



ICLife: Inclusion of People with Intellectual Disabilities in Higher Education

Introduction: Towards inclusive higher education

Inclusion is a policy that recognizes diversity as standard and creates conditions so that everyone can participate. It is linked to democratic participation within and beyond education.

The United Nations Convention on the Rights of People with Disabilities obliges States to “ensure equal access for all women and men with disabilities to affordable and quality technical, vocational and tertiary education, including university, and lifelong learning”¹.

Inclusion of people with disabilities in higher education institutes is thus not only a non-committal policy, but also a legal requirement. Beyond this, the practice has many added values for students with and without disabilities and for the institute itself.

Higher education institutes are places for teaching and learning. Their quality is measured in how well

their students are prepared for their future careers with public or private employers or in research. In most employment areas of higher education students will encounter people with disabilities and/or special needs. These same students will perform better in their future jobs if disability awareness could be part of their initial studies. Inclusion increases effectiveness and efficiency of higher education and enables graduates, especially in leading and planning positions, to plan for an inclusive society at all levels (see also Kleinert, Jones, Sheppard-Jones et al 2012)²

For some students the engagement goes even further: for teachers, psychologists, therapists or social workers, it is essential that they experience disabled people not only in the social role of being “their client”. People with disabilities in the teaching staff of higher education can bring about a new perspective that favors participatory work, in co-production³ as well as in participatory research, with e.g. sociologists, anthropologists and teachers,⁴ and other areas.

¹ CRPD: General comment No. 4 (2016) on the right to inclusive education, article 24

² Kleinert, H., M. Jones, K. Sheppard-Jones et al (2012). Students with Intellectual Disabilities Going to College? *Absolutely! TEACHING Exceptional Children* 44(5): 26-35.

³ Co-production is a practice in the delivery of public services in which citizens are involved in the creation of

public policies and services. In contrast with traditional citizen involvement, citizens are not only consulted, but are part of the conception, design, steering, and management of services. Christian Bason: *Leading public sector innovation: Co-creating for a better society*, Bristol, Policy Press, 2010

⁴ See for an example of such participatory research in social work Van der Aa, J. & J. Blommaert (2017).

Human Rights support services, non-discrimination centers, legal support services and other NGO activities are important employment opportunities for graduates of law schools. Inclusion of people with intellectual disabilities in their training thus prepares them for better employment opportunities.

In social research, the needs and participation of people with disabilities are often overlooked, although they represent about 10% of any population. Inclusive higher education can contribute to more representative and valid research. This can be achieved by undertaking inclusive research projects comprising of a collaboration between students and persons with intellectual disabilities. Additionally teachers and researchers can also be involved in such projects. Inclusive research conducted in cooperation with persons with intellectual disability is still relatively in its infancy, although there is increasing evidence that such research contributes to the reliability and validity of research data (Bigby et al 2014a, 2014b; Johnson et al 2013)⁵. Importantly, one needs to consider the competencies of persons with intellectual disability to successfully participate in a research project and one needs to be aware of the several approaches to inclusive research (Embregts et al 2018; Bigby et al 2014a, 2014b)⁶ i.e. so as to prevent tokenism.

Inclusion of people with intellectual disabilities on a campus of higher education is thus a concept that promises positive results for all people concerned:

- It supports the professional training and education of students of all faculties by bringing them into direct contact with their future clients.
- It improves the quality of higher education by ensuring that these same future clients are part of the teaching process in higher education.

Ethnographic monitoring and the study of complexity. In: *Researching Multilingualism: Critical Perspectives*, pp. 259-271, London: Routledge.

⁵ Bigby, C., P. Frawley and P. Ramcharan (2014a). A collaborative group method of inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 27(1): 54-64.

Bigby, C., P. Frawley and P. Ramcharan (2014b). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1): 3-12

- It provides workplaces for people with intellectual disabilities in all areas of the campus, for example in the teaching faculties, but also in all kinds of support jobs.
- It empowers people with intellectual disabilities by allowing them to learn as students alongside non-disabled students.
- It allows higher education institutes to distinguish themselves as inclusive from other similar institutions.

To achieve inclusion in higher education we have to increase the capacity of settings and systems to respond to diversity in ways that value everyone equally. First and foremost, an inclusive campus requires a new way of thinking. This is important for the attitude of stakeholders such as fellow students, teachers, or the management.

In what follows, we identify (1) our vision on people with intellectual disabilities in higher education; (2) we identify some successful examples; and (3) finally offer some tools for enabling inclusion on campus.

(1) People with intellectual disabilities in higher education - a contradiction?

People with intellectual disabilities are also called 'people with learning disabilities'. This does not mean that they cannot learn at all, but that they learn differently and at a slower pace or that they learn different things than other people of their age. What's the place people with intellectual disabilities can occupy at the highest level of a competitive education system, in higher education?

For an answer, we have consider distinct roles: (a) the role of a teacher and (b) the role of a student in higher education.

The role of people with intellectual disabilities as *teachers* in higher education has been mentioned above. But what qualifies them as teachers?

Johnson, K., G. Minogue and R. Hopklins (2013). Inclusive research: making a difference to policy and legislation. *Journal of Applied Research in Intellectual Disabilities*, 27(1): 76-84.

⁶ Embregts, P. J. C. M., Taminiu-Bloem, E. F., Heerkens, G. C. J., Schippers, A., & van Hove, G. (2018). Collaboration in inclusive research: Competencies considered important for people with and without intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 193-201. See footnote 5 for Bigby et al 2013, 2014

Firstly, we have their experience of having lived a lifetime of exclusion and segregation from society. This experience forms the character and perception of a human being and possibly sensitizes people for similar situations. Transferring this ability and perceptions to students from different faculties can help students to develop more realistic and person-centered approaches to their profession.

Apart from education, there is an increasing focus on modern 'development and management' theories in all areas of society, such as co-production, behavioral design in policy-making⁷, person-centered programs, personal budgets or user-led services. All these approaches require an effective communication with all stakeholders, among them also people with intellectual disabilities, in order to understand and implement them.

In addition, students can learn from people with intellectual disabilities the need for clarity: instead of burying meaning under heaps of words and jargon, people with intellectual disabilities need and use simple and clear words and sentences. They force students to focus on the real core and meaning of their messages. And when they 'get it right' for people with intellectual disabilities, they are also understood by everybody else, including migrants, people with lower levels of education, etc.

People with intellectual disabilities have come to more and more understand their own potential more and more of where they contribute to society in various forms. Under the flags of self-determination and self-advocacy⁸ many of them have undergone trainings on how to speak and present confidently about different subjects. Their organizations (who often care for them) could provide the necessary support to make presentations and guest lectures in different higher education faculties an easy possibility. Below we also mention some aspects to support this approach.

Secondly, people with intellectual disabilities can also benefit *as students* from participation in higher education.

However, it is important to keep in mind that they learn differently and different things as compared to other students. But they certainly will benefit by

discussing legal capacity together with law students or concepts of learning with pedagogues. Of course, they would need different assignments and probably would not gain credits⁹. But not everyone who studies medicine needs to become a medical doctor and not everyone who studies law will become a legal practitioner.

(2) Examples of successful inclusion

Below, we show some practical examples of successful inclusion of people with intellectual disabilities in higher education from both within and outside this project. As you will see, their roles as teachers and students often vary and merge, to a point where defining their role becomes less important than the contribution they can offer.

a. Inclusion in education

Inclusion in Faculties of Law is happening in various contexts. In the renowned Harvard Law School and many others, students organize disability law clinics in which they support people with intellectual disabilities to understand and exercise their rights under the United Nations Convention on the Rights of Persons with Disabilities.

The issues surrounding legal capacity and supported decision-making are of ever growing importance, not only for people with disabilities, but also for the elderly. The Centre for Disability Law and Policy of the NUI Galway, Ireland, works regularly with co-trainers with intellectual disabilities to discuss these issues with their students and to research the impact of legal capacity legislation on people with intellectual disabilities.

Bachelor students in engineering at Thomas More in Belgium can register for the Diploma Supplement 'socially ingenious'¹⁰. Students work in direct cooperation with the target audience, the persons with disabilities who will be the end users of their developed products. Being fully part of the accredited University courses, students enrich their technology degree with a social dimension, a slice of authentic engagement. Direct involvement of users with a disability improves the developed products, but also the qualification of the students

⁷ See e.g.: Behavioral insights and new approaches to policy design. OECD, Paris 2015

⁸ Meaning: speaking up for themselves

⁹ Under the Bologna Agreement on the European Higher Education Area

¹⁰ <https://www.thomasmore.be/site/socially-ingenious>

in areas like user-led design, communication skills and applicability.

In the area of Disability Studies one of the best ways to identify possible issues and shortcomings in accessibility are Campus Accessibility Audits carried out by people with disabilities themselves. This applies especially to people with intellectual disabilities, for whom few standards in terms of architecture or communications exist. This Accessibility Audit is often carried out by a mixed group of students with and without intellectual disabilities. While students with intellectual disabilities perform some activities without support in the foreground, the regular students may be more involved in background activities, such as recording what happens and where difficulties occur.

At the end of the tasks, the whole group of students evaluate the experiences and take in account especially the feelings of the students with intellectual disabilities: were they treated dismissively, could they remember all the directions, how did they feel when they got lost, etc. With the direct participation of people with intellectual disabilities, the insights gained as well as the learning process of the whole group is much more based on, and in tune with reality. As we mentioned earlier, institutions are often very poorly adapted to include everyone, so establishing the problems and difficulties firsthand is an absolute must.

Teachers at primary and secondary level are more and more challenged to be able to manage diversity in their classrooms. This necessary skill is required because students are much more diverse in modern societies: different cultures and religious beliefs, different genders and sexual orientations, as well as different abilities and disabilities make diversity management a necessity. Some authorities, schools and teachers see this as a problem, an obstacle to the achievement of national educational goals, while for others it offers new opportunities. Successive PISA ¹¹ reports have shown the relative lack of success in addressing the needs of diverse school populations and helping children develop the

competences they need to succeed in society. However, PISA has also shown that diversity in the classroom can be a driving force for excellence in education as well.

Teacher training at schools and universities must take pupils' diversity much more into account. Teacher training in many countries must be adapted to make future teachers at all levels much more aware and able to deal with diversity in the classroom. Lecturers who reflect diversity themselves, including lecturers with intellectual disabilities, are in an excellent position to train students on this issue. Quality and excellence in education for everyone really depends on adequate and practical diversity training of teachers.

In addition, diversity management in the classroom also will need the employment of teacher assistants and helpers. Certainly there are people with (intellectual) disabilities who can fulfill these roles and who could be trained alongside future school teachers.

At Utrecht University of applied sciences, practicing 'nothing about us without us' with 4th year undergraduate students Social Work and persons with a mild intellectual disability through inclusive projects utilizing an inclusion focused approach (Wilken & Knevel 2015, 2016; Knevel 2018)¹² has proven very fruitful.

The objective is to have students (future social workers) gain a deeper understanding of comprehensive concepts such as social inclusion, basic equality, power relationships between the social worker and service user, empowerment and emancipation.

Thus students are offered three options:

- 1) Conducting an inclusive cooperative research
- 2) Undertaking a product innovation
- 3) Set up and carry out a so-called '*kwartiermakersproject*' i.e. social projects creating safe places for otherness,

¹¹ OECD: Programme for International Student Assessment. www.oecd.org/pisa
¹²

Knevel, J. & Wilken, J.P. (2015). *Inclusie, (on)gewoon doen!* Utrecht/Amersfoort: Kenniscentrum Sociale Innovatie.

Knevel, J. & Wilken, J.P. (2016). Zo werk je Inclusiegericht: Het recht op meedoen en meetellen. In: *Sozio* (2).

Knevel, J. (2018). *The inclusion focused approach. Practicing 'nothing about us without us' with students and persons with a mild intellectual disability through inclusive projects.* Posterpresentatie SWSD 2018 Dublin.

promoting hospitality for 'otherness' (Kal, Post & Scholtens 2012)¹³

Having chosen one of these options the student sets up a small project team consisting of persons with a mild intellectual disability and one or two students from the university. The project and the learning process is guided through a mix of discussions, keeping an *inclusive cooperation* log drawing exercises, and other resources and tools to support students in the process. It is a self-paced course. Students start learning and understanding the abovementioned concepts and theories through experience (action learning) and reflection.

Among other things this course results in increased awareness of the power relationships with persons with intellectual disability, increasing awareness of your own attitude as a social worker with respect to persons with intellectual disability, awareness that persons with intellectual disability have more competencies than expected and a lived understanding of comprehensive concepts such as inclusion, basic equality, empowerment, emancipatory practice.

b. Accessibility

For the involved persons with an intellectual disability the inclusive projects resulted in experiencing new social valued roles, feeling competent and feeling acknowledged, pride, self-esteem. Furthermore the involvement expands their life-world and opens new perspectives (discovering new interests, new competencies, new opportunities).

At the Thomas More University of applied sciences in Belgium, socially vulnerable target groups (in particular people with intellectual but also physical disabilities) sell their self-made goods together with social partner organizations in a specially tailored mobile shop. The aim of this tool is to achieve boundary-breaking inclusiveness inside and outside the campus.

The mobile shop (for usage on campus and on location) itself is developed by Construction students in close consultation with people with disabilities and is made up of various individual elements that can be adjusted in height to meet everyone's needs and expectations. There can even be a built-in refrigerator and a sandwich maker to make e.g. waffles or toasted sandwiches.

The cash register is also specially developed for people with a (mental) disability as an application on a tablet, by ICT students, again in consultation with people with disabilities.

c. Other areas

In the field of medicine and health care, lack of training and awareness of disability can have serious consequences. In a survey of medical schools¹⁴,

- over 50% of deans reported that disability training had not a high priority
- 81% of medical students reported no training on disability issues
- Seniors and graduates expressed an inadequate competence in the care of patients with disabilities

Without training, healthcare providers also tend to underestimate the abilities of patients with disabilities and grossly underestimate the quality of life of patients with disabilities. They also minimize the extent and importance of the patient's expertise in his or her own condition. This leads to a lack of recognition of the patient's self-capacity to contribute to their own care and thus to avoidable costs and wrong health care planning. Several universities and medical centers have already invited trainers with disabilities to address this issue.

In addition, a research¹⁵ carried out with Special Olympics¹⁶ athletes showed the consequences of shortcomings in healthcare access:

- 1/3 of athletes required prescription glasses and did not have them; more than 25% had never been screened
- more than 3/10 of athletes failed hearing tests
- more than 1/3 of participating athletes had obvious tooth decay

¹³ Kal, D., Post, R., & Scholtens, G. (2012). *Meedoen gaat niet vanzelf: kwartiermaken in theorie en praktijk*. Amsterdam: Tobi Vroegh.

¹⁴ Holder, M., Waldman, B., & Hood, H. (2009). Preparing health professionals to provide care to individuals with

disabilities. *International Journal of Oral Science*, 1 (2), 66-71

¹⁵ Corbin, SB; Malina, K; Shepard, S. (2005). *Special Olympics World Summer Games 2003, Healthy Athletes Screening Data*, Washington, D.C., Special Olympics, Inc.

¹⁶ Special Olympics is a sports programme focused exclusively on athletes with intellectual disabilities.

These findings correspond with a lot of other data that prove people with intellectual disabilities are far from having equal access to health, with the ensuing consequences.

A training and awareness-raising in medical schools and universities by people with intellectual disabilities themselves has proven to have great potential to remedy this unacceptable situation.

(3) Results: How to achieve inclusion in higher education

So far, the project Inclusive Campus Life (www.ICLife.eu) has developed a number of detailed guidelines and tools which can help Higher Education Institutes to become inclusive campuses. The available documents can be found on the project website. In the following we want to highlight some crucial issues in this process.

Staff training and awareness

To welcome people with intellectual and other disabilities on a campus of higher education it is useful for the staff and employees on campus to learn about their specific needs. This does not have to be a long training seminar, but can best be integrated into regular meetings of different groups of staff that take place anyway. This has the advantage that the management sends an inclusive message to everyone and that the awareness-raising can be repeated e.g. annually to remind existing staff and to introduce new staff to the principles of an Inclusive Campus. If only short time is available, one can also address the needs of only one group of people with disabilities, e.g. during shorter time periods of 20 minutes at an already existing meeting.

As a general rule, and whenever possible, it is important to involve people with intellectual disabilities themselves in these awareness-raising sessions. It is important that staff members become familiar with talking directly with a person with an intellectual disability, have the possibility to ask questions and understand the contributions that these people are making to society. For organising such a training, it is always helpful to cooperate with a local, regional or national organisation of people with intellectual disabilities and their families.

Higher Education staff at all levels should understand that people with intellectual disabilities are an integral part of society. They have a right to full participation and inclusion, also in education. In Higher Education Institutes it is usually a challenge to explain why people with an intellectual disability should and can participate at this level of education. Therefore, it is important to convey the following two core principles:

- The Higher Education Institute is committed to be an Inclusive Campus, not excluding any group of the population.
- Most of the graduates will later work in positions where they have direct contact with people with disabilities: as lawyers, teachers, architects, designers, medical doctors, etc. Thus it is important that they get to learn about their future clients or colleagues.

Equal Opportunities Recruitment

Higher Education Institutes should welcome diversity amongst their staff, should ensure that all candidates for employment are treated fairly, and that selection is based solely on the individual merits of candidates and on selection criteria relevant to the post. As employers they should be committed to the principle of equality of opportunity.

The legal basis for equal opportunities in the workplace in Europe is the Employment Equality Directive 2000/78/EC that has been transposed into national law in all EU Member States. It prohibits discrimination on grounds of religion and belief, age, disability and sexual orientation. It covers the fields of employment and occupation as well as vocational training.

People with intellectual disabilities are often experiencing indirect discrimination when an apparently neutral provision, criterion or practice (e.g. 'objective criteria' during job interviews) puts them at a disadvantage compared with other persons. In Higher Education Institutes, this may be the case if, for example, a certain unnecessary degree would be required for jobs such as cleaner, kitchen aid or gardener.

Moreover, many services within a Higher Education Institute may be sub-contracted to external service providers, such as cleaning, gardening, catering, etc. The management of an Inclusive Campus should thus carefully review their conditions for the sub-contracting of services and include requirements for the sub-contractor to

employ a certain number of people with disabilities, including people with intellectual disabilities. This 'positive discrimination' is allowed as positive action.

Also, work placements or traineeships have proven to be an excellent tool to see if a specific person is able to perform job-related activities before recruitment.

Higher Education Institutes have a statutory obligation to make such adjustments to the workplace and to reasonable working arrangements to accommodate suitably qualified disabled applicants. Possible reasonable accommodations for people with intellectual disabilities could be, for example, a reduction of the required working time or job-sharing between a person with and a person without a disability. Some countries also finance specific training on the job, re-training, job coaches and other workplace-related support, or provide financial incentives for employers of people with intellectual disabilities.

Peer support

Peer support or 'buddy' systems are well known in many areas of societal life. They comprise pairing experienced people with people having less experience for mutual learning. Peer systems encourage open and effective dialogue among peers and tend to break down social barriers. They help creating a collaborative learning environment in which peers feel less hesitant to raise questions. This enables people to develop social networks and cross-cultural experiences. Peer systems have a large place in higher education and professional training: pairing students with more achievements to newcomers, or pairing foreign students with national ones are two examples. Peer systems have a great potential to be really inclusive for everyone and to become a mainstream feature of University life¹⁷:

- **For learners with intellectual disabilities** a peer can make a real difference when e.g. they want to learn about the locations of rooms, or when they do not know who to address. A peer can also be a conduit for social contacts to other students.
- **For learners without disability** at University, becoming a peer can give them valuable insights into questions and issues their future clients may have, regardless if they are studying social work, law or medicine. People

with intellectual disabilities often help professionals to see their work from a new perspective and to understand their real life concerns.

A peer system is mutually beneficial for both buddies and volunteer students at the same time. We propose the implementation of the system not solely to help students with an intellectual disability but to help all students, especially first-year students, students from other countries, etc. The peer system thus becomes an added value for everyone on campus.

Legal capacity issues

Although international legislation in force is clear that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life"¹⁸, there are still many guardian systems in place that reduce the legal capacity of persons with intellectual disabilities to take their own decisions or to sign valid contracts. Administrators should be aware of these limitations and inquire about the situation of a specific person and find legal ways for contracting and obtaining valid consent.

Another highly discriminatory practice is the so-called 'benefit trap'. Most people with intellectual disabilities receive some form of benefits from the State because of their disabilities. Of course, these benefits should be reduced or even stopped when persons are able to earn their own living. However, in some countries employment is seen as 'proof' that people are no longer disabled and as such they may lose their rights to disability benefits forever.

Higher Education Institutes who want to work with people with disabilities should be aware of this situation and check it case by case. To be clear: the objective is not to avoid taxes or gain unlawful benefits, but a disability is defined as a *permanent situation*.

The inclusive way forward: Against tokenism

We are aware that the issues described in this paper may present a challenge to many administrators of Higher Education Institutes. To overcome these challenges it may be best to cooperate with organizations of people with disabilities and their families. On the website www.inclusion-europe.eu a list is provided of first-line contacts that may be able to support this

¹⁷ For a detailed description and much practical advice see: Inclusive Campus Life (GA N° 2016-1-BE02-KA203-017365), Intellectual Output 2: How to organize a buddy

system for people with intellectual disabilities.

www.ICLife.eu

¹⁸ CRPD Article 12.

process. Only if we really actively include people with intellectual disabilities in a diverse range of activities, from cleaning and catering to co-teaching and doing research, we can escape a probably well-intended tokenism. However, in the long run this will turn counter-productive. And IC Life advocates through its outcomes and tools a productive way forward

You may have received this paper also directly from people with intellectual disabilities who speak for themselves. We have encouraged these self-advocates to personally contact higher education institutes to advocate for their own inclusion in higher education.