

**Pacific Autism Family Centre Society**  
**2010 Community Focus Group Meetings**

**Final Report**

**January 13, 2011**

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# Executive Summary

The goal of the 2010 Community Focus Group Meetings, conducted on behalf of the Pacific Autism Family Centre Society (PAFC) was to:

- Identify existing services in communities and regions
- Identify how the PAFC can help to address service gaps in communities and regions

Between October 12 and November 18, 2010, 13 focus group sessions were held throughout the province. These local, public meetings were held in the communities of Cranbrook, Nanaimo, Powell River, Prince George, Fort St. John, Kamloops, Vernon, Kelowna, Victoria, Chilliwack, Terrace and two meetings were held in Vancouver. Approximately 270 people participated in the sessions with numbers of participants in individual meetings ranging from 10 to 70. Participants included individuals who identify as having Autism Spectrum Disorder (ASD), parents, grandparents and other family members of individuals with ASD and professionals from a range of disciplines who work with individuals with ASD and their families. These meetings were part of the PAFC's Community Consultations on autism services and the proposed PAFC model. Meeting participants were invited to provide further input and to invite others to provide input by completing the on-line survey on the PAFC website.

The community focus group sessions were generally well attended and well received. Invariably, participants were strongly committed to examining barriers and proposing solutions to the challenge of ensuring timely access to assessment, diagnosis, supports and intervention services for individuals with ASD and their families.

Participants expressed that there are significant concerns with current services and processes related to the needs of individuals with ASD and their families. Individuals residing in northern and rural areas are particularly disadvantaged. While many participants noted significant improvement in service quality and funding for autism services over the past decade, they also noted significantly increased demand for services as well as inconsistent and some cases inadequate service quality, and/or coordination and/or capacity. Concern was expressed over recent provincial government cuts to Early Intensive Behavior Intervention Programs; the lack of service coordination, especially during periods of transition and a general lack of services to adults with ASD who do not meet Community Living British Columbia (CLBC) eligibility requirements.

The following were identified as key issues in the current/existing autism services:

1. **Lack of and/or inconsistency of services, service coordination and provision of information** – It is difficult for individuals to navigate through the systems currently in place. Particular difficulties relate to:

- a. Transition periods.
  - b. Communication and awareness of services.
  - c. The need for a single, reliable point of contact for families.
2. **Inadequate Resources and Additional Barriers in Small Communities and Rural Areas** – There are not enough trained people to fulfill all the roles that are needed. Travel and weather related issues put small communities and rural areas at a distinct disadvantage.
3. **Assessment, Diagnosis and Medical Services**
- a. Lack of access to adequate, timely, appropriate assessment and diagnosis.
  - b. Lack of a diagnosis process for adults.
  - c. Lack of awareness of autism in the medical profession.
  - d. Reluctance of some doctors to make a diagnosis of ASD until child reaches a certain age.
  - e. Appropriate support for families during and following the assessment process.
  - f. Recognition and acceptance of diagnoses obtained.
4. **Lack of Family Support Services**- Many families report feeling overwhelmed during the diagnosis process and following diagnosis. Transition times are particularly difficult.
5. **Lack of services for adults** – There are few or no services for adults with autism if the individual does not meet CLBC eligibility criteria and/or disability benefits criteria. Desired services discussed include:
- a. Life-skills & social skills support and training - banking and financial planning, general housekeeping, grocery shopping, social/recreation activities.
  - b. Employment supports and disability benefits.
  - c. Assistance accessing and support during post-secondary education.
  - d. Support for independent living, housing and in-home support opportunities.
6. **Training specific to autism for families and professionals** - Participants highlighted the need for unbiased training opportunities and specified:
- a. Training and education at all levels.
  - b. Regional access to training - people working with the child on a daily basis need the support to be able to implement interventions properly.
7. **School and Education Issues** - Participants identified concerns about the quality of instruction, knowledge of roles and an inability to ensure consistent and qualified EAs due to union and seniority issues.

8. **Research** - Many participants expressed a desire for an institute or agency that could conduct research, link with a university and/or regional colleges.
9. **Inefficient Payment System for Autism Funds** – Participants in virtually all meetings indicated that the payment system for autism funding in the province is inefficient and slow and represents a primary barrier.

Focus group meetings varied with respect to the level of discussion devoted to the questions relating to the proposed PAFC model. In some meetings there was a greater focus on the existing service system with more limited discussion of the components and use of local/regional “spoke” services and of provincial “hub” services. In other meetings, more in-depth discussion of the model took place. Participants in 12 of the 13 sessions were generally positive about the PAFC initiative and model. Even in the meeting where participants were generally upsupportive of the PAFC initiative, there was also great concern for improved service coordination and communication, both of which were identified by many participants as potential benefits of the “hub and “spoke” model. There was a variety of ideas expressed regarding the type and configuration of service components. A number of participants emphasized the potential for increasing service accessibility and coordination and the profile of ASD issues with government and the general public under the PAFC initiative. All groups cautioned against the duplication of services and any reduction in existing community services.

The following themes emerged from focus group discussions related to the proposed PAFC Hub and “spoke” model:

### **Regional Centres /The “Spokes” Themes**

1. **Create Regional Centres First** - While many participants valued the idea of a “hub” a consensus emerged around the recommendation that the regional centres or “spokes” should be started before the “hub”.
2. **“Navigator” Role** (suggested as a good name for this function). This person would be knowledgeable about all services (for all ages) and “linked in” into the hub and its resources.
3. **Location and Amenities** – Some communities envision having meeting space with video-conferencing capabilities. Others saw that this type of space could already be found and utilized from within the community.

### **Vancouver-Based “Hub”**

1. **Clearinghouse for Best Practice Information** – The “hub” could collect and disseminate information related to ASD, best practices, etc. This information

could be made available to everyone in the province through the regional centres and online.

2. **Advocacy/Watchdog Role** – The “hub” could receive and organize information about issues in accessing autism services regionally and advocate with all involved parties for resolution of individual and systemic problems.
3. **Research** - Many communities envisioned a centre that could link with universities and colleges to conduct research, link with research in regions and bring awareness of international research.
4. **Training and Support** – Offer on site, as well as through “webinars” and other linkages with the regional centres.
5. **Family support and counselling** – Some participants suggested that the hub and “spoke” centres could contribute to family support and counselling options.
6. **On-site accommodation for families and/or people attending training** – While some participants (including many parents) were opposed to this function, others (also including many parents) felt that this, along with financial support to families for travel would be a valuable option for families and people attending training events.

This report presents a snapshot of existing services as experienced and reported by individuals, families and service providers. No follow-up activities were conducted to verify or research identified issues. The information presented in this report is based solely upon input received at the community meetings and in subsequent communications initiated by participants and service providers. The Results section of this report expands upon the main “themes” emerging from the discussion of current services and the proposed PAFC model. Full meeting reports are presented in Appendix B.

# Process Overview

## Purpose of the Meetings

The purpose of each meeting was for participants to:

- Identify existing services in this community and region.
- Identify how the PAFC can help to address service gaps in this community and region.

## Meeting Venues and Invitations/Announcements

Meeting venues were selected in consultation with the PAFC Steering Committee and regional contacts. In most instances, meeting venues were hosted by or identified in consultation with local contacts. Invitations were communicated through a number of different organizations, including the Autism Society of BC (ASBC), ACT - Autism Community Training, Families for Early Autism Treatment (FEAT), ABA Support Network, BC Pediatric Society, Ministry of Housing and Social Development (MHSD) and Ministry of Children and Family Development (MCFD). Focus group sessions were advertised in the Vancouver Sun, The Province, The Victoria Times Colonist and other regional newspapers.

## Meeting Participants

Meeting participants included individuals with ASD, family members and professionals including teachers, educational assistants (EA), behavioural interventionists (BI), behavioural consultants (BC), speech language pathologists (SLP), occupational therapists (OT), health care professionals, administrators, social workers and others. Overall, the participants in this consultation represented a diverse group of committed, concerned and informed individuals encompassing a wide range of perspective in the province's autism community.

## Meeting Activities

The community meetings were facilitated by Fred Ford, an independent consultant, with event organization and recording conducted by Dana Hough of CitySpaces Consulting. The meetings followed a consistent format and agenda with some variation based on the topics of greatest priority and importance to participants.

1. The facilitator presented background information about PAFC (purpose statement, activities, proposed model, etc.) and plans for the meeting.

2. This was followed by participant introductions (in smaller groups) and polling of participants to identify the perspectives (family member, professional, individual with ASD, etc.) and home communities of those in attendance.
3. A facilitated discussion was held, with participants responding to 3 questions:
  - a. What should the Pacific Autism Centre Society know about the current / existing services in this community and region?
  - b. What should be at the “spoke” (in regions) that would support individuals and families in regions/communities?
    - i. What service components should be offered/what should this service be (a person, place, services)?
    - ii. How should these services be delivered?
    - iii. Where would these “spokes” be and what kind of building could it be in or share?
  - c. What should be at the “hub” (Vancouver) that would support you in your region/community?
    - i. What service components should be offered?
    - ii. If you visited the “hub”, what facilities would assist you during the visit - starting with arrival at the building?
    - iii. What would the relationship between “spokes” (regional centres) and the “hub” look like?

Participants were encouraged to complete the online surveys or to contact Dana Hough if they had additional input. The facilitator thanked the participants and indicated that the report and notes from the meeting would be posted on the PAFC website in the New Year.

# Results: Focus Group Meeting Themes

This section includes:

- Compilations of “common themes” emerging from the Focus Group Meetings. These themes are presented in 2 sections, the first summarizing current service issues and the second summarizing themes related to the proposed PAFC model.
- A table summarizing divergent views among participants and overarching suggestions for which there appears to be consensus. This is intended to highlight some key philosophical differences along with areas of fundamental agreement.

## A. Common Themes: Current/Existing Autism Services Discussions

1. **Lack of and/or inconsistency of services, service coordination and provision of information** – Individuals and families consistently report that it is very difficult to navigate through the systems currently in place. Difficulties are experienced in all aspects of assessment and service delivery, including accessing assessment and diagnosis, finding service providers and establishing a team following diagnosis, advocating for and maintaining services during school years and accessing adult services. Additionally, service providers and families expressed difficulty in finding credible information and research on the internet, due to the volume of information and lack of standards on which to gauge the credibility of information presented. The following areas were highlighted in discussions:
  - a. **Transition points** - Families encounter challenges when entering the school system and advocating for services for their child in the classroom. Many parents expressed frustration with the level and quality of support for their child in the classroom, lack of ASD awareness from teaching and administration staff, and lack of awareness and respect for their legal rights. Other difficult transition times include moving from Under 6 Autism Funding to Over 6 Autism Funding (what is eligible, how to submit expenses), transitioning from the school system and into adulthood. Parents in all regions identified prohibitive barriers presented by eligibility requirements for government-funded services for adults, especially CLBC services and disability benefits. Families are finding it difficult to navigate through these transition points, figuring out what services are available, what they are eligible for, how to access, and knowing what they are entitled to legally.
  - b. **Communication and awareness of services** – Individuals and families report that when working with various government and community agencies the knowledge and awareness about other

government and community agencies and programs is poor. It was reported that there is a wide variability in the knowledge and experience of MCFD CYSN workers - some know about autism services in the community while others do not. Many individuals said that it was only by chance that they found out about a service that has benefitted their situation. Family members at several of the meetings reported that they were unaware of specific supports and services that other family members in the meetings referred to.

- c. The need for a single, reliable point of contact for families – Participants in all sessions emphasized the need to have one knowledgeable person (or organization) to call for information about what services were available in their community. Families expressed the importance of having a knowledgeable individual to provide credible information as well as support and assistance at critical points in the individual's/family's life to ensure access to needed services and supports.

## 2. **Inadequate Resources and Additional Barriers in Small Communities and Rural Areas**

– Individuals and families consistently report that there are simply not enough people to fulfill all the roles that are needed - SLP, OT, PT, respite workers, pediatricians, mental health, counseling. This is particularly true of the communities visited outside of the Lower Mainland and Southern Vancouver Island. Waiting times for services ranged from several months to several years (Vernon example). It was reported that some agencies are reducing service levels offered in order to serve more children and lessen waiting times, so that some children receive less service than they need. The issue of traveling costs coming out of Autism Funds through MCFD - and being capped at 20% - puts individuals and families in the regions at a distinct disadvantage. This situation can result in drastically reduced access to ASD services in these areas (one parent reported having to use  $\frac{3}{4}$  of her autism funding on travel time for professionals).

3. **Assessment, Diagnosis and Medical Services** - The issues surrounding assessment and medical services varied by community. One consistent concern is that waiting times for assessment are too long (varied from several months to more than a year for assessment and diagnosis of children under 6 and longer for children over 6). For adults, access to assessment and diagnosis is a much longer process. One family member at the Nanaimo meeting reporting a 3-5 year waiting period for assessment. For those living outside of larger regional centers such as Kelowna or Prince George, travel time and expense present prohibitive barriers. Many families – including many who report that they cannot afford to do so – indicate that they have paid private practitioners for assessment and diagnosis where this is available, in order to avoid excessive wait times and subsequent delays in funding and service access. Particular concern was expressed regarding limitations on the number of assessments which publicly funded practitioners are funded to provide. In one instance, a parent was told by a doctor that he could not

diagnose her child with autism because he was limited in the number of autism diagnoses he was allowed make in a year. Issues identified related to assessment and diagnosis include:

- a. Lack of access to adequate, timely, appropriate assessment and diagnosis.
  - b. Lack of diagnosis procedures for adults.
  - c. Lack of awareness of autism in the medical profession. Regionally, the lack of pediatricians and medical professionals with appropriate expertise was identified as a significant issue.
  - d. Reluctance of some doctors to make a diagnosis of ASD until child reaches a certain age.
  - e. Appropriate support for families during and following the assessment process – Parents highlighted the need for information and support during the assessment process. How families are treated during the assessment process and after diagnosis was a consistent topic of concern. While information (a large binder) is provided after a diagnosis, families indicate that they feel overwhelmed and cannot absorb information in this manner at this time. The variability of service availability in each community is a problem - many families leave the assessment being told they need to hire individuals to work with their son or daughter but many do not know how to do this and in some communities, parents report that recruitment is difficult or impossible.
  - f. Recognition and acceptance of diagnoses - Many examples were given of different assessments not being accepted by schools (K-12 and post-secondary), or MCFD (private assessments). Clear communication to families about what documentation is necessary and how to ascertain is needed.
4. **Lack of Family Support Services-** Many families report feeling overwhelmed during the diagnosis process and following diagnosis, and transition times are particularly difficult. Having a “one-stop” shop for information would help to alleviate stress, but access to family support services such as counseling and respite was also identified as a critical need for parents, siblings and other family members. Some communities had active parent or support groups of some kind while others did not. In several communities it was noted that parent-led support groups have been difficult to create and sustain without financial or administrative support.
5. **Lack of services for adults** – In many communities, participants expressed concern that there are few or no services for adults with autism. If an individual does not meet CLBC eligibility criteria or disability benefits criteria there are few, if any supports available. Many families reported the isolation and loss of developmental gains of adult sons and daughters who graduated from school, but have been unable to find employment, post-secondary education, relationships or meaningful activities outside of the home. Parents with children

transitioning into adulthood are deeply concerned about what will happen as they age. Desired services discussed include:

- a. Life-skills & social skills support and training - banking and financial planning, general housekeeping, grocery shopping, social/recreation activities.
- b. Employment supports and disability benefits.
- c. Assistance accessing and support during post-secondary education.
- d. Support for independent living, housing and in-home support opportunities.

6. **Training specific to autism for families and professionals** – One of the major needs identified in every community was the need for opportunities for training and education for parents and for all professionals involved with individuals who have autism – health care professionals, teachers, BI's and all related professions. It was emphasized by many participants that training opportunities must be presented in an unbiased way, that is, in a way that does not disproportionately emphasize one particular intervention approach.

Participants highlighted the need for:

- a. Training and education at all levels. Participants stressed the need to have opportunities to learn and advance skills at every stage of learning.
- b. Regional access – Participants in the regions stressed that existing training and education opportunities are primarily available in the Lower Mainland and cannot be accessed by those in the regions. If training and education are to be made available regionally, the need for on-going, consistent follow-up was stressed. The people working with the child on a daily basis need the support to be able to implement interventions properly.

7. **School and Education Issues** - Many issues with the school system were identified and discussed. While many participants cited excellence in their schools and among teachers, educational assistants and other professionals, other participants cited a lack of expertise and understanding in dealing with autism on the part of the schools and school personnel. Parents identified concerns about the quality of instruction, knowledge of roles and an inability to ensure consistent and qualified EAs due to union and seniority issues. Parents expressed difficulty in dealing with School Boards and administration staff with these issues and identified the need for support in advocating for their children.

8. **Inefficient Payment System for Autism Funds** – Participants in virtually all meetings indicated that the payment system for autism funding in the province is inefficient and slow and represents a primary barrier that serves to destabilize autism personnel, services, and supports. It was not unusual to hear of payments taking several months and stories of resulting staff hardships and instability. Parents and professionals also identified that the range of services for which funding was approved was unduly limited and did not take into account the therapeutic benefits of social and recreational activities.

## B. Common Themes: Hub and “spoke” Model Discussions

1. **Regional Centres /The “spokes”** – Participants in most sessions were primarily concerned with local services. Predominantly, participants emphasized that it would be beneficial to have one person that you could call for information about “all things autism”.
  - a. **Create Regional Centres First** - While many participants valued the idea of a “hub” a consensus emerged around the recommendation that the regional centres or “spokes” should be started before the “hub”.
  - b. **“Navigator” Role** (suggested as a good name for this function). This person would be:
    - i. Knowledgeable about all services (for all ages) existing in the community, all applicable government programs (and how to access, eligibility requirements, paperwork).
    - ii. Knowledgeable about the assessment process and could offer guidance and support.
    - iii. Linked into the hub and knowledgeable about what was happening there and how to link in. For example, if there was an innovative training program, the “navigator” could arrange for them to provide the program in the community. This person would also link into the hub to advocate for regional needs.
    - iv. Located in an office space but would spend time traveling to communities outside of the primary location. The “navigator” would not be affiliated with any service provider (location of office would need to be carefully chosen to avoid this perception) and would provide unbiased, evidence-based education and advice.
  - c. **Location and Amenities** – Some communities envision having meeting space with video-conferencing capabilities. In some communities this type of space may already be available and could be accessed for this purpose.
2. **Vancouver Based “Hub”** – The most useful components of a Vancouver-based “hub” or provincial centre were deemed to be:
  - a. **Clearinghouse for Best Practice Information** – Many people advised that a central body – the “hub” could collect and disseminate information related to ASD, best practices, etc., that could be available to everyone in the province through the regional centres and online. Some participants suggested that the hub could also be responsible to set and monitor standards. Many participants stressed avoiding “reinventing the wheel” and suggested that we learn about and from models that are successful elsewhere (e.g. Ontario, Alberta, etc.).

- b. **Advocacy/Watchdog Role** - In many communities, participants emphasized the need for a body that could receive and organize information about issues in accessing autism services regionally and provincially and with this knowledge, to advocate with all involved parties (government, college of physicians and surgeons, etc.) for adequate funding, quality services, increased accountability and coordination, resolution of individual and systemic problems. The need for affordable legal advice (particularly in dealing with issues in the school system) was strongly emphasized by some. Individuals and families also identified the need to increase public awareness and acceptance of autism.
- c. **Research** - Many communities visited expressed a desire for an institute or agency that could conduct research, link with research in regions and bring awareness of international research (vetted). Affiliation with a university and regional colleges was seen as important.
- d. **Training and Support** – Offered on site, as well as through “webinars” and other linkages with the regional centres. Training, like research, could be affiliated with colleges and universities. The hub could help to coordinate (and not duplicate) and increase accessibility to existing excellent training available for families and professionals. Could develop or stimulate development of needed training modules. Some participants suggested it may be better to have someone (experts) travel to the region rather than send people to the “hub”.
- e. **Family support and counselling** – Some participants suggested that both the “hub” and “spoke” centres could contribute to family support and counselling options.
- f. **On-site accommodation for families and/or people attending training** – While some participants (including many parents) were opposed to this function, others (also including many parents) felt that this, along with financial support to families for travel would be a valuable option for families. Objections related primarily to the idea that assessments in particular should occur in natural settings and that travelling to Vancouver for assessments was inappropriate.

## C. Divergent Views and Areas of Consensus

The following table summarizes a) issues in which strongly held divergent views were noted in discussions about autism services and the PAFC plans as well as b) areas of consensus or fundamental agreement among participants in discussions.

<b>Divergent Views</b>	<b>Areas of Consensus</b>
<ul style="list-style-type: none"> <li>Segregated vs inclusive settings (divergent views about acceptability of separate school, training and recreational activities for individuals with ASD).</li> </ul>	<ul style="list-style-type: none"> <li>Service levels are inadequate/current waiting times for assessment and services are unacceptable.</li> </ul>
<ul style="list-style-type: none"> <li>Willingness to travel to Lower Mainland for assessment/intervention versus demand for availability of all such services locally.</li> </ul>	<ul style="list-style-type: none"> <li>School system needs improvement.</li> </ul>
<ul style="list-style-type: none"> <li>Demand for an exclusive focus on autism (services, training, etc.) versus demand for a broader focus on all developmental disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>Little to no services exist for adults (who do not meet CLBC eligibility criteria).</li> </ul>
<ul style="list-style-type: none"> <li>“PAFC model not needed” (minority view, strongly expressed) versus “PAFC is an idea with potential for improving supports for individuals and families”.</li> </ul>	<ul style="list-style-type: none"> <li>Use PAFC to address the deficiencies in the system (inadequate services and supports, lack of coordination and information).</li> </ul>
<ul style="list-style-type: none"> <li>Local “navigator” should be a PAFC employee and not affiliated with service providers versus the principle that PAFC services should be integrated with and not replace existing services.</li> </ul>	<ul style="list-style-type: none"> <li>Inefficient payment system is a primary barrier which destabilizes autism personnel, services, and supports.</li> </ul>
	<ul style="list-style-type: none"> <li>Don’t duplicate services and do not use current ASD resources to fund PAFC.</li> </ul>
	<ul style="list-style-type: none"> <li>Transition to adult services needs attention.</li> </ul>

# APPENDIX

## **A: Community Focus Group Meeting Materials (sample from final session)**

Slide 1



Slide 2

## Vancouver Meeting Agenda Thursday, November 18, 2010

- 7:00<sub>p.m.</sub> Welcome; Meeting purpose and agenda review; Introductions.
- 7:20<sub>p.m.</sub> PAFC background, vision, goals, “Hub and Spoke” concept.
- 7:30<sub>p.m.</sub> Identification of current/existing service issues.
- 7:45<sub>p.m.</sub> Ideas for components and use of local/regional “Spoke” services.
- 8:15<sub>p.m.</sub> Ideas for components and use of provincial “Hub” services.
- 8:55<sub>p.m.</sub> Review of discussions; concluding comments.
- 9:00<sub>p.m.</sub> Adjourn.

### Slide 3

## PAFC Provincial Consultation Components

- Online survey
- Local public meetings/consultation sessions

### Slide 4

## PAFC Provincial Consultations

### Purpose

- Identify existing services in this community and region
- Identify how the PAFC can help to address service gaps in this community and region

Slide 5

## Local Public Meetings

### ~ Roles ~

#### Meeting Participants:

- Identify current service issues
- Share ideas and suggestions for PAFC planning

#### Fred and Dana:

- Facilitate and record discussion
- Accommodate needs of the group
- Accomplish the task (answers to 4 consultation questions)

Slide 6

## Group Norms for Today's Meeting

- Start and finish on time
- Everyone participates /No one dominates
- Share your unique and valued perspective
- Respect - one person speaks at a time
- Stay open
  - to a range of ideas (reserve judgment)
  - to new ways of doing things
- Focus on intended outcomes/questions, but capture all issues in recording/report
- Other group norms?

### Slide 7

## Pacific Autism Family Centre

### Background

- In 2008, the Government of British Columbia announced that it would support the development of a new centre for autism that would create a provincial hub for research, information and family support.
- Pacific Autism Centre Society (PACS) has worked with a large number of stakeholders in the autism community to develop a vision for the project.
- The goal is to build provincial capacity to meet the lifespan needs of individuals with Autism Spectrum Disorder (ASD), and their families.
- The project is in the early development stages and is envisioned as a "hub and spoke" model: with a central "hub" in the lower mainland and regional "spoke" centres located in communities throughout the province.
- Plans for the centre have evolved and will continue to evolve based on consultations and partnerships with families, organizations and agencies already operating in the field.

### Slide 8

# Pacific Autism Family Centre

## Core Purpose

*A provincial Knowledge Centre that brings together state of the art resources for research, information, learning, assessment, treatment and support to build capacity for addressing the lifespan needs of individuals with Autism Spectrum Disorder and their families across British Columbia. Our goals are to help maximize potential and achieve meaningful inclusion in the community.*

### Slide 9

# Pacific Autism Family Centre

## Guiding Principles

- We encourage the ongoing participation of all members of the autism community in BC.
- We actively foster, and benefit from, the synergy of bringing together families, practitioners, researchers and policy makers.
- We are a family-centered service organization.
- We customize our services to the needs of the individual and family.
- We maintain an environment that promotes innovation.
- We embrace evidence-based practice.
- We believe families should have access to information on a wide variety of therapies, delivered in a respectful manner.
- We strive to provide and advocate for fair, equitable and inclusive access to services regardless of location or economic situation.

### Slide 10

## Pacific Autism Family Centre Hub and Spoke Concept

- Serving the province is an essential feature of PAFC.
- The main “hub” will be located in the Vancouver area with regional “spoke” or “satellite” centres located in communities across the province.
- The physical regional centres will have full access to the expertise and information services offered in the hub location.
- The locations for the spoke/regional centres are yet to be determined.

### Slide 11

## Identification of current/existing service issues

1. What should the Pacific Autism Centre Society know about the current / existing services in this community and region?

### Slide 12

## “Spoke” Component and Service Questions

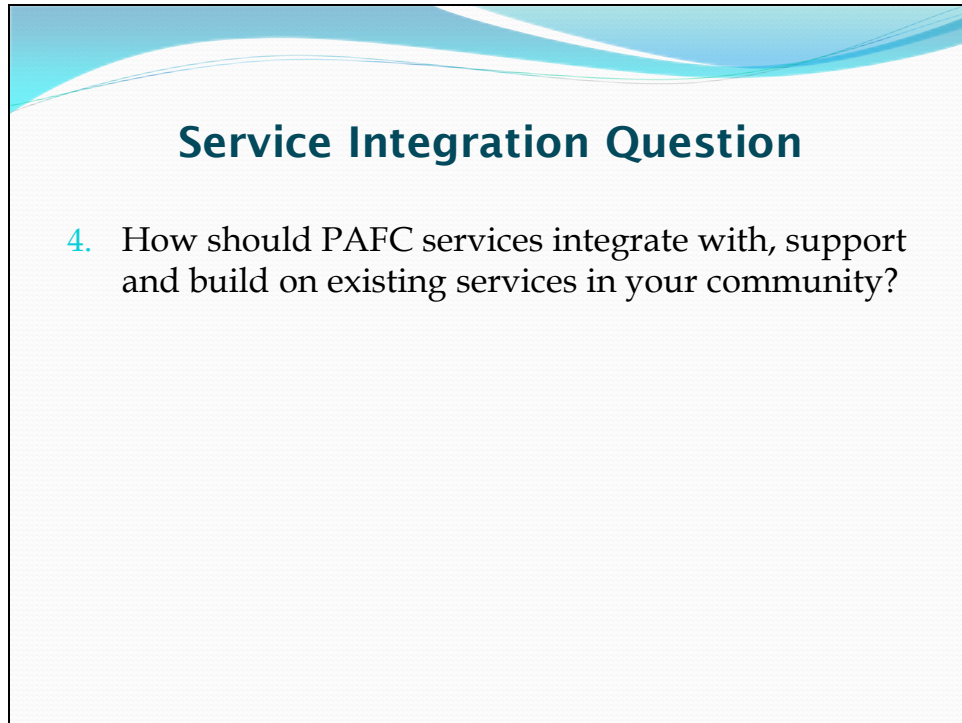
2. What should be at the “spoke” (in regions) that would support individuals and families in regions/communities?
  - a. What service components should be offered/ what should this service be (a person, place, services)?
  - b. How should these services be delivered?
  - c. Where would these “spokes” be and what kind of building could it be in or share?

### Slide 13

## “Hub” Component and Service Questions

3. What should be at the “hub” (Vancouver) that would support you in your region/community?
  - a. What service components should be offered?
  - b. If you visited the “hub”, what facilities would assist you during the visit - starting with arrival at the building?
  - c. What would the relationship between “spokes” (regional centres) and the “hub” look like?

### Slide 14



**Service Integration Question**

4. How should PAFC services integrate with, support and build on existing services in your community?

This slide features a light blue background with a white wavy graphic at the top. The title 'Service Integration Question' is centered in a bold, dark blue font. Below the title, a single question is listed as item 4 in a dark blue font.

Slide 15



**Pacific Autism Family  
Centre**

~ Thank you ~

This slide has a dark blue background with a lighter blue wavy graphic at the top. The text 'Pacific Autism Family Centre' is centered in a light blue, sans-serif font. Below it, the phrase '~ Thank you ~' is centered in a dark blue, serif font.

## Appendix B: PAFC Focus Group Meeting Notes

The following notes were recorded at focus group meetings throughout the province. Every effort was made to record what people said as accurately as possible. Notes have not been edited for grammar or to qualify statements made.

### Cranbrook Focus Group October 12, 2010

#### Participants

At this meeting, there were nine attendees including parents, grandparents and service providers.

#### Discussion

##### *Existing Issues & Gaps*

- Cranbrook now has two pediatricians (only for the last year); pediatrician is responsible for making referral. Previously would use Alberta Children's Hospital.
- IHCAN (Interior Health) sends doctors (out of Kelowna) to Cranbrook twice per year (typically only send a pediatrician and a psychologist).
- IHCAN says wait is about 3 - 6 months but is realistically a year. Can be seen more quickly if willing to go to Kelowna.
- Parent experience of diagnosis: had to go to Vancouver to get diagnosis and then they tell you you're supposed to hire this person and that person but they don't exist back in Cranbrook. If you do need to go to Vancouver for assessment need much more notice than two days (was told would lose spot) and everything is at your own expense. You get there and have no idea what to expect and are not told anything. To be able to stay on site would be very helpful. The whole process is very traumatic for families.
- Parent experience of diagnosis - was given an appointment for June in Kelowna (on waitlist since December) but couldn't manage to go to Kelowna and subsequently lost appointment.
- No SLP in Cranbrook right now (on maternity leave).
- Only one Behaviour Consultant in East Kootenays (Kaslo). None in Cranbrook.
- Within three months of a diagnosis a plan must be in place, is difficult to do with limited resources in East Kootenay area.
- Restriction of using only RASP - must fly many consultants into region which costs money and time. In addition, RASP only allows 20% of funds for travel costs.

- CYSN worker is involved but only really to help fill out forms.
- Issue with AFU - people not being paid for more than a month, potential to lose employees. Need to help working on bureaucratic issues.
- Huge issue - lack of behaviour interventionists. Community is looking at training up of Child Development Centre support workers. Difficulty in training BI's without Behaviour Consultants.
- Need a daycare setting where you can do behaviour intervention. There is nowhere to do it if you can't do it at your own home.
- Supported Child Development is designed to support the child being integrated into whatever activity is going on. Behaviour Intervention pulls out the child to work to do work that supports inclusion, but licensing rules, technically do not allow workers to leave the room with the child to do intervention. In reality, workers do it anyway.
- No OT/PT - only consults will be provided, there is nobody providing private SLP (on mat leave) and OT. Public OT & PT have huge caseloads. Would be great to have someone come even 3 days to do therapy and training, provide some mentoring to local assistants. Really need SLP to help develop social and language skills.
- Need babysitters and respite!
- Cannot access CYMH in Cranbrook.
- A lot of young adults/adults can be employed but have difficulty holding down jobs without support.
- Need support for depression and other mental health.

### ***Hub***

- Want to build capacity in the community. Hub could help to provide training support to build capacity in the community that way all money can go to direct intervention.
- Having one location to go to for information across the lifespan would be huge! Would be great to have one website to go to.
- Would want to have continued discussion with hub - so can say in 3 months - this isn't working and we need this instead.
- Like the focus on child-centered, family focused, providing wrap around services and supporting parents. Don't lose this focus.
- Very supportive of PAFC addressing lifespan needs - especially adults and teenage years.
- Should always be checking in with regions - make sure services are responsive.

### *Spoke*

- Kelowna wouldn't work as "spoke" centre for Kootenay region. More difficult to fly to Kelowna than Vancouver, particularly for low income families. Flights are cheaper to Vancouver.
- If "spoke" in Kootenay (more specific if East Kootenay) it would make the most sense to be in Cranbrook - has new hospital, new initiative to create Child Health Development Centre (Community Connections Society) to serve birth through 19. CHDC would co-locate Infant Development, Supportive Child Development, tele-health ability, would host IHCAN team when comes to Cranbrook.
- Would like to be in a physical space to connect with other people.
- Want training for parents, need to realize the difficulty of traveling for many months in this region. Sometimes it is very hard to physically go somewhere. Need to empower the parents. Videos and webinars are great but would also like to be able to go somewhere and to watch with other parent and have a chance to debrief. Or to even have a facilitator there as well - help build expertise in the group.

### *General Comments*

- Families that are able to make connections do okay with accessing and connecting to services, good community network on finding right services.
- It is hard on the parents/families that are able to connect - both parents can't work full-time, MCFD funding is not enough to cover hours of intervention that is needed per week. You find yourself going through interventionists.
- Those with intellectual disabilities or the parents could potentially be on the spectrum, fall off the radar – I don't know what happens to these people. Onus is on the parents (grandparents) to follow up and figure out what to do next. This group needs support - these kids become adults that need support (financial) because they are unprepared moving into adulthood.
- Existing services providers end up doing a lot of work off the side of their desk to help families b/c some aspect is not working out - service availability, finding services, and navigating paperwork.
  - Idea - It would be great to track families for a year after diagnosis to ensure connecting to services and doing okay.
- CYSN worker really only helps fill out forms doesn't really provide any coordination function.
- Would be great to have support before and after diagnosis, perhaps a parent mentor and could be someone on the phone. Create a resource pool of parents to call and can offer support. Help families move forward - empower them.

- Going through diagnosis it feels like your whole life is derailing and the professionals keep telling you that it will get better but doesn't feel like it. Just compare what happens with the support you get going through cancer.
- A lot of information online or in libraries is outdated, would be nice to have new updated information.
- Cranbrook has two snoozelin rooms.
- Parent experience - child diagnosed very recently at age 17 - do you sign disabled papers or not? Struggling with decision that will affect for the rest of life and there is nowhere to turn or talk to.
- For adults we do have some supported employment (REALM) but would be good to have more and there are no services for those over an IQ of 70. There is also a stigma attached with going to CLBC.
- Look at the name PACIFIC - too associated with coast and not representative of other regions. Maybe "spokes" could have more identifiable names.
- Would be great to know what people are doing elsewhere.

## Nanaimo Focus Group October 13, 2010

### Participants

At this meeting, there were ten attendees including parents, grandparents, service providers and professionals from the education sector.

### Discussion

#### *Existing Issues & Gaps*

- Hope there is no implication on existing funding for this initiative.
- \$6000 dollars not very much funding and concerned about difficulty of accessing funds and services. Wants to have recreation activities (CAN) where you don't have to educate everyone else, can just be yourself. Schools not doing a very good job, there is only so many resources, lack of skilled people to do a proper job.
- Concerned about service cuts and child will receive no services, get no support at college or university. Looking at potentially moving to Alberta where services are much better. Idea that your cured at 6, cured at 13 and cured at 19, no help in getting from A to B. Seems like often it is just chance that you find the right info/services. Took a long time to get services because of centralized services through BCAAN. Have to advocate constantly.
- There have been drastic cuts at every stage - pre-diagnosis, support at CDC's, school and transitioning to adulthood.
- Diagnosis - the whole process and getting funding took a long time. Fortunately, granddaughter lived in Surrey but still took 6 months. If it is hard to figure out how to go about everything and is even harder if living in isolated areas - might not know anything is wrong until the child leaves the home and enters pre-school.
- Wait lists seem to be about 3-6 months for under 6, over 6 has a lower priority but about the same time.
- Vancouver Island University asked for son to get re-diagnosed, even though the last assessment was within 4 years in order for him to get at any support at university, even though there is an info-sharing protocol in place. Was told there would be a 3-5 year wait list for an assessment, only other option is to pay \$3500 for a private assessment.
- If you get a diagnosis, some doors open but only if you know them. Received diagnosis through Nanaimo CDC and they did a relatively good job but they only find out about things by bumping into them. Your social worker is the person who should be providing this info to you.

- The system is too fragmented, you should have one place to call and figure out what to do next. Example of one parent only finding out about disability tax credit now and could have been claiming for years.
- There is a lack of resources - not enough OT/PT/SLP/BI - we need to increase the number of these professionals or figure out alternative ways. Parents need the info to be able to work with their kids too.
- Recreation activities - difficult when other parents and coaches don't know about ASD and why your kid is acting a certain way. Coaches need resources too.

### ***Hub***

- Would be great to have a central place - hub - that can put out information to the "spokes" - for example, a course offered following diagnosis, weekly sessions on various things.
- Everything is very piecemeal right now; need one hub that acts as a clearinghouse for everything. The hub could have all the infrastructure and receives inputs from local areas. Would like to see "spoke" person as a non-parent (when you're working with a parent they naturally focus on the age of their child or only know about services for that age), they would be a full time employee.
- Avoid re-inventing the wheel, there are lots of little organizations doing the same thing. Social workers have so many diagnoses under their mandate, they can't be experts in everything.
- Hub could serve local needs too - lobbying, research. Wouldn't it be great if the government came to you once you got a diagnosis. Hub should support local "spokes" but also allow them to be individualized.
- Hub should be doing work bigger than what the smaller individual "spokes" can do and be a face at a provincial level. Hub should have a great interactive website.
- PAFC should leave training to the educational institutes.
- A central hub was seen as very helpful - once you get a diagnosis you are heartbroken, it is too overwhelming and hard to go through all that information on the web.
- Would like to see hub take on advocacy, scholarships, work on issues in education system. Education and awareness about ASD is a need at all levels around the province.

### ***Spoke***

- It needs to be a person at the "spoke" (group agreement) - they must know about everything going on in the community.

- “spoke” person should be a full time employee that gets info from hub and can advertise, they cover a region and know everyone in that region.
- Workshops are expensive, videos and webinars are great.

### ***General Comments***

- ASBC is seeing many more grandparents involved in raising kids. Would be good to have support groups for grandparents.
- Questions about which comes first - hub or “spoke”? Same budget or separate budgets?
- The politics around diagnosis need to be addressed.
- ASBC does put out an information package at CDC but there is no option to have a face to face meeting, would like to but not enough funding.
- Paperwork is very daunting - it is a lot to take in at once.
- Attitude should be about accepting versus fixing.
- One grandparent took an online course through Douglas College (intro to behaviour analysis) which was very helpful, government funded half of cost. Enjoyed the chat group option. Parents want to know about the training that BI’s have and what they are supposed to be doing with your child.
- Community needs to come together in an inclusive way, advocacy should be left to individual non-profits.
- We need to be realistic about training teachers to be experts in autism. EA should be the person advocating because they modify/adapt behaviour not the teacher. Train people for where it will be most effective.
- There are a lot of great people already working in community. Marketing is always an issue for non-profits, would be great to have someone that could create one easy accessible and known location for people to go to figure out what to do next. Example of coach thinking kid on team might have ASD can go to website to find tips on how to work with kid.
- Having a constant person (EA) is so important, every year risk of losing your EA.
- Advocacy should not be tied to government funding. Issue of receiving funds and advocating against.

## Powell River Focus Group October 14, 2010

### Participants

At this meeting, there were seven attendees including parents, grandparents, service providers and professionals from the education sector.

### Discussion

#### *Existing Issues & Gaps*

- SD does receive services from POPARD, educators get access and families can access information and resources. Observations are done at school and families are always involved. POPARD consultant lives in Comox.
- We have different funding constraints in PR, it is very expensive to bring any specialists in - BC, SLP etc, kids are getting minimal amounts of service in school and a lack of consistency in getting services. It is easier for consultants to come from the island but you are restricted by ferry times and so can only see so many people.
- Can only use a certain amount of AF money for transportation, the rest is out of pocket. Travel costs can amount to 3/4 of your monthly funding.
- Often consultants won't bring car because of cost, so families must entertain and/or drive them around for the day.
- Training is very key, we need someone to provide training opportunities in town, need a continuous flow of training. Turnover is an issue. Not enough trained people in the community. If you're over 20 people leave to get education/training, come back in 30's to have family.
- You get all this funding but can't use it how you would like, very limited in the way it can be used and in the availability of people to spend it on.
- Currently there is no one in PR that is on the RASP, families are under-using funds because they don't have anyone to spend it on.
- PR does not have a team sent from Sunny Hill to complete assessments, however, teams travel to North Island through VIHA.
- Took one parent 10 years to get a diagnosis.
- Would like help with paperwork - transition from direct to indirect funding has been a struggle for families.
- Some people don't know the CYSN workers exist - they can provide assistance with paperwork etc.

- For the size PR does have good resources - would be great to have someone come to PR for a couple days every two weeks or so.
- Adults leaving high school - what happens to them, where do they go? Some adult services are provided by Powell River Association for Community Living (PRACL) but not enough. They need support to live as independently as they can - general life skills support.
- CLBC PSI initiative isn't meeting needs - many don't fit into this criteria and there are not the appropriate professionals to provide this support in PR anyway.
- Need supports for independent living and supported employment.
- Parent experience - son is in private school and finding it very difficult to navigate system. Didn't know about POPARD.

### ***Hub***

- It would be very appealing to have onsite accommodation. Going to Sunny Hill affects the child's behaviour, they should be in their own environment and with regular supports for a proper assessment. This can be traumatic for the child and result in invalid results because the child is behaving differently.
- It costs families a lot to travel down to Vancouver - time, money, stress, taking time off work. It would be cheaper to fly a team to PR.
- Like the idea of a research component - families need help sorting through the research.
- Onsite accommodation would be great, would have liked to have both parents in the same room during the assessment.
- If going to hub would like to see a "welcoming" person, they would guide you through the whole process, tell you who you are meeting with, why your meeting with them, how it fits into the bigger picture. This person could be a parent or a professional. There would be rooms with two-way glass so that you could see your child and know they were safe during meetings. Kids pick up on parents feeling anxious.

### ***Spoke***

- Would be great to have a Centre (& "spoke") to gravitate to and learn about everything and the Centre takes responsibility for dissemination of best practice information. It is too hard for parents and professionals to always be seeking it out.
- Parents are bombarded at time of assessment would be nice to have ability to follow up with doctors and team to ask the questions you forgot or to involve them in the assessment, could link in by phone or video and involve all the people that are supporting the child to help develop the IDP. This would also take pressure off

parents to remember what information they need to feed back to various professionals.

- Focus should be on continuing to build capacity in the community - for some families and kids it is not an option to pack everything up and go down to Vancouver.

### ***General Comments***

- Youth Transition Protocol - starting to identify transition plans for youth starting at age 14, but CYSN worker is playing catch-up and starting with caseload of people about to turn 19.
- Estimated that there is a fairly high number of people with ASD in PR. There was a support group in the past but it has dissolved (burn out, kids got older), PRACL is looking to start one now. Need to have outlet to bring people together, families feel isolated, provide some psychological support for families.
- Similar issues in Gibsons and Sechelt but have even less resources.

## Prince George Focus Group October 20, 2010

### Participants

At this meeting, there were ten attendees including parents, grandparents, service providers and individual on the spectrum.

### Discussion

#### *Existing Issues & Gaps*

- Extreme difficulty in accessing counseling through CYMH - they will not see you unless the individual has attempted suicide, otherwise 2 - 3 year waitlist for counseling services.
- Lack of services offered in the lower mainland being brought to PG (even when promised).
- Many or all are only in lower mainland or by webcast. Families must travel at significant cost. Bursaries are available in some circumstances (typically cover one day of workshop or part of costs) but do not cover enough costs to make it financially feasible for families from the north to attend. Attending one workshop or training session would essentially reach the maximum allowance of expenditures of funding from the Autism Funding Program (20%).
- Assessment - improvement has been seen because you no longer have to travel to Vancouver. Northern Health does assessments quarterly. The wait-list is 7 - 8 months where it used to be 2-3 years. Going to do a diagnosis in Vancouver takes the child out of their element, creates stress and will make the diagnosis less accurate. Northern Health can only do a certain number of assessments based on funding allotment. There are not enough services providers (private and public) to do all the follow up services. The team that does the assessments is flown in.
- Comprehensive Psychological Assessments leaving high school - their needs to be subsidies for individuals with lower incomes. These assessments are very expensive (performed by a registered psychologist). Employers/schools/universities will not make academic accommodations without an assessment. It makes it even harder for individuals on the spectrum to succeed without support.
- There are very few Behaviour Consultants in the whole of the north (2 or 3) and their caseloads are full.
- There is a barrier for those from the North right from Assessment. You must go to Victoria or Vancouver to get a behaviour plan. There needs to be a commitment to train people locally and to get them to stay here.

- The psychological assessments done in school are not good/consistent with more comprehensive psychological assessments done outside of school - (example) participant's son had a two-day assessment done with a result of an IQ of 138. The school did an assessment with someone provided from the school that had never met her son, spent 1.5 hours with him with a result of an IQ of 70. The assessment provided by the school was taken as the official assessment. Part of the problem is that school assessments are education based while Neuro-psych assessments do a whole battery of tests. Psychologists need to have more knowledge of autism.
- Everyone should have a right to psychological-education assessments (need to be broader than just education, need to look at adaptive functioning), it should be mandatory when leaving grade 12. Kids are leaving school without skills. If you did not have a TA in your 12th year at high school, you get no services at college.
- Sources/Gateway provides functional behavioural assessments in the north and has consultants in Terrace, Fort St John and Prince George. Also provide letters for autism funding. Currently have a two-year wait-list for services. Families currently receive one year of services but are looking at changing service delivery to reduce duration of service in order to serve more families and shorten the waitlist.
- Behaviour interventionists are the front line staff - there is a high need for these (trained). Need training for respite workers. There is an at-home program (through MCFD) but no respite workers in PG.
- School district is in chaos, parents are not being consulted or allowed input on IEP. When IEP's do happen it is fragmented, some schools use old format, some use new, there is no continuity. School District puts up roadblocks for private consultants working on behalf of parents. They are not being allowed to attend meetings and so parents have to go on their own. Apparently is due to union issues, seen as contracting out work, but is also not consistent among schools - some will allow private consultants and some won't.
- Adult services - would be great to have help with financial planning and management, life-skills, housekeeping, organizational skills etc. Example was cited that seniors get help with this type of services but not for adults with autism - if you have an IQ over 70 there are no supports available.
- CLBC PSI program - believed to be only 8 people potentially able to meet requirements in Northern region and only 4 have been able to access because of requirements around adaptive functioning.
- Individualized Education Plans do not exist in schools. Transition periods are very difficult, often meetings don't even take place.
- Would like to see workshops for kids, teens and adults on life-skills, anti-bullying, etc. Kids will often not take instruction from parents.

### *Hub*

- Role for centre could be in providing training for professionals, schools, parents, providing more behavioural support. Would be great to connect with UNBC to create training opportunities in PG, for people that are already here.
- POPARD has provided training (20-hour course) in PG for training Behaviour Interventionists, but is very expensive (approx. \$1100). Participant took training to work with her own child. Training should be available to all parents but at a better rate. Another example of Douglas College's online training courses. The need for more advanced training was also discussed for those already working/professionals in the field.
- Repository of knowledge, source of information and dissemination of information.
- Need for research opportunities and access to autism specialties within universities and training opportunities. Opportunities are restricted due to a lack of specialization in the north would like to specialize in Autism but no mentor is available. Not having training/education opportunities in this area at UNBC only further deters professionals from coming to PG.
- Recruiting and retaining professionals is an issue - there is no private practice OT, BC, SLP in PG.
- Affiliations with UNBC, UBC - O, College of New Caledonia, opportunities for researchers at universities. Would be great to have opportunity to take part/conduct research in home community and be part of province wide research as well. Need research conducted in the North - there are different issues here and research done by researchers living in the region would better understand the issues.

### *Spoke*

- See a hub in PG, bring together CYSN, CYMH, pull in professionals to bring in expertise, collaborative environment. Example - walk-in clinic.
- Prince George was seen to be the most logical location for a "spoke" but should really be three for the north - Peace River Valley, North West and Cariboo-Chilcotin.
- Example of traveling court system - based out of PG and visit smaller communities one day per week or once per month.
- Important to consider traveling difficult winter conditions, there are many smaller communities in the area and road conditions are very poor, if families in outlying area had to go to Vancouver it is a long drive to PG and then a flight on top of that. Better for services to go to the community instead of making families travel. The less stressful, the better the family and individual are able to receive services. Local pilots are able to fly in many types of weather and will fly to many places that Air Canada can't or will not fly to.

- There is a lot of medical activity going on in PG, PAFC could jump on the bandwagon. PG is a potential area for a mini-hub, easier for people from Fort St. John to get to PG (100 miles to FSJ). Anyone who is dealing with autism should be in the same place - pediatricians, occupational therapists, etc.
- Would be great to have a resource database to be able to look for resources. The “spoke” is a place that this could happen.

### ***General Comments***

- Concern was expressed around the possibility that the creation of the PAFC could reduce operating funds available to the agencies currently operating in the community. Question around where the operating funds will come from for the PAFC.
- The payment system from MCFD is a big problem, service providers are not getting paid, sometimes as long as 40 days.
- Currently qualifications are all over the place, no consistency of qualifications for people providing services.
- Look at Courtenay-Comox area - the city is very welcoming to those with special needs. The City employs a special needs coordinator that will help you access any type of info or activity that you need.
- Like the idea of womb to tomb seamless services. All ministries would need to be on board (Health and Social Development, Advanced Education, Education, Children and Family Development) to bring services together. CYSN and CYMH have a great framework.
- Tele-health is used widely and heavily in the Northern health region, not a new thing, there is equipment available wherever Northern Health is located and is an adjunct to service provision.
- Many teachers have archaic attitudes towards those with special needs. Viewed as dealing with those with special needs rather than teaching those with special needs. Policy should be practiced not practice becoming policy.
- There is a lack of public awareness about ASD in general.
- Ensuring services that are available in the lower mainland are also available in Prince George.
- Concern expressed about the difficulty in attracting professionals to the north.
- Concern about providing services to those over 19 because do not meet eligibility criteria and consequently those people are falling through the cracks.

## Fort St. John Focus Group October 21, 2010

### Participants

At this meeting, there were fourteen attendees including parents, family members and service providers.

### Discussion

#### *Existing Issues and Gaps*

- No services for families.
- CDC is over burdened, there is nowhere else for families affected by ASD to go in the community. The CDC is also limited in the services they can provide due to funding restrictions.
- The CDC is the hub for all services and resources, the MCFD CYSN workers is also a good resource and is very responsive. CDC has also started to offer hearing services.
- Number of services and amount of funding is much higher for Under 6 and once you turn 6 the same services - OT/PT/SLP etc - are much harder to get and you have decreased funding. You must turn to private services once you turn 6. It is very difficult to find these professionals in the community. Families need to have a Behaviour Consultant to create a plan but eats into a lot of the available funding and it is very difficult for families to prioritize needs.
- One parent has gone through 5 in-home workers, has funding for two kids and could give someone full-time work but it is too difficult to figure out the paperwork - essentially you are becoming an employer. Then once you hit 6 you get nothing. All your services and funding disappear.
- The transition into school is very difficult on families - services are available up until 6 and then they fall off, child has to transition into going to school, funding is cut, services are cut (lost all the on-on-one work), parents are trying to educate themselves. It is very stressful.
- School board has an SLP and PT but no OT. The PT is doing work that the OT would normally do. The caseloads for the SLP and PT are hundreds for one person. The School Board will not accept CDC OT information.
- Generally kids will have to be very high needs to receive anything once they enter the school system.
- POPARD does come sometimes but there is not much follow through, essentially you get a great report but that's about it.

- There is no central training location for finding and hiring behaviour interventionists. Parents don't know what BI's are supposed to be doing or how they are supposed to be working.
- Parents do know what they need, and we do have it in the community, but it is not under any one umbrella.
- Finding BI's is very hard on parents - they have to do a lot of work behind the scenes. It ends up that one parent stays at home and becomes the BI.
- Space to do intervention can be an issue - it is not always possible or practical for it to be done in the home but then you get into liability and community issues. Can do at pre-school but that is only to age 5.
- The CDC is a great resource, provides respite and skills work for ages 0 -19, has recently expanded into providing therapy for youth but there is not enough awareness of this in the community.
- There is a great need for educational opportunities for interventionists, parents, people working in schools and professionals.
- There are no opportunities to do intervention work after school out of the home. It would be great to have a supervised place - gym, place to play, or a quiet place to work on sensory issues - after school.
- Recreational opportunities specific to ASD are lacking in the community. Need to have one-on-one time to work on strengths and help support inclusion.
- CLBC has a day-program that adults with ASD can attend and offer some form of respite.
- Adults with ASD receive a disability pension and can get some respite services. Adults with ASD in this community experience a lot of isolation because no longer in school and have difficulty getting around on public transportation. Isolation is a big issue in this community.
- Participant was aware of a 23 year old with ASD that receives services at home twice a week. They just stay at home and are entirely dependent on parents for getting out into the community or for anything else.
- Gateway/Sources - the position is too small and covers a region from Fort Nelson to Mackenzie. Staff is burnt out and can only take a limited caseload. This organization is challenged because it is non-profit, does not receive any funding out of the AFP. Each consultant can only serve 4 or 5 families each year and they only get 120 hours per year (includes travel time). One year will serve FSJ, DC & FN. Next year will serve Mackenzie to Tumbler Ridge. Can only serve U6 and a lot of the families time is spend on travel time. Travel in the north can be very dangerous for a large portion

of the year. A solution would be to have a full time person in each community. The total contract hours also need to expand.

- Community Living Association provides some housing and can get a couple hours of home support but they have very little services and limited funding.
- If an adult with ASD has an IQ over 70 they get very little support (because of CLBC requirements for funding) - they are essentially out on their own.
- Families with kids that are high functioning/aspergers don't get or access services. They are also dealing with the stigma and will sometimes keep it hidden.
- Very difficult to diagnose as adults - there is no structure to perform an adult diagnosis.
- Need more social skills and respite programs.
- Parents need outside help because they are emotionally attached. Sometimes it is too hard emotionally to simply take your kid to soccer practice.

### ***Assessment/Diagnosis***

- The CDC co-ordinates the assessment team to come from PG but this is done off the side of their desk. The team will come into town from PG.
- One parent shared his experience in getting diagnosis through the CDC was very quick and workers were very helpful.
- One parent knew someone was wrong at 4 months old, was turned away until the age of one. Parent felt that success was contingent on their perseverance and ability to learn to use "their" language. Finally was able to get diagnosis at age 1 or 2 in Prince George. Also shared experience of niece's diagnosis that was received when she was 5 and was not accepted by the school.
- One parent shared experience of getting diagnosis - she was denied multiple times and had to fight very hard to get an assessment. Had to struggle very hard to get diagnosis and felt like medical profession treated her very poorly. When child's file and documentation was requested, she was denied by the doctors.
- Assessments are getting better in FSJ over the years. It is very difficult to recruit professionals to the area and to stay in the area.

### ***Hub***

- Would really like to see family housing at the hub centre. Would like to be able to get parent training while kids have therapy or other training/treatment sessions. Sibling support and emotional support for families would be great. The family is the support system for the kid with ASD but the whole family needs support too.

- Would be great to develop training modules - for example, for dental hygienists creating an educational piece to prepare them on how to work with autistic children.
- Experience of navigating the autism world is daunting even for parents that work in government positions and are well connected. For families not in this position would be incredibly difficult.
- Would be nice to have access to training from different methodological viewpoints, very helpful to see different types of training and new viewpoints.

### *Spoke*

- It would be great to have a training component for parents - teach them global skills, learn the “language” and basic skills on how to work with their child.
- Continuous education for BI’s is needed - particular for working with kids over pre-school age. Many BI’s feel like things get over their head.
- Would be great for once a month BI’s could access training, information and resources. You would create a group of BI’s that parents could have confidence in. These definitely need to be located in FSJ (group agreement).
- North Peace Community Resources could be the umbrella organization for an autism worker. They used to have a CYMH worker. It could be a natural fit for someone to be an autism expert and work out of this organization. CYMH worker has been brought back into MCFD.
- Felt that it would not work to have PAFC person associated with the CDC because of the age restrictions.
- Having a separate key autism worker to do research, could potentially be connected with the CDC because of the early connection.
- Participant raised an issue of First Nations Communities - would expect that they experience even more isolation. It would be important to reach out to these communities with the “spoke” concept.
- Support for adults, give them a place to belong, opportunities to connect socially, job support and opportunities, support inclusion in the community.
- Some place to phone and figure out what resources are needed/available - a repository of information.
- Help with finding BI’s, aid workers - some are great, others are terrible. Some people only want to work with older kids, some only with younger kids. Need more opportunities for social activities. It is difficult to find people that work with autism.

### ***North “spoke” - FSJ vs. PG Discussion***

- Important to consider that 7 or 8 months out of the year we can't get to PG. Don't really see a Centre in PG as helping to serve FSJ. If it was a choice between Vancouver or PG, choose PG but don't think necessary to have both.
- For some families it is a nightmare to go to PG and there are very few housing opportunities.
- Would rather go to Vancouver than PG, but there are financial barriers. Parents have to take time off work to travel anywhere, would be important to make programs available in the summer time. There is a hospital bus that goes from FSJ but it is not a good option for our families.
- This region will experience a lot of growth because of the dam being built. Important to consider.

### ***General Comments***

- It would be more helpful to have the professionals than the money.
- There is a perception that ACT is the governing body in BC.
- Comment that you can't find the professionals to spend the money on anyway, filling out all the paperwork is too stressful anyways.
- It was acknowledged that a collaborative working nature and team atmosphere is absolutely necessary.
- Physician in FSJ does work with families and follows ABBLS criteria, requires parent to do training and essentially the parent becomes the behaviour interventionist. Ends up doing a lot of coordination for families - not paid because it isn't treatment.
- Physician Parent - has been educating herself about autism because of son and in 2005 had to start home schooling her son and had to stop working in the community as much.
- There is a perception that people in Vancouver are more skilled than people here.
- Example of Quesnel - A women has started a private business where she provides an umbrella of services - creates behavioural plans, OT etc.
- CDC has expanded recently and has better facilities.
- Parent experience - hired someone from Victoria to live with their family. The situation was really great for as long as it lasted but then they left. Since then the mother stopped accessing MCFD AFP funds (has 2 kids eligible) because it was too stressful with paperwork and what it would cover etc. For the last 2 years has not bothered to access the funds her children are eligible for.

- AFU issues - swimming lessons are not covered by the AF. The AFU is so tight on rules and restrictions, everything is very black and white. The rules change when funding changes from U6 to over 6 and it becomes very hard to navigate and very confusing. Parents are burnt out.
- Would be great to be able to pool AFP funding to create a centre and get some of the resources that we want but can't sustain individually.
- More flexibility with funding so you can make better use of funding. School districts get to allocate their funding, why can't parents have more flexibility. Why couldn't the money go to community service agencies, with money attached to the kid and then they access services.
- People new in the field, don't know how to get their name out there but also don't really know what else is out in the community services wise.
- 3 full time positions are needed - one looks at co-ordination and training, one doing intervention work, and one doing behaviour consultations. Also need to look at training for families and parents. Consultants look at assessments holistically and create a plan geared towards where the family is at the time. Gateway/Sources is looking at ways to reduce wait-lists, rotating children so they can see more families but for less time - 2.5 hours 3 times per week for part of the year (not 12 months).

## Kamloops Focus Group October 26, 2010

### Participants

At this meeting, there were fourteen attendees including parents, family members and service providers.

### *Questions about Project*

Questions were asked about details of the project and some of the early reports/ideas of including a residential component and a swimming pool. Questions raised about how the announcement was made.

Expressed concern about difficulty working in the non-profit world and to ensure longevity. Where is the operating money coming from?

Why is this project getting government funding for capital construction costs while services are being cut, and where is the money coming from while services are being cut and waitlists are getting longer?

Question regarding involvement of ACT - already acting as a knowledge centre and there are already resources for research through universities.

### *Existing Issues & Gaps*

- Assessment experience - range of experience from parents from 3 months to 2 years.
- AFP is not enough - you can't bring anyone in on \$22,000 because of the travel costs.
- There is relatively no government provided services once you turn 19.
- Need of support for independent living - not a group home but more home based facilities, family orientated - want to create a home in the community with supports.
- Moving a child out of their environment changes everything, need to provide services in the home and work with the kid in their natural environment to see if services are working. There is nothing out there for adult services, need a Chris Rose Centre but for adults. Need supports to be offered out in the community, such as OT, SLP, music therapy and other workers skilled to work with autism.
- Sister wants housing and supports for her brother, but keeps getting bounced back from CLBC, her last hope is to qualify under the PSI but is fairly sure will not qualify due to the requirements and has not even been able to get an assessment.
- There are no available services once you turn 19, the perception is that you are cured. Activities that are available are piecemeal and it takes parental vigilance to ensure that they are being run properly.

- Want social opportunities to meet other people like him (adult brother), such as social groups. Would be nice to have a housing situation with support so that they can live independently.
- Parents are desperate for help - bringing kid up to one physician at the mall and asking for help and opinions.
- There are no standards in place for anyone working with autism after the age of 6 and no repercussions if they are not any good. The RASP standards are high but could be even higher. Look to examples of college/board in California as a model.
- Sister shared her story of her and her brother being flagged by CLBC as being in crisis but will still take another 3 months to even get an appointment to see if qualify under the new PSI. Could be faster but only if her brother was a student.
- Physician sent child to psychiatric colleague on query of aspergers but they said no. There needs to be a team in place to consult with because the kid was able to get through the assessment by acting normal but should have diagnosis of aspergers.
- Finding that there are a lot of kids of teenage age that don't really fit in with any services.
- Couldn't spend all the of the \$22,000 funds from AFP. Budgeted for certain services throughout the year but then couldn't find them in the community. Would like to see AFP cover a wider range of things - bio-medical intervention, alternative medicines have been great for child. Money needs to cover a broad range of things and used for unbiased alternatives.
- In late elementary and high school there isn't much, particularly for girls. There are some social groups for boys. Lack of services for teens, you get \$500 per month but isn't much to spend it on.
- Need a place for these kids to hang out.

### ***Hub***

- We need these services in the community, are you hearing in other communities that a Centre is wanted?
- Need treatment and support to address life-span needs but don't need this in Vancouver, need it in the community. It is too difficult to travel down to Vancouver. Kamloops is one of the best cities for services, did not have to wait a year to get assessment. Concerned about aging out once you turn 19.
- Mental Health should be at the table, there should be standards and accountability procedures in place.

- As a professional it is very difficult to keep up with what is going on out in the community, it takes a lot of effort. Communication needs to be better and less fragmented.
- Would like to see teams like in mental health - professionals (psych, social worker, etc.) working as a team. This would be great for ASD - the team can share the caseload, is mobile and integrated and would serve cradle to grave.

### *Spoke*

- Another “spoke” would just be another non-profit that is sucking money away from existing non-profits.
- The community is disjointed, but do have someone that helps you connect to family services (Betty Ann). The problem is in getting assessments and the lack of services after 6.
- There is a need to help coordinate communication but no need for a bricks and mortar facility - this could be done online. There is a community professional member doing this and is exceptional but is not paid enough and that kind of passion is unsustainable.
- It isn't just one person providing services, person needs to be un-biased and be able to connect you to services and there needs to be funding behind this. There is actually a spoke that is already here but this person needs to be funded for more hours and paid more money. She does this because of her passion.
- Parents want to come to talk to a co-parent, get parent-to-parent support for what they are going through, to help guide them through their journey. But is a bit of catch 22 situation - if a parent has bad documentation from a professional or they believe the price was too high, it is difficult for another parent or “non-professional” to criticize. There needs to be a layer of accountability on top, support for parents to be able to get services and provide advocacy.
- We need an advocate for funding, help to work through all the forms and documentation, to advocate with MCFD. Families are struggling through things they really shouldn't have to. This role, technically, should be done by your social worker, but they are essentially just signing papers and aren't really doing much of anything else.
- Training for parents is needed, help to access funding.
- Instead of a hub and “spoke”, why can't it be a web?
- Don't want a building but would like to see more training opportunities for professionals, more professionals and to help attract them to Kamloops and support to prevent burn out.

- It would be great to get seed money to help start/create support groups. We have building space already in the community that could be used for this but you need the staff time and funding to support and coordinate.

### *General Comments*

- In the new rehab centre we have no problem filling the beds but can't find enough staff to work.
- The idea of centralized services seems like a giant leap backwards, look at the Oregon model where people go to a centre to learn then go home and then there is the aftercare/follow up. Doing the follow up takes resources.
- There has been a building up of services but it is still patchwork, the EIBI programs were good but needed nurturing. There is no current mechanism in place for people to talk to each other currently. If you look at how brain injuries are treated in the medical profession, there are clinical leads that work with all the professionals and the treatment is delivered in home. There is no actual building that the team works out of. You also have to look at the financial side - does it make sense? The EIBI program in the Kootenays cost a huge amount per child.
- Parents are having to be advocates - had to advocate for services for years and kept getting brushed off.
- Concern about what happens to these kids once they leave high school. It is like once you turn 19 you fall off the face of the earth, you have no opportunities for further learning. Day programs are not allowed because if you have 2 or more people with a disability in one location is treated as a group home.
- Government is just downloading services to the community and there is too much pressure to offer generic and simple programs. Inclusion is not happening, adults are becoming isolated and lonely and services are drifting off. They put some money into the PSI but made it too hard for many to qualify.
- Lose of funding after age 6 means that we are undoing all of the great work that was done with ABA once the child enters kindergarten.
- Autism is treatable in adulthood and throughout the life span, individuals are able to continue to learn. A lot of the social-cognitive goals that are aimed for a younger age, my child was ready for them at a later age. Parents are having to save their money to have financial security for their child as they get older.
- There needs to be disciplinary recourse for parents. There are a lot of people out there trying to get your money and some parents are taken for a ride. It is a buyer beware model out there and we need to have checks and balances in place. RASP was the first effort to do this but need it for across the life span.

- There is a lot more people now getting a diagnosis or thought to have autism at a later age than there was before.
- There needs to be a minimum care pathway in place for autism - there is no accountability or responsibility mechanism in place to ensure a minimum level of care.
- Concern about families where the parents are not educated or don't have financial resources, if everything feels like a fight/like losing a war. I can't imagine what it must be like for others. Feel like I am having to trick services out of an agency (CLBC) when it is so clear that my brother needs help.
- Experience of working with two parents with special needs who had two kids with special needs, they struggled with getting access to funding through the AFU but worker can even help them because the AFU won't accept her. Parents shouldn't have to go through this and workers shouldn't have to wait 3 months to get paid.
- AFU is not even accepting calls and there is no option to leave a message.
- We don't need a Centre we need a program - Autism Services Program. It would create a service pathway, set standards and be consultative, provide advocacy, be a broker for services. Essentially provide a case manager function.
- You shouldn't centralize care for a common diagnosis.
- We have capacity in the community but need funding support.
- There are gaps in the community. We have wait-lists. I am angry money is going to a building; we could hire more staff if we had sustainable funding.
- One parent would like to move family but staying in Kamloops because of the services that are available.
- Acknowledgment that Kamloops is doing a lot of good things but there are still holes in the community. There isn't a ton of different models of treatment, lack of Behaviour Consultants, OT, SLP and appropriate staff to one-on-one work. Existing resources are stretched really thin already.
- Operational funding needs to be stable. Example of down to 1.0 FTE physio in hip hospital because all the funding that was initially given was reduced.
- Bullying is a problem in schools. There really should be a social goal in IEP. Kids come home tired and have had no productive work done all day but are too tired to do work at home.
- Any service or program should be offered in the home, should be accessible, cheap and focused on education and continuing education.

- Inspired by group of people at the meeting, would like to create an Autism Service Provider council in Kamloops to be a forum for sharing, help address holes and gaps in services. Create an Autism service team to perform medical outreach that is multi-disciplinary with less paperwork. This service team could connect to the council which is then connected to a provincial body. Similar to how a clinical lead connects to the BC Cancer Agency.
- Autism should be in the critical disease toolkit that is being pushed on medical professionals. Every GP should have more knowledge about ASD.

## Vernon Focus Group October 27, 2010

### Participants

At this meeting, there were five attendees including parents, service providers and a professional in the education sector.

### Discussion

#### *Existing Issues & Gaps*

- NONA (North Okanagan Neurological Association) is the main autism leader in the community and employs several behaviour interventionists that work with families. Nona has recently hired or is in process of hiring a behavioural consultant. Were given a house as a donation and are now running autism programs out of the house. BI's will be provided out of house rather than in home. House will be running life-skills programs, respite program.
- Without NONA there would be a huge void. Feeling was that they are ok, there isn't really anything else or the time to find anything else. Would be scared to lose NONA because there are no other options, but standards need to be in place. Need for increased services and options in the community.
- Feels like we are falling down at the door, the very place where we are starting. Services in the community are not interconnected.
- NONA has key worker that deals with ASD and FASD on staff (funded by MCFD) which is supposed to act as the liaison to community services, facilitate referrals to IHCAN, Okanagan Disabilities etc.
- It is difficult to work with kids on behavioural issues after school because they are too tired.
- There are a lot of poor, poorly educated, blue-collar families in this community (earning less than \$23,000). A lot of families on welfare and have no access to services, no access to computers. These people are difficult to reach. Experience of putting an ad for a job and many people applying were from job centers - limited access to internet.
- Resources in Vernon are very limited.
- Only able to use AFP if you have a behavioural consultant.
- Parents getting burnt out looking for BI's. It is very overwhelming to have to search for a BI, figure out what is required to hire someone, get WCB insurance, Ministry does provide some information on what you need to do but nothing on how to do it. Very quickly leads to burn out or some parents just stop accessing funding.
- Once participant reported that there are some inter-agency issues that limit/prevent staff from two of the agencies working in the same setting.
- Schools rely on the key worker- children are referred to the MCFD/NONA key worker from the schools. There is some confusion about what the roles are. The

workers themselves aren't always clear about what their roles are - they have large case loads and insufficient capacity.

- Currently there is a one year wait list for assessment in Vernon.
- Difficulty accessing respite in the community because of wait times and lack of individuals providing service. Families get \$233 per month which can be spent in someone to help watch kid while doing things like grocery shopping etc. There are three ways to get funding and services in community - 1. Receive funding directly each month (9 -12 month wait). 2. Get onto the foster family list which is a 4 - 5 month wait list. 3. Get onto NONA wait-list but they only have 30 spots and limited in the amount of hours you get.
- Assessments through IHCAN are done at NONA, it is the logical location but gives the perception of some blurring of the lines.

### ***Hub***

- Want parent support and information.
- Set standards and accountability practices.
- Concern that PAFC is going to be used to make sure that the government is doing their job. Duplication should be avoided, there should be some sort of regional advisory committee that knows the community in place for checks and balances.
- Should be a watchdog kind of group in place responsible to families. Something that is neutral - service providers are very territorial in their fight for clients, avoid having it pulled in one way.
- Need a provincial voice that can go after the AFU or service providers who are not performing their job.
- Hub needs to be informed by regional boards.
- Educational resources for professionals (autism specific - OT, SLP etc), someone to act as a school liaison, educational services for parents - e.g., of one-week immersion program.
- Advocate role, somewhere you can go to meet with professionals and your kids are being watched and you know they are safe.
- Communication back and forth from hub to "spoke" and vice versa. Can't actually see going down to Vancouver.
- Financial subsidies - financial barrier to go down to Vancouver, someone to watch your kid while you are there, some sort of intensive program for a couple days. It would be great to have a place to stay.

- The Hub shouldn't be a place that families have to go to, it should have video, teleconference, webinars available to the communities. Look in SMILE program.
- Would be great to have affordable legal advice and help available at the hub. Getting legal help is too expensive for most so you don't even try.

### ***Spoke***

Would be great to have information workers, like the key worker position, that was educated about community services and gaps and could have access to the hub as support if needed. This person would need to be aware of private providers.

Need an autism "ambassador".

When parents get a diagnosis they are lost – "leaf flying in the wind" metaphor. Need mental health for the family - family supports, counseling.

Need to strengthen the parents to avoid burnout, also helps to avoid divorce and lessen the problems created down the road.

Would be nice to have a person in the community that you could go to for help and information.

As a parent, it would be great to have someone to connect with post-diagnosis. It is currently a 4-month wait to even see the CYSN worker. Example of position in Campbell River - disability coordinator position paid for by the City.

Would be great to have one spot to check - a coordinated list of people you could access. This could be the "spoke" role. This individual would need to be independent of existing service agencies.

The key worker/info officer should be someone attached to an assessment team and should be specific to family supports. If a family gets a diagnosis - that person should be able to say: here is your social worker, here is ACT, point you to resources and help to guide you through the process of working with the AFU and provide some counseling support.

There is lots of expertise already in the community, would be great to have somewhere in the community that could connect in by video, observation room to the hub. Use Skype so you could actually have the kid in the room.

Lots of parents don't have access to computers. Would be great to have laptops loaned out so that they can connect by Skype or watch webinars etc.

### ***General Comments***

- Questions about Steering Committee - would like to see a direct service provider on the Steering Committee.

- It is a bit hard to swallow when travel money is coming out of AFP monies which is supposed to be for treatment and intervention.
- There were 4 sites for EIBI programs - Kamloops, Kelowna, Penticton and Vernon but these are now closed.
- Would like to see more Canadian experts used rather than Americans being paid big bucks to come up for seminars and workshops.

## Kelowna Focus Group October 27, 2010

### Participants

At this meeting, there were fifteen attendees including parents, family members and service providers.

### Discussion

#### *Existing Issues & Gaps*

- Assessment - feel Kelowna is doing ok, from time of referral it is about 3-6 months (Under 6) to get an assessment, if you are over 6 it is longer. The issue is that families are waiting for the referral as well, although you can be on the wait-list simultaneously. Is there follow up for people waiting for assessment to avoid them falling off? - An Infant Development workers or OT is attached to them.
- One parent said it took 14 months for a referral to IHCAN.
- Overall, more kids are being referred now.
- Penticton only gets two assessment sessions from IHCAN done every 3 months which are done at the CDC, CDC provides the OT and SLP and these parts can be done before IHCAN gets there. This has moved up from only doing 2 sessions a year previously. The same psychologist that is used in Kelowna is used in Penticton; this is for U6 only.
- Seems like it is dictated by the psychologists' timeline, there are certainly more kids than that who need assessments. IHCAN needs more professionals.
- If over 6, typically the school or CDA refers and it is a 1 - 1.5 year wait for assessment.
- We do have a two-tier system - some people are paying to get assessments. The OK Ability Centre has the contract with IHCAN to do assessments but also offer private assessments from a private psychologist. Some people pay to avoid the wait. Need to recruit more professionals.
- Seeing more kids come in for assessments after 6 because some pediatricians won't consider ASD until after 6.
- Know of some families that will go back for a second assessment at Sunny Hill if don't get diagnosis right away - double dipping, however is not the norm.
- Need more staffing in the school system - there is a lack of specialization. There needs to be better mechanisms in place to match the right EA with your kid and for them not to be moved because of union or seniority issues. Currently, it is pretty much luck of the draw on who you get and their ability/expertise to work with your

kid. More free educational opportunities need to be provided for EA's - they are expected to do further training on their own time and you just can't expect everyone to do that. School district did put on a one week program for autism but not mandatory.

- Public perception about autism is still outdated, need to get more accurate info out there.
- Teachers don't have enough training, even resources teachers don't have enough training specifically in autism. Inclusion is required but teachers are not prepared. Further - there needs to be more credible information available, some information is available but people don't know how to use it or implement that information when working.
- There was a support group in Kelowna but it sort of petered out.
- Everyone agreed the current payment system with the AFU is a big problem. Some people have been waiting since July for payment - creates huge problem to try and to retain workers or attract people to the field. When you contact the AFU they tell you they have lost your email or information that was sent in. Ultimately impacts the kids because they lose therapists.
- There is a big gap with the CYSN workers - families go there for forms and information but the worker doesn't know anything plus they change so frequently. It is very frustrating for families.
- There is no link between assessment and intervention, especially for over 6. Group did not see that it should be the CYSN worker who was doing this. You are given a binder but no help/assistance to utilize any of the information or no help to move forward. You're in shock after diagnosis, parents want someone they can talk to and get help and to not be steered in one treatment direction. Whoever is doing this needs to be objective with no biases.
- There is essentially nothing for adults over 19.
- Mental Health services are badly needed and support at transition times, lots of secondary health issues.
- Kids in high school need training of vocational skills in real environments, kids are leaving school with absolutely no skills.
- ECE and many teachers know nothing or not enough about autism. Training in autism should be mandatory, there are programs offered but is optional and on their own time.

### ***Hub***

- A role for the hub could be to set standards, conduct hands on research based on practice and feed that back out to the regions.

- Would be really nice to be able to go online and see who is qualified in various areas, all current info available is very piecemeal. Create a regional handbook - list SLP, OT, PT, respite and qualifications and all these have been vetted by someone. Could be a role for PAFC.
- A role for PAFC could be as a watchdog, making service providers, government more accountable, to be an advocacy organization and to encourage collaboration.
- Travel is often very stressful, if don't have to go to hub would be better.
- Would like to see education at the hub but with webcasts offered out to the "spokes", affordable educational opportunities. Many employers have a cap on the amount of continuing education available and it often does not cover very much.
- Look at Inspire Health - cancer research hub run by medical doctors, PhD researcher filters everything. There is lots of crap out there would be nice to know someone qualified has filtered the information. This could be a role for PAFC.
- PAFC could play the role of helping to find job - supported employment. Estimate that something like 80% of adults with aspergers are not employed but they could be, they just need support. PAFC could work with employers on hiring and education. Could it offer incentives to employers for hiring adults on the spectrum? Example of one community member working at restaurant - working out great, he loves working as a busboy, has a great support team and has been very successful but this was a one off thing.
- Could the hub influence courses offered at universities or make autism education mandatory in teaching programs? Opportunities to get to the next level education/training wise are also needed.

### *Spoke*

- Would be nice to have a local representative to take these issues/be a liaison to the government.
- Location - Conflict if associated with a service provider - must have no personal investment.
- Everything that can be should be available online.
- More continuing education opportunities here in Kelowna, or by webcast. It is very difficult to get Board Certified - have to go to Vancouver to get the right courses. Would be great to have the possibility of getting board certified here.
- Physical place in Kelowna for parents to get resources, they often have a lot of information but need help putting all the pieces together.

### *General Comments*

- Question about ACT's involvement? Don't want just lists, needs services too but last thing we want is someone in Vancouver telling us how to our job.
- One BCBA said she was unable to work in the school district even though she has additional credentials and has worked as a special education teacher but because she is a private contractor, she is not allowed to work with client in school unless it is a catholic school.
- There should be standardized training to work in the field - if someone is working with over 6 the only requirement is that they have a criminal record check. Under 6 is more stringent. It is important to know that people working with your child have appropriate training.
- It is so daunting to figure out how the funding works, would guess that all the paperwork and reimbursements deter people from going into private practice.
- Would like to see proof that the cutting of EIBI programs has actually made more money available to a larger amount of people.
- Needs to be funding to encourage collaboration between psychologists, OT, PT etc.
- The issue of key workers for FASD - if you get a diagnosis you have a key worker attached. Most kids diagnosed live in rural areas but there are no services available. Recruitment issues are important, need to look at wages and retention.
- The over 6 funding is not enough to hire a team.
- Would like to have a physical location where people can connect, there is nothing for over 6 and adults in this community.
- Seems like this is moving back to a centralization of services, don't want to do this.
- Feel like information from ACT is biased.

## Victoria Focus Group October 28, 2010

### Participants

At this meeting, there were approximately 40 attendees including individuals on the autism spectrum, parents of all age groups, community support group members, education sector and service providers.

### Discussion

#### *Existing Issues & Gaps*

No services for high functioning adults - if your IQ is too high there are no services available in the community. While there are services for adults with other disabilities, find that these service providers are not trained to work with ASD individuals.

Would like for son to be able to access college. New research is showing that ABA therapy is still useful after the age of 17 but there are not resources to support this - people trained to provide service or funding to support. Ongoing therapy is necessary, miracles don't just happen before 6. A lot of young adults with ASD are employable or want to go college but need supports.

There are adults in the community that suspect they have ASD (Aspergers) but are going undiagnosed - see doctor but they say they are fine. Need more awareness in medical profession and diagnostic tool for adults.

There are no private diagnosticians in Victoria - must go to Lower Mainland.

One adult shared experience - took 7 years to find someone to see (through Victoria Mental Health services). They told her she couldn't have ASD because she was a girl and was too smart, that she was that way because her parents sucked. She was on disability and ended up getting diagnosis because was required to in order to access vocation support services while on disability.

Families are being forced into poverty to provide services for their children - experience shared of one family on 5th mortgage.

Parent with son that has co-morbid issues - bipolar, ASD, OCD. Very difficult to get any treatment that addressed the cluster of issues going on, need a range of services for all ages that take into account co-morbid issues - you can't treat issues in isolation. Parents are providing all the support for their children and it gets very challenging for them.

U6 families get a large amount of funding but once you hit 6 everything decreases drastically once you enter the school system. The thinking is that the school system will pick up the services but in reality it doesn't work out because schools are underfunded, your child doesn't necessary get the services they should be getting.

Over 6, in the school system - kids are waiting to see the district psychologist, waiting to see the doctor, waiting for services - taking too long, they need support.

There is only a certain number of SLP, OT in the school district - you are lucky to get a 15-minute consult for the whole semester. These professionals have huge caseloads.

There is no BC (someone else said there is one) in SD61 - one person to look at all behaviour issues in the whole SD and they have no specialty on autism. Teachers are scrambling and they have a lack of education on autism as well. There is no behaviour intervention for kids at school.

EAs assigned to your classroom just basically manage your kid, no therapy or intervention is given. If your kids need certain items parents must pay out of pocket, usually things are very expensive and end up disappearing.

A teacher shared that the majority of teachers have no specific training in ASD, the SEA might have some special training, POPARD offers a crash course but is really only scratching the surface. Teachers end up going to the parents to ask what works with child. Behavioural plans are great but useless if you can't carry them out, things are imploding at the teaching level. Training for ASD should be mandatory.

One parent had great EA for son in grade 1, invested money over summer for them to train and when entered grade 2 the EA is gone because someone with more seniority wanted position. There needs to be mechanisms in place to keep EA's that are working for your child with them.

Group agreement that payment situation is not working. Even a meeting with Minister Pollack directly gained nothing - acknowledged the issue and agreed with the studies that show early intensive therapy works but nothing has been done yet.

Problem with federal inconsistencies in diagnosis procedures - moving between provinces had to have child re-diagnosis, just clogging the system. Inter-province diagnosis should be possible.

Ongoing immediate support for newly diagnosed families is needed - need grief counseling, support for the parent's relationship. Therapy for the kid won't be too useful if the family is falling apart.

### ***Hub***

Would like to see more programs with ASD on career planning, education, seminars to support independent living and community inclusion. Look at example in Ontario. Role for PAFC - advocating for families.

Would like to see “spoke” & hub rather than the other way around, regionally based. Don’t necessarily need a building, that would be the last place for his kid.

Would like to see mentoring opportunities for adults with ASD and young kids with ASD.

PAFC should use existing organization in communities.

Would like to see an advisory council of individuals on the spectrum.

Need a place that the government can go to find out what is going on.

Would like to see the hub being more focused on education - know where the resources are in Victoria (another parent approached after said there are many parents who don’t know where the resources are) would like online courses or weekend courses.

Need for coordination and to create political power, somewhere for parents to go because they are having to go out and learn on their own. This can’t be done off the side of your desk, needs funding support.

### ***Spoke***

There are already parent advocates in the community - these people should be supported.

### ***General Comments***

Some parents opt for independent schools because funding for your child is more focused on that child, but this is at financial detriment to the parents.

One individual on the spectrum shared experience while in school system - got put in with special needs but is high functioning. Wasn’t what he needed because it was geared towards a lower intellectual level and he was bored. He did not get the services he needed in school.

Hope that PAFC planning looks at other organizations and how they are dealing with transition times - e.g. Down syndrome institute. Course at EMI on relationship skill building would be very useful.

Lack of people trained adequately in ASD - went through 3 -4 BI’s, a BA in psych has no standardized training to work with ASD. Need standardized training as proof that they are trained in autism.

Need for more programming, more money, more resources and professionals - but how do you do this without government involvement to coordinate at a higher level. Wonder how much with PAFC initiative will really be done? Feels like we had this when we had the EIBI programs - it was making a real difference and then it was cut, how are they going to make a commitment to truly make a difference?

Concern about sustainability - track record of government cuts, how is this going to be sustainable?

Parent experience - school system has been dismal, 2 kids in class with ASD and daughter needs one-on-one help but someone just basically sits beside her. Moved to home schooling, she now stays at home and it has been wonderful for child but has been financially very hard for family.

Concern that once we have a Centre like this everyone will forget about ASD - blue box example - now we have blue boxes so we don't have to worry about recycling anymore. The reality is that it is a full time, forever commitment for families - costs around \$80,000 per year and families have to take this on. Divorce rate is very high - 80%

Individual with Aspergers - concern about "mainstreaming" our kids. What can we do for people like us - different but struggling along at own pace. The reality is your kid is being bullied the second that EA leaves the room - we need to take care of our own. ASD spectrum - more than just Aspy's many of our kids have serious cognitive difficulties and may never get past grade 5 or 6 in cognitive ability but are very social. Need to accommodate everyone and individual needs.

Parent experience - kid was bullied with EA now refuses to have EA but really needs it. Great social thinking program in California.

Concept of hub and spoke is very paternalistic - services should be based in regions and it should be a network between regions. To imply wisdom is flowing out of Vancouver is silly, we should get away from the focus on a building. Services should be portable and local. All of the things that are being talked about can be done without a building - colleges, schools. More money to services and less to real estate.

Individual with ASD - long wish list of services that I would like to see. Started a support group and am now flooded with emails asking about services, info. Would be great to have a building, resource centre or liaison person who has knowledge to contact.

The law is not being followed in the schools, it is being violated systematically. Would like to see some legal advocacy/watchdog (group liked this suggestion) role to enforce that legal rights are being upheld. Regional organizations to act as watchdogs. EA's are mandated to have instructional control not functional control. Parents have to act as the advocate, but things only get done if they are assertive.

Difficulty with spending all this money to do something that should be done by social workers, to ensure that government is doing their job.

Social workers don't feel good about not being able to call you back or not being able to help you, their hands are tied.

Individual with ASD - trying to deal with a social worker or government workers was very difficult, parents had to get a counselor to go with me to advocate and help explain

needs because could not do on own. Only got diagnosis because had other health problems (recently - past summer) and had been going to a psychologist all his life. There are zero services available for him.

Parent experience - get diagnosis, given funding but have no idea what to do, don't know what is available and the social workers don't know either (even if you can get a hold of them) - need something that is un-biased and someone to help you connect. You are given a binder but have no idea what to do with it. As a parent just getting the diagnosis you are a deer in the headlight, any info you are getting you can't really take it in at that time.

We all know that we need more services but there isn't enough people to do these services, have funding but can't get the services, parents are quitting work to home school and losing an income. We need to think outside the box, look at tax cuts, incentives etc, different ways to channel funding.

EA's are being refused training by SD - need a vehicle to help bring training in, it seems there is no communication between MCFD and MoE.

Figure out a way to get what is already here running better. Had the start with the EIBI programs - need to be bigger, address the life span and address the wait list issue. Got diagnosis in California at age 4 was referred to a regional centre where could get diagnosis and counseling, family support, sibling support and therapy. Wonderful program - professionals were dispatched to you locally and it was all paid for. Experience in Canada - met social worker once in 6 years.

Need traveling, portable team that has funding attached to it to support the regions.

Description of parents as suffering, patient.

Need an organization that can be independent of government to put the feet to the fire - corporate memory is only two years. Need people outside of government with lifelong interest in ASD and that are in it for the long term in a solid determined way.

Nothing will happen without a government that will take ASD seriously - building a centre is a typical Gordon Campbell solution, should try to restore resource centres, get social workers involved and specialized in autism. Need a ministry of autism!

Instance of an adults being diagnosed as an adult in the forensic system.

Parent - invaluable to have an independent watchdog and opportunities to learn new therapies and to have a neutral space, many parents don't want to go to a support group.

Autism is very political, need a group that can be un-biased and independent. Look at Alberta, different groups work together with little competition to provide the best services they can for kids. Don't see a coming together from different groups to create services for the individual here.

Teachers need to be educated but doesn't happen unless there is staff buy in, if only 2 staff want it you won't get POPARD to come in. Training should be mandatory and for EAs too.

Support for a de-centralized system, A centre that isn't a centre - would like to see Universities involved, research, education, training, therapists - all at different levels of training, critical to be able to train more.

## Chilliwack Focus Group November 3, 2010

### Participants

At this meeting, there were approximately forty-seven attendees including parents, family members and service providers.

### General discussion – Existing Services, Assessment, Gaps in Services

PAFC project is a big surprise, wondering what the impact is on existing services? We are already stretching for every dollar now, would like to see financial assistance with this project.

Experience of living in 3 different provinces, in BC “aging out” is a concern, age out of U6 funding, age out of the education system at 18/19 and then there is nothing, no funding or services available.

There is no child/youth psychologist in the area and even GP’s are not familiar enough with Autism. Lack of specialization in autism in the medical profession/community. They are the front line for families and feel like they just shrug their shoulders and don’t know what to do.

Took 1.5 years to get an assessment.

Daughter was in public school, teachers thought something was wrong and said she should get assessed for ASD but only two kids per year could be sent through the school. Ended up getting a private diagnosis in Mission and had to pay.

Took 2.5 years to get an assessment through FHAN, they said no ASD and parent knew something was wrong and ended getting a private diagnosis.

FHAN has ceased to exist since May 2010.

Grandparent - knew something was wrong since age of 2 but took until 5 to get an assessment and then only had 1 year of the U6 funding, took 6 months to see a pediatrician.

Mom - knew something was wrong, took one year through FHAN to get an assessment, they said no ASD, eventually went private.

Son was diagnosed at age 6 and was already aged-out of U6 funding, kept son out of school for a year b/c not ready but then not eligible for pre-school services. Took 2 years to get respite, took 4 years to get a behaviour consultant, took 1 year to get an assessment but with strong advocacy. Gap for families without savvy/ability to advocate.

Some participants had had a good experience with diagnosis but all were generally conducted in Vancouver (Sunny Hill).

Parents who can't afford to get a private diagnosis, their kids end up in the school system undiagnosed, schools don't get funding from MoE, teachers are overwhelmed and the kids don't get the services they need to succeed.

Went for assessment at age 6 through FHAN but no diagnosis. At age 10 was diagnosed with Fragile X and continued to struggle with FHAN & BCAAN and was finally given a diagnosis at age 14.

The reality is that parents are having to educate themselves about everything before going to see any doctors to advocate and to get proper treatment.

Child in Maple Ridge school district - only getting 2 hours per day of Educational Assistance, there is a serious lack of EA's in the district.

Parent of two kids with ASD - youngest, at age 2, was thought to be deaf was able to get a very quick appointment for assessment, unfortunately there was no services available at the time (1998), second son was "normal" until age 9 ended up having to get a diagnosis privately at SFU and pay \$3500 which was not reimbursed by the AFU.

Parent - could see something was wrong, thought son was deaf and ended up at Sunny Hill with an assessment - took 9 months of her calling every day and finally got a cancellation.

Seems like you can get quick service if willing to go to Vancouver or Richmond - hard to do if you are in crisis.

Went to ABLE Clinic in Surrey to get diagnosis - know lots of families that have done this as well.

Impossible to find an SLP (son is 19) that can work with adults.

School aged kids are not getting what they need - the school system isn't picking up services and only the kids that are the most neediest will get services.

We get reduced funding because the school system is supposed to be picking up services but this isn't happening.

MCFD won't allow Speech and Language Assistants to be covered under the AFP.

Most of funding in schools go to EAs - SLPs and BIs are way below EAs in priority. Is a catch-22 - can't get a diagnosis but then the school doesn't get any funding and your child won't get any services.

The \$18,000 for you child doesn't actually go to your child in the public school system. Distance education schools do provide more services - there is a huge discrepancy.

End up with a situation of piggy backing - two kids will get the support from one EA, it is not a good situation.

One parent shared that that principal said that there were other kids with similar issues and that their EA needed to be used to help those other kids too.

Finds things that would like to spend AFP money on but there are huge waitlists so you can't even spend it.

One parent requested a forensic auditor because their child wasn't getting any services in the school.

An EA shared experience - have taken all courses offered by District, am now expected to implement learning with no time or support given. There are no teachers or resource teachers that can offer support. Need follow up opportunities with professionals.

Asperger's kids with no behavioural problems get almost nothing and are given no social skills training.

EA's and similar professionals are in a rock and a hard place - there is an obvious need for more people working in this area.

In Surrey and Langely school districts - therapists are trained to work in this area.

Need to ensure when talking about high functioning kids that recognition of core challenges are the same, careful not to assume they need less service. They may be functioning well but there are other issues - social gap can turn into mental health issues etc.

CYMH runs some support groups for anxiety in Abbotsford through MCFD for kids aged 15 - 18 which is useful but specific to autism - uses dialectical behaviour therapy.

Very little respite for parents available - very hard on a marriage, two year wait for respite.

Son is non-stop, they wear you down, even having 3 hours to just go for a coffee would be great.

After-school activities - acceptance of our kids with ASD in sports leagues. If coaches don't know about ASD they are reluctant to take them. Need to provide some education about ASD.

Canucks Autism Network will pay for your kid to do sports and provide one on one support and do sponsor camp Sajak. CAN in Chilliwack has now been cut have to go to

Abbotsford now. Another program is Kids in Action - they will match volunteers to your school aged kids.

You get a diagnosis but are left wondering what to do next. Need someone to help you navigate the next steps and learn about what to do next. Need someone who will give unbiased information and can provide some support. This role is not funded because it is not a direct service.

Travel money should not be coming out of AFP funds. It seems consultants are making a lot of money out of travel costs.

No parent support group in Chilliwack right now - one is shared that alternates between Abbotsford and Chilliwack.

Need legal assistance for kids when they turn 18, need affordable legal advocacy. Should increase the minimum mental health allowance.

There is no recreation director for Chilliwack - this person would ensure services are in place, their job is to meet community needs and help direct funding.

There is nothing in place for high functioning adults to help them become productive members of society which they can be. Need supports for teens and youth to get summer jobs, should be recognition for employers too.

Personalized Supports Initiative is too restrictive, parents are not even applying. Majority of kids ageing out of services are on their own.

Concern about funding once turn 18 and supports to access post-secondary.

University of the Fraser Valley does have a year long fully funded program, most of students are successful in getting grants - called the TASK program. Works on resume development, inter-personal skills, looks at interest and tries to match them with jobs. Course available in Alberta on independent living would be great to have here - hard for parents to teach these skills.

Parent of a son in his twenties discouraged because it doesn't seem like any progress has been made since her son was 2. Son has had employment but was too stressful, needs social support, lifeskills coaching, speech and language. She is really the only support for her son.

Make sure enough centres and services because the incidence of ASD is increasing. Concern that with PAFC all government funding will go through Centre - not wanted. Concern that all services will only be ABA. Families want choice of services providers and therapies.

Could schools be utilized for the spoke?

Would like to see a physical person on staff, where you can walk in and get guidance and information and support.

The medical community should be involved, there is a shortage of pediatricians and informed people in the medical community.

Teacher training in ASD should be mandatory not optional. Big discrepancies between school districts level of BI and EA expertise and expectations of education in ASD (Surrey, Langely, Abbotsford).

Kindergarten teachers need to have training in autism - they are the front line and can see it if they are trained.

Want to see broader therapies covered under AFP - RDI, SOL.

Need to get rid of stigma of autism - educate parents.

Need opportunity to learn about things such as the disability tax credit.

Need more daycare.

### **Hub and Spoke Model**

“Spoke” person could liaise with School District, police, help to coordinate and enforce their rights.

Langley or Abbotsford would be a more accessible location for the Hub.

Fraser Valley Autism Services (FVAS) do a great job in the community, would hope that a hub would compliment them.

CDC provides services up to age 18 and have offices in Mission, Abbotsford, Chilliwack, Hope, Agassiz.

Is spoke duplicating existing services and taking away funding from existing services?

Not interested in power struggles, political boundaries between organizations - people should be working together, losing sight of the goal to help our children.

Like the idea of a Hub for information, it would be fantastic to have a clearing house for information, and a place for more training of SLP/OT/BC etc.

Need to also look at mental health services as part of hub.

Ensure two-way communication - must be a strong enough voice to take our problems to government (education, healthcare, diagnosis).

We could start here tonight - start an advocacy movement right now. There are too many little groups, we need cohesion to affect policy.

## Terrace Focus Group November 4, 2010

### Participants

At this meeting, there were ten attendees including parents, family members, service providers and professionals in the education sector.

### Discussion

#### *Existing Issues & Gaps*

- SLP's working with the school district have extremely high case loads are spending at least 3 hours traveling each day and have to choose what age they are going to focus on, they rely heavily on the SSAs.
- Currently must travel to Prince George for assessment but by the end of it end up going 6 or 7 times before getting access to funding.
- BCAAN seems like a great idea on paper but because Terrace does not have the right kind of hospital, we can't have assessments done here. Teams should come here, they used to come here but don't anymore. Must go to PG or Vancouver because of we lack the right facilities.
- One child that was in grade 7 with a query of autism – parent was told repeatedly that it wasn't worth it to go through with trying to get a diagnosis, that it would be a waste of time and that they wouldn't qualify for funding anyways.
- It is very hard for parents to navigate the medical system, community members ends up doing a lot of things outside of their mandate such as driving people appointments etc. Lots of families are in poverty. The whole process needs to be swifter and smoother.
- CDC typically refers to get a diagnosis, CDC is great and very strong in the community but there are communities in the region that are very isolated. If you don't get a diagnosis prior to entering school it can be a very long wait-list.
- One parent noticed problem of delayed developmental milestones. Got aid through CDC for pre-school then once entered Kindergarten was undoing all the work done and decided to go for the diagnosis. Was told it would be 6-month wait for PG but ended up flying in a psychologist from Vancouver for 3 days to do the assessment. And it was quite a battle to have the diagnosis recognized because it wasn't through BCAAN. Was told that child would need to need to be re-diagnosed by BCAAN within a couple years.
- Seeing kids in the community getting diagnosed too late.

- CDC while great has such limited resources which usually go to higher needs kids.
- Get 5 - 28 hours of aid time at school depending on need and it is a constant battle to keep aid time. SLP's are overworked, only have a PT for 0.1 FTE so only very extreme cases are seen, no sensory assessments are done.
- POPARD is active but will only see a kid once, very briefly and then will come back in 1 - 2 years and the onus is on the school to justify them coming back. Essentially must show extreme need to get POPARD or Provincial Integrated Support Program (multi-disciplinary team that works with cognitive issues - not just autism) to become involved. SET BC is in the northwest but office out of Prince Rupert serves the entire north-west.
- No one place in community that supports cradle to grave.
- SLP's through outreach try to integrate First Nations communities but it is very difficult. The awareness of what everyone is doing in the community is not very good.
- It is very difficult to get professionals here - Prince Rupert has not had a PT or OT for 5 or 6 years.
- Gateway/Sources does have someone serving the northwest but it is a yearlong wait-list to get services.
- Dealing with the AFU is ridiculous, CYSN workers don't know how to fill out paperwork, had to go to five different agencies to figure out how to fill out all the paperwork.
- One parent saved up all AFP money to set up a program over the summer but workers ended up not getting paid October. For some they can't afford to wait.
- Terrace and Distric Community Services Society is also late in getting paid but they can afford because are a larger agency.
- TDCSS does offer programs for 0 - 99, day programs for adults and strive for inclusion and integration into the community and skills building. We see a lot of adults that haven't been assessed and would very likely be diagnosed but there is no mechanism to do diagnosis for adults.
- Not very clear what supports CLBC offers and the new regulations under PSI are very hard to meet.
- What family supports exist?
- Parents are provided some information on how to relate, basic skills through the School District and on the internet but not really sure what to do with everything. They need to be doing stuff at home but they are not really sure what. Extended

families are used as a resource and help. If you don't have friends and family as supports there really is nothing.

- There are no BI's in the community. Even if you get the funding through the AFP there is very little to spend it on. One parent could only end up buying a computer.
- Burn out is a huge problem for BI's too, one kid almost needs 3 BI's - one to do outside the home stuff, one to work at home and one for respite.
- Need after school programs - soccer, swimming etc. A lot of these kids have physical issues as well that make it difficult to do regular programs. Therapeutic riding is available but expensive. One parent was able to work with soccer league to create a team that would work and be accepting but required huge amount of parent involvement and effort.

### ***Hub***

- Want to see goals attached to this project - what will be achieved within one year, two years?
- Free plane tickets, place to stay and help with all the other travel costs. Example of Ronald McDonald House. Although it is better, more preferable, to have teams of people come here but need to be here longer than half a day and for them to develop some expertise in the community that stays here.
- Need to work on public awareness - educate public and parents who can be in denial and won't accept help.
- Need emphasize on training teachers and more opportunities for advanced education in autism related fields. Provide courses for parents to become BI's. Huge issue of co-morbidity - how can we study this or do more work on this issue?
- Would be nice to be able to go to the hub for training and education as both families and professionals, need continuing education opportunities but these could be done through the internet too. Online works for some things and some people but not everyone. Parents need hands on education at their level - caution about talking above their heads.

### ***Spoke***

- Would like to see PAFC provide an autism expert for the community.
- Need a 1-800 number to call when issues come up, video-conferencing facilities, counseling, OT/PT/SLP, pediatricians in the area. Example of asthma - there is a number to call if any problems come up and there is someone to answer and help you 24 hours a day.
- Would be great to have someone come and train up BI's - and return regularly for ongoing education and support.

- Would like to see one professional that would work with TDCSS, CDC, School District to provide that life span support and expertise. Having all the information available in one location or person to help guide you through would be great.
- Why can't we have the spokes before the hub?
- Would be great to have research chair at local college to do autism research and connect to other research going on.

### ***General Comments***

- Is anyone looking at how other provinces work with autism? For example, Alberta and Saskatchewan ... avoid re-creating the wheel.
- Will PAFC replace existing services? PISS, POPARD? Concern was expressed about new initiatives taking over existing organizations.
- Feel positive about the family focus mission. Would like to know who has been involved to date - Steering Committee and Advisory Council names were mentioned and participant said felt more confident knowing that those people have been involved to date.
- Not very confident to hear that it is another new non-profit is being created when we are seeing cuts to other non-profits and government programs. For example, access to POPARD - kids need direct time with experts and they need to come for longer than a day. Requests for their services far outweigh what they are able to give us.
- Concerned about longevity of programs - we are a small community where everyone knows each other and can help keep track of people. This works to our advantage.
- Kids where parents become advocates end up maximizing their potential and doing okay.
- Hard to say what we would want from the PAFC model if we don't know what you can afford.
- Have heard of a family that set up a micro-board for their adult child - this could be a model but caution difficulty around setting up due to the archaic language around how boards can function and their role, they are not really designed to support the individual. There are limitations in this model.
- Working hard to create awareness in schools but more awareness in communities is needed. It is a lot of work to set up volunteer programs and is hard to do off the side of your desk.
- Kitimat has done a lot of work in the community with developing services, expertise and community awareness - could be a logical partnering location.
- It is very stressful to take a kid out of their environment and will make the assessment not very accurate. Need to ensure that we aren't setting up kids to be

able to function somewhere else - they need to be able to live in their home community.

- When you live in the north, you have to be a generalist but we need more BIs and BCs, a centre of experts that we could access would be great. North has its own unique culture and we focus on how we can maximize what we have here.

## Vancouver Focus Group (1) November 17, 2010

### Participants

At this meeting, there were approximately 70 attendees including parents, family members, service providers and professionals in the education sector.

### Opening Question and Answer Session

Parent stunned to hear announcement of government funding commitment for PAFC when son's programs are constantly being cut and it is a constant struggle to keep/maintain funding. There are huge waitlists and people are being under served.

Parent of adult daughter with ASD, sees cuts to services from CLBC with the move from group homes to home-share living situations and even further cuts to respite funds for families who take care of disabled adults (new rate tables coming into affect are grossly inadequate). Would like to see PAFC play an advocacy role, families are facing service shortages because of government inefficiencies. Hope that advocacy will be one of the functions of the Centre.

Grandfather of 2 boys with ASD. Attending school at and luckily a teacher there has taken special interest but resources are very limited. Trying to find out about more resources.

Parent of teenage son with aspergers. Would like to see more support for smaller parent led support groups that have limited budgets. It is very challenging to find time and funding. Often the perspective is "what are you complaining about" towards parents of kids with aspergers - but they face similar challenges, need life-skills support, employment support. Son currently on waitlist with CLBC. Would like to see more transition services - high school to the work force, these supports should start when they are in school.

Look into evidence based software from Concordia University. Hope that the Centre will be a place of research. Look into Aspergers association of New England - they have incredible resources available online.

Parent of two teen boys on the spectrum, advisory council sounds like the dream team, concern is with mental health and other chronic health issues as they age, and support for employment. Difficult to tease apart all the co-morbidity issues - would like to see a psychiatrist that is trained in dealing with autism in terms of mental health in the Centre. GP's should also have more training in working with autism. Would like to see someone that is a wife, mentor, and job coach in one.

Parent of 5 year old, hitting another transition phase and currently figuring out what to do next. Got a private diagnosis because it was going to be an 8-month wait. Then once funding was in place what do you do? Called everyone on the RASP but there was no one available to actually execute the plan that had been developed. Eventually recruited someone from Douglas College (get additional practicum hours). Now back to square one as entering kindergarten, feel like you're always starting at square one. Want a life plan that isn't just 3 years long.

Assessment times varied from 3 months to one year.

Challenges with family doctors - reluctance to refer until older age because of the thought they will "grow out of it"

Parent of adult son who is partially dependent and living with them. Knew something was wrong at infancy, son has a university degree but no one will hire him - he is very bright but very odd. Recently got him disability status but worried about his future - what will happen when they are gone?

SLP - worked with autistic people for years, see the lack of coordination of services and impact on families - the stress involved in just coordinating everything, hiring people, the strain is killing families. Also see a lack of consistent quality of services across the board.

BI - works with 8 different families, there is no standard for the services she delivers, also working with families that have a language barrier, they don't have a consultant but don't know that they need this. Would like to see treatment offered in other languages.

Explanation of what a BI does - works 15 - 40 hours in the home, part of a team, doing on-on-one therapy with child in the home and works under a consultant who sets the goals for the family. They carry out the behavioural plan.

Hope that this Centre could create a database of everything related to autism that currently exists, what they do, waitlists. Leave no stone unturned. Families could access this online, right now it is very difficult to go online and figure out what fits for you, there is a huge amount of information out there right now and families are very frustrated.

Would like to see counseling for families - could also be done online.

Parent of teenage daughter worried about those families where parents don't have the advocacy skills, look at the FASD key worker structure that the Ministry has set up, they are supposed to be looking at the whole picture.

Would like to see the Centre as a recognized place where you could walk in and have someone to talk to, and they could make the appropriate referrals. This would be wonderful.

Would like to see Centre play a role in advocacy. When you get a diagnosis, you get a binder of information and it is very overwhelming, would like to have someone to sit

down and talk to so you don't have to find your own way alone. ASD is a spectrum, a lot of the services that you are pointed to don't fit for your child. Someone to help you navigate.

Challenges entering the school system, had to fight to get our BI into the school as an EA, essentially had to go to school every day until it was approved. Every year is a struggle with maintaining your child's team once they enter the school system. Would like to see the PAFC play an influencing role with School Districts for parents to be able to get services for their kids or get their BI's as EA for their kid.

Only have experience with schizophrenia parent support services but was very helpful in figuring out what works and how to deal with things on a daily basis. Something like this could be coordinated through the hub.

Parent of 2 boys at opposite ends of the spectrum (PDD, Aspergers) concerned about what happens when she is gone? Her boys won't be the ones to pick up a phone and call for help. Would like to see a non-passive single point of contact that was continually checking on these people to ensure that they are getting support.

Grandfather of teenage grandson who is 6 ft 9, 230 pounds, there is nowhere for him to go, very difficult to find respite help or someone to watch him. Would like to see help/respite coordinated through hub so that parents don't have to be there all the time. Parent of adult son, no ASD diagnosis but needs a lot of support to get through the day. Families are very dependent on service delivery, would like to see a community development component. When younger, they were told what school he would go to, there was no integration support, doors were constantly closed, attitude was that these people should be hidden away and the community really hasn't come around yet. Awareness and understanding would lead to people hiring because they are not afraid and realize the contribution they can make.

Agreement that the AFP payment delays is a large issue. People waiting 60 – 90 days and even up to 4 months for payment

Advocacy and speaking with one voice is key, decisions are always going to be political but if we can speak with a unified voice more attention will be brought to our cause.

Parent led social group now has to go through AFU to get funding, still waiting to see if falls under accepted activities. Must claim for each individual family, taking 2 months for processing with Ministry, very frustrating for a small parent led group.

Have heard a lot of opposition to PAFC because of so much money being thrown at it but if you started to provide information now and marketing would do a lot to change minds.

SLP and sister of brother with ASD, from experience of helping to take care of brother a lot of people don't know about ASD and it is important to offer services in other languages

Parent shared experience with an independent school - only 17 kids in school, her kids are happy to go there, walk in with a smile on their face, phenomenal program, families

are welcomed. Need to change people's thinking, get them to see our kids through our eyes, get rid of shame for adults and teens

Idea of build it and they will come - use it as a marketing tool to provide online training.

Sibling of an adult brother with ASD, there was nothing for him when younger, very hard on parents and him as a brother because no one knows what is wrong with your brother. Important to raise awareness, there is more acceptance of people who are different today. Important to have a place where parents, families and individuals with ASD can go and they are safe.

Why not create the spokes now, that way it would be easier to join up the spokes once the hub is built. Build it and they will come.

The autism field is dog eat dog right now, need to become peaceful and collaborative, we have lost track of the goal - support for kids and families. System is too fractured. Need a database other than the RASP - it is inconclusive and biased. There are more services now for adults but still hard to navigate and figure out.

## Vancouver Focus Group (2) November 18, 2010

### Participants

At this meeting, there were nine attendees including parents and service providers.

### Discussion

#### *Existing Issues & Gaps*

- Everything seems inconsistent - had no regular contact with social worker and they didn't know about any services, everything seems ad hoc.
- School system is no too bad once you learn the system, takes a little while and then you are always transitioning and having to learn again.
- Coordination issue - fluke that you hear about certain things, very little therapy for adults offered. Looked into setting up a micro-board and planned for over 3 months but very disillusioned because when push comes to shove the money is gone very quickly.
- SLP's for over 6 are very hard to find, families are taking out second mortgages just to get the therapies they need.

#### *Hub*

- Would like to see counseling for getting through the diagnosis process and follow up. You are going through a death/grief when your child stops developing and losing what they have. Hard to find someone to connect with and talk to, was referred to child psychologists only. Read books, couldn't find anything that fit; talking to other parents was helpful.
- The Centre could have sibling shops, ongoing series of workshops for teachers and parents to support inclusion in schools.
- Would like to see on call respite or childcare available to relieve parents. People who are speaking the same language as the parents and working together.
- A lot more work needs to be done with the College of Physicians and Teachers - too many people graduating without specialized knowledge. Autism isn't even a subject in some courses because educators are not able to teach it.
- Parents are in survivor mode, they are tired, exhausted and sometimes can't go out and get services. There should be an outreach function from the Centre. We are falling short with the Ministry - you only get action if a situation is drastic.

- Centre could be similar to a grocery store - all the different services you want or need and can choose.
- Want a place where you can go and know the information and help is credible, it is very confusing out there - a database of service providers and organizations.
- Centre needs a service component - somewhere where families and individuals can go and feel welcome and safe - a sense of community. People centered. We have a huge cohort of kids that are growing up and services have not caught up.
- Would like to have opportunities for adults with ASD to take/have leadership roles, space for young kids to connect on their own - parent area, kid area. Would be great if people with ASD had valued roles - it would really set the tone, should be a gathering place.
- Could the Centre include a business component that provided real opportunities for people with ASD?
- See the Centre's basic function as a switchboard. Parents tell you what they need, the Centre tells you where to find it in your community
- See the Centre as having an advocacy role, increasing the profile of issues, building peoples advocacy and leadership muscles.
- Cheers model - somewhere where everyone knows your name.

### ***General Comments***

- The whole process of diagnosis is very overwhelming. Didn't wait long to get diagnosis but have heard of families waiting a long time.
- Concern about lifelong supports for people with ASD.
- More support for alternative therapies from existing agencies, can make people feel discouraged and not welcome.
- Discouraged because it seems like nothing has really changed in 13 years, still a challenge to figure out what to do after a diagnosis.
- Frustrated because told by professionals 19 years ago to stop what you're doing it is wrong, was trying to set up a team to work with child (very expensive) based on giant steps out of Montreal and the 'experts' then said stop it doesn't work. Was asked to leave the school system then was told by a doctor that they have wasted 20 years of their son's life in private school.
- Parents want a timely diagnosis and response, they want someone to listen to them and who can connect them. We need to figure out how to help sustain families and stop them being beaten down by professionals. Need advocacy and to build community capacity and stop being at the mercy of the service system.

- Families have choice but not enough, difficulty if the family's philosophy doesn't mesh with educators or service providers. Would love to see an arts and cultural component to the Centre.
- School is the primary community for our children, have had good experiences and had some nightmare experiences. Parent needs to be an advocate. Now when moving look to move to where the right school is - principal with a vision and teachers on board. Family is deciding where to live based on school.
- Change lens from "fixing" to acceptance, parents need to be supported, they have been guilty for a long time thinking that they did something wrong. We are turning families into small business - making them have to hire people. What parents need is a really good team that parents can choose.
- Need to look from the perspective of people are resourceful, capable and resilient. Coaching model could be extended to families - making space so they develop their own answers.
- Should be family and individual centered. Example of education liaison - what do you want and 'hold space' for you to figure out what you need or want. Just there to support.
- Integrate rather than duplicate.