

Families for Change

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

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ADVOCACY

All My Life's A Journey

With only a few weeks to go until Family Advocacy's first national conference, *The Odyssey...a journey of enrichment and possibility*, the time felt right to dedicate an edition of *Families for Change* to the personal journeys undertaken by some of Family Advocacy's associates and supporters. Each person has their own unique path to traverse, and with the assistance of family and friends, can forge their own way to reach their own destination. The contributors to this Journal give their perspective on life, either from the viewpoint of a person with disability or as a person of significance in the life of a person with disability. All the stories have one thing in common - a belief that life should be and can be *a journey of enrichment and possibility*.

In his article, Andy Putnam recounts his first meeting with Joel Satherley, a young man with multiple disability. Joel's story is told through Andy's description of their relationship over the past 10 years. Andy met Joel in high school and has accompanied him on his journey into life beyond the school gates.

Pam Morris uses the metaphor of colour to 'create a way for Robert's life to be seen'. Robert is Pam's son and Robert's life journey has not been an easy one. Pam's love for Robert and her belief in his potential encouraged her to look beyond 'prevailing ideas' and to assist Robert to travel his own path, along which he 'monitors'

and 'audits' the many people and service systems that cross it.

While describing her journey as a young woman born with cerebral palsy, Ya'el Frisch reflects on the many opportunities she has been offered over the course of her 23 years. Ya'el encourages parents to 'dream big' for their children with disability and to raise the bar high!

"The goal is a 'real life', not a 'parallel life'"

Along with these inspirational stories, Peter Millier's article 'A struggle for a real life' reminds us about what we are really striving for when we insist that people with disability must be offered the same opportunities as their non-disabled peers. The goal is a 'real life', not a 'parallel life' where 'normal' is a construct created by professionals in an attempt to replicate an ordinary, typical life experience, but which somehow misses the point completely! As Peter writes "The struggle for a real life must be real."

Our society recognises the systems and institutions of the past are not the answer, and yet, the road forward for people with a disability is still blocked by prejudice, ignorance and popular politics. Waiting for Government to provide a solution is not the answer. Rather, people with disability, together with their family and allies, need to choose how and where they want to live, and then create the framework to get there.

It will not be an easy journey; there will be disappointments and pain, exhaustion and heartbreak. But it may also be enlightening and uplifting, joyous and meaningful, uniting friends and family to strive for the best for their family member with disability.

When Family Advocacy decided to host a conference this year, we did so hoping it might 'open the door' to families who were looking for 'another way'. We hope the conference might encourage more families to begin their own journey, to dream of a better life for their family member with disability and for them to take the steps that will turn that dream into a reality. We hope to see you at *The Odyssey... a journey of enrichment and possibility*. It just may be 'the ticket' that starts you on your own journey.

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The Colours In Robert's Flag

Pam Morris

Pam Morris reflects on the journey her son Robert has taken, from an institution to living closer to home in the community.

This story is Robert's, yet because our lives are intertwined it is also about his family and the decisions we have made for him. I have used colour to create a way for Robert's life to be seen and felt by others as he cannot speak and tell this story himself. The colours in a country's flag tell a story. The colours in Robert's flag tell his story.

Robert is my son. He is 46 years old. He lives in a house not far from me having moved there in 1989 when the Richmond Program opened houses in the community. Before that he was in an institution.

Robert was welcomed into our family in 1961. At 11 months he was diagnosed with severe intellectual disability. The paediatrician said "have another baby"; grandfather said "send him away before you get too fond of him". We were conditioned by the prevailing ideas. It was a time of limited options.

I can only choose **Red** to portray Robert's vibrant life, his strength of character, his determination through bad experiences to be his own person, his courage in adversity, his generous forgiveness, his warm and steady personality.

Black is for our decision to admit Robert to an institution. It shows our rejection and our ignorance of his rights and needs. **Black** is for the pain and trauma Robert must have experienced deeply at this time. **Grey** colours the lost years he spent in two institutions; the barrier of institutional officialdom and attitudes; the lack of education; the prescription of 'sedating' drugs; locked doors and segregation.

Blue is the constancy with which Robert and his family kept in touch, creating a continuing and deepening bond despite the distance apart. Weekends and holidays were spent together. Throughout this time Robert welcomed, forgave and accepted us.

I think of **Green** for the period of change when people with disabilities fought for their rights in the International Year of Disabled Persons, and when I met courageous parents who would not accept the status quo, who wanted their sons and daughters to be valued and accepted into the community. **White Gold** represents the enlightenment we achieved as a family and the conviction that we must make change for Robert.

"I can only choose Red to portray Robert's vibrant life, his strength of character, his determination through bad experiences to be his own person..."

Orange is for the support we found amongst those early spokespersons to begin the process of returning to Robert his right to be valued, and to be among us. **Purple** for the day I stepped out of my private role of parent into the public one of advocate to actively seek, against strong opposition, a new direction for Robert. **Gold** is for the day Robert and I drove away from the institution.

I believe he understood the change we wanted for him. He grew in confidence and well-being in the new house. He put paid to those who said he could not do it. We are much closer, and he knows we are involved in his life.

We hoped, at first, there would be more individual support and greater community involvement. But a service is embedded in a bureaucracy, and a bureaucracy is limited by the constraints of its resources and leadership. What can be delivered is variable, sometimes damaging, occasionally better. I keep close contact with Robert at the house in order to monitor what is happening.

Robert has epilepsy and other health needs. He supports the public and private health systems. He supports a dentist who understands his needs. From time to time he audits the emergency department in the hospital.

He is a brother, brother-in-law and uncle, he pays rent, is an investor, a shopper, a swimmer, a listener, and an example of patience and tolerance. He monitors afternoon teas with the family every Sunday, always reminding me to take the cake. He knows the local district and neighbours from his walks with us. He has been the instigator of many complaints to Departmental heads, and letters to Ministers.

Rob likes people to sit with him and talk to him. He likes to be recognised and responded to. He likes people to have confidence in him and trust him.

Often we arrange things for him and leave out the element of trust. Most recently I found at the last moment that, instead of fasting, he had been given breakfast the day he had an appointment for an ultrasound. I re-scheduled, making sure everything was arranged, especially the sedation I thought he needed. This time the house remembered he should fast but the hospital forgot about the sedation. After waiting an hour the technician said it was now too late, and "could we try the ultrasound anyway?" "Yes, we would try". Rob, with a few protests, succeeded in lying still, and crowned himself in glory as the only person in the complex and crowded network of support who did the right thing.

Rob broke two toes recently and had to wear a heavy black boot. He adapted immediately without complaint. Rob has wisdom that I call **Indigo**. He teaches us the deeper knowledge of who he is and who we should be in his life. It's an on-going journey.

Making The Most Of My Journey

Ya'el Frisch

Ya'el Frisch is in her final year of social science law at the University of New South Wales, and aims to use the law as an instrument of social change. She has a passion for human rights, loves an argument, and spends spare time with friends - drinking coffee, listening to jazz, watching movies, or just chatting.

My journey began with two 'accidents of birth', one fortunate, the other unfortunate.

In a lucky 'accident' I was born into comfort in 20th century Australia, into an involved and highly supportive family.

In an unlucky 'accident', I was born with severe cerebral palsy, restricting my ability to perform fine motor tasks independently.

My life has evolved as a combination of these two 'accidents', the challenge of my journey has been to use the tools offered by my supportive network to make the best of life with my disability.

My first source of enrichment and possibility has been my parents, who have always recognised my abilities above my disability. In my early years, they were urged by relatives worldwide to uproot the family to Hungary so that I could attend an intensive 'walking program' and be 'fixed'. Fortunately, they recognized that I would never be able to excel at walking, that wheelchairs served a purpose and that my time would be better spent in play, forming friendships with my pre-school peers. By accepting what could not be changed, my parents allowed my journey to expand and encompass new areas of possibility.

My parents' attitude encouraged others to see my abilities. I always attended mainstream schools, where teachers focussed on my intellectual ability, rather than physical inability. Had I attended a 'special' school, I feel that much effort would have been put into giving me 'extra therapy', that indeed was my area of weakness! But by concentrating on strengths, rather than weaknesses, I was able to excel.

Much of my journey has been spent surprising others, and myself, with what I can do. From primary school, I found that despite being shy and having dysarthria (a speech impairment connected to cerebral palsy), I really enjoyed debating, and was good at it. I was able to represent my school competitively, using my memory to compensate for my inability to take notes. I would see the way people looked at me after I had spoken, surprised and impressed. High expectations from others had allowed me to challenge people's preconceived judgements about me.

"...each person has unique strengths which will shine if they are individually supported."

I've been lucky to have been brought up with a strong cultural identity. As a member of the Jewish community, I've learnt that difference, shared with a group of like-minded people, can generate pride. I've been encouraged to embrace this pride in difference and to develop as a multi-dimensional person.

An invaluable source of enrichment in my journey has been the opportunity to meet and connect with diverse people. In senior high school, I became close friends with people from a wide range of backgrounds, who were extremely accepting of difference. I became less aware and self-conscious of my disability among my diverse friends than among my peers in a mono-cultural school. The more different people were in general, the less different I felt personally. I was able to 'share' my disability and my Judaism

as part of my uniqueness, just as my friends were able to share their cultural heritage with me.

Recently, I participated in research into increasing civic participation of young people from diverse backgrounds. At a two day workshop, I met, for the first time, indigenous peers and people who had been in care. Engaging with them opened my eyes to the great disadvantage faced by some people my age in my country. I felt acutely aware of how lucky I was to be part of a supportive family and community, and to have been given the opportunities I had been. A unique aspect of the workshop was that many looked at my difficulties and felt a similar 'inspiration' and appreciation of what they had. The group truly affected each other, showing how important it is for people from different backgrounds to intermingle and learn from each other.

In my daily life, my disability is a pain. But perhaps it has helped me develop an innate sense of social justice. I am (finally) in my final year of a law degree, which I hope to use to make a difference to vulnerable groups and individuals. I feel that the obstacles of disability have helped me become stronger and more compassionate, and have developed my sense of empathy. Importantly I want to stress that disability is not the only way to develop these qualities, it's just that sometimes being in a 'disempowered group' has its advantages!

I feel that the sources of enrichment and possibility which I have drawn upon can be applied to all people with disability. No matter what a person's limitations, each person has unique strengths which will shine if they are individually supported. A support network around each individual will

allow them to reach their full potential, and to grow. Limitations should not stop a person from engaging as part of society, which is only as 'regular' as its members. By being present and included in society, people with disability can change society itself by changing the way people think. I am certain that not everyone I have met likes me, yet it is possible that I changed their preconceptions about people with disability simply by being around.

When I think about what makes life worthwhile for me, it is when I'm truly respected as ME! I'm a complex person, and refuse to be labelled. I'm not only a law student, but also a music and movie lover. I support social justice, but don't agree with all left wing ideas. I may not be able to walk, but I love to swim. I may be empathic, but I can also get angry and irrational. No one can be 100% consistent, and my disability no more represents all my

“Accept what can't be changed, but fight for the rest – no diagnosis or service provider should stand in your way!”

identity than your hair colour does. I've resisted wearing a disability 'badge' as I can only represent me. Recently, I've made a choice to connect with peers with disability, but this is in an attempt to broaden my identity not restrict it.

It hasn't all been smooth sailing, there's been great uncertainty and many tears. Yet as I look to the future, I feel that my supportive family and friends will help give me the strength I need to face new challenges, such as moving out and dealing with paid personal care support.

If support is to improve the lives of people with disability, it should be as flexible and as person centred as

possible. I was shocked to learn that some attendant care providers would expect a young woman to go to bed by 9pm, just when life begins! I want supports to be a help not a hindrance to me, assisting me to lead the life I dream of. It's possible – there are 'night life' services in Brisbane and Melbourne which provide on call personal care services 24 hours a day!

I urge parents to 'dream big' for their children with disability, you set the bar, so raise it high! Look for strengths, not limitations, and allow the world to embrace the person you love. Accept what can't be changed, but fight for the rest – no diagnosis or service provider should stand in your way!

When I was born, doctors were uncertain if I would live beyond a few months, yet to date, my life has been a journey full of enrichment and possibility. I guess what didn't kill me has made me stronger.

Resources from the Inclusion Collection

Below is a selection of resources about people with disability and the personal journeys they have embarked upon. You can view articles, books, videos and kits from the Inclusion Collection online at www.family-advocacy.com or order by phone on (02) 9869 0866 or 1800 620 588 (for non-metropolitan callers).

David's Journey: From a Locked Ward to a Life of His Own

File 10827

This article is about David, a young man labelled as having destructive and challenging behaviour. Key people and family members come together to focus on who David really is and what is important to him. They develop a 'life plan' that identifies essential requirements for a lifestyle that will suit David's needs. Workers concentrate on helping David to feel safe and relaxed, and assist him to take more control over his life. David moves into his own flat and this, combined with a change of lifestyle, improves the way he is perceived.

Growing up in your own Community

File 10989

Bev Budden, co-ordinator of the Moving Ahead Program based in Atherton, Queensland, describes the journey made by a young man from school pupil to young adult. She provides insights into the cultural sensitivities that are needed when working within an indigenous culture and community.

Sharing our Wisdom

Book: 3282

22 people share their experiences of autism and tell a very different tale to the one universally accepted by many medical/therapeutic practitioners and the media. These are stories of hope and achievement, often against great odds. Their message: we are only limited by the limited understanding of those around us and not by our abilities. An insightful read for parents and professionals, that will give a fresh perspective to interactions with people with autism.

Inside the Edge: A Journey to Using Speech through Typing

DVD 144

This documentary is written and narrated by Jamie Burke, a 15 year old high school student with autism. Whilst the focus of this video is on Jamie's personal experiences with facilitated communication, he also talks about being in mainstream high school.

The Best Ride

Andy Putnam

Joel Satherley is a young man with high support needs who has a passion for extreme rides and lives life to the full, as his long-time friend and support worker, Andy Putnam, writes.

I first met Joel in 1997, by the gate of the old Nimbin Central School. His mother, Zoe, introduced us and I said hello. A small eternity seemed to elapse before he responded. My mind quickly filled with thoughts of uncertainty like 'can he communicate?' or 'will he want to speak to me?' But then I heard an unmistakable acknowledgement of my existence. I immediately felt validated and intrigued by the experience. Our journey together had begun.

Within the next week I had become his temporary English teacher and within two weeks I'd visited his home and swum in his pool. Joel was in year 7 but I didn't really start teaching him until year 9. He was in my history class that year. It was a wild group but Joel remained on an even keel. He was one of the few students to make an oral presentation that year and I was impressed by his strength of character.

When he was in year 11, I worked with him one day a week and really got to know him. We related well to each other because of our love of words and music. By year 12, I was running a program for a group of people which included Joel. We had fun acting in a video and performing a number of plays.

The following year Joel enrolled in a TAFE drama course. I had been teaching at Nimbin for 15 years but decided it was time for a change, so I became one of Joel's support workers and supported him at TAFE. Joel excelled that year with a number of stunning performances. He also developed a greater awareness of his own physicality by undertaking

a human movement course, followed by dancing classes the next year. He was quite fun to tango with.

Soon after that we began busking in Lismore's CBD. We were immediately successful - Joel plays keyboards, I play guitar and we both sing. Around the same time we became regular radio personalities on NimFM with the help of our presenter friend and musician, Tim. We go busking, buy a CD and then play it on radio.

"...through being a part of Joel's life, I have been inspired to overcome my fears...."

With so much music happening, Tim and I began a project to record Joel's music. Tim recorded and edited Joel's improvisations, as well as playing a variety of instruments himself - the result is an ambient album with a difference. The CD also contains Joel and his father's radio play. We successfully launched the CD and still have a few copies on hand.

Joel and I decided to try frisbee golf at The Channon, a small village between Nimbin and Lismore. We now go most Wednesdays and Joel is a firm fixture within the frisbee family. He is very aware of who's there and who isn't there each week. Joel participates in golf but has become even more interested in playing 'ultimate frisbee', a fast moving game with constant turnovers and non-stop action. As usual, Joel plays the game in his own way, and gets right in the middle of the action on his knees. Often the game is modified

to enhance his inclusion. The games are followed by a BBQ and provide a wonderful all-age environment for him to relate to others and make genuine friendships.

As Joel's real ambition is to experience extreme rides, we go to many theme parks and shows and recently visited the Brisbane Show where the highlight was 'the big drop' and the 'ghost train'. Next year he wants to take us all to Blackpool, England just to visit an amusement park.

Joel and I travel around the world each week on the Net. He is always discovering new amusement park web sites. Joel's journey through his life has taken me along for the ride. He has taken me from being a teacher who wanted to be a musician to a musician who is beginning to believe in himself again. Who knows where we'll go next? I just know he is part of my life and that through being a part of Joel's life, I have been inspired to overcome my fears and to reach for elusive but attainable dreams.

The Odyssey... 
a journey of enrichment and possibility

25 & 26 October 2007

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The Struggle For A Real Life

Peter Millier

Peter Millier is a consultant and trainer who lives in South Australia. He has been a strong ally to people with disability for many years. Peter's passion to create positive change for individuals with disability comes from his former experience in senior positions in Government, and currently as a Senior Trainer in Social Role Valorisation in Australia and internationally, as well as his involvement in Citizen Advocacy.

This article was written for CRUcial Times by Peter Millier, and has appeared in a number of other publications. It makes the important point that there are no short cuts to a typical, real life – our lives are the sum of all the experiences we have had.

Whenever I have a discussion with an individual or group about what a typical, ordinary, “real” life looks like, we quickly agree on the broad outlines: the way we live our lives; our families, intimate relationships, children, close friends, pets, acquaintances; homes, jobs, education, recreation, worship, celebration; a sense of citizenship, belonging, community, contributing, mutuality, reciprocity; sadness, struggle; connections to our past, belief in, and hope for, the future; learning and growth. The details may be different in degree or kind, but we easily identify in the lives of others (and they in ours), the essential elements of a real life.

Something seems to change, however, when we discuss, aspire to, or try to organise or support a typical, ordinary life for, or with, a person who has a disability. Although the intent is usually good, the homes, friends, schools and jobs for people with disabilities do not look quite like the home we would want to live in, the friends we would want to be with, the schools we would want our children to attend, or the jobs we would want to go to each day. When any of the elements (either individually or collectively) of our typical lives are used as a measuring stick, people with disabilities seem, for the most part, to be leading very “atypical” and “unreal” lives. Why is this so?

There are probably many reasons, but some are fundamental. Firstly there is the assumption made by people in society generally, and in the human services in particular, that people with disabilities are not like the rest of us and so will not learn, grow and develop in the same way and therefore will not achieve a “real” life.

“It is important that we do not pretend that creating typical, valued lives for people with disabilities is easy or that it can be conveyed by fine words and promises, or by some new type of program.”

An acquaintance of mine, who has cerebral palsy, recalls with great clarity her early school days when she was the only person in her class who was not asked what she was going to be when she grew up. Assumptions such as these are usually the starting point for a life which is lived on a parallel set of tracks whereby the person can see the real world, and experience some parts of it (for example, be part of a real family) but never really belong to that world in the typical, ordinary way that non-disabled people do.

Another barrier to a real life is the assumption that the service system can somehow replace or supplant natural, freely given relationships which are the very substance of our own lives. I sometimes ask people to imagine what it would feel like,

and how they might respond, if the human service worker was to knock on their door, introduce themselves as the local area case manager, and offer to help prepare a plan for them. This is not to suggest that some of the things that human services have to offer are not needed, but what is at issue is the assumption that human services are relevant in such domains as relationships, the building of individual, family or community capacities or in having control over one's life. There is mounting evidence that precisely the opposite is more likely to be true.

The roles played by both the servers and those served often create a mutually reinforcing, and mutually dependency-making situation whereby the person with a disability learns not to become too competent in case the support or love of the other person is lost. The worker, on the other hand, learns to be objective and professional and not to become too personally involved, and to speak to and about the person who is served in ways which make it quite clear who is in charge and who is the boss. The community learns from this how to treat a person with a disability. In this cycle, the person with a disability becomes reinforced in the role of client as well as in the sense of where she or he belongs. Of course the roles played by the server and the served are not always so overt. The roles are sometimes masked by the language of “friend”, “co-worker” or “housemate”, concealing their true nature. It is partly deceit, but more often than not it is merely self-deceiving. Usually people in the community know, only too well, the true nature of the relationship.

Often the language of “rights” and “choice” is used to convey the impression that a person with a disability is leading a real life. Under this disguise some people have been left unsupported in the community or merely dumped while others have been exposed to crime, drug and alcohol addiction and, ultimately, to prison or death. More often though, it is the case that the purported rights and choices are merely a mirage. Most people with disabilities have little choice about where they live and with whom, and what they do by way of work or leisure. The manager of a supported employment project I recently visited was asked if workers were able to resign from their jobs. He said it was possible, but probably for only one day as the person would quickly be sent back to work by staff at the group-home because “they had to go somewhere and they could not stay at home.”

The seductiveness of the “typical” and the “ordinary” is so powerful

that there is a great temptation for workers, parents and advocates to try to re-create them outside of their natural context. The need to be loved and to belong is so strong in us that many people with disabilities will play their part in the charade in the hope that, somehow, this is the “real” world. The reality is that people who are already extremely vulnerable and wounded may simply have another wound added.

There are no short cuts to a typical, ordinary, real life. Our lives are the sum of all the typical experiences we have had, how we have integrated these experiences, and what we have learned along the way. A “real” life cannot be invented or commanded into being.

It cannot be the product of an individual service plan. What is typical and valued in our society does serve as a useful and worthwhile frame-of-reference, but the problem for many generations of people with

disabilities has been the framework for reform has not been what is typical and valued. Rather, it has been a history of flawed reform, usually attempting to improve on previously flawed reforms, any of which had their origins in institutions and institutional practices.

It is important that we do not pretend that creating typical, valued lives for people with disabilities is easy or that it can be conveyed by fine words and promises, or by some new type of program. The struggle for real life must be real.

(This article was originally published in CRUcial Times, Issue 8 March 1997 and later in ‘A Good Life, An Ordinary Life’, A collection of writings from CRUcial Times, Vol 1, 2001 CRU publications, Community Resource Unit, Suite 5B/19 Lang Parade, Auchenflower, Brisbane, Queensland 4066.)

Conference Offers Diverse Range Of Speakers

A diverse and exciting range of international and Australian speakers will make presentations at Family Advocacy’s conference *The Odyssey...a journey of enrichment and possibility*, to be held in Sydney on October 25 & 26, 2007.

Well known advocate and Chief Executive Officer of the Alberta Association for Community Living, Bruce Uditsky, will attend the conference and speak about ‘creating inclusive lives that transform communities’.

Bruce is the author of numerous writings on community inclusion and social justice. He has pushed for the development and implementation of legislation in the province of Alberta, that promotes inclusion, and ensures children and adults with intellectual disabilities, and their families, have access to funding and supports. His presentation will highlight how families are creating exciting, dynamic and inclusive lives for their sons and daughters with developmental disabilities. Stories will be shared that illustrate the difference an inclusive life makes across the life-span, from childhood to adulthood.

Also speaking at the conference is Darcy Elks, who has worked with people who are marginalised for over 20 years. Darcy has been employed in a variety of human services, conducted many training events, and has been a consultant to programs that are striving for quality. She has been invited to share her insights and experiences throughout the United States, Canada, England and Australia. Her presentation at *The Odyssey* conference will focus on pathways to full, meaningful, and inclusive lives. It will discuss the importance of assisting people who are marginalised to escape negative stereotypes that they are often trapped in, as well as strategies to support people to find, enter, and grow into roles that uplift, empower and sustain people in inclusive walks of life.

The Odyssey conference will provide a unique opportunity to hear the real life experiences of inspirational, local, national and international speakers. Participants will also have the opportunity to meet with speakers to further share ideas and examples. For more information about *The Odyssey...a journey of enrichment and possibility*, please contact Family Advocacy.

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A D V O C A C Y

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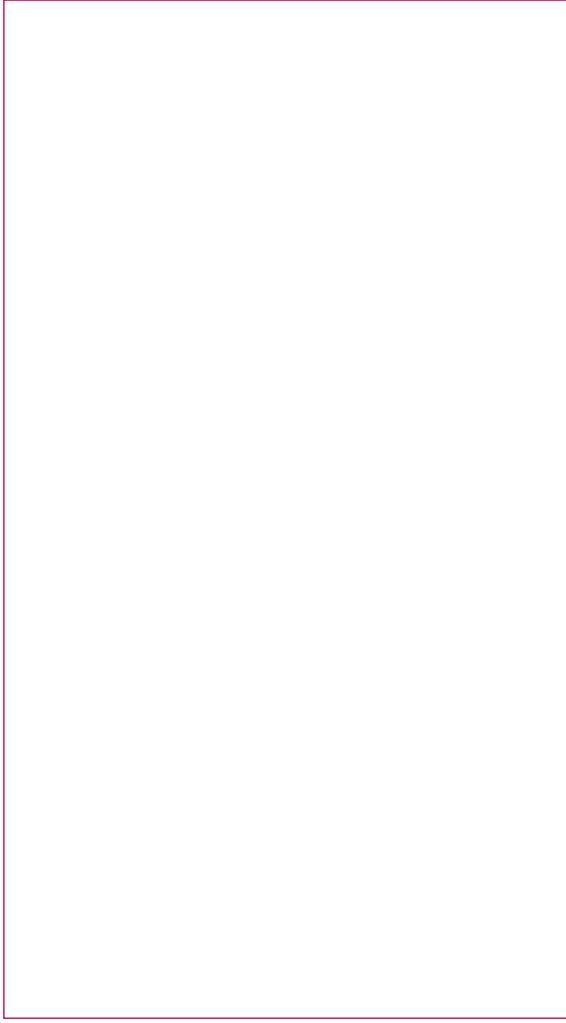
Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

Advocacy

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