

# Practice Insights



Community Development  
and Disability Special Issue



**WITHOUT COMMUNITY DEVELOPMENT  
THERE IS NO SUSTAINABLE DEVELOPMENT**

# About IACD

IACD is the only global network for professional community development practitioners. We support development agencies and practitioners to build the capacity of communities to realise greater social and economic equality, environmental protection and political democracy.

## What do we do?

IACD links people to each other. We facilitate learning and practice exchange, both virtually and face-to-face. We work with partners to deliver regional, national and international events, study visits and conferences. We document the work that our members are doing around the world by collecting case studies, tools and materials on community development, and sharing these through our website, publications and ebulletins. We carry out research projects, drawing on international experience.

IACD aims to give its members a voice at the global level, advocating for community development principles and practice in international forums and consultations. IACD has consultative status with the UN and its agencies.

## Contributing articles

Our international *Practice Insights* publications are issued three times a year, each one focusing on a particular theme of relevance to community development. If you would like further information or to contribute to future editions, please contact [charlie.mcconnell@iacdglobal.org](mailto:charlie.mcconnell@iacdglobal.org) Alternatively, IACD members are welcome at any time to contribute news items, research, case studies or other materials to our members' Facebook site and to the IACD website.

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For full details and to join, go to [www.iacdglobal.org/join-us](http://www.iacdglobal.org/join-us).

Benefits of membership include:

- Daily Facebook News posts about community and international development;
- Access to the Global Community Development Exchange resource bank on the IACD website;
- Opportunities to participate in Practice Exchange study visits;
- Discounted rates at IACD conferences;
- Discounted subscriptions to the Community Development Journal;
- Opportunities to share your work and experiences with a global audience, through our website, Facebook sites and other publications;
- Members also have the opportunity to nominate to serve on the IACD Board of Directors. Our next Annual General Meeting will take place in June 2020 in Kenya.

[www.iacdglobal.org](http://www.iacdglobal.org)

The views expressed in this publication are primarily those of the respective authors and not necessarily those of IACD.

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# Editorial

Charlie McConnell

In this issue of IACD's magazine *Practice Insights* we present articles from fifteen different countries – from Kazakhstan to the Philippines, from Peru to Australia, Scotland to Belarus and more. This special issue of *Practice Insights* is special for two very important reasons.

The first is the theme – community development and disability. This is the first time that we have given over the whole magazine to issues related to physical disability and mental health – and not before time. This issue offers enormous hope that practitioners around the world are now giving greater attention to community empowerment and inclusion strategies and projects involving disabled people.

From the sixteen articles presented, we can see that a community development approach to addressing the needs (and 'assets') of people with disability around the world appears to be growing. This has been a neglected area of practice and policy development for far too long. We hope that these articles will educate and inspire us all to do more to support and empower the millions of people in all countries dealing with physical disability, invisible disabilities and mental health challenges, which can affect community development practitioners as well as the communities we work with.

The second reason why this is an important first for IACD, is that we are publishing almost half of the papers from former Soviet Union countries. In the past two years IACD has witnessed a growth in membership from practitioners living and working in countries of the former USSR. Many of those new members are working with disabled people. Here we have discovered a huge interest amongst practitioners in adopting community development approaches to tackling social exclusion and discrimination, in a context of previous 'institutionalised' approaches. And as a result IACD has also been working closely with the pan 'Soviet Space' network called *Inclusive Practices*, becoming one of the supporters of two international conferences focussing upon disability in 2018 and 2019.


As this issue comes out, we celebrate the *International Day of People with Disabilities*. The theme for the 2019 IDPD is 'promoting the participation of persons with disabilities and their leadership: taking action on the 2030 Development Agenda'. This reminds us all of the need to focus more upon the empowerment of persons with disabilities for inclusive, equitable and sustainable development as envisaged in the 2030 Agenda.

Finally my thanks to all of the authors and translators and to Past IACD President Charlie McConnell for co-editing this issue.

Anastasia Matvievskaya



Anastasia Matvievskaya

 Find us on Facebook

We want to provide you with contemporary news and information about what is happening in the world of community development on a more regular basis. Since April 2016 we have been utilising our main Facebook Page much more, to post daily updates on events, resources and news. We have been covering news from Alaska to Mongolia, Hungary to Brazil, from the United Nations to the smallest grassroots community development agency. If you have not yet looked at the IACD Facebook Page, please do. [facebook.com/IACDglobal/](https://www.facebook.com/IACDglobal/)

# The struggle for social justice, rights and freedom of association for people with disabilities in the post-soviet space

Anastasia Matvievskaya



Of the 295 million people living in the former Soviet Union, more than 30 million people have disabilities.

## What is the post-Soviet space?

Until 1991, the Soviet Union occupied 1/6 of the earth's surface and included 15 republics, where 290 million people lived. People had lived together for almost 75 years and suddenly one by one, the republics were leaving the Soviet Union and proclaiming their independence: Latvia, Estonia, Lithuania, Georgia, Ukraine, Azerbaijan, Uzbekistan, Moldova, Kyrgyzstan, Tajikistan, Armenia, Turkmenistan, Kazakhstan, Belarus and Russia.

The term "post-Soviet space" is commonly understood as a unifying space of eleven of these States – former Soviet republics that are not members of the European Union (i.e. Latvia, Estonia and Lithuania are not members of the post-Soviet space). Despite the fact that the ways of the former Soviet republics have diverged significantly, and they differ in the types of political regimes, the processes of national construction, foreign policy aspirations, economic

openness and prospects, in the cultural and social aspects – it is still a single space.

## Association for people with disabilities

Of the 295 million people living in the former Soviet Union, more than 30 million people have disabilities. And this is a low estimate, because many parents are afraid of the stigma of "disabled" for their child and try to manage on their own, without seeking state or medical support. In Soviet times, there was a well-established system of special institutions for disabled people with full state support but which was based on a general policy of complete social isolation from the rest of society. The collapse of the Soviet Union in 1991 and the long economic and social crisis destroyed this well-established system of 'support' along with the rejection and isolation of people with disabilities. On the one hand, families raising children with special needs have lost guaranteed state medical and other

care, on the other hand, they have gained freedom to choose their life path and social prospects.

More than 85% of the founders of the associations or communities of interest defending the rights of people with disabilities are disabled themselves or their parents (Interstate Statistical Committee of the Commonwealth of Independent States, 2018). Over the past decade, the number of such communities has increased significantly. For example, in Kazakhstan in 2008 there were about 10 associations for disabled people, today there are more than 250 (the research of the project "Autism is Overcome" in 2017). And this trend is true for most post-Soviet republics. What are the goals of these associations? What tasks do they set for themselves and what do they want to achieve as a result? From the data of the research conducted by "Inclusive Practices" in 2018, we have identified the following list of common goals across the associations for people with disabilities:



- Promotion of the ideas of social equality regardless of the physical or intellectual ability
- Social adaptation of people with disabilities
- Provision of intensive rehabilitation
- Equal rights to education together with their peers
- Requirement for guaranteed free public medical care

**Since the collapse of the USSR, organisations and national associations working with and for people with disabilities in the post-Soviet space have achieved a lot**

### Achieved results

Since the collapse of the USSR, organisations and national associations working with and for people with disabilities in the post-Soviet space have achieved a lot: ratification of the UN Convention on the rights of persons with disabilities, adoption of laws on inclusive education, many universities are training social workers and professionals to work with people with disabilities, more large companies and manufacturers are becoming sponsors of inclusive projects,

and there has been an increase in the number of private benefactors supporting associations for people with disabilities. Actions (concerts, flash mobs, sports competitions, etc.) promoting equality of people regardless of their disability are now regularly held across these countries.

National Associations related to inclusive sports and the arts (including drama) are particularly successful (inclusive theater, inclusive

creative groups, art workshops). Playing sports or engaging in any form of artistic activity provides a positive diversion and enables people with disabilities to feel the support and recognition of others. Through sport, drama and art new qualities and talents are revealed to us. Awesome strength of mind, mobilization, efficiency, sincerity, hypersensitivity... this is just a few of the qualities we often witness when we see people perform.

But performances come to an end, competitions, tours, come to the end. And the daily life of an association for people with disabilities continues. But we have found that many local community associations working with people with disabilities, unfortunately struggle, even after very successful social projects. In some cases, they have closed down.

### The reasons for the collapse of local community associations working around disability and inclusion

Regardless of the goals, we have identified a general trend of the disintegration over the past 5 years. Local community associations working with people with disabilities are very unstable. About 70% of emerging social associations have existed for no more than a year. At first glance, it may seem that the problem is the lack of money, state support, and negative public reactions. But paradoxically, as the main reason for the collapse of associations, their founders don't give the above objective reasons, but the constant stress and rapid emotional burnout of community members. Even very successfully developing community associations note the levels of depression among community

association members and the frequent feeling of inner emptiness even after very successful social projects.

We recognize the main issue for an association for people with disabilities is the impact of disability itself. A person with a disability constantly lives with the circumstances and consequences of their disability: limited mobility/behavioral capacity, dependence on others, fake and hostile reactions, the presence and possibility of pain, dissatisfaction, depression, loneliness, alienation, etc. Such experience can make long-term social contact difficult both for themselves and for others. No social inclusion, financial difficulties or external pressure harms the community as much as their own permanent negative experience.

The most difficult situation is in rural areas. Now we are seeing parents of children with disabilities come together, buy land, build houses, and create a farm to organize a safe and happy environment for their families. In the beginning, parents have to fight bureaucracy and corruption. But this struggle and the defense of their rights strengthens the community and attracts new members.

In the post-Soviet space between 2008 and 2018, we have found only 17 parent associations that were able to raise money and build a village for their special children. Of these only four have survived. The rest have broken up, due to internal disputes and unresolvable differences.

### The fight only begins

In 2018, we - Inclusive Practices, held an international event/ competition called "Best Inclusive Practices". It was attended by more than 300 associations for people with disabilities from 72 cities of the former Soviet Union. Almost every participant in their description about their project's development, wrote about the need to train members of the community to manage stress and empathy.

**The most difficult situation is in rural areas. Now we are seeing parents of children with disabilities come together, buy land, build houses, and create a farm to organize a safe and happy environment for their families.**

Following this event, in January 2019, we launched a program for the development of inclusive communities in the post-Soviet space. This was based upon the practical implementation of IACD's Shared International Standards for Community Development Practice, launched previously at the WCDC2018 in Ireland. In the first 30 days alone, we received over 400 applications from community associations for people with disabilities. In response to a question about the purpose of participation in the program, one of the founders of an ensemble of 'sign songs' in Ukraine wrote wonderful words:

**At first it seemed to us that the main task is to fight with the state for their rights. Then we looked for money and thought that when we find them – all problems will be solved. Now we see that in fact, the main struggle that we have – is a struggle with ourself.**

"At first it seemed to us that the main task is to fight with the state for their rights. Then we looked for money and thought that when we find them – all problems will be solved. Now we see that in fact, the main struggle that we have – is a struggle with ourself. We know so many ways to put pressure on the state and we are completely helpless before the depression, painful state and despair."

Thus, we see that despite the achievements in defending social justice and their rights, associations for people with disabilities will have to fight for independence of their lives and self-determination as the basis for sustainable development of their communities.

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# Developing inclusive communities as a resource for the development of an inclusive culture in society.

Tatyana Zhuk

**The development of an inclusive community and society requires the adoption of values such as respect for diversity, tolerance for differences, cooperation, promotion of the achievements of every person and the development of an inclusive community on their basis. In other words, tolerance is the foundation of inclusive culture.**

The concept of tolerance has many meanings. Each culture has its own definitions of tolerance, which are largely similar. Etymologically, the word “tolerance” goes back to Latin tolerantia, which means “endurance”, “stamina”. In English, tolerance means willingness and ability to perceive a person or thing without protest, in French - respect for the freedom of another, their way of thinking, behavior, political and religious beliefs. In Chinese, to be tolerant means to allow, enable, show generosity towards others. In Arabic, tolerance is forgiveness, clemency, gentleness, consideration, favor, patience, disposition towards others, in Persian - patience, endurance, readiness for reconciliation, in Russian - tolerance means the ability to accept another as they are.

**A variety of approaches to understanding tolerance show that it is regarded as an important social value, the norm of social life, the principle of human relationships and behaviour, and personal quality.**

Tolerance, which is a national feature of Belarusians, involves taking into account the inclinations, interests, free will of a person and not depriving a person of any degree of their freedom.

A variety of approaches to understanding tolerance show that it is regarded as an important social value, the norm of social life, the principle of human relationships and behavior, and personal quality.

**Three interconnected directions are taken as the basis for building inclusion in any community: development of an inclusive culture, development of an inclusive policy and introduction of inclusive practices.**

Tolerance is basically focused on the recognition of another as equal to oneself. As an international principle, it takes the form of the expression “We all are different, but we all are equal.” In 1995, the UNESCO “Declaration of Principles on Tolerance” was adopted. It defines tolerance as “...respect, acceptance and appreciation of the rich diversity of our world’s cultures... the virtue that makes peace possible...” [1]

We consider the development of a tolerant attitude, first of all, towards children with disabilities as a component of an inclusive culture of the whole society. In our opinion, an inclusive culture implies a benevolent atmosphere, overcoming environmental barriers and often negative public outlooks. Thus, it can be assumed that inclusive culture is a system of certain moral values and attitudes of each individual – a member of the community, aimed at the willingness to fully accept the “other”.

Booth and Ainscow in their manual “Index for Inclusion” (2007) show that three interconnected directions are taken as the basis for building inclusion

in any community: development of an inclusive culture, development of an inclusive policy and introduction of inclusive practices [2].

We also see network or interagency interaction, which is understood as a system of connections and relations that contribute to the most efficient use of existing practices, as a powerful innovative resource. Network interaction includes mediated connections of participants in the educational process, representatives of different structures and departments: educational authorities, state educational institutions, financial and public organizations, parent associations, the media, etc. Due to network interaction, each participant has the opportunity to develop and improve shared inclusive values to promote the development of an inclusive culture in society.

**In Brest (Republic of Belarus), a Regional Inclusive Festival “Together we can do more”, timed to co-incide with International Children’s Day, is held annually.**

Each country chooses its own path in building an inclusive society and the development of an inclusive culture. Our practice shows that this process is most successful in the course of informal interaction of children with disabilities with their peers and adults in creative activities.

In Brest (Republic of Belarus), a Regional Inclusive Festival “Together we can do more”, timed to co-incide with International Children’s Day, is held annually. Its participants are children

with special needs, including those with severe disabilities. Children prepare joint creative acts to perform on stage, learn to interact and feel support and responsibility for each other. This festival is of great importance, as it allows 400-450 children from educational institutions across the entire Brest region to be involved in joint creative activities and be equally successful in them.

The organizer of the festival “Together we can do more” is the state educational institution “Brest Regional Center for Developmental Education and Rehabilitation” with the direct support of the Brest Regional Executive Committee (<https://brest-edu.gov.by/news/p-63823.html>).

The goal of the festival is to attract public attention to the success of children with disabilities and to spread the positive experience of social inclusion. Another important aspect of this event is to attract a large number of sponsors from business and

financial institutions, public organizations, etc. School and university students participate as volunteers. For many of them it is the first experience of participation in such an inclusive event and they are sincerely amazed by the limitless opportunities and talent of children with disabilities.

Our main goal is direct interaction and tactile contact of an adult with a child, for example when dancing, participating in games, as well as while watching inclusive creative performances. At these moments, a person, who has not encountered the problem of disability before, has a chance to reassess their values and accept the “other” as they are. A person ceases to see an “ordinary disabled child”, they see a distinctive and talented member of society. Each time we try and include new people in our events, and each time they enthusiastically share their “discovery” with us.

In Lutsk (Ukraine), the Volyn Regional Public Organization of parents of children with Down syndrome and other developmental disorders has been working for 14 years. The organization is headed by Elena Melnik, the mother of a child with Down syndrome. In Lutsk, thanks to the activity of parents, significant work is being done to create an inclusive culture among the local community. Mass events organized by a non-governmental organization are inclusive and popular among residents of the city, and also aim to draw public attention to the problems and successes of children with disabilities. It is quite uncommon in Lutsk and encouraging to see the initiative coming from a non-governmental organization, and not from the state. It should be noted that local authorities are eager to support the initiative and are doing their best to provide assistance, including in organizing international cooperation.





**In Ureki (Georgia) in 2018, the AAIP "Inclusive Practices", a member of the IACD, organises the International Inclusive Practices Festival "Pushing the Limits".**

access to them by parents, specialists, organizers of inclusive communities and other interested parties. This is a unique project, since the geography of the dissemination of inclusive experience is already gaining world significance, although it consists of small inclusive practices of local communities.

On June 4, 2019, during the "Together we can do more" festival in Brest, we brought together more than 500 participants, members of the Volyn Regional Public Organization of parents of children with Down syndrome and

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other developmental disorders and the AAIP "Inclusive Practices" presented their creative inclusive performances. This event pursued two goals: the opportunity for communication and experience exchange, on the one hand, and promoting the importance of the development of inclusive society on the other hand. In addition, an increasing number of interested parties, including the media covering the event in the entire region, become involved in the festival. You can find a youtube link below <sup>[3]</sup>.

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# There are no persons with limited abilities

Farrukh Ahrorov



There are a lot of civil initiatives successfully working to improve quality of life in Central Asia and other regions of the World now. Activities of many of these organizations are so unique, that on comparison a single public organization, like ours, has a hard time creating something completely new, innovative and socially significant.

**I'd like to tell you about a small project we carried out. We offered few NGOs to try and form more favorable opinion in society about persons with limited opportunities using modern information technologies.**

Our organization promotes the development of democratic institutions and media in our country and had never carried out any social projects before. That's why in the activity I'm going to tell about, our team of journalists and mass media professionals had only planned to use already existing modules for professional journalists and had not expected to be offering the audience of the project new ideas in addressing the issues of vulnerable persons. Particularly,

**Our organization promotes the development of democratic institutions and media in our country and had never carried out any social projects before.**

since our organization doesn't have professionals specializing in social sphere.

This project had started with the series of training events, which we held for employees of organizations working with vulnerable persons on methods of effective cooperation with media and society. This initiative aimed at giving the participants the knowledge for effective ways of dissemination of information about their activities through media, social networks and information campaigns. We mostly held practical classes during which we talked about effective public statements, basics of designing of posters and magazines, editing of photo and video products, holding of press conferences, etc. We installed necessary professional software on PCs of the participants for carrying out information campaigns and designing of materials, as well as provided 2 GB of relevant electronic materials. In general, we expected this to be an ordinary educational project for dissemination of socially significant information, like a lot of others our organization had implemented and our colleagues are continuing to implement.

**During our communication with representatives of these organizations our team examined their informational materials and found out that majority of these messages about persons with limited abilities, addressed to the general public, contained elements of pity and endless cries for help.**

But it's noteworthy; during our communication with representatives of these organizations our team examined their informational materials and found out that majority of these messages about persons with limited abilities, addressed to the general public, contained elements of pity and endless cries for help. And most likely, this is the reason for the development of the stereotypic view in society, that these people are good for nothing and need



constant side support and compassion. In our opinion, this information policy is wrong and doesn't contribute to solving the issue. We studied practices from different countries, where the information accent is made on individuality and uniqueness of persons including those who are considered "a person with limited abilities". That's why in our project we offered our audience not to rule out of their information materials the idea, that abilities of a person might be much more diverse, than stereotypical view, adopted by society, suggests, but a person may not know how to demonstrate their abilities or our society is not ready yet to recognize them.

In the history of our country and other countries there are a lot of examples of success or even brilliance of persons that doesn't fall into average norm. That's why during training, our audience first of all worked on changing the main message about vulnerable people, which is addressed to society through media and other information resources. We suggested to the audience that it's preferable for the public information not to contain such labels as "disabled", "vulnerable", "in need for help", "persons with limited abilities", "persons with developmental challenges", etc. The results of our research shows that these labels, while often unconsciously used, are used because the majority of the population on our planet collectively define standards of a person and those who do not fit in these standards are considered abnormal.

In modern information message we offer to relinquish stereotypical views and existing standard assessments of these persons. These assessments are most likely wrong and create incorrect impressions about their mental and physical abilities. There is not much to these standards – driving a car, play football, ride a bike and so on, in other words these, not the most important,

values and things become an obstacle for full-fledged social life of these people. If we are guided by these "standard" expectations, "persons with limited abilities", alienated from society, will always be around us.

**Messages should be based on the idea that these people are not worse than the rest of society, they are just different, but still the same as everyone else; and they are able to actively participate in social life and contribute to the development of our society.**

Also, researching the topic of the project, our team found out that stereotype labels like "disability" are used only in relation to persons who have clearly visible so-called "abnormalities", in other words, persons who use a wheelchair or have problems with their eyesight. But you'll never hear, for example, "a person with sciatica", "a person with allergies", although these and hundreds of other chronic, but invisible to others, health



problems can significantly limit physical abilities of a person.

We suggested to our audience not only give vulnerable people skills necessary for full-fledged life in this difficult world, but to inform society in the right way about these activities. These information messages should be based on the idea that these people are not worse than the rest of society, they are just different, but still the same as everyone else; and they are able to actively participate in social life and contribute to the development of our society. It's important to start to implement this way of informing now, because identifying these people even with the kindest of words, we are still making the point, that they are NOT the same as others, because every one of these words are the labels. Better to stop using these terms in relation to these people, but to identify them by their names, profession, education, and so on, in other words, the same way as we describe any person.

Let me stress one more point. Doubtless, a lot of public organization, including our target audience, work in the area of integration of these people in society for a long time and there are a lot of successful experiences. But there is an issue, that aside from a small group of colleagues and professionals, ordinary people know almost nothing about this activity. According to our observations, although there are a lot of publications, but in majority of cases, due to lack of effectiveness, this information can't compete with the main information flow, created by professional teams. There is not a lot of information about the projects of organizations, working with special needs although these organizations carry out a lot of interesting activities. This is one of the key reasons that problems of so-called "persons with limited abilities" are not being solved fundamentally.

**We believe that civic activists can and should effectively talk and write about their projects. But more needs to be done to disseminate information and draw attention of the mainstream media and society.**

We believe that civic activists can and should effectively talk and write about their projects. But more needs to be done to disseminate information and draw attention of the mainstream media and society. There are a lot of modern technologies, that need to be studied or qualified professionals need to be involved, to effectively get information out to the general public. Journalists, probably, would look for and disseminate information about activities of organizations, working with vulnerable people, not as often, as we would like. But they, using their opportunities, can help to summarize information that is given to them by these organizations and specialists and use it to create news and raise and awareness of society about our projects. That's why it is important to carefully prepare the content of the initial message addressed to society and, especially, media.

Representatives of many public organizations lamented the fact, that the media demands a payment for the placement of their materials. But we offered them to imagine the following situation. For example, some person likes apples. If you'd offer them fresh and nice apples, they will not only accept them graciously, but will want to show their gratitude. If the apples are rotten, you'd have to pay a person a lot to take them. The same principle applies to information. The point of media is in gathering interesting and quality information, and if you offer to media exactly this kind of information, publications about your activities wouldn't leave news feeds, moreover, without the need to pay for it.

It's important to notice, that most of public organizations, according to our reckoning, don't have significant experience and skills for preparation of public information. Many educational information programs the employees had studied are not effective anymore for different reasons. Probably, in the future, this will be one of the obstacles for the development not only organizations, working with vulnerable people, but for the development of civil society in general.

We may recommend to our colleagues to study the basics of multimedia tools, informational graphic, create attractive texts, photos, videos and etc., in other words to improve the quality of information materials according to modern standards.

For example, within our project, we decided to solve this issue the following way: we adjusted the goals of the project as we went along, expanded the skills and experience of the audience in the preparation of modern press releases for media, writing scenarios for social videos and documentaries and shooting video materials on video cameras and smartphones. In other words, during trainings we adjusted their experience to our educational materials. During practical classes we wrote press releases about one of the projects and sent it to media. In few hours we already had had more than 20 materials, published in media, based on our press release, and this became a practical experience of attracting journalists' attention to the information.

Our audience offered to divide the topic of people with limited abilities in three directions. The first one, about their talents and successes; the second one, about their lives and problems; the third one, about many healthy people who harm themselves consciously or unconsciously, for example, not driving

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safely and getting severely injured because of it. According to these suggestions we created three social videos on the base of partner private TV channel, which were broadcasted more



than one thousand times by local channels.

For example, one of the videos is the musical video of the girls dancing in wheelchairs. They joined dances of all regions of Tajikistan in one theme. This was the first video of this kind in our country, and for the first time these women called for union of the regions. This video was important because one of the reasons for civil war in Tajikistan was separation of regions. During the first few days after publishing the video in social media it had been watched by more than 7,5 thousands viewers, there were dozens of reposts and enthusiastic comments.

For such a small country as Tajikistan, it's a lot. You can see it for yourself: [www.facebook.com/farrukh.ahrorov/videos/pcb69654843169676/1369638366504657/?type=3&theater](http://www.facebook.com/farrukh.ahrorov/videos/pcb69654843169676/1369638366504657/?type=3&theater)

According to our research, the music video was a reason for the popularization of wheelchair dances in Tajikistan, especially in Dushanbe. Wheelchair dancing collectives are being formed; there are more of similar projects that encourage all the people, regardless of their physical abilities, to actively participate in the development of our country. And although this information campaign hadn't been planned, after it there were a lot of persons on wheelchairs on the streets demonstrating they feel confident full-fledged members of society.

This September, our project won in the "Ideas" nomination at the International festival "Pushing the Limits" in Georgia and received a special prize from IACD. To learn more, follow: <http://www.iacdglobal.org/2019/11/06/announcing-the-winner-of-the-inclusive-practices-of-the-future-iacd-special-prize/>

[https://youtu.be/Gm6ATOIA\\_WY](https://youtu.be/Gm6ATOIA_WY)

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# Charitable activity of youth as a basis for community development

Taisiia Tsurkan



Being a young person and a student can be characterized by creativity of thinking, a desire to recognize this world in all its social dimensions and to change the environment for the better. Personal growth and self-affirmation, development of intellectual potential, spiritual enrichment, moral, aesthetic and physical self-perfection are characteristics of being a teenager and young adult. Therefore, we especially consider young people the most potent human resource of the state, which should be coordinated in the right direction in order to achieve a sense of community, caring activities, ethnic and cultural equality.

*We especially consider young people the most potent human resource of the state, which should be coordinated in the right direction in order to achieve a sense of community, caring activities, ethnic and cultural equality.*

At the conference "Development of Inclusive Communities" in Georgia in 2018, we had an opportunity to get acquainted with the author of Analyzing Community Work - Keith Popple (Keith Popple, 1995). His words "the values -

are not what you have to learn, the values - are what you have to feel", prompted us reflect and rethink the work of the Ukrainian charitable organization "M'YATA". The values we seek to put into practice - which are social unity, empathy, willingness to help, perception and acceptance of external, physical and mental differences, is possible provided that the various communities we work with are attracted to and immersed in such an atmosphere.

In order to address, to live in and take on the problems of different layers of society and to choose the best ways to help or to generate new ideas aimed at productive changes, we have chosen the

way in action through workshops, master classes, flash mobs, meetings with parents of children with special needs, holidays and informal education. And last summer, we organized a "School of Vital Competence", where children with special needs, from large families and poor children deprived of parental care, were able to master basic personal and social life skills through cooking classes, financial literacy lessons, and sports. This contributed not only to the adaptation of the child in different contexts, introducing them to new knowledge and skills and enabled them to try themselves out in different roles.

The teachers in the project were professionals of our business, together with students and invited guests, for example, a participant of beauty competition "Miss Universe 2017", who lives in our city, a well-known boxing trainer and others. The activities included making holiday cards and coloring eggs for Easter, making toys from cloth for St. Valentine's day, costumed New Year's parties, beauty salons and boxing lessons and dance flash mobs. We also organised children's holidays. Such holidays are filled with joy and fun and aimed at creating a sense of community.

One tradition has become the organization of a Christmas photo session for children with special needs and their families. This event not only unites the family members but also distract them from everyday worries. The result of this work is bright photographs, which allow everyone to see a family that cares for a child with a disability from an another angle. The young people themselves also act as assistants and help to care for children

*The role of our students and teachers is to support the children and adults with disabilities and other needs, but each project belongs to the person with the special needs.*

behind the scenes in a relaxed atmosphere. Incredible pleasure and a sense of community also comes from the classes on the production of ice cream, baking pastries and pancakes. The work is organized in such a way that every child or adult with disabilities has a student assistant who helps to mix the dough, form ice cream balls or pick up a pancake stuffing.

*Only together, without being divided by race or appearance, age or mental development, wealth or poverty, will we achieve equality in our society.*

As a rule the role of our students and teachers is to support the children and adults with disabilities and other needs, but each project belongs to the person with the special needs. After such collaboration the barrier of communication disappears, with our student assistants learning with enthusiasm more about the life and experiences of the person with special needs and together they consider the best options for further cooperation. It is equally important for the mothers and fathers of people with disabilities to understand that their child is more likely to make more efforts when he or she is working with our team and, where he or she wants to show herself and do their best. These families are always grateful about the opportunity to join and feel themselves part of our great community, because, unfortunately, they too often feel rejected.

One of the ways we use for promoting the activities of our community is the use of web and the resources of the Internet, developing wider social networks through photo-presentations, videos and motivating posts. In this way, we draw the attention of the whole society to the challenges and the opportunities of disabled children and adults.. We have achieved good results and many people of different

professions and Ukrainians living abroad are increasingly concerned with the development of our community and help to organize charity events which support our work.

Our community cares not only about children deprived of parental care or people with disabilities, but also about the elderly who are left alone and live in geriatric homes. For the elderly, the most important thing is the sense of importance, attention and understanding. The students who work in our projects make a great contribution to the development of a community where all its members are involved by visiting them with fruits, hand-made presents or just to ask about their health and hearing their interesting life stories .

Only together, without being divided by race or appearance, age or mental development, wealth or poverty, will we achieve equality in our society, a harmoniously developed community that can progress and improve. In such a community, every member of society feels important, may be useful to others, help in simple affairs or in difficult choices, be an individual, but not be alone. In the developed community we strive for everyone, sympathize with others and find the words of support, but moreover, we strive for everyone and rejoice at the success of each community member and accept their achievements as a victory for the whole community. Consequently, we believe that in order to feel and shape the most important human values of the present in a developed community, we must care for the involvement of all members of society in the activities of charity, with tolerance and love.

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# Lessons from the Center for Social Inclusive Programs in Kazakhstan

Saltanat Murzalinova-Yakovleva



**It is natural for children and adolescents to want to be a part of a group or a community. This is human nature, and young people, with characteristic enthusiasm, try and find like-minded people and partners for their activities and interests. Adolescence is a time in a life of a person to search for values, meaning, ideals, a place in the world and society. Working with teenagers requires adults to maintain a delicate balance, on one hand, adults must give maximum freedom and initiative to young people, on the other hand, to direct their activity in a constructive way, provide a positive experience of overcoming difficulties. Formal communities, established and guided by adults, most likely to have clearly defined development goals and strategies, but often do not take into account the difference in generations, especially youth subcultures, and the psychology of young people. Informal communities,**

**created by young people themselves, however, may experience problems with organizing productive activities, focused development, and stability.**

The mission of the Center for Social Inclusive Programs is to consult and facilitate the development of communities of young people. We conduct projects, search for new ideas and organize meetings and events, aiming to unite adolescents around constructive activities, opening up opportunities for creating communities. At the moment, the priority, relevant direction of our activity is the development of an inclusive community.

I would like to give you some examples of successful engagement of children and teenagers in our inclusive community. Arthur and Katya. He's 15, she's 11. Arthur has autism, Katya has a disorder of psychological development. Their beautiful mother, Oksana is a strong and steadfast lady. When she first

came to The Center for Social Inclusive Programs, she was clearly sceptical, she had seen it all. Now she's one of the most active and concerned mothers involved in the program. Arthur is everybody's friend and Katya is a star of our theatrical performances.

Arthur is in fifth grade, and he's an active participant of our inclusive community. Just recently, together with his classmates, we've been making sociograms – children were defining what kind of relationships they have with each other. After we finished and the children put their sociograms side by side, it became apparent that all of them considered Arthur to be their best friend. Why is that? It's easy really: he says Hi! and Bye! to everyone. He readily accepts invitations to play, he responds when his classmates communicate with him, he's always ready to come to help, he's kind and generous. So, it turns out, children say, it is we who are special, and he's the most socially healthy person of us all.



Damir is 16, he has a hearing impairment and autistic symptoms, and being a member of our inclusive community completely changed his life. He has been bullied in all the schools he's attended. Damir was used to aggression from other kids and responded in kind. He also used to pretend not to hear them. He started to speak when his friend Sasha, an exceptionally kind and responsible teenager from a foster family, told him: "Damir, I want to be your friend, but I need you to speak to me". And Damir started to speak, apparently

because he's finally met a person, who wanted to hear him, to understand him, to be friends with him. Sasha was incredibly happy.

In 2016, our community started the Inclusive Sports project and for the first time we invited families with nondisabled children to join. We were curious how they would respond. At that time, we did not know that we started a new phenomenon in our country - equal inclusion. Not the kind, where persons with special needs perform before the

audience of ordinary people on appropriate occasions, and ordinary people applaud politely, but feel sorry for them. Not the kind, where these two worlds meet from time to time, but the kind, when disabled and nondisabled people communicate on daily basis. Now our nondisabled teenagers, also participants of our inclusive community, are proud that their teammates with special needs do not hesitate to show their emotions and feelings, both positive and negative, because it means that they care.

There are more than 50 families in our community, some of them have children with special needs and some do not. And all of them have their own way of joining the community. Some came to us by recommendation of their friends, some heard about us in social media. It's very encouraging that recently more and more families with nondisabled children came to join us. For socially conscious parents, working to create inclusive communities and an inclusive society, this is vitally important. And if parents take this social position, their children will follow.

***They adopted the values of our inclusive community, such as social equity, empathy, leadership, participation, empowerment and social change***

In 2017, our community took a step forward. We found out, that as a result of our Inclusive Sports project, a lot of teachers and coaches were really interested to work with inclusive teams and we started to conduct inclusive workshops to train them on methods of inclusion on the basis of our community. Their sincere happiness for success of each child, no matter with or without disability, became our inspiration. They adopted the values of our inclusive community, such as social equity, empathy, leadership, participation, empowerment and social change.

One of the activities of our inclusive community is inclusive classes. During the classes children do a lot of things with their own hands, discovering the world and communicating. In 2018, within the framework of our community activity we started experimental inclusive education. Prior to that, we, together with the Almaty Department of



# A gaze toward equality: Inclusive community development in Peru

Jazzmin Arévalo Olivera



*“My dream was to be able to ride a bike without training wheels, now I can do it and I can also write on the board with my prosthesis”*

*Dajhana, 8 years.*

Education, conducted training for teachers and parents in schools. We held eight external sessions, the main purpose of which was to acquaint teachers and parents with the phenomenon of social inclusion. Our children took part in those sessions; we conducted open classes and inclusive games. This was a very important period for us, as it allowed us to once again understand the values of our community.

Studying the topic of educational inclusion in our state, we realized that a huge number of legal acts and other documents extensively define education of students with special educational needs. But there's no wider community, infrastructure and environment for these children outside schools. Children and adolescents with disabilities have no opportunities for extracurricular activities, active and meaningful leisure and informal communication with their peers. Participation in inclusive communities is a way for children and teenagers with special educational needs to get social experience necessary for their successful development and adoption into society.

In 2019, we integrated our inclusive community into private school “Dana”. This required active preparation. Nevertheless, many teachers, unused to also working with special needs children, were not ready for additional difficulties, the need to understand, to accept, and to develop new pedagogies of teaching and learning. We are very lucky that the

owners and the school administration believed and continue to believe in the necessity and effectiveness of inclusion. Alongside children with physical and learning disabilities, children with psychological issues (such as cancer survivors) and those from foster families are also supported by our community.

***We often talk with teenage participants of our inclusive community about the current situation in our country, about the tendencies in the development of society and about our values for them to understand their role in development of inclusive, humane society.***

Our task is to convince the pedagogical community it's necessary to work, first of all, with ALL children together, to build allies in creating an inclusive society. In many ways, this is a huge opportunity to support the social development of children in our society today, helping them move beyond a world of virtual communication, from indifference, aggression and bullying to care and inclusion.

We have since received many letters and inquiries from various regions of

Kazakhstan. Expanding the map of like-minded people who help us ideologically and financially, we have been able to expand the inclusive community and accumulate resources to be able to work in any city of Kazakhstan.

We often talk with teenage participants of our inclusive community about the current situation in our country, about the tendencies in the development of society and about our values for them to understand their role in development of inclusive, humane society.

Whatever they become, whatever professional path they choose, the kind of experience they receive now is the basis for the development of their personalities. If children are involved in the development of inclusive community from the early age, inclusion becomes the value and natural way of life for them. We understand that adults are often rigid in their view of the world, they have social stereotypes and change doesn't come easy for them. We believe that prospects of inclusive community development are with youth.

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**In Peru, a child with a disability has three times fewer opportunities to be educated than any other child of his or her age. Many schools do not have the proper infrastructure to receive people who have mobility and learning difficulties, lack materials for children who need to study with braille or for those who must communicate through sign language. One of the options that many parents take is to withdraw their children after completing primary school and then begin to develop workshops that empower their children's talents.**

One of the biggest problems in this situation is that although there are many types of intelligences, we have a system that only allows us to prioritize linguistic and logical-mathematical intelligence, and we have underestimated people who have the ability to develop their bodily-

kinesthetic, spatial, creative, musical, and all other intelligences. In this way, the lack of inclusive policies and of support in their implementation, create a barrier both educational and in relation to work opportunities for all people who are in a situation of disability. This is not just the challenge of a single country. Most of Latin America's countries still need policies that allow everyone, without exception, to develop in an equal manner.

However, despite all the discouraging figures, there are community development associations that are working in favor of inclusive, educational and employment development: organizations that, through their work, have generated initiatives to promote equal rights and opportunities. These are examples of organisations that have focused on promoting sustainable inclusion for disabled people in Peru.

## **PIXED Perú**

Pixed Peru is a social enterprise that contributes to the United Nations Sustainable Development Goal (SDGs) to reduce inequalities and is committed to work for a more inclusive society. It works to provide accessible tools for all people with disabilities who need it, through the manufacture of personalized prostheses, many of the which have been manufactured thanks to strategic alliances with donors who have financed prostheses for people who do not have the economic resources to access one. The psychological support that people have received, has allowed them to improve their self-confidence and the social skills necessary to achieve successful inclusion at work, social and educational levels, as well as recognizing and strengthening their abilities in the family and social environment.



Thanks to this endeavor, Ricardo Rodriguez, CEO of PIXED Peru, has been nominated for MIT Technology Review's Innovators Under 35 Award. In 4 years, 54 lives have been changed thanks to the prosthesis provided.

"My dream was to be able to ride a bike without training wheels, now I can do it and I can also write on the board with my prosthesis" - Dajhana, 8 years.

### Empanacombi

Empanacombi is a project for young people with disabilities. It is the first inclusive kitchen in Peru, contributing directly to the SDG 8: Decent Work and Economic Worth. In Peru, it is estimated that only 2 out of 10 people with disabilities can get access to a job.

Cynthia Rodriguez, its founder, started this project with the objective of giving work to her sister Naty (who has Down's Syndrome), and over time she adapted her business to provide work opportunities to other people with Down's Syndrome too. She has also sought to solve the problem of labor exclusion of the population with disabilities. Empanacombi has demonstrated the incredible results of empowering these young people, both in their culinary and personal skills.

### Misión de vida

Misión de vida provides education for people with disabilities who lack economic resources, with no age limit. The group of mothers who founded it, have the objective of enhancing the abilities of the students after leaving school, because 11-years within the educational system in the country does not equip them sufficiently in terms of social and vocational development for when they leave school.

This project has demonstrated the incredible skills that these people can develop in weaving, painting and embroidery. In this way, they use their talents to sell products manufactured by themselves, demonstrating once again that "disability" is not synonymous of "incapacity".

Each of the above non-governmental organizations are clear examples that the lack of government support around the issue of social inclusion is not a limitation to implement ideas that contribute to community development. On the contrary, they are opportunities to propose new initiatives that reduce inequalities and injustices.

**Each of the non-governmental organizations are clear examples that the lack of government support around the issue of social inclusion is not a limitation to implement ideas that contribute to community development.**

Despite this, governments in Latin America are obliged to advocate for the well-being of people, and provide opportunities that address the circumstances of every person, both education, employment, transportation, political life and social opportunity. For this reason, it is so important to celebrate the International Day of Persons with Disabilities every year, as this reminds us that we are still in a constant struggle for equality, and that we should not be oblivious to issues that may not directly affect us, but that determine our development as a society.

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# LibRehab: The Community-based Rehabilitation Program

Mark Anthony D. Abenir

The University of Santo Tomas is the oldest existing university in Asia located in Manila, Philippines. It was founded in 1611 by the Dominicans. In 1974, the university established the Institute of Physical Therapy in response to the need of producing healthcare professionals who can address the growing concerns of persons with disabilities in the country. In 2001, the institute was renamed the College of Rehabilitation Sciences (CRS) and as of 2019, currently offers four Bachelor of Science degree programs.

As part of the three-fold mission of higher educational institutions in the area of community extension services, the College is constantly looking for opportunities to increase social awareness and social action among its students, as well as its administrative and academic staff through yearly community development projects anchored upon its LibRehab program for disabled and older people.

LibRehab, which is a combination of the Spanish word libre and the English word rehabilitation, stands for (a) "free" rehabilitation services for people with disabilities and older adults, and the other is, (b) "liberating" rehabilitation program that is anchored upon Community-Based Rehabilitation (CBR), a community development strategy for rehabilitation that seeks to equalize opportunities by involving their participation, together with their families and respective communities, in the achievement of their general well-being in the areas of health, education, livelihood, social welfare, empowerment, and environmental development.

The vision of the LibRehab program is that it looks forward to the day where people are living together, respecting differences, and where people enjoy full participation and equal rights. The program does this by working together with communities and sectors working with the disabled and older adults towards the removal of physical and social barriers that contribute to their disability.

In order to operationalize this, as shown in Table 1, the program has six directional



areas with corresponding measures/interventions and desired outcomes for its LibRehab program, namely: (1) establishing healthy communities, (2) promoting inclusive education, (3) sustaining livelihoods, (4) encouraging social participation, (5) empowering disabled people's organizations (DPOs) or senior citizen organizations (SCOs), and (6) building a disability friendly environment.

**The vision of the LibRehab program is that it looks forward to the day where people are living together, respecting differences, and where people enjoy full participation and equal rights.**

**Table 1. Librehab Program Directional Areas**

Directional Areas	Measures/Interventions	Desired Outcomes
<b>Establishing Healthy Communities</b>	No. of health promotion and prevention seminars / activities given.	Less prevalence of Morbidity and Mortality rates in the community. Less disability prevalence in the community.
	No. of free medical consultation and diagnostic disability assessment. No. of rehabilitation home instruction training given to healthcare workers, parents or caregivers of disabled and older people. No. of free therapy services Maintain or prevent medical complication of disability	
	No. of free consultation on custom fitted assistive devices	Disabled people are able to make use of assistive devices to effectively participate in activities of daily living in the community.
<b>Promoting Inclusive Education</b>		
No. of disabled assessed for school readiness. No. of disabled enrolled in mainstream or vocational education. Disabled are able to stay in school and graduate.		
<b>Sustaining Livelihoods</b>	No. of health care workers and disabled and older people who are able to train other healthcare workers in rehabilitation home instruction.	Skilled healthcare workers and disabled and older people second liners who can train others on rehabilitation home instruction.
	No. of vocational trainings provided for disabled and older people and/or their parents. Disabled and older people and/or the parents of disabled are self-employed.	
	No. of disabled people who have been given work capacity evaluation.	Disabled people are integrated in the workforce based on skill-job matching.
<b>Encouraging Social Participation</b>	No. of leisure and recreational assessment given to disabled and older people. No. of leisure and recreational activities given to disabled and older people Disabled and older people are able to participate in leisure and recreational activities	
	No. of sports clinic given to disabled	Disabled people are able to participate in sports activities
<b>Empowering Organisations</b>	No. of advocacy seminars on the rights of disabled and older people Disabled and older people advocating and safeguarding their rights. Community is less discriminating and more inclusive	
	No. of CBR management cycle training where disabled and older people are involved. No. of existing and active parent support groups for disabled people No. of existing and active Disabled People's Organizations and Senior Citizens' Organizations	Disability and senior citizen organisation staff and Barangay Healthcare Workers involved in the CBR management cycle Disability and senior citizen organisations and parent support groups are part of the Barangay development council
<b>Building a Disability Friendly Environment</b>	No. of communities assessed based on the Batas Pambansa 344 accessibility law Local government complies with the standards set by Batas Pambansa 344 accessibility law	
	No. of Disability Inclusive Disaster Risk Reduction trainings given	The community is able to pass disability inclusive evacuation drill.

The directions mentioned in Table 1 are implemented in various forms together with eight partner communities and institutions:

- Municipality of Abucay, Bataan:** In partnership with the local government of Abucay, Bataan, UST CRS maintains transdisciplinary internship programs which focuses on addressing the health, social, and empowerment concerns of PWDs and their families and capacity building of the Abucay Rural Health Unit staff and volunteers in managing a CBR program.
- Naga City, Camarines Sur:** In a tripartite partnership among UST, the Parents Advocates for Visually Impaired Children and the Naga City Local Government, UST CRS serves in helping establish research-based CBR programs that would benefit disabled and older people in Naga City. UST CRS also provides technical expertise in training the city's selected Barangay Healthcare Workers to become competent CBR Specialists.
- Ursuline Sisters of the Roman Union CBR Program:** In partnership with the Ursuline Sisters of the Roman Union in Doña Carmen Subdivision, Quezon City, UST CRS provides capacity building for Ursuline volunteers, supports healthcare for the mothers of children with special needs through basic rehabilitation exercises; and conducts medical disability assessments, and facilitating play, cognitive and communication skills activities for the children.
- Parent Advocates for Visually Impaired Children (PAVIC):** In partnership with PAVIC, which is headquartered in Cubao, Quezon City, UST CRS provides consultancy services, rehabilitation services, and rehabilitation skills training in order to help build and sustain PAVIC's CBR program that is being implemented in partnership with the local government of Naga City, Bicol.
- Cottolengo Filipino:** An orphanage institution for abandoned children and adolescent PWDs managed by the Little Work of Divine Providence Congregation in Rodriguez, Rizal. In here, UST CRS helps train caregivers in the proper feeding and exercise of children with disabilities, splinting consultation and fabrication and provide play and leisure activities for the children.
- Tanglaw Buhay Gabay Kapalaran:** An older adult people's organization located in St. John of God, Hidalgo St., Quiapo, Manila that advocates and safeguards the rights of their fellow age groups. In here, UST CRS provides activities aimed at improving and maintaining their health and wellness such as seminars and workshops on

vital signs taking and monitoring, aerobic and dance exercises, health promotion lectures, and leisure activities.

- Hospicio de San Juan de Dios (St. John of God Priory):** A hospice that is run by the Brothers of Mercy in Bgy. Igulot, Bocaue, Bulacan that helps adult males with mental health problems. In here, UST CRS provides Neuro-Psychiatric Consultations, Occupational Therapy, Pre-Vocational Skills Training in Vegetable Gardening and Wellness Physical Activities such as exercises and Tai-Chi.

*The College of Rehabilitation Sciences maintains good relations with its partner communities and institutions by involving them in the planning, implementation, monitoring, and evaluation of community development projects*

The College of Rehabilitation Sciences, maintains good relations with its partner communities and institutions by involving them in the planning, implementation, monitoring, and evaluation of community development projects done annually within the school year through the University-wide organized and sponsored Kamanlalakbay Training Program. The Kamanlalakbay Training Program serves as a venue to annually gather and meet leaders and representatives of the different partner communities and institution of UST which often includes conducting participatory evaluation and participatory planning sessions. Such practice clearly demonstrates that UST does not adopt communities or institutions, but partners with them. As a policy, this has far-reaching implications since it demands treating partners as co-equals and recognizing their capacity to counterpart resources. Truly, it can be claimed that the university in general, and the College of Rehabilitation Sciences in particular, adhere to the empowerment and participation principles of community development, specifically, in its LibRehab program.

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**An intergenerational garden has been created by a diverse group of people who now grow fruit, flowers and a multitude of vegetables in raised beds. Along with a tractor tyre pond, plastic bottle greenhouse, pallet furniture and planters and a living green roof to attract pollinators**

# Community Development: The Use of Social and Therapeutic Horticulture for an Integrated Approach.

Denise Sewell and Annette Fox

**There's a wonderful term used in horticulture known as "the biophilia effect". Its definition of 'a love of life and the living world; the affinity of human beings for other life forms' makes gardening an instinctively inclusive pastime.**

Perhaps that's why Social and Therapeutic Horticulture (STH) is gaining in popularity worldwide; recognition of the empowering effect it can have on marginalised groups, including but not limited to those with physical, mental and psychiatric disabilities, is powerful.

The Republic of Ireland is on the cusp of creating a national network of social and

therapeutic horticulture practitioners who are delivering and promoting this alternative, transformative approach to community development, education and therapy. More training is becoming available as linkages are made with UK neighbours, who have years of experience in this field with organisations such as Thrive UK. In the meantime it has fallen upon individuals and organisations to discover STH for themselves, and how it can positively impact upon communities of people. As more evidence of its success surfaces, it is hoped that this will change.

In the south-east of Ireland, Carlow County Development Partnership

recognised the community development opportunities that STH can bring to people with disabilities. They have recently been working with a local horticulturist and community education tutor Dee Sewell, who has been promoting, reaching out and working with several groups of people with disabilities in gardens for the past ten years. Clients have included nursing homes, day-care centres for service users with psychiatric and intellectual difficulties, the Irish Wheelchair Association, a local methadone and alcohol rehabilitation centre, as well as a group of adults with intellectual disabilities who live in assisted housing, to mention a few.

Although goals and outcomes might be similar, no two groups are the same. Some clients hope to improve fine motor skills, connect with people and improve their mental health, some are looking to alleviate boredom and learn new skills that will help with further education or work opportunities, whilst others look for a therapeutic focus for improving cognitive skills, team working and communication, or are keen to grow food that can be used in their assisted living classes or to help their gardens become self-sustaining.

One successful community project that began in 2015 has a different approach altogether and it happened almost by accident.

### Gleann na Bearú Community Garden

The small community growing area is enclosed within the walls of Gleann na Bearú estate within a Respond Housing Community Centre. In the middle of a town with high levels of disadvantage, the community garden started in 2015 at the request of the landlords who wanted to provide a growing space for local residents in the estate.

Since then, an intergenerational garden has been created by a diverse group of people who now grow fruit, flowers and a multitude of vegetables in raised beds. Along with a tractor tyre pond, plastic bottle greenhouse, pallet furniture and

planters and a living green roof to attract pollinators, there is evidence that a strong focus on the environment and emphasis on upcycling has been encouraged. This not only makes the material costs of growing food more affordable for those on lower incomes as they are encouraged to reuse and think about their 'rubbish' differently, it also allows for environmental education to be delivered in an outside setting.

For two hours, one morning a week, 50 weeks a year, adults meet and work together, while in the evening times, members of Carlow Youth Services arrive. The youth members use the garden for mainly recreational purposes as they shoot videos, but also plant seeds, tend to the garden and are in the process of building a barbeque that they have designed.

The garden facility is used by members of the local community at large, as well as the surrounding estate, several adults with intellectual difficulties who live independently in the town, and older people who travel in from isolated rural locations.

On average, ten people turn up in all weathers, though more come when designated educational horticulture classes are provided. When it rains they chat, drink tea, share recipes and food tips, sort through their seeds and discuss their planting and growing plans. When the weather is more favourable, the

adults work outside together, growing and harvesting different varieties of fruit and vegetables that they've never seen for sale in supermarkets. They've hosted Christmas and pumpkin parties where everyone is encouraged to bring in or cook a new dish at the community centre, and they've welcomed visiting community garden groups from neighbouring counties. The community gardeners have gained an understanding of the food system in general and appreciate the value of it.

Because the garden hasn't been limited to people with or without disabilities, an environment of tolerance and inclusivity has developed. People who wouldn't ordinarily come into contact with one another have developed and practice a new understanding which has led to a growth in confidence of all participants and a general feeling of empathy and wellbeing.

Of the adults who regularly attend the garden, three of the original members have returned to part-time education as mature students to study Quality and Qualifications Ireland (QQI) Levels 4 and then 5 in horticulture and one member with intellectual difficulties took an additional course in woodwork. He now enjoys helping with the structural builds, as well as creating bird boxes and feeders to populate the garden and encourage natural predators into it.

Another participant, a young grandmother who lives on the estate, commented at the beginning of the project that until that day, her only interaction with other people was online or with her immediate family. In 2018 she returned to adult education in horticulture and undertook a social enterprise course provided by Carlow Development Partnership. Her mental and subsequent physical health improved so greatly that she took the brave decision to come off Disability Allowance and has set up a social enterprise in the gardening business, employing people who are long-term unemployed. She's now growing flowers and plants and selling them in a local market during the spring/summer.

A further course is being provided by Carlow Development offering all members of the group a certificate, showing future employers that they have attended basic first aid, manual handling and horticulture training. Gleann na Bearú community garden was chosen by the local newspaper to represent Carlow in the national SEIA Get Involved campaign and they won a county upcycling award for their innovations.

This integrated approach to social gardening has been vitally important with this project. Multi-agency support began when Respond Housing applied for community education support from the local Education Training Board

(ETB). This was followed by continual backing from the ETB, Carlow County Council and Carlow County Development Partnership, as well as local social enterprises, business' and national corporate organisations.

### What have we learnt?

Providing opportunities for Integration and inclusion is key to breaking down barriers in communities as it creates a space for tolerance and understanding.

These projects take time and commitment. Gardens are a year-round activity and the most successful projects have 'Gardenisers' or STH practitioners in place to keep them running, to encourage new members, seek funding, prepare programmes and provide outreach for further participation. Until STH becomes more widely recognised for its ability to impact community development and provide alternative solutions, the multi-agency supports remain pivotal to funding these practitioners.

Setting realistic goals, outputs and potential outcomes is essential. Achieving identified objectives encourages the group to keep going, creates a sense of pride and accomplishment and builds up resilience for when things may not go entirely to plan and allows for a positive 'Plan B'. Aims, outputs and outcomes are also increasingly necessary for successful funding applications.

Effectively communicating and disseminating the learning and experiences is very important. This helps to encourage other organisations to consider the integrated approach of enabled people and those with disabilities working together and the benefits of an intergenerational and intercultural approach. It also encourages people to get involved and raises the profile of the project in terms of attracting funding.

Working with people in gardens is a leveler that cuts across all socio-economic spectrums. Creating tranquil, sensory, edible or social spaces provides people with disabilities with new opportunities to work and learn together in nurturing environments. Guided by occupational therapists or horticulturalists, men and women are able to come together to create collective solutions to common problems in their lives. They are able to collaborate, be encouraged to make their own choices and decisions, strengthening future opportunities for their work and personal lives, as well as empower others as their stories are shared and the greater community influenced by them.

When an integrated approach is used, magic can happen!

*Denise Sewell, Business Owner Greenside Up. Vice Chair Community Gardens Ireland and County Carlow Environmental Network.*

# Frontline working when you have a hidden disability; insights from a community development practitioner living with Bipolar.

Louise Tully

I am a postgraduate, I am a step mother, I am an Arsenal fan, I am a Manager of a team of Community Development Workers and I have Bipolar. I'm more recognised for my wild curly hair and bicycle than my mental health condition. On one hand I am lucky because my disability is hidden, and therefore I am not immediately judged for it. However, on the other hand I can exhibit behaviours that people don't understand and judge those instead. I have been diagnosed for 10 years and over this time I have had a mixed experience as a disabled community development practitioner. I have experienced discrimination and lack of understanding and I have experienced supportive inclusive environments that enable me to stay well. I don't represent all people with mental ill health, but hopefully this will help give you an insight into my journey.



## Community Development Work and the big contradiction

Crucially I think that many Community Development employers are conflicted. They ask their teams to embody community development principles about equality and social inclusion when working with residents and communities and yet struggle to set up employment structures that reflect this for their staff. At times I have been asked to work long hours that interrupts my medication schedule, and have been told to be at meetings at 7.30am and 8pm on the same day, which interrupts my sleep and rest schedule. It's always been a challenge to get regular support and supervision sessions because everyone is so busy delivering. Unfortunately, it's the mantra of putting communities first which causes practitioners to burn out.

Staff with mental health conditions also feel conflicted, they want to work hard for the communities they are committed to and often feel that they want to keep their heads down, not cause a fuss and just get on with things. However, this attitude just stores up problems. I know my colleagues would go the extra mile and I genuinely wanted to do the same. However, when I was continually overstretched, always asked, and I was expected to say yes it became an impossible trap. I never wanted to say no, I wanted to keep going. However, an imbalance in sleep, rest, medication schedule and extra stress has led to a complete relapse and needing months off work.

There's also a juxtaposition between being a community development practitioner and having bipolar. You may think they are mutually exclusive: an impossible marriage between a

condition that can isolate you from people because of crying and being housebound and a vocation that places you in the heart of neighbourhoods talking to strangers every day. A condition that can see you have psychosis, go on wild spending sprees and exhibit risky behaviour and a profession that requires you to advise groups on prudent financial next steps, governance and sustainability. Part of the condition leaves you feeling as though you are in no position to offer support when your own mental health is so uncertain.

## Staying well at work

So how have I survived a decade in community development work with these contradictions? I have become a talker. I was initially embarrassed to tell people I had a mental health condition but overtime I have realised that like a





*I cycle to work every day, because it's cheap, because it's green and because the exercise is good for maintaining a fragile balance. Simply, I cycle because the endorphins and serotonin fight off dark days and manic thoughts.*

visible disability such as visual impairment, unless I talk about my needs I will simply be overlooked. Not overlooked through malice, but because our work environments are high energy, reactive and busy. Where have I found the confidence to talk about it? Through the principles of community development work; we know that to be inclusive and value equality it requires adaptations – we deliver this every day in our practice, so we should understand that we need to adapt our environments to be inclusive for staff with disabilities. It has been hard to come to terms with having a disability. It has been hard to talk to others about it. Community development principles have helped enormously, and I am grateful that when we have excellent practice I have benefitted from it as a staff member.

How do I talk about it? First I tell my manager and my Human Resources (HR) team. In my current place of work I have been supported with an Occupational Health Assessment which outlines the adaptations my employer has to make to accommodate my disability. This independently written document from a health professional protects me from needing to negotiate around my needs. It simply states that I am allowed time off for bipolar episodes and this cannot be counted towards my sick record. I am allowed time off for medical appointments related to bipolar and I am not expected to come in early because this interrupts my sleep schedule which is crucial to staying well. It sounds simple but my Occupational Health Assessment has kept me well and able to deliver work even when I was experiencing bipolar symptoms.

I've learnt about being an effective manager and honesty, open dialogue and a reciprocal relationship is key to making things work. I employ people I will manage that I think will understand. Having a robust recruitment process that tests empathy and how candidates interact with community members can

tell you a lot about whether someone will be a supportive team member. I think this is important because my team genuinely care, they will sensitively book things in my diary, they will take messages on days I am unable to come into the office and they act in a compassionate way without me having to point out my condition all the time. I also believe in investing in staff, so we have all completed mental health first aid training. This takes the burden away from me to be the oracle of information and it also helps equip my team to better work with members of our community.

### Self Care

I also have become better at understanding my condition with time. With this insight comes awareness about how I can adapt my role and stay at work without having to have time off. I cycle to work every day, because it's cheap, because it's green and because the exercise is good for maintaining a fragile balance. Simply, I cycle because the endorphins and serotonin fight off dark days and manic thoughts.

After a depressive episode I asked for flexible working and now do two afternoons a week working from home. This adjustment means I can still work even when my social anxiety is crippling. It means I can focus on my job rather than cry in the office or freeze at a community event. I have also adapted my role when I have been unwell. When I was really struggling with depression, I found it difficult to look people in the eye and my bipolar brain fog meant it was hard to have a conversation. Not exactly ideal at a community jumble sale! So instead of being the connector introducing residents to people they didn't know, I self nominated to become the refreshment person. I was still useful, I still contributed, but it meant at most having a two sentence conversation with anyone and I could hide in the kitchen. I've learnt that I have to take responsibility for what I need and to adapt around it. I have to

think proactively about what I could adapt to make things easier. I can do this because my manager wants me to be well and at work, and the team understand.

### Bipolar Bonuses

There are good things to be said about employing someone with a mental health condition – it's not all hard work and going the extra mile. I feel that I can empathise and build real connections with residents that have mental health conditions and hidden disabilities. I completely understand the challenges and the turmoil of having an outside persona and an inner struggle. I can fully relate to the feeling that you can be both flawed and confident, strong and vulnerable, capable and frail. I am also a champion for wellbeing, and my approach to managing my own condition rubs off on my team. They feel confident to speak openly and this has avoided their own absences because of poor mental health. I make sure they take their annual leave and Time owed in Lieu. I never ask for evening cover and morning cover in the same day, I ban them from checking emails and taking phone calls outside of their working hours, and I understand that people have complex lives and work should not become so stressful you want to avoid it.

One in four of us will have a mental health condition at some point, so every workplace in the world is affected by hidden disabilities. If you are affected, please talk about it, and if someone confides in you please listen. The unique and wonderful thing about community development is that we are already working in a framework that celebrates difference, embraces uniqueness and sees strength in all people. We don't judge our communities, and that's how we should see our team members.

**Louise Tully, Neighbourhood Manager, Great Yarmouth Borough Council**  
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# People-led Policy: Co-production with the Scottish Government

Deirdre Henderson



*Independent living means all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community.*

**The Community Empowerment (Scotland) Act came into law in 2015. For the first time there was an expectation that public services would involve service users in decision making that affected them, with a requirement to consider inequalities.**

As a Disabled People's Organisation, run by disabled people, Inclusion Scotland had known for some time that adult social care support had been failing to ensure independent living in Scotland, for supported people, and their carers. Dr Sally Witcher, the Chief Executive Officer of Inclusion Scotland, was challenged by Scottish Government officials to come up with a good way to involve people who use social care support in policymaking. This resulted in the Scottish Government funding Inclusion Scotland to pilot a People-led Policy Panel for Health and Social Care Integration. This would then co-produce the reform of adult social care support by people who need adult social care services working in partnership with Scottish Government officials.

From the start we were keen to ensure that we had a good range of representation from across Scotland. We recruited an online advisory group of people whose work connected with adult social care support throughout Scotland. They helped us to put together a list of over sixty areas of representation to ensure that those recruited created a balanced panel. These

representation indicators were wide ranging, for example, someone could be an unpaid carer; a supported person (or both); where they lived; what their home set up was like; protected characteristics such as race, religion, sexuality, etc.; how they were funded (e.g. Self-Directed Support) as well as people who experienced communication and access barriers.

We had to create a very long and detailed application form that also needed to be fully accessible. We achieved balanced representation during the very short time we had to recruit through using social media and the networks of over 150 organisations across Scotland to promote this volunteering opportunity.

Anyone recruited to the People-led Policy Panel of 50 people was selected because of their background and experience of needing the adult social care support system. They were not expected to represent everyone in a similar position, as they were only experts in their own experience.

We asked applicants what their hopes were for the People-led Policy Panel so that we could use their responses as a benchmark we could return to in the evaluation. We recruited a balance of experienced activists and people who had never been involved in this kind of process before. Within the Panel is a Core Group of about 20 people who committed to meet with the Scottish Government officials

and ministers four times over the pilot phase, which ends in June 2019.

Jeane Freeman, the Cabinet Secretary for Health and Sport, launched the Panel at an event in October 2018 where she said:

'Everyone in Scotland, every single person in Scotland should have an equal right to live as independently as they can and as they wish to.'

Independent living means all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life. We knew that this was not happening and that the experience of getting social care support to live independently was getting harder, especially with reduced budgets, due to austerity, resulting in ever tightening eligibility criteria, increased charges and the removal of existing supports in the community.

The People-led Policy Panel aims to work constructively with officials from the Scottish Government and the Convention of Scottish Local Authorities (CoSLA) to identify problems in the system, offer solutions, and set the priorities to reform the system. In my experience of co-production,



people who need services to improve are very reasonable and motivated to find practical solutions with decision makers.

The People-led Policy Panel is driving the agenda for change. As people are experts in their own experiences they are best placed to explain where the system is not working and how to reform it to ensure that people are treated with dignity and respect and can live life to their potential.

Back in October 2018, at our launch, the full People-led Policy Panel talked through what they thought good adult social care support was and what their experiences of the system had been. At the same time the Scottish Government and CoSLA had circulated a discussion paper on adult social care reform to stakeholders and received over 50 responses from organisations and individuals, which the People-led Policy Panel then saw summarised.

The Core Group of the People-led Policy Panel has now identified priorities for the reform of adult social care support which have gone to a Programme Delivery Team partnership of organisations who provide adult social care support and civil servants. This team then developed work streams to give to a Leadership Alliance of the key partners who will make the reform happen.

Clearly, with meeting only four times in nine months it is not realistic to expect all the systemic issues to be changed in that time. The Scottish Government is working with CoSLA and partner agencies to develop the work streams to meet the priorities for reform. Meanwhile the Core Group continue to meet as part of an ongoing dialogue to discuss that work. The wider public and organisations across Scotland will also have the opportunity to give their views. The Panel's Core Group will soon meet the Leadership Alliance to look at how co-production can continue during the implementation of the reforms.

The Core Group has expressed their appreciation of the openness of the Scottish

Government and CoSLA officials, and the build-up of trust is clear as honest discussions have ensued. We hope to build on this positive and productive relationship. While this has been a pilot phase, the People-led Policy Panel will continue to co-produce the next stages of the reform of adult social care support.

The learning that can be taken from the process so far would be the importance of:

- An advisory group to ensure that recruitment of participants was robust, fair, and wide ranging (each advisory group member then promoting this volunteering opportunity through their own networks, memberships and social media).

***The People-led Policy Panel is driving the agenda for change. As people are experts in their own experiences they are best placed to explain where the system is not working and how to reform it to ensure that people are treated with dignity and respect and can live life to their potential.***

- Developing a good working relationship with partners through ongoing planning and reflection meetings, and the sharing of materials to be used. In this case we worked with both the Scottish Government and CoSLA officials to plan the launch workshop and facilitate Core Group meetings.
- Building in capacity building time for participants through sharing information in accessible formats. For Policy Panel members plain text and easy read versions of all information were needed which they required to be sent a fortnight before meetings by email or post. As well as

sending out relevant information (e.g. 'What is co-production?'), time was built in for a session prior to each meeting for the participants and Inclusion Scotland staff to review the information sent out in advance, to ensure everyone understood it, felt comfortable commenting on it and to make informed decisions. This made the decision-making sessions that followed run more smoothly and productively for everyone.

- Developing an open and productive co-production group through recognising the different levels of understanding of the topics and the communication barriers for participants.
- Setting ground rules and recognising that co-production is a messy process where disagreement is quite healthy.
- Involving participants and partners in ongoing evaluation through gathering feedback on the day and again a week later meant that people had time to reflect and offer suggestions to change the format or raise concerns that could be addressed. We also asked the participants about their measure for success in the process, helping us to understand what was important to the participants.
- Facilitating the relationship-building between the participants and the officials was important to build trust and understanding. This was well reflected in feedback comments by participants who appreciated feeling respected and in the openness of discussions with the Scottish Government and CoSLA officials.
- It was important to establish a direct link with a key decision maker. The Cabinet Secretary for Health and Sport not only launched the People-led Policy Panel but has accepted briefings updating her on progress and is planning to meet with the group again, meaning the group has real influence.
- In relation to practical issues, co-production is a deeper, more time intensive process where time and resources need to be built-in to planning and addressing practical issues such as ensuring there is ample parking and resourcing for reasonable adjustments to support the range of people taking part.

As we continue, we hope the learning will be shared with the wider policy making community. We also welcome the opportunity to talk to other organisations who wish to develop co-production and the People-led Policy Panel approach as a useful way of developing intelligently designed services, and using budgets and other resources more effectively.

**Deirdre Henderson, Public Health Practitioner, People-led Policy Officer (Adult Social Care Support), Inclusion Scotland**

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# The Inclusion Movement: Transforming ourselves and our communities by embracing diversity

Janice L. Maxwell

If there is a movement afoot to build more inclusive communities, then our family were amongst the pioneers in that movement. Our journey began in 1979, when our daughter Melanie was born 10 weeks premature and developed cerebral palsy. For the past 38 years, our focus has been on trying to get Melanie included. Once people connect with Melanie they enjoy her company. It takes a little extra effort to connect is all! But it is well worth it.

During the past year, we have become inspired to take action to promote inclusion in a broader way. This is the

story of how Melanie, my husband Robert, and I came to see ourselves as part of a world-wide, interconnected Inclusion Movement made up of

***Instead of being included, Melanie has been petted like a puppy, had her cheeks tweaked, and referred to as "she" and "her" instead of by name.***

individuals and groups who are transforming ourselves and our communities by embracing diversity.

The deinstitutionalization of persons with mental illnesses and developmental disabilities was in process across Canada and other parts of the world when Melanie was born. I remember when it was called Integration. The most we could ask was for people to tolerate persons with disabilities. In 1985, Melanie was the first student with multiple disabilities to go to regular public school in a typical classroom in Victoria, British Columbia, Canada. She even received an





award in 1989 at the province of British Columbia's Government House for being special enough and brave enough to go to a regular school. At the time my husband and I felt guilty that we rejected the special label and swallowed the pain of patronization. We didn't want Melanie to be labelled and tolerated as special. We wanted her to be included which is to feel important, respected and valued.

**From the minute our car pulled into the parking lot of the conference centre, we felt important and included.**

Instead of being included, Melanie has been petted like a puppy, had her cheeks tweaked, and referred to as "she" and "her" instead of by name. At one time Melanie told me she felt like people saw her as a bee; they seemed to want to swat her away and get her out of their space. It broke my heart. And so we became involved in the Disability Movement. We joined with thousands of self advocates and their families who are fighting lonely fights for basic human rights. To me this seems so fragmented. In June 2018, Tyson Sylvester, a 22-year-old with cerebral palsy, publicly locked himself in a cage in Winnipeg to bring attention to his human rights complaints. Imagine a person in a wheelchair putting himself in a cage to show the community that he has been sentenced without committing a crime.

And people are still being pushed into living situations that they don't want based on funding issues. We have lived through it all!

Because of these life-experiences, I expected to be exploring familiar territory in February 2018 when Robert, Melanie and I attended an Inclusive Leadership Adventure Weekend on Vancouver Island, BC, Canada. However, I was also prepared to be disappointed. Over the years Melanie has felt excluded in various situations that were described as inclusive. We have often felt that so many efforts to be inclusive and welcoming, even though well-intentioned, might be missing the mark. It turns out that we all enjoyed this weekend of experiential Inclusive Leadership education so much that we have been inspired to view ourselves as Inclusive Leaders who are part of the Inclusion Movement; a movement of people from diverse backgrounds taking action to promote inclusion.

From the minute our car pulled into the parking lot of the conference centre, we felt important and included. The weekend was co-facilitated by a diverse team of trained Inclusive Leaders. One of these Inclusive Leaders came to welcome us and offered to help and direct us as to how to get registered and find our rooms. We were provided with a program and schedule written in plain language and we were given a chance to explore the physical layout of the venues at our own pace.

The conference opened with a thorough orientation that engaged everyone in

**Some of my most painful memories and poor performance are related to times when I was viewed as a problem. It felt terrible when I didn't fit in with the group, community or workplace.**

developing the guidelines for the culture of inclusion we would be cultivating during the weekend. Right from the start we shared leadership in accommodating our diverse abilities, learning styles, and ways of communicating. I could feel the positive emotion and increased participation as people were feeling the inclusive atmosphere. I thought to myself, "Here is a group of people who know - just like I know - how important it is to understand what is expected in new environments."

An experiential approach was used to facilitate learning through relaxed experiences that supported skill-building and emotional processing. We learned a lot about how to behave in ways that promote inclusion for all human beings regardless of age, ethnicity, gender, gender orientation, sexual preference, physical ability, mental ability, health status and other differences. We not only practiced the skills we were learning with each other, we went outdoors and practiced in nature. We learned that plants, animals and the environment have value and importance when considering how to create an inclusive world.

Throughout this weekend of being immersed in a culture of inclusion, we expanded our awareness of the feelings and behaviours behind exclusion as well as inclusion. We are still nowhere near inclusion in Canada and so sometimes to remind myself what inclusion is, I describe what it is not. Many people experience exclusion in mainstream settings and so there are many everyday examples of exclusion. If the doctor's office is not sharing why they are running late and how long it might take, I feel unimportant. If the airport doesn't explain why the flight is delayed, I feel like I don't matter. When we pollute and avoid recycling garbage we are telling the environment that it isn't important. In non-inclusive environments, I hear people being labelled as behavior problems.

Some of my most painful memories and poor performance are related to times when I was viewed as a problem. It felt terrible when I didn't fit in with the group, community or workplace. People didn't look at me. I was criticized and judged as being not good enough. My unique learning style was ignored. I wasn't given time to practice what I was being taught. I had no control or autonomy. No one took time to ask me what I needed or how I felt. My opinion was never considered. I felt left out, excluded, rejected and discouraged. Very few good things happen when people are excluded. If I feel excluded and undervalued, my hands shake and my mind goes blank. Sometimes, I retreat with a sick feeling in my gut. Other times, I get angry and lash out. I make more mistakes. It hurts. Behind exclusion is aggression. Behind aggression are feelings of hurt, helplessness and fear.

**Melanie has taught us that all behaviour is communication.**

In contrast, inclusion makes me feel like I belong. I feel valued and heard. It feels safe to ask for what I need. My human differences are accommodated, understood and accepted. My creativity and best performance comes forth. I learn to identify my feelings and acknowledge them. I become more thoughtful and skillful in my interactions. During this weekend of exploring inclusion, many participants shared that they feel comfortable and included when others notice and welcome them, listen, empathize, respect, accept, encourage, value and support them.

My family and I returned home from this Inclusive Leadership Adventure with the realization that we are global citizens with much to offer this world-wide Inclusion Movement.

"The emergence of a global civil society is creating new opportunities to build a democratic and humane world. Our environmental, economic, political, social, and spiritual challenges are interconnected, and together we can forge inclusive solutions." (www.earthcharter.org)

Melanie has taught us that all behaviour is communication. With Melanie's help we have all become skilled at accepting and welcoming alternate, augmentative communication styles and other languages. We know how to respond

helpfully to hurtful situations with empathy, adjustments and reconciliation. I connect with differences by checking to see if the persons in my presence feel important. I acknowledge and appreciate nature as well as people. I build bridges to equality everywhere I go.

What if all of us involved in the Disability Movement could participate in and contribute to the Inclusion Movement? I see that this Inclusion Movement is contagious. There is a ripple effect. A few inclusive leaders can change the tone and improve quality of life in their families, community, workplaces and beyond.

**An Idea for Further Reading:**

Those of us in the Disability Movement have so much to offer to the Inclusion Movement. One way to get involved is to enroll in an online Inclusive Leadership Adventure called "Discover Your Inclusive Leadership Potential" that is available free or by donation. Here is the website: <https://inclusive-leadership-global-village.thinkific.com/>

(An earlier version of this article called "Inclusion is When We Belong" was posted in the Inclusive Leadership Co-operative Blog, <https://inclusiveleadershipco-op.org/2018/04/09/inclusion-is-when-diversity-belongs/> April 9, 2018.)

**Janice L. Maxwell, Retired Health Professional, Family Member of a person with a disability.**

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# Creating the Conditions for Successful Community Building with People with a Disability

Meredith Baylis, Dee Brooks, Lynn Lennon and Charlotte Saunders

The best practice case studies offered here encourages us to consider the “essential conditions” needed for successful community change initiatives, because community change doesn’t exist in a vacuum. These conditions are:

- A willingness to learn
- A change of belief
- Knowledge of the community
- Leadership capacity
- Relationships and teamwork



To aim towards inclusive, equitable and sustainable development as part of the 2030 Agenda for Sustainable Development and to ensure we “leave no one behind”, people with a disability, as agents of change can participate in and co-create the process towards inclusive development, as described in the stories below.

## Don't underestimate the power of small steps! When in doubt, DRUM!

By Charlotte Saunders

Holyoake DRUMBEAT is a 10 week evidence-based social and emotional learning program that uses hand drumming as a base for engagement. Using a combination of rhythm-based games, core rhythms and group discussions, facilitators assist participants to build skills relating to friendship, community, leadership, and emotional regulation. We make adjustments as necessary to cater for differing needs and are as inclusive as possible. In the following example there are six children with developmental delays, one child using a wheelchair and three typically developing children.

Jacob\* (name changed for privacy) is a twelve year old boy, diagnosed with

Autism Spectrum Disorder. He described himself in our first session as “shy and anxious”, said he “doesn’t like to try new things” and he was only at DRUMBEAT because his parents made him attend. Starting the first session, Jacob sat in the circle listening, not drumming, and speaking during discussions but “zoning out” when others talked. By the end of the session, he matched the rhythm of the group, tapping on his drum with his pinkie finger.

The other kids watched Jacob but didn’t comment and slowly Jacob began to play along at full volume. By the fifth session, Jacob asked to lead a rhythm. He surprised everyone with a catchy, fast-paced rhythm, and slowed down to help another child find the beat. When the session was over, he asked me if he could lead the final performance and said he had a great idea. We talked about his idea, he presented it to the group and the others agreed to follow his lead.

**“The UN Flagship Report on Disability and Development 2018 – Realizing the SDGs by, for and with persons with disabilities shows that people with disabilities are at a disadvantage regarding most Sustainable Development Goals, but also highlights the growing number of good practices that can create a more inclusive society in which they can live independently.”**

**UN Secretary-General António Guterres’ message on the International Day of Persons with Disabilities, observed on 3 December 2018**

In session 10, Jacob’s DRUMBEAT community helped to tell the story of two yetis, who were disturbed during their dinner by giants coming to eat them! Two children drummed the loud, stomping giants, 8 drummed the yetis’ terrified heartbeats and Jacob and another child drummed the scurrying mice who rescued the yetis by “tickling the giants feet” and scratching on the drum’s surface. The giants giggled, fell down, then got up and ran away while the yetis and mice cheered.

When I asked Jacob to reflect on the performance, he said, “you don’t have to be big and loud to save a yeti from giants, sometimes being small and quiet is good too!” When asked to describe himself again, he stated, “I’m shy, but getting braver, and I found out I’m actually good at being a leader!”

## H.O.P.E. (Helping Other Possibilities Emerge): If Plan A falls over... remember, there’s a whole alphabet to go!

By Lynn Lennon

Jeremy was a defeated man, whose joy for life, belief in himself, faith in others and goals in life had hit rock bottom. After meeting Jeremy it was evident he had dreams and goals for his life but believed his accident had made them impossible. Jeremy wanted to join the Army, but believed his Acquired Brain Injury would stop him.

After connecting him with support workers to explore if there were more doors to knock on, questions to be asked or possibilities to explore, he slowly began to see that maybe his dreams could become a reality. Others within the community were excited to join Jeremy on his journey and offered their wisdom, services and moral support and in turn, Jeremy began to encourage others with a disability to explore their possibilities.

Unfortunately Jeremy wasn’t accepted by the Army although, when reflecting on one of Jeremy’s first conversations around personal goals, he had wanted to help others, who had been through a similar experience, to connect more broadly to their community.

The team that had been supporting Jeremy remained in contact and they talked and wondered until finally a new dream was realised. In training for the army, Jeremy had shown a “quiet achiever” leadership style and the



Personal Trainer who had been working on his fitness believed that he would be an ideal trainer for others, to support their health and well-being and today, the exploratory journey of becoming a personal trainer continues!

## If it takes a village, build one! You might not change your destination overnight but one person can change your direction.

By Meredith Baylis

Karime was born at 26 weeks with significant issues. He was not doing well and his mum was asked to turn off his life support as they believed he would never walk or talk and would not have any “quality of life”. Instead, his mother whispered to 10 day old Karime, “Choose whatever you want to do, I’ll be by your side.” By the next day, Karime had turned the corner and was taking 1ml of milk and slowly improving.

Little did they know! Karime, now 22 years of age, has gone on to have an amazing life, doing what he loves most in the world... music! Karime heads to Brisbane (Australia) once a month to attend various music events and catch up with friends. He has carved out a life of his choosing, with the help of his biggest supporter and personal assistant; his Mum, who shares the following story.

A random support worker encountered Karime when he was at a club with his mates. The worker asked him, “where’s your worker?” and Karime said, “I don’t need a worker, I’m here with my mates.” The worker really struggled with

this concept and asked to know more so, Karime reluctantly agreed to chat outside. The worker explained that he works in a group home with 5 participants [PWD] and when he said he knew some of them would love to go out to a club and listen to live music, Karime asked, “Why don’t they?” The worker explained that the service provider at the home wouldn’t allow it.

The worker couldn’t fathom that someone in a power wheelchair like Karime could be out at a club, getting loose and having a great time! After that conversation, the worker said he was going back to ask his employer why his clients couldn’t go out, too?

That’s the stuff that makes me proud of Karime! Having those difficult conversations and being assertive is not easy for him as he just wants to have fun with his mates but he’s making a difference, one conversation at a time.

Karime has travelled Internationally and interstate for conferences, worked unpaid at community events (Multicultural Week, Youth Week, Mental Health Week) and is now receiving regular paid DJ gigs. Karime entered a National DJ Competition “Your Shot Queensland” and now works with that crew, on performance days, supporting emerging artists.

Accessing paid DJ gigs has been challenging as he is often overlooked in favour of his able-bodied colleagues however, with authentic conversation, education and time people have come to know Karime personally and to see his passion and commitment. Despite Karime having only one (1) functional

arm and hand, being deaf and in a power wheelchair due to his moderate/severe Cerebral Palsy, he can do anything an able-bodied person can do. All it takes is one person to give him a go.

Karime is well known and connected in his home and work communities and has become a well respected local DJ and Music Producer. He has a Diploma in Electronic Music Production, Diploma in Events Management, Cert III in Music Industry and Cert II in IT, Web Design, Animation and Multimedia and despite his identify and mental health illness struggles, he is currently studying his Audio Engineering Associate Degree.

Life has not been easy and Karime has fallen through many cracks, particularly in his early years. Although, with strong, unwavering support from his Mum and her tenacity and innovative thinking, they have found strong allies, community supports and the most amazing adventures.

Karime is the captain of his own ship and he wouldn't have it any other way!

The Jeder Institute is an international not-for-profit, strengths-focused organisation, based in Australia with extensive experience in creating the conditions for collective action locally and throughout the world. We create positive change for individuals and communities by bringing people together to realise their full potential, increase collective knowledge, explore insights and engage community members in conversations that matter to empower individual's choice and control by:

**Facilitating community conversations around critical social issues**

**Building individual and community resilience**

**Coordination of supports and capacity building**

**Engaging and connecting with a diverse range of communities**

**Identifying and mobilising individual and community assets and strengths**

When people with a disability are connected to community and they shift from the peripheral of community to the

centre, we are building the bridge from client to citizen and honouring and acknowledging their wealth of strengths, assets, wisdom and experience to be co-creators of change and to find creative ways to help themselves and others achieve their goals.

*For further information about the Jeder Institute and to find free person-centred and community-driven resources to download, click here: <http://jeder.com.au>*

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# Who Speaks For Whom?

Anita Montgomery



*Just as it is improper for a White America to speak for – or over -- African Americans about their lived experiences, or cis-gendered people to speak to the lived experiences of the LGBTQ, so it is improper for abled people to speak for those with disabilities.*

**There are currently an estimated 3.5 million autistic adults in the United States, with an additional half-million children expected to enter adulthood over the next decade. My son is one of those adults. His clinical diagnosis is FG syndrome, a genetic anomaly that includes not only autism but also hearing loss, epilepsy, attention deficit/hyperactivity, cognitive challenges, and physical issues, as well as elopement issues. He is functionally non-verbal but will quickly tell people "I not 'tupid" or "I not a baby" when they talk around him or will throw out a clear curse word when he finds something or someone especially disagreeable.**

The query for my research and practice is what communities are doing to support autistic adults. The study gathered information from a community of interest through an appreciative inquiry survey, along with content analysis of YouTube and TED videos and my journal. The data was sub-coded into the Community Capitals Framework so that the information can be applied to the community of place as needed. An overwhelming number of the survey responses were coded into Human capital: tolerance, leadership (or advocacy),

education of others, and social programs, the majority of which applies to any other minority population.

Just as it is improper for a White America to speak for – or over – African Americans about their lived experiences, or cis-gendered people to speak to the lived experiences of the LGBTQ, so it is improper for abled people to speak for those with

*The fight for social, political, and economic rights for persons with disabilities seems never-ending. In place of the old systems of institutional care, persons with disabilities are now being housed in institutional alternatives, such as hospitals, nursing homes, or worse, criminal justice systems. City ordinances that require perfectly manicured lawns disproportionately penalize disabilities.*

disabilities. In fact, research shows the further away a proxy is from the person with disability, the less accurate the information that is provided. Individuals and organizations whose livelihoods are dependent upon the medical and charity models are even more suspect because of the inherent economic self-interest. Just like other minority groups, the disabilities community has demanded a seat – and a voice -- at the table through sit-ins, demonstrations, the self-determination movement, and "Nothing about me, without me." Self-advocates and many families have begun pushing back against the annual "Autism Awareness Month" in favor of "Autism Acceptance Month," recognizing a Community Day of Mourning for those lost to filicide and altogether rejecting a "cure" for autism.

When my son was diagnosed with autism in 2001, statistics at the time said that 50 percent of autistics "never talk," and roughly 90 percent were considered to have co-morbid intellectual disabilities. Appropriate speech services and alternative communication devices have brought the non-verbal number down to 25 percent, and with more appropriate evaluations co-morbid intellectual disabilities diagnoses have dropped to 32

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percent. Even if an autistic adult is non-verbal, an understanding of language should be assumed. Just as neuro-typical adults are life-long learners, including languages, so are autistics, and who that person is as a child in a meltdown at the store is not who they will become as adults.

### Social Capital

Uncertain of their children's future in a typical community, some families in urban areas have begun to create intentionally designed communities for their children. For others, the role of caregiver will fall to a sibling. For those of us who are determined to keep our children in an inclusive setting, the future is far more challenging and uncertain, especially as state and federal budget cuts affect community care services.

The impact of social exclusion has been well documented in community development. Those findings also apply to autistics. Autistic adults and many parents have turned to building social enterprises to overcome isolation, in the absence of employment opportunities, and rejection of segregated programs such as adult day programs or sheltered workshops.

For those like my son who will need 24/7 supports, social capital is critical to inclusive sustainability. Through my social capital, my son recently began stocking soda coolers three days a week at minimum wage and has since started stocking condiments and cleaning tables. The financial capital is secondary to the social capital because the intent is for people in the community to know him, to know his schedule, and to know when something is wrong in his behavior to stem potential abuse later. The ladies at the store genuinely love him, and he is proud of his job for which his associative language is "Big Daddy!" He is the first person at his functioning level in the county to obtain a public job. To further expand his social capital – and for community development in a nearby town that has seen a critical loss of capitals due to two school consolidations – I purchased an unfinished building. The building, which is in a food and information desert, will serve not only my son's needs, but also the community's once renovations are completed.

### Financial Capital

One of the critical issues for autistic adults on discussion panels available on YouTube is jobs, and, just like the neurotypical community, not everyone wants to be a business owner. (A social enterprise, micro-enterprise, or self-employment counts as financial capital only if it is more than a hobby.) Bill Novelli, who leads the Global Social Enterprise at Georgetown

University and who wrote the foreword of *How Change Happens* (Crutchfield, 2018), found in his research that human resources directors do not think about disabilities as a part of inclusion and diversity. Perhaps his findings explain why when social justice warriors list the litany of marginalized populations, persons with disabilities are rarely mentioned. Walgreen's was the first company this mother was aware of that intentionally hired autistic adults because Randy Lewis (2014), then-vice president of Walgreen's supply chain, has an autistic son. Lewis relates his 16 Principals for hiring people with disabilities in his book, *No Greatness Without Goodness*.

Before the passage of the ABLE Act in 2016, persons with disabilities who received Supplemental Security Income, Medicaid, and other government benefits were severely limited in earned income. The



ABLE Act allows income to be deposited into an ABLE account, and, if that money is used for approved expenditures will not count as income against means-tested benefits.

### Built capital and intersectionalities

One discussion that has occurred between my daughter and me on several occasions is housing, in case my son at some point cannot remain in our home. We have discussed a duplex, a tiny house, or a suite – depending on the level of supervision required -- as options so that she may look after him if needed. The intentionally designed communities by parents mentioned earlier may be a great idea in theory, even if segregated. However, group living situations may not be optimal for those living with post-traumatic stress or a social anxiety disorder. Pharmaceuticals may be necessary for compliance. Some cities have restricted or prohibited duplexes or tiny homes; however, some states have argued that such restrictions violate the Fair Housing Act for people with disabilities.

Autism can be combined with other diagnoses including epilepsy and sensory

processing disorder, and accommodations are intersectional with other disabilities. Fluorescent lighting can trigger not only seizures for those with epilepsy but can also be a significant irritant for those with autism. (LEDs or incandescent bulbs are preferred.) Perfumes that stores use to create a "memorable" shopping experience can trigger not only asthma attacks, but also serve as a trigger for those with post-traumatic stress and autistic individuals with sensory processing disorder. Deaf design not only benefits those with hearing impairments but also autistic people. These are just a few examples.

Following the sit-ins of the 1970s that led to the Rehabilitation Act of 1973 and the "Capitol Crawl" in 1990 leading to the passage of the Americans with Disabilities Act, design standards have stalled primarily after addressing mobility access, and service animals stereotypically thought of as only for those with visual or hearing impairments. As Ralf Dahrendorf (2012) wrote, "Revolutions are melancholy moments of history... the honeymoon does not last" (p. 1). More are still excluded than included. Complaints are lodged. Lawsuits are filed.

The fight for social, political, and economic rights for persons with disabilities seems never-ending. In place of the old systems of institutional care, persons with disabilities are now being housed in institutional alternatives, such as hospitals, nursing homes, or worse, criminal justice systems. City ordinances that require perfectly manicured lawns disproportionately penalize disabilities. Property tax systems that are not understood by persons with disabilities are dislodging them from their inherited homes.

Does "First, do no harm," and implicit and explicit biases preclude us from incorporating the autistic community's needs, interests, and culture in community development research and practice? If we are not actively engaging persons with disabilities in research and planning, then our job is incomplete.

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# Community+Education= Empowerment

Barbara Coley

I am speaking to you from my own experience. What I know to be true. I was diagnosed Paranoid Schizophrenic in 1991. Like many people with the onset of a mental illness there were many loses. My daughter went to live with her father. I was unable to work and had to go on disability. I couldn't afford living where I was and had to move. And with all that I lost many friends who just didn't or couldn't understand what I was going through. I was no longer a part of my community.

**I didn't know anything about mental health services when I had my break. But I did attend a therapy group at a hospital where a person told me about a job on the Warmline. It provided mental health services at a drop-in center in San Rafael, USA. She said she thought I'd be good at it. I didn't know it then but the programs at the center were soon to become the core of a community I would participate in. Eventually I was to become the Director of these programs. Not just the drop-in center but all of Community Action Marin's Mental Health Peer Programs (CAM).**

Peer Programs are unique services because people with lived experience provide the mental health services as well as administer them. Later when I was hiring as the Director the staff I was looking for was someone who had received mental health services themselves. Someone with lived experience.

**Peer Programs are unique services because people with lived experience provide the mental health services as well as administer them.**

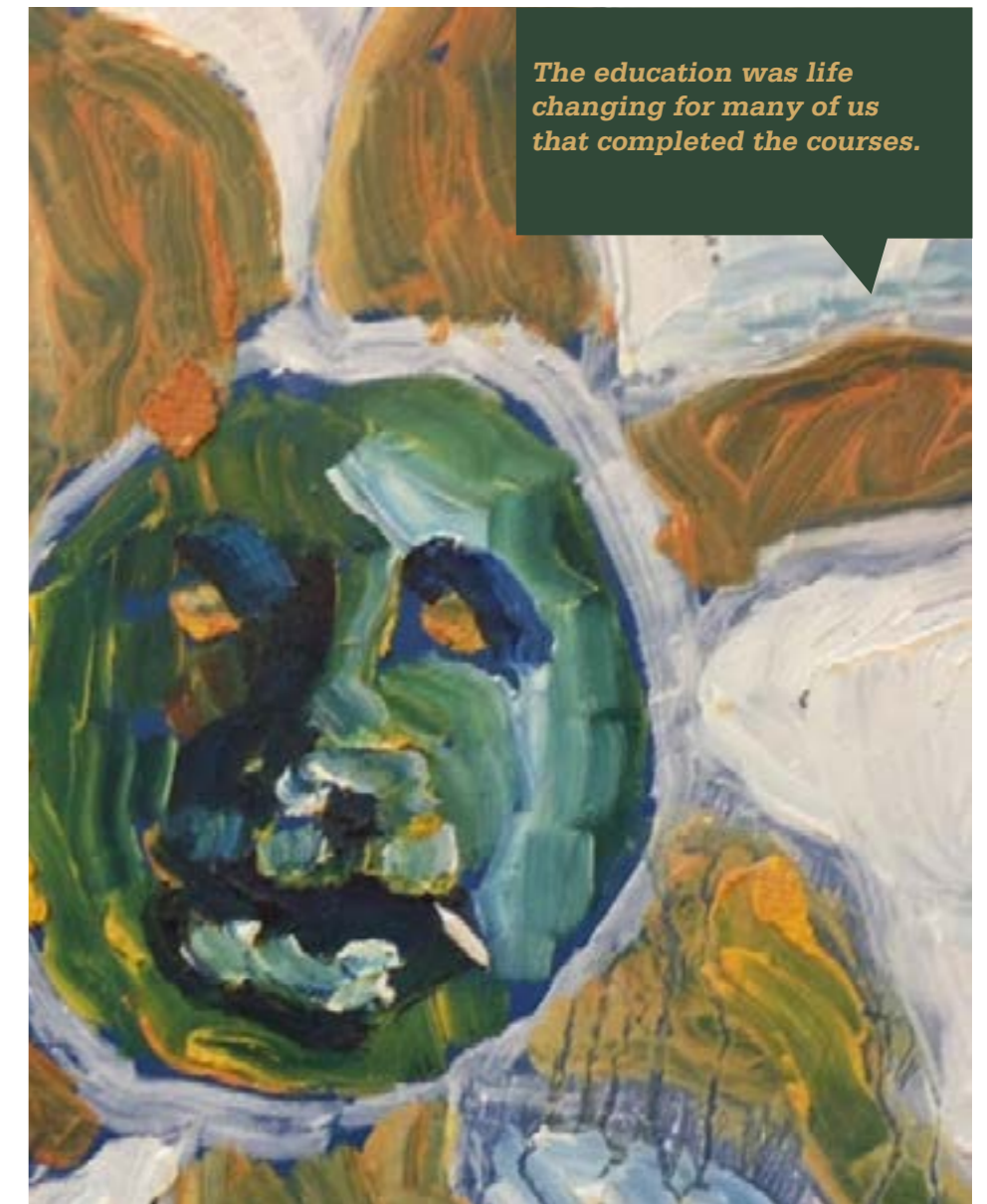
I became director of included direct and indirect services as well as outreach. The direct services billed Med-i-cal and provided case management. The indirect services were provided at the drop-in center. CAM contracted with the County of Marin Mental Health to provide those services. The outreach services were provided out of vans that worked on the streets of Marin.

All of the peer providers were required to take Peer Counseling Courses as pert

of their training. The courses' curriculum was originally written by Michael Payne. There were five courses you took in succession. The Basic Peer Counseling Course was required for all of the peer providers but was available to anyone wanting to learn about peer services. The second course Peer Case Management was for those interested in

becoming a Peer Case Manager. Abnormal Psychology, Medications and Advanced Peer Case Management were also required courses for those people providing case management as peers.

The education was life changing for many of us that completed the courses. For others it was an accomplishment



**The education was life changing for many of us that completed the courses.**

**The drop-in center which housed the education program provided many other services geared to educate and support the people seeking help.**



# Outreach services for stressful mothers living in Hong Kong: A Community Work Approach

Wong Chi-kan, Lau Sing-ping, Tang Sin-kit and Fung Kwok-kin.

they took pride in. For all of us it created a community. We were trained mental health providers with lived experience. We felt empowered. The Peer Programs in Marin had 32 staff and approximately 30 volunteers trained and certified to provide services. The education we had received was not just to benefit us as staff and volunteers but was to be used as tools to serve the people needing services.

Peer Case Managers worked with County staff on their different teams. The Odyssey Team served the homeless mentally ill population. The Bridge Team provided support to those that fit the criteria of seriously mentally ill. While the STAR Team worked with people who had been incarcerated and were mentally ill. Shelter Plus Care served the population that were just housed having been homeless and needing support to maintain their housing. The Peers working on each of these teams had a case load of approximately 12 people.

The drop-in center which housed the education program provided many other services geared to educate and support the people seeking help. The Warmline, a phone line for people that isolate, connected the people calling in with a Peer Counselor. Linda Reed was a day program that focused on activities as a source of support. People coming to the center could meet with a Peer Counselor one-on-one. It was not to provide therapy. The peer counselor was to listen and possibly refer the person to other services if needed. The center also had groups that were ongoing every week like WRAP, Dual Diagnosis, Bipolar Support Group and an Art Group every Sat. Other groups and trainings were offered through the center. There was Cognitive Behavioral Therapy, Dialectical



Behavioral Therapy, Motivational Interviewing, Advocacy and Mindfulness. All of these services striving to support an individual in a MH community where they feel empowered. An average of 55 people a day accessed the services.

**The Outreach Team on the other hand had the difficult task of working out on the streets.**

The Outreach Team on the other hand had the difficult task of working out on the streets. People who had been homeless for years were difficult to engage and many were dually diagnosed not wanting services. For some the

drop-in center was a viable solution for receiving services. For others appropriate services might mean detox first.

The final program I'd like to speak about is the gallery we added to our programs. Art has always been a support to many people with a mental illness. Many of them are creative in nature and find empowerment in doing their art. When the opportunity came with an available space we were able to create the 1108 Gallery. This added a space that was in the community of downtown San Rafael, where the gallery participated in its' monthly Art Walk and where artists from the center were able to show and sell their work. To become part of yet another community.

To help keep people informed about all of our programs a newsletter was published by our center. It highlighted the employee and volunteer of the month. There were articles about events and mental health information. It also covered our yearly retreat to Stinson Beach that focused on team building and employee appreciation. It was important that staff know their value and felt appreciated. In fact our programs may have functioned in part as back to work programs. Simply though it is peers helping peers whose lived experience is invaluable.

My work has lead to 20 years hoping to build a community where education empowers people like me with lived experience.

**Barbara Coley, Mental Health Rehabilitation Specialist**

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**In Hong Kong and most Chinese societies, individuals with mental health challenges tend to be reluctant to seek help so as to escape from being stigmatized by the general public.**

**In this paper, we outline our newly started community work project, which is aimed at identifying the high-risk mothers living in sub-divided units in deprived and low-income community of Hong Kong, Shamshuipo, linking them up with mental health services and developing empowering community networks among them for their future development as self-help communities.**

In Hong Kong and most Chinese societies, individuals with mental health challenges tend to be reluctant to seek help so as to escape from being stigmatized by the general public.

In addition, professional effort to identify and support these high-risk people is inadequate. In view of such a huge service gap, some social/community workers have

started initiating a long-term community-based program to reach out to high-risk groups, because current mental health services have had difficulties in reaching them due to resource constraints. With effort, the program described below, attained the support of the Fu Tak Lam Foundation Limited and launched an outreach service in July of 2019.

We believe that people with mental health problems are capable of making rational choices in seeking help, if the support resources are available, but they have been discouraged to seek help because of different socio-cultural barriers e.g., stigma and public perception of mental health problems. Our community work approach aims at developing the mutual support capacity of disadvantaged communities to act upon their needs and to push for the needed policy changes.

The project follows an asset based community work approach that seeks to empower this group of service users.

Sympathetic listening by lay people with mental health needs and sharing of experiential knowledge among people with mental health challenges may help to reduce the barriers to seeking help and provide momentum for people with mental health needs to deal with their problems directly. In this way, developing

**The project follows an asset based community work approach that seeks to empower this group of service users.**



mutually supportive networks, both formal and informal, through a community work approach can help develop social capital among these service users, and in turn reduce their distress, sense of loss and social isolation. Through the genuine care and concern of the community worker, people can be helped in releasing their pain and suffering. Community workers in this project take an active role to reach out to home-bound service users, rather than passively waiting for them to visit our support centre.

Our project started since April 2019. We use door knocking home-visit to reach out to “home-bound distressed mothers”, and to deliver support services directly to their home. Through the service provision, we build up a trustful working relationship with the mothers and facilitate them to develop the mutual help networks for their continual empowerment. The services delivered at home include home-based counseling, and the provision of advice relating to community resources. To help their access to the community resources, a community resource booklet has been published and delivered to them through the home-visits.

This outreach strategy has enabled our community workers to successfully network 107 mothers in sub-divided house since April. 57% of them leave their mental health challenges unattended; 40% prefer seeking help from families, friends and relatives but receive a very low level of support; and only 6% seek help from their neighborhood.

Our project has rented a small flat unit where we have developed a Family Mutual Hub. The Hub is located in the area of Shamshuipo where sub-divided flat units are concentrated. We encourage the mothers to bring their children together to join our child mutual support service. Such service extends the interaction space for these mothers to build up their parent-

child relationship. Also, it extends the social networks of these mothers as they have developed friendship with each other. Their stress is released throughout the process.

**One of the goals of our work includes facilitation of the participating mothers to become more aware of the causes of their mental health challenges.**

One of the goals of our work includes facilitation of the participating mothers to become more aware of the causes of their mental health challenges.

Under the supervision of a psychiatrist, who is our voluntary consultant, the community workers are trained to assess the mothers’ mental state. 52% of the mothers were identified to have depression symptoms while 77% have both depression and anxiety symptoms. In addition, 59% of the mothers identified poor living environment as the problem that leads to their high stress and anxiety. Because of the limited living space, conflict occurs frequently between them and their neighborhood. Limited space also brings about problem for their children to study. Damp housing and rats lead to the bad health of children and the whole family. However, these reinforced the belief of the mothers that they are to blame as a “failing mother”, further sustaining their stress and anxiety.

At this stage, stress management training has been used to help the mothers with depression and anxiety symptoms to release their stress. As well as providing them the stress management skills, the community workers empower these mothers through group sessions to facilitate their identification of the external/

**The encouraging results of the project confirmed our effort in using community work model to support the needs of low-income mothers who have low motivation to seek help.**

and the impact of traditional gender role stereotype in intensifying their stress. In future, the community workers will continue to facilitate the development of the mutual help groups and empower them to redefine “Good women” as well as developing their problem solving capacity.

In future, the community workers will organize different forms of self-help groups through which a mother-care self-help community will be developed. Such a self-help community will continue to develop the mothers to become peer counselors and home-visit and child care volunteers themselves. In addition, capacity building to deal with the environmental causes of their problems, through the development of their ability to advocate for social/policy changes, will be supported by the self-help community.

At present, our project has had positive impacts identified among the mothers. 39% of the mothers have accepted our case referrals services to relevant non-governmental organizations within the community. In addition, these service users have expressed to the workers that their main problems were eased and their stress reduced too.

The encouraging results of the project confirmed our effort in using community work model to support the needs of low-income mothers who have low motivation to seek help.

Though community work approach is not new in social services in Hong Kong, employing such an approach to distressed mothers residing in sub-divided units in low-income communities in Hong Kong is not common. In order to examine the effectiveness of the model, a research study employing participatory action research as methodology, has been built into the planning and implementation of the project. The research results will be shared with colleagues in the social service field to further the support of distressed mothers in the future.

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# Nothing About Us Without Us: Bridging University and Community towards Empowering People with Disabilities

Nor Wahiza Abdul Wahat



The U.N. sustainable development goals (SDGs) address disability specifically in parts related to education, growth, employment, inequality, and accessibility. Goal 4 focused on inclusive and equitable quality education and promotion of life-long learning opportunities for all. It focused on eliminating gender disparities in education and ensuring equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities. Meanwhile Goal 8 focused on promotion of sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all based on collected empirical data.

In Malaysia, the introduction of the Law of Malaysia Act 658, Persons with

Disabilities Act 2008 indicated a new push towards the empowerment of persons with disabilities in Malaysia. In line with this law and to achieve the above SDG goals, a social model which promotes accommodative values, norms, culture, perception and support system serves as the best guideline for us at our university to gear towards the empowerment of people with disabilities.

It is in line with the 'Nothing about Us Without Us' slogan which emphasizes the central roles of important stakeholders in voicing out their opinion and rights towards sustaining their well-being. In this article, we shall narrate on our action research approach in collaborative efforts with several communities within and outside of our campus towards empowering not only the people with disabilities, but also the communities themselves.

## Raising Awareness of Campus and Community Members

In our particular context, community members refer to both the campus community as well as the community outside the University campus. Our community projects involved not only academic experts on disability in Institute of Social Science Studies and also undergraduate students of Bachelor in Human Resource Development programme.

Prior to approaching the community members, our first step was to provide the knowledge and skills of our involved students about disability. They attended the Disability Equality Workshop (DET) conducted by a DET coach who is a visually impaired psychology officer from the Department of Welfare, Ministry



*The first objective was to initiate the socialization between our students and Sri Serdang community members with the disabled trainees and teachers at the centre. Socialization among stakeholders served as a very important function in an empowerment project.*

of Women, Family and Community Development. The purpose of the training was to prepare the students with right perspectives on disability based on the social model of disability.

Next, our focus was to build our rapport with the involved university students, leaders and members of Sri Serdang Community. In order to do that, various meetings between our team members and student representative with the Sri Serdang community leaders were held to understand the extent of their awareness and involvement in relation to disabled members within the Sri Serdang community. The community leaders were inclusive of women and youth leaders of the community as well. However, at the initial cycle, there were no representatives of disabled members at all. As a matter of fact, it was only at the later stage that they were aware that there were almost 100 persons with disabilities within their community.

Collected data via in-depth interviews, survey and observation showcased low awareness towards enablement and empowerment of the disabled members within the community. Hence, the next stage was to increase the awareness among the community members on their roles as inclusive society members.

One of the planned and implemented projects was a two-hour pantomime on disability which had involved 20 students of Bachelor in Human Resource Development programme, 5 youth members of Sri Serdang Community and a disabled student from the Industrial Training and Rehabilitation Centre as actors and crews. The project was funded by University Community Transformation Centre of Universiti Putra Malaysia. The director of the pantomime project was a student from the Bachelor in Human Resource Development

programme. The socialization experience with one of the actors with multiple disabilities during the pantomime training and rehearsals has gradually built better understanding and empathy towards the disabled among the youths.

About 400 audiences from various parties inclusive of Sri Serdang community members, university students, academic as well as non-academic staff of University Putra Malaysia filled the seats at the university hall on the night of the performance. There were also invited guests from nearby colleges and the disabled trainees from the industrial and rehabilitation centre. The number of the audience itself indicated encouragement towards this empowerment project. Positive feedbacks from the audiences at the end of the performance indicated empathy and support for the people with disabilities.

## Bridging the Community with the Disability Agency

Following the positive outcome from the pantomime project, several meetings among the stakeholders took place and led to another cycle, which focussed upon bridging the university student community and Sri Serdang community with the Industrial Training and Rehabilitation Centre in Bangi Selangor. Upon the consent of the centre's director, two programmes were charted. First was the community visit to the centre and second was to organize an entrepreneurship workshop for selected teachers and trainees of the centre as well as the university students and Sri Serdang community representatives. The Industrial Training and Rehabilitation Centre had about 200 trainees with physical, mental and multiple disabilities. They were trained for various skills including painting,

batik painting, sewing, multimedia, administration and electrical skills.

The first objective was to initiate the socialization between our students and Sri Serdang community members with the disabled trainees and teachers at the centre. Socialization among stakeholders served as a very important function in an empowerment project. The second objective of the visit was to expose the community members on the potentials of the trainees with disabilities at the centre. Commercial products by the trainees were also exhibited at the working workshops. Forty community members participated in the visit and attended a briefing session conducted by the counselling officer of the centre. The experience served as an eye opener to the community members.

The entrepreneurship workshop, was conducted to initiate commercialization plans for the products made by the trainees at the centre. The workshop which consisted of five groups was coached by an entrepreneurship consultant. It resulted in marketing plans for the products such as oil paintings, cloth bags and batik paintings. One of the implemented plans was selling the products at seasonal events held by Sri Serdang community.

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