Living and Being Included in the Community Regional Perspectives on Choice, Support and Inclusion
As a part of the Global Campaign on Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), Inclusion International conducted regional forums with our member organizations in each of the five regions. These forums were an opportunity for family organizations and self-advocates to share their perspectives on the right to *live independently and be included in the community*; and explore the particular challenges and context for achieving this right in their region.

From these forums, and with information collected through surveys, focus groups and the regional coordinators, we have learned about key issues which are common across regions and specific issues that relate to the cultural, political and economic context of the regions.
Stretching from Lesotho, Swaziland and Namibia in the South to Ghana, Burkina Faso, and Benin in the west to Kenya, Tanzania and Ethiopia in the east, Africa is the world’s second-largest and second-most-populous continent and also the least economically developed of the regions in Inclusion International. More than 850 million people live in the 48 countries of sub-Saharan Africa. Over 15 million people of these are believed to have intellectual disabilities and majority live in abject poverty, neglect and social isolation. Many more are victims of catastrophic human rights violations; the most marginalised underclass in the remotest, most isolated places in Africa, with hardly any safety nets; always at the bottom of the pile, even within the disability movement. The few national action plans that target people with disabilities do not routinely recognize those with intellectual disabilities in education, health and poverty reduction.

Despite the continent’s vast size and number of cultures many similarities exist across the countries: for example, in aspects of cultural beliefs and practices, state investment in welfare- or to be precise, the lack of it - and the strength of civil society. Almost all the countries of Africa share numerous features in common in relation to people with intellectual disabilities.

Inclusion Africa, which now has 17 national members, the oldest being Zimbabwe Parents Handicapped Children Association in Zimbabwe (founded in 1987) was newly established several years ago. Over the past 20 years or more there has been various formations of this African network but recent efforts to support the regional level work (supported by NFU Norway) have enabled the members to meet regularly once a year. The self-advocacy movement is still fledgling, having been initiated only in 2007 and in many countries remains untried. The regional forum held in Johannesburg along with focus groups and interviews with members helped to identify common issues related to the implementation of the right to live and be included in the community.

The latest Swaziland census of 2007 has statistics of people with all disabilities except that of people with intellectual disability. The disability grant of E250 (approximately USD 30) that people with disabilities who are registered receive every three months, is not given those with intellectual disability.
KEY ISSUES

● Cultural and societal attitudes
Societal prejudices and beliefs contribute to many of the issues faced by people with intellectual disabilities, making it harder for them to access education, become aware of their rights, reach those in power and access appropriate facilities and services.

● Weakened Communities
Extended families are becoming less the source of support to people with intellectual disabilities. This is more so taking into account the fact that particularly in urban areas, the communal way of life is fast breaking down. The worst affected are those with multiple and severe disabilities who cannot leave their homes, and who despite living with their family, in the community, are not included in the community in any meaningful way. The main worry for their parents is how their children would survive when the parents die.

● Access to and/or availability of employment
Opportunities for income generating activities are limited to non-existent for both adults with intellectual disabilities and their family members. Extreme poverty results in further marginalization in the community. People with intellectual disabilities and their families are among the poorest of the poor.

● Lack of governmental support
The pressure on public health services is enormous, and many people must travel long distances to reach the services they need. None of our participants, had experience of readily available community-led services and institutions are often the only way to access vital services at an affordable cost. Many African governments have enormous strains on their health services, with a fast-growing population and low formal employment keeping tax remittances low.

● Access to education
Children and young people with intellectual disabilities invariably get less education than that for their peers and lack of education is identified as an obstacle to inclusion in the community as the main concern of most of the participants in the focus groups discussions. In a few countries, special schools exist which admit children with special needs rarely supported by welfare services and often with inadequate or no specialized services in the form of therapists, and special educators. They, however, promote segregation, and the children enrolled in these schools cannot escape from social stigma. As a result, the vast majority of young people with intellectual disabilities are excluded from their age-group and community, and face problems later in life obtaining employment.

“Whenever I pass where people are gathered, they say that I am dead; this makes me feel very unhappy”

– A self-advocate from Addis Ababa, Ethiopia.
The Americas are a vast region with some similarities between nations, but substantial differences on the daily life for people with intellectual disability and their families; depending upon which country they live in and, within countries, which state, province or region.

Inclusion Inter-Americana is a federation of parents and friends of persons with an intellectual disability throughout the Americas. IIA is an assembly of the voices of persons with intellectual disabilities and their families promoting a vision of inclusive communities: “To ensure social well-being for all people, societies have to be based on justice, equality, equity, inclusion, and interdependence, and recognize and accept diversity. Societies must also consider their members, above all, as persons, and assure their dignity, rights, self-determination, full access to social resources and the opportunity to contribute to community life.”
(Declaration of Managua, 1993)

IIA has national members in 18 countries. Some of the active members are the national parent federations in: Argentina, Bolivia, Brazil, Canada, Chile, Colombia, Cuba, Ecuador, El Salvador, Guatemala, Honduras, Jamaica, México, Panama, Peru, Nicaragua, Uruguay and CAMRODD (Caribbean Association). From 1994 to 2004 IIA maintained offices in Managua, Nicaragua and delivered programme activities throughout the region with support from international funders. Since that funding has been cut the organization maintains links with family-based organizations in all other countries of the Americas and holds regional events.

The regional forum held in Colombia along with surveys and focus groups held throughout the region helped to identify key issues. While countries like the United States and Canada have made progress in closing institutions there remains significant work to do in improving the inclusiveness of mainstream systems of education, health care and employment. In Latin America the lives of people with intellectual disabilities continue to be shaped by poverty and exclusion.
KEY ISSUES

- **Lack of Support to Families**
  The major similarity, between high income countries and low-income countries, between middle income countries and the rest, is that families assume, often for a lifetime, significant responsibilities for care of their family member, across the lifespan, not only when they are children. The extent to which they are adequately supported or not supported to do so, however, varies greatly. In many countries there are various support programs, some even providing cash, and in the US, Canada and in some countries in Latino America, healthcare but the programs do not make up for the direct cost of caring for a family member, as well as the opportunity costs of caring for a family member. Families report one member not working or working less than full time to provide care. In every country people with disability are disproportionately present in poverty reports.

- **Education**
  Schooling is universal in some countries in the region, while others report limited opportunities for schooling, or schooling that is only available when the family can pay school fees. In far too many instances, the schooling that is available is unnecessarily segregated, even when national laws call for inclusion.

- **Institutions and residential options in the community**
  Both children and adults remain in institutions throughout the region, with some States/Provinces in the US and Canada now providing only community supports as government run institutions have been successfully closed and in low income countries they are part of the growing numbers of abandoned children with the slim possibilities of a family through adoption.

- **Supports to live in the community**
  In some places, people with intellectual disability and families experience person/family centered supports, helping people enjoy a decent life supported in their community. But far too many people experience little to no public support for a lifetime of care, and families are stressed, exhausted and feel little hope for a better future. Their lives experience depends highly on what families can provide.
Asia Pacific is the largest and most disparate of Inclusion International’s regional groupings. Representing two-thirds of the world population with vast differences between countries in terms of size, population, wealth, language, religion and culture. While Inclusion International members in the region do not have a regional structure, for practical purposes based on the vast size of the region, the work of Asia-Pacific region has been divided into 4 sub-regions, namely the Pacific, South Asia, Southeast Asia and Northeast Asia.

The regional forum held in Nepal, the surveys and stories provided by member groups helped draw a picture of what the right to live and be included in the community means in different economic, social and political contexts. In countries like Australia and New Zealand while enormous progress has been made in closing institutions and building services in the community, there remains significant challenges in improving the inclusiveness of mainstream systems of education, health care and employment. In countries with emerging economic power but large population bases such as India and China there is the double challenge of building appropriate supports in the community which can meet the overwhelming needs while restructuring traditional systems which focused on protectionism. For Japan and South Korea, societal attitudes towards disability present significant challenges for inclusion in the community. In the Pacific Islands the cultural of indigenous populations can provide a good basis for building inclusive communities but with little or no social infrastructure to provide supports, the reality for most is isolation in the community and even within the family.

Throughout the region there has been a recent emergence of self-advocacy groups. In 2012 a workshop for self-advocates organized by APCD and JICA attended by Unity, the first self-advocacy group in Myanmar; Daoru Ang from Thailand and Rose from Cambodia participants identified common challenges for self-advocacy groups: having a small number of members in their groups, limited financial capacity, limited technical support, limited capacity of supporters, limited participation and support from family members, lack of coordination, lack of capacity to develop projects, and limited ownership.
KEY ISSUES

- **People with intellectual disabilities continue to struggle to have their voice heard**

  The voices of people living in institutions, their families and those with higher needs and communication challenges were absent from the stories we heard, still those who spoke mentioned the challenges they faced with their support people helping their voices to be heard, they said they needed their supports to be: very hard working and understand us, very resourceful, open minded, respectful…but above all know that they should listen, represent their voices and respect their choice, “they cannot speak for us” be with me, understand me and have time to listen to me.

- **Limited residential options**

  Residential schools for people with disability (especially deaf and blind students) as well as for others without a disability are common in the region especial as a means to get education for people that live in rural areas. In high income countries residential options such as group homes, residential homes and institutions for more than a 100 are common.

- **Limited access to inclusive education**

  Countries such as Australia, Japan and New Zealand report universal education coverage including people with disability although in Japan and Australia in the majority of cases it is in segregated schools. In India, Myanmar, Nepal, Vietnam report not being able to access education for people with disability of any kind.

- **Limited Support to Families**

  Throughout the region the role of families and the lack of support which they receive was clearly identified as an issue. In New Zealand, a recent case was brought forward by families through the courts seeking financial support for caregiving responsibilities. In Vietnam, Nepal and Myanmar we heard that people with intellectual disabilities of all ages live with family members (mostly parents) until they die. Siblings are also playing an important role in people’s lives. In some of the focus groups there was participation by brothers and sisters and there were a number of times when living with a sibling was mentioned as a common residential alternative. Living in the community, for the majority of people with intellectual disability, still depends on the family’s beliefs, their resources and their capacity to innovate and advocate.

- **Employment and community involvement**

  Availability of vocational training for people with disability falls short of the needs reported in every country. For some the only form of daily activity is in sheltered workshops, special schools, volunteer options or helping at home. In the focus groups many report having activities in the community with others who in many cases have a disability because they live in the same house, attend the same school or sheltered workshop, the majority spend their time in activities by themselves (watching TV, in the computer, walking a dog etc.) or with family members. Participation in the community continues to be evasive for most. Supports to encourage participation and citizenship are in short supply. As for jobs all the countries report huge gaps, the most common job where they exist is in sheltered workshops.
Stretching from Iceland, Ireland and Portugal in the West to Russia, Armenia, and Turkey in the East, Europe is the most compact of the regions in Inclusion International and also the economically most developed. More than 500 million people live in the 27 countries of the European Union and another 230 million in 22 other countries. Studies suggest that perhaps 1% of these in high income countries and 2% in low-to-middle income countries are people with intellectual disabilities. Despite this relative compactness and affluence, there is considerable diversity across these countries: for example, in economic development, recent history, state investment in welfare and the strength of civil society.

The family associations which make up Inclusion International originated in Europe and its regional member, Inclusion Europe, now has 38 national members, the oldest being Mencap in the United Kingdom (founded in 1946). Since the 1980s, there has also been significant growth in the self-advocacy movement, now with a European Platform, although in many places self-advocacy remains fragile or underdeveloped.

Europe is unique in the strength of its political institutions at the continental level. In recent years both European political entities, the European Union and the Council of Europe have given new impetus to protecting and promoting the human rights of disabled persons with the entry into force of the UN CRPD. Despite this basis for progress significant challenges exist in achieving the right to live and be included in the community. The regional forum that took place in Peniche, Portugal along with surveys, stories and group discussions at the Europe in Action conference in Brussels helped to identify common issues across the region.
KEY ISSUES

• **Institutional approaches in the community**
  In many places, the alternative provision relies on small group homes (e.g. with six or sometimes rather more people) where both through group living and the continuation of institutional staff practices, residents have limited rights, limited autonomy and often limited engagement with other ordinary members of their communities.

• **Some examples of personalized supports**
  Recent reforms have encouraged more people to become tenants in their own small homes, sometimes sharing with one or two other people of their own choosing, and put people ‘in control’ of their own lives through individual budgets and personally-tailored support plans. But typically these more ‘personalised’ services are only available to a minority.

• **Isolation in the Community**
  For many, presence in the community has not equated to full participation, for example in education, employment and leisure opportunities – indeed large, segregated day services (e.g. in the form of sheltered workshops in Germany) are still the norm in many places. Put most simply, many people with intellectual disabilities still report lifetimes of loneliness and discrimination. Moreover the emphasis in rich countries on professional services seems sometimes to be at the expense of fostering the opportunities for life-sharing with other citizens which are essential to really being part of the community.

• **Uneven availability of quality supports**
  Despite what has been demonstrated in the best examples, even within countries there remain wide variations in what is available to people in different places and similar variations in the quality of support.
Middle East and North Africa (MENA) refers collectively to the Asian countries of Bahrain, Iran, Iraq, Palestine (the Gaza Strip and West Bank), Jordan, Kuwait, Lebanon, Oman, Qatar, Saudi Arabia, Syria, the United Arab Emirates, Yemen, and the North African countries of Algeria, Egypt, Libya, Morocco, and Tunisia. The region’s population is estimated to be 355 million, with 85 percent living in middle-income countries, 8 percent in high-income countries and 7 percent in low-income countries. Understanding the dynamics of different sub-regional groups and the ongoing political conflicts and uprisings that have been going on for more than 60 years is important as context for the right to live and be included in the community.

While there is a registry of persons’ with disabilities in some countries, mainly it is for persons with physical disabilities and does not identify the number of people with intellectual disabilities. But if the statistics in the rest of the world are reflected in the region then, at least 4 million people with intellectual disability live in the region and this does not take into account the number of people that developed a disability during the latest uprisings in; Tunisia, Egypt, Iraq, Syria, Lebanon, The Gaza Strip and Bahrain.

There are several factors that are unique to the region, which makes it a challenge to implement and promote social issues and human rights, particularly the rights of people with disabilities. First, there is a misperception that a common language (Arabic), except for Iran, reflects common social structures or policy. Second, cultural diversity, for example more than 50 percent of the population in the Gulf Region is of non-native and more than 30 percent of those is non-Arabic speaking migrant workers.

There are six official member associations (there are several family organizations that are affiliate members) which represent Inclusion International in MENA. Inclusion MENA as an organization was only established four years ago. The regional forum which took place in Amman, Jordan along with survey results and consultations with member organizations helped to identify common issues across the countries in the region.
KEY ISSUES

- **Access to Health and Education**
  The Health and Education laws which impact all people living in these countries are very different from country to country but access to public health and education is often made available only to national citizens. This means large parts of the population including people with intellectual disabilities do not have access to publicly funded education or health care. While some efforts are being made to provide access to education in some countries, the major problem is that the ministry of education shares the responsibility of educating and serving people with intellectual disability with ministries of social affairs.

- **Faith and cultural restrictions**
  MENA region is unique when it comes to culture and religious values. There are policies that govern not only social service but education and health care. Often only the local population (not the expatriate community) has free access to public health, public education and support of the social services available. In some countries the services are segregated by religion, so if an individual with intellectual disability is a Muslim Sunni, he/she is not allowed to attend a program founded and run by a Christian or Muslim Shi'a organization.

- **The role of families**
  Due to the lack of services and public awareness families are the only support for their family member not only as a child but into adulthood. Families fear what their family member’s fate would be once they are no longer able to care for them.

Without any support from government, families started organizing services, in some cases a new institution, or a small and limited project.

- **Self- Advocacy**
  One positive aspect that has been raised in the past few years is the significant growth in the self-advocacy movement, now with a one strong organization in the region based in Lebanon, there has been outreach to others in the region to help develop and strengthen self-advocacy groups that are still underdeveloped.
Globally the common message from people with intellectual disabilities and their families is that in order to achieve the right to live and be included in the community we need **Choice** about where and with whom we live, **Support** to individuals and families and **Inclusion** in our communities.

## Using the Results of Inclusion International’s Research on the Right to Live and Be Included in the Community

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<th>Research Finding</th>
<th>Strategies</th>
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<td><strong>1</strong> People with intellectual disabilities don’t have the chance to decide where and with whom they live.</td>
<td><strong>Encourage and support children and adults who have an intellectual disability to speak for themselves and to express their hopes and dreams.</strong></td>
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| **2** People with intellectual disabilities have few choices about where they can live. | **Focus on planning with individuals so they can create futures around their interests and desires.**  
**Take advantage of services, programs, jobs that are available in the community for all and provide support options there.** |
| **3** Institutions deprive people of their rights. | **Don’t build new large centres to house people with intellectual disabilities.**  
**Don’t invest in refurbishing existing large centres.**  
**Start planning for the people now living in large centres so that they can become included in their communities.** |
| **4** Most individuals with intellectual disabilities live at home with their families and receive little or no support. | **Remove all incentives that give more support to children or adults if they move away from their families.** |
| **5** Families receive little or no support to help care for a person with an intellectual disability. | **Provide supports to families AND to individuals with disabilities. Support organizations of families as well as self-advocacy.** |
| **6** Even when people with intellectual disabilities live in the community they are often isolated. | **Conduct public awareness about people with intellectual disabilities to reduce stigma and prejudice.** |
| **7** Community systems – education, health, transportation, political processes, cultural and religious groups, employment, etc.—exclude people with intellectual disabilities. | **Invest in making community programs and services accessible and inclusive rather than in programs exclusively for people with disabilities.** |