

Families for Change

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

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ADVOCACY

Editorial

We finish this year on a high note with Part 2 - the final issue - around the life changing parent exchange held in Canada earlier this year, between Albertan families and a contingent from Australia and New Zealand.

The brainchild of Bruce Uditsky from the Alberta Association for Community Living (AACL) and supported by Australians: Catherine Hogan (Family Advocacy, NSW), Ross Wormsley (Community Living Project, SA) and Darrell Wills (PLEDGE, WA).

Many thanks again to all our authors who gave so generously of their time so that we could all share their journey, thereby encouraging us never to settle for anything short of inclusion for all.

Finally, a journey of a different kind - in an effort to better inform New South Wales' families and the professionals who support them, we need your help.

Inside this issue you will find a survey covering many of the aspects that are part of *Family Advocacy*. Make yourself a cuppa, sit down and relax and spend 5-10 minutes ticking some boxes and adding notes, where applicable. When you are finished, you only need to write the *Reply Paid* mailing address (it is on the survey) on an envelope and pop the survey in the post box. We will be very grateful for this feedback and it will allow us to provide YOU with the information YOU need, and in the format YOU find the most convenient. Thank you.

Family Advocacy wishes you a wonderful Christmas - a time to reflect and recharge - and may 2010 be the start of the 'good life' for every member of our community.



The office will be closing 5pm
Wednesday 23 December 2009 and
reopening Monday 4 January 2010

My Experience of Canada

Anita Speed

Anita is married to Mark and mum to Dale and Joel. She is passionate about inclusion, planning, and supporting families that are on a similar journey.

I first heard about Bruce Uditsky's idea of a family exchange in 2007, at the end of the Family Advocacy *Odyssey Conference* in Sydney where he was speaking. (Bruce Uditsky is the Alberta Association for Community Living's (AACL) Chief Executive Officer.)

I found myself on an email list from Bruce in 2008 that went to a number of organisations and parents around Australia, asking what an experience, such as a family exchange, might look like. After a couple of teleconferences and, in my role as Parent Program Coordinator with Mamre Association in Brisbane, I approached my networks in Queensland in search of parents to go on the trip. Two parents from each state were very generously sponsored by AACL to attend, and others were also able to go if they found funding, or were self funded. At this point, it didn't occur to me to put my hand up as I thought it was my role to look for others to go.

My networks came up with a list of families who could most benefit and have an effect on other families by attending this trip. It was then that the Director of Mamre, Kathryn Treston, suggested I was a good candidate. So, along with

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Jane Hudson from Goondiwindi, we began to make plans. With four weeks to go, my family decided I wasn't going without them so, my husband Mark and two boys, Dale and Joel, came along for the ride.

What a privilege to meet Canadian and other Australian families in this way. Lifelong friendships have been forged and unforgettable and life changing moments were experienced. We all got to live with Albertan families, which was incredible. Our hosts, Wendy, Blaine and Kyle McDonald, were amazing and we have all become great friends. Wendy is also the President of AACL and she has an amazing knowledge and wisdom around issues of inclusion.

It was a long trip and they worked us hard! Bleary eyed from jetlag, we undertook an intensive learning experience of how things work for families in Alberta who have a member with a disability. The week ended with the AACL annual family conference where many of the Australians were to present. Mark and I were interviewed for TV, much to our boys' mirth and our terror!

There were many things I found enviable, such as a province that had far greater funding capacity than anywhere in Australia, and having a powerful and respected organisation like AACL. Queensland has had its great organisations too, but they had gone through hard times and it has been a challenge being able to connect families without that strong, state wide organisational support behind us. AACL has been around for a long time, and it shows. It is very organised, has clear structures and strategies, works collaboratively with a range of entities and is highly regarded. They look at systemic as well as individual issues and are clear in their values and objectives. You know you are safe there and have their strength and support behind you when going into the lion's den.

There were a couple of outstanding experiences for me. The first was hearing from a group called the Multicultural Health Brokers Co-operative. The powerful stories, from parents who were refugees and immigrants, were

something I will never forget. Once you've heard a parent with halting English talk about wanting the same for their children with a disability as our families; and they have the added barriers of language and racism; you feel like there can never be an excuse for not fighting for inclusion ever again. Whenever I get tired and think I need to let a bit too much go to the keeper, I remind myself of these gracious and courageous parents and forge forward.

It was the moment I knew anything was possible, that there are good people in the world that can and do make good things happen in education.

Another moment was meeting the high school principal of my dreams. This woman was a true educator who understood and implemented inclusion in her very large suburban high school. It was the moment I knew anything was possible, that there are good people in the world that can and do make good things happen in education.

Given the inspiration of some of the great examples of inclusion that happen in Alberta, there was an overwhelming impression of how similar we all were. The issues we face in Australia are the same issues families face in Canada. It didn't matter that there were better structures, or funding, or that there was an AACL; families still have to fight for their children to attend mainstream schools and still have to face discrimination and exclusion from general society. Although it was disheartening to see how universal these issues are, it also brought a strong global sense of solidarity. Meeting and getting to know the Albertan families and hearing their stories brought us together and we have a sense of mutual support, understanding and love. Our boys went to a scout meeting in Edmonton with our host family's son Kyle and are the only kids in their scout troop at home who have earned their world badge!

I also loved how the Australian contingent connected as a country and not as families from each of the states. I am very excited that we now have a base to strengthen a national movement of parents, to share our collective wisdom and take inclusion forward at a national level of communication. Our states have unique issues which need to be dealt with, but knowing that we can have a national network of support that collaborates on major campaigns and experiences gives me a renewed sense of hope and excitement.

Interestingly, I have since moved out of the sector and have taken on a job completely unrelated to disability. It has freed my mind to concentrate on planning for our son and be available to support other families in a different way. The Canadian experience taught me that we are in this for the long haul, and I have to pace myself in order to make it work

for Dale in the long term. Once I've settled into the new job, I am planning to use my renewed energy to assist in developing a stronger communication on the national level. A wonderful conversation has been going on with many of the contingent on our return, through the Family Voices email forum. Jane Hudson, myself and some others, have developed a website that has captured the content of the Alberta experience and hope to launch it soon so other families who weren't there can participate in our conversations.

My family has strengthened in its resolve to not just survive but to prosper, since our return from Canada. Planning for Dale's future and having him as a full member of his community has benefits for all of us. Dale now has a job at KFC and continues to remind us how our communities and our lives are richer for his being part of it.

An Opportunity of A Lifetime

Helen Durbidge

We are the Durbidge family consisting of Helen & Gary and four amazing children, Jasmine - 31, Talia - 21, Shari - 20 and Joel - 19. We live just south of Coff's Harbour - the best place on earth. We have been strongly advocating for inclusion for our daughter Shari for 20 years.

In March this year I was offered an opportunity by Lifestyle Solutions to be their representative to attend the Alberta Association for Community Living's (AACL) Annual Family Conference and to spend some time staying with families in Canada who share similar experiences to our family. After discussion with my family and presenting a thousand reasons why I should not go, they insisted I was more than a little crazy if I did not take up this amazing offer.

My family; consisting of four children, my husband of 32 years and myself; are no strangers to challenges as our amazing daughter Shari, who is now 20 years of age, is the reason I believe that anything is possible. The Canadian trip was going to be another step in the learning opportunities that she has allowed us.

Of all the people who attended from Australia, I knew just one and we had only met on one previous occasion. You soon realise that, through our children, we share a strong commonality with people worldwide. Ours is a unique bond that arises from common challenges that only those who have experienced could begin to understand. I felt right at home and made some incredible friends, both Australians and Canadians. I listened intently, and with sincere interest, of the trials, tribulations, successes and joy of many other families. These stories became the impetus to continue to advocate for our children and also the realisation that we must never give up and never doubt our belief that our children deserve the same opportunities as every other human being.

AACL is real proof that one man with a vision can bring together people

from every walk of life, and gain momentum from numbers, to hold the flag high and permeate communities and governments with the very basic belief that we all belong. I soon learned that the experiences and triumphs in Canada were not all that different to ours here in Australia, it just became more evident that we are a vast land and, in Alberta, they appeared to have the advantage of working in a more contained area. I also observed the strength of their association and the many levels they were covering. They are leaving no stones unturned and have gained enormous respect and power from starting small and remembering to include all facets and family needs.

Maybe we need to come back together a little better and project the power gained from being united in our commonality.

The AACL Annual Family Conference was an absolute joy and honour to be part of. It is all about reflecting on the past year, providing a common place for all of those associated to look back and marvel at the trials and tribulations and, most importantly, to set the stage to move forward. It is a special opportunity to educate and to spread the knowledge and beliefs of each and every person involved.

I came away with the realisation and the affirmation of something that has concerned me for some time now. It is my belief that, in Australia, there have been many attempts by governments

to place bandaids on disability issues and that in doing so, I believe that our commonality as parents and family members has become far too fragmented and widespread. I have now observed in Canada, and had it reiterated to me, that we have sometimes allowed governments to take too many diversions in too many directions. Maybe we need to come back together a little better and project the power gained from being united in our commonality. Perhaps Australia is not such a wide land after all.

My lasting impression on inclusion in Alberta, as I boarded the plane to come home, was the way they had established the core need to place enormous energy and resources at a community level. As I reflected, this was profound for me and I realised the immense importance of each family with a member with developmental delays, to seize every opportunity to carefully mould and change the preconceived judgments that so many people hold where disability is concerned. Every time we step out of our doors we must realise the enormous gift of being able to change society for the better and create more fulfilling lives for our families and we must never let an opportunity pass that allows us to effect change.

I will be forever grateful for the incredible hospitality of the Canadians, at every level, and their willingness to share their powerful knowledge, experience and love with us Australians. The world will benefit from their very desire to narrow the distance between us and to empower and enthuse us here in Australia to move forward.

Assisting Our Children's Children to Have Ordinary Lives

Darrell Wills

Darrell Wills BA/MEd is Director, Senior Educational Consultant for the Parent Learning and Educational Development Group (PLEDG), a parent advocacy group in Western Australia. Originally trained in education and psychology, he did post graduate work in education, training as a 'trouble-shooter' for the American State of Washington, before returning to Australia in 1976. Since then, Darrell has lectured Australia wide and works directly with families and teachers to demonstrate what inclusion could and should look like for children and families.

Are we there yet?

I am the eternal child in the back of a car always wondering if we will ever arrive. The journey in this case is one towards a more inclusive society and the trip for me has been nearing four decades, so it was good to find a 'sign' that we had indeed arrived. As we stretched our legs in the Canadian outback and photographed a sign that read, "Celebrate inclusion: it benefits everyone", Al Mason and I pondered if it was indeed a sign of things we would find ahead on our journey with the Alberta Association for Community Living (AACL). Sure enough. It was.

Do they get 'it'?

I heard a good answer – the best one yet - from our friend Bruce Uditsky. "We are there when we observe the people and come away knowing that they 'get it'". Thanks to Bruce and the Canadians for this one. Knowing people 'get it', sounded at first a pretty unscientific measurement devise. 'Getting it' is something people can't hide. They do or they don't. When you don't 'get it', you are confused by what others see plainly. That is inclusion.

What does it take to have ordinary lives when one is faced with life with a label?

How simple it still seems that all we ask is to have a typical life and yet we are still faced with daily offers of 'special' lives.

A mother reminded me today as I penned this introduction, of an expo to be held soon on the alternative to employment. My quip in return for this alert was,

"In the real world, the alternative to employment is unemployment or retirement. An expo on 'something else' will surely be something 'special'". Her quick response, "I cling onto the hope that one day I won't let the forest cloud my view of trees and that I will enjoy seeing those things without them needing to be pointed out to me." Therein lies the journey we all face each day - sorting out the special forest from the typical trees.

In the Canadian outback there was a sign that read, 'Celebrate inclusion: it benefits everyone'.

Nearly four decades ago, when I entered this work, some labelled children weren't allowed in schools and those that were, were grouped together. When they got older they worked with other labelled people away from non-labelled people or not at all. The degree of separation has changed over the decades but not the underlying structure of separation. Our view, based upon historical analysis, is that society has basically 'structured itself up' for segregation. Why it did so is a varied story – from not knowing any better; to believing people would be "better off with their own kind"; to believing there was some science that was suggestive and supportive of classifications and labelling, leading to some useful, fruitful and good ends; to addressing the wants and demands of groups who either wanted to be separated or others being powerful

enough to enforce separation; to simple ignorance of the facts.

There are a number of why's but in the end, we arrive here, today, with WHAT we have been passed forward and it is, in the main, a series of social structures and stories that promote the continued separation of people based upon ancient labels. That is why it was so refreshing to meet 600+ other folks with a set of new stories designed around a 'structuring up' around life in the community. In Kununurra we are lucky to speak to a dozen people who 'get' this journey and in other places, only a handful 'get it'. 600 is a revolution, a peaceful revolution.

In Canada we saw how AACL, Rotary and a couple of young people and their families, had made this leap. We saw a woman living in her own home and running an upmarket, viable business in Edmonton. She and her parents, together with AACL, showed us how they are working on this - not as a 'one-off' - but as a systemic and strategic pathway of typical adult opportunity; in the same way as showing us university and other post-secondary education as systematic, strategic inclusionary opportunities.

To close this short chapter, let me say thank you to our hosts, Bruce, Wendy and the team of people called AACL - not only for your amazing hospitality but for allowing us to see the structure behind a new life of community.

Families For Change – Canadian Exchange

Anita O'Brien

Anita is a strong advocate and supporter of people with disability. Her younger son, Warren (34) moved out of a group home and now lives in his own place with the natural support of a housemate. Passionate about sharing Warren's journey, Anita has become a speaker and writer; along with her work at Rights, Employment, Accommodation and Leisure Inc (REAL), the Victorian organisation she founded 12 years ago.

My decision, to join the Aussie team who had accepted an invitation to visit the Alberta Association for Community Living (AACL), was made on the run. Despite the hurried arrangements, I wanted to be part of the contingent because I knew AACL had so much to share from their many years of experience working alongside families, organisations and the community. We were to learn much by observing working examples of community inclusion and successful community partnerships, as well as through workshops and presentations, culminating in a conference in Edmonton.

I have beautiful memories of the shared experience with the Aussie and Canadian families – times we laughed and times we cried. We were all brought face to face with the struggles and heartaches, but were also encouraged by the possibilities and AACL achievements. Maureen McLeish was the other Melbourne participant in the team and we enjoyed the time afforded us to further share our experiences, celebrate heart to heart the achievements of our children, as well as our struggles over the years. I have to add that sighting the snow capped Rocky Mountains from the plane was an amazing and uplifting experience.

I was very interested in the employment partnership that District 5370 Rotary Club has with AACL and two other community organisations, as I learnt how my efforts with our local Rotary Club could be taken to another level. The purpose of the partnership is to create meaningful employment opportunities for people with developmental disabilities in

association with business owners and employers. They state in their brochure that, "Like everyone else, people with developmental disabilities have strengths and interests, talents and abilities". AACL and its community partners provide all the necessary assistance and follow up to ensure success.

"Like everyone else, people with developmental disabilities have strengths and interests, talents and abilities." AACL

It was a delight and privilege to visit 'Sheena's Sweets', a truly inspiring story about following your dream. Sheena is a remarkable young woman with a wonderful family. They embraced the challenges and, with volunteers and occasional paid staff, have built a delightful and well run business. To read a snapshot of her story and see her shop, visit her online at www.sweetsandsuch.ca/store.htm. Many hours were obviously spent by Sheena and her family in dreaming, planning, creating and establishing her shop, as well as the inevitable ongoing changes and additions to build the business.

I find it a real challenge to find a balance in building the life and telling the story. As more opportunities for inclusion are forthcoming for our son, the more support he and our family experiences from new friends and relationships, the more Warren realises his dreams; the more I want to share

with other parents that the rollercoaster ride is worth it. Taking responsibility for enabling others to achieve purpose in the face of uncertainty is for me a natural progression of gratefulness for the encouragement I have received. So thank you to Personalised Lifestyle Assistance for the guidance, teaching, and support on our journey. Thank you Sheena, for sharing the realisation of your dream for your own business with your Aussie friends!

We visited schools that used strategies to enable students with disabilities to be part of a regular classroom and this 'real' inclusion was a delight to see. I loved the video shown to us that included a young girl reading to her classmate, where it was obvious that both of them were receiving benefit from the exchange. On one school visit, a teacher told me at morning tea of the positive experience she has with one young boy (with autism) in her class, that he was naturally included as any other student in the class, but also on a practical level how she managed the challenges. When visiting her class I would not have known which student he was unless he was pointed out to me. In a nutshell, the only prerequisite to inclusion should be breathing.

AACL has experienced what happens, when direct payments are compromised, by lack of support given to families receiving funding directly (not through an Agency). It is interesting to note that although it is 20 years since 'Direct Payments' to families in Alberta was introduced, it has been compromised by families not having the support, guidance and know-how to vision, plan and achieve their goals and so

they turned to agencies to do it for them. In the process they lost so much authority and choice for their family member. AACL has now developed 'Family Managed Supports' to try and reverse this outcome. One of the important learnings was that families want and need a family resource centre that is virtual and concrete, specifically designed for and directed by families, that is user friendly.

There is so much more to tell, including the conference in Edmonton and the special privilege of experiencing

first hand the wisdom, knowledge and thoughtfulness of John O'Brien; however, that will be for another time.

During this time we were asked what values we affirm and what we challenge, what possibilities can be explored, how could we strengthen the support available to families? We were encouraged not to fight alone and my experience is that this has been one of the most important stimuli to successful change in our son's life.

I stayed with delightful hosts in both Calgary and Edmonton. It was just

wonderful to share with people who understood, who have travelled the journey with their daughter or son and who were so embracing of us. My heartfelt thanks go out to them, to all the families and staff at AACL for their generosity, and particularly Bruce Uditsky for germinating his idea for a parent exchange. The acorn has started its growth to a beautiful tree of sharing and learning across the miles. I hope it is not too long before Australia can host our cherished Canadian friends.

Inclusion Collection Book Reviews

Safe and Secure – Six Steps To Creating a Good Life For People With Disabilities by Al Etmanski with Jack Collins & Vickie Cammack.

This book is based on the experiences of families who live in Western Australia and Canada who had a common desire – a good life for their family members with disability, now and in the future. Who would care for their family member when they were no longer around? Who would protect them and keep them safe? Who would appreciate and nurture their gifts? Written to inspire families to action, it provides information and options related to trusts and government benefits, home and lifestyle options, financial and estate planning, guardianships and alternatives and social supports. It includes worksheets and practical examples of how families have approached and developed their own plans for the future.

Moving Out, Moving In – How seven people with disability found their own home by Rea Dennis and Lesley Chenoweth.

A collection of stories about relocating to the community, this book presents the personal stories of seven Queenslanders with severe intellectual disabilities. The book raises a number of key challenges for those contemplating such a move, and offers inspiration and insight into the planning and personal commitment required to ensure the success of this significant life event. It also looks at the various impacts on the individual, their families and the services that support them.

Laying community foundations for your child with a disability: How to establish relationships that will support your child after you're gone by Linda Stengle.

Every parent who has a child with a disability wonders what their son or daughter's future will look like: this book shows families how to take action to ensure that their son or daughter's life will be more satisfying. The author emphasises the importance of building a support network of social



relationships over time and gives strategies for seeking and cultivating relationships, illustrating this with examples. This book sends a clear message that it's never too early to start preparing for 'after you're gone'.

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 contains hundreds of articles. Articles on planning, having a dream and how to make it a reality, education, supported living, a home of your own, life after school, inclusion, etc.

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, if you have access to the Internet, you can 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.

You can also contact Family Advocacy by phone 02 9869 0866 or 1800 620 588 (non Metropolitan callers) or, by email to resources@family-advocacy.com to request information.

Shared Challenges

Maureen McLeish

Maureen and husband Murdoch McLeish live in Melbourne and have three children and two grandchildren. With the right support, our 25 year old daughter Lauren is able to pursue her passion around film, movies and television. Lauren is a volunteer usher at a theatre and television organisation in Melbourne and also helps out in their marketing department. She has a job at a local farmers market selling produce, is an avid Kangaroo Football Club supporter/member and a member of a local gym. Lauren pursues all of her aspirations, as other people do – in the community!

An invitation to travel to Canada came to Anita O'Brien and I from Deb Rouget at Personal Lifestyle Assistance (PLA). We were extremely honoured to be invited to be part of a parent exchange with families from Alberta. We have both worked closely with Deb, who assisted us to think about a good inclusive life for our young ones. While we both have very different family stories, our passion and our commitment to inclusion is the same. So off to Alberta we went!

The wonderful people from the Alberta Association of Community Living (AACL) warmly welcomed us and over ten days we experienced stories of support in education, workplaces and community. We shared stories, often similar and some amazingly different to each other. But always our focus was on inclusion and how we can assist our young ones to get a good life in the community.

Before we left Melbourne we were not sure what to expect and who exactly AACL were. It started to unfold within the first few days in Calgary when we realised this wonderful organisation is right at the forefront of assisting people with disabilities in Canada.

A big focus of the exchange was around education, and this wasn't something either of us is into at this stage of our family member's lives. Most of our focus was to hear and learn about inclusion in the work place and community. How young people are assisted in their employment and then how they are supported to think about independent living. For the two of us, this was where we are at with our thinking. However, we were still captivated by the education focus AACL has and all the assistance they can offer on advocacy for parents and

families entering education, right from kindergarten to university. This was most enlightening and we have been able to bring home some encouraging stories around this to share with our parent groups.

Focus was on inclusion and how we can assist our young ones to get a good life in the community.

In 2008, Anita and I both participated in a family leadership course in Melbourne with PLA. So, we were most interested to hear about the wonderful opportunities AACL offers to the parents in Alberta who they encourage to do the family leadership course. While the organisation of the course is very different to what we experienced, the content was similar and we came away encouraged to seek new initiatives in assisting families to think more deeply around inclusion for their family members.

Over the past two years, I have been involved with a Department of Human Services pilot project around direct funding in Victoria and I had heard how Alberta had lead the way with funding people directly to support themselves. So, I was very interested in hearing how this has been rolled out over the past 20 years. I was amazed to learn that direct funding has started to be taken back from people and returned to services. This has been a huge learning curve for me and I have related this knowledge to our Department of Human Services so that we can profit from this and ensure people are well supported once they receive their funding. This will be a big challenge for our State Government

once they roll out the payments to hundreds of people in 2010, which is the aim. I attended a meeting for the Direct Payments Pilot immediately on my return and everyone there was most interested to hear the updated Canadian story.

Another interest Anita and I both have is around Family Governed Groups and how they assist people to utilise their funding and create good community lives. Whilst we didn't see anything like what we have in Victoria, we did learn about Family Managed Supports and were keen to explain that idea to our groups on our return home. It became clearer that if you receive your funding directly you don't have to be isolated and the idea of Family Managed Supports is an excellent idea for some families. This was very innovative for us, as there has been a perception here that if you have direct funding you could be isolated.

It was clear to us that there are many challenges we all face constantly. These challenges are not unique to Canada or Australia! We seem to all hold the same concerns for the future of our family members with disability. Their health, wellbeing, education, security, housing and the big question of how they will manage when we are no longer around.

We are most grateful to AACL for inviting us to their beautiful country, to meet people with the same concerns we have and to encourage us to think about real inclusion in our communities. Our memories and experiences of Canada in March 2009 will stay with us forever.

family
A D V O C A C Y

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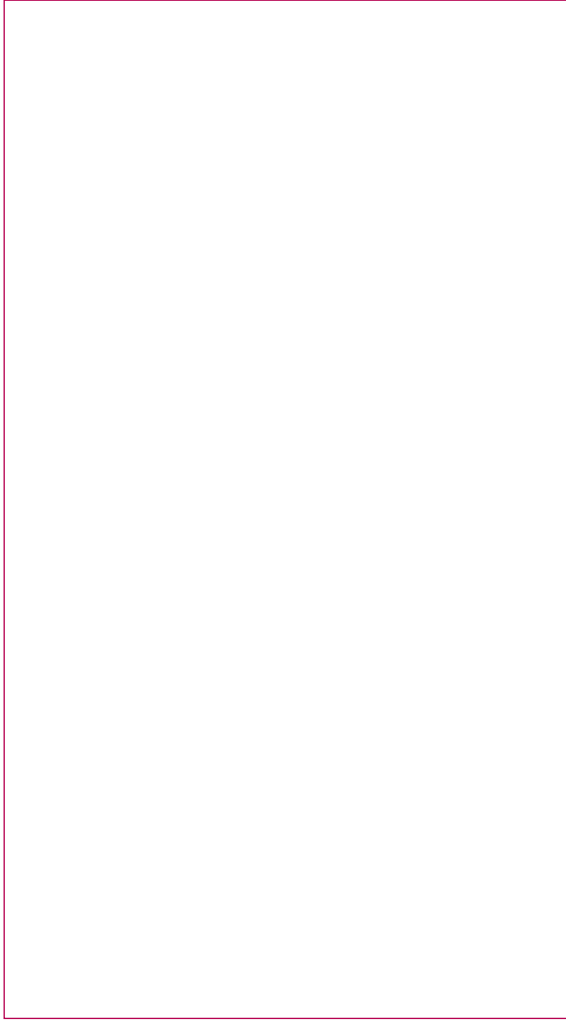
Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

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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