

# Families for Change

Promoting and defending the rights and interests of people with developmental disability.

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A D V O C A C Y

## Editorial

### The Global Village...It's Much Smaller and More Familiar Than We Think!

In October 2007, at Family Advocacy's national conference, *The Odyssey*, a terrific idea came to light. One of the keynote speakers, Bruce Uditsky, Chief Executive Officer of the Alberta Association for Community Living (AACL), Canada, made a commitment to coordinate a 'parent exchange' between Alberta and Australia. Bruce has worked in Australia many times over the past 20 years and has been one of the leaders internationally on inclusion for people with developmental disability.

Bruce had met families and people with disability in his travels here and felt that there was a wealth of experience and stories that should be shared...so he determined to create an opportunity for some Aussie parents to travel to Canada to meet with families there and facilitate a sharing of experiences, stories and ideas.

Bruce remained good to his commitment and in March 2009, 22 parents from around Australia, two parents from New Zealand, Family Advocacy's Director Catherine Hogan and two allies of people with disability spent eight amazing days on a whirlwind tour of Calgary and Edmonton. This experience was predominately funded by AACL. Family Advocacy partly sponsored two parents and fully sponsored one other to attend.

Bruce had devised a combination of social get togethers, formal presentations, visits to colleges and a university, workplaces, people's homes and schools. Each of these activities was used to demonstrate how the inclusion of people with disability was going in Alberta - the good as well as the not so good - and AACL's role in creating, supporting and advocating for it.

To cap the trip off, the Australian and New Zealand contingent were warmly welcomed at the annual, two day *AACL Family Conference*.

The exchange will be complete when, in the not too distant future, a contingent of families will come from Alberta to Australia to experience a similar sharing and exchanging of ideas. We are not certain when or how at this point...but where there is a will there's a way!

This edition of *Families for Change* is Part 1 of a 2 part series that captures this experience from the perspective of the Alberta Association for Community Living, and eight of those who went from Australia. Some of the experiences are similar, but the perspectives are unique. Part 2 will be published in December just prior to Christmas. Family Advocacy wishes to thank the authors for putting their thoughts to paper.

## Global Parent Exchange Forges Deep Friendships, Understanding

Karin Melberg Schwier

*Karin Melberg Schwier is the editor of 'Connections' published by the Alberta Association for Community Living (AACL). This article was printed in Connections Volume 2, Issue 2 – Summer 2009 and is reprinted here with Karin's kind permission.*

During the week before the Family Conference, 26 parents and allies from Australia and New Zealand had the unique opportunity to spend time with a comparable number of Alberta families. For many the experience was profound and life changing, stretching their imaginations to consider new possibilities forged through the commonality of life long dreams and challenges even while living on the other side of the world. For 22 parents from Australia, including one grandparent, two parents from New Zealand and two Australian leaders in the field of community inclusion who spent eight mind-altering days together, the world will never be the same.

The international parent exchange was conceived by Bruce Uditsky (AACL Chief Executive Officer) and supported by Ross Wormsley of Adelaide (Executive Director, Community Living Project); Darrell Wills of Perth (Project Director, Parent Learning Education Group [PLEDG]); and Catherine Hogan of Sydney Australia (Director, Family Advocacy). They worked together to select parents from every Australian state, along with the New Zealanders, who visited Alberta in an exchange of ideas, learning and stories. A rigorous schedule of educational and workplace tours in both Calgary and Edmonton was augmented by time in the homes of AACL

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parents where they were billeted. The group rounded out their visit at the Family Conference.

“There’s a deep commonality in our experiences and I always felt it would be such a powerful thing for other families to share what I was feeling each time I went to Australia over the last 20 years,” says Uditsky. “We were finally able to act on the idea and I am thrilled we were able to do this. Friendships and relationships have been forged and we know we are bonded together by our sons and daughters.”

The parents from Australia, New Zealand and Canada spent a whirlwind few days prior to the conference in Edmonton. Arriving in Calgary on March 14th, they visited various inclusive post-secondary education initiatives, inclusive school settings, and employment efforts, and were introduced to a variety of AACL projects and initiatives. The group was in a reflective mood as they met with members of AACL’s Executive Committee. The visiting parents expressed a deep appreciation for the chance to “get in the same room as like-minded people on the other side of the world.”

Auckland parent Francesca Voykovich has been advocating for her son James, 5, to attend kindergarten. Like her own mother who worked in traditional group homes, Francesca felt drawn to support people with disabilities. Along came James.

“It’s an absolutely incredible feeling to be with a group of people who feel the same way about an inclusive life,” she says. “It’s wonderful talking about James, and not having to justify why I want my son to go to a mainstream school. I’ve been so inspired by the families here.”

Al Mason is from “way up top” in Kununurra in the Kimberley region of Western Australia. To say his family is isolated is an understatement. Presented with an invitation to “go snowmobiling in Canada, to be billeted with and meet a bunch of like-minded people who believe in inclusion” was nothing to pass up. In a town of 7,000, there are only five other people who have disabilities besides his son, Elliott, 16. But those families “seem to be locked into segregated things with carers and funding and all that. They all think

we’re a bit weird wanting our son to be included,” Mason says.

“After seeing what’s working so well here, I’m kicking myself now for not pushing Elliott’s school harder,” says Mason. “I understood inclusion was possible, but I never, ever took the steps to make it happen. Most of the people on this exchange didn’t know each other before, but now we’ve got this good bond not only with the Canadians, but now with the other parents in Australia and New Zealand. Listening to Sheena’s mom and going to see Sheena’s shop [Sheena Small owns and operates Sheena’s Sweets, a successful candy store in High River, Alberta] was so inspiring because I could see Elliott having a business. I’ve got this vision now of Elliott at the podium, with me behind him, giving a speech about a business he’s created. That’s in my head now and I think it could happen.”

***“There’s a deep commonality in our experiences and I always felt it would be such a powerful thing for other families to share what I was feeling.” Bruce Uditsky***

Seeing first-hand how successful inclusion in the community works was a key for many parents during their Alberta experience. They praised AACL families for being open and welcoming. One mother said she now feels a different future is possible for her son. “I met with Sharon at her daughter Brenda’s home,” she explained. “For me, because Brenda has profound disabilities very similar to my son’s, I felt incredibly inspired that this was something I can go out and do for him. It was tangible and I could see it and I want to thank AACL for the opportunity.” Wendy McDonald, AACL President, praised the “enormous power” that comes from connecting families and sharing common experiences, hopes and dreams with other parents whose children have disabilities.

“Where else can you go and have a mom talk about her child in kindergarten being invited to a birthday party, see her break down in tears yet have everyone in the room know exactly what that

means?” she asks. “It is wonderful for us to know there are families who share our commitment and passion for inclusion, whether we live in Australia, New Zealand or Canada. There is huge power in that knowledge.”

Lynne Cousins Hughes of Canberra has a 15-year-old son named William, a “very busy boy”. His mother was always nervous about loosening her grip, even for something as simple as a swim in the neighbour’s pool.

“William sometimes looks over the fence, wishing he could go. But when the neighbour invited him, I thought, no, it’ll be too difficult. He’ll want to go all the time. The neighbour said, ‘Don’t worry, if it’s too much, I’ll just tell him!’ Still, I said no,” Cousins Hughes sighs. “But being here in Canada has changed my thinking. This has been such a wonderful experience.

“William goes to a special school, but I feel like I have more confidence about him now and what he might be able to do. I’ve always been so afraid I might offend somebody, but now I think I might have to go talk with the school—in the nicest possible way! It’s never too late, is it?” The first thing she plans to do at home is to knock on her neighbour’s door to see if the swim invitation is still open.

The determination to make changes has solidified for many parents on the exchange, including Sheree Henley, also of Canberra. Son Isaac is 11. At times as she supports Isaac, Henley feels “like I’m at the bottom of Mount Inclusion. All his life, my son Isaac has been in special education. I’m going to change that now that I’ve been here. And he’s had no friends. I’m going to change that, too.”

Bruce Uditsky is already working on the next step in the process to have Alberta families visit Australia and New Zealand. The friendships forged between the Northern and Southern Hemispheres means that parents will never think of their struggles and successes in quite the same way again.

“As we reflect in the days to come and no matter what happens now, we will never lose the memory of this time together,” said Wendy McDonald in her farewell to the group. “I know your faces are what I call upon for support the next time I’m in a meeting about my son.”

# Reflections on Alberta

Gina Wilson-Burns

*Gina is mum to Macdonald, Meg (deceased) and wife to Shawn. She is an unapologetic advocate for Mac who, at six, has a lot to learn, but possibly has more to teach...if we are willing to listen.*

I was among the lucky contingent of Australian and New Zealand parents chosen to attend a parent exchange hosted by the Alberta Association for Community Living (AACL) in conjunction with Family Advocacy and other organisations around Australia and NZ.

I wasn't aware of the behind the scenes work that went on to make this opportunity a reality. I wasn't sure why I was chosen, and didn't dare ask for fear someone realise I wasn't the right person to send or that they had made a mistake selecting me. I simply took the opportunity before me and set off for Canada, for what I can only describe as a watershed moment in cementing our family philosophies, in dreaming big for the future and for striving to make it a reality.

Firstly, there were logistical elements to consider. Our son Mac had just started kindergarten some weeks earlier. Mac is in a mainstream class at his local school and has multiple disabilities. My parents stepped up to do morning preparation for school and the transportation and my sister and brother in law were there as back up. My husband had just started a new job one hour away from home so wasn't as flexible as he would have been two months earlier. My brother and sister in law made their house (near school) available for Mac and his Grandfather to wait after school until they could be collected. At this stage, if nothing else came out of the trip, there was the very important personal achievement of 'family involvement and engagement in Mac's life'. We had been a little too 'competent' in the past, never needing help, never asking, soldiering on. I realised we needed to do this more and more - my Canadian experience only cemented this fledgling thought.

Arriving at the airport ready to leave, I started meeting others traveling with us. Just that was enough to make me realise I was about to embark on a most amazing adventure. Here were a group of people, all but one parents of children or adults with disabilities, all who had

travelled the inclusion path or who were interested in pursuing it. The Sarah Caldwell quote "**Learn everything you can, anytime you can, from anyone you can** - there will always come a time when **you** will be grateful **you** did." was never more apt. I tried to listen, take it all in, learn from these amazing people... and we still hadn't boarded our flight.

***A quote from Colleen F Tomko (inclusion advocate) sums up what I believe AACL, Family Advocacy and all those I met embrace, "Let not our needs determine our dreams...but let our dreams determine our needs."***

We arrived in Calgary, and had free time until the next morning when we literally hit the ground running. I was collected by my billet family Sheilagh and Darrell Cooke; amazing people, parents of two adult children. I was able to meet their daughter Jocelyn in her own 'condo' where she shares the two bedroom apartment with a university student who acts as a support person for her. Jocelyn works six hours a day, five days a week in open employment.

The next day was our scheduled day trip to Banff - a wonderful sightseeing opportunity but, there is something to be said for spending some time with like minded individuals. I know it is important to have your thinking challenged, but for me it was equally important to understand from those more 'seasoned' in this journey, why there is no alternative but to ensure all children are afforded an ordinary and inclusive life - and how it can be done.

Let the learning begin.....

As you know I was already well on the way. The official portion of the Parent

Exchange was packed with information and opportunities most days running from 9am to 9pm.

The first three days were spent in Calgary, the remainder in Edmonton. Some of the information was at times overwhelming, particularly the post school information, I guess because we are the parents of a young child - adult options are seemingly a long way off. That being said retrospectively, all this information is now just part of my knowledge bank I (hopefully) use to make better decisions for us and Mac.

Some of the learning opportunities afforded to me included:

#### **Supportive Communities: Strengthening Families**

An AACL project to promote awareness of how communities can work together to improve supports and possibilities for children with disabilities. A focus on the reality that if any other family seeks temporary care of their children (by grandparents/babysitters etc) it is not considered 'respite', but rather a normative and natural part of child raising. However, for families of children with disabilities, there are often barriers to similar opportunities. This project aims to remove these barriers.

Personal Highlight: The recognition that communities have the capacity, they need not have the expertise nor all the answers but they can, given the opportunity, learn and in some instances, become 'drivers of change'.

#### **Inclusive Post Secondary Education**

Post secondary education opportunities have been occurring in Alberta for over 20 years. I attended the University of Calgary where we met the coordinator of the program and one of the students. Students are able to undertake units of study in line with their chosen fields and to enhance employment opportunities for them when they complete their study. They attend classes on their own and have 'inclusion facilitators' who assist (almost invisibly) with both inclusion opportunities and study/learning outcomes.



**Personal Highlight:** This was a real 'wow' moment. I would love to see a growth of these opportunities in Australian universities.

### Family Voices

This is a network of individual families who advocate on behalf of children and adults with developmental disabilities. These networks work with school districts to improve inclusive education; with child and family service authorities to improve supports to families and with the regional offices of Persons with Developmental Disability (PDD) (their version of ADHC), to improve supports to adults with developmental disabilities. Each network is supported by an AACL Family Voices Coordinator.

**Personal Highlight:** An amazing and diverse group of people. The depth of knowledge and experience in this group was inspiring. For those of us with young children, the horror of institutions is something we don't recognise; therefore, we need to be wary of any return to the 'bad old days'.

### Community Navigator Project

I wonder if there was ever a choice of title as apt as 'navigator', to help you traverse your community when striving for an inclusive life. The Navigators help identify the appropriate balance between government funded services and supports available through generic community resources and natural community supports.

**Personal Highlight:** The removal of the terms and roles of caseworker, aide, support staff etc to a very appropriate 'navigator' who describe themselves as 'community connectors' - a reminder that language is so very powerful.

### Multicultural Project

This is a partnership between AACL, the Multicultural Health Brokers Cooperative (MCHBC) and the Edmonton Child and Family Services Regional Authority, to support immigrant and refugee families to access appropriate supports and services, as well as create family networks in their ethnic communities.

**Personal Highlight:** The strength of these families, particularly the women of the MCHBC to fight for what they know to be innately right - amazing and awe inspiring.

### Rotary Employment Partnership

In this initiative, Rotary Clubs work in partnership with AACL and PDD to develop jobs for people with developmental disabilities within the

business community. This project taps into the respected voice of Rotary and fosters community commitment to the ongoing development of genuine and meaningful employment opportunities. A coordinator works with the employers to help establish the position but do not undertake the role of 'job coach'. If additional supports are required they are identified and sought by the employer and the coordinator.

**Personal Highlight:** A great project which could be emulated in any community and any Rotary Club. The Rotary Clubs currently engaged in this initiative are keen to help other clubs embrace this project in their own towns.

### Family Managed Funds

There has been individualised funding for 25 years in Alberta - something only just starting to gain momentum in Australia. However, it is about to cease in its current form. This has largely come about due to the fact many families simply defaulted to relying on service supports and were not given training/education on how to truly manage individualised funding.

**Personal Highlight:** The insight into this area was greatly appreciated and not something I had been exposed to previously. I was most intrigued by the recognition that when funding amounts were capped, people spent to the cap, but when they were uncapped, the overall costs dropped and people only used what they truly needed. I can see huge benefits in individualised supports for families.

### Elementary School Visits

I was fortunate to attend two elementary schools during our stay. The first was an award winning, AACL recognised school, an excellent example of inclusive education. Being a former 'teaching school' there were viewing platforms behind one way glass into the classrooms. You could observe without upsetting the true class environment. A large 1-2 composite class of 50 children was managed by two trained educators and two support staff. There were five children in the class with additional support needs. Interestingly, not only could we not identify who was a learning support staffer and who was a teacher, we couldn't identify any child who may have had additional support needs because the class was structured in such a way there were group learning and peer based learning activities going on throughout the entire classroom.

The second school I attended was based in Edmonton with a different

vibe entirely. It was considered to be a progressive school offering different learning style opportunities for students. You could choose their standard school program or a 'Cogito' program where whole group, direct instruction, is employed. Students are taught in an orderly and structured setting in an academically oriented program. From my understanding, this type of program does not allow for adaptive education practices and therefore would not be suitable for inclusive practices. Their standard program was more likely to provide these opportunities, however, I did not feel there was a truly inclusive approach. It appeared that if children had significant additional needs they were channeled away from that school setting.

**Personal Highlight:** Having the opportunity to attend with others more experienced than me was a great opportunity when it came to wading through some of the 'illusions of inclusion' and some of the 'spin'. It has made me more confident in questioning tried and true methods and highlighting deficiencies in the system.

### The Annual Family Conference

This two day conference was a fitting end to our Parent Exchange. One of the keynote speakers was Dr. June Downing, Professor Emeriti of Special Education, California State University, Northridge. She is a national leader in the field of special education that targets the needs of students with severe disabilities, especially with regard to inclusive education. For me this was without a doubt the highlight. I have struggled finding practical solutions in education for a child like Mac. Dr Downing was able to break lessons down into manageable chunks, both high tech and low tech examples were given.

### In Conclusion

There was no downside to this trip. The goals of inclusion globally are the same; it is nice to know we are not alone. The friendships forged, the insights gained are so invaluable and intrinsic to every plan we now make for Mac's future and our future. We dare to dream big and are determined to make those dreams a reality. Was it life changing? It was certainly life consolidating and life confirming. I think to be granted the luxury of that type of affirmation this early in our journey will end up being life changing. Family Advocacy has without a doubt been the catalyst for all of this. I am eternally grateful for this experience.

# My Canadian Experience

**Meg Sweeney**

*Meg Sweeney and her husband, Todd, live in country New South Wales with their three teenage children. Meg has been active in advocating for inclusive communities since the birth of her daughter, Joscelyn, 18 years ago.*

In March this year I was very fortunate to be invited by the Alberta Association for Community Living (AACL) to participate in a parent exchange to Alberta, Canada. Similar in philosophy to Family Advocacy, AACL has been pursuing community recognition of the inherent value, worth and contributions of individuals with developmental disability for many years by assisting them and their families achieve an individualised, included life.

As a parent of three young adults, I have been actively pursuing a better life for my family by enabling my daughter to have the same opportunities and experiences that her brother and sister enjoy without the barriers she faces.

I often feel that in achieving progress towards Joscelyn being seen as an individual and accommodated in the community as such, it is one step forward and two steps back. The same discussions need to be had over and over again. The only benefit of this is that I have become very experienced at being clear about my vision and practiced at making my point. However, I do feel overwhelmed at times at the lack of larger community progress towards typical lives for people with developmental disability.

I embraced the opportunity to see progress towards these goals in another country.

On the week long visit to Calgary and Edmonton we were guided through many AACL initiatives, some current Alberta Government policies and reviews, in addition to meeting adults and children experiencing individual lives in their community. Inclusive education, a home of ones own, tertiary study at universities and colleges, open employment, business initiatives and inclusive recreational opportunities were all discussed and witnessed first hand.

The lived experience of the individuals with developmental disability that we met was overwhelming. People

with significant disability showing immense personal growth, satisfaction and belonging due to the inclusive community opportunities they experienced. People were known by their name as a workmate, fellow store owner, student, flatmate or homeowner. We experienced lives rich with family and friends, opportunity, safety and with a wealth of capacity for individual choice making and change if desired.

***People were known  
by their name as a  
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or homeowner.***

Unfortunately, Alberta faces the same community and political pressures as we do in NSW. The people we met and their lives were not reflective of the majority of citizens with developmental disability and AACL has a long and strong history in trying to make such a life available for all. In spite of many gains over decades, during our visit, AACL were dealing with government reviews of education that threatened inclusive practice in schools and a direct payment program limiting future individual decision making capacity of adults. I was reminded that change is slow and requires sustained effort. Any gains are to be guarded with vigilance as they can be lost with the stroke of a pen.

As in Alberta, it is people with disability, their families and allies that hold the historical knowledge of shared life experience in NSW. Politicians, government and non-government staff, academics, and workers come and go, however, the people with the lived experience remain, year in, year out. Successfully harnessing the authority of the lived voice is essential in the development of policy and practice as it reflects the real outcomes of decision making. Organisations such

as AACL and Family Advocacy are pivotal in connecting that collective voice, organising opportunities for engagement with decision makers and disseminating information so informed responses can be made in both private individual lives and on the public stage.

I was very interested in a direction of AACL that focused on unlocking typical community capacity in addition to their work fixing, developing or adjusting disability systems and supports. AACL holds the belief that the ordinary community is rich with opportunity for people with developmental disability to be included, they just haven't ever thought about it or been asked. Talking to ordinary community groups such as Rotary, sporting and other generic community organisations about the opportunities or barriers they may present to people with disability has had substantial results. Employment, engagement in sporting and holiday programs, tertiary study are some of the outcomes that individuals are experiencing in Alberta through this initiative.

I would love to report that I witnessed the formula to make our community truly inclusive, however, I'm afraid that was not the case. What I discovered was a shared journey so similar to ours here in Australia. As here, the large majority of people's lives are captured by government decision making or lack of it; policy, bureaucracy, politics, history and indifference. Strangely, I didn't feel depressed by this. I felt supported that even though our efforts are endless, taxing and repetitive, they are not in vain. Opportunities for community inclusion are always available if we seek them. Every single life that benefits from community inclusion has immense value, not just to that person, but as part of the puzzle that is community education towards inclusive change.

# The Alberta Exchange

Jaquie Mills

*Jaquie Mills is a parent; runs a consultancy that facilitates planning and learning for individuals, families and human services organisations; is Chair of Vela Microboards Australia and teaches Inclusivity and Diversity in the School of Education at Edith Cowan University.*

The trip to Alberta came right in the middle of our son Eli's transition from school life. Eli is 18 and has a significant disability, which means he needs help with every aspect of his life, 24/7. His challenging behaviours mean that he can never be without somebody watching out for him and those around him. I thought we had been very brave to consider a future which includes Eli running his own business and being able to share a house with friends, but the Alberta experience made me wonder if we could have even higher expectations for Eli's future.

Unable to find the examples we needed in Western Australia to learn how to create a good life for Eli out of school, we went to the US four years ago to meet other families in the hope of learning from them, and this experience laid the foundation for where we are now. That trip resulted in us formalising a circle of friends for Eli and working towards establishing a microboard for him (Vela Microboards Australia has since begun in Perth, WA in 2007. See <http://www.microboard.org.au>).

Eli's fledgling microboard have done most of the planning for his future, finding creative ways forward at a time when I was feeling, frankly, a bit tired and less than brimming with the energy for innovation. Where I might have said with shame that Eli's compulsion to seek and destroy all things electronic makes life extremely difficult, his friends said with admiration that he is 'gifted at dismantling'. Where some might say that Eli is nonverbal and uncommunicative, his friends see him as someone who is 'uniquely verbal' and who has the knack of teaching others how to communicate in deeper and more meaningful ways.

Eli is so skilled at dismantling and destruction that he was not able to use any of the usual communication devices, and so had been exploring an extra rugged notebook computer as a communication tool. Created for

military use originally, Eli managed to break his about six times before we managed to 'Eli proof' it, and so his role as a product tester of the durability of everyday technology was born. Part of his business ('Merger of Minds' began on 4 July this year) is now hiring and selling these notebooks to families and helping them to incorporate technology into their lifestyle. Eli also runs workshops teaching people how to communicate more effectively. This is tricky stuff – Eli won't perform to a pre-determined schedule, but so far he has been magnificent in making every presentation unique and meaningful, in his own wonderfully random way.

***When the leadership for change is driven by the person first, by their family, and by the natural community around them, the potential for success can be the stuff of our wildest dreams.***

At the same time, we have been in the process of moving out of the family home whilst some of Eli's friends move in with him. The planning for this has been much more messy...and more natural...than the planning for his business. One day, a few months ago, Eli's mate Liam suggested it was time we moved out and that we invite his other mate Joe to move in. Joel, another friend, already lives here (we have been experimenting with living arrangements with others for quite a while). The young people have been having private conversations about how this will all work and as far as we can see, have come up with some really solid strategies for living together and for supporting Eli.

So, what effect did the Alberta experience have on the way we manage

these two aspects of Eli's life? Firstly, the Albertans have questioned deeply the role of paid support and redefined it with a move away from the 'one size fits all' role of support worker which dominates in Australia. Secondly, they are way more ambitious than we tend to be! So, when looking for staff to work with Eli in developing his business, we have avoided support workers altogether and instead employed people with the skills to make his business work, such as a business coach and a general manager. Others in his business work alongside Eli rather than *with* him and are there because they have skills which contribute to Eli's business. He is still supported by the team, but in a less visible and more personalised way. Eli is responding to this new way of doing things by becoming much more independent. There have been many unsolicited firsts this year, including him getting his own snack from the fridge and putting on his own shoes. Less intensive daily support seems to be more effective than years of therapy!

We also now realise that Eli's business will only be sustainable if it can support enough staff that we, as his parents, don't have to be the backup support so, we have been focussing on how we can charge enough for this to be possible. Asking people to pay Eli significant sums of money for his time (instead of it being the other way around!) is quite a paradigm shift for us, and one which I struggle with. Luckily his business mentors don't, so we leave that part to them!

This question of the role of paid support has also influenced the way we approach Eli's shared home. Previously, I might have stuck to my guns in terms of him having staff for things like personal care, but now I am more respectful of his friends' perspective on this. In the discussion about whether they want paid support to come in and help Eli, the young men



are quite indignant. “We don’t want some stranger coming into our house and messing with our mate!” they say to me, so cross and yet so sweet. “AND, what makes you think we can’t do it? We’ve done it lots of times. We have our own ways of helping him...” Now, we have known these young men for years and trust them completely and by ‘our own ways’ I know what they mean. There is no gentle maternal coaching from these chaps who replace my soft, “Time to wake up sweetheart” with, “Get the #\$\$\$% out of bed you lazy git!” The thing is, their way works more often than mine does.

This is just such a different experience to what I expected. I remember thinking years ago how hard it would be to find people to share with Eli. I never expected this kind of joyful anticipation from others. I think if I hadn’t gone to Alberta and seen the overwhelming evidence that an inclusive life is possible, that the rest of the community does want to be with our kids, they just need the invitation and the education to make that happen, then this might have all panned out quite differently.

The Alberta experience has really made me question the way that the need for the formal disability system is so deeply embedded in our psyches. I think we do need formal support and better funding, but I also wonder if we have developed a too pervasive dependence on systems to help us. The dynamic in Eli’s life is less structured now, more fluid, and whilst admittedly more frightening for me, it seems to be more effective so far. We haven’t nailed it by any means – we are right at the beginning of this new journey and who can say if we will succeed or not in the years to come? Right now all I know is that our boy is happier than he has ever been.

Seeing what the Albertan families have done, and how they have done it, has given me the confidence to persist in this path that is so daunting because it is so unknown and so uncertain. If there was a single core lesson from Alberta, it is this: when the leadership for change is driven by the person first, by their family, and by the natural community around them, the potential for success can be the stuff of our wildest dreams.

## Read any good books lately?



Such as, *Widening the Circle – The Power of Inclusive Classrooms* by well known author and speaker, Professor Mara Sapon-Shevin? Although written in a disarming, easy to read style, Sapon-Shevin lays out the moral and educational case for inclusion through powerful storytelling and argument.

Or, *Our Presence has Roots: The Ongoing Story Deohaeko Support Network* by Janet Klees? Janet reveals to us, in thoughtful detail, the fundamental principles and values that have guided the processes for people to live well in their own homes and in the community. This book takes us to a place of hope where potential runs deep and possibility strong.

The extensive **Inclusion Collection Library**, consisting of articles, books, DVDs and videos, provides information for families, professionals and students, to support inclusive lives.

The Library has hundreds of articles such as, *Creating Personal Portfolios: Tools for Transition, Communication and Inclusion* written by Paula Kluth. This article will provide you with a structure for creating a personal portfolio of information that can be used to start conversations with others or to familiarise new teachers, employers, coaches with the person with the disability.

**Are there any fees?** There are some charges but, these have been kept to a minimum. Articles, and some booklets, can be emailed at no cost to you or posted. You can borrow up to two books and one DVD, for up to three weeks, from as little as \$5 for one item to \$10 for three items (this just covers postage and includes a pre-paid envelope for their return). There is also a refundable deposit of \$30 (one item) to \$55 (three items) and, if you quote your credit card, the card won’t be processed until the items are safely returned and then, only the postage fee will be charged.

**If you live in Sydney**, why not phone us and make an appointment to come into our office at Epping and have a look at our significant Inclusion Collection Library?

**Wherever you are, go to our website:**

**www.family-advocacy.com** and search by topic or keyword. You can choose from articles, books, DVDs or videos (each summarised), then have the option of placing an order online or submit your request by email, fax or phone.

**Contact the Information Coordinator, Wendy McKinnon - phone 02 9869 0866 or 1800 620 588 (non Metropolitan callers) or, by email to [resources@family-advocacy.com](mailto:resources@family-advocacy.com)**

**f**amily  
A D V O C A C Y

If undeliverable, return to:  
The Institute for Family Advocacy  
and Leadership Development  
PO Box 502  
Epping NSW 1710

Tel: (02) 9869 0866  
Freecall: 1800 620 588  
Fax: (02) 9869 0722  
Email:  
familyadvocacy@family-advocacy.com

We're on the web!  
[www.family-advocacy.com](http://www.family-advocacy.com)

## Family

Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

## Advocacy

Standing alongside an individual who is disadvantaged - and speaking out on their behalf in a way that represents the best interests of that person.

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