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Jacqueline Kool studied Social Work and Theology in the Netherlands. She is the cofounder of *Disability Studies in the Netherlands* (www.disabilitystudies.nl) and still works there. She also works as a consultant on disability experiences.

Jacqueline has published extensively on participation and representation of people with disabilities. She has written two books: about religious perceptions of disability, and about disabled women and sexuality, *Goed bedoeld* (2002) and *Eros in de kreukels* (2010).

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The museum as a Wunderkammer of the 21st century

An ode to diversity from the perspective of disability studies

Jacqueline Kool and Sofie Sergeant

We shall not cease from exploration and the end of all our exploring will be to arrive where we started and know the place for the first time.

(T.S. Eliot, *The Four Quartets*)

What is normal?

A large-scale art event was held in Amsterdam in 2010 called 'Not Normal'. It was intended to encourage people to think about the norms of perfection in art, science and society. Who or what is normal, and who decides so? Which bodies can or cannot be shown as belonging to 'normal' people? 'Not Normal' was the first cultural institution to bring inclusion in the Netherlands to the attention of a broad public.

Something happened before the event was fully in place that demonstrated the need for it. The exhibition poster showed a white marble statue of the artist Marc Quinn: a naked man in an assertive pose, with half an arm and half a leg missing (see illustration). The poster was displayed in various public areas, but Dutch Rail refused the posters on the grounds that they might cause offence. They were afraid of negative reactions from the public, not because the man was naked, but because he lacked an arm and a leg. 'A station must be a comfortable place for people to be in', a spokesman stated. There are hardly any limits to what can be shown in our visual culture: semi-pornographic adverts barely provoke debate. But apparently a disabled

body cannot be shown in a public space, not even when it is a work of art. Or perhaps that is precisely the reason why it cannot be displayed? It looks as though disabilities are only presentable in a context that focuses on their medical or problematical aspects, not as a classical image of beauty.

This is precisely the subject matter of disability studies: How do we ensure that people with a disability, whether visible or not, and their bodies are recognised as a part of human diversity? What is needed to guarantee that all people, in all their diversity, are naturally regarded as forming a part of and contributing to society?

This question arises in every sector of society, and the world of art and museums is no exception. How can museums make more space for visitors with various disabilities in a way that corresponds to thinking about diversity? And, in particular, how can art help us to extend and challenge our views of who and what is normal or not? Disability studies and museums can be interesting partners for one another in joining forces for inclusion. After explaining what disability studies is and what disability researchers do, we shall indicate why the museum of the 21st century is an ideal place to bring about inclusion. In doing so, we reinterpret the traditional *Wunderkammer* in a way that challenges conventional thinking and viewing.

<u>Disability = diversity = richness</u>

The discipline of disability studies has not been existence in the Netherlands for long. Since 2009, partners have been working together to create the discipline through the Disability Studies in the Netherlands Foundation, while internationally the discipline has been in existence since the 1980s. The foundation's mission is to collect, develop

and share knowledge in order to contribute to a good quality of life for people with a disability and their immediate circle, and to an inclusive society. Research, education and knowledge networks (knowledge transfer and exchange) are the main instruments. The goal and methods are always interconnected: disability studies always involves the people concerned in every possible role, under the motto 'Nothing about us, without us'.

This is necessary. On the one hand, there is a large and growing group of people who have to deal with disability in some way or other, whether physical, psychological or cognitive. According to the WHO, around 15% of the world population lives with chronic disabilities (*World Report on Disability* 2011). The corresponding figure for the Netherlands is 12% (Netherlands Institute for Social Research). If we include relatives, friends, partners and colleagues, a large group in our society experiences every day the obstacles that the same society creates for people with a disability – at close quarters or personally. Furthermore, the quality of life of people with a disability and their participation in the social domain can be greatly improved by comparison with the average Dutch citizen (Meulenkamp 2011; Hemstede 2013).

It is not for nothing that considerable stress has been laid on improving the participation of people with a disability label in the last few years: think, for example, of the Social Support Act (WMO), the Participation Act, and the UN Convention on the Rights of Persons with Disabilities. All these laws state that inclusion and participation are general guiding principles and that besides being a right of persons, it is also an obligation of governments. The UN convention that the Netherlands has finally ratified is particularly insistent on the importance of the freedom of people

with a disability to make their own choices and of the strengthening of their position (United Nations 2006).

Knowledge from experience as a gift

Inclusion can be summarised as recognising that 'people with a disability matter, that they participate and that society views differences positively' (Kröber in: Hemstede 2013). Working towards inclusion is working towards a hospitable society in which 'it is normal that we are here' (Kal 2003). Inclusion, though, goes a step further than participation; whereas participation is often concerned with the question 'How can you participate in society in spite of your disability?', the key question for inclusion is 'How can you contribute to society in your own personal way?'.

The question of whether people are themselves involved and their voice is heard is crucial, leading to a different vision of disability from the conventional one. A disability is often seen as an individual problem to be solved by medical or other professionals to enable a person to 'take part' as far as possible again. Disability studies arose, however, from the recognition that people with a disability are left in the hands of experts and deprived of their own experiences and visions. Such a narrowly medical view also glosses over the fact that disabilities are largely a social issue: whether a disability is experienced as a handicap depends on how the public space is organised and on conventional thought regarding who and what is normal. Setting out from this social model of viewing a handicap, disability studies has preferred an integral cultural model of viewing disability: this entails taking a critical view of what counts as a disability, what inclusion can mean, and how exclusion is

given form. (We deliberately use the word 'disability' rather than 'handicap' because the former critically pinpoints social factors that work in a disabling way.)

Disability studies also examines the question of how disabilities are represented in our everyday culture and set out to counter stereotypes with examples taken from experience. Disability studies is opposed to thinking in tidy compartments and stigmas, and are emancipatory in striving for an inclusive society. We share this activism with other disciplines, such as mad studies, gender studies or queer studies. We recognise the same spirit in the Van Abbemuseum project Queering the collection: 'The process focuses on what is awkward, unexpected and fluid in identity, sexuality and politics. Queering sees sexuality as something fluid and rejects the general categories and standards' (Van Abbemuseum 2017).

This transforms disability from an unambiguous, personal medical condition to a complex social phenomenon that changes and *can* change depending on time and place. This creates scope for a positive appreciation of the experiences and critical voices of people with a disability and the transformative social force that can proceed from that. For example, a project to make the Brussels metro more accessible for people with a visual disability led to an analysis of how, generally speaking, people can feel more at home in a chaotic environment like a metro station. The routing and other resources needed by people with a visual disability proved to make those places more welcoming and easy to negotiate for others too (DeVlieger 2012). So the experience-based knowledge of people with a disability can make a contribution to society, but only if society is receptive to that input. This is only possible once people recognise that diversity offers richness and that disability is an aspect of human diversity.

Disability studies and art

Museums too must respect legislation and conventions that oblige them to be inclusive, but thinking about art and inclusion goes further than that. As the British anthropologist Tim Ingold puts it: 'A place owes its character to the experiences it affords to those who spend time there – to sights, sounds and indeed smells that constitute its specific ambience' (Ingold 1993, p. 155).

We hope that museums will discover that inclusion makes them richer places of experiences for *all* visitors. The Van Abbemuseum Special Guests programme demonstrates that this is possible in a powerful, playful and surprising way. In the museum you can smell, feel and represent art with your own body; thus the museum space offers a multiplicity of sensory experiences.

Art is an ideal means to achieve what disability studies stands for. The substantive ink between art and disability studies is multi-layered. Art is an important social domain for inclusion. This works in two directions: first, the world of art (for example, the museum) can itself be a welcoming place for people in all their diversity, including persons with a disability. (We shall return to the accessibility of museums later.)

Second, their disability does not stop people from engaging with art as artists, critics or, for example, through outsider art (by people with psychiatric labels). Sometimes this can lead to the emergence of new art forms, such as deaf poems in which poetry, sign language and performance art are combined. (See e.g. the DVD by Emmerik et al. 2005).

In providing answers to the question of how people can learn to think differently about such polar opposites as abnormal/normal or healthy/ill, disability studies sets out to be not only theoretical, but also playful and transformative. They aim to bypass the domain of rational language as it is not fully available to everyone. The search for a different language and images is part of the nature of art.

Disability studies in the Netherlands is increasingly using art as a basis for the development of knowledge about community and participation, for instance via arts-based research and creative, cooperative research methods (together with the people concerned).

The museum as a welcoming space

A museum that wants to implement an inclusive policy is faced with four challenges: physical, mental, financial and digital accessibility (Sergeant 2015). These challenges match the principles of Universal Design. Universal Design is about making buildings accessible in the broadest possible sense by taking the reality of a diverse population into account right from the start. Universal Design comes from architecture but its field is much broader. It is a way of looking and a philosophy based on the richness of diversity. Universal Design takes differences into account in advance, instead of making adjustments or focusing on individual personalised solutions later (UDL Nederland 2017).

Physical accessibility

Experience-based experts emphasise three forms of physical accessibility: making the museum accessible, making it possible to enter through the main entrance and not

through the basement, and making usable tools and methods to discover works of art or objects (Sergeant 2015). Unfortunately, physical accessibility is often not a reality. The buildings are often not adapted to the aids used by people with a disability. They are often not (all) easy to enter, or only via a complicated system of corridors and lifts afterwards. Many works of art are not easy to see, touch, hear or feel. It is a creative challenge for museums and artists to enable people to experience art not only visually, but also by hearing, feeling, smelling and tasting.

If we are to explore and discover an object, it has to be perceptible by our senses. This process of perception and appropriation is a form of translation: the translation of sensory perceptions into ideas and feelings. Sometimes we convert these ideas into words or sketches, or they may even lead to changes in our lives. 'I' have been changed, have learnt something, and now see differently. A museum is par excellence a place that creates opportunities to perceive and translate images into ideas, words and new images. This process of perception and learning takes place in different sensory ways (Dewulf 2012).

Mental accessibility

Mental accessibility is concerned with questions like: How can we provide a warm welcome? How can we address and approach visitors respectfully? How can we provide information about the collection so that a lot of people can understand it? Which training do members of staff require for this? How can we ensure that visitors feel personally addressed without a sense of (positive) discrimination, patronising or awkwardness? In that sense, some people are also critical of the programme title 'Special Guests' used by the Van Abbemuseum for suggesting that persons with a

disability form a separate category. Or are we allowed to make mistakes and is this the key to successful inclusion? We believe so.

Instead of one-off initiatives such as the Day of the Blind or free admission for persons with a disability, mental accessibility is about the creation of an environment in which people in all their diversity can enjoy what the museum has to offer and can obtain information about it via various media – word, image, sound, film, etc.

Mental accessibility is also about the creation of spaces in which people feel welcome without the need to conform. This is where dilemmas arise: How do we do this respectfully? Can we call for silence? Should people be allowed to touch works of art? Does the museum have a code of behaviour, and is it explicit and clear enough? How do we deal with reactions and criticisms of other museum visitors? Should we intervene if people do not abide by the code of behaviour?

Financial accessibility

Inclusion also means policy for all financially, so the museum must take specific groups into account beforehand. People on a tight budget – a category that includes many people with a disability – are also entitled to enjoy culture. The *Uitpas* scheme of the city of Ghent (Stad Gent 2017) is inspiring in this respect. The digital information on the pass determines to which discount the holder is entitled, thus enabling poor people to obtain a personalised admission price in a discrete manner. This stimulates the enjoyment of art and participation without stigmatisation.

Digital accessibility

E-inclusion is about the right to be able to take part in the digital society. In order to do so, you have to be able to understand what happens where and when. In our

society information is primarily conveyed digitally. Mailings, newsletters and social media play a major part. People with a cognitive disability are often unable to find this digital information: because they do not have a computer, tablet or smartphone, because they cannot read (well), or because they are overwhelmed by the mass of information. This is sometimes difficult for persons with a visual disability too.

The digital gap – the inequality in society between those with access to and comprehension of digital information and those without – can be filled by offering courses, but also by a clear website and the use of forms of communication other than written communication.

The Flemish Network Organisation Konekt has conducted research on the accessibility of cultural centres together with persons with a cognitive disability. One of the main findings was that this category can benefit from trailers – short videos that provide insight into what museum visitors can expect from a collection, exhibition or works of art. Trailers can be useful for other visitors too.

The museum as Wunderkammer

Wunderkammers are also known as curiosity cabinets. These Wunderkammers emerged in the sixteenth century and were 'places in which collections of precious works of art (Artificialia), rare natural phenomena (Naturalia), scientific instruments (Scientifica), exotic objects (Exotica) and curiosities (Mirabilia) were housed and displayed'. (Collectors Room Berlin, Stiftung Olbricht).

We would like to conclude by playing with terms like wonder, curious, extraordinary, abnormal/normal and strange. These words express our astonishment, but also our distance and insecurity when we are confronted by somebody or

something different. A museum is a place where you find what you were not looking for: 'A peculiar environment awaits you: one in which almost nothing can be taken for granted', is how *The Guardian* wrote about the exhibition The Production Line of Happiness (Cummings 2015). This makes the museum a place that challenges you to explore objects and the space between ourselves and the object – that exciting area of multisensory perception and interpretation.

People with a disability sometimes perceive in a different way from the conventional one and thereby enrich our idea of what perception is. That is the kind of place that a museum ought to be: one where we can perceive differently, where we can be different.

This makes the museum a special kind of *Wunderkammer* (Sergeant and Verreyt 2016). The traditional curiosity cabinet contained different things: rarities, obscurities, exotic items, neatly arranged in compartments. We see modern museums as 21st-century *Wunderkammern* where encounters with unfamiliar objects and images can show us just how and how quickly we often pass judgement. These encounters confront us with our way of thinking in compartments and make it easier for prejudices about what is normal or abnormal to be called into question. We can discover and learn to be receptive to what is new and different in the museum of the 21st century where objects are positioned and connected to create a narrative. It also enables us to experience that perceptions are highly personal and connected with our own life stories.

Ideally a museum is an ode to perception and diversity, to rooms where wondrous things are connected with one another and where wonderful experiences are allowed – for everyone.

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