

The Pacific Autism Family Centre

Initial Strategic Plan December 2008

Prepared for the Board of the Pacific Autism Family Centre
by Larry Colero, Crossroads Consulting
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Consultant's Preface

Members of the BC autism community came together for two historic days of dialogue and consensus in a strategic planning session held on November 28 and 29, 2008.

Participants reflected a wide range of ideologies and stakeholder organizations. In spite of the diversity in the room, and in fact enriched by it, participants were able to move forward in a unified way in support of the creation of the Pacific Autism Family Centre (PAFC).

The following is a summary of the consensus reached, forming the basis for the PAFC's initial strategic plan. Participants' comments about the session itself are attached as Appendix A.

All participants were provided an opportunity to comment on the session, and to make corrections in this report, thereby confirming the consensus reached at the end of the strategic planning sessions.

*Larry Colero, CMC
December 11, 2008*

Purpose and Principles

Our Core Purpose

The Pacific Autism Family Centre is a provincial Knowledge Centre that brings together state-of-the-art resources for research, information, learning, assessment, treatment, and support in order 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.

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 with ASD.
- 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.

The Vision

Our Inspirational Goal

Within the next decade, to help BC become the best place in the world for people with ASD and their families.

Our Vision of Future Success

1. We will provide high quality information, treatment and support to our diverse cultural and geographical communities.
2. We will provide innovative programs based on best practices that will serve as models to provide training to parents and community professionals across BC.
3. We will foster and maintain close relationships with researchers across BC and Canada to ensure that the programs we develop are informed by research and contribute to research. A state-of-the-art research facility will be an integral part of the Centre.
4. We will foster and maintain close relationships with community professionals and organizations to better serve British Columbians with ASD across the age span.

Major Components of the Centre

What the Centre will Do (Core Components):

- Learning and Growth
- Research
- Training
- Access to Information
- Access to Materials
- Assessment and Diagnosis
- Range of Therapy (*including trials of new approaches*)
- Support Groups
- Lifespan Supports
- Support for Concurrent Disorders
- Mental Health Services
- Advocacy
- Public Awareness
- Job Services

How the Centre will Do These:

- Interdisciplinary
- Province-Wide
- Family-Centred Care
- Facilities (*e.g., recreational*)
- Reputation

Essential Building Components

The following were agreed upon as essential components to include in the Centre's main building:

- Information and Referral Centre
- Library
- Family Centre
- Clinical Research Facility
- Place to develop and demonstrate Model Programs
- Training Facility, which would include: meeting and training rooms; videoconferencing and media facilities

The Centre might also include a range of other facilities, such as a Recreation Centre, a Medical Centre, etc.

Key Strategies as of December 1, 2008

The following is a set of initial strategies, agreed upon by all participants attending the afternoon session on Nov. 29, 2008. These are listed as ST (short-term) or LT (long-term) strategies. Short-term strategies are to be implemented immediately, while long-term strategies are more enduring and not time bound. They are expected to provide direction both immediately and well into the future.

Philosophical Approach

- LT - The Centre will bridge and possibly combine differing ideologies by merging the medical and functional models
- LT - The Centre will provide unbiased, non-inflammatory, comprehensive (public and private services) and outcome-based information in layperson's terms, delivered by people who have nothing to gain from the information provided [An early activity may be to study the experience of other Centres.]

Capacity Building

- ST - Develop the "spoke and hub" model (e.g., satellite services, applications of technology, etc., starting with identification of existing facilities in the province) in order to include all communities across BC
- ST - Work together to develop a process to decide who and what will be included in the Centre in order to deliver core services [See Essential Building Components]
- ST - Start a dialogue with adults with autism (e.g., regarding language to be used)
- LT - The Centre will build the knowledge capacity of families affected by ASD
- LT - The Centre will build the capacity of communities to support and improve the Quality of Life for families affected by ASD
- LT - The Centre will provide ASD professionals and aspiring professionals with opportunities for practical experience, information exchange, and a professional support network (supported by affiliations with educational institutions)

Partnering and Affiliations

- ST - Engage other organizations in BC to obtain input on the Centre's proposed Strategic Plan [See Appendix C: Other Stakeholders]

Partnering and Affiliations (continued)

- ST - Reach out to those in the Autism community who are concerned, and engage in ongoing dialogue. [Early activities might include conducting a survey, using the PAFC website and Blog, and informing local libraries across the province.]
- LT - The Centre will initiate and develop “true” (formal) partnerships and affiliations with other organizations, including:
- Universities and Colleges (for research and widely-accessible education)
 - Professional Associations
 - Foundations and Funding Agencies
 - Etc.
- LT - The Centre will provide opportunities for organizations to connect and integrate their activities in order to optimize the service delivery model in BC
- LT - [Possible Activity: The Centre will partner with other organizations to foster a National Disability Strategy.]

Publicity

- ST - Create a unified, positive set of key messages about the Centre that can be communicated “with one voice” to the media and public [Key messages might include the intent to include other disorders and disabilities, and the idea that \$20M invested could lead to \$?M in additional donations.]
- ST - Identify a central contact/spokesperson for the Centre, as well as spokespersons within each organization participating in the Centre’s development
- LT - The Centre will provide a unified voice to advocate for people throughout the province who are affected by Autism Spectrum Disorders
- LT - Publicity for the PAFC will reflect inclusiveness of other disorders and the intent to share with other disability communities
- LT - The Centre will strive to educate the non-Autism community through public media

Funding

- LT - Develop a fundraising strategy and a fundraising plan for sustainable funding

The Initial Experience

The following steps were considered essential to a typical experience for an individual or family who contacts the Centre for the first time:

1. The individual or family contacts the Centre (this may or may not be in person)
2. They are provided with a one-on-one interview, which includes objective information provided in a reputable, emotionally-safe and supportive setting
3. Customized advice and support is provided, based on the individual or family's "stage", i.e., where they can go next (not necessarily to the Centre itself) and what they could do over the long term
4. The individual/family is offered access to further information (e.g., a library)

In addition, and depending on the situation and individual/family preferences, the following *might occur*:

- A Contact Person is assigned to each individual/family
- Opportunity is provided to connect (in person or virtually) with others in similar situations
- Opportunity to participate in research and model programs
- ESL accessibility to Centre services and programs

Appendix A: Comments from Participants and Invitees

“The sessions concluded in an extremely positive outcome. There was a historic sense of camaraderie in the group, and the consensus was absolutely remarkable.”

Dr. Glen Davies

Director

The ABLE Developmental Clinic

“These sessions were a productive and ground-breaking two days where all voices had an opportunity to be heard. I was so impressed that this diverse group could agree on strategies and next steps that have the potential to positively impact so many children with autism and their families in BC.”

Dr. Karen Bopp

Senior Behaviour Consultant, Children and Youth with Special Needs Policy

BC Ministry of Children and Family Development

“I am encouraged to see parents and families included in the Governance section of the Mission draft. For years it has seemed as if there was an abundance of professionals and organizations around to tell parents of newly diagnosed children that there was not enough funding for actual services. That lack of direct support and/or funding is what has had the most negative impact on families. Overall I am extremely optimistic about the future of the Centre and the influence it will have on not only uniting the stake holders, which was ground breaking, but on future studies, training and family services.”

Debra Antifaev

Director

FEAT of BC

“It was very heartening to meet with a broad based constituency at the recent two day discussions in which we worked to further develop a vision and plan for what we hope to happen within the walls of PAFC. Fears of divisiveness and mistrust amongst participants were quickly dispelled and the overall agreement about our hopes for the centre was remarkable. I am excited to see what happens next.”

Clair Schuman

Executive Director

ACT Autism Community Training Society

“It was an amazingly productive session, with evidence of real collaboration and cooperation across sectors. I look forward to moving into the future with this project.”

Pat Mirenda, Professor

*Department of Educational & Counselling Psychology and Special Education
University of British Columbia*

“This process represents the coming together by the Autism community to encompass a high level of knowledge and capacity building, and is right on the mark - an excellent piece of work. It was clearly a proactive, strength-based process, and appears to have been successful in transcending the controversies replete in this field. I couldn't attend the session, but don't disagree with any of the outcomes. I believe the notes capture the vision previously outlined, and build on the good ideas of a wide spectrum of interests and parties in the community, including parents, professionals and other stakeholders.”

Jim McLaughlin

Executive Director

The Children's Foundation

“Together we witnessed a remarkably dedicated, diverse group of professional and parental delegates within the autism community unite in opinion, passion, vision, determination and overwhelming support for a critically needed Pacific Autism Family Center - a Center that reaches out to all stakeholders within the BC autism community to enable full citizenship and quality of life for persons and families in British Columbia living with autism, and autism-related conditions.”

Suzanne Lewis, MD, FRCPC (Pediatrics)

Clinical Professor, Department of Medical Genetics, UBC

Director, Autism Spectrum Interdisciplinary Research (ASPIRE) Program

B.C. Children's and Women's Health Center, and Child & Family Research Institute

“The Autism Society became engaged in the PAFC initiative at the beginning of the process and remains optimistic about the potential for such a Centre. We will continue to actively participate and are impressed by the level of engagement of all concerned. Much has been accomplished and those involved are committed to continuing the more detailed development work that is still before us.”

Michael Lewis

*On behalf of the Board of the
Autism Society of BC*

“As a parent, and a member of FEAT of BC, I have networked with many families who are struggling to provide treatment for their children diagnosed with autism. I have also met many families trying to access and create services for individuals across the lifespan who require ongoing support to be meaningfully included in our society. It is time for change and collaboration of parents, families and professionals in order to expand capacity and ensure access to treatment and services for all individuals with autism. I felt this was a common goal amongst all participants in the sessions.

“I was welcomed into the discussions during the strategy meetings and feel optimistic that the Pacific Autism Family Centre can become a centre of excellence in BC, which will enrich the lives of individuals with autism, their families and supporters.”

Dione Costanzo

Parent

Member of FEAT of BC

“The Canucks Autism Network shares the vision of a centre to enhance the quality of life of families with autism. CAN hopes the atmosphere of collaboration witnessed at the strategic planning session continues within the walls of the Centre once it is up and running.”

Katy Harandi

Chair, Board of Directors

Canucks Autism Network

“We came together as a diverse group of parents and professionals representing many different experiences and perspectives, knowledge and skills relating to autism. We spent two days in dialogue, listening to each other, and learning that in spite of our differences, we all want a better life for persons with autism and their families and that we would achieve this by working together. We also acknowledged that our work could lead to better outcomes for families with children with other disabilities, and are committed to sharing our successes when possible to make that happen. Much of the dialogue was led by the parent voices in the room. To a large degree, I attribute the success of this process, and our consensus on moving forward together, to the dedication and foresight of the parents. Most of the services for children with disabilities that we have in BC have been created through the hard work and passionate commitment of parents who want a better life for their child. The Pacific Autism Family Centre will be another example of this commitment.”

Dana Brynelsen

Provincial Advisor

Infant Development Program of BC

Appendix B: “Invitees”

The following list represents organizations, who were invited to participate in the strategic planning discussions.

- Wendy Lisogar-Cocchia - PAFC
- Sergio Cocchia - PAFC
- Dr. Pat Mirenda - University of B.C.
- Dr. Grace Iarocci - Simon Fraser University
- Dr. Jim Tanaka - University of Victoria
- Dr. Georgina Robinson - Provincial Outreach Program for Autism and Related Disorders
- Michael Lewis - Autism Society of B.C.
- Clair Schuman - Autism Community Training
- Debra Anitfaev - Families for Early Autism Treatment B.C.
- Pamela Collins - Richmond Autism Interagency Committee
- Lori Woods - Douglas College
- Dr. Steve Wellington - BC Autism Assessment Network
- Dr. Suzanne Lewis - BC Children’s Hospital Researcher
- Dr. David Batstone - Vancouver Island Health Authority
- Jim McLaughlin - The Children’s Foundation
- Katy Harandi - Canucks Autism Network
- John Esson - Autism Society of BC
- Sue Wastie - BC Association of Speech Language Pathologists
- Mary-Ann Falks - Occupational Therapists
- Dr. Glen Davies - BC Psychological Assn.
- Karen Kalynchuk - CDBC
- Dione Costanzo - Families for Early Autism Treatment BC
- Tamara Kulusic - Community Living Manager
- Dana Brynelson - Infant Development Program
- Elizabeth Sparling - BC Assn of Applied Behaviour Analysts
- Dr. Ellen Domm - Caplano College University
- Nancy Walton - Surrey College

Appendix C: “Other” Stakeholders

The following list represents organizations, some outside of the autism community, who did not participate in the strategic planning discussions, but may wish to be involved in the Centre and will likely be provided the opportunity to engage in planning discussions at a later date.

- Autism Community Groups (eg. Campbell River Community Autism Network, Cranbrook Autism Community Group, etc.)
- Child Development Centres across BC
- Foster Parents Association
- Community newspapers
- At-risk and low-income families (conduct focus groups?)
- Multi-cultural parent groups
- Aboriginal communities / programs
- Teenagers and adults (e.g., BCACL Self-Advocates)
- PLAN
- Professionals in other organizations and related professional societies
- Other government ministries