

# Self **Advocacy** Report **2005**

Self Advocacy Report 2005

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(Chairman, National  
Commission Persons  
with Disability)

## Introduction by Mr **Jospeh M Camilleri**

**The slogan ‘Nothing About Us Without Us’ is known by many disabled people today. But when we say nothing about us without us, do we really know what we’re saying? Many people who do not have a disability think that when we say these words, we are saying that we do not want anyone to help us and that we want to cut ourselves off from everybody and not have contact with non-disabled persons.**

But this isn’t true. We know and acknowledge that we need help and support to be able to have a good quality of life. Therefore, we respect non-disabled persons. We greatly appreciate the support that we are given from many people who do not have a disability, people such as our parents, our siblings, other family members, friends, members of religious orders, as well as some professionals who work in this sector.

So, what does ‘Nothing About Us Without Us’ mean? For me, these words mean that no one can take decisions about me that will affect my life if they do not consult with

me and see what I want first. For us, these words are very important because we want to say: Ask me before you do anything!

As a disabled person, I also say: ‘Ask my opinion on everything: what food I want to eat, what clothes I want to wear. If we’re going out together give me the opportunity to choose where to go and what to do. The same goes for those who attend Day Centres. If the Centre organizes an activity, careworkers should always give the clients the chance to choose for themselves. No one should address disabled persons as if they were little children. An adult person with disability

is first and foremost an adult.

And so we, disabled persons, are saying: “LISTEN TO US!” because we want to have our say as well. We want to make our voice heard, just like everybody else. I believe that most of the time, we disabled persons know what is good for us and so our opinion is important.

Unfortunately, many disabled persons remain silent when they have the chance to speak out. This can happen because they are shy, or afraid, or maybe they are so unused to giving their opinion that they think they do not have anything worthwhile to say.

We, disabled people, need to support each other so that we start making our voice heard and have a strong voice in this country.

The National Commission Persons with Disability has always believed in the abilities of disabled people. Therefore, we have always encouraged disabled people to show more interest in, and speak about, issues that affect them directly.

This includes issues such as how Maltese society looks at us; an accessible public transport system for persons with mobility impairments; specialised educational services and sign language interpreting services for Deaf persons; teaching of Braille, computers, and mobility in schools for blind persons; better educational services, community services and day services for persons with intellectual impairment.

Together with the 'Speak Out!' course, we should mention an excellent initiative that started at the

Hal-Far Day Centre. This initiative started in 2003, the European Year of Disabled Persons, and consists in Self-Advocacy activities, that is to say how disabled persons speak for themselves. Ms Rita Formosa will be giving us more detail about this.

These two initiatives together gave rise to the setting up of a self advocacy group made entirely of people with intellectual impairment. This group is called *Flimkienaslu* (together we can make it)! I note with satisfaction that many of the members of this group are in the audience.

We hope that this group continues to grow in strength and that its members continue to make their voice heard. In fact, I have no doubt that during today's seminar you will participate actively! Today you not only have the chance to make your voice heard with the Maltese public, but also to send your message across to one of the most respected disabled people's

organisation worldwide. I am referring to *People First*, whose Director, Mr Andrew Lee, I have the honour of welcoming among us today.

Mr Lee, on behalf of all disabled people in Malta and Gozo, and especially on behalf of all of us here today, may I extend our sincerest greetings and express our appreciation and satisfaction with your visit and your participation here today. Welcome and thank you!

Now, I will start today's seminar by inviting our first speaker, the Hon Clyde Puli, Chairman of the House of Representatives Social Affairs Committee to deliver his speech.

## Message from the Hon **Clyde Puli**

**Today we met in order to give a push forward to the disabled person's slogan 'Nothing About Without Us'. By means of this slogan, disabled persons mean that decisions that affect their life cannot be taken without their direct involvement in these decisions. This is true for all disabled persons, those who have mobility, hearing or visual impairments, as well as those who have intellectual impairment**

In the case of people with intellectual disability, unfortunately, many people think that they are not capable of speaking for themselves and that they always need someone to represent them in all aspects of life.

But in fact this idea is wrong as can be seen from the large number of self advocacy groups around the world. *People First* is a good example of this kind of group, and is an organisation which has groups all over the United Kingdom. These groups have made huge progress in giving people with intellectual disability the opportunity to speak out for themselves. Apart from being able to stand up for their own rights, members

of these groups also send out the message that they have the necessary capabilities to understand their rights and defend them.

The fact that in Malta too there are self advocacy groups in which people with intellectual disability can speak out is encouraging. In this way, they can add their voice to that of persons with other disabilities who are increasingly at the forefront of the fight for their right to a better quality of life and more inclusion in society.

At the same time, it is important to remember that there are persons with disability for whom it is not so easy to speak out for themselves. This includes

children and those persons whose intellectual disability is so severe that they cannot represent themselves. In these circumstances, one understands the need for other persons, for example parents, to represent them. However, we have to be careful not to assume that a person cannot represent themselves.

On our part, we, non-disabled persons, have to be careful not to create discrimination by ignoring disabled persons who speak out, or by not giving them the necessary support for them to be able to do this.

# Keynote Speech by Mr **Andrew Lee**

Director of *People First*, UK

**Thank you for inviting me to your conference. I hope it will lay the foundations in Malta for a user led self advocacy movement run and controlled by people with learning difficulties.**

'People with learning difficulties' are the words used in the UK. In the 1960's and 1970's in the UK people used the words 'Mental Handicap'.

People hated these words because it stripped them of their identity and dignity and humiliated them each time the words were used. The word handicap comes from the expression 'cap in hand', which refers to how disabled people used to have to beg for a living. These words come from a medical way of looking at someone's life, making an assumption about someone's abilities before their life has even started. We choose to be called people with learning difficulties.

We say: label jars not people.

## **History of *People First* in the UK**

When people with learning difficulties started moving

out from long stay institutions and into the community they found they were still being treated unfairly and kept apart from the rest of society.

<sup>1</sup> Self advocacy first started up in the USA where groups of people with learning difficulties had set up *People First* groups.

Self advocacy is people with learning difficulties speaking up for themselves.

Self advocacy came to this country when a group of people from the organisation Values Into Action went to visit the *People First* groups in the USA in the early 1980's.

One of the people who went on the trip was a man with a learning difficulty named Gary Bourlet. When he came back he started up the

first *People First* group here.

Since then *People First* has grown stronger and there are groups all over the country now. We have 161 speaking up and self advocacy groups on our membership.

When the government bring out a new law or policy that will affect people with learning difficulties they come to *People First* groups to ask us what we think.

## **Aims of *People First***

*People First* supports people with learning difficulties to speak up for their rights and to fight to be included properly and fairly in society.

*People First* promotes the Social Model of disability. The Social Model is a way of looking at disability that sees it is society that

needs to change in order to include disabled people; it is not disabled people who need to change to fit in with society. If you tell a person that they are unable to do something for 20 years and they are 20 years old is it a wonder that they will believe that they cannot do it. The Social Model is all about starting from the point you can do it, maybe with the right support but you can do it.

*People First* challenges attitudes that look at disabled people as if there is something wrong with us. Society needs to learn about disabled people and how to include us. The government has spent billions of pounds over the years on services that we have hated. Now they are starting to realise that money is wisely spent if it is spent on services that we actually want.

Society benefits from including all different people including people with learning difficulties. People with learning difficulties have

outstanding gifts and talents just like everybody else.

I have lost count on how many parents who are members of carer led organisations tell me my son or daughter cannot do that but often this is because parents hopes for their new born son or daughter are shattered by medical or educational professionals right at the beginning when their children are born and they are given really low expectations of what their children will be able to do.

**People who are part of a self advocacy group:**

- Learn to speak up for themselves
- Find out what their rights are
- Share their experiences with other people with learning difficulties
- Learn to express choices
- Have the chance to take responsibility
- Are treated with respect
- Speak up to government at all levels and change laws

Self advocacy groups are places where people with

learning difficulties feel safe to talk about things that have happened to them.

Often people with learning difficulties use the word bullying to describe physical and emotional abuse because they do not understand long words like physical and emotional abuse and in the cases I have been involved with the person would never have spoken to a person without learning difficulties first.

People change through being involved with self advocacy groups. It gives confidence and teaches independence. People who are too frightened to even say their name when they join a group can go on to chair conferences of hundreds of people.

Being part of a self advocacy group has an impact on people's home lives. Members of *People First* have gone on to move out of group homes and into their own homes, have got married and have got jobs.

Most importantly, they know their own rights and

are not so easily pushed around by other people.

### ***People First* is a user led organisation**

*People First* is run by and for people with learning difficulties.

All the members, management committee, and paid workers are people with learning difficulties running the organisation with support where needed.

I am the Director with the responsibilities of any Director of an organisation and I get paid a real wage. I have support from a team of supporters with skills in different areas.

When you give people responsibilities and treat them with respect as an adult they become responsible and show how much they can do. People sometimes say that people with learning difficulties involved in self advocacy only have low support needs. That is not true.

Peoples' support needs get lower through being given choice and control and the chance to have responsibilities.

There are still carer led organisations in the UK. These are good at representing the views and needs of carers but they cannot properly represent the views and needs of people with learning difficulties.

There can be a conflict of interest between what a carer thinks is best for the person they care for and what the person themselves thinks.

Imagine if you had lived your whole life according to what your parents thought was best for you. I bet many of you would have had very different lives and not done half the things you wanted.

### **Success of the self advocacy movement**

*People First* groups have made a difference to the lives of people with learning difficulties in the UK. We are being listened to more than we ever have before.

In 2001 the Government brought out a White Paper called 'Valuing People: a strategy for services for people with learning disabilities in the 21<sup>st</sup> century'. The key

principles of this Paper are that people with learning difficulties should have choice and control, be supported to be independent and be included in society.

*People First* was involved in the advisory group that worked with the government on putting the paper together. Our Chairperson at the time, Carol Lee, was given an MBE for her contribution to the work. Carol was the first person with a learning difficulty to be given an MBE. An MBE is a Queen's honour that is given to people who have made a significant change and contribution to UK society.

Just because there are big improvements like 'Valuing People', politicians always need reminding about the issues faced by people with learning difficulties on a day to day basis, because sometimes they can forget! An example I can give is the Mental Capacity Act, a new law our government recently brought in. The idea was to make laws around what happens if a person is

thought not to be able to make decisions for themselves. Disabled organisations thought that this was a very medical model approach, looking at what people cannot do instead of what they can do. At the moment many people with learning difficulties are not given choice and control over their own lives even when they are capable of making decisions for themselves. This is because staff and carers do not have time or the resources or the skills. We were worried that the new law would make this situation worse so that staff and carers could make decisions for other people even though it was not what they wanted. We campaigned against the law. *People First* groups sent petitions and letters to the government. We were invited to speak in the House of Lords about our worries. While myself and our campaigns officer were speaking inside, other members of *People First* were protesting outside, like this.... We tied up our manager, Raymond Johnson. People pretending to be doctors, social workers and parents

stood holding the ropes that bound him. We wanted to get across the point about people with learning difficulties not being given a voice and being told what to do by other people. The disability media came down and took photos that went into several magazines.

When the law was passed the Government put in about a person's right to advocacy when a decision is being made on their behalf, which was a step forward, but over all the disability movement believe that this one bill could set back disability rights if there is not the right education given to doctors, nurses and professionals that have an input into our lives. An example I can give is a parent who took her daughter in the Accident and Emergency part of her local hospital. Her daughter had her own form of communicating. She had a heart condition and lung problems. Her daughter needed a new heart. Another patient came in also needing a

new heart. The patient was next to her daughter. The doctor looked at her daughter and looked at the other patient and her Mum could see that the doctor was weighing up whether the new heart should be given to the person without the learning difficulty or the person with the learning difficulty. I wonder how many parents would understand how the mother felt having to fight for her daughter's life in the middle of the Accident and Emergency unit of a hospital because that is exactly what this mother had to do.

On the upside, last year a report came out from the Government's Strategy Unit called 'Improving the Life Chances for Disabled People'. This report gives a target date of 2020 by which time all disabled people should have the same chances in life as anyone else. Disabled people are involved from the grassroots in the development of this policy and in making sure that this actually happens. It has the backing of our Prime Minister, Tony Blair,

which means it cannot not happen.

I would like to finish by talking about me. The first thing my parents were told by the doctors was I wouldn't walk, I wouldn't talk and I'd be a complete cabbage for the rest of my life. I wonder if the doctors saw me today if they would think of themselves as complete failures! The more important point that really needs to be addressed is do doctors and professionals generally have a right to say what a person could or could not achieve in their own life.

My parents had to fight for everything I did. They took on a local education authority that was responsible for schooling in the area that I lived in at the time. Even though they were poorly paid they had to bring in a private tutor so that I could learn to read and write so although I was going to school which was what the law said I had to do, I was being educated at home and kicked, punched and violently beaten in my

school life. This was a school, which they called a 'Special Educational Need school'. My parents successfully got me moved to a different part of the country, which meant moving house. It was while I was at this school my parents were told about a college called Derwen in Wales. It was when I was at Derwen that I learned independent living skills and was given the training and knowledge to hold down my first job based on the report that all students got when they left college. The last thing that happened was a mock interview which all leaving students had to go through to give them an idea of what it would be like to be interviewed for a proper job. The important point here is that my parents went against every single professional they came across to get me to this stage. If they had not ignored professional advice I would not have learnt to be as independent as I am today.

I started in the self advocacy movement in 1994. My first meeting was at a barbecue when I started talking to a member over a beer and a burger about why they had no access to their own benefits. The benefits were supposed to be around helping my friend who I will call Steve get control of his money. His parents actually thought it was ok for him to spend his money on beer and fags rather than household bills. This one conversation started me asking lots of questions about how controlling people I had known in my life had actually been towards me. From that I recognised how many people who were supposed to be there to support me to be independent actually did not want me to be independent at all. It made me question their ability to listen to and understand what I was saying, needing and wanting. I realise that so many people involved in my life were not there to help me get to where I wanted, they were there for their pay cheques or

for their best interests. I wanted people in my life who would empower me to do things for myself, not do things for me with the illusion that I was in control.

I went into the self advocacy movement because I would be working on issues that come from within, that I know about, that I have felt. I was actually speaking at a conference about my personal life and what had happened to me and a professional turned round to my supporter who was in the audience listening, not supporting, and said "How can he speak for people with learning difficulties, he doesn't have a learning difficulty". It was only when the support worker told him where I started from that the professional realised he was wrong and quickly exited the building! This was embarrassing for the organisers as he was the person who was supposed to close the conference!

My biggest advice to any person with a learning difficulty in Malta is if someone tells you, you can't do something because you have a learning difficulty, ignore them and do it anyway!

I am very pleased that Malta is developing self advocacy because self advocacy is the key to people with learning difficulties getting their voices heard and their rights respected. Through self advocacy you will see how much people with learning difficulties can do and all that we have to offer!

Representative  
of Flimkienaslu Group,  
Sub-Committee, Maltese  
Council of Disabled Persons

## Speech by Ms **Marthese Deguara**

**I'm Marthese Deguara, and attend the Adult Training Centre at Imtarfa. I enjoyed a lot attending the Speak Out as I met new friends. We helped each other and also we took good care of each other.**

Speak Out began by having a group of about 15 individuals and everyone attended. Attending the meetings together, we became friends.

The meetings were held at the National Commission Persons with Disability. We also went to T.V. and radio studios and we discussed what matters to us and regarding our rights.

We also discussed items that bother us such as people making fun of us, or people annoying us.

I really enjoyed the meetings and really looked forward for them. We met between 5.30 and 7.30.

A new sub-committee was established following these meetings, within the Maltese Council of Disabled People, aimed for persons with intellectual disability. 6 persons compose the group that meets once every three weeks. I enjoy a lot attending such meetings. Donatella and myself are the persons in charge of keeping the minutes of such meetings. We discuss items like what we like to do.

We also discuss what we don't like. We wrote a letter so that in our day centres people don't smoke in the units because this is against the law. After we wrote this letter, the few careworkers who used to smoke in the units, stopped doing this.

Till now, we have managed to organise activities a disco in which nearly 4 members of the group participated. I enjoyed this activity and also we made friends with many young people.

Also, we are going to have a visit in Latvia, an activity which I'm really looking forward for it.

I would like that my friends and I go for a harbour cruise and have really good fun. In the near future, we are planning to organise a seminar from which we can benefit and have fun.

I would like that other people are honest with everyone and they take care of everyone.

Representative of Flimkien Group,  
Hal Far Day Centre

## Speech by Ms **Rita Formosa**

**I'm speaking in the name of FLIMKIEN, a group based at the Hal Far Adult Training centre. We have two groups that meet once a week. The leaders of these groups are Patrick and Nadine, speech language pathologists. Charlotte, Ronnie, Yvonne, Mariella, and myself form one group. Occasionally the two groups meet together.**

During the meetings, we sit around a table and discuss various topics, including sports, how to maintain the garden surrounding the centre, and how to manage the meetings. We also discuss our involvement in the centre like for example drawings, knitting, cane, crafts, etc. We were also informed about a time table set specifically for ourselves, in order to know what is happening in the centre. Occasionally we go out as a group and the last time we did so we went for lunch at Sliema and also we visited Baystreet.

The group began to function about three years ago, precisely at the end of the European Disability Year. At the beginning we discussed those items that

we enjoyed doing and what we don't like. Once we visited RTK studios, where we participated in a radio programme along with Susan Mulvaney. One of my friends could not attend, as there is no lift. Regarding this matter, we sent a letter. Also, we had a meeting with the director concerning our centre and we discussed matters that we wanted to change. Some of these matters were changed, but still, there others that have remained the same, and thus, we are still waiting.

While thanking all those persons that help us to lead a better life, I would like to mention some things in the centre and outside that are still the same although we raised

them with the authorities. Accessibility in bays where we go to swim, the hall ceiling in the centre, the lack of drivers and means of transport suitable for us at Hal Far centre.

Due to such a deficiency, activities outside the centre are not being organised such as cultural and educational activities. Also, activities such as picnics and outings in the community are not organised. We are afraid that this year activities such as swimming, visits to Gozo, and harbour cruises, will not be organised.

We would like to have activities such as weekends at Gozo, where we could have fun together.

Thank you.

Self advocacy group  
support members

## Suggestions and Recommendations by Ms **Helen Attard, Anne-Marie Callus** and **Mauro Farrugia**

*This is a resumè of the research found in the Appendix*

- We should start by saying that there are those who believe that people with learning difficulties should speak for themselves and others who do not believe in this principle.
- A fundamental principle of self advocacy is that we should give most importance to what people with learning difficulties have to say for themselves.
- Countries where self advocacy is well developed have been enjoying its benefits, especially in terms of self-esteem and self-confidence and a better quality of life.
- In Malta, self advocacy still has to develop for us to reap the benefits of the seeds that have been sown.
- This means fighting against negative opinions, prejudice and low expectations that are associated with people with learning difficulties.
- In the words of a British self-advocate: "Self advocacy is about sticking up for yourself, people need to understand what it is like to be a person with learning difficulties. Don't let people get you down."
- People need support from their families and those who are closest to them so that they can have the space to grow in confidence and develop their ability to speak up for themselves.
- This support is also needed from those who work directly with people with learning difficulties.
- A person needs space and opportunity to practice and live in everyday life what she/he has learnt in a self advocacy group so that it is reinforced.
- All this can be made possible as long as there is the basic belief in the abilities of people with learning difficulties.
- Where there are service-based groups, it is recommended that there is a contract signed by the parents through which they accept to give their support. This ensures that parents know what is going on and give their full support.
- These groups are not independent by their

very nature. Therefore, support members need to check that they always act in the best interest of the people with learning difficulties. In this type of group, the collaboration of the whole staff team is essential.

- Where children with learning difficulties are concerned, it is important to invest in them early. This means increasing opportunities for them to speak out. In practice, this means full participation in meetings to plan the individual educational programme that has a direct impact on the lives of the children. This can happen in an education system that gives a sound basis.
- In self advocacy, people with learning difficulties speak for themselves, with support if necessary. In citizen advocacy, the person is always helped and

represented by someone else. As far as possible, people should represent themselves. However there are persons who need support to communicate what they want. For these persons, there should be an independent person who is trained in facilitating this communication.

- Very often, citizen advocacy focuses on the impairment rather than the potential of the person. Therefore, if it's introduced in Malta, it should emphatically be utilized only by those who would benefit more from citizen than from self advocacy.
- In Malta there are already service-based self advocacy groups as well as an independent one. There still need to be opportunities for people with learning difficulties to become active members of boards of

organizations that provide services to them.

- It is important that this participation also takes place on an international level especially since there are countries which have a lot of experience in this area.
- And finally, we end with the words of a participant of the "Nothing About Us Without Us" training weekend for disabled persons: "Persons with a disability are able to speak for themselves, are able to lead their own issues, thus they have to represent their own queries and difficulties regarding their own rights and equal opportunities". This is true for everyone, including people with learning difficulties.

# Conclusion

## by Mr **Andrew Lee**

Director of *People First*, UK

**I would firstly like to start by thanking KNPD for inviting me to speak at this seminar and making me feel so welcome. I would also like to thank Anne-Marie for all her help and organising, getting me to various meetings and showing me some sights of your beautiful country. I have really enjoyed my short time here in Malta and hope we can continue to keep the good ties we have made.**

I would like to end by wishing you well and good luck in your steps to setting up your own self advocacy group and organisation.

From the meetings I have had while being here, I can see you have come a very long way in such a short time. I hope you can continue going from strength to strength.

I wish Malta's self advocacy group and all those who have supported it the best of luck in the future.

# Appendix

## Letting the voice of people with intellectual disability be heard

*Research by Helen Attard and Anne-Marie Callus*

### Section 1

#### International

#### Developments

#### Background and Context

The self advocacy movement of people with intellectual disability can be seen as a natural progression of two major developments: the rise of the disability movement in general and the development of inclusive practices in education and other areas.

The twentieth century witnessed the emergence of a consciousness on the part of disabled people of their human, civil and legal rights and of the way these rights were, at best, being ignored by government, institutions and society in general. Perhaps the most significant aspect of this disability movement was the realisation on the part of disabled people that they had to take the struggle in their own hands; that is that they should no longer let

professionals, especially those in the medical field, speak on their behalf. For example, this was how Disabled People's International (DPI) was set up in the early eighties. A group of disabled people attended the Mobility International World Congress, when they realised that the professionals present would not let them speak, they walked out and set up their own organisation. DPI today

“is a network of national organizations or assemblies of disabled people, established to promote human rights of disabled people through full participation, equalization of opportunity and development.” (DPI website)

The emergence of organisations of disabled people, that is ones controlled by disabled people themselves, led to an increasing awareness

on the part of disabled people of the way society creates disabling barriers, and of the distinction between biological impairment and the social construction of disability. Mike Oliver, among other disabled people, developed the social model of disability, which places the responsibility of removing disabling barriers squarely at the door of society as it were. This model contrasts sharply with the medical model of disability which views it only as an impairment and therefore all responsibility lies at the door of the individual (Oliver 1996). As Goodley (1997) argues, the philosophy of self advocacy is compatible with the social model of disability, since both look at disability as being constructed by societal prejudice and at self-advocates as persons who are “actively striving for their own self-determination in the face of

a society that denies such rights” (p374). On the other hand, the medical model emphasises the impaired intellect of persons with intellectual disability. Seen through this lens, these persons may be allowed a degree of choice, but the focus still remains on what is perceived as their intellectual deficit and final decisions are taken by non-disabled people.

At the same time that people with physical, visual and/or hearing impairments were finding a voice and asserting themselves, changes were also taking place in the field of services for people with intellectual disability. In the fifties and sixties, Bank-Mikkelsen and Nirje in Scandinavia and Wolfensberger in the United States were developing and implementing the principle of normalisation. This principle was intended to mean ‘giving people with intellectual disability the chance to live a normal life’, that is a life outside institutions and in the mainstream of society, where they can develop

their abilities and interests. However, it has also often been interpreted as meaning “making people with intellectual disability normal” This principle was further developed in theory and practice by John O’Brien who identified five accomplishments which should be the benchmarks of services for people with intellectual disability. These are:

1. growing in relationships
2. contributing
3. sharing ordinary places
4. dignity of value roles
5. making choices

*(O’Brien 1989, p23)*

Normalisation, practised especially in North America, Scandinavia and the United Kingdom, led to an improvement in the quality of life of people with intellectual disability. Most of them have moved from large-scale isolated institutions to smaller homes in the community, where they can enjoy 24-hour individualised support and participate in community activities. They now have their own room instead of living in dormitories, and have

relatively more control over their own lives, even regarding daily activities such as meal times, when to go to bed and when to wake up and what to do with one’s day.

One off-shoot of normalisation was the development of citizen advocacy, whereby a non-disabled person allies themselves with a person with intellectual disability and represents the latter’s interests as if they were their own. However, it has been argued that citizen advocacy is based very much on the medical model since it is based on the assumption that people with intellectual disability cannot speak for themselves. (Walmsley, 2002) In reality, there are people with intellectual disability who would benefit from support by non-disabled people or other people with intellectual disability (as in peer advocacy). However, this issue is beyond the scope of this paper and we certainly recommend that it is taken up through another forum.

One of the effects of the

rise of the disability movement was a demand for formal education for students with disabilities to be offered not in segregated schools but in inclusive settings. The World Conference on Special Needs Education held in Salamanca, Spain in 1994 affirmed the need for governments to ensure that disabled children have access to good quality education and that mainstream education practices become inclusive of all students. The Statement issued by the Conference also acknowledges the important role that disabled children and their parents have to play (UNESCO 1994).

In some countries, people with intellectual disability have also begun to enjoy the benefits of an education in the mainstream, as well as to have opportunities for pursuing further education courses and for developing their skills and abilities. Thanks to these new opportunities, they have become increasingly more aware of the fact that, although their quality of life

is now much better than that of their predecessors, they still do not have full control of their own lives.

### **The Rise of the Self-Advocacy Movement**

In the sixties, self advocacy groups which were controlled by people with intellectual disability began to be formed in Sweden. People with intellectual disability in the USA and Canada followed suit a decade later. The formation of the first self advocacy group in Canada followed the same pattern as the setting up of Disabled People International. A group of people with intellectual disability attended a conference that was supposed to be for them. However, they felt it was dominated by professionals. So they walked out and formed their own group which they called '*People First*' (Schoultz, n.d.). British people with intellectual disability set up their first advocacy group in 1984. Today, there are *People First* and other self advocacy group all over Scandinavia, the USA, Canada and the UK as well as in Australia, New

Zealand, Germany, Mexico and Japan, among other countries. These organisations offer a wide range of services including support groups, training courses, conferences, newsletters and other publications with information that can be read and understood by people with intellectual disability.

### **Self advocacy is defined by *People First* as:**

- speaking up for yourself;
- standing up for your rights;
- making choices;
- being independent;
- taking responsibility for oneself.

*(Aspis, 1997)*

Furthermore, Goodley (2000) links individual self advocacy to "collective self advocacy . . . sticking up for yourself on our own and with (and for) others" (p7).

Membership of many of these organisations is also open for non-voting non-disabled persons who act as supporters for disabled members. In fact, there are different types of self

advocacy groups. There are those, such as *People First*, which are autonomous, that is they are not linked to any other organisation. Others are off-shoots of existing parental or professional led organisations (such as Mencap) or are service-based, that is they are open to people with intellectual disability who use specific services. The UK government has also acknowledged the contribution people with intellectual disability can make in the development of services. Valuing People, the UK Department of Health's strategy for the development of services in this area, identifies the need for people with intellectual disability to be given more choice and control as a key priority. The strategy also allocated £1.3 million a year for three years for the development of advocacy groups (Department of Health 2001). Part of this funding was used to set up Learning Disability Partnership Boards across the UK to provide a forum for local authorities, service-providers and people with intellectual

disability to work together. People with intellectual disability are also members of national and state boards and committees in the USA (Schoultz, n. d.).

These different self advocacy groups all emphasise the importance of people with intellectual disability developing self-esteem, building confidence and becoming assertive. For example, the beliefs and values of Inclusion International are listed as:

- being a person first
- being able to make our own decisions
- believing in my value as a person
- having other people believe in you as a person

(ILSMH 1994, p.9)

Similarly, the Self-Advocacy Action Pack gives the following answers to the question "What is self advocacy?":

- Self advocacy is about speaking up for yourself
- People meet in self advocacy groups and classes and talk about lots of different things
- Learning how to speak

up with others can help you feel more confident and more in control of your life.

*(Department for Education and Skills 2001, p24)*

Like many others, both of these publications are aimed at people with intellectual disability. Such publications are written in simple language, avoiding jargon and complicated sentences, and are usually also full of pictures that help explain the text. There are also organisations that have produced CDs full of pictures that can be used in publications for and by people with intellectual disability.

Many organisations produce accessible versions of their publications in order to make important information available for people with intellectual disability. For example, 'It's Your Choice' is a publication that helps people learn more about making choices (Values Into Action, 2001) while 'My Life' is a guide designed for people with intellectual disability to conduct a review of the services they

receive (Cattermole and Blunden, 2002). Mencap have a guide to accessible writing, 'Am I Making Myself Clear?' (Mencap 2000), while their website (along with that of other organisations) has an easy-to-read version.

People with intellectual disability have themselves produced publications. *People First* have a long list of publications and individuals with intellectual disability have also produced books about their lives such as the one written by Jason Kingsley and Mitchell Levitz (1994), two young people with Down Syndrome.

These publications can be used directly by people with intellectual disability who are literate and can also be used by advisors, trainers and other non-disabled supporters who are involved in self advocacy groups.

### **The Role of Non-Disabled People**

Self advocacy is about giving a voice to disabled people, specifically those with intellectual disability, and putting into practice the slogan 'nothing about

us without us'. But it also gives scope for non-disabled people to play an important part. Within self advocacy groups, there are non-disabled people who act as advisors but do not have voting rights.

The role of non-disabled people within the disability movement in general has been, and still is, the subject of much discussion. Drake (1997) argues that, while it is inappropriate for non-disabled people to speak on behalf of disabled people, the former have an important role to play in supplying resources, services, information and other forms of help requested by the latter. What is important is that this support has no strings attached and "not to compromise the principles and goals of disabled people's groups . . . it may be acceptable for 'non-disabled' people to join with disabled people to lobby . . . it is in my view unacceptable for them to lobby on behalf of disabled people". (p644)

In the case of working with people with intellectual

disability, the debate mostly centres around the danger of non-disabled people taking over control of advocacy groups and not really listening to the concerns and opinions of members who have an intellectual disability, and the danger of over-protectiveness. Goodley (1997) states that advisors need to be aware that their work should be embedded "within a political framework of empowerment. Therefore to understand how self advocacy can be practised in ways that empower its members, it is necessary to listen to what self-advocates say they want from their supporters." (pp374-5)

This approach ensures that self advocacy groups are truly groups of disabled persons. Moreover, it works on the premise of interdependence, that is that people are dependent on each other and that everybody, in different ways and to different degrees, needs other people. Thus, within self advocacy groups, disabled people may depend on the organisational skills of non-

disabled advisors to varying degrees – the more experienced self advocacy groups will need less support than ones that are just starting out.

Conversely, non-disabled people depend on intellectually disabled persons to set the agenda and priorities for the group, since no one knows more what the concerns of intellectually disabled people are than these people themselves.

Some persons with intellectual disability may be perceived as being unable to give this contribution. But the belief that they cannot represent themselves and take decisions is completely incompatible with the principles of self advocacy. Some persons may have attended segregated schooling and adult services all their lives, settings which are not usually conducive to developing the skills necessary for self advocacy. Being involved in a self advocacy group, on the other hand, can give people to develop these very skills. As Schoultz (n. d.) states:

“For many people . . . involvement in the self advocacy movements has built self-confidence, supported self-determination, and provided opportunities for learning about and contributing to their communities and their countries.” (p1).

Consequently, the impetus for the development of self advocacy groups may sometimes need to come from non-disabled persons who are ready to give people with intellectual disability the opportunity to build their self-esteem, become assertive, and develop skills related to belonging to and participating actively in a group, organising activities, speaking in public and other skills necessary for running a self advocacy group. In these circumstances, non-disabled persons must be all the more aware of the fact that they should act only as advisors and facilitators to the group, and of the pitfalls of ending up having control of the group, even if there is no intention to do so.

Simone Aspis, a British self-advocate whose achievements are an inspiration for other persons with intellectual disability, is an accomplished writer who has also made contributions to prestigious journals such as *Disability & Society*. She is all too aware of how easy it is for non-disabled people to control groups that purport to embrace the principles of self advocacy. She argues that it is important for non-disabled advisors to go beyond the provision of training in self advocacy and public speaking skills. They also have to show people with intellectual disability how their rights are being ignored and how they should go about to bring about change in their lives by challenging the system (Aspis, 1997).

Like Goodley, she also argues that it is important for non-disabled people involved in the self advocacy movement to keep in mind the long history of oppression of people with intellectual disability by society and its institutions. For a very long time, they have been

wrongly perceived as being incapable of learning, rather than having difficulties in learning. It is therefore extremely important for non-disabled persons working in this field to act with sensitivity and to be always ready to give people with intellectual disability the chance to prove themselves as competent self-advocates and to develop the skills to become so if necessary.

Finally, it is worth listening to a few comments made by self-advocates:

- Self advocacy is being able to speak up for yourself and having confidence in yourself to be able to do it;
- Self advocacy, it's about feeling confident and being in control of your life;
- Self advocacy is about sticking up for yourself, people need to understand what it is like to be a person with learning difficulties. Don't let people get you down."

Department for Education and Skills (2001, p28)

## Section 2:

### Developments in Malta

Disabled people in Malta have made great strides in terms of asserting their rights and speaking up for themselves. Their achievements are perhaps epitomised in the training weekend entitled "Xejn Dwarna Mingħajrna" (Nothing About Us Without Us) which was held in 2003. During this weekend, sixteen persons with different physical and sensory disabilities participated in seminars and workshops that were led by disabled persons. The persons involved had met in the Speak Out course organised by the National Commission Persons with Disability (KNPD), which has the aim of helping disabled activists develop advocacy skills. They had also attended a meeting with Ms Jacqui James, a British disabled activist and a strong advocate for the empowerment of disabled persons. The meeting was attended by disabled persons, parents and representatives of non-governmental organisations (NGOs) and the need for disabled

persons to have their own forum for discussion was keenly felt. As one participant of the weekend seminar put it:

"In this seminar we saw how important it is for persons with disabilities to stand united in order to ensure there is agreement on the fundamental rights of persons with disabilities, and that these rights are recognised and respected." She added: "This weekend proves that persons with different disabilities can work together in important decision making and enjoy themselves in the process." (KNPD 2003, p2)

As a result of this meeting and the 'Nothing About Us Without Us' weekend, the need for disabled persons to have more direct involvement in their own decisions became clearer. It was also felt that there needed to be more organisations of disabled persons to work alongside NGOs that work in the field of disability. This led to the formation of the Maltese Council of Disabled Persons (MCOOP). It was ensured that persons with intellectual disability and

mental health difficulties formed part of the representative board.

### **The establishment of self advocacy**

While parents of persons with intellectual disability and persons with mental health difficulties as well as their relatives had taken part in Speak Out Courses, no persons with intellectual disability had ever taken part directly in anycourse, prior to the formation of the MCODEP. However, by the time this was formed in mid-2003, some steps had been taken to promote self advocacy in Malta. In 2002, in preparation for the European Year of Disabled Persons of 2003, a self advocacy group for persons with intellectual disability was proposed as a pilot project for Day Services users attending the Hal Far Centre. This project went ahead with the collaboration of KNPD, the Assistant Director responsible for Day Services, the Hal Far Day Centre as well as the speech and language therapists from the Health Division working at Hal Far. Twelve clients were initially selected for this group. The

criteria used for their selection were:

- Communication skills of the person,
- Personality of the person,
- Motivation level of the person.

Before this group was formed, speech therapists used to hold communication groups with clients using Day Services. Thus self advocacy was considered to be a formal extension of these groups. During the week, careworkers based at the Day Centre could also perform followups on what was being done in the groups during their daily activities in the units of the centre. A senior speech and language therapist acted as a facilitator of the group. A careworker was identified to attend the group and it was felt that it would be better for the same careworker to attend all meetings since in that way the group could grow and evolve together. It would also be easier to maintain confidentiality although there was the disadvantage that when the careworker or speech and language pathologist

was on leave or sick leave it was difficult for the group to meet.

Support to the group was also given by a KNPD representative and the Assistant Director in charge of Day Services. Videos and books used by self advocacy groups abroad were also presented as guidelines and support for the implementation of the project. These had to be adapted to the Maltese cultural situation, which poses a reality of lack of support from a lot of aspects in the community. For instance, on certain occasions what is discussed in the groups would not be respected by the parents at home or the careworkers in the centre. Thus this posed the urgent necessity to educate the parents and community members at the same time to back up what was being done in these groups. In fact, once the pilot group was established, a meeting was held with the parents and close relatives of the participants for them to be aware of the aims and working methods of the group. This was also an

opportunity to consult with the parents and relatives about the needs and wishes of the persons with disability.

The main goal of the group was to promote assertiveness and social communication skills. This was based on ongoing assessment which focused on both verbal and non-verbal communication skills and which was usually performed by the speech and language pathologist. This was also backed up with assessment of social skills, based on the individual's needs and level of individual's motivation. It is also important to point out that the targets for each individual varied according to his/her own ability and the level of difficulty of each topic. Topics selected were related to the daily lives of group members

both at the centre and at home.

Since this pilot project was considered to be a success, these groups were extended in each of the day centres and continued to be led by speech therapists. The following table outlines the number of groups which are existent in Malta in each centre and the number of members in these groups.

Thus there are currently 62 persons with intellectual disability attending 6 different groups which mainly follow the same principle which is that of supporting and enhancing the ability of these persons to speak up for themselves and speak out about their rights. These groups hold meetings on a weekly basis in the larger centres and once a month in

Pembroke, which is a small day centre.

These groups are centre specific, i.e. they are based on the different needs presented by each group attending a specific centre, but each of which follow some basic rituals such as the following:

- They have the responsibility to find and organize the place/room where the meeting will take place.
- The time is agreed in each of the sessions.
- Record of attendance is kept in an accessible format such as, for instance, photos being used instead of names.
- Each member has different roles and responsibilities. For example, one person is in charge of time-keeping, the other is in charge of maintaining order and respect

Centre	No of facilitators	No of members	Period of existence (years)
Hal Far	2	12	2.5
M'Scala	2	1	2
Santa Venera	Grupp1	11	2
	Grupp 2	12	1
Mtarfa	2	12	2
Pembroke	2	4	1

- amongst the members.
- The topic is usually chosen by the members.
  - What happened in the last meeting is summarized in the beginning of the next one.
  - Something which took place in the centre is usually brought up for discussion.
  - Personal problems are also usually discussed and supported in the group by encouraging each member and giving value to each others' suggestions. It is found very effective when encouragement is given to try out the suggestions to internalise the learnt value through one's experience. For instance, after a negative experience on a boat trip, the group wrote a letter to the owners of the boat with the list of complaints and each member supported it with their own signature.

These groups are facilitated through various measures, most common of which is different

approaches in questioning. For instance, it is important that not many things are asked at the same time. It is found beneficial that information is given or asked for, bit by bit. It is also important to continually check for feedback from the person to make sure that they have understood. Guidance and help is always needed in such groups. The aim is to offer support to a person in developing skills in articulating their thoughts. This is especially valuable for older persons with intellectual disability who have not benefitted from any educational programme. It is important to take into consideration the different levels of ability, how much training or education the person was exposed to and the social and cultural environment the person was brought up in. All these factors lead to a different outcome for each group. On the other hand, it is equally important not to underestimate the ability of group members to represent themselves and to be wary of the danger of non-disabled group

members imposing their own agenda on the group. As discussed in the previous section, support by non-disabled persons should be given '... within a political framework of empowerment' (Goodley, 1997, p374).

It should be noted that these groups are still very much led by the support members who are professionally trained. While this ensures that the group members are given the necessary support, one should also guard against the danger of subjectivity of the professional involved, as discussed in the previous section. Therefore, the way these groups will develop may depend to a very large extent on the opinions and attitudes of the professionals rather than the disabled persons.

Parents and carers have also been involved in the development of these groups. In a Maltese context, where family links tend to be strong for everybody, this involvement is important. After all, these links are also strong for most

Maltese disabled people who rely on the support of their families in various aspects of life, as evinced by the research carried out by KNPD (Callus & Bezzina 2004). In fact, parents and carers are invited on a regular basis to attend specific sessions as decided by the group. However, these are not always well attended. For instance, for one particular meeting only two parents turned up. It is important to remind ourselves that some of the parents might be elderly and find it difficult to attend meetings. Workshops are also organized for parents and carers to supplement group meetings, especially when issues which are directly related to parenting and care-giving are brought up by group members. This helps ensure a more solid and constructive backup.

Moreover, it should be noted that Maltese society tends to be quite patriarchal especially when it comes to children and those who are not considered to be able to fend for themselves, including people with

intellectual disability. This phenomenon is probably due to two main factors: the country's small size (which makes it very easy for people to keep in close contact with each other) and the strong Catholic tradition (with Roman Catholicism being the religion of almost all the population). These two factors also mean that the perceived meaning of helping others is practically synonymous to doing things for others, which can mean that people are disempowered rather than empowered.

Within this context, as part of the goals and achievements reached by these groups in the initial period, one can find the following:

- They often represent themselves with their own issues and problems at their respective local councils.
- They have taken part in various radio programmes.
- They have also represented themselves in the Maltese Disabled People's Parliament.
- They have taken part in Disability Issues talks organised by KNPD.
- They have developed the ability of making their own choices starting from the decisions in the day centre, extending it to home and eventually in the community. Given these choices, their awareness is enhanced and eventually they start to ask: "Why?", instead of accepting everything as it is.
- They have become aware of the right to ask and of the importance of identifying the appropriate person to ask specific questions to. For instance, when they were trying to find a place in Valletta, they asked information from a police officer; for a bus number they identified a bus driver.
- Problem solving and social communication skills are being developed.
- They have presented findings of a research study on the wishes & desires of people with intellectual disability  
(Attard & Callus 2003)

Apart from the above, the milestones reached by the groups have led to a higher level of assertiveness in everyday life and enhanced the ability of decision making especially for themselves. For instance, in one group, the members have managed to take action in their centre when they discussed the issue of transport problem in the centre, the lack of a nurse and the problem in the stage which is situated in their hall. Results were achieved in all three cases. An article appeared in a local newspaper regarding complaints about this particular centre. It is important to note that these complaints had already been made by the clients at various points, as well as by the parents. The lack of progress regarding these issues was not due to the inability of persons with intellectual disability to represent their own issues, but simply due to bureaucratic delays which are a reality of any governmental organization.

The progress made by these service-based self advocacy groups led to the organisation of a Speak

Out course for persons with intellectual disability. This was a continuation of the self advocacy groups, but was also aimed at extending the communication skills of the participants including reaching out to the media. Fifteen persons attended this course. The following is what they had to say about the course:

“We really look forward to attending this group, not only because we meet our friends, but also because we have our space to talk and express ourselves, our feelings and share a bit of what happens at home, at the centres and at work. We were also taught to think and speak about our rights and that we do not have to say yes to everything which is said to us”.

The participants of this group expressed the wish to continue meeting after the end of the course and, for this purpose, elected five persons to form a representative group to organise activities. This smaller group is meeting regularly with a view to forming an independent

self advocacy group with the support of non-disabled persons.

### **Opinions about self advocacy in Malta**

The efforts of persons with intellectual disability to represent themselves and strive to assert their rights cannot meet with success without the collaboration of their families, those who work with them and society in general. To date, no research has been carried out with family members and with the public. KNPD, however, did ask for the opinion of disability NGOs and service-providers. The opinions of organisations working in the disability sector in Malta vary greatly regarding this issue, with some fully supporting it, others seeming unclear in their ideas and some sustaining the idea that persons with intellectual disability are not able to represent themselves in decisions regarding themselves.

Regarding the latter, the strongest opinion is represented by the following:

“We think that persons who are under age and those

with intellectual disability should not be burdened with the responsibility of handling and fighting their own issues”.

They also sustain that distinction should be made between age and ability of the persons concerned. Age imposes limitations on both the natural and juridical possibility of someone taking a decision for him/herself.

Others suggest that: “..it is important that such factors are discussed within a framework of a seminar holding the same aim, which gives space for all ideas held by parents, professionals and persons in care of people with intellectual disability”.

But yet again, there is no suggestion, that persons with intellectual disability themselves should in fact be included.

The other side of the coin voices another reality. For instance, as part of the statute of a particular foundation we find as the main objectives:

a) To work in collaboration with

individuals with disabilities of all ages, and with families and the community, promoting informed personal choices to provide and facilitate meaningful lives.

- b) To create awareness of the fact that all persons, including the disabled, can be contributing members of the community.
- c) To ensure that parents, caregivers and the individual will be included in the planning, designing, implementation and evaluation of all goals and objectives.

On these lines another foundation insists that: “...we are in favour of self advocacy for persons with intellectual disability, since we feel that it empowers this sector of the population that has for long been voiceless. The development of self advocacy in Malta means that Maltese people with intellectual disability can also benefit from it, in the same way that people with intellectual disability in other countries have been benefitting for many years”.

Other organisations seem to be unclear as to what self advocacy is all about in that they feel that discrimination has been faced when choosing members for the self advocacy groups in the day centres. They did not seem to understand exactly the criteria which were used in this regard.

### **Conclusions and Suggestions**

While there seem to be as many people who believe in self advocacy as there are who do not agree with its principles, it is also important to see what self-advocates have to say for themselves. As was seen in the first section, those who live in countries where self advocacy has long been established are very much aware of its benefits, especially in terms of persons with intellectual disability building self-confidence and working towards a better quality of life.

In Malta, the full effect of these benefits still needs to be felt since a solid base for self advocacy is still being rooted. Establishing this base means

combating negative opinions and the stigma and low expectations that are still all too often attached to intellectual disability. As one self-advocate quoted in the first section put it:

“Self advocacy is about sticking up for yourself, people need to understand what it is like to be a person with learning difficulties. Don’t let people get you down.”  
Department for Education and Skills (2001, p.28).

Self-advocates therefore need backup from their parents and close relatives, as well as from those who work closely with them. They need more space so that their self confidence could be developed for a more constructive control of their life. It is useless to practise one thing in a group and experience another reality. A skill which is learnt in a self advocacy group needs to be practised in daily life and currently not ample space is being given to this.

In the case of service-based self advocacy

groups, one helpful approach would be a contract which parents sign in which they declare their support for such programmes. This system is currently in place in some non-governmental organisations in Malta. This ensures that parents are fully aware of what the programme entails and do not feel threatened by it. It also ensures better followups and collaboration from parents who are aware of what their sons and daughters are involved in and do not feel threatened by it. A transdisciplinary team is also suggested to cooperate in such groups to give a better insight in each area of specialization, for instance a psychologist might create a better awareness of personal and emotional issues. Proper training for careworkers and better co-operation with families and parents are seen as fundamental. More material resources would also be of great help to facilitate such groups especially when it comes to dealing with more abstract topics.

Investment in children with

intellectual disability is also very important. The younger a person is involved in such groups, the better chances he or she stands of becoming an effective self-advocate. These children should therefore be actively involved in case conferences, assessments and meetings about their individual education programmes, transition planning meetings as well as any other meetings in which decisions are taken that will have a direct impact on their lives.

As regards the development of citizen advocacy in Malta, one foundation said in its letter: “...it would welcome the development of citizen advocacy programmes so that those people with severe intellectual disability who may not be able to represent themselves can benefit from the services of an independent advocate who represents their interests as if they were his/her own”

It should be noted that the emphasis in this quote is on representation for those who are least likely to be

able to represent themselves without a great deal of support. If a proper chance is given, many persons with intellectual disability can more than take up the opportunity to be their own advocates. From the consultations that have been made, and the limited research that has been carried out, it has clearly emerged that not enough chance is being given. It cannot always be assumed that persons with intellectual disability and those who live or work with them are striving towards the same goals. Nor can it be assumed that starting points are the same. One might highlight an important division which subtly separates two different groups: those who fight for disability rights focusing on inability and those who fight for disability rights starting from ability. Our focus should be on how we can all participate in a constructive and empowering way of promoting these rights, rather than an intrusive one.

Support can be given in a number of ways. User groups can be set up within governmental and non-governmental organisations who provide services for persons with intellectual disability. Self-advocates should also be able to represent the concerns of persons with intellectual disability by being appointed as memberships of management boards, such as happens in the UK and the USA (see Section A). More importantly, the existence of fledgling independent self advocacy group is a promising development and should be encouraged.

The persons who participated in the Nothing About Us Without Us training weekend delivered the message that:

“Persons with a disability are able to speak for themselves, are able to lead their own issues, thus they have to represent their own queries and difficulties regarding their own rights and equal opportunities”.

*(KNPD 2003, p2)*

Given the breakthroughs made by the self advocacy movement in other countries as well as the progress achieved in Malta so far, there is no reason why persons with intellectual disability should not be included in this quote and in the disability rights movement.

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#### Websajts

Asist: <http://www.asist.co.uk>

Down Syndrome Association: <http://www.downs-syndrome.org.uk>

Mencap: <http://www.mencap.org.uk>

*People First*: <http://www.peoplefirst.org.uk>

Inclusion Europe: <http://www.inclusion-europe.org>

Inclusion International: <http://www.inclusion-international.org>