

Intellectual Disability

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What is intellectual disability (ID)

Intellectual disability is characterised by significant limitations in both intellectual functioning and adaptive behavior which covers many practical skills. This disability originates before the age of 18. To be classified as having ID a person must have both a low level of IQ (under a score of 70) and a deficit in two or more adaptive behaviours.

An intelligent quotient (IQ) test measures the capacity to learn, reason, problem solve and so on. Adaptive behaviour on the other hand is a collection of skills; conceptual, social and practical that are learned and used by people in their everyday lives. These are things such as;

Social skills – being able to interact with and showing awareness of others, wariness (ie displaying basic road sense), gullibility, showing responsibility, etc

Conceptual and learning skills – the ability to read and write, to understand how to use money, to tell the time etc

Practical skills – to be able to brush ones teeth, use a toilet, make a phone call, have basic work skills, be able to use public transport etc.

Problem solving skills.

Worldwide there are many tests that can be applied in order to determine the above. (Goodenough, Merrill Palmer, Vinelands social maturity scale are but three examples).

Children with ID develop much more slowly than other children. They typically take longer to sit and to crawl, take longer to develop language skills and to learn how to dress or eat. Those with an IQ of 50 to 69 are typed as having mild intellectual disability. In the early years the disability may not be obvious, though the child may be labeled 'slow'. However once the educational process starts then ID tends to become clearer. Those with mild ID are perfectly capable of learning how to read and write and of obtaining a reading age of approximately 9 to 12 years of age.¹

Moderate ID is characterised with an IQ of 35-49 and is much more obvious. In particular speech development is inhibited. Within a school environment they will require assistance and independent living is not possible though they will be able to do some things without support.

Persons with severe ID will require support in all activities throughout their life.

Historically the term used was mental retardation but this has fallen into disuse, at least in the West, though a survey by the World Health Organisation (WHO) in 2007 found that worldwide the most used term was still mental retardation. Within the educational sphere the term intellectually subnormal was also once used.

“Developmental Disabilities” is an umbrella term that is often used to include intellectual disability but also includes other disabilities that are apparent during childhood. Developmental disabilities are severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before the age of 22 and are likely to be lifelong in duration. Some developmental disabilities are largely physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that includes a physical and intellectual disability, for example

Down Syndrome or fetal Alcohol syndrome (FAS).

Intellectual disability encompasses the “cognitive” part of this definition, that is, a disability that is broadly related to thought processes. Because intellectual and other developmental disabilities often co-occur, intellectual disability professionals often work with people who have both types of disabilities.

What Causes ID

Intellectual impairment is caused by underdevelopment of, or damage to, the brain during different stages of the person’s development. These stages are referred to as:

1. Pre-natal;
2. Perinatal and postnatal
3. Childhood
4. Idiopathic

1. **Pre-natal impairment can occur**

- at conception because of chromosomal abnormalities (for example Down Syndrome);
- during pregnancy (eg infectious diseases or exposure to chemicals);
- as a result of use of drugs and/or alcohol ;
- due to poor nutrition ;
- and from failed abortion.

2. **Peri and postnatal**

- difficulties arising from premature birth;
- brain damage caused during labour;
- inadequate oxygen;
- trauma caused by instruments used during birth.

3. **Childhood incidents and conditions such as**

- head injuries;
- disease and illness (eg meningitis or very high fevers);
- poisoning;
- poor nutrition.

4. **Idiopathic**

- This is when the cause is unknown and occurs in 25% of cases

About half of all cases of ID are due to either Down Syndrome, Fetal Alcohol Syndrome or Velocariofacial Syndrome. The rest can be caused by a multiplicity of disorders; genetics, toxicity during pregnancy, lack of oxygen at birth, iodine deficiency, malnutrition and problems during pregnancy such as the baby not developing properly in the womb. Diseases such as whooping cough, meningitis and measles can also be a causative factor. Recent research is also leaning towards environmental factors such as pesticide use being a cause.²

Some of these such as iodine deficiency are preventable. Iodine deficiency affects the thyroid gland is easily preventable for a small cost and is the most common form of preventable incidence of ID. Lack of iodine reduces a persons IQ by an average of 15%. Cretinism is a condition associated with iodine deficiency and goiter, commonly characterised by mental deficiency, deaf-mutism, squint, disorders of stance and gait, stunted growth and hypothyroidism.

Most countries have strategies already in place to try and reduce the incidence of ID. These range from adding iodination salts and folic acid to bread, the running of alcohol awareness programmes; particularly regarding the dangers of using alcohol during pregnancy, pregnancy screening and toxicity tests to detect lead, hypothyroidism etc. The majority of these interventions take place in upper and middle income countries and those with well developed medical systems in place.

Both the incidence of ID and the effects of ID can be reduced or mitigated somewhat depending on the cause of the condition. Down Syndrome is due to extra genetic material in chromosome 21. It is well known that the risk of giving birth to a baby with Down Syndrome increases with the age of the mother (although many young mothers also give birth to children with the condition). As a result many countries offer prescreening for the condition in the early stages of pregnancy and allow the mother the option of termination. The estimated incidence of Down Syndrome is between 1 in 1,000 to 1 in 1,100 live births worldwide. Each year approximately 3,000 to 5,000 children are born with this chromosome disorder.³ Children with the condition respond well to early intervention; as with all children the earlier that learning begins the better and gives the child a better foundation for life.

Fetal Alcohol Syndrome (FAS) is caused by heavy drinking during pregnancy. Children with this condition are born with characteristic physical and mental defects, including short stature, and small head and brain caused by damage to the central nervous system. They have distinctive facial characteristics caused by damage to the brain caused by consumption

of alcohol. There is no cure. Often such children are diagnosed with behavioural problems, but whilst the problems are seen as behavioural the behaviors exhibited are actually due to the damage to the central nervous system. Treatment is focused on mental health and medical services to manage the resulting lifelong disabilities that include learning difficulties, behavioural problems, language, delayed social or motor skills, impaired memory and attention deficits.⁴ The Western Cape of South Africa has the highest reported incidence of this in the world. Most countries have awareness programmes for expectant mothers to advise them of the damage that can be caused to the foetus by alcohol.

Velocardiofacial syndrome (VCFS) is a genetic condition that is sometimes hereditary. VCFS is characterised by a large combination of medical problems that vary from child to child. These medical problems include: cleft palate, or an opening in the roof of the mouth, and other differences in the palate; heart defects; problems fighting infection; low calcium levels; differences in the way the kidneys are formed or work; a characteristic facial appearance; learning problems; and speech and feeding problems. Most children with this condition are missing part of a chromosome. They suffer from a huge variety of conditions. Over 90% of children with VCFS have learning difficulties.⁵

In terms of prevention the WHO noted that 'More than half the countries that participated in the survey, [WHO Atlas of Intellectual Disability] across all country-income categories and WHO regions, had programmes designed to prevent intellectual disabilities. Implementation tended to be proportional to income. These strategies targeted all categories of risk factors, from environmental factors (e.g. iodine supplementation) to behavioural factors (e.g. maternal alcohol consumption)'.⁶

ID is distinguished from mental illness such as schizophrenia or depression.

Brief history of the approach to intellectual disability

In 1799, Jean-Marc Itard, a medical doctor developed the first systematic and documented course of intervention for ID. This was subsequently developed further by doctors who worked on a programme to educate the "feble-minded" at Salpêtrière Hospital in Paris. Some of the

basics of this program, such as individualised learning and behavior management, are still practiced today.

The first recorded residential facility for people with ID was established by Johann Guggenbuhl in 1841 in Switzerland. The facility, billed as a prototype for institutional care, was called "Abendberg care"⁷. Gradually more organised facilities became available. Throughout Europe and North America People with Intellectual Disabilities (PWID) were housed in large institutions, usually part of large psychiatric hospitals.

The first public training facility for people with ID (PWID) was opened in Boston, U.S.A. in 1848. However people were disappointed in that, however much training residents received, they were unable to become 'normal'. The more recognised term for PWID at this time was feebleminded. Fear drove people to blame PWID for many of the social ills and crime of the time. This ran the gamut from being the cause of T.B., through to prostitution, poverty, bad housing, crime and so on. Part of the reasons for this was due to the changes within society itself. The rural way of life was giving way to a more industrialised age and with that came a need for people with better education and skills. PWID who had hitherto been more hidden within their communities then stood out as they were unable to develop skills to work alongside others and they became marginalised as a result.

Due to the host of social ills for which PWID were blamed the general consensus became that the numbers of people with ID should be reduced through sterilisation. The eugenics movement, as it was called, began in 1869 with the publication of a book called Hereditary Genius by Sir Francis Galton. Followers of eugenics argued that reproduction needed to be halted in order to reduce the degeneration of mankind. Many likeminded publications followed.

In response to the eugenics movement, several American states enacted sterilisation laws,⁸. Indiana passed the U.S.A's first sterilisation law in 1907 for (among others) "imbeciles" who had been diagnosed as "unimproveable"⁹. By 1944, 30 American states had such legislation. It is

estimated that between 1907 and 1944, around 42,000 people were sterilised. Another 22,000 people were sterilised in order to prevent ID and other similar conditions between 1943 and 1963. Germany went further and forcibly sterilised people who were classified as feeble minded. Other countries placed PWID in institutions to keep them away from the rest of the gene pool. Meanwhile various psychological tests had begun to be developed and these, such as the Vineland Social Maturity Scale and the Wechsler Intelligence Test for Children, were used to help identify those feeble minded individuals who should be sterilised.

By the 1960's further research showed that ID applied across the social spectrum, the upper classes were just as likely to produce a child with ID as a working class person. Also it was shown that environmental factors could be just as important in the establishment of ID. Most sterilisation programmes ended in the 1960's. At this time various governmental programmes sought to address some of the social problems that lead to children being born with ID. In 1994 the United Nations passed the Standard Rules on Equalization of Opportunities for Persons with Disabilities which lead to the provision of international standards for programmes, policies and laws for those with disabilities.

Around this time the entire approach to PWID changed. Instead of institutionalisation it became the norm to move people to live in communities. The trend began in Scandanvia and gradually spread throughout the world. Experience showed that PWID flourished when placed in so called normal environments but that also had support systems to help them.¹⁰ The process of deinstitutionalisation then began in earnest although there are regional variations. Whilst Sweden has no-one with ID living in institutions today both Australia and Ireland continue to house PWID in this way. Other countries have a mix although Argentina continues to keep PWID in a psychiatric setting.¹¹

Within the West the perception of and the approach to disability has changed hugely over the last 30 years. People are far more aware of disability issues and disability has become mainstreamed. Historically the advertising world kept strictly away from disabilities, preferring to glamourise products and consumers rather than showing life as it is. There were a few adverts featuring wheelchair users in the 1980's (Levi's produced the first one in 1984) but it was not until 1993 that a child with Down Syndrome was seen in an advert on mainstream television.¹²

ID in the African context

Most studies relating to ID have been carried out in the West. Although some studies have been carried out within Africa most of them are very old and generally they relate to disability in the general sense rather than ID. Throughout Africa persons with disabilities are often seen as being linked to super natural forces ; 'these misconceptions stem directly from a lack of proper understanding of disabilities and how they affect functioning'.¹³ The effect of this is that persons with ID in Africa are probably the most marginalised of all groups and Western approaches to the subject do not fit well within the African context. Socially excluded, poor and with no voice there is little research undertaken into their circumstances that will help to initiate change. There is also often a lack of awareness of the difference between mental illness and intellectual disability.

According to Cape Mental Health (the biggest NGO in South Africa dealing with intellectual disability) 2.5% of South Africans have an intellectual disability. This can range from a very mild to a very profound disability.

Within Africa there are few studies on ID and any studies on disability usually look at physical and other disabilities together. There are 130 million people with intellectual disabilities around the world, according to Inclusion International (a body that comprises family based organisations that advocate for the human rights of PWID worldwide). In Africa, some 10 to 15 million people – from a population of over 800 million – have an intellectual disability. Many of these live in rural areas far away from access to medical care and support. Across Africa higher proportions of children acquire an ID as a result of poor antenatal care of mothers in pregnancy and through illnesses such as cerebral malaria.¹⁴ Malnutrition is rife across Africa and this can cause or exacerbate ID. Traditional healers are common in rural areas throughout Africa yet they have no training in ID. Many children still live in rural areas where there are no facilities at all, and those that there are not tailored towards people with disabilities. A lack of readily available medical care and poverty only exacerbates the situation. One the positive side children in rural communities are often taught basic tasks and are involved in the carrying out of household chores from early on and are encouraged to be useful as much as possible.

Often those with disabilities are associated with witchcraft and evil spirits though some are seen as pacifiers of evil spirits rather than being harmful. Others are seen as protected by supernatural forces and thus bringers of good luck¹⁵. Treatment of persons with disabilities runs the gamut from abandoning them to die, to tying them up so that they don't wander around to treating them with great reverence. In some African communities, such as Zimbabwe and Kenya, the disability of a child is seen to reflect on the whole family in a negative way. Across Africa in general persons with disabilities are seen as hopeless and helpless. Perceptions are only slowly starting to change. As with all things the more educated the person the wider the view, younger persons also tend to be less superstitious and more accepting of PWID.

In Tanzania if a mother has a disabled child then the bad karma associated with this is seen to accrue to both the immediate family concerned and also to the clan to which that person belongs. It is considered taboo to marry women who already have a child with any sort of disability. As a result such children are often not talked about in the hope that no-one will notice the disability. The lack of contact with PWID with the general population builds up more stigma and discrimination. Because of this there is very little information available either about physical or intellectual disabilities and almost no attempts at advocacy. Attempts to collate data have often failed as people refuse to acknowledge any disability in their family. In recent years some inroads into the problem have been made by NGO's but governments within Africa have been slow to develop a response.

In Nigeria the government is looking at facilities for people with disabilities but not for PWID per se whilst the Gambia is actively working to prevent disabilities through the provision of vaccines and health advice during pregnancy. Whilst no data is actually kept there is some provision for people with disabilities at school and at sheltered work centres.¹⁶

Sexual abuse of both adults and children with ID and physical disabilities is rife, both within communities and within institutions that are designed to care for them. There is little discussion around ID and sexuality, many people find it hard to get to grips with disabled people living active sex lives and prefer to pretend that it doesn't happen. As a result there is little sexual and

reproductive health education taking place. Whilst many African countries now have HIV/AIDS programmes up and running almost none of these are aimed at PWID although in South Africa The Western Cape Forum for ID produces several books and a DVD on sexuality and HIV/AIDS.

The African approach of hiding children with ID out of sight has only recently begun to change. Most often children are thought to have been disabled as a result of divine retribution or through witchcraft. These beliefs are particularly strong in rural communities and in older generations. However this is changing with the televising of programmes such as the Paralympics and wheelchair basketball which are widely acknowledged as having an influence on peoples perceptions. The Special Olympics, which is for PWID only, is not as yet televised but as an event is starting to gain media exposure, this is particularly due to the efforts of the President of Malawi, Mrs Joyce Banda, who is an enthusiastic supporter and Chairperson of the organisation. The Special Olympics has 4.2 million athletes in 170 countries throughout the world. Recent events, which have partnered abled with disabled athletes, have increased media exposure for the event which is likely to lead to greater participation and greater awareness.

Unlike Europe, Africa never built large institutions to house people of various disabilities. PWID stayed with their families who did the best that they could. The exception to this was South Africa which built several large institutions. Within South Africa not only were people separated by their disability but apartheid meant that institutions also ran along colour lines. Deinstitutionalisation started much later than elsewhere in the world; it was not until the 1990's that the big institutions began to decant their populations into the community. Hospital care was to be reserved more for the treatment of psychiatric disorders rather than housing PWID.¹⁷ Most PWID are likely to suffer from other health conditions and hospitalisation at some stage in their life may be necessary. In addition to physical health problems between 8% to 15% of PWID have a psychiatric illness which requires medical treatment¹⁸ which may include intermittent hospitalisation.

Across Africa psychotropic drugs are widely used and misused.¹⁹ These medications are often prescribed for symptom control rather than for psychiatric disorders. In many parts of East Africa

barbiturates are the only available sedatives and their use, particularly in school going children, impairs their already reduced learning capacity. Outside of South Africa it is common for older types of drugs that are no longer used in the West to be used for all types of conditions, often inappropriately.

Throughout Africa knowledge, training, medication and understanding of ID is substantially behind that of the West. Many people with ID present with multiple problems and this adds to the challenge for health professionals. South Africa is the only country on the African continent to offer a post graduate course in mental health.

Slowly, things are changing. In 2008 many African countries ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD).²⁰ The CRPD requires governments to provide training and employment opportunities for disabled jobseekers alongside non-disabled workers. People with intellectual disabilities are entitled to gain from the provisions of the CRPD, as well as people with other types of disabilities. However within Africa PWID and disabilities in general remain more marginalised than most. Access to education and thus income generating activities is far more limited for PWID. The lack of advocacy that could be a pioneer for change is also lacking. Within Africa itself there are large differences in the way that PWID are treated. International policy direction is to expand support for children with ID in mainstream settings as a means to reaching larger numbers in financially sustainable and socially just manner.²¹

In 2010 the International Labour Organisation held a Conference on 'People with intellectual disabilities: 'Opening pathways to training and employment in the African region'. This concluded with the Lusaka Declaration on People with Intellectual Disabilities: Achieving Full Participation in Training and Employment. What was perhaps unique about this gathering was the fact that, for the first time, African nations started to embrace and acknowledge the problem of ID. The final declaration provided a set of recommendations and actions to be undertaken by governments, employers and their organisations, trade unions, non-governmental organisations and parents' groups in the disability field. One of the main outcomes was the agreement that the aims of the CRPD are often unobtainable as PWID are often excluded from school and vocational training and thus lack the skills to gain employment. Each country was urged to

develop an action plan to develop training and employment opportunities for PWID. Employment could be encouraged through incentives, advocacy and networking and the piloting of projects to develop life long learning.²²

In 2013 a seminar took place of the East African Network on Disability Mainstreaming. Delegates from Rwanda, Kenya, South Sudan, Ethiopia, Uganda and Tanzania developed a framework with minimum standards for disability mainstreaming. This specifically included PWID and put together a three year strategic plan. This followed on from the 2012 report "Global Report on Article 19, Living and Being Included in the Community, Inclusive Communities = Stronger Communities"²³ which investigated what living in the community meant to PWID and their families. They concluded "Despite the promise of the Convention and Article 19 the reality for the vast majority of people with intellectual disabilities is that they are almost always denied the right to make decisions about where and with whom they want to live. They have little or no access to services and supports (other than those provided by their families) and they are excluded from participating and contributing in their communities because community supports are not welcoming or accommodating and/or because they lack the supports necessary to use these services (e.g. accessible transportation, personal supports, financial capacity).'

President Joyce Banda of the Republic of Malawi, a vocal champion of the rights and protections of those with intellectual disabilities hosted the first ever African Leaders Forum on Intellectual Disability in partnership with the Special Olympics on February 2014, in Lilongwe, Malawi. "Malawi has approximately 400,000 people with intellectual disabilities. In many cultures throughout Africa, stereotypes, entrenched stigma and misunderstandings about intellectual disabilities exist and the effects are devastating, with many people with disabilities experiencing severe social isolation and suffering from neglect, abuse and violence," said President Banda. "It is our moral obligation to turn the tide from intolerance and inaction to foster understanding and make real commitments to influence change. I look forward to engaging my nation, Malawi, and indeed the entire continent, to join me in developing a results-

driven, inclusive approach to improving the plight of our children and adults with intellectual disabilities".

At the forum The African Leadership Alliance on Intellectual Disability was established. President Banda said, "There is something about the plight that faces individuals with disabilities, including those with intellectual disabilities, that is compounded by an entrenched stigma that has endured, unjustly, for centuries and centuries. Before we can tackle the environment barriers that block our children from school, before we can address the lack of training of doctors that block our children from hospital, before we can strengthen the social policies that streamline family services, this stigma must become yesterday's news." ²⁴

There was broad agreement at the Forum on four priorities for advocacy and action: the collection of data regarding PWID; goals to be set concerning health, education, and inclusion; resource allocation to include PWID; and securing broad participation in these aims, through the African Leadership Alliance on Intellectual Disabilities.

Education

Within education, in particularly in the West, the approach to educating children with disabilities has changed dramatically over the last 30 years. Whereas once children were sidelined today most are educated within the national educational system. However this varies widely from country to country.

Although the UN Salamanca Declaration (see below) was a starting point for developing inclusive education, by 2006 so little progress had been made that EASPD (European Association of Service Providers for Persons with Disabilities) noted in the Brussels Declaration that many children were still unable to claim their right to inclusive education. The report looked at disability in general terms and did not look specifically at PWID. The report noted that many countries were still looking at teacher education in terms of disability being a special specific need in itself rather than just being a subset of education. EASPD see special schools as they

exist today moving to becoming more of a resource unit for education in the mainstream. So, for instance, assistive technology to enable learning would be available in all schools not specialist schools. The EASPD report of 2012 noted 'it is still a major challenge to find intelligent ways of categorisation of learners that allows access to additional support in mainstream educational settings without producing segregation and stigma'.²⁵

In Africa the picture is quite different. A World Vision report in 2007 estimated that 77 million children in the world were not in education at all, of which approximately one third were disabled. It noted that in Africa less than 10% of disabled children attend school. Of these, those with intellectual disability are most likely not to attend²⁶. A study by the African Child Policy Forum²⁷ found that in Senegal only 13% of children with ID attended school. In South Africa, where education has to be paid for, many parents of children with ID just don't see the point of their child attending school at all. Without access to schooling a persons future is limited even further. For girls in particular, who are often taken out of school early, the problem is even worse. Girls are traditionally expected to burden the responsibility of family care and may well have to give up their own educational prospects should, for example, a relative with ID need support and care. Many PWID are brought up within a family setting by someone untrained, uneducated and poor which can lead to further health complications.

In most African countries specialised schools rather than inclusive education is the norm. However some African countries are striding forward; Botswana integrates special needs educational courses as part of teacher training. Lesotho also recognises inclusive education although putting policy into practice shows a number of gaps. Lesotho has limited teacher training and little in the way of teacher support and of monitoring and evaluation of effective teaching practices. Where children do attend school often there is a lack of supportive devices to help those with ID or physical disabilities so that whilst they may physically be in school they are still unable to learn.

In 2008 Chataika²⁸ et al identified a number of recommendations in order to mainstream effectively children with ID into education. These were:

- 1/ The development of inclusive education systems that acknowledge African realities and serve to combat negative stereotypes of disability;
- 2/ Family and parents involvement in education using partnerships to make the best use of limited resources;
- 3/ Governments to commit to the provision of education for disabled children in line with the Millenium Development Goals (MDGs) and the UN CRPD;
- 4/ Intersectoral collaboration especially at the level of early childhood development, leading to a smooth transition to primary education.

ID the United Nations and the World Health Organisation

1981 was the International Year of Disabled Persons and seminars, conferences and workshops were held throughout the world. This was followed in 1982 by the World Programme of Action Concerning Disabled Persons.²⁹ The intention was to remove the barriers that stopped disabled persons from taking full part in society and life and sought to develop a framework for disability action which spilt policy into the three ongoing areas of prevention, rehabilitation and equalisation of opportunities in order to allow full participation in social life and development. This was also the first shift whereby disability moved from a health to a human rights perspective.

In order to develop these themes further and to ensure that a programme of action was carried out the UN declared 1983 to 1992 to be the decade of disabled persons. This was followed by the adoption by the assembly in 1993 of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (resolution 48/96). One of the major aims was to try and develop better educational and employment opportunities for people with disabilities and to create greater awareness of disability. In 1989 the Tallinn Guidelines for Action on Human Resources Development in the Field of Disability (which only mentions intellectual disability once) were adopted. The guidelines recognised that much more needed to be done to improve the living conditions of people in developing countries but those with disabilities even more so. The guidelines also encourage equalisation with able bodied persons alongside measures for the prevention of disability, for rehabilitation and to enable full participation through education, employment and training.

These themes were considered further at the 1992 UN Conference on Environment and Development held in Rio de Janeiro and The World Conference on Human Rights, held in Vienna in 1993. The latter recognised that any discrimination, intentional or unintentional, against persons with disabilities is per se a violation of human rights.

At Cairo in 1994³⁰ The International Conference on Population and Development stressed the importance of the equalisation of opportunities for persons with disabilities. The objectives endorsed by the Conference included "ensuring realisation of rights...and participation in all aspects of social, economic, and cultural life ...to create, improve, and develop necessary conditions...to ensure equal opportunities ...and dignity while promoting self-reliance" of persons with disabilities. 189 countries signed up to commit themselves to these goals which formed part of the 8 Millennium Development Goals (MDG's). These are eight goals to be achieved by 2015 that respond to the world's main development challenges. The MDGs are drawn from the actions and targets contained in the Millennium Declaration. The eight MDGs break down into 21 quantifiable targets that are measured by 60 indicators. Nowhere is disability mentioned. Since then the disability sector has been working towards the effective inclusion and active involvement of persons with disabilities in the post 2015 development agenda.

The World Summit for Social Development, held in Copenhagen in 1995,³¹ committed nations to the goal of eradicating poverty in the world. To this end signatories would, amongst other commitments, develop and implement policies to ensure that all people have adequate economic and social protection during unemployment, ill health, maternity, child-rearing, widowhood, disability and old age.

Following on from the Fourth World Conference on Women the Beijing Declaration in 1995³² committed to "intensifying efforts to ensure equal enjoyment of all human rights and fundamental freedoms for all women and girls who face multiple barriers to their empowerment and advancement because of factors such as...disability."

After the UNESCO Standard Rules on the Equalisation of Opportunities for Persons with Disability were adopted by the General Assembly (1993) the Salamanca Conference of 1994

adopted a policy of inclusive education. This was agreed upon by 94 countries and many NGO's. One of the main arguments for inclusive education was that this reduced the stigma of disability and made people reappraise their attitudes to disability. However the World Health organisation Atlas on Intellectual Disability shows that the vast majority of countries still have special schools for PWID.

Amongst the outcomes was the standardisation of collation of statistical information for disabilities in order to develop better monitoring of progress as each country collects different information in different ways and as such it is impossible to get a clear picture in order to develop proper monitoring and evaluation techniques.

The Salamanca Conference policy enhanced the right found in the Convention on the Rights of the Child (1989) and the World Declaration of Education For All. This was compounded by the goal to achieve "education for all" by 2015. This will only be achieved 'when all nations recognise that the universal right to education extends to individuals with disabilities, and when all nations act upon their obligation to establish or reform public education systems that are accessible to, and meet the needs of, individuals with disabilities.'³³ At the time this convention was adopted it was estimated that 98% of children with disabilities in developing countries did not attend school.

The Salamanca Conference principle of inclusive education was reaffirmed in 2009. within a Manifesto on Inclusive Education that arose from reviewing the Salamanca Statement 15 years on (European Association of Service Providers for Persons with Disabilities, EASPD) (2009).

By 2006 the UN took this further in linking intra governmental agencies in working towards education for children with disabilities. Countries that signed ratified the Convention report on an annual basis regarding implementing Article 24 of the Convention which requires that "effective individualised support measures are provided in environments that maximise academic and social development, consistent with the goal of full inclusion"³⁴. Building on the convention the concept of inclusion challenges education systems to look at transition for people with

intellectual disabilities who wish to move from secondary education into further and higher education. Such a challenge can be met through a range of post school education options and training leading to subsequent employment.

The Convention on the Rights of Persons with Disabilities (CPRD) was adopted unanimously in 2006. This is a commitment by all signatories to the inclusion of the disability perspective and persons with disabilities in all aspects of society and development. However concrete goals were not established. The CPRD states that disabled people should have the right to education at all levels on the basis of equal opportunity. This also includes further education and training. The CPRD obliges its State Parties to ensure that:

- 1/ Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from education, on the basis of disability
- 2/ Persons with disabilities can access education on an equal basis with others in the communities in which they live
- 3/ Reasonable accommodation for the individual's requirements
- 4/ Persons with disabilities receive the support required to facilitate their effective education
- 5/ Individualised support measures are provided in environments that maximise academic and social development, consistent with the goal of full inclusion

By 2010 another review of the progress towards achieving the MDG's took place. This adopted another resolution (65/1) in which 'disability was included in the context of promoting full and productive employment and decent work for all; providing more equitable access to economic opportunities and social services and making special efforts to meet the nutritional needs of those living in vulnerable situations'.³⁵ it goes on to state that the MDG's cannot be achieved without the inclusion of ...persons with disabilities.

In 2007 the World Health Organisation surveyed 147 countries, covering on their approach to ID. Of these approximately half still kept PWID in institutionalised settings.³⁶ The atlas was ‘the first study to provide world information on critical issues related to intellectual disabilities, such as the terminology, use of classification systems, funding, care patterns, legislation, public awareness campaigns and training; as well as role of NGOs and international organisations and sources of information and research’³⁷

The WHO Atlas of Global Resources for People with Intellectual Disabilities noted that “Persons with intellectual disabilities are frequently the most vulnerable group and, on many occasions, are exposed to human rights violations and deprived of minimum services and dignity. These persons are also the most likely to be secluded in large institutions, unable to access basic health and educational services, and excluded from ordinary social relations. Although it is well known that intellectual disability is a neglected area, essential information about the presence or absence of resources and services for this population does not even exist in most of the countries of the world.”³⁸ Generally the report found no agreement as to the definition of ID or no reasonable tracking and statistics of PWID. The problem was worse in lower income countries. The report reviewed information from the 147 countries who reported and called for a mobilisation of resources to help PWID.

The report further noted the trend to move PWID away from asylum type institutions to living in the community. However, over half of the countries surveyed still had adults with ID living in asylums. “Asylum-type institutions for children and adolescents were less common in low income countries (33.3%) than in countries with an upper middle level of income (64.7%). The lowest rates of asylum-type institutions for adults with intellectual disabilities were seen in low-income countries (50%) and high-income countries (47.1%). Higher rates were seen in the upper middle income (68.8%) and the lower-middle income (57.1%) categories”.³⁹ Where community based living was available only 28% of African counties offered support for independent living.

In 2011 the World Health Organisation and the World Bank produced the World Report on Disability⁴⁰ which gives an overview of the status of disability in the world. This estimated that almost 20% of the estimated global total of persons living with disabilities (between 110-190 million people), encounter significant difficulties. The report stresses that few countries are able

to respond to the needs of people with disabilities. Barriers such as stigma and discrimination, lack of adequate health care and rehabilitation services; and inappropriate transport, building, IT infrastructure and communication technologies. As a result, people with disabilities experience poorer health, poorer educational standards, fewer economic opportunities and higher rates of poverty than people without disabilities.

The Consultative Meeting on the African Disability Forum took place at the UN Economic Commission for Africa in Addis Ababa in November 2012. The meeting aimed to establish the African Disability Forum, a partnership of governments, NPO's civil society organisations and academic institutions to promote the rights of persons with disabilities and to push for a disability inclusive development agenda.⁴¹ The meeting noted the challenges in Africa in promoting disability rights. It recommended strengthening of networks and in particular of mainstreaming disability in the work of the African Union and the Economic Commission for Africa. Whilst some countries had made progress often there were good policies on paper but little tangible progress made on the ground. There was a great need to work on disability issues on both regional and local levels and much capacity building remained to be done. The lack of adequate data and the wide variety of standards meant that there was no big picture to look at.

The International Disability Alliance (IDA) was founded in 1999 as an international disability network representing an estimated one billion persons with disabilities worldwide and acts as an authoritative and representative voice of persons with disabilities at the UN. It's mission is to advance the rights of people with disabilities using the UN convention on the Rights of Persons with Disabilities. On the International Day of Persons with Disabilities, 3 December 2013, they called on the United Nations, Member States, civil society organisations and other relevant stakeholders to ensure the full and effective inclusion of persons with disabilities in the post 2015 development framework. "Since the development of the MDGs, there has been significant progress at the international level in recognising and proactively addressing the exclusion faced by persons with disabilities. While this is a positive step forward, broader and deeper commitments to persons with disabilities in the new post-2015 development framework must be made". The Open Working Group (OWG) for Sustainable Development Goals (SDGs) has been mandated to prepare a set of goals for consideration by the UN at the September 2013 – September 2014 session that address the rights

and needs of persons with disabilities and the discrimination and exclusion faced by persons with disabilities worldwide.

"The new post 2015 sustainable development framework must be inclusive and accessible, and promote the rights of persons with disabilities," said Mr Yannis Vardakastanis, chair of the IDA. "It must ensure the full and effective participation of organisations of persons with disabilities at every stage of the process. In order to be effective, any framework or action plan in relation to sustainable development must be inclusive of persons with disabilities". In March 2014 the IDA hosted a summit in Nairobi, Kenya which specifically looked at the post 2015 development agenda and the UN CRPD in Africa. Over 14 organisations from throughout Africa attended. The Nairobi Declaration calls on member states to ensure that persons with disabilities were visible and included in all phases of development and agenda setting for the post 2015 CPRD agenda.

In September 2013 the UN held a special one day meeting on disability and development. Whilst noting that despite the fact that some progress had been made in improving the life of persons with disabilities nevertheless disability remains largely invisible in most development processes including the MDG's. In 2010 the General Assembly had proposed a high level meeting on disability from which, in 2011, it was decided to have a one day meeting in September 2013 with the theme "The way forward, a disability development agenda towards 2015 and beyond'. The declaration noted that whilst progress had been made there was still a long way to go for the estimated 1 billion people of the world with disabilities, of which it is estimated that 80% live in developing countries. No breakdown is given of the estimated number of PWID. The draft calls for the strengthening of protection access to full and productive employment on an equal basis, skills development and training to enable independence, better education, data collection and analysis, accessibility to buildings amongst a slew of other recommendations.⁴² The intention is to mainstream disability in the efforts to achieve the MDG's. Despite this, disability is not included in either the goals, or the monitoring and evaluation targets and indicators with the result that there is a lack of policies and mechanisms for ensuring that the aims are met. The knock on effect is that there is a lack of resources and

facilities and services available to people with disabilities which would enable them both to contribute to and to benefit from development processes.

There is a continual lack of statistics to enable better management of processes.⁴³ Where there is data collection frequently all disabilities are lumped together, so figures for intellectual disabilities are not generally available. The lack of evidential based criteria for data collection also impedes progress. The African Network for Evidence to Action on Disability (AfriNEAD) is working to ensure that research is undertaken with multiple stakeholders in order to develop and collaborate to develop a global approach in the area of disability research in order to support the CPRD.

ID and ageing

Throughout the world people are living longer. At the beginning of the 20th century average life expectancy was 31, in developed countries it was 50. Today in most developed countries the average age is 86, but in many African countries it has reduced to approx 32 due to HIV/AIDS. Changes throughout the world, particularly as regards nutrition, have contributed to the increase in longevity. This applies across the board and includes those with ID. One particular example is that people with Down Syndrome now live the average lifespan. At the beginning of the 20th century children with this disorder would rarely live beyond the age of 10 years. Today the average life expectancy is 55 to 60 years and many live into their 70's. Historically many died of simple infections, they have a very poor immune system compared to the average child. Even in the 1960's a child with Down Syndrome would seldom live beyond childhood. Throughout the world the life expectancy of people with disabilities in general is increasing and this poses a major challenge for the everyday support and care for people with intellectual disabilities. Professionals in health and social care services have very little knowledge and experience of working with such older people. For the population at large the age of 50 is generally regarded as the start of age related conditions. For those with Down Syndrome and cerebral palsy however the age of 40 is more appropriate. Dementia is also more common amongst those with Down syndrome than other conditions.

The WHO report Healthy Ageing – Adults with Intellectual Disabilities, Women’s Health and Related issues looked at the knowledge base about ageing females with ID throughout the world and in particular the effects of promoting good health and health services amongst women with ID.⁴⁴ This noted that many women are treated with psychotropic and/or epileptic medicines which may increase the risks of age related illnesses and in particular impact on memory function. In addition older women with ID who have used anti-epileptic medicine for a long time are at higher risk than average of osteoporosis. They also receive far less preventative health care than women in general and have sedentary lifestyles. Medical professionals often have little training in dealing with PWID and the machinery and equipment used for examinations is often difficult to use for those with disabilities. Communication problems exacerbate the situation with little educational work being undertaken in most countries to encourage women with ID to have regular preventative scans and procedures and to explain just why they are needed. As they age women with ID are likely to be alone as they have often been sterilised or encouraged not to give birth thus, in the later years, there is often no extended family to help care for them.

The WHO paper Healthy Ageing – Adults with Intellectual Disabilities. Ageing and Social Policy⁴⁵ was one of a series of papers arising from the 1999 UN International Year of the Older Person. One of the main difficulties noted was the large variations around the world in terms of life expectancy and the resulting impact that would have on developing a common set of standards. Secondly the gap between developed and developing countries impacts on the development of common principles. Despite this the report affirms “that respect and dignity are the rights of all human beings and pursues four elemental guiding principles: inclusion, full citizenship, self determination and family support’. These all apply to PWID.

PWID have nearly all increased their life expectancies even though certain conditions mean that people do not live as long as others. People who have cerebral palsy, epilepsy, severe motor handicap and Down Syndrome still have reduced life expectancy compared to the general population. The drift from rural to urban living also has an impact. Whereas once upon a time people in rural communities looked after older people societal breakdown has left many with no-one to care for them.

PWID are far more likely to be affected by health problems than those without ID. Those with a more profound ID and Down Syndrome are more at risk than most of chronic conditions than

those with a milder form of ID. Preventative medicine is also more difficult as someone with ID may have great difficulty in verbalising any conditions that they may have. They may also be less likely to discuss it with others as a result of which they do not get the medication or medical attention that they require.

In developing countries primary needs such as for food and shelter come into play. Often the paucity of overall health systems in such countries are exacerbated by a lack of specialists in general and with experience in ID issues in particular. Medical training in developing countries in particular often fail to address any issues of ageing and ID. The lack of services available, particularly in developing countries, make it harder for PWID, especially those who also have a physical disability to join in daily life; for example a lack of a mobility devise can keep someone permanently indoors.

Many older adults with ID often live either with their families or in community group homes with support. The problems of age alongside already existing intellectual and physical disabilities can mean that it often becomes too difficult to continue with community placements and that a move back to institutionalised care is necessary. PWID are less readily able to accept change to their environment than others and are generally disorientated by change. Consequently such life changing moves, after perhaps years of living semi independently, can often have a catastrophic effect on the person. When people are relocated the trauma of moving can often set off a chain reaction of other health related conditions. In order for such moves to take place successfully there needs to be some psychological intervention. Facilitating such a move and communicating successfully as to why and where the move is taking place is a major challenge for PWID who often have verbal difficulties and/or are unable to express themselves as they might wish. To make such transitions successfully often involves several medical practitioners and in the developing world there is often an acute lack of such personnel.

Even in the developed world there has been a lack of research into the effects of ageing on PWID. This has a knock on effect in that there is little or no findings to support policy change. There is a paucity of research into developmental processes and the life span of PWID. One of the few in depth studies was carried out in 1993 by Selzer.⁴⁶ who developed a model based on the environmental and social history of a person alongside their experience and exposure to a variety of social conditions. Whether someone is looked after in the home, in an institution or in

a community based organisation most PWID live protected lives. They generally have fewer life experiences and limited social interaction and therefore can be hit harder than most by things such as bereavement. Separation from a parent or a move into a different environment can cause greater anxiety and- changes in behavior for a PWID than others. The lack of expert medical care in many parts of the world means that mental illness is often diagnosed in the elderly when the real problem is a change in behavior resulting from a PWID experiencing change in the world around them i.e. the problem is simply adapted. Furthermore the tests for mental illness can seldom easily be applied to PWID. In addition the effects of polypharmacy can start to show themselves to negative effect. Due to the verbalisation difficulties that many PWID have the end result can often be a hopeless misdiagnosis. A change to the home environment or the provision of a mobility or hearing device may have been what was needed. Instead a change of drug or the addition of another drug to the user was made which can have a host of other knock on effects, the side effects may be worse than the original problem. Sedative drugs in particular can have the effect of reducing the social functioning of a person within his/her community and lead to more stress and loneliness. Psychotherapy may help if the communication issues can be overcome.

There has only been limited research into the problems of ageing and ID and what little there is has been undertaken in developed countries where there is both a system and the medical personnel available to be able to input into research. Generally research has focused on treatment rather than diagnosis and prevention. The lack of research, funding for same and the lack of specialised personnel in these fields means that there is little output available that could influence government policy. Even within developed countries the medical approach to PWID can differ hugely. Outside of developed countries no-one really knows what the situation is for aged PWID. For developing nations any research that has been undertaken has lumped mental illness together with ID so that no meaningful data is available. "Consistent with the Standard Rules of the United Nations, if recognition is to be given to the value of persons with intellectual disabilities and to the provision of resources to improve their general health status so that longevity becomes a norm, nations will also have to devote resources to aiding in treatment of mental and behavioural disorders that impede or distort normal ageing. However, first nations will need to internalise beliefs that value human life and the productivity of persons with intellectual disabilities."⁴⁷

Knowledge that people with Down Syndrome are likely to develop dementia, visual and hearing problems for example, should help the development of screening for such conditions. Certain health disorders could be improved or delayed through early diagnosis. People with Fragile X syndrome are another example, as they are more likely to suffer from problems with heart conditions, musculoskeletal disorders, epilepsy and early menopause, conditions which could be avoided or lessened if they were screened for on a regular basis. The long term use of drugs is another problem which is just starting to be recognised. Apart from the long term effect of a particular drug or combination of drugs increasing ageing also tends to the prescription of further drugs which can cause a multiplicity of interactions. As ageing increases throughout the world hopefully greater research will take place in the near future into the compounding of conditions, both physical and intellectual.

¹ Daily D, Ardinger H, Holmes G, 2000, *Identification and evaluation of mental retardation*. American Family Physician 61 (4):1059–67

² Rzhetsky A, Bagley S, Wang K, Lyttle C, Cook E Jr, et al., 2014, *Environmental and State-Level Regulatory Factors Affect the Incidence of Autism and Intellectual Disability*, PLoS Computational Biology 10(3): e1003518.

³ World Health Organisation, Genomic Resource Centre, <http://www.who.int/genomics/public/geneticdiseases/en/index1.html>

⁴ *Bulletin of the World Health Organization*, 2011, 89:398–399. doi:10.2471/BLT.11.020611

⁵ National Human Genome Research Institute, 2014, *Specific genetic disorders, What is velocardiofacial syndrome*, <http://www.genome.gov>

⁶ World Health Organisation, 2007, *Intellectual Disabilities Atlas*, p71

⁷ Beirne-Smith M, Patton J, Kim S, 2006. *Mental retardation: An introduction to intellectual disabilities*, 7th edition, Pearson Merrill Prentice Hall.

⁸ Sofair AN, Kaldjian LC, 2000, *Eugenic sterilization and a qualified Nazi analogy: the United States and Germany, 1930-1945*. Annals of Internal Medicine 132(4): 312-319.

⁹ Reilly PR., 1987, *Involuntary sterilization in the United States: A surgical solution*. Quarterly Review of Biology 62:153-170.

¹⁰ Beadle-Brown J, Mansell J, Kozma A, 2007, *Deinstitutionalization in intellectual disabilities*. Current Opinion in Psychiatry 20:437-442.

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- ¹¹ Mental Disability Rights International (MDRI). 2007. *Ruined Lives: Segregation from society in Argentina's psychiatric asylums*. Washington: Mental Disability Rights International.
- ¹² Haller, B, *Disability Studies Quarterly Spring 2001*, volume 21 number 2.
- ¹³ Abosi CO. ,2006, *Education: Attaining Millennium Development Goals, Barriers and Solutions*. A paper presented at Leonard's Cheshire International Southern African Regional Conference held in Lusaka, Zambia.
- ¹⁴ Maulik P, Darmstadt G, et al *Childhood Disability in low and middle income countries*, Pediatrics 2007
- ¹⁵ Wright, BA, 1960, *Physical Disability; a psychological approach*, Harper and Row
- ¹⁶ World Health Organisation, 2007, *Intellectual Disabilities Atlas*, p69
- ¹⁷ Berrange E, Molteno CD. 1995, *Inpatient care of mental handicap*. S African Med J 1995; 85: 1380-1384.
- ¹⁸ Deb S, Hunter D. 1991, *Psychopathology of people with mental handicap and epilepsy*. II: Psychiatric illness. British Journal of Psychiatry 1991;159: 826-830.
- ¹⁹ Peter E, Molteno CD, le Grange C, Krajewski A, MacDonald S., 1997, *Psychotropic medication in hospitalised people with mental handicap*. S African Medical Journal 1997; 87: 1750-1753.
- ²⁰ United Nations, 2008, <http://www.un.org/disabilities/convention/conventionfull.shtml>
- ²¹ McKenzie J, McConkey R, Adnams C, 2013 ,*Intellectual Disability in Africa; Implications for Research and Service Development*, Disability and Rehabilitation Journal, 2013
- ²² People with Intellectual Disabilities: *Achieving Full Participation in Training and Employment Lusaka Declaration*, 2010, http://www.ilo.org/wcmsp5/groups/public/@ed_emp/@ifp_skills/documents/meetingdocument/wcms_141158.pdf
- ²³ Inclusion International, 2012, *Global Report on Article 19, Living and Being Included in the Community, Inclusive Communities = Stronger Communities*, ISBN 978-0-9917430-0-1
- ²⁴ <http://specialolympics.org/RegionsPages/content.aspx?id=30366&LangType=1033>
- ²⁵ EASPD, 2009, *Budapest Manifesto on Inclusive Learning*, Madden, P
- ²⁶ African Child Policy Forum, 2011, *The lives of children with disabilities in Africa, a glimpse into a hidden world*, Addis Ababa: The African Child Policy Forum
- ²⁷ African Child Policy Forum, 2011, *The lives of children with disabilities in Africa, a glimpse into a hidden world*, Addis Ababa: The African Child Policy Forum

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- ²⁸ Chataika T, McKenzie J, Swart E, Lyner-Cleophas M, *Access to Education in Africa, responding to the UN CRPD*, Disability Society 2012;27(3)
- ²⁹ United Nations 1982, a/37/51 *Official Record of the General Assembly 37th session supplement number 51*
- ³⁰ United Nations, 1994, *International Conference on Population and Development* <http://www.un.org/popin/icpd2.htm>
- ³¹ <http://www.un.org/documents/ga/conf166/aconf166-9.htm>
- ³² <http://www.un.org/esa/gopher-data/conf/fwcw/off/a--20.en>
- ³³ UNESCO *Dakar Framework for Action 2000*
- ³⁴ United Nation Convention on the Rights of persons with Disabilities, 2006, Article 24, para2e
- ³⁵ UN General Assembly 30 July 2012, Report of the Secretary General p4
- ³⁶ World Health Organisation, 2007, *Global resources for people with intellectual disability*, Atlas
- ³⁷ Salvador-Caruella, L, 2007 World Health Organisation, *Intellectual Disabilities Atlas*, p105
- ³⁸ World Health Organisation, 2007, *Intellectual Disabilities Atlas*, p108
- ³⁹ World Health Organisation, 2007, *Intellectual Disabilities Atlas*, p41
- ⁴⁰ http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf?ua=1
- ⁴¹ *Report of the Consultative Meeting of the African Disability Forum*, 2012, UN Convention Center at the Economic Commission for Africa Addis Ababa Ethiopia 28 29 November 2012
- ⁴² UN resolution 68/95, 2013
- ⁴³ *The way forward: a Disability Inclusive Agenda towards 2015 and beyond*, 2013, UN General Assembly
- ⁴⁴ Walsh, PN, Heller, T, Schupf, N, van Schrojenstein Lantman-de Valk, H, & Working Group, 2000, *Healthy Ageing - Adults with Intellectual Disabilities: Womens Health and Related Issues*. Geneva, Switzerland: World Health Organization
- ⁴⁵ Hogg, J, Lucchino, R, Wang, K, Janicki, M.P., & Working Group (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Ageing & Social Policy*. Geneva: Switzerland: World Health Organization
- ⁴⁶ Seltzer, G.B, 1993, *Psychological adjustment in midlife for persons with mental retardation*. In Sutton E. (ed.), *Older adults with developmental disabilities* (pp.157-184) Baltimore, USA: Paul H. Brookes Publishing Co.

⁴⁷ Thorpe, L., Davidson, P., & Janicki, MP, 2000, *Healthy Ageing - Adults with Intellectual Disabilities: Biobehavioural Issues*. Geneva, Switzerland: World Health Organization