacting The Children's Centre, Thunder Bay, and Confederation College in general and disability related departments in particular to explore resources, opportunities to collaborate.

Bringing back Community Links in person is greatly desired.

Board Members' Suggestions/Ideas To Increase Connections/Relationships

With Families

"We need to cultivate more relationships and we want more direction from families."

"It's time to get back to family to family ... we need that 1-1 to be a hallmark of the Network."

"We need to devote time to Network membership right now!"

People feel it is worthwhile to continue engaging families virtually somewhat but that there also needs to be more in person get togethers. Connections can be fluid, ebbing and flowing from in-person to virtual, with possibilities of a hybrid once a month, as well as virtual and in person.

“People are Zoomed out...we need a real sense of community!”

Similar to suggestions from Families not on the Board, ideas included connecting more with Families of people supported by organizations and with other Family Networks and family groups.

It was suggested to have a once a month drop in for Families with coffee and cake, and to revisit the book club.

Somewhat like the suggestion by a family member to combine fostering connections with sharing information was the idea of combining a learning event with something that is fun, and that could include parents and kids through ICAN.

With Community Groups and Organizations

***“What tables, what groups, and connections are we part of
and which ones do we need to be on?”***

A number of groups and organizations were mentioned by the Board as being valuable to connect with initially or increase involvement. Again, not a complete list. But some that were mentioned include:

- City related groups, such as the Accessibility Committee for Thunder Bay, Adult Inclusion Services of Thunder Bay, Junior Inclusion Services of Thunder Bay
- Other Disability groups such as Cerebral Palsy, March of Dimes, more types of disability groups beyond Autism
- Education related organizations, School Boards, Community College, University, NW School of Medicine
- Expand the Partnership model to other organizations, foster some connections with more roles within the organizations
- Special Olympics
- Early On/Early Intervention Centres

Summary of Suggestions on Connections/ Relationships

Families' Suggestions

- Connect the Goals of helping Families become better acquainted and sharing information with them...when planning events combine both opportunities
- Have a first contact available when a family reaches out...a Board Member or a Family Network volunteer
- More 1-1 opportunities for Families to connect
- Connecting more with other Family Networks
- More connection with others around specific disabilities, beyond autism
- More connections to Families outside of Thunder Bay and to Families connected to various service organizations

Professionals' Suggestions

- Echoing Families' idea to combine events that both inform and intentionally build connections, developing alliances through education.
- Contacting organizations such as The Children's Centre Thunder Bay, and Confederation College ... in general and disability related departments in particular, to explore resources, opportunities to collaborate
- Collaborate to bring back Community Links in person

Board Ideas to Increase Connections/Relationships

With Families

- More in person get togethers along with some virtual and some hybrid
- Connecting more with Families of people supported by organizations and with other Family Networks and family groups.
- Have a once a month drop in for families with coffee and cake and revisit the book club
- Combine fostering connections with sharing information and combine a learning event with something that is fun, and that could include parents and kids through ICAN.

Facilitator Suggestions

As mentioned above, building a Network depends first and foremost on inviting and engaging more Families. Feedback from the Board has identified that so far Surveys have not yielded much return. As you share information about TBFN through a variety of means, I would suggest that some old fashioned, grass roots person to person conversations may need to be relied on, especially in the beginning. Taking time to create three **Community Maps**, each taking between 45 minutes to an hour, will offer so much concentrated practical information for you to act on.

A **Community Map**...sometimes done with graphics and sometimes just words, is simply a way to gather all information in one place in a very visible and accessible way. It really requires being done on a flip chart so that everyone can see what is being put up there, and using a bit of colour also twigs various parts of our brain and memory. It could be done virtually, if need be, especially if someone has some tech expertise around screen sharing as writing in the moment.

I suggest doing the first one of these as the most important:

A collective **Community Map** of other Families that you know/are aware of and who specifically has some connection to each

Once identified, Board members can begin to determine how each person could be approached individually. This can be done over time and as mentioned earlier, could take precedence over many (though not all) other activities during this slower Summer season. It is this grass roots, personal work which usually yields the greatest results. It is not initially about quantity but rather quality of engagement with people who hopefully will become resources as well as wanting to avail themselves of what TBFN has to offer.

As this is progressing and as the Board feels they have the time and energy I would then suggest that the next two **Community Maps** be explored:

A collective **Community Map** of Family Groups that you know/are aware of and who, specifically has a connection to each

A collective **Community Map** of Organizations in the disability or related fields that you know/are aware of and who, specifically has a connection to each

Unlike the initial effort required to connect with Families identified from the first **Map**, some contact and connections could begin to be made with Family Groups and Organizations through a quick phone call to see if sharing information with people involved could be through an effective pamphlet offered both virtually, where there is no physical office space, and in hard copy as well, where a physical space exists.

When I think of pamphlets, what comes to mind usually is some rather innocuous pastel folded sheet with lots of writing on it, which I usually take and then frequently never get around to reading. Seeking out artists and students in PR and other related fields of study for some free advice could result in something that is compelling and effective, in design and also in the wording, especially if the latter really reflects what you want to share and what you want to know in a simple, straightforward and attention-getting description. And perhaps organizations that aren't able to donate dollars to the Network would be willing to cover or contribute to the costs of paper and colour copying. You may also need to choose initially, based on expense, which Groups and Organizations might yield the most return on this endeavour, and include more places later. Of course, the virtual promotions would be free.

Over the Summer you may also want to brainstorm ideas for one or two events where there is a strong interest in an information topic, and that also includes, as Families and professionals suggest, opportunities for Families to connect and get better acquainted as well.

When you have more time, I suggest exploring more connections through the fourth ***Community Map***, A collective ***Community Map*** of ordinary Community Groups that might be helpful to Families and People with Disabilities, that you know/are aware of and who, specifically has a connection to each. And you could also keep a running list of Provincial groups, organizations, and individuals who can be allies and resources for TBFN.

Communication

Closely aligned with Connections/Relationships is Communication...again both internally among the Board and between them and Staff, and how TBFN communicates externally with the wider community. In this time of so much social media it becomes all the more important to understand each person's and each group's preferred means of contact, and to keep in mind that there are times when people need to talk individually to someone, in person or on the phone.

Families' Thoughts and Experiences About TBFN Communication

People like receiving the monthly emails with the calendar of events. There are still those for whom email remains the most preferred way of knowing what is going on.

"If you're not on Social media you miss a lot."

All families interviewed have email, some are on Facebook, and most look at the Website from time to time.

One parent said she finds the emails, “a bit vague” at times and another mentioned that often the information about a specific event came without enough notice.

A seemingly small point, but keeping a former staff’s name on a Network email address has been confusing to some.

Families said they would like to see a revival of the Newsletter when there are people to do this and to have it and all means of communication be regular.

Some families want “family to family support”. One parent mentioned that as their child is moving into adulthood they would appreciate some 1-1 phone conversations as well as info from emails, etc.

Professionals’ Thoughts and Experiences About TBFN Communication

Organizations also think the emails are important and to keep in mind that not everyone uses Facebook.

They noticed and appreciated that there were lots of attempts by TBFN to connect virtually when Covid started.

Organizations agree with Families about reviving the Newsletter when that is possible.

One Partner remarked that strong relationships depend on clear and regular communication.

Families’ Suggestions About TBFN Communication

Approaches to Communicating

People thought that sharing information in a variety of ways ... in person, through email, and on the Website and Facebook are all important to offer.

Don’t overwhelm with too much at a time but increase frequency a bit.

Don’t send too many emails but increase info in them (see below).

People appreciate timeliness of information about events, being given enough notice with specific details, and prompt responses to inquiries.

It was suggested that the Website needs to be monitored for comments/questions and then respond quickly.

Content

People would like increased practical information on the Website, including specifics such as what disability related items are covered by funding, i.e., eye glasses covered or a good user friendly resource to find this type of information.

Include in emails what else the Network is doing, what they offer, what they do.

Also valuable would be information about who's who... Board and Staff... on all social platforms.

Many enjoy some "quick nuggets/small bytes" of information.

It would be helpful to include a specific Board, Staff or Volunteer contact for each area or event, and have some of that on Facebook as well...who to contact around various aspects.

Reaching Out

It was mentioned that the Network's goal of visibility should reflect that they are both a family resource AND a community resource.

Information should be available to many generic community groups as well as ones related to disability.

There was a suggestion that people involved with the Network, including Volunteers beyond the Board, speak to various groups about the Network and about issues affecting families, and share written materials as well.

People hope the Network will determine all the places that should have their flyer, including doctors' offices.

Professionals' Suggestions About TBFN Communication

Hard copies of a Newsletter (in addition to an online version) would allow organizations to share something tangible with the families and people they support. It was felt that a print option is an important one.

As with families, professionals interviewed believe that some condensed information, where sensible, can be effective.

Include texting as an option where appropriate; i.e., if people have a quick question they could text a Staff member.

It was suggested that emails could be one way to send updates and reminders of events or changes happening, that refer people to the Website or a longer Post on Facebook for more details, where relevant.

Board Members' Thoughts, Experiences, and Ideas on TBFN Communication

Like Families and Professionals, Board Members see various platforms for communication for different roles and purposes, i.e., perhaps Messenger among Board, emails for Staff and Board, emails, Facebook and Website for the wider community.

There needs to be ongoing openness regarding what may work and what may not.

One person thought that the least effective way seems to be by phone, although sometimes a longer 1-1 conversation may be what is really needed, whether in person, on Zoom or phone. There could be some family engagement by phone calls. It was mentioned that sometimes some staff have been reluctant to make calls.

Another Board member thought that text could sometimes be helpful between Staff, between Board and Staff, and for quick questions from Families to Staff.

There was a suggestion that Group Messenger could be helpful at times for the Board (it was useful for the working group for this planning process). Not every Board member is on Facebook, though you can join Messenger without being active on Facebook.

People thought that they will likely still need Zoom for some things, i.e., possibly ICAN on Zoom once a month.

Tea time with Sharon on Facebook Live would still be good.

The Board also sees a need to clarify their image and the message they want to share about the Network, in all formats, including speaking about TBFN in person. Perhaps there can be an event that celebrates this once everyone is clear about the message, focuses, and activities.

Summary of Suggestions on TBFN and Communication

Families

Approaches/Formats

Sharing information in a variety of ways ... in person, through email, and on the Website and Facebook are all important.

Don't overwhelm with too much at a time but increase frequency a bit.

Don't send too many emails but increase info in them.

Consider timeliness of information about events, being given enough notice with specific details, and prompt responses to inquiries.

The Website needs to be monitored for comments/questions and then respond quickly.

Content

Increase practical information on the Website, including specifics such as what disability related items are covered by funding, or offer a good user-friendly resource to find this type of information.

Include in emails what else the Network is doing, what they offer, what they do.

Provide information about who's who... Board and Staff... on all social platforms.

Include some "quick nuggets/small bytes" of information.

Offer a specific Board, Staff or Volunteer contact for each area or event, and have some of that on Facebook as well...who to contact around various aspects.

Reaching Out

TBFN's visibility should reflect that they are both a family resource AND a community resource.

Provide Information to many generic community groups as well as ones related to disability.

Have people involved with the Network, including Volunteers beyond the Board, speak to various groups about the Network and about issues affecting families, and share written materials as well.

Think about all the places that should have their flyer, including doctors' offices.

Professionals

Have hard copies of a Newsletter (in addition to an online version)

In agreement with Families that some condensed information can be effective.

Include texting as an option where appropriate.

Use short emails to send updates and reminders that refer people to the Website or a longer Post on Facebook

Board

Important to use various platforms for communication for different roles and purposes.

Use phone and in person for some family engagement.

Group Messenger could be useful at times for the Board.

Tea time with Sharon on Facebook Live would still be good.

TBFN needs to clarify their image and the messages they want to share about the Network, in all formats.

Facilitator Suggestions

Over the Summer some practical research could be to ask for input from students and others who have knowledge about social media platforms, for any suggestions to enhance existing virtual communication.

You might also brainstorm all the Facebook Pages and Websites already in existence where “nuggets” of information could be copied and shared. I am not sure who currently oversees the Network Website and Facebook Pages and although these are quite informative, I wonder if this responsibility could be shared with more people, not just Board...almost as “stringers” on a Newspaper, who perhaps don’t have the authority to Post, but to share possible items with whoever does have that authority...thus spreading the work out more. There may also be Families who are part of other relevant groups, who could submit Posts for approval.

Using a few of ***Brainstorming Questions*** that have made a significant difference in personal planning with people can also be effective in group planning. This isn’t rocket science but the wording focuses on including numerous possibilities. So, in thinking about Communication, you could ask:

1. What are all the messages and information we want to share with people?
2. What are all the ways we could reach people?
3. Which ways will be most effective for each of our messages?
4. Who do we know or who could we contact who could help?

Again, I suggest seeing how students at various levels of education and with various focuses could help. I also saw a lot of expertise among members of the Northern Autism Families group around social media.

Information/Learning

TBFN is already aware that family members are so frequently overwhelmed by the systems they need to navigate. There is also a desire to learn more about approaches and innovations outside of systems, that will help to make life easier for their family member with a disability and themselves. There is no lack of topics on which to share information with Families. The creative aspect of offering these will be to consider what

approaches/processes will also be most helpful to them in forming and developing connections as well as the most efficient and effective ways for TBFN to provide these learning opportunities. Only mentioned once was the importance of information and learning for professionals, students, and Network Board members and Staff, which, over time, will be an important part of TBFN's success.

Families' Experiences of Learning Events

Remarks about these events were mostly positive. One parent attended some family sessions several years ago, including one on housing quite a while ago...she liked some of the content and found other parts were less relevant

Others mentioned favourably a presentation by a lawyer on Hensen Trusts, the support worker speed dating sessions and when Al Etmanski did a workshop.

Content

One parent said she remains confused about services and not sufficiently informed ... just dealing with application forms feels like too much, along with things that may seem simple, like getting her son his own health card or dealing with issues regarding meds. She and other families would like all the information they can get that demystifies the system.

More learning about Circles, Microboards, and the ever changing nuances of Passport funding were mentioned, along with information on issues regarding parenting and supporting family members of different ages. Other topics of interest are: info on Individualized Funding; creative ways to share support (i.e., one worker with two people); peer support with other caregivers; more about the APSW Community Integration Program; and Community College and other aspects of transition from high school.

It was stated that many parents are afraid when their children move to adult supports and want to know what helps them gain more independence and still be safe. Parents are afraid to let their kids try and fail, so information on people taking the bus, going to College, and trying things with the necessary support is very much needed.

More stories would also be very helpful.

One person mentioned the idea of a 411capacity kit.

Process

Several people wanted more new information, that sometimes the same Sessions are repeated.

As mentioned in the Section on Relationships, events that combine connecting with information are greatly desired.

Speakers with some focus and structure are appreciated but balancing that with a setting that is welcoming and informal, where families can connect with each other, was also stated as important.

Professionals' Ideas on Information and Learning

Content

It would be helpful for families to learn how to manage resources creatively.

Helping families learn to work together is valuable.

Information on Person-Centered Planning, Circles, and Microboards was suggested.

“Many answers aren’t within the system! I hope the Network will also help Families gain the skills and information to work outside the system, because the system isn’t going to be the answer!”

“Families need more knowledge and expertise and to know how to ask the right questions.”

Process

It was suggested that some virtual events could be all right, though everyone acknowledged the importance of in-person ones.

People mentioned including students for speed dating events for support workers.

A suggestion was to share resources step by step so that people understand.

Board

Sharon has done presentations on mental health.

TBFN has a good Data Base of resources

The Network also put together a Sensory Lending Library, which has been stored since Covid for health and safety reasons.

Summary of Suggestions on Information and Learning through TBFN

Families

Content

Families would like all the information they can get that demystifies the system.

People want to learn about Circles, Microboards, and Passport funding and Individualized Funding.

More information is wanted on issues regarding parenting and supporting family members of different ages, creative ways to share support (i.e., one worker with two people); peer support with other caregivers; more about the APSW Community Integration Program; and Community College and other aspects of transition from high school.

More stories are wanted.

There was a suggestion for a 411capacity kit.

Process

Several requests for more new information were made, that sometimes the same ones are repeated.

Combining learning with connecting is greatly desired.

Having speakers with some focus and structure in a setting that is welcoming and informal was seen as important.

Professionals

Content

It would be helpful for families to learn how to manage resources creatively.

Assisting families to learn to work together is valuable.

Information on Person-Centered Planning, Circles, and Microboards was suggested.

Share innovations from outside of the system.

Process

Some virtual events could continue but people are eager for in-person gatherings.

People mentioned including students for speed dating events for support workers.

Share resources step by step so that people understand.

Board

Sharon has done presentations on mental health.

TBFN has a good Data Base of resources.

The Network also put together a Sensory Lending Library, which has been stored since Covid for health and safety reasons.

Facilitator Suggestions

As you are determining all the different educational topics you would like to share and the best ways to offer these, a couple of practical steps over the next few months would be to explore more ways to keep sharing some of the “nuggets” mentioned by Families, through re-Posting what some relevant groups are sharing and increasing the number of these groups from which to draw.

One area in which to provide these small “bytes” is to provide quick updates about what you are exploring and planning from this recent process. This can be energizing for people and could also offer ways in which they think they may want to become involved.

Another very worthwhile, foundational effort would be to take time to figure out and Brainstorm how events can best include the dual Goals of sharing information and building in effective ways for people to get to know each other better as well. Reaching out to others who do training or host events, for ideas, would be worthwhile, as well as drawing on your own experiences and thoughts.

One idea might be to plan an event for the Fall that embodies this combination of Information on a relevant topic with enjoyable opportunities for Connections and Relationships. It could be a celebration of reconnecting after so much time apart (fingers crossed that there is not another serious wave) and to also share more about what you are working on from the Network planning process. Again, this can re-energize people and possibly inspire some to get a bit more involved, especially if you can offer some gentle ideas about ways in which they might help, that aren't a burden.

Advocacy

TBFN has done some very important work to support family advocacy at local and provincial levels before and during Covid. There is still a great...and growing...need for this type of help, and making strategic choices regarding how the Network can be most effective in providing this support is essential. As pointed out by professionals in the Section on Information and Learning, it is equally important that Families gain knowledge and experience of solutions outside of the system, so that not every problem has to be addressed through advocacy struggles.

Families' Experiences and Suggestions on TBFN Advocacy

Content

TBFN has shared resources and documents, shared information such as The Family Advocacy Resource Package on how to engage with families, communicate with different levels of government, do press releases, etc.

The Network has also provided Provincial advocacy resources through organizations such as Family Alliance Ontario, the Ontario Independent Facilitation Network, Individualized Funding Ontario and others.

TBFN advocated with David Lepofsky for changes to the government's Triage protocol during Covid.

Parents mentioned being so frustrated by the lack of houses, supports, respite, community activities ...and with the whole system.

They want more strategies and approaches to housing and sustainability of supports, especially practical ideas/solutions on issues such as housing.

People want to know, ***"What else is there for caregivers?"***, and they feel a need to vent.

They need help to demystify bureaucracy and jargon and some wondered where they can get help to fill out forms.

Information about advocacy strategies such as protests, meetings with MPP's, communication with media, newspapers, etc., are all helpful

Process

There was a desire to move from talk to action, such as having small groups on specific aspects where advocacy is needed and inviting MPP's to town halls.

Several people would like to meet with other families whose vision is to explore needs beyond specific disabilities:

"In some aspects of life needs are needs and the help required, such more OT's, PT's, therapists, etc., benefits people with various disabilities."

There was the suggestion that "how to's" on advocacy be shared in small easy to follow steps.

Template letters would be very helpful for various circumstances so that families can use these as a basis for advocacy.

One parent appreciates anything that takes some of that pressure off of families:

***"I want to be a mom: I don't want to have to advocate for services.
I want paid people to do their job!"***

A question was raised about similarities and differences between the types of help offered by TBFN and other disability and family groups. For example, one parent sees Autism Ontario as being more about supporting parents than about advocacy.

TBFN did some outstanding work in supporting and mentoring the Northern Autism Families group.

“They taught us so much about advocacy and not to advocate just for ourselves but for all of Northwest families. No-one else created the space for us that they did.”

“We continue to learn from TBFN. They are always there for us”

Professionals' Suggestions on TBFN Advocacy

“My hope is that TBFN will help to elevate and amplify the voices of families individually and collectively and when strategic, to speak with one voice.”

Summary of Suggestions on Advocacy Through TBFN

Families

Content

People would like more strategies and approaches to housing and sustainability of supports.

People want to know, *“What else is there for caregivers?”*

Families want information to demystify bureaucracy and jargon and help to fill out forms.

They also want information about specific advocacy strategies.

Process

There was a desire to move from talk to action.

Small groups on specific aspects of advocacy were mentioned.

Inviting MPP's to town halls was also suggested.

Several people would like to meet with other families whose vision is to explore needs beyond specific disabilities.

Have template letters for various circumstances to save time and energy for families.

Professionals' Suggestions on TBFN Advocacy

Find ways to elevate and amplify the voices of families individually and collectively

Facilitator Suggestions

Much of Advocacy support is directly related to Information and Learning, so as TBFN is determining ways in which they can continue to offer help to families, you could consider highlighting some Advocacy strategies in Website and Facebook Posts/Re-Posts.

Another area where gathering more information will be very helpful is to Brainstorm or do another Collective Community Map of all the other groups you know...disability related and not ...who share a common goal for change in a particular area....housing, education, poverty, accessibility, long term care, and others. More collective voices and coalitions are needed to make a difference and to add power to Advocacy initiatives.

The ways in which TBFN supported and mentored the Northern Families Autism group is a great story. Who might you invite to help you develop this into a story you can share and also learn from? Stories are important not only for what they inspire but also for what we can learn from them. "What did it take ...on everyone's part...for this to happen"?

Sustainability

It was primarily the Board who identified Issues of Sustainability, though Families and Professionals agree that the Network needs more funding and volunteers. Each of these areas need much more thought and expanding upon, but below are the topics raised in Board discussions.

Structure Board

Issues

Length of terms of office for Board members

Mentioned by a Family member: "Don't micro manage."

Ideas

Maintain autonomy of Network

Expand Board to ten members

Need for a few Committees

Need for some working groups ...ongoing or ad hoc, who may report to a Committee or directly to the Board

Need to diversify Board backgrounds, skill sets, etc.

Need restructuring but we need to know what we want to do before we create job descriptions

Some virtual board interaction would be good to keep but some in-person as well

Staff

Issues

Retaining Staff

Issues of Staff hours, duties

Need more help with the human resources piece... more support

Ideas

What material resources are available to staff? What human resources?

Staff with different skills and areas of knowledge

Help Staff see themselves as a resource ... valued ... listened to

How can Staff feel connected...do they feel isolated?

Need to provide skill building for Staff i.e., go to conferences, etc.

Staff as a catalyst

Staff who know the services, can do some family engagement, know the system

Need more in person contact between Board and Staff

Job description for the community development staff is hard to write; the job varies so much and requires lots of different capacities

“The role of staff looks different everyday because each family’s need are different”

“There was some disconnect when the former full time Staff left.”

People

Issues

Need more volunteers and more Families involved

More diversity in membership, around various disabilities, ages, geography, etc.

Need others to help so Families don't feel they have to do it all themselves

Everyone on the Board works full time and devotes time and energy to TBFN, but can only do so much

"What makes people willing to help?"

Ideas

Use students at College, University to help with Website, social media, community projects.

Do outreach to high schools regarding their community service hours.

How can the Network and Partners collaborate in more ways, that serve everyone?

The Northern Autism Family group can be a great resource to the Network.

How volunteers, potential volunteers, others can be resources.

Goals

Issues

TBFN can't take on all issues.

Ideas

A Family member suggested setting **SMART** Goals: ***Specific, Measurable, Attainable, Relevant, Time-Based***

The Network should have major and minor focuses.

Board needs a regular, detailed, yearly plan and keep referring to it at every Board meeting

Board said they need to show they are working on Goals ...updates.

Network needs to choose its priorities then ask for help from the Partners and other Families for help.

Celebrating accomplishments: ***"Anything we have done has helped someone!"***

Network Image and Visibility

Issues

Several Families mentioned that the Network needs to be clearer about their focus.

Ideas

Let Families know what the Network has to offer once they have decided on their priorities and focuses.

TBFN needs to hold sessions about the Network and advertise themselves.

Funding

Issues

Grants are needed, including trying for one from Trillium.

Presently payroll takes up 90 per cent of the budget money.

Ideas

The Partnership agreement could be expanded to include more groups and organizations, that could lead to more dollars and in-kind support.

Physical Space

Issues

Space for ICAN, Space for Board and others to meet, Office space for Staff

TBFN moved three times in three years... it's hard to keep moving files, furniture etc.

Learning and Capacity Building for Board, Staff and Volunteers

Issues

Need to keep building leadership and confidence

Ideas

Have some learning and team building sessions with Board

Helpful for the Board to include some discussion of values ... are we coming from different places in our values and vision?... do our actions as a Network reflect our beliefs?

Facilitator Suggestion

I would suggest that one of the ongoing Committees or Working Groups be around Sustainability since it is a permanent issue, and that involving people from strategic organizations and community groups be included.

Summary of Suggestions on Sustainability

Structure Board

Ideas

Maintain autonomy of Network

Expand Board to ten members

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Need for some working groups ...ongoing or ad hoc, who may report to a Committee or directly to the Board

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Ideas

What material resources are available to staff? What human resources?

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Help Staff see themselves as a resource ... valued ... listened to

How can Staff feel connected...do they feel isolated?

Need to provide skill building for Staff i.e., go to conferences, etc.

Staff as a catalyst

Staff who know the services, can do some family engagement, know the system

Page Thirty

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Helpful for the Board to include some discussion of values ... are we coming from different places in our values and vision?... do our actions as a Network reflect our beliefs?

Facilitator Suggestion on Sustainability

I would suggest that one of the ongoing Committees or Working Groups be around Sustainability since it is a permanent issue, and that involving people from strategic organizations and community groups be included.

Gifts of the Network

Families

The Board seems quite organized.

They keep trying to figure out what they can do to help families and what their community needs.

They have been around a long time.

They offer the space to be heard...we can talk about anything.

“The Network is like a rock a safe community.... you know you’re not alone!”

There is a lot of knowledge.

Page Thirty-Two

They are willing to deep dive to learn what they don’t know about.

Board members are from different walks of life.

They are dedicated to do what they can do.

They keep track of what's going on with government and advocacy issues.

There is a community feeling.

***"I have received moral support on a personal level ...
there is willingness to hear you out."***

They can relate as individuals not just as an organization."

Professionals

"When I came to Thunder Bay I was excited about the existence of a Family Network!"

There is some good leadership.

The network has stability.

They keep us informed and apprised.

"They are a presence and a known resource in the community."

The Network uses relationships to advance their goals.

They have passion and a desire for collaboration.

"They have great enthusiasm and energy for things to happen".

Board

Belief in family-to-family connections (more before covid)

We do our best to be responsive and to listen to each other, even when our opinions may differ somewhat ...we work hard at being non- judgemental

We have persistence and are focused on the needs of families ...dedication

Everyone brings something different to the table ...we try new ways

There is a friendly welcoming atmosphere

We dig through the layers to look at nuances

Adaptability (Covid is a good example)

ICAN is known to do events really well

The Network has the trust of the community

Facilitator Suggestion Gifts/Talents

A gratifying and practical exercise to do in any group is Honouring and Identifying each Member's *Gifts/and Talents* ...in this case each Board Member.

For each Member, others in the group take turns identifying what they see as the person's Gifts and Talents...things they are good at and qualities that they admire about them. People then take turns recording these on a piece of paper for the person, that they can keep.

After everyone else has shared what they see as the focal person's Gifts and Talents, the person can add any they would also like to acknowledge. Once this has been done with each person, it is helpful for people to share how they feel some of their Gifts have made a difference in their life...connecting with others, pursuing activities and interests that are meaningful, making a difference. And the final step is to invite each person to consider how some of their Gifts contribute to their involvement with TBFN or how they feel they can play a part as the Network keeps moving forward.

The Gifts and Talents that the Board has identified in themselves individually and those they and Families and Professionals see in the Network as a whole are one of the keys to resolving the Challenges they face, as well as accomplishing the Goals they wish to pursue. Along with additional people, Gifts and Talents are among the greatest resources of the Network.

Challenges for TBFN

Although most of the Challenges identified are also mentioned in other areas of this Report, I decided to leave them here in this Section, because these answers were the result of my asking this question specifically, rather than people bringing up problems as part of their answers in other categories, such as Connections/Relationships, Information/Learning, Advocacy, and Sustainability.

Focus

Some mentioned the need for more clarity of the TBFN role:

“Where are the general family members of the Network?”

“Are they a service provider or a community network? “

Focus Too Narrow: Need more diversity in age and disability, more men involved

Focus Too Broad: Board can take on too much

Information

“Even when we read things it’s hard to keep up with everything, so we so rely on the Network to highlight and condense information from other sources“

Other Challenges mentioned by Families for TBFN included:

- Funding
- Staff turnover
- Covid
- Trying to meet the needs of different families, trying to be all things to all people

“Families are tired of having to tell their story over and over

Professionals

- Families are losing hope, especially around issues like housing
- Creative planning with individual people isn’t going well right now
- Helping Families maintain a hopeful vision during difficult times
- Some differences in the Network between approaches that are more traditional and more inclusive regarding support

“My sense is that they need to have a clear focus ... Family Networks cannot do all things.”

“They can sometimes have trouble with implementation, which can partly be from lack of enough help”.

Board

Geography

Challenges keeping people engaged in a large geographical area

It's hard to create events that cover the whole territory

Balancing Change and Tradition

Issue of the focus and activities of ICAN including different viewpoints

Space

Funding and Money

Always a challenge

Visibility

Not Always Turning Ideas into Action

Trouble at times moving Goals forward

Not always completing things

Sometimes the dreaming is easy but the doing has challenges

Not Enough People

Not always the help to do it, so Goals not always implemented

Lack of participation in some events can be discouraging

Staff

Problem retaining Staff

Facilitator Suggestion on Challenges

Just as it has been stated by the Board and others who care about the Network, that TBFN can't do everything, so a Challenge that offers a solution by its very nature is some reflection and discussion about the role of the Network in various areas. When is its support hands-on and when is it as a conduit for information, ideas, resources, connections? It can be both to some extent, but remembering that there are allies and other sources of information that can support the vision of TBFN, and over time, seeking these out and opening space, will result in creating a stronger Network.

What are all the ways that TBFN can be a catalyst for change and connection that invite that vision as a common goal?

ICAN: Independence Confidence Achievement Networking

Part of the Legacy of TBFN is ICAN, which the majority of people interviewed as Participants, Families, Professionals, and Board, still value. However, some among all groups except the Participants said they wonder about future directions of this support. This doesn't have to be an either/or situation but some honest exploration needs to occur regarding how this support can be the most meaningful to Participants and also reflect most closely the Mission and Values of the Network and the Goals of ICAN by promoting opportunities for people to grow in *Independence, Confidence, Achievement, and Networking*.

Participants' Responses

How People Found Out About ICAN

Several people found out about ICAN through friends or family, one through March of Dimes and one through The Boys and Girls Club.

What People Said They Enjoy

Specifically, Tim Horton's and swimming were mentioned, and just social time in general. The volunteer present mentioned how much she likes helping people with various things, including Zumba.

People Said They Would Like More

Mentioned were: Tim Hortons; movies; going for ice cream; casino; bowling; ice fishing

People Said They Have Learned About

Police safety; drug and alcohol safety; St Johns Ambulance; and medical issues like diabetes and high cholesterol

“I learned to be more friendly and happy”

Relationships

Some Participants met new people. Many of those interviewed said they also see each other in places like March of Dimes Crafts once a week and Special Olympics, and where several may be volunteering at the same place, such as Habitat for Humanity.

“I love it...I miss seeing people in person”

Families

People said they would like to see more variety of activities and as things open up again fewer activities like Bingo.

Some mentioned that they would like to have things be more community oriented.

“Is TBFN ‘s role a service provider? “

Several Families hoped for activities for younger people, to engage with youth and children.

*“There is a warm, welcoming environment from ICAN participants and staff...
I would now be confident to drop off my child there”*

Professionals

“People really like ICAN and those involved still want it.”

“It’s really like a club...mostly a social gathering.”

“Sometimes the activities aren’t reflecting valued roles or age appropriate activities for people.”

“ICAN was initially a good program; it was hoped that it would have more inclusive types of events.”

ICAN is a social environment, to network, participate in activities, develop relationships
There used to be family members in one room and kids in the other; there are fewer parents now

Facilitator Suggestions on ICAN

A few considerations come to mind regarding ICAN. One is to go back to the original intent of this support and how it was hoped to support Families. I believe that originally family members came with their children and it was a time for both to connect with others. I wonder how ICAN might pursue this idea and what would make it valuable for everyone to attend? I realize that Families need access to respite and people with disabilities also want time when they are not hanging out with their parents or siblings.

However, an important consideration to reflect on and discuss is whether TBFN's role is to provide that directly or be more of a catalyst...a "mid-wife" if you will ... to help, encourage, and invite more opportunities for social gatherings for people who have a disability to be provided by other groups in Thunder Bay, and also to increase the Network's focus on supporting Families to share in opportunities to grow in Independence, Confidence, Achievement, Networking with their children and siblings and relatives who have a disability.

Following the suggestions of Families and Professionals in other areas of this Report for the Network to find ways to combine Information and Learning with Connections and Relationships, perhaps ICAN could also reflect some joint activities that include both aspects.

Part of Advocacy is also Self-Advocacy and the Goals of Independence, Confidence, Achievement, and Networking that comprise the ICAN acronym are certainly reflective of helping people with a disability as well as Families to increase their ability to have more voice in all areas of their lives.

Perhaps Families and their relatives with a disability can find ways to grow and learn and also have some fun together, to increase their capacity and power and relationships? There could be some creative approaches to expanding the scope of ICAN, while still retaining that sense of community. I believe there is some interesting potential there!

There is a lot of information here and a lot more questions to ask and decisions to be made...though as mentioned in the Introduction, not all at once. An image recently occurred to me inspired by the saying that a particular initiative may be a Marathon, not a Sprint. In thinking of this more I realized that there are additional ways to move forward that expand on this metaphor:

Planning as Movement in Various Athletic Races

- **Sprints:** In the Moment, Very Short Term Planning
- **Middle and Long Distance:** The Usual Balance in Planning Over Time
- **Relays:** The Need to Include Others in the Process
- **Hurdles:** Brainstorming, Breaking Down the Challenges You'll Encounter
- **Race Walks:** Keeping Some Movement Going When Thing Slow Down
- **Jumps (High Jump, Long Jump, Triple Jump):** Things Speed Up, Sudden Change
- **Marathon:** Keeping the "Long Haul", The Big Picture" in Mind ... Persistence



TBFN has many resources to keep going on your path ... the support of one another as well as that of local, district, and provincial communities, and the heart and will to continue. I look forward to celebrating with you about your continued endeavours and successes on this journey.

Summary of Suggestions on Connections/ Relationships

Families' Suggestions

- Connect the Goals of helping Families become better acquainted and sharing information with them...when planning events combine both opportunities
- Have a first contact available when a family reaches out...a Board Member or a Family Network volunteer
- More 1-1 opportunities for Families to connect
- Connecting more with other Family Networks
- More connection with others around specific disabilities, beyond autism
- More connections to Families outside of Thunder Bay and to Families connected to various service organizations

Professionals' Suggestions

- Echoing Families' idea to combine events that both inform and intentionally build connections, developing alliances through education.
- Contacting organizations such as The Children's Centre Thunder Bay, and Confederation College ... in general and disability related departments in particular, to explore resources, opportunities to collaborate
- Collaborate to bring back Community Links in person

Board Ideas to Increase Connections/Relationships

With Families

- More in person get togethers along with some virtual and some hybrid
- Connecting more with Families of people supported by organizations and with other Family Networks and family groups.
- Have a once a month drop in for families with coffee and cake and revisit the book club
- Combine fostering connections with sharing information and combine a learning event with something that is fun, and that could include parents and kids through ICAN.

Facilitator Suggestions

As mentioned above, building a Network depends first and foremost on inviting and engaging more Families. Feedback from the Board has identified that so far Surveys have not yielded much return. As you share information about TBFN through a variety of means, I would suggest that some old fashioned, grass roots person to person conversations may need to be relied on, especially in the beginning. Taking time to create three **Community Maps**, each taking between 45 minutes to an hour, will offer so much concentrated practical information for you to act on.

A **Community Map**...sometimes done with graphics and sometimes just words, is simply a way to gather all information in one place in a very visible and accessible way. It really requires being done on a flip chart so that everyone can see what is being put up there, and using a bit of colour also twigs various parts of our brain and memory. It could be done virtually, if need be, especially if someone has some tech expertise around screen sharing as writing in the moment.

I suggest doing the first one of these as the most important:

A collective **Community Map** of other Families that you know/are aware of and who specifically has some connection to each

Once identified, Board members can begin to determine how each person could be approached individually. This can be done over time and as mentioned earlier, could take precedence over many (though not all) other activities during this slower Summer season. It is this grass roots, personal work which usually yields the greatest results. It is not initially about quantity but rather quality of engagement with people who hopefully will become resources as well as wanting to avail themselves of what TBFN has to offer.

As this is progressing and as the Board feels they have the time and energy I would then suggest that the next two **Community Maps** be explored:

A collective **Community Map** of Family Groups that you know/are aware of and who, specifically has a connection to each

A collective **Community Map** of Organizations in the disability or related fields that you know/are aware of and who, specifically has a connection to each

Unlike the initial effort required to connect with Families identified from the first **Map**, some contact and connections could begin to be made with Family Groups and Organizations through a quick phone call to see if sharing information with people involved could be through an effective pamphlet offered both virtually, where there is no physical office space, and in hard copy as well, where a physical space exists.

Page Forty-Two

When I think of pamphlets, what comes to mind usually is some rather innocuous pastel folded sheet with lots of writing on it, which I usually take and then frequently never get around to reading. Seeking out artists and students in PR and other related fields of study

for some free advice could result in something that is compelling and effective, in design and also in the wording, especially if the latter really reflects what you want to share and what you want to know in a simple, straightforward and attention-getting description. And perhaps organizations that aren't able to donate dollars to the Network would be willing to cover or contribute to the costs of paper and colour copying. You may also need to choose initially, based on expense, which Groups and Organizations might yield the most return on this endeavour, and include more places later. Of course, the virtual promotions would be free.

Over the Summer you may also want to brainstorm ideas for one or two events where there is a strong interest in an information topic, and that also includes, as Families and professionals suggest, opportunities for Families to connect and get better acquainted as well.

When you have more time, I suggest exploring more connections through the fourth ***Community Map***, A collective ***Community Map*** of ordinary Community Groups that might be helpful to Families and People with Disabilities, that you know/are aware of and who, specifically has a connection to each. And you could also keep a running list of Provincial groups, organizations, and individuals who can be allies and resources for TBFN.

Summary of Suggestions on TBFN and Communication

Families

Approaches/Formats

Sharing information in a variety of ways ... in person, through email, and on the Website and Facebook are all important.

Don't overwhelm with too much at a time but increase frequency a bit.

Don't send too many emails but increase info in them.

Consider timeliness of information about events, being given enough notice with specific details, and prompt responses to inquiries.

The Website needs to be monitored for comments/questions and then respond quickly.

Increase practical information on the Website, including specifics such as what disability related items are covered by funding, or offer a good user friendly resource to find this type of information.

Include in emails what else the Network is doing, what they offer, what they do.

Provide information about who's who... Board and Staff... on all social platforms.

Include some "quick nuggets/small bytes" of information.

Offer a specific Board, Staff or Volunteer contact for each area or event, and have some of that on Facebook as well...who to contact around various aspects.

Reaching Out

TBFN's visibility should reflect that they are both a family resource AND a community resource.

Provide Information to many generic community groups as well as ones related to disability.

Have people involved with the Network, including Volunteers beyond the Board, speak to various groups about the Network and about issues affecting families, and share written materials as well.

Think about all the places that should have their flyer, including doctors' offices.

Professionals

Have hard copies of a Newsletter (in addition to an online version)

In agreement with Families that some condensed information can be effective.

Include texting as an option where appropriate.

Use short emails to send updates and reminders that refer people to the Website or a longer Post on Facebook

Board

Important to use various platforms for communication for different roles and purposes.

Use phone and in person for some family engagement.

Page Forty-Four

Group Messenger could be useful at times for the Board.

Tea time with Sharon on Facebook Live would still be good.

TBFN needs to clarify their image and the messages they want to share about the Network, in all formats.

Facilitator Suggestions

Over the Summer some practical research could be to ask for input from students and others who have knowledge about social media platforms, for any suggestions to enhance existing virtual communication.

You might also brainstorm all the Facebook Pages and Websites already in existence where “nuggets” of information could be copied and shared. I am not sure who currently oversees the Network Website and Facebook Pages and although these are quite informative, I wonder if this responsibility could be shared with more people, not just Board...almost as “stringers” on a Newspaper, who perhaps don’t have the authority to Post, but to share possible items with whoever does have that authority...thus spreading the work out more. There may also be Families who are part of other relevant groups, who could submit Posts for approval.

Using a few of ***Brainstorming Questions*** that have made a significant difference in personal planning with people can also be effective in group planning. This isn’t rocket science but the wording focuses on including numerous possibilities. So, in thinking about Communication, you could ask:

5. What are all the messages and information we want to share with people?
6. What are all the ways we could reach people?
7. Which ways will be most effective for each of our messages?
8. Who do we know or who could we contact who could help?

Again, I suggest seeing how students at various levels of education and with various focuses could help. I also saw a lot of expertise among members of the Northern Autism Families group around social media.

Summary of Suggestions on Information and Learning through TBFN

Families

Content

Families would like all the information they can get that demystifies the system.

People want to learn about Circles, Microboards, and Passport funding and Individualized Funding.

Page Forty-Five

More information is wanted on issues regarding parenting and supporting family members of different ages, creative ways to share support (i.e., one worker with two people); peer

support with other caregivers; more about the APSW Community Integration Program; and Community College and other aspects of transition from high school.

More stories are wanted.

There was a suggestion for a 411 capacity kit.

Process

Several requests for more new information were made, that sometimes the same ones are repeated.

Combining learning with connecting is greatly desired.

Having speakers with some focus and structure in a setting that is welcoming and informal was seen as important.

Professionals

Content

It would be helpful for families to learn how to manage resources creatively.

Assisting families to learn to work together is valuable.

Information on Person-Centered Planning, Circles, and Microboards was suggested.

Share innovations from outside of the system.

Process

Some virtual events could continue but people are eager for in-person gatherings.

People mentioned including students for speed dating events for support workers.

Share resources step by step so that people understand.

Board

Sharon has done presentations on mental health.

TBFN has a good Data Base of resources.

The Network also put together a Sensory Lending Library, which has been stored since Covid for health and safety reasons.

Facilitator Suggestions

As you are determining all the different educational topics you would like to share and the best ways to offer these, a couple of practical steps over the next few months would be to explore more ways to keep sharing some of the “nuggets” mentioned by Families, through re-Posting what some relevant groups are sharing and increasing the number of these groups from which to draw.

One area in which to provide these small “bytes” is to provide quick updates about what you are exploring and planning from this recent process. This can be energizing for people and could also offer ways in which they think they may want to become involved.

Another very worthwhile, foundational effort would be to take time to figure out and Brainstorm how events can best include the dual Goals of sharing information and building in effective ways for people to get to know each other better as well. Reaching out to others who do training or host events, for ideas, would be worthwhile, as well as drawing on your own experiences and thoughts.

One idea might be to plan an event for the Fall that embodies this combination of Information on a relevant topic with enjoyable opportunities for Connections and Relationships. It could be a celebration of reconnecting after so much time apart (fingers crossed that there is not another serious wave) and to also share more about what you are working on from the Network planning process. Again, this can re-energize people and possibly inspire some to get a bit more involved, especially if you can offer some gentle ideas about ways in which they might help, that aren't a burden.

Summary of Suggestions on Advocacy Through TBFN

Families

Content

People would like more strategies and approaches to housing and sustainability of supports.

People want to know, *“What else is there for caregivers?”*

Families want information to demystify bureaucracy and jargon and help to fill out forms.

They also want information about specific advocacy strategies.

Page Forty-Seven

Process

There was a desire to move from talk to action.

Small groups on specific aspects of advocacy were mentioned.

Inviting MPP's to town halls was also suggested.

Several people would like to meet with other families whose vision is to explore needs beyond specific disabilities.

Have template letters for various circumstances to save time and energy for families.

Professionals' Suggestions on TBFN Advocacy

Find ways to elevate and amplify the voices of families individually and collectively

Facilitator Suggestions on Advocacy

Much of Advocacy support is directly related to Information and Learning, so as TBFN is determining ways in which they can continue to offer help to families, you could consider highlighting some Advocacy strategies in Website and Facebook Posts/Re-Posts.

Another area where gathering more information will be very helpful is to Brainstorm or do another Collective Community Map of all the other groups you know...disability related and not ...who share a common goal for change in a particular area....housing, education, poverty, accessibility, long term care, and others. More collective voices and coalitions are needed to make a difference and to add power to Advocacy initiatives.

The ways in which TBFN supported and mentored the Northern Families Autism group is a great story. Who might you invite to help you develop this into a story you can share and also learn from? Stories are important not only for what they inspire but also for what we can learn from them. "What did it take ...on everyone's part...for this to happen"?

Summary of Suggestions on Sustainability

Structure Board

Ideas

Maintain autonomy of Network

Expand Board to ten members

Need for a few Committees

Need for some working groups ...ongoing or ad hoc, who may report to a Committee or directly to the Board

Need to diversify Board backgrounds, skill sets, etc.

Need restructuring but we need to know what we want to do before we create job descriptions

Some virtual Board interaction would be good to keep but some in-person as well

Staff

Ideas

Have one full time one part time Staff or at least two part time

What material resources are available to staff? What human resources?

Staff with different skills and areas of knowledge

Help Staff see themselves as a resource ... valued ... listened to

How can Staff feel connected...do they feel isolated?

Need to provide skill building for Staff i.e., go to conferences, etc.

Staff as a catalyst

Staff who know the services, can do some family engagement, know the system

Need more in person contact between Board and Staff

Job description for the community development staff is hard to write; the job varies so much and requires lots of different capacities

“The role of staff looks different everyday because each family's need are different”

“There was some disconnect when the former full time Staff left.”

Ideas

Use students at College, University to help with Website, social media, community projects.

Do outreach to high schools regarding their community service hours.

How can the Network and Partners collaborate in more ways, that serve everyone?

The Northern Autism Family group can be a great resource to the Network.

How volunteers, potential volunteers, others can be resources.

Goals

Ideas

A Family member suggested setting **SMART** Goals: ***Specific, Measurable, Attainable, Relevant, Time-Based***

The Network should have major and minor focuses.

Board needs a regular, detailed, yearly plan and keep referring to it at every Board meeting

Board said they need to show they are working on Goals ...updates.

Network needs to choose its priorities then ask for help from the Partners and other Families for help.

Celebrating accomplishments: ***"Anything we have done has helped someone!"***

Network Image and Visibility

Ideas

Let Families know what the Network has to offer once they have decided on their priorities and focuses.

TBFN needs to hold sessions about the Network and advertise themselves.

Funding

Ideas

The Partnership agreement could be expanded to include more groups and organizations, that could lead to more dollars and in-kind support.

Ideas

Have some learning and team building sessions with Board

Helpful for the Board to include some discussion of values ... are we coming from different places in our values and vision?... do our actions as a Network reflect our beliefs?

Facilitator Suggestion on Sustainability

I would suggest that one of the ongoing Committees or Working Groups be around Sustainability since it is a permanent issue, and that involving people from strategic organizations and community groups be included.

Facilitator Suggestion Gifts/Talents

A gratifying and practical exercise to do in any group is Honouring and Identifying each Member's *Gifts/and Talents* ...in this case each Board Member.

For each Member, others in the group take turns identifying what they see as the person's Gifts and Talents...things they are good at and qualities that they admire about them. People then take turns recording these on a piece of paper for the person, that they can keep.

After everyone else has shared what they see as the focal person's Gifts and Talents, the person can add any they would also like to acknowledge. Once this has been done with each person, it is helpful for people to share how they feel some of their Gifts have made a difference in their life...connecting with others, pursuing activities and interests that are meaningful, making a difference. And the final step is to invite each person to consider how some of their Gifts contribute to their involvement with TBFN or how they feel they can play a part as the Network keeps moving forward.

The Gifts and Talents that the Board has identified in themselves individually and those they and Families and Professionals see in the Network as a whole are one of the keys to resolving the Challenges they face, as well as accomplishing the Goals they wish to pursue. Along with additional people, Gifts and Talents are among the greatest resources of the Network.

Facilitator Suggestion on Challenges

Just as it has been stated by the Board and others who care about the Network, that TBFN can't do everything, so a Challenge that offers a solution by its very nature is some reflection and discussion about the role of the Network in various areas. When is its support hands-on and when is it as a conduit for information, ideas, resources, connections? It can be both to some extent, but remembering that there are allies and other sources of information that can support the vision of TBFN, and over time, seeking these out and opening space, will result in creating a stronger Network.

What are all the ways that TBFN can be a catalyst for change and connection that invite that vision as a common goal?

Facilitator Suggestions on ICAN

A few considerations come to mind regarding ICAN. One is to go back to the original intent of this support and how it was hoped to support Families. I believe that originally family members came with their children and it was a time for both to connect with others. I wonder how ICAN might pursue this idea and what would make it valuable for everyone to attend? I realize that Families need access to respite and people with disabilities also want time when they are not hanging out with their parents or siblings.

However, an important consideration to reflect on and discuss is whether TBFN's role is to provide that directly or be more of a catalyst...a "mid-wife" if you will ... to help, encourage, and invite more opportunities for social gatherings for people who have a disability to be provided by other groups in Thunder Bay, and also to increase the Network's focus on supporting Families to share in opportunities to grow in Independence, Confidence, Achievement, Networking with their children and siblings and relatives who have a disability.

Following the suggestions of Families and Professionals in other areas of this Report for the Network to find ways to combine Information and Learning with Connections and Relationships, perhaps ICAN could also reflect some joint activities that include both aspects.

Part of Advocacy is also Self-Advocacy and the Goals of Independence, Confidence, Achievement, and Networking that comprise the ICAN acronym are certainly reflective of helping people with a disability as well as Families to increase their ability to have more voice in all areas of their lives.

Perhaps Families and their relatives with a disability can find ways to grow and learn and also have some fun together, to increase their capacity and power and relationships? There could be some creative approaches to expanding the scope of ICAN, while still retaining that sense of community. I believe there is some interesting potential there!