Proceedings Report
Calgary and Area Regional Collaborative Service Delivery
Joint Executive and Leadership Team Development Day
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Prepared by:

Bruce Uditsky, M.Ed.
Chief Executive Officer
Inclusion Alberta

Table of Contents

Participants

Aleta Ambrose	Senior Project Manager, Child and Adolescent Addiction and Mental Health, Alberta Health Services	Facilitator
Bruce Uditsky	Chief Executive Officer, Inclusion Alberta	Guest Presenter
Alex Hillyard	Regional Director, Calgary FCSD/PDD, Community and Social Services	Executive Team
Andrea Holowka	Superintendent, Specialized Program Schools, Instruction, Religious Education, Calgary Catholic School District	Executive Team - Co-Chair
Annamarie Zobatar	Parent Representative	Leadership Team
Avril Deegan	Director, Child & Adolescent Community & Specialized Services, Child & Adolescent Addiction, Mental Health & Psychiatry Program, Alberta Health Services	Leadership Team - Co-Chair
Brenda McInnis	Vice President, Community Services, Providence, Calgary & Area Private Schools	Leadership Team
Carl Price	Parent Representative	Leadership Team
Catherine Morrison	Manager, Alberta Children's Hospital, Ambulatory Care, Calgary Zone, Alberta Health Services	Leadership Team
Christina Tortorelli	Associate Director Case Management, Prevention of Family Violence and Bullying, Children's Services	Leadership Team
Cindy McNiven	Superintendent Learning, Calgary Board of Education	Executive Alternate
Daniel Sadler	Project Coordinator, Calgary and Area RCSD	Secretariat
Deb Davison-Morgan	Supervisor Learning Services, Calgary Board of Education	Leadership Team
Don Andrews	Director, ISAC, Calgary & Area Independent Schools	Leadership Team
Gary Chiste	Chief Deputy Superintendent, Christ the Redeemer Catholic Schools	Executive Team
Greg Roberts	Director of Learning, Rocky View Schools	Leadership Team - Co-Chair
Janet Chafe	Executive Director, Addictions and Mental Health, Alberta Health Services	Executive Team
Janice Popp	Regional Manager, Calgary and Area RCSD	Secretariat
Jeannie Everett	Superintendent Learning, Calgary Board of Education	Executive Team
Karen MacMillan	Co-Executive Director, Calgary and Area Private Schools - Foothills Academy	Executive Team
Lana Dunn	Care Manager, School Based Mental Health, Child & Adolescent, Addiction and Mental Health, Alberta Health Services	Leadership Team
Linda Sunderland	Parent Representative	Leadership Team
Lisa Warner	Director Allied Health Calgary Zone (Rehab), Alberta Health Services	Executive Team - Co-Chair
Liz Mackay	Admin Coordinator, Calgary and Area RCSD	Secretariat

Lori Anne Schultz	Pediatric Program Manager, Rehab, Alberta Health Services	Leadership Team
Lorne McDonald	Coordinator School Development, Calgary & Area Charter Schools- Foundations for	Leadership Team
Pat Firminger	Regional Executive Director Calgary Region, Community and Social Services	Executive Team
Patti Brown	Complex Needs System Review Coordinator, Calgary and Area RCSD	Secretariat
Rosemarie Earle	Student Services Coordinator, Christ the Redeemer Catholic Schools	Leadership Team
Sheliza Ladhani	MSW Student, Calgary and Area RCSD	MSW Practicum Student
Tom Brinsmead	Supervisor Diverse Learning, Calgary Catholic School District	Leadership Team
Uma Thakor	Senior Manager, Community and Social Services	Leadership Team
Valerie McDougall	Tsuut'ina Education Director, Tsuut'ina Education	Leadership Team
Wayne Braun	Secretary Treasurer/RCSD Financial Consultant, Palliser Regional Schools	Leadership Team

Introduction

Calgary and Area Regional Collaborative Service Delivery (RCSD) held its Third Annual Learning and Development day for its Executive and Leadership Teams with the objective being to further its understanding of inclusive communities and its role in supporting inclusion. In relation to this interest, RCSD was also seeking to explore the "power of parents" and their role as a natural means of sustaining the community inclusion of their children, with the assistance of an integrated service delivery system.

The previous two Development Days focused on "governance, strategic direction and inter-partnership relationships". The Executive and Leadership Teams now wanted to consider how RCSD could improve its capacity to support families and move from the individual visions of the RSCD partners to a common vision of inclusion. The desire was for a day that required substantive personal and system reflection with respect to the right relationship RCSD should hold in relation to families as the primary point of responsibility for influencing a child's future life pathway.

The day was facilitated by Aleta Ambrose, Alberta Health Services and the Author was enlisted by Calgary and Area RCSD as the content expert.

In preparation for this day, RSCD established a Joint Planning Working Group, which met on March 9, March 21 and April 19, 2017, with the Author in attendance, to discuss and review the purpose, content and process for the Development Day. During the course of these meetings the following documents were reviewed:

> ➤ Family Evaluation Report June 2016
> ➤ Calgary and Area RCSD Service Delivery Rubric
> ➤ Provincial RCSD Guiding Principles
> ➤ Proceedings Report Development Day May 2016
> ➤ Family Smart Spectrum of Engagement for Child and Youth Mental Health April 2012

Over the course of the above three meetings the purpose, content and process were refined as reflected in the following Learning and Development Day Agenda. Participants were provided with two articles in advance of the day:

> Chrislip, David D. *The Collaborative Leadership Fieldbook, Chapter 4.* (San Francisco: Jossey-Bass, 2002.

> Kendrick, Michael. *The Natural Authority of Families.* Crucial Times, Brisbane, Australia, 1995.

In addition to the planning meetings the Author interviewed, via phone, three of the four parent representatives on the Leadership Team. Given that one of the primary purposes of the day was to gain a better understanding of how to engage and collaborate with families, gaining knowledge and insight from the parent representatives seemed, and proved to be, a worthwhile endeavour.

Core Concepts

Inclusion

The structure of the day was primarily one of short presentations by the Author followed by small and large group discussions. The day also included a session on empathy with material provided by both the Facilitator and the Author. In addition, there was a short ice breaker to enable participants to engage and intermingle socially. At the beginning of the day participants were asked to set aside any reservations about costs and dollars and to engage as if monetary issues were non-existent.

The day began with an elucidation of inclusion, which, while typically the default for children and adults without disabilities, confronts many individuals both conceptually and in practice. One aspect to the challenge of understanding and appreciating the benefits of inclusion results from the simple reality that the vast majority of individuals without disabilities live a fully inclusive life, but the term inclusion is not used to describe this life. Inclusion for those without disabilities is not only unquestioned, it is expected. If a child without disabilities is drawn or pushed to the margins or otherwise excluded, all of the actors in that child's life naturally respond to re-establish that child's inclusion. Parents, teachers, relatives, friends all intuitively understand not only what it means to belong and be included, but the emotional and stigmatizing impact of rejection and exclusion, however momentary those conditions might be.

The description of inclusion, provided in spoken word, photo and video during the first presentation depicted a vision and experiential life for a child with disabilities no different than if the same child did not have a disability. If one assumes a child with disabilities, irrespective of the nature or severity of their disability or of their ability to communicate readily or not at all, is no different in their essential human makeup, then just as an inclusive life is the expected, necessary and desired life for a child without disabilities, it is as true for a child with disabilities. From this, it flows that the view that a child with disabilities needs to be segregated from children without disabilities and congregated only or principally with children with disabilities is entirely a question of perception. That is, if a child with disabilities is perceived as differently human, where perhaps their disability is perceived as their essential identity or as "other" in the philosophical use of the concept of othering, then understandably inclusion becomes a controversial matter, as has been the case more than four and a half decades. Enabling inclusion across the lifespan is sufficiently challenging on its own, but altering the values and

perceptions that see and understand an individual with disabilities, is an entirely different struggle. Calgary and Area RCSD, by wanting to learn more about inclusion and family collaboration, is to be commended for wading thoughtfully in territory it knows to be controversial and where contrasting points of view are deeply ingrained.

Inclusion however has "travelled" (Slee, 2005) or been conceptually appropriated to the point today where any conversation about inclusion requires the speakers to identify precisely what they mean by the term. In its initial inception inclusion was understood and promoted as a radical concept, intended to challenge societal devaluation of people with disabilities as evidenced through segregation, exclusion, discrimination, marginalization and oppression (Nguyen, 2015). Over time inclusion has travelled from a radical and distinct concept to one where the term is applied to almost any practice. It was important for the purpose of the Development Day that participants understood that inclusion had particular and specific meaning. If inclusion were to mean whatever people wanted it to mean, it would make not only dialogue and debate pointless, but learning impossible. By unpacking the concept of inclusion, participants were invited to consider its meaning and decide for themselves if they agreed with the concept or not. From a starting point of understanding the concept, then debate and dialogue can proceed to advancing inclusion or to choosing other ways of life for individuals with disabilities. And participants would be free and enabled to compare their practice and that of their programs and colleagues, as they stood, relative to inclusion.

PowerPoint Slides

Growing up at home, being fully included in regular classrooms and schools, having friends, developing a career identity, being included in community activities, being a teenager, having dreams, playing sports, music/dance/art, going to college/university, traveling, falling in love, getting a meaningful job, having a home of your own, having friends over for dinner, owning a business, looking after your parents

This also defines what is not inclusive – separation, congregation, depersonalization

INCLUSION: 50 YEARS OF RESEARCH FINDINGS

Improved health

Minimizes vulnerability

Improved learning/skill development

Improved rate of learning

Friendships/relationships/ social networks larger

Culturally literate

Improved communication

Improved behaviour

Greater likelihood of

career and employment

More comparable life outcomes to people without disabilities

People without disabilities benefit

Segregation is harmful

Program quality cannot compensate for the limitations imposed by segregation & congregation

Inclusive/Normative Pathways

The means to an inclusive life requires an approach that is consistent with the ends. Inclusion occurs across the lifespan, but it also occurs across multiple points of life at any one moment in someone's life. For example, a child might be receiving an inclusive education, included in extra-curricular and/or community recreational activities, included in family life and playing with friends, all during the course of a single day. Then add the pattern of life of a week, a month, season, a year and life stages across the years to weave a complex, variable and cumulative experience of inclusion.

These normative pathways across life's many dimensions and across time form a cultural pattern, particular to different cultures. These pathways, while forming a life pattern in which the vast majority of the citizens of a culture participate in, result in the unique and personalized expressions of human identity and purpose. In other words, while the pattern is common to almost all, the end leads to the expression of a unique person and the potential for a fulfilling life. The normative pathways of our culture result in the overwhelming majority of Canadians growing up as part of a family, going to school, forming relationships, participating in leisure activities, being a teenager, transitioning to adulthood, possibly continuing one's education, falling in love, creating a home and working; yet each of us remains distinct in character and personality.

In the course of one's life and if one has friends, family and caring others, efforts will almost always be made to draw one back into the valued streams of life should one by accident or intent fall into pathways that can or will lead to marginalized or harmful life states. In essence, while the pathways are culturally embedded and invisible, people do recognize when someone without disability, particularly someone they care about, is not on a normative/inclusive pathway. That is, pathways can be discernable. The challenge is, as these are normative and culturally integral pathways, they are not subject to ordinary conversation, observation or recognition. It is just how we live our lives. However, these pathways hold tremendous power; as previously noted, most people live valued and inclusive lives which unfold unpredictably over time leading to meaning and purpose.
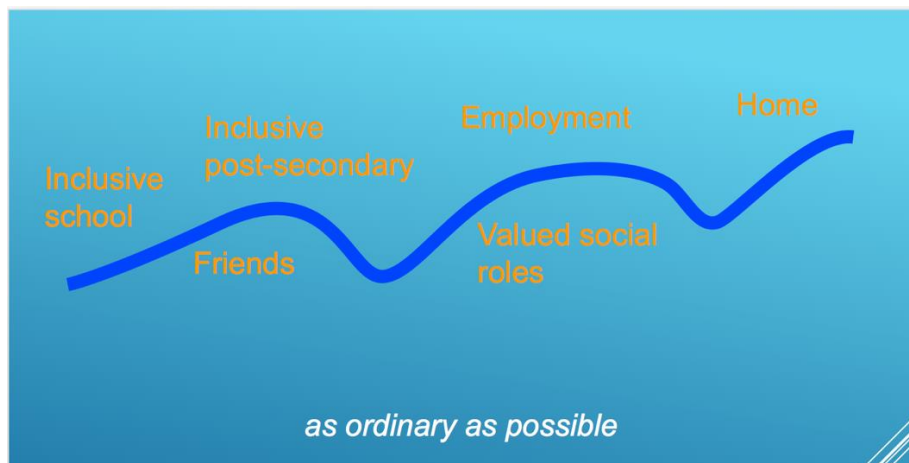
To illustrate the power of inclusive/normative pathways a number of examples were shared, only one of which will be shared here in the interests of brevity. Over 70% of Canadians are in the workforce and for most, a job and a career not only offers income, but a sense of identity and purpose for decades of their lives. Canadians with disabilities, however, are employed marginally with some populations experiencing unemployment rates of close to 80%. This abysmal outcome has remained true for decades, irrespective of either special education or human services dedicated to generating employment. In large part, as the work of Inclusion Alberta has demonstrated, the poor outcomes are because these approaches do not capitalize on the power of embedding individuals with disabilities in the same inclusive/normative pathways occupied by people without disabilities.

Career identities are forged in early childhood through inclusion in the normative pathways of play, family life, schooling, engagement with the world where examples of people working abound, encouragement to continue education, high expectations, caring others and the oft repeated question of "what do you want to be when you grow up?". One of the most critical factors in gaining employment is having a social network, which is made possible, again, by inclusion in normative pathways where the opportunities to form relationships require interactions with untold numbers of others. When children with disabilities, who start life disadvantaged by their disability, are removed from this normative and inclusive pathway, they are denied the needed and proven means by which to develop a career identity, form relationships, be surrounded by high expectations, and have the opportunity for continuing inclusive education. The loss of the power and value of in being embedded in a normative pathway cannot be replaced by exclusionary means, as all the statistical evidence illustrates. Some might claim the lack of employment is a function of the disability and not the lack of an inclusive life; however, substantive evidence exists to the contrary when inclusion in a normative pathway is pursued and enabled.

Inclusion in a normative/inclusive pathway is not something that just happens, even when desired. It requires, for example, the support of family, professionals, staff and other services dedicated to this means to an inclusive life. And when challenges exist, it requires the problem solving expertise of a collaborative team to obtain, secure or regain momentum within an inclusive/normative pathway, particularly at those times when it is a struggle.

PowerPoint Slides

❖ Normative and inclusive pathways:

❖ Immersion within the normative and valued pathways of family and community life is one of the primary means to a life of meaning, belonging and possibilities

❖ An inclusive life requires immersion in these pathways which are both then means and ends to a good life

❖ And in those pathways the art of facilitating relationships is honed

❖ Inclusion is both a means and an end

Inclusive school

Inclusive post-secondary

Friends

Employment

Valued social roles

Home

as ordinary as possible

Community Capacity and Natural Supports

The concept of community capacity refers to the understanding that the community and its members have the capacity to foster and support the inclusion of individuals with disabilities beyond what is commonly assumed or history might suggest. The capacity of community to be rejecting and devaluing is better understood than the greater capacity to be accepting and welcoming. Both exclusion and the growth of human services, as places and experts for people with disabilities, has led the community to believe that it lacks the capacity to be inclusive as they reinforce the view that people with disabilities must require other and separate places in society, staffed by those with disability-related knowledge. However, there is a growing recognition that a model of service delivery premised on the belief that to have a good life every child and adult with disabilities must have access to an array of qualified and sustained individual staff who are ever present is not possible. The implication is that lives will either remain unrealized or at best sporadically, as staff come and go, have moments of promise. There is greater benefit and promise in utilizing a limited, but specialized and knowledgeable, human resource in enabling and engaging the natural support, meaning voluntarily and freely given, of ordinary community members. This requires a changed focus for many professionals and support staff from perhaps an overly exclusive focus on a disability in contrast to a focus, with the knowledge and expertise, on engaging the natural supports reflected in community capacity.

Today, there is a growing understanding of the fact that the community and its members have untapped capacity to accommodate and include individuals with disabilities. In schools and classrooms, capacity and natural supports are represented by general or regular education teachers and classmates, as both practice and research over the last 40 plus years has demonstrated. However, when facts as these confront beliefs; beliefs tend to persist. This suggests the need for cultural change, a far more difficult challenge than altering practice, because in a changed culture research and knowledge that does not conform to expectations can be capitalized upon, rather than dismissed or ignored.

Other shared examples with participants, via video and slides, included the 30 year success of inclusive post-secondary education for individuals with significant intellectual disabilities who are supported in regular classes and programs of study by their non-disabled peers and taught by their regular professors and instructors who adapt their instruction and modify their assignments. Eighty percent of students who experience a fully inclusive post-secondary education secure employment upon completing their studies, often in their chosen field of studies. Inclusion Alberta's employment partnerships with Rotary, municipalities and the business community illustrated how Rotarians as business leaders, owners and professionals are voluntarily tapping into their personal networks to create employment opportunities by the hundreds, and where close to 90% of individuals with intellectual disabilities are supported in their jobs naturally by their colleagues and supervisors. External and paid staff support may be necessary for some, and for some this might be extensive; but with this approach that limited qualified expertise can be applied where most needed.

COMMUNITY CAPACITY & INCLUSION

▸ Community capacity is realized when informal and formal generic organizations and associations:

--- include but better yet invite and welcome individuals with disabilities to become participating members

--- create policies and practices to sustain and facilitate inclusion

--- recognize the 'societal good' achieved by inclusion

--- experience and acknowledge the mutual benefits of inclusion

--- recognize the individual and societal harm of exclusion

In effect embrace inclusion

The Role of Families in Creating and Enabling a Vision of an Inclusive Life

Through a series of slides illustrating two individuals' lives and how they unfolded from childhood to adulthood by being embedded inclusively in normative pathways, the importance and relevance of families to this process was referenced. A vision of a promising life for any child beings with family and over time that vision both acquires greater specificity and clarity, with its shape being gradually impacted and directed by the individual as they mature and grow.

However, families of children with disabilities are often thrown off balance and into a place of uncertainty, to say the least, when their child is first diagnosed with a significant disability. Having little lived experience or examples of children and adults with significant disabilities living inclusive lives and achieving valued outcomes, parents lose sight of the inclusive and normative pathways and life outcomes they aspire to for their other children, or aspired to for their child prior to the diagnosis. As well, they are likely interacting with and trying to understand professionals and systems, who as well may have either little experience with inclusion or prefer an alternate life pathway. As such, the vision of an inclusive life and the means to that end may be lost or seem impossible. It is not unusual for parents to lower their expectations and limit their dreams. While most dreams may never be realized, they are essential to instilling aspirations within children. While not all dreams will be fulfilled it is clear that limiting or narrowing dreams leads to limited life outcomes.

When families are introduced to the possibilities being realized and lived today by individuals with significant disabilities who have pursued an inclusive life, many, although not all, find within themselves the capacity to dream anew and, with support, begin to construct a vision of a promising life. Having a sense of this vision and being able to begin to articulate it, allows

those offering support, advice or intervention to better ensure their actions are in service to that vision. Further, the hope is that in service to that vision advice, interventions and other actions will be coherent with the vision and thus contribute to enabling an inclusion across time and place.

After the provision of this overview of these three core concepts there was an opportunity for participants to seek clarification of the concepts where needed. The following two questions were put before the small groups for personal reflection, small group discussion and, in turn, points were shared with the large group.

> ❖ Clarifications?
>
> ❖ Guiding Questions
>
> 1) How do I know when I'm being included or have been and when has that not been the case?
>
> Particular contexts and which ones; over what period of time; how did this impact you; did it define you in any particular way?
>
> 2) How do you know if RCSD is contributing to life outcomes that are typical of children without disabilities? What would be your indicators and benchmarks (what indicators would point toward those benchmarks) relative to your organization, your work or role within RCSD?

The first question was presented as a direct means of demonstrating everyone knows the difference between when they are included or not and the emotional response when one wanted to belong but was not invited.

A review of the participants' notes, gathered and accumulated from throughout the day (copies attached) illustrate that the core concepts were well understood and provoked reflection and worthy comment. A sample of the comments should serve to illustrate this observation:

- o "Ordinary lives are extraordinary"
- o "Inclusion cuts across disciplines and dimensions of life"
- o "Goodwill trap – where we increase human services we decrease community engagement"

- "Parallel growth of human services vs. parallel growth in community – unintentionally creating dependence (lives wait)"
- "Embrace inclusion – change conversations"
- "Capacity of children/youth to support each other to grow"
- "Transition to adult services vs. transition to adulthood"
- "Facilitating transitions – age has little to do with transitions"
- "Kids need to feel wanted first, then understood"
- "Leadership is key to renewing hope"
- "This is my child's life!"
- "Where is the conversation of hope"
- "Restore hope for families – infuse possibility"

In respect to the question of how RSCD was contributing to, or could contribute to, inclusion and what indicators and benchmarks would be used to this end, some challenges were evident. For example, "Not sure if we can ensure if RCSD is being effective in terms of inclusion right now." Inclusion is not necessarily common practice and indicators and benchmarks to this end are not yet well articulated. To a fair degree this current state could be a motivator for action and the basis upon which the RSCD approach to inclusion could be refined within and across its partners. This can be seen in the comment, "How could RCSD identify the possibilities that are not realized for children and youth and work together to realize those? Maybe that is our real work together."

Comments focused on the challenges of different partnering systems with different measures or ideas of what constitutes success. There is a need for strength based evaluation tools while recognizing RCSD is at a developmental point in time when it can just now seek to create and measure shared outcomes to a greater degree. Comments also noted the need to engage the broader community in considering how together outcomes are being achieved and to take into account the whole child – to be flexible and extend beyond mandates as children do not fit neatly into specific mandates. Another comment noted the need to bring to bear resources that support the unique needs of each child rather than "pushing" families from system to system to given specific and limited mandates with boundaries that are not readily bridged.

Parent Perspective: Applying a Family Lens

The next section of the day included a brief and generalized overview of how Calgary and Area RCSD might take into account parents' perspectives; in effect, applying a family lens to RCSD's approach. What follows is a summary of a few key points. A family centric approach, while of critical value and import, runs the risk of making the family the object of attention; the subject under the gaze of the professionals. A family lens implies trying to look at RCSD the other way around – from where and how the family sits and views the world, inclusive of RCSD. This idea is related to that portion of the day which addressed the subject of empathy. That is, in assuming a family lens, one is attempting to "stand in the shoes" of the family; to feel as the family does to the degree possible and then to use this evaluative lens to alter and improve practice as a continual improvement exercise.

The object of a family lens is to remind those working with families that there is no other human relationship comparable to that of parent to child. For parents, it is their child's life that is at stake and with a child with significant disabilities parental engagement in that life will likely last the parent's lifetime with a degree of intensity, commitment and never resolved apprehension distinctly different than any worry over a child without disabilities. Professional involvement, while necessary, is nevertheless time and event limited. When professional intervention fails (and failure might simply be adding to the complexity of life for a parent in contrast to the failure of a specific therapy), parents, and their child, live with the limitations long after the professionals have moved on to the next family.

Families live in a conflicted world, which can impede collaboration. For example, time passes differently for parents than professionals. Every day lost is a day never to be regained. As such, when parents have had to wait for service responsiveness, the professional may approach the meeting assuming parents will be grateful the time for action has arrived when, in fact, the parent may be resentful of the eternity they and their child have waited to gain access and progress. Choosing an inclusive pathway is still counter cultural and, while it holds the most promise, it also offers more challenge and heartbreak than a segregated and congregated approach to life. As such, parents who choose inclusion live in a "heightened state of vulnerability", needing to anticipate rejection and resistance. In fact, many parents find their way to inclusion outside of the very systems and services in which they're engaged, supposedly to the benefit of their child.

It is not uncommon to hear families share that negotiating and navigating the human service system is far more challenging than their child's disability. As all parents willingly sacrifice for their children, so do parents of children with disabilities; however their sacrifice is often outside the norm. Typically they forego more of life's possibilities for themselves than is usually true. Given this reality, when parents choose an inclusive life, and at the very least this choice ought to be genuinely offered and available, they want their choice to be respected and honoured not diminished or negated. This is the possible beginning of establishing a relationship of trust.

Adjunct to this presentation were a series of videos, one of which highlighted the concept of empathy with others being clips of parents and principals sharing their experiences of how trusted relationships were created.

The small group discussion questions below followed this presentation.

Parent perspective

In working with families what are some of the factors that contribute to an environment of trust and which are inhibiting or constraining trust?

If you are not the parent of a child with disabilities what are the parallels, the bridges, the connectors to parents of children with disabilities you can bring to a collaborative process from your own experiences as a parent or life experiences?

If you are a parent of a child with disabilities, what are some of the commonalities between yourself and parents/families who do not have a child with disabilities?

Many comments acknowledged the need to create an environment and relationship of mutual trust and respect by listening to parents and taking into account their life experiences. Parents need to be heard and do not need to hear "no" or "but" as this closes down the conversation. Even when wanting to hear a parent's hopes and dreams, it's important to appreciate if they have been lost and wounded they may need support to dream again. For those who are parents, reflecting on your own aspirations for your child or when you experienced a challenge as a parent may help you to build a bridge to a family in difficulty. Of particular note was the comment, "Being cognizant of when rhetorical change is occurring rather than transformational change" as parents can tell the difference between a genuine change and a superficial difference. Other comments captured the need to blend interventions into the context of a family's life rather than turn the home into a therapeutic environment and, in this regard, support parents to be parents and not their child's therapist ("What's done in terms of therapy should occur in a natural context like play and language development.").

Building Opportunities for Collaboration: The Challenge of Organizational/Cultural Change

As time was becoming limited by this point in the day, this presentation was more cursory than anticipated; however the discussion appears rich from the notes. The intent was to highlight both the need and the means to involve parents as senior partners in a collaborative process relative to their child. However, collaboration, as envisaged here implies mutual responsibility and accountability. The culture and history of human services is one much more of coordinating supports and services than in true collaboration, where whatever team is engaged with respect to a child and family the entire team is mutually responsible for success or failure. In a culture of coordination, particularly if there is no point of responsibility, no one may be responsible for the outcome or lack thereof.

Collaboration is challenging from multiple perspectives, not just accountability. For example, as much as humanly possible collaborating teams should meet collectively, inclusive of the family, to share assessment results, proposed approaches and to review progress or needed alternations in the approach. This requires timing and scheduling accordingly. For example, if multiple therapists observe a child collectively and then meet to share their learning and recommendations, often with a synergistic effect, these recommendations can be offered in an integrated manner that can be implemented more effectively than if each therapist makes their recommendations individually leaving it to parents or others to integrate them. This would be an example of cultural change if it is not already the practice.

Policies and practice guidelines, to accommodate the known reality that every child is a complex being requiring a holistic approach, must encourage and enable RCSD partners to work beyond or outside of their mandates. Creating flexible mandates that stretch across the gaps inherent in any multi-system endeavour requires a shift in workplace cultures that, while desirable, is not easy to achieve. It is at the boundaries or edges of mandates that the greatest degree of creativity and innovation in service to children and families can be found, especially if there is a culture that embraces blending mandates rather than standing on their edges as if on a precipice of inaction routed in fear of stepping over the line.

The following comments, which are only a representative sample, can be used to formulate an action plan for advancing RCSD's approach to inclusion, community capacity, and mutual responsibility for action in collaboration with families. Although some comments were framed as questions, they still lend themselves to consideration of future actions. In the debrief with the Joint Planning group in preparation for the writing of this report, one critical reflection was the need for greater clarity by the end of the day for specific and subsequent steps upon which to move forward. While this goal was not achieved during the course of the day, I am of the opinion, which I hope is shared, that the discussions and comments which flowed from them, do lend themselves to next steps.

Comments:

- "Utilizing a life pathway model when thinking about service delivery"
- "Help families create and sustain a vision of an inclusive life"
- "How do we have cross system transformation about inclusion?"
- "Find out how each family envisions an inclusive life for their child"
- "RCSD can play a role in aligning and championing an understanding of inclusion and inclusionary practices across the partnership"
- "Think about how to integrate the practice of inclusion into the service delivery rubric"
- "How much is currently offered to families to build hope and capacity for the future?"
- "Health in early years could focus on how we or do not contribute to a trajectory of hope-opportunity and achievement …"
- "Figure out how we can meet the family needs/what they want, now what we assume/think they want"
- "All discussions, positions at leadership meeting should include questioning how this applies (inclusion principles and needs of families, viewpoints of parents"

Moving forward would likely require additional in-services and consultations given the multi-layered partnerships that Calgary and Area RCSD embodies. Possible places to begin might include agreeing on a common definition of inclusion and the meaning of inclusion within the different environments that Calgary and Area RSCD engages children, their families and associated resources. While not all parties may endorse an inclusive life as the desired outcome, it would be essential to understand what is inclusion and what it is not, particularly where and when an inclusive life is to be the benchmark against which outcomes are to be evaluated. For those where an inclusive life is not the goal, then alternate benchmarks and outcomes would need to be articulated.

A subsequent step might be for collaborative teams to learn how to work together inclusive of families to support the development of an inclusive vision, which must be the family's vision, and which must incorporate how this might unfold over time and across environments and dimensions of life. Further steps would entail learning about how the role of the team, in holding shared responsibility, can support the inclusion of the child, capitalize on community capacity and engagement, review progress and adjust the pathways accordingly. Initially this could be done with select families who have already chosen or are interested in pursuing an inclusive life and, with sufficient successful exemplars, practice could be expanded. Not intending to gloss over the learning and work required to tap into community capacity it must be noted that in addition to a conceptual understanding, engaging community to be voluntarily and naturally supportive requires both the allocation of time and developing the necessary skill sets.

Conclusion

Calgary and Area RCSD is poised to embark on, and would seem ready to do so in acting collaboratively with families, moving Beyond Imagination as the closing presentation illustrated, to what can be achieved for those with significant disabilities and life challenges. Being a mutually responsible party to promising life outcomes is a creative and renewing force that will only enhance Calgary and Area RCSD's approach to children and families.

Given the controversial nature of some of the topics, I would like to express my sincere appreciation for all of the participants to have set aside for the day their particular beliefs and be open to listening and engaged dialogue. It was this professional commitment in service to children and families that contributed to the success of the day more significantly than any other factor.

Appendix 1: Notes

Presentation Notes – General
- The desire: an inclusive life. Embedding in normative pathways across the lifespan
  - Limitless, belonging, contribution
  - Most of us have lived a life of inclusion without question
- Inclusive education – theoretical construct, pathways are normative and inclusive (e.g. career and identity formation)
- Pattern of outcomes: as ordinary as possible
- Perspective ordinary/extraordinary
- Social determinants of health
  - Inclusion cuts across disciplines and dimensions of life
  - Creating different lives
- Parallel universes
- The longer you stay the more you're removed from the context (e.g. employment prep programs vs real life experiences)
- Parallel growth of human services vs. parallel growth in community – unintentionally creating dependence [Lives Wait}
- Other areas of diversity have made significant public gains – have more of an ability to speak for themselves?
- Capacity of children/youth to support each other to grow
- Projection of outcomes
- Enrichment over time
- Compensation for minimal opportunities
- Facilitating transitions – age has little to do with life transitions
- Mandates and boundaries get in the way
- To what degree are parents supported in fulfilling that pathway (e.g. pediatrician to family physician)
- Multiple systems think and define transitions differently
- Transition is artificially constructed
- Transition is behind the scenes within systems, not to be seen in the lives of families
- Emotional piece for service providers/professionals who may not feel equipped to provide the care and support beneficial for children and youth
- Challenges: acculturation of professionalism/ loss of idealism around inclusion; the change we're asking from them is deeper and complex
- Leadership is key to restoring hope
- Challenges of systems to move to a strength-based model
- Rhetoric/dominant cultural knowledge rather than applying professional knowledge
- Assessment tool evolution? Strength based tools not necessarily taken up by the profession

- First encounters with systems and agencies*
- Where is the conversation of hope
- Systems are acculturating families to this way of reaching for resources rather than hope

Group Discussion #1
Question 1
- Using the collaborative lens of the RCSD
- Not saying no, being invited to the strategic planning day, valuing of perspectives
- Parent representatives are asked for their opinions
- Moving from "special education" to inclusion
- It was acknowledged that some change has occurred within our education systems, though there is still a long journey ahead
- Being given the option for segregation does not feel like inclusion
- Hearing the voices and perspectives of the families who are wanting to have access to specialized programs
- Challenges of not being resourced as well as families need schools and systems to be
- Broader inclusion of families
- Using the service model reform in health that involves clients and families in the development of programs
- Inclusion of cross-ministerial perspective at the RCSD is a good start, though we have not heard the diversity of perspectives within each sector/ministry (silos are still present)
- A good assessment has to include strengths
- Parent perspective – "The current system requires parents to embellish and make their child sound 'bad' to gain access to funding and resources
- Establishing trust: Give trust as a starting place, do not expect it to be earned. Reassess and adjust
- Honor the story
- Families may not begin from a place of trust; importance of an empathetic approach, be prepared and informed when working with families
- Stay with the family until its done
- Tell families when we as service providers or systems are wrong or misinformed – humanity + apology
- Barriers to trust: lack of clarity between systems, accountability to families and each other as systems.
- Do what we say. Step into conflict in a healthy way
- Invest in individual long term relationships with parents
- Understanding of systems; more clearly articulated and defined

- Ensure alignment with known organizations (e.g. in education, re: inclusion & relationships) system→Principal→Teacher→Support Staff
- Focus on Family vision for the future as the basis for discussion (hopes, dreams, wishes, goals)
- Common language between systems
- Shift from a "fix it" approach to one of acceptance and hope

Insights from the Larger Group Share
- Personal reflections: many of us have always felt included, more worried for our children's experiences of inclusion or painful exclusion
- As an RCSD we are simply a mechanism for discussion and resource
- Value & not always feeling valued
- Getting past pseudo-inclusion; how do we support inclusion in classes as the norm
- Unique experiences and characteristics of the family "walking along side"
- Easier to think about moments of when we were excluded, wondering if this is the reverse for children with disabilities
- Do isolated experiences of inclusion worsen/deepen feelings of exclusion
- Inclusion of Indigenous peoples →impacting the willingness to participate and partner with the RCSD? How do we do this better?
- Can we step back and think about opportunities for RCSD to support more personal authentic social networks? (recreation? Personal?)

Question 2
- We aren't measuring the RCSD impacts on outcomes for children/youth/families yet; there is a need to look at broader outcome measurements
- Push back against the idea that "the need will go away" that is not an indicator
- Wellness indicators, subjective quality of life
- Challenge of inadequate tools; need for quantitative strength based measures
- Discussed the developmental stage of the RCSD collaborative, acknowledging that the RCSD is now arriving at a place that would allow for this type of evaluation work to be undertaken
- Alignment of different system measures (What do Education, Health, Children's Services & Community & Social Services define as success?)
- Currently not capturing what is happening for children/youth across the board as in ALL children, then look to see how the RCSD is contributing
- Looking to our communities as a whole to see how we all are supporting families
- Finding the resources that support the needs of each unique child/youth/family throughout their lives rather than pushing of responsibilities from system to system because of stringent mandates and boundaries
- Identified that silos in systems impede professionals as well

Group Discussion #2: Parent Perspective
Question 1

- Inclusion and the importance of the timing of inclusion
- Allowing the parent to be part of the team, to be heard and not managed
- Technically speaking practitioners and professionals to know what family centered means for their roles and responsibilities and being able to communicate that to the family and reduce the assumptions/preconceived notions we all have
- Parent representative: Understand my child and their strengths. See the child in the child and not as a problem
- Giving children and families time and investment for more understanding and validation
- Genuine and authentic inclusion
- Make the experience/environment less daunting and more welcoming
- How do we build capacity of our educators and providers?
- "resources are not available" as a means and/or reason to segregate
- Thinking about purposely resourcing "needs based budgeting"
- Equity; not equal all the time but where the most need is
- System constraints balanced with family centered approach
- Meet parents where they're at
- Positive and strength based
- Every life stage is a transition
- Definition of inclusion
- Need to listen to what kids are telling us their behaviors regarding what they need and want
- Still need much more funding for inclusion
- Positive contributions are not recognized, just needs
- Need to educate principals as they set the tone for the whole school
- Des the individual feel their participation is valued by those around them
- It is more than doing things that look like inclusion, needs to be real inclusion; "lives as ordinary as possible"
- Individual story & Family Story
- It is about the feeling/emotion that goes along with an experience – the association you create based on an experience for yourself → the vulnerability; this translates to families who share that experience
- Experience creates an expectation and the expectation sets you up for future experiences

Question 2

- What are the parallel bridges?
- Everyone wants their child to be happy, healthy, successful and to be able to contribute and be valued (potential of the child)

- Ensure that their rights are protected
- Wanting to hear positive feedback from educators about their children
- Wanting to be understood
- Supporting children/youth/families to navigate the challenges of life; normalizing the challenges that cut across
- The challenges of transitioning from "parenting to protect" to "parenting to prepare"; some families staying in the protection phase longer
- Showing respect for children and support them in mobilizing their abilities
- Begin from a place of trust
- What are your hopes and dreams? Being careful with this if families are lost or wounded. Work with them to get them to a place where they can begin to move toward their hopes and dreams
- Thinking about some of your most difficult experiences as a parent and imagine those times as constant or extended (this may get you closer to understanding what some parents are going through)
- Be there for the whole walk
- Mutual respect
- Be deliberate
- Collaboration
  - Being cognizant of when rhetoric change is occurring rather than transformational change
  - Continuity across space and time
  - Parent as the change agent, without interfering in the parent-child relationship (e.g. what's done in terms of therapy should occur in a natural context like play and language development)
  - Subtly integrate therapy into the lives of the family
  - How do goals get realized (from the Service Delivery Rubric
- How do we support the child to stay in the school rather than being moved into a "specialized" environment – included rather than segregated
- Need to be planned from the beginning that is a child is to move to a specialized program the plan is to move back to the regular classroom as quickly as possible – easy transition back
- Also need to balance what's best for individual child and the whole classroom
- Not sure if we can ensure if the RCSD is being effective in terms of inclusion right now
- What happens when the family system is not able to provide the supports needed; how do we support the families?
- Cultural influence on inclusion
- Need system level support for families ; volunteer mentors (parents) for families who may be going through similar challenges

- RCSD to be "collectively" responsible for the child and family experience vs. handoffs/accusations toward one another (system mandate challenges?)
- Knowledge of each other's systems have improved
- Action item: explore the real opportunities for children/families to create an early trajectory of hope
  - Graduation fairs that really go deep to the opportunities for students
  - Entry level opportunity fair – set the stage for hope, together
  - Multi-pronged approach (ESL, LEP, culture)
- How could the RCSD identify the possibilities that are not realized for children and youth and work together to realize those? Maybe that is our real work together
- We need to have professional and engaging relationships; over communicating vs under communicating
- We set each other up; system to system, within systems, families to system, families between multiple systems

Insights from Larger Group Share
- Is it the resources or is it trust?
- Inclusion is about good teaching
- Family vision, sustained hope, family directed supports and inclusive community
- Need to come to the table with more than just the organizational mandate (don't bring the silo to the table)
- Child's life comes first and then everything we do should be in service to that
- Think about family concerns at large transition times (e.g. into adulthood)
- Getting to cooperation after you get to trust
- Legal rights vs human rights discussion; welcoming vs rights based approach
- The whole culture/view/beliefs of society has to change

Group Discussion #3
- Inclusion of the parent voice at the Executive level at the RCSD
- Utilizing a life pathway model when thinking about service delivery
- How do we have cross system transformation about inclusion? (from executive to the front line service provider level) *Knowledge transfer
- Capturing the child/youth voice and/or experiences
- Inclusion of our First Nations communities
- Parent perspective: Raise awareness of contemporary meaning of inclusion to all front line providers (educational opportunity for the learning partnerships committee?)
- Attempt to measure the success and uptake of inclusion initiatives
- Engage families
- Challenge different partners to use different models

- RCSD can play a role in aligning and championing an understanding of inclusion and inclusionary practices across the partnership; Also think about how to integrate the practice of inclusion into the service delivery rubric
- What is the benchmark?
- Enhanced navigation and way finding
- Advocacy role
- Being able to contribute to a piece of the work that is already underway
- Integrated wraparound touch base with all of the team including the family
- Solution focused: we all need more information from families as to what is important holistically, and educators need more information
- Efforts to shift own thinking to one which recognizes and focuses on normalization and real inclusion and to recognize and appreciate the role and perspectives of parents
- RCSD could support engagement workshops to train professionals and parents – Perhaps the November learning partnerships event
- All discussions, positions at leadership meetings should include questioning how this applies (inclusion principles & needs of families, viewpoints of parents)
- Health in the early years could focus on how we do or do not contribute to either a trajectory of hope-opportunity and achievement (or not) in our own interactions
  - Life vs event
  - Relationships & life goals vs resources for diagnosis and disability
  - E.g. opportunity fairs vs resource fairs
  - E.g. learning and connections for families instead of professionals
- Through our transition funding, create a position that assists families to navigate through education and health systems "Family Advocate for Transitions"
- Greater knowledge of systems to support the development of a life plan
- Appreciate the idea of parent workshops (5 weekend series) on how to collaborate; parallel: workshops for professionals on how to listen, engage, interact with parents

General Notes May 5th, 2017
- Be comfortable being uncomfortable
- Separate ourselves from $$
- Embrace flexibility
- Focus on what is possible rather than what isn't
- Alberta Association for Community Living (former name of Inclusion Alberta)
- ordinary lives are extraordinary
- Parallel universe
- Leisure for kids
- Cultural illiteracy e.g. teen jargon
- Goodwill trap - When we increase human services we decrease community engagement

- Lives wait
- Embrace inclusion – change conversations
- "othered" – invite and include
- We all learn more when we teach
- Transition to adult services versus transition to adulthood
- Importance of immersion (e.g. being included in peer activities – unchaperoned)
- Need connections to know what options can be
- Mind map transition to adulthood
- Finite plans don't usually work
- Strength based model
- Emotional professional preparation – is it taught
- Willingness (e.g. recreation and business leaders) versus other professionals
- Contribute toward life outcomes
- Provide leadership in creating an environment of trust
- Restore hope for families – infuse possibility
- All assessment tools are deficit based
- Chris – can we trail something?
- Power of experience – forks in road.
- Our current models have us fighting for resources versus knowing they'll be available if and when we need them
- Relationships have the power to improve behaviour
- Kids need to feel wanted first then understood
- Navigating Human Services (e.g. health, education, children's services) more challenging than having a child with complex needs
- Follow through is difficult
- Don't oppress or silence families nor label them as being non-compliant and uncooperative
- This is my child's life!
- UN rights of disabled people
- What is the right thing to do?
- Friends are not a human right

Individual experiences of inclusion
- parent - when my kids are not included – I have no control over my child's happiness
- staff– when I went to boarding school at 17 – got to practice what my life was like
- I was included by another student who took a chance on me (the new person) to join bowling and party. That person made sure I was included and felt safe. They were willing to take a risk to include me as an outsider.

- Include where most comfortable – as listener, talker or leader

How is RCSD Contributing? How do we know?
- Life outcomes
- we have uncomfortable conversations
- Not just about one system with difficulty – multi system community/school/education
- Whole child and youth
- Individual silos to broader perspective
- Low Incidence Area – Anxiety. Invisible/unique needs
- Dual roles + flexibility = critical to success

Factors that contribute to an Environment of Trust
- Mutual respect
- Cow analogy – a "good mom" runs over us (rancher) if we are going to hurt her child (e.g. branding calf). That's normal – we expect that and manage ourselves accordingly.
- Active listening

What inhibits or constraints trust?
- Lack of mutual respect
- Not listening
- Focus on money
- Individual priorities
- no focus on what can / could be
- 'no' and 'but' – when a parent hears these words it shuts down creative 'yes' thinking
- Understanding of the aide role varies by Community and Social Services, School, parent. When the focus is on title rather than need (e.g. 1:1 time with aide versus group inclusion with an aide present).

Parallels / Bridges / Connectors
Can you bring your own experiences (life) to collaborative process?

- Model honesty and transparency
- Be curious – take time to dig deeper
- Be empathetic not sympathetic
- Be aware of everyone's realities
- Think outside the box – be creative with parents – adopt a strength based approach
- Parenting a child with disabilities is more intense – love them the same but stakes are higher for child with disabilities.

Commonalities between yourself and parents/families without a child with disabilities

- Same but the intensity changes.
- Have to fight harder – don't fit in the same

Commonalities between parents of children with and without disabilities – what can you bring to the collaborative process?

3 key RCSD actions to help families create, act on and sustain a vision of an inclusive life

- Help families create and sustain a vision of an inclusive life
- importance of good ideas – inclusive but not all will fly
- include key partner (and families) in decision making and planning
- Ask to meet with families
- find out how each family envision an inclusive life for their child
- figure out how we can meet the family needs/what they want, not what we assume/think they want
- meet early with each family (timing)
- Transition consultants – family advocate for transition (what are we transitioning too next?)
- How much is currently offered to families to build hope and capacity for future?
- ACH offers a lot and individuals within partner systems can be excellent, but the systems aren't excellent

Calgary and area RCSD Joint Development Day

Evaluation Results

Statement	1	2	3	4	5	NR
The content of the day was relevant to me/my organization	1*		1	7	15	
The information presented added to my personal knowledge base	1*			10	13	
I will use the information presented and what I learned throughout the day in my work with families, communities, systems	1*	1	1	6	15	
I have a greater understanding of the concept of inclusion and inclusive communities	1*		2	9	12	
I have a great understanding of how Calgary and Area RCSD partners can collectively support inclusion and inclusive communities	1*		8	9	6	
I have a greater understanding of the family experience	1*		6	8	9	
I have a greater understanding of how Calgary and Area RCSD partners can work together to enhance the family experience	1*		6	11	5	1
There was enough time in the day to network with colleagues	1*	2	3	10	8	
I have a plan for how to transfer the information from the day into action in my respective area/organization	1*	1	6	8	3	5
Overall rating for the day			2	8	5 7	1

N=23

*all from the same submission, gave the day a 5 overall; assumed that the scale was reversed.

Why did you give it that rating?

- The session made me see that we have to always look at continuing the work we do
- Relevancy
- Great information. Difficult to bring into action
- Need time to reflect on how to action this as the topic was very relevant and important
- Awesome meaningful content
- Excellent information and tone in the room. Would have liked to have seen additional time for engagement and to set a RCSD region goal
- Generated excellent conversation, idea exchange
- Valuable, common connection point, important topic
- Information was good, relevant to my job
- Provide great opportunity to bring forward to RCSD
- Bruce's presentation

- Enjoyed the day, but given the fact that we can only get this group together once per year, was this topic the #1 priority?
- Bruce was excellent! My team would really benefit from this info!
- If not today – then soon – we the RCSD should develop an idea with families ,create an action plan and act on even some small aspect of inclusion
- I have ideas – I don't think we as an RCSD have captured a collective set of ideas and commitment today

What parts of the day were most valuable to you?

- The focus on the importance of what the families wants and listen to their expertise as we move forward
- Presenter
- Stories
- Bruce's insights
- Inclusion component
- Films and group work
- Early presentations and discussion
- Parent perspective discussions and defining inclusion
- Listening to Bruce and his perspective on things
- Discussion/networking
- Bruce's presentation – great
- Group discussions
- Group discussions at the table
- Hearing alternative perspectives, being challenged with different perspectives
- All
- All
- Reflective conversations
- Insight into the family experience and issues of trust
- Networking

What would have been beneficial to include that wasn't?

- More collaborative time
- More focus on the practical next steps – map to get from where we are now to where we want to be
- Perhaps more time to connect to RCSD and create an action plan. We have great discussion but not always accountable for follow through

- More info how to apply – although I recognize there are no easy answers
- Perhaps a decision on transition planning
- More time
- More conversation (too much sitting and receiving) more collaborative action plans
- What do we do when we can't meet the child's needs?
- More diverse voices, parent voices around their diverse paths around what is right for their child

Comments

- Thank you
- Excellent day!
- Thanks to Bruce and Aleta and the planners for an excellent experience
- I think the value of the day will only be achieved if there is an effort to truly attend to these shifts and revisit them within RCSD on a regular basis
- Well planned and organized – thanks Liz! Thanks for the lunch and morning snacks
- Thanks to planning team!
- Thanks!