4 A transdisciplinary and participatory exhibition: Setting the bar for good practice – *TOUCHDOWN. An exhibition with and about people with Down's syndrome*

4.1 Introduction

This chapter investigates the development process of a thematic temporary exhibition and reflects on the value of a transdisciplinary approach as a tool for validating and championing embodied knowledge alongside academically and curatorially based disciplinary knowledge. It is the first of three case studies which have informed and constitute the subject of enquiry of this practice-based research. In this chapter I argue that the exhibition *TOUCHDOWN. An exhibition with and about people with Down's syndrome* (2016–2018) serves as an example of a successful transdisciplinary and socially participatory project from the cultural realm that integrated different ways of knowing and producing knowledge, including advanced scientific knowledge.

The exhibition and the accompanying book aimed to research and tell the history of people with Down's syndrome for the first time, as they had hardly been part of a shared written history so far, and not only in Germany. Including a wide range of disciplines such as history, archaeology, social science, genetics, medicine, and art, this curatorial research was conducted in a closely-knit participatory production process, together with a group of people with Down's syndrome. Focusing on describing and analysing the specific actions that were taken to create and facilitate integration within the curatorial team, my practice-based research also tries to unveil where we failed to facilitate *interdisciplinarity* (and in this case more specifically transdisciplinarity) which, also judging from this experience, needs to be created and enabled and is thus a predominantly practical and process-oriented tool. An *interdisciplinary* or transdisciplinary research strategy or collaboration process is intrinsically integrative and thus highly fitting for addressing societally relevant topics from a multitude of perspectives.

The following sections of this chapter will first introduce the exhibition (4.1), and subsequently analyse the development process of the exhibition along the basic steps and phases during its production. Section 4.3 will discuss the process of building the curatorial team including people with and without Down's syndrome, whereas section 4.4 is dedicated to investigating the process of conceiving of the exhibition's concept and storyline (4.4.1), with a special focus on using a joint language amongst participants with and without a learning disability (4.4.2). The choice of objects as well as the production of interpretative texts for the exhibition and the accompanying book will be explored in section 4.5. The challenges of developing the exhibition design in this specific project will be the focus of section 4.6 of this chapter. Section 4.7 will position this transdisciplinary and participatory project within the theoretical framework of the overall book.

4.2 The exhibition *TOUCHDOWN*

The exhibition TOUCHDOWN. *An exhibition with and about people with Down's syndrome*[1] was developed by the Bundeskunsthalle in cooperation with the research project TOUCHDOWN 21,[2] which was founded by the human geneticist Katja de Bragança. The exhibition was staged at three venues: At the Bundeskunsthalle,[3] Bonn, from 29 October 2016 to 12 March 2017 (Fig. 4.1), at the KulturAmbulanz,[4] Bremen, from 14 May to 27 August 2017 (Fig. 4.2), and at the Zentrum Paul Klee,[5] Bern, from 24 January to 13 May 2018. Altogether, the show attracted 81,400 visitors, a figure which considerably surpassed our most

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[1] I have published a short discussion of this exhibition in: Baumgart and Pleiger 2018.

[2] The research project TOUCHDOWN 21 is accessible at: https://touchdown21.info/de/news/archiv.html (last accessed 10 July 2023). It will be introduced in greater detail in section 3 of this case study.

[3] The Bundeskunsthalle produced a short film about the exhibition in 2016: Touchdown – Eine Ausstellung mit und über Menschen mit Down-Syndrom – Behind The Art (https://www.youtube.com/watch?v=wF7w_E71eHs) (last accessed 2 April 2024).

[4] Accessible at: https://www.kulturambulanz.de/kalender/2015-2018/index.php (last accessed 10 July 2023).

[5] Accessible at: https://www.zpk.org/en/ausstellungen/rueckblick_0/2018/touchdown-1583.html (last accessed 10 July 2023).

ambitious hopes.[6] As it turned out, an exhibition about Down's syndrome was, at that point in time, anything but an 'outsider' or 'niche' project, a fear that had been raised in an initial internal discussion about the exhibition proposal. Instead, the exhibition was received as being of great societal, political, and, surprisingly, also of high personal relevance to many people.

Fig. 4.1 and 4.2: Exhibition posters of the first and second venue of the exhibition TOUCHDOWN *in Bonn and Bremen, 2016/2017. The photos show Johanna von Schönfeld and Daniel Rauers, 2013,* Ohrenkuss *edition 'Superkräfte' (Superpowers) (details), © Martin Langhorst (www.lichtbilderlanghorst.de). Posters: © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn / © KulturAmbulanz, Bremen.*

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[6] The estimated figure for the first venue in Bonn was only 4,500 visitors. The final figure was over 35,000.

4.2.1 The exhibition title and a twofold storyline

The exhibition title was chosen with great care and reveals some of the different motivations and intentions behind this project. As stated in the introduction to the book accompanying the exhibition, written by Katja de Bragança, Heinz Greuling, Rikola-Gunnar Lüttgenau, and Henriette Pleiger, 'TOUCHDOWN is an English word for landing. We hope it is a pinpoint landing,' (de Bragança et al. 2016, p. 9).[7] Apart from this more common meaning, which suited the exhibition's storyline, the word 'touchdown' in our context also implied that we wanted to really 'touch' our subject, Down's syndrome. We wanted to get closer to it, instead of shying away from it. Therefore, we selected this word as the main exhibition title because its multiple connotations perfectly matched both intended layers of the exhibition narrative. These two layers comprised a fictional (science-fiction-style) storyline and another narrative rooted in real life. Especially the fictional part of the story became an important vehicle for participation as it was later fantastically extended and embellished by the group of people with Down's syndrome, who took part in the exhibition-making process. This process was supported and facilitated by the comic artist Vincent Burmeister as well as by exhibition designers Harry Vetter (Bonn, Bremen) and Paula Sansano (Bern).

The fictional story went like this: 5,000 years ago, a First Mission from the planet kUMUSI had settled on planet Earth. The inhabitants of kUMUSI were people with Down's syndrome. In 2016, a Second Mission arrived and 'touched down' on Earth in a spaceship (Fig. 4.3) to investigate and subsequently report to the kUMUSI authorities whether any descendants of their people were still living on Earth. The Second Mission was to explore their history and present living conditions, and finally ask them whether they wanted to stay on Earth or return home. The exhibition was the story of the Second Mission's research expedition, and the accompanying book, titled *TOUCHDOWN. Die Geschichte des Down-Syndroms* (TOUCHDOWN. The History of Down's Syndrome, de Bragança et al. 2016), was their journey's logbook.

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[7] All quotes, especially from the book that accompanied the exhibition and the interviews conducted for this case study, were translated from German to English by the author, if not stated otherwise. Apart from the texts in a simplified language that we called 'clear German' (see section 4.4.2 of this book), the exhibition also provided texts in Easy English, translated by Ute Schulz, www.easy-english-experts.de (last accessed 10 July 2023) in 2016. These will be used in this case study as well.

Fig. 4.3: The spaceship of the Second Mission, illustration by Vincent Burmeister for the exhibition TOUCHDOWN *and the accompanying book (de Bragança et al. 2016, pp. 12–13). The red symbol of the Second Mission, representing trisomy 21, was created by Sebastian Urbanski, a German actor with Down's syndrome (de Bragança et al. 2016, p. 224), © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.*

Fig. 4.4: The crew of the Second Mission, illustration by Vincent Burmeister, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

This story was told in comics by Vincent Burmeister and texts written by people with Down's syndrome. In the exhibition, the comics were presented in life-size. The portrayal of the crew members of the Second Mission (Fig. 4) as strong and confident people with Down's syndrome (created in a superheroes comic aesthetic) stood against their usual depiction as constantly in need of help – for example, by self-help groups and other social organizations relying on donations. The seven crew members (together with their dog) represented a fictitious *interdisciplinary* research team, as each of them was a specialist in a different discipline and was equipped accordingly (de Bragança et al. 2016, pp. 22–31): captain wELLE, officer lAPU, security woman jUDOYOU, engine driver fLOWREW, doctor aZU, communication expert lAPONION, adviser tEIYU, and the dog called '!'. Five of the altogether eight 'alien arrivals' were female (including the captain and the dog), and three were male.

4.2.2 The seven exhibition chapters

The story was structured in seven chapters or exhibition rooms: After (1) a spectacular spaceship (Fig. 4.3) landing on the roof of the Bundeskunsthalle (depicted in life-sized comics in the main building's foyer, and similarly staged at the next two venues in Bremen and Bern), the Second Mission entered room (2) which was called 'Today – Here and Now' (Fig. 4.5). Here, the crew explored the following real-life themes involved in the social and everyday life conditions of people with Down's syndrome, including education, work, money, love, marriage, violence, autonomy, and legal rights. In this room, the co-curators with Down's syndrome, for example, presented 'talking objects' that spoke of their various experiences.

Fig. 4.5: The second exhibition chapter 'Today – Here and Now' at the first venue in Bonn, 2016. Photo: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

In this first encounter between the fictitious Second Mission (and the exhibition visitors!) and people with Down's syndrome living in Germany today, the crew members from kUMUSI were introduced to the present real-life conditions of their people on Earth. After those first impressions they decided to do some historical research. In the following three exhibition chapters (3–5), the Second Mission tried to gather historical evidence of the whereabouts of the descendants of their First Mission throughout the centuries. The first room of this research excursion into history was room (3) titled 'The Invisibles – Searching for Traces in the Past' (Fig. 4.6). The results from this room – presenting only a few objects, amongst them two archaeological artefacts and one medieval document – were quite frustrating, because the historical evidence about people with Down's syndrome before the 19th century is extremely scarce.[8]

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[8] Our research for this room was mainly based on this article: Starbuck, J. M. (2011), 'On the Antiquity of Trisomy 21: Moving Towards a Quantitative Diagnosis of Down Syndrome in Historic Material Culture', in: *Journal of Contemporary Anthropology* II(1), pp. 19–44: https://docs.lib.purdue.edu/cgi/viewcontent.cgi?article=1019&context=jca (last accessed 11 July 2023).

Fig. 4.6: Uschi Baetz (left) and Verena Günnel (right) during a tandem guided tour in the third exhibition chapter 'The Invisibles – Searching for Traces in the Past' at the first venue in Bonn. Photo: Uschi Baetz, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.[9]

Stepping out of the small and dark room (3), room (4) felt like a mixture of relief and excitement. It was called 'The Great Appearance – John Langdon Down' (Fig. 4.7) and was devoted to the British medical doctor who first described Down's syndrome in 1866 (only much later to be identified as trisomy 21). Despite the later tragically racist history of the term 'mongolism' (sadly coined by Langdon Down himself, but at that point devoid of any racist connotation) in the late 19th century, this exhibition chapter nevertheless allowed for a positive depiction of the man and his exceptional work with and for people with Down's syndrome, making him a historical figurehead for them within

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[9] The image shows the 2,500-year-old skeleton of a woman excavated in Germany in the 1970s. The research related to these human remains and the reason for displaying them is elaborated on in section 4.5 of this book. We paid great attention to follow the established guidelines: https://www.museumsbund.de/wp-content/uploads/2021/07/dmb-leitfaden-umgang-menschl-ueberr-en-web-20210625.pdf, pp. 42–44.

their own history book. 'The Great Appearance' referred not only to the appearance of those with Down's syndrome on the 'world stage' but also particularly to Langdon Down's theatrical work with people with learning disabilities at Normansfield Hospital in Teddington near London.

Fig. 4.7: The fourth exhibition chapter 'The Great Appearance – John Langdon Down' at the first venue in Bonn. Photo: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

The last of the three historical rooms in the exhibition was designed as a separate chamber. Access to this room was intentionally not as straightforward as it was in the other rooms, because the curatorial team wanted to allow visitors to make a conscious decision on whether to enter this room (5) or not. It was named 'In the Twilight – The Extermination' (Fig. 4.8) and was about the Nazi era in Germany and Austria during which more than 300,000 disabled people were killed. The showcase in the centre of the room showed three empty glass containers. The labels on them told the names of three small children with trisomy 21 who were murdered in 1942 and 1943 in a Viennese hospital (Kinderfachabteilung Am Steinhof). Originally the glass containers held the brains of these children. The 'specimens' were used for medical education at least until the 1970s. The human remains were finally buried in 2002 (de Bragança et al. 2016, p. 169).

Fig. 4.8: The fifth exhibition chapter 'In the Twilight – The Extermination' at the first venue in Bonn. Photo: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

In the following exhibition chapter (6) 'Research – I am what [sic!] I am' (Fig. 4.9) the crew of the Second Mission resurfaced from the past to further investigate present issues. The focus here was on thoroughly informing the museum audience about the syndrome itself (especially about it not being an illness) involving genetics and health questions. On the table set up in this room stood a microscope. On every weekend during the exhibition period, human geneticists from Bonn University explained trisomy 21. The scientific knowledge that was explained here in clear language also included the unbiased information about prenatal diagnosis and abortion (the latter being an extremely difficult topic for people with Down's syndrome – emotionally similar to but ethically very different from 'euthanasia'). Other themes raised in this room were a more in-depth look at learning and education as well as the importance of family relations. The knowledge and information presented in this room was meant to enable and empower both people with Down's syndrome and their relatives to take independent decisions regarding their own lives, instead of being treated as mere medical and social 'objects' within our societies' administrative systems.

Fig. 4.9: The sixth exhibition chapter 'Research – I am what [sic!] I am' at the first venue in Bonn. Photo: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

The final room of the exhibition was dedicated to the sound installation (7) 'The Discussion – Staying or Leaving?' In an audio piece, people with Down's syndrome discussed this question among themselves including members of the Second Mission crew and people with Down's syndrome living on Earth today. At the end of the piece, they decided for themselves, in a secret vote, whether to stay on Earth or to return to kUMUSI, a decision people without Down's syndrome have all too often taken for them in the past and are still taking for them in the present.

Fig. 4.10: The last (seventh) exhibition chapter 'The Discussion – Staying or Leaving?' the first venue in Bonn. Photo: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

None of the texts written by people with Down's syndrome, in either the exhibition or the book, were corrected orthographically or regarding their content. All other texts that were written by people with just 46 chromosomes[10] were translated into clear language.[11] Apart from this consistent approach concerning a joint language, two of the most significant achievements of this exhibition regarding producing knowledge and enabling participation were the following: firstly, in addition to the exhibition itself the result was a history book written for and by people with Down's syndrome; secondly, people with Down's syndrome acted as paid docents in their own exhibition and were thus not only part of the knowledge production but also of the interpretation and dissemination of the knowledge generated during the process of making this exhibition. Especially this – at that time radical – approach to participatory educational programmes is today viewed as a milestone in the context of German museum education (see, for example, Maul and Röhlke 2018, Jacob 2017).

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[10] People with trisomy 21 have 47 chromosomes (a third copy of chromosome 21). I am not using this distinction in a political sense.

[11] The term *clear language* will be further explained in section 4.3.

4.3 The transdisciplinary exhibition team: Involving people with 46 and 47 chromosomes and different ways of seeing the world

The following sections of this case study will analyse the development process of the exhibition along its production phases. The analysis will include reflections on my own role as manager and institutional co-curator in this exhibition case, using critical autoethnography, but it will also rely on three qualitative semi-structured interviews with my co-curators in this project. I spoke with Heinz Greuling (HG), physicist and TV journalist, on 26 February 2021. On 4 March 2021, I conducted a joint interview with Katja de Bragança (KB), human geneticist and founder of the pioneering magazine *Ohrenkuss* made by people with Down's syndrome (since 1998), and Anne Leichtfuß (AL), online editor and professional translator and interpreter for easy/clear language. On 25 June 2021, I interviewed Rikola-Gunnar Lüttgenau (RGL), historian, exhibition curator and head of strategic communication and public outreach at Buchenwald Memorial.[12] These four colleagues and I share the fact that each of us has only 46 chromosomes.

Approximately as many as 70 colleagues with Down's syndrome contributed to this exhibition at its three venues. The core group of people with Down's syndrome, who participated in the curatorial process, consisted of about 15 to 20 persons (in slightly varying constellations). It is therefore essential that their voices are included in this case study. I chose not to interview colleagues with Down's syndrome for this study due to ethical reasons,[13] but in order to achieve inclusion, I have drawn on several rich sources written and produced by colleagues with Down's syndrome for and in response to the exhibition: At least fifty per cent of both the exhibition texts and the published book (de Bragança et al. 2016) that accompanied the exhibition, were written by colleagues with trisomy 21. Some of their names are (in alphabet-

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[12] Because of the COVID-19 pandemic all three recorded interviews were conducted online via Zoom.

[13] According to the University of Manchester's 'Policy on the ethical involvement of human participants in research' (Version 2.2 May 2021, accessed 23 March 2023), 'involving vulnerable groups, including […] adults with special needs' would have led to a high-risk research setting. As the project itself produced enough material with direct quotes from our colleagues with Down's syndrome, this risk was avoidable and therefore not taken.

ical order): Julia Bertmann,[14] Natalie Dedreux, Angela Fritzen, Julian Göpel, Verena Günnel, Andrea Halder, Björn Langenfeld, Marc Lohmann, Jeanne-Marie Mohn, Antonio Nodal, Ansgar Peters, Anna-Lisa Plettenberg[15], Daniel Rauers, Johanna von Schönfeld, Paul Spitzeck, Marley Thelen, Martin Weser (full list of 56 names:[16] de Bragança et al. 2016, p. 292). After the exhibition in Bonn, in 2017, the magazine *Ohrenkuss* (including all authors mentioned above), published a special issue[17] reflecting on the exhibition, from which I will quote here as well. I have also consulted past project files, insofar as they do not violate any personal or institutional rights, especially with the aim of providing an accurate account of the development process of the exhibition.

The analysis of the practical process of making this exhibition starts with the following observations on how we built a transdisciplinary and socially participatory curatorial team to develop the exhibition narrative and content.

> Participation means:
> Everybody takes part. In everything.
> Because they can.
> And because they are allowed to.
> Because they have the possibility.
> (Carina Kühne, in: de Bragança et al. 2016, p.100)

I open this section with a brief autoethnographical account of the events at the beginning of this exhibition project. In 2013, I met KB, a human geneticist and founder of the progressive and highly decorated magazine *Ohrenkuss*, made

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[14] Julia Bertmann and Anna-Lisa Plettenberg formed perhaps the strongest engagement with the exhibition's content amongst this group, truly viewing it as 'their' exhibition (according to the interview with KB and AL on 4 March 2021). Julia Bertmann had a special role as member of the advisory board of the exhibition and ultimately also as our opening speaker.

[15] Among others from this group, Anna-Lisa Plettenberg was officially employed by the Bundeskunsthalle as docent for the exhibition *TOUCHDOWN* in 2016. She stayed on as a freelance docent and later also guided visitors through other exhibitions, for example about Ernst Ludwig Kirchner (2018) and Johann Wolfgang von Goethe (2019).

[16] This list of 56 participants with Down's syndrome only includes those who contributed to the first venue in Bonn and to the publication (see also https://ohrenkuss.de/team/; last accessed 11 July 2023). Additionally, many more people with Down's syndrome participated in the following two venues in Bremen and Bern.

[17] *Ohrenkuss … da rein da raus – 2017 – Ein Update*, no. 38 (February 2017), Bonn: downtown – Werkstatt für Kultur und Wissenschaft gGmbH, www.ohrenkuss.de.

by people with Down's syndrome. The invented magazine title – which when translated into English means 'Earkiss' – refers to an important or interesting word, sentence or story that stays in your head, instead of 'going into one ear and straight out of the other ear'. When founding the biannual magazine in 1998, KB at first intended it to be a research project (in the academic context of human genetics), aiming at understanding how adults with Down's syndrome 'see the world' (KB, interview). Although assisted in their work, the journalists and authors of this magazine are treated as professionals without the interference of their families or primary caregivers and without any correction in content and orthography.

Fig. 4.11: Authors of the magazine Ohrenkuss, *made by people with Down's syndrome, who participated in the exhibition-making process. Portrait series in the image: © Britt Schilling. Photo, taken on the opening day in Bonn, on 28 October 2016: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.*

Fascinated by this project, I suggested working together on an exhibition concept – back then without any idea of what such an exhibition could possibly look like. KB was enthusiastic about the idea, as she had at that time already started working on a larger participatory research project about Down's syndrome, which was supposed to serve as an 'academic umbrella', under which the exhibition could be developed as one possible product (alongside a website, a conference, and a number of publications). This still ongoing research project was named TOUCHDOWN 21 and later – amongst other support – received a large grant from the charity Aktion Mensch e.V., which the exhibition indirectly benefited from as well, especially regarding its unique educational programme at all venues, which required extensive training for docents with Down's syndrome. She had already been in contact with two TV science journalists, HG and Georg Wieghaus (GW left the team in 2015). HG had previously made a TV documentary on John Langdon Down (1828–1896), who first described the syndrome in 1866. GW had worked about 'euthanasia',[18] the euphemism used to cover up the murder of probably more than 300,000[19] disabled people during the German Nazi period. Both were experienced filmmakers and storytellers. RGL, historian, exhibition curator and back then interim vice director of the Buchenwald concentration camp memorial, also joined the team. Uniting us from the start was an interdisciplinary approach to the topic and the most important aim of all, namely that this exhibition should be developed together with people with Down's syndrome in a participatory process. In order to emphasize this aim early on, an official advisory board for the exhibition was implemented, consisting of Heinz Schott, in his function as a renowned medical historian, Julia Bertmann, a woman with Down's syndrome, as well as AL.

Interdisciplinary and transdisciplinary teams require three layers or levels of knowledge: (1) 'disciplinary knowledge' and (2) 'expertise in interdisciplinary […] collaborations', as well as (3) 'transdisciplinary competence', meaning (experience with) practical knowledge (Krainer and Smetschka 2014, p. 68, transl. HP). Our core exhibition team, consisting of up to seven people with 46 chromosomes and 15 to 20 people with 47 chromosomes, possessed all of these qualifications, but in hindsight, our collaboration within the team went through different phases that oscillated between integration and separation. Justified by the fact that this exhibition project was at the same time an ambitious research project in which we had to create new knowledge – 'and new images of Down's syndrome' (HG, interview) – and were thus in a 'constant learning and research process' (HG), these phases can be analysed by using

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[18] Here, setting the term 'euthanasia' in quotation marks means to acknowledge its unequalled history in the context of the German Nazi period.

[19] For this figure see: https://www.bundestag.de/dokumente/textarchiv/2017/kw04-de-gedenkstunde-490478 (last accessed 11 July 2023)

the research terminology from interdisciplinary studies introduced earlier, discerning between multi-, *inter-* and transdisciplinary processes. Apart from very intense integrative periods during the development process of the exhibition, which can definitely be characterized as *inter-* and transdisciplinary, we also had times when not 'everybody took part in everything' (see the above quote by Carina Kühne). These moments of separation – or lack of integration – might consequently be described as merely multidisciplinary.

During the interview, KB aptly described multidisciplinary research as 'flat', compared to *inter-* or transdisciplinarity which she understood as 'three-dimensional'. A 'flat' way of conceiving this exhibition would have been to just gather preconceived or separately commissioned bits of knowledge, but we soon found that there were hardly any academic answers to the questions we wanted to ask with this exhibition, which from the start intended to include disciplines such as history, science and art in order to create and present a bigger picture. A first drawn mind-map – which AL and KB named 'Koralle' (Engl. coral) – in the early conceptual phase (2014) 'quickly laid bare the fundamental gaps in knowledge about people with Down's syndrome' and 'it became clear to us that we would have to generate new knowledge on our own' (AL). This exhibition definitely required a 'three-dimensional' group effort. For the research project TOUCHDOWN 21, led by KB and AL, it was crucial to increase the state of knowledge about trisomy 21 *for* and *with* people with Down's syndrome, but independent from other stakeholder groups which – with best intentions, of course – have all too often represented only the perspective of parents of people with Down's syndrome, but have not paid enough attention to supporting their autonomy (KB and AL, interview).

One of the most important preconditions at the start of our teamwork was that we had to 'tune in' to a joint working culture, in which everybody had different abilities, expertise and subsequently also different tasks, but the main point about participation in this project was the flow of information and the warranting of a mutual understanding (KB and AL, interview). Lerchster and Lesjak state with respect to interdisciplinary research: 'Only the communication about the unifying and divisive aspects (within a team) enables a joint beginning. This already creates orientation and a (joint) culture' (Lerchster and Lesjak 2014, p. 89, transl. HP). During the process of developing the exhibition, we worked on various aspects of the content in separate subgroups, but all results had to 'go through the brains' (AL) of our colleagues with Down's syndrome, for example in a workshop about the discriminatory and racist history of the term 'mongolism'.[20] Therefore, in this specific exhibition case, even the moments of separation during the process of content development might be viewed as necessary steps in an *interdisciplinary* and transdisciplinary (instead of a merely multidisciplinary) research setting, in which a mutual understanding of the research process is crucial. Apart from contributing their own expertise to the exhibition content, KB and AL were our 'communication experts' – like lAPONION from the Second Mission – acting as 'interpreters' (RGL, interview) between the two worlds divided by one additional chromosome.

This process of creating a joint working culture also involved a special training for HG, GW, RGL and me, as we were invited to take part in a number of editorial meetings of the magazine *Ohrenkuss* in 2014 to get to know their mode of operation. On another autoethnographical note, on one unforgettable evening – I had rarely been so nervous before an event – I was asked by the editorial team to explain to them how Chinese characters work, because they wanted to write a letter to the Chinese artist Ai Weiwei[21], and they knew that I had earned an MA degree in Chinese studies. After I had told them about the historical abstraction process of pictograms while drawing the etymological evolution of the Chinese character for 'cat', I looked into their faces and asked what they had taken from my lecture. One astonishing response was: 'The Chinese language seems to be quite difficult, but I know one thing for sure: The Chinese don't know how to draw.' I had no clever answer to that at the time, but while I had been giving my brief presentation, another member of the team, Paul Spitzeck, had drawn a picture for me that played with the idea of visual abstraction in pictograms so deeply and beautifully as I had never seen before.

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[20] In order to understand how the authors of the magazine *Ohrenkuss* work, it should be added that a few years before the exhibition development started, the team had made a trip to Mongolia to underpin their research on 'mongolism'. This journey was documented in *Ohrenkuss* (no. 15, October 2005): https://ohrenkuss.de/ausgaben/46-mongolei.html) and had some repercussions in the exhibition, as a Mongolian yurt was set up in the museum square during the opening weekend in Bonn in October 2016 as a deliberately provocative and ironic invitation to the exhibition.

[21] See *Ohrenkuss*, no. 34, March 2015: https://ohrenkuss.de/ausgaben/25-wer-bin-ich-wer-bin-ich-nicht.html).

Fig. 4.12: Paul Spitzeck, Pictograms, 16 September 2014. Photo: © Henriette Pleiger, 2021.

This experience helped enormously to get to know each other's way of thinking and to earn each other's trust and respect as co-curators, which are essential ingredients for a successful participatory and transdisciplinary research process. 'Participation […] means going back and forth, exchanging looks and thoughts […]' (Hamers et al. 2017, p. 61), it means taking the time to engage with each other. KB and AL took it upon themselves to safeguard each organizational step of this integrative process particularly in terms of the developed content of the exhibition which was thoroughly discussed in numerous workshops with people with Down's syndrome in a long process of explanation, negotiation, consultation, and feedback over a period of three years (2014–2016, and after the opening in Bonn continuing for the following venues). Weekly smaller meetings and several multi-day workshops focussed on their understanding of, opinions about and suggestions for the exhibition content, especially regarding the extremely difficult topics of 'euthanasia' and prenatal diagnosis and its consequences (an abortion rate of over ninety per cent in Europe).[22]

Fig. 4.13: Members of the core exhibition team and the director of the Bundeskunsthalle, Rein Wolfs (2013–2019), on the opening day, 28 October 2016. From left to right: Heinz Greuling, Julia Bertmann, Rikola-Gunnar Lüttgenau, Henriette Pleiger, Rein Wolfs, Heinz Schott, Anne Leichtfuß, and Katja de Bragança. The portraits on the left wall show other core team members with Down's syndrome as individually named in section 2 of this chapter. Photo: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

Sadly, it was not wise planning that provided this seemingly comfortable timeframe of about three years, which proved to be absolutely necessary in hindsight, but the initial hesitance of the Bundeskunsthalle to accept the exhibition. HG said in the interview that he had felt an 'apparent timelessness'

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[22] Mansfield, C., Hopfer, S., Marteau, T. M. (1999). 'Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review. European Concerted Action: DADA (Decision-making After the Diagnosis of a Fetal Abnormality)', in: *Prenatal Diagnosis* 19(9): pp. 808–812. doi:10.1002/(sici)1097-0223(199909)19:9<808::aid-pd637>3.0.co;2-b.

when working with our colleagues with Down's syndrome, which was contradicted especially by me, who, as the exhibition manager and internal curator of the Bundeskunsthalle, had to deal with a continuously increasing time-pressure and had to act as the 'midwife' (HG) of the exhibition. KB and AL reflected in their interview that, when the initial idea for an exhibition had come up in 2013, they had estimated that it would take five years to realize this project. While for me three years seemed comfortable compared to the usual pace of exhibition-making in our institution it still seemed short from their perspective.

4.4 Developing a joint narrative and struggling with a joint language

The work on the actual exhibition concept had started with merely good intentions amongst the curatorial team without Down's syndrome (at the beginning consisting of KB, AL, HG, GW, RGL, and me), whose first aim was to develop the basic narrative of the exhibition in an *interdisciplinary* process among ourselves, in order to introduce the exhibition to the director of the Bundeskunsthalle, back then Rein Wolfs. It took almost two years, from 2013 to early 2015, for the exhibition to finally be accepted by the institution and for the curatorial team to be contracted. When that important milestone within the project history was reached, the team had already been working on the exhibition for many months. Apart from me as the institutional co-curator none of the curators had been paid for this work until early 2015.

As mentioned above, the initial team combined expert knowledge from disciplines such as human genetics, history, medical history, ethnography and art history, complemented by a strong expertise in journalistic, dramaturgical and exhibition-making methods, but nevertheless we just had a few thematic bits and pieces to start from: The scientific question 'What is a trisomy 21?', the almost complete lack of historical evidence before the syndrome was described by John Langdon Down in 1866, Langdon Down's photographic estate preserved in archives in London and Surrey, the devastating history of around 300,000 disabled people murdered during the German Nazi period, and the more recent question of prenatal diagnosis and abortion, to name just the most important facts with which we set out. How on earth would we be able to address all these topics in one narrative that would also be accessible and understandable for people with Down's syndrome, many of whom do not know about 'euthanasia' and abortion?

Regarding the latter question, we decided from the outset to only describe the facts around prenatal diagnosis and its consequences in order to inspire a better-informed public debate instead of providing set answers. We did not want to 'deliver a moral judgement' but instead 'provide neutral facts' (AL, interview) about this emotionally and politically highly contested topic, today also involving activists with Down's syndrome (see the conclusion of this chapter). Nevertheless, the exhibition clearly attempted to strengthen and empower not only grown-up people with Down's syndrome themselves but also parents of children with the syndrome, by creating a public and easily accessible exhibition as a forum for dialogue, where they were welcome, and by providing concise and comprehensible information as well as spreading hope regarding a fear-laden and often still socially tabooed topic. Apart from using a clear and barrier-free language, dialogue amongst visitors was, for example, also supported by creating an intimate atmosphere with the exhibition design (see section 5), and also by training guards and docents to be open to and supportive in case of questions and conversations.

But ultimately these real-life bits and pieces from the historical and present-day experience of people with Down's syndrome only started to make sense when we managed to weave them into an overall storyline. Of course, we could have just lined them up as an array of important facts in what would have probably turned out to be a very informative –multidisciplinary – exhibition, but as Victoria Forster writes in her excellent book *Collaborative Arts-based Research for Social Justice*, 'arts-based storytelling in research' can result in 'immersive tales' that 'are constructions, just as accounts produced by more conventional methods are, but they arguably offer something extra, some temptation to *listen*' (Forster 2016, p. 52, emphasis added). Storytelling may help 'to reach out and engage with an audience in order to raise awareness of marginalised groups and challenge stereotypes' (p. 52). It is exactly this, what we wanted to achieve with the science-fiction story that we came up with (see section 1 of this chapter). But this story had to be tried and tested by our colleagues with Down's syndrome. Was this a story they could relate to? And did they want to adopt and transform it into their own story, as we hoped?

Four important methodological vehicles or tools were crucial to engaging and including colleagues with Down's syndrome into the creative process and thus enabling transdisciplinary research by integrating different ways of knowing: (1) thinking through and embellishing the basic science-fiction story that we set out with, and working on its visualization (section 4.4.1), (2) using clear language throughout the process and in all texts to uphold communication and information among the diverse team (section 4.4.2), (3) continuously working with a model of the exhibition space, and (4) choosing and creating objects for the exhibition. Points (3) and (4) will be discussed in section 5 of this chapter.

4.4.1 Exclusive superheroes

When presenting the science-fiction story that introduced people with Down's syndrome as a 'species from outer space' in an early meeting at the Bundeskunsthalle in 2015, a colleague from the institution's education team asked, whether we were not afraid that the story might be received negatively as being 'exclusive' rather than 'inclusive'. KB and AL took this question to their next meeting with the colleagues with 47 chromosomes and came back to us with the following answers, which confirmed, what we had already known and what had inspired our fictitious narrative in the first place: the perception of them as 'aliens' is, sadly, a part of their reality.

> Down syndrome is beautiful.
> And the Down syndrome for others not knowing I came from the moon
> or I may have fallen from the sky.
> (Ruth Schilling, transl. HP)[23]
>
> I have Down syndrome, but I stand by it and I am not an alien, because I am like I am,
> and everybody should understand and respect me.
> (Svenja Giesler, transl. HP)[24]

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[23] Quoted from: https://touchdown21.info/de/seite/5-trisomie-21/article/38-welt-down-syndrom-tag.html (last accessed 10 July 2023).

[24] Quoted from: *Ohrenkuss*, 'Du bist ein Mensch' (You are a human being), no. 34, October 2010: https://ohrenkuss.de/ausgaben/34-du-bist-ein-mensch.html (last accessed 10 July 2023).

People with Down's syndrome know the uncomfortable feeling of alienation very well, and they are used to being stared at. We wanted to work with this predominantly negative experience and turn it into something strong and special. These new 'aliens' in our science-fiction story were, in fact, superheroes: They were cool, intelligent, and highly specialized astronauts, who had travelled through space and were able to move on Earth with a confidence that was based on their 'exclusivity' in a very positive and empowering sense. In the second exhibition chapter 'Today – Here and Now' (see Fig. 4.5), which focused on the social and everyday-life conditions of people with Down's syndrome, we juxtaposed the life-sized comics depicting the Second Mission with a very telling installation. Anna-Lisa Plettenberg and Daniel Rauers had agreed to being filmed just standing upright and gazing into the camera for some minutes. These two filmed portraits were displayed in almost life-size. They were deliberately inviting visitors to look at them – stare at them – without having to fear an awkward reaction, but in doing so, people gradually felt ashamed of their own awkward behaviour, as several visitors expressed to guards and docents during their visit.

Being literally stared at, as if they were 'aliens', is a reality that people with trisomy 21 do not like, of course, but – to our great relief – our colleagues still welcomed the analogy and its irony, and enjoyed immersing themselves into embellishing the story of the Second Mission's adventurous journey from the planet kUMUSI to Earth in all its wondrous details. The comic artist Vincent Burmeister was essential in this process as he developed the characteristics of the crew of the Second Mission as well as all their technical gadgets and the design of their spaceship together with the co-curators with Down's syndrome (de Bragança et al. 2016, pp. 10–33; see also Fig. 4.3 and 4.4 in this chapter). This extremely creative and inventive process in itself (see *Ohrenkuss*, no. 38, February 2017, pp. 8–11) could be described in terms of an arts-based research method, for not only did it deepen all participants' factual knowledge (for example about space travel and planet Earth as seen from outer space (pp. 17–19), but it also opened up a window to the way in which our colleagues with Down's syndrome viewed themselves. The fictitious crew of the Second Mission resembled some members of the group in many details (such as their interests and favourite food, for example). The crew apparently turned out to become an alternative version of themselves, just in a slightly freer, cooler, and perhaps also a little bit brighter parallel universe.

> Earth is dark is. Dark is, all of stone. And the moon, too.
> (Björn Langenfeld, in: de Bragança et al. 2016, p. 21, transl. HP)

The science-fiction story held together the diverse array of topics, objects and artworks on display and had therefore also an important methodological function with regard to exhibition-making. James Quina and Jean Greenlaw have early on advocated science fiction as a method for interdisciplinary education (Quina and Greenlaw 1975, pp. 104–111), because a future-oriented 'broad spectrum approach' to knowledge and education allows for speculation and creativity by cutting 'across broad fields of knowledge' (p. 106). 'Science fiction provides a bridge to possibly an infinite range of knowledge' (p. 111), and it is this open approach to and perception of knowledge that suited our endeavour with this exhibition project, which was also about exploring 'strange new worlds, to seek out new life and new civilizations, to boldly go where no man [and no woman] has gone before.'[25] However, we were not aiming to merely speculate on our topic – although the scarcity of facts about Down's syndrome might have suggested it – but we definitely wanted to cross disciplinary boundaries to increase knowledge about the topic from more than just a medical perspective.

4.4.2 A joint foreign language

Both, using a fictional storyline as well as using a clear language as a joint language (or meta-language) – that for some of us felt like a foreign language – were, in fact, *interdisciplinary* and transdisciplinary tools or methods to synthesize our exhibition narrative and to integrate our mutual understanding of the exhibition's content. Both tools were essentially 'bridges' between two different ways of seeing the world. Klein mentions 'the epistemological challenge that transdisciplinarity presents' as it calls 'into question disciplinary thinking', as opposed to 'forms of multi- […] and *inter*disciplinarity' (Klein 2004, p. 524, italics added). This means that transdisciplinarity admits other forms of knowledge into the realm of predominantly disciplinary knowledge production. Transdisciplinarity 'is not a new discipline', it is 'the science and art of discovering bridges between areas of knowledge and different beings' in order to 'permit genuine dialogue' (Klein 2004, p. 516).[26]

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[25] *Star Trek*, the starship's mission: https://en.wikipedia.org/wiki/Star_Trek:_The_Original_Series (last accessed 11 July 2023).

[26] Based on Nicolescu, B. (1996). *La transdisciplinarité: manifeste*. Paris: Editions du Rocher.

AL was the professional translator and interpreter in this exhibition project. Being very experienced in all regulated forms of simplified language in German,[27] she chose for us, what we called a *clear* language, a free form closer to 'Simple Language' rather than 'Easy Language'. This clear language was supposed to be understandable for all participants and visitors to the exhibition and all readers of the accompanying publication, without being easy in an infantile way. Unlike regular Easy German, we included foreign words and complex technical terms, but always explained them. The readers were taken seriously as intelligent adults, being the main target audience, while at the same time supporting them in case of a learning disability. It turned out to be a language the great majority of our visitors seemed to be comfortable with, as many of them remarked on this after their visit to the exhibition (see Jacob 2017, p. 78, 86).[28]

In his interview, RGL observed that by using clear language we refused to be divided in an 'us' and 'them', which would have been the case if we had simultaneously used standard and easy language. All texts were either written by people with Down's syndrome or, judging from the language, could have been written by people with Down's syndrome, and thus seemed to be entirely speaking from their 'inner perspective' (RGL, interview). This appearance did not match reality, but with the decision to only use 'their' language, the curatorial

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[27] The German system largely discerns between 'Simple Language' (Einfache Sprache) and 'Easy Language' (Leichte Sprache). 'Simple language is a simplified version of standard language. Another name for simple language is "citizen-oriented language". It often differs only slightly from the original texts and is also not visually recognisable at first glance as an easily understandable text. In Simple Language, sentences are shorter and the sentence structure simpler than in standard German. Simple Language avoids foreign words, technical terms and metaphors wherever possible. The aim of Simple Language is to inform and reach as many people as possible. This includes people with low reading skills. Easy language is often confused with simple language – but there are clear differences. This is also due to the fact that Easy Language was developed specifically for people with disabilities and learning difficulties. Unlike Simple Language, Easy Language follows clear rules. These include language rules, content rules and spelling rules. There are also recommendations for text design, because barriers can also occur in media design. Unlike Simple Language, Easy Language follows its own rules for spelling.' Cited from: https://www.capito.eu/en/what-is-easy-to-understand-language/ (last accessed 22 March 2023).

[28] The texts in the exhibition were provided in clear German and Easy English. Unlike the freer handling of our native language German, we decided to stick to the official rules in the case of Easy English.

team without Down's syndrome built a strong bridge towards a marginalised group of people and expressed firm solidarity with them and their families.

HG admitted in his interview, that, in all honesty, he wished that we had allowed ourselves to speak in our own languages (standard German and clear or simple German) respectively, as he was struggling with having his own texts translated into clear language. I, myself, had felt an initial reluctance about this radical step, too, as it meant to let go of the control over the text production for the exhibition and the accompanying book. As the responsible exhibition manager, I was not used to sharing responsibility in such an important part of the project. But we all supported this joint decision, and the result proved us right. This was a joint language that enabled the transdisciplinary integration of knowledge as well as a socially participatory and empowering dialogue by supporting a mutual understanding.

4.5 Experts in their own right: Object choices and the production and dissemination of different types of knowledge

Our exhibition narrative and choice of objects had to enable two things: Firstly, a storyline and language that *all* visitors with 46 and 47 chromosomes would be able to follow, and secondly, a flexible choice of objects, open to suggestions and personal creations by people with Down's syndrome. One method to achieve – and continuously adapt to – this aim was working with a scale model of the exhibition space from the start in order to document and comprehend our joint progress.[29] This method[30] can likewise be understood as an *interdisciplinary* and transdisciplinary tool to facilitate the integration of knowledge.

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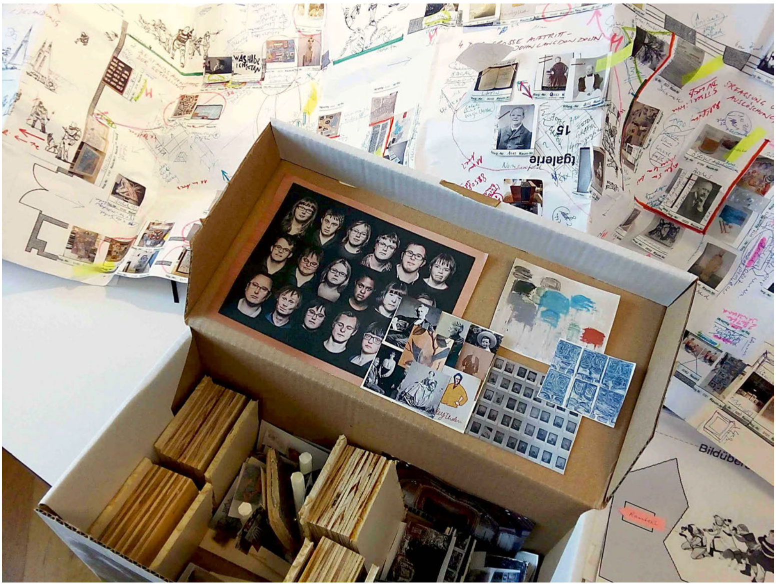
[29] Jade French describes a similar method in her excellent practical guide for inclusive curating (French 2020, pp. 99, 100).

[30] And this method lives on until today. After the exhibition's three museum venues, the research project TOUCHDOWN 21 transformed the exhibition into a high-quality model that is still used as a performative and educational tool, called *TOUCHDOWN mini*. This tool evolved from the didactical model that was used for the workshops and docent training with people with Down's syndrome during the exhibition-making process. Numerous performances and educational workshops have been staged in universities, schools, theatres and at festivals since 2018, not only in Germany, but for example also in Kiev, Ukraine. See https://touchdown21.info/de/seite/6-vermittlung/article/291-touchdown-21-mini.html (last accessed 11 July 2023).

Fig. 4.14: The first draft of a layout for the exhibition TOUCHDOWN *and the remains of an early exhibition model. Photo: © Henriette Pleiger, 2021.*



The exhibition model not only helped with developing, understanding, and memorising the exhibition storyline, but it also helped us all with finding out what kind of objects would speak to all the questions and content mentioned earlier that we wanted to include in the exhibition. Apart from historical and scientific objects, mostly chosen by the curators without Down's syndrome – for example from the estate of John Langdon Down or from a medical context for explaining trisomy 21 – we naturally wanted to also incorporate objects either chosen or created by people with Down's syndrome as experts in their own rights. These could be objects from their everyday life – we later called these objects 'Sprechende Gegenstände' (Engl. talking objects; see Daston 2004) – or artistic creations. One of these 'talking objects' was a plastic imitation of slices of cold cuts.

> Julia Bertmann's slices of cold cuts: Addressing people with 'Du' and 'Sie'[31]
>
> Many people with Down's syndrome look younger than they are.
> Therefore, it is often difficult to estimate their age.
>
> 'How I feel: I don't feel old. And you cannot tell that I am 35 years old.
> People say to me: "One does not see it."
> An example: I go to Edeka and do shopping.
> First, I go to the meat counter and buy cold cuts.
> The seller asks: "Do you [German: Du] want a slice of cold cuts?"
> Then I say: "No, thanks. You can address me with "Sie"."
> Then she is perplexed and says sorry.
> Then I buy bread. The bread seller asks: "Which bread do you [German: Du] want?"
> I roll my eyes and say the sentence again: "You can address me with 'Sie'."
> Then the bread seller says: "Sorry. I didn't know that."
> When I came to the same supermarket next time, the same thing happened again.
> Then I said: "I want to talk to the manager".'
> (Exhibition text by Julia Bertmann, see also de Bragança et al. 2016, p. 50, transl. Ute Schulz)

These 'talking objects' provided stories that were both written out on exhibition labels and were also publicly told by docents with Down's syndrome during their tours through the exhibition. Other 'talking objects' included a set of keys from Julian Göpel representing the autonomy of living in one's own flat, or an alarm clock chosen by Verena Günnel to explain that many people with Down's syndrome have difficulties with comprehending time and time periods, turning clocks into essentially important devices for mastering their daily schedules (de Bragança et al. 2016, pp. 46, 47).

Apart from these everyday-life objects, we also wanted to include art by people with Down's syndrome as one of their most important means of ex-

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[31] 'Du' is the German informal form of 'you' used to address children, family members, and close friends, while 'Sie' is the polite form that is used to address adult strangers.

pression apart from texts, but not in a – nowadays quite common – display of 'outsider art'[32] without giving any context of the artists' biographies and living conditions. We were looking for art that expressed a freely chosen idea or reflected on a situation or topic from their everyday lives. Two especially moving artworks were the wedding suit by Pascal Tassini and the wedding dress by Birgit Ziegert. They expressed the longing for love and marriage which for many with Down's syndrome stays unfulfilled due to social and legal obstacles.

We wanted to look at our topic from a multitude of perspectives and present it in a way understandable for all our visitors, and this aim informed our choice of objects which we clearly also wanted to be of educational value. Revisiting the term 'contact zone',[33] from the visitors' point of view, Philipp Schorch advocates '*humanizing* the "contact zone" through interpretive actions […] made by museum visitors' (Schorch 2013, p. 68). This is what we tried to facilitate by using, in both the exhibition texts and the accompanying publication, a clear (not just easy) language that everybody can be comfortable with, and, perhaps most significantly, by employing trained and paid docents with Down's syndrome. Schorch criticizes James Clifford's notion of 'contact zones' as being imbalanced in only focussing on the museum's interpretive actions and content translations, and he argues for a 'shared symbolic terrain which can convert translations into understandings' (p. 78). Offering curatorial translations of content does not necessarily ensure understanding. Although Schorch talks about the interpretive relationship between curators and visitors, the interplay between the conveying, translating, and understanding of content is also important for the relationship within an *interdisciplinary* team of curators from different disciplinary backgrounds and working cultures on the producing end, which is my research focus. And it is even more important within a transdisciplinary team setting.

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[32] Judging from my professional experience I personally doubt that the term 'outsider art' is always understood in an empowering way.

[33] A term coined by Mary Louise Pratt in her work 'Arts of the Contact Zone' (1991) describing social spaces in a cultural context.

Fig. 4.15: Wedding suit by Pascal Tassini and wedding dress by Birgit Ziegert in the second exhibition chapter 'Today – Here and Now' at the first venue in Bonn. Photo: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

Creating a 'shared symbolic terrain' is also reminiscent of the term 'common ground', originally established in communication theory. Kockelmans (1979, pp. 141–145) borrowed the term as a fundamental element of all *interdisciplinary* research (Repko 2008, p. 272). A large aspect of the knowledge production in this particular exhibition revolved around a mutual understanding. The exhibition became a daily 'contact zone' with visitors talking to each other and sharing their stories and knowledge in often surprisingly intimate conversations in a frequency and intensity we had not witnessed at the Bundeskunsthalle before. People with and without Down's syndrome became part of the knowledge production of this exhibition, simply by trying to 'make sense of each other' (Schorch 2013, p. 78). Schorch calls the awareness that we can do just that, 'one of the greatest achievements of anthropology' (p. 78).

Fig. 4.16: Jeanne-Marie Mohn presenting her (at the date of the photograph unfinished) scientific artwork, an embroidered set of chromosomes (karyogram) to explain trisomy 21, 2016. Photo: © Raw Art Foundation, Frankfurt am Main.

Fig. 4.17: Daniel Rauers, Paul Spitzeck and Björn Langenfeld working in the exhibition room 'The Great Appearance – John Langdon Down' in Bonn. Photo: © Sandra Stein, 2016, www.sandra-stein.de.

Amongst many possible examples of the knowledge production in this exhibition was an *interdisciplinary* collaboration regarding the genetic examination of a 2,500-year-old skeleton of a woman excavated in the early 1970s in southern Germany. According to the anthropological literature (Starbuck 2011, p. 22, 44), it had been suggested, based on her bone structure, that she might have had Down's syndrome. For the third exhibition chapter 'The Invisibles', RGL had consulted an interdisciplinary research cluster at the University of Bremen called 'Homo debilis. Premodern Dis/ability History', searching for evidence of disabled people in archaeology, history, and art history (see Halle et al. 2019). In the course of our collaboration, the colleagues in Bremen applied for a grant to conduct the first ever ancient DNA testing of an archaeological specimen with the research question of Down's syndrome, hoping to later present their findings in our exhibition. As the grant decision was continuously deferred, the Bundeskunsthalle finally paid for this scientific premiere. One week before the opening in October 2016, the skeleton already having been installed (see Fig. 4.6), the results came in. We had proven that this ancient woman did *not* have Down's syndrome, but our docents with Down's syndrome loved her all the same and proudly presented her as a scientific sensation, probably because the process up to this point had been very exciting and had endeared the woman of Tauberbischofsheim to them. We had expected to find them disappointed on this seemingly bad news, but they were obviously lacking our positivist thinking in terms of knowledge production. The woman from Tauberbischofsheim thus became part of their own history and historical identity, partly because of the emotional attachment that they had formed towards her during this scientific experiment but also because of the accompanying workshops in which the group had intellectually worked on understanding the research question and scientific procedures. RGL observed in his interview, that this has been one of his favourite experiences with regard to this project. With attracting and inspiring archaeologists and anthropologists to conduct pioneering research, our exhibition project has been transdisciplinary in another sense, namely by transcending their academic disciplinary horizons.[34]

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[34] In 2020, the earliest incidence of Down's syndrome in an infant who was buried before 3200 BC was found in an excavation in Ireland. See https://www.rte.ie/news/2020/0617/1148049-genomes-study/ (last accessed 11 July 2023). But as far as we know, we were the first to inspire such a DNA analysis on an ancient person, asking the question of trisomy 21. Regarding the display of human remains we complied with the established guidelines: https://www.museumsbund.de/wp-content/uploads/2021/07/dmb-leitfaden-umgang-menschl-ueberr-en-web-20210625.pdf, pp. 42–44.

4.6 Working culture clashes and institutional limitations: Exhibition design

There was one task within the process of making this exhibition in which we – as a diverse curatorial team – failed to collaborate in the integrative way we had planned and managed to do in other areas of the project. After months of constructive joint work with our self-built in-house model of the exhibition (see Fig. 4.14), the Bundeskunsthalle hired Harry Vetter to design the exhibition graphics. Mainly because of time constraints, the director of the institution together with me as the exhibition manager decided on the submitted design ideas by Vetter very quickly without consulting the whole curatorial team. When we presented the outcome of our internal decision, the team was very happy with the suggested design, but they clearly missed having been part of the process of arriving at this decision. KB recounted in the interview that Vetter's ideas 'were sensational. But it would have been cooler if he had explained them [to us himself]. I would have loved to know why he decided on these colours, for example. [...] I have a knowledge gap [about this], and with such knowledge gaps people with Down's syndrome must live all their lives, a hundred times a day.'

We as an institution – and I as an exhibition manager and institutional curator – had left our colleagues behind at this point. We had not been able to adjust our allegedly required work speed to a level that would have enabled their participation in the decision-making process. Jade French writes that 'inclusive curating is "slow curating"', which can 'challenge systemic inequalities within museums' (French 2020, p. 3). She also aptly describes (p. 104) how tight and pressured exhibition schedules can become, especially towards the end of the development process nearing the installation of an exhibition. In her practical guide to inclusive curating, she offers the interesting solution 'to record the chain of events' (p. 104) to enable transparency to all project participants. We sadly didn't take the time and thought to come up with such a good idea, which would have 'democratized' the curatorial process (see French 2020, p. 111) in this important task. We had failed in 'the enabling of multiple subjectivities' (MacLeod 2021, p. 9) with regard to the design of the exhibition space. MacLeod writes that 'museums have the opportunity [...] to nurture [...] parts of our human being' such as 'reflection, empathy, [...] imagination, compassion, [...] solidarity, curiosity [... and] criticality [...] which [...] enable all of us to play an active part in shaping our shared social world' (p. 9). Despite this gap in our mutual understanding and knowledge transfer within our diverse team, the exhibition design of *TOUCHDOWN* did meet many of these criteria in all its three venues.

The exhibition space (comprising about 400 square metres) at the first venue in Bonn was kept in a light and friendly atmosphere (see figures above). The life-size comics as well as graphics details in pink to purple colour gradients, reminiscent of NASA-imagery from outer space, created a warm and intimate setting which aimed at an 'emotional and intellectual involvement – without involvement no participation' (Schnegg 2012, p. 180). In our case the size of the comics, apart from their high visual attractiveness, considerably contributed to the feeling of involvement.

> I just went into the exhibition.
> It is very beautiful to be in the exhibition.
> I want to come back always and forever.
> I am proud.
> (Anna-Lisa Plettenberg, in: *Ohrenkuss*, no. 38, February *2017, p. 30)*

In her interview, KB described that the choice of partner with whom to develop such an exhibition was very important for her. The Bundeskunsthalle as an institution with a multidisciplinary programme scope, including natural sciences but programmatically leaning towards the arts, seemed to her an ideal choice to place the topic of Down's syndrome, because there were no disciplinary biases to overcome. We literally started with a blank canvas. The two further exhibition venues were extremely openminded but, rooted in their permanent collections, narrower in their disciplinary focus. And indeed, the exhibition felt different at its three venues, the multidisciplinary exhibition hall Bundeskunsthalle in Bonn, the psychiatry museum KulturAmbulanz in Bremen and the art museum Zentrum Paul Klee in Bern.

4.7 Transdisciplinarity and participation: Positioning the exhibition in accordance with the theoretical framework

Based on the previous chapters, I would like to postulate that this exhibition should be understood as a transdisciplinary research project. According to the terminology established in the methodology chapter (see 3.2.3), multi-, *inter-* and transdisciplinarity are terms which describe a growing intensity and quality of integrative and collaborative research practices (see Klein 1996, p. 6 and Klein 2010, p. 18).

Let us remind ourselves that transdisciplinarity has been defined in a twofold way: Firstly, as a research strategy towards a more universal understanding of knowledge, which transcends disciplinary divides 'with the intent of developing an overarching synthesis' (Lattuca 2001, p. 83), mostly with regard to a problem or question of a more universal societal relevance. Secondly, transdisciplinarity can be defined as an academic outreach strategy which integrates knowledge from stakeholders in society, other than from the academic realm. It is this second – sector transcending – understanding which has brought transdisciplinarity to the forefront of the discourses in interdisciplinarity studies[35] since the millennium, especially at European universities and science academies.[36] The fact that transdisciplinarity has gained momentum in recent years, is thus a consequence (and subsequent driver) of increased outreach activities at universities.

In the definition of the Network for Transdisciplinary Research (td-net) of the Swiss Academies of Arts and Sciences, transdisciplinarity involves three types of knowledge[37]: (1) 'target knowledge' representing 'values' and 'politics' ('What ought to be?'), (2) 'systems knowledge' representing 'facts' and 'science' ('What is?), and (3) 'transformation knowledge' representing 'agency' and 'practice' ('How to?'). A transdisciplinary research project therefore tries to acknowledge and integrate these three aspects and potential sources of knowledge production: 'values', 'facts', and 'agency', or using a different terminology: (1) political and ethical goals, (2) academic theories and results, and (3) practical experiences, claims and solutions. The latter type of practical knowledge might perhaps be linked to anthropological concepts of 'embodied knowledge'. In her

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[35] Allen F. Repko states that transdisciplinarity studies have established themselves as a separate field, different from interdisciplinarity studies (Repko 2008, p. 15).

[36] Most importantly the Network for Transdisciplinary Research (td-net) of the Swiss Academies of Arts and Sciences (active since 2008): https://transdisciplinarity.ch/en, and the EU initiative SHAPE-ID (Shaping interdisciplinary practices in Europe, launched in 2019): https://www.shapeid.eu/. In May 2021, I had the opportunity to introduce my research in the SHAPE-ID Blog: https://www.shapeid.eu/interdisciplinary-exhibition-making/ (all links last accessed 11 July 2023).

[37] The three types of knowledge which constitute transdisciplinary research: https://transdisciplinarity.ch/de/transdisziplinaritat/was-ist-td/drei-arten-von-wissen/ (last accessed 11 July 2023).

PhD thesis *Doing Dis/ordered Mapping/s: Embodying Disability in the Museum Environment*, Janice Rieger speaks of 'the embodied know-how' (also referring to the concept of 'techné') of people with disabilities and argues that it is important 'that the everyday experience of people is recognized as knowledge that can inform other kinds of practice' (Rieger 2016, p. 32, 33).

Based on these theoretical frameworks, I argue that the exhibition *TOUCHDOWN. An exhibition with and about people with Down's syndrome* can serve as an example for good practice in a transdisciplinary research project from the realm of arts and humanities, especially because it managed to integrate different ways of knowing and of producing knowledge (as outlined in the discussion of transdisciplinarity in the methodology chapter). Some of the examples and their analysis given earlier in this chapter might have supported this claim: (1) The exhibition advocated political activism *by* (and not only for) people with learning disabilities, specifically people with Down's syndrome; (2) It aimed to comprehensively inform the public about Down's syndrome using the available academic facts drawing on a wide range of disciplines such as history, archaeology, law, social sciences, genetics, medicine, art history, and art, just to name the most important ones; and (3) The exhibition integrated the everyday life experiences, knowledge, and opinions of people with Down's syndrome. It documented their questions and suggested possible societal solutions, as well as empowering them by strengthening their views – not only those of their parents or caregivers – and by including them in the decision-making processes during the development of the exhibition.

The concept of *participation* – quite aptly defined by one author from the field of arts and design (and with a focus on practice) as empowering but with 'risky trade-offs between makers and participants' (Huybrechts 2014, p. 14) – has played a decisive role in justifying the categorization of this exhibition project as transdisciplinary. I have already elaborated on the relationship between transdisciplinarity and participation in section 2.2 of the literature review. The production process of the exhibition had strong *interdisciplinary* qualities and dynamics regarding the integration of knowledge, for example in building a diverse team as well as in content development and interpretation. But this process and all its products additionally had to *pass the approval and welcome the input* of one group of people within the exhibition team, i.e. the colleagues with Down's syndrome, who – apart from their own intellectual knowledge about their condition – also brought to the table a practical, 'embodied' kind of knowledge, which made them experts in their own right. Furthermore, their participation in this project was of utmost social relevance.

Whilst the multi- and *interdisciplinary* aspects of the development process of this exhibition were reflected in the word '*about* People with Down's Syndrome' in the exhibition title, the part of the title that read '*with* People with Down's Syndrome', spoke of its transdisciplinarity. Liesbeth Huybrechts[38] adds an important characteristic to the established definition of transdisciplinary collaborations, in which 'people work together in a way that is *new to all participants* [emphasis added]' whereas in multidisciplinary 'zones, everyone works from the perspective of their own expertise' (Huybrechts 2014, p. 143). And this exhibition project was indeed new to all its participants, not only in its envisioned research content but also in its attempted production process, requiring from each of us to cross the borders of our disciplinary and non-disciplinary comfort zones, including, for example, our own language, as was discussed in section 4.4 of this chapter.

Participation, understood here predominantly as the co-production of knowledge, seems to be situated at the interstices between multi-, *inter-* and transdisciplinarity, because, as outlined in the literature review and methodology chapter, it is the level of knowledge integration and social participation that delineates the differences between these three categories or qualities of collaborative research (Klein 1996, p. 6, and Klein 2010, p. 18). Nina Simon, the author of *The Participatory Museum*, discerns between different models of participation that are quite similar to the introduced taxonomy of interdisciplinarity. Describing a growing intensity of audience participation, she distinguishes between 'contribution projects' (which can be viewed as similar to multidisciplinary projects), 'collaborative projects' (which can take on interdisciplinary qualities), and 'co-creation projects' (which might reach a transdisciplinary quality of integration between makers and participants) (Simon 2010, p. 187). In the case of *TOUCHDOWN*, participation was not explicitly directed towards the exhibition audience, but to a group of participants who co-curated the exhibition and, by doing so, also guaranteed that a very important part of the audience – people with Down's syndrome – were enabled and empowered to engage with the exhibition.

In this case, participation was conducted with an intensity that could be called radically innovative, as it had never been tried on this scale together with

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[38] Herself citing from Nigten, A. (2000). *Processpatching: Defining new Methods in aRtD.* London: SMARTlab Programme in Performative New Media Arts, Central Saint Martin's College of Arts & Design, University of Arts, PhD thesis, Processpatching.net/Publishing (without page reference).

people with a learning disability, at least not in Germany – and it really felt revolutionary during the production process: We were treading on new land – both in content and method – and, remembering a phrase by Jens Hoffmann, as already mentioned in the literature review (chapter 2), this exhibition truly felt like an 'anthropological endeavour' opening up a 'passage through unfamiliar territories' (Hoffmann 2015, pp. 56–57). Perhaps the most important predecessor of *TOUCHDOWN* was the exhibition *Der (im)perfekte Mensch* (The [Im-]perfect Human) at the Deutsches Hygiene-Museum, Dresden, in 2000.[39] This pioneering project, also yielding two excellent publications (Vogel and Staupe 2001, and Lutz et al. 2003), was a revelation regarding its conceptual aim 'to consistently put the perspective of disabled people in the foreground' (Vogel and Staupe 2001, p. 9), and to be as 'barrier-free' and accessible as possible. But, some fifteen years later, we took the idea of barrier-free access – and especially the aim of participation – much further, at least with respect to people with learning disabilities. Jade French describes a similar breakthrough with regard to 'inclusive curatorship' in her exhibition project *Auto Agents*, which happened parallel to our exhibition in 2016/2017 in Liverpool (French 2019).[40] Key aims in her project such as the support of 'self-advocacy' and 'disability activism' by people with learning disabilities, especially with regard to autonomy (French 2019, pp. 152, 153) in all aspects of life, were also driving forces of the exhibition *TOUCHDOWN*.

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[39] That exhibition had two venues: Deutsches Hygiene-Museum, Dresden: 20 December 2000 – 12 August 2001, Gropius-Bau, Berlin: 16 March – 2 June 2002: https://www.berlinerfestspiele.de/en/berliner-festspiele/programm/bfs-gesamtprogramm/programmdetail_293729.html (last accessed 11 July 2023).

[40] See also: https://www.jade-french.com/autoagents.html (last accessed 11 July 2023).

4.8 Conclusion

> We are proud of ourselves. We are proud of the exhibition.
> I wish you a lot of fun. Take a look at everything.
> Ask questions. Tell us what you like.
> And what you don't like. And if you are courageous,
> you are also welcome to speak to us.
> (Closing lines of the opening speech by Julia Bertmann on 28 October 2016)

During the opening weekend in Bonn (28–30 October 2016), around 500 people with Down's syndrome visited the Bundeskunsthalle. This was breathtaking for all of us, and KB is quite sure that 'this had never happened before, nowhere' (KB, interview).

It is probably palpable from my writing that this project still deeply enthuses and affects me, but this is not only rooted in its success but also in its difficulties. In her PhD thesis on art curating as collective knowledge production, Corina Oprea speaks of the need to create 'a space for dissensus' (Oprea 2016, p. 106), and I agree with her that a collaborative process of exhibition-making necessarily needs to allow for constructive debate and even conflict. We had many disputes along the way, especially about institutional barriers. But the feedback conversations (interviews) that we – that is the curators with 46 chromosomes – had in preparation for this case study had a healing and clarifying effect, especially for me. I was reminded once again of the joy and enthusiasm that we had set out with, which had sometimes been overshadowed by the pressures and obstacles along the way.

Fig. 4.18: Advisory board member and opening speaker Julia Bertmann giving a press interview on the opening day in Bonn, 28 October 2016. Photo: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

Fig. 4.19 and 4.20: The opening night in Bonn on 28 October 2016: The Democratic Disco. The graffiti on the wall in the left picture reads 'Free of primary caregivers.' Photos: Jirka Jansch, 2016, © Kunst- und Ausstellungshalle der Bundesrepublik Deutschland GmbH, Bonn.

This exhibition has certainly been the most important, most satisfying and, at the same time, most exhausting exhibition of my career as a curator and exhibition-maker so far, occupying and accompanying me for altogether almost five years (2013–2018). This exhibition is an interesting case both in terms of the complexity of the collaborative processes for realising a transdisciplinary and participatory exhibition, but also because of its significant results in the production of new knowledge. And it holds important institutional lessons about the resources needed for interdisciplinary and participatory exhibition-making. I will elaborate on these lessons in the overall conclusion to this book.

People with learning disabilities are a rather quiet group compared to other groups for disability activism (KB and AL, interview). But the exhibition was and is still conceived as an important step towards more 'self-advocacy' (for this term, see French 2019, p. 152). Natalie Dedreux, a member of the exhibition team, for example, became a so-called 'incluencer', working as an activist, blogger and journalist.[41] She became famous nationwide, when she asked the German chancellor Angela Merkel in the pre-election live TV programme of the ARD *Wahlarena* (Engl. election arena) on 11 September 2017: 'In Germany, nine of ten babies with Down's syndrome are not being born, they are aborted. [...]

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[41] Natalie Dedreux's website: https://www.nataliededreux.de/ (last accessed 11 July 2023).

How do you feel about the issue of late terminations?'[42] Earlier that year, on 27 January 2017, the German Bundestag acknowledged and commemorated for the first (!) time that more than 300,000 disabled people were murdered in Germany during the Nazi period.[43] One of the speakers was Sebastian Urbanski, an actor with Down's syndrome, who invented the symbol of our Second Mission (see caption to Fig. 4.3). These two topics can, by no means, be compared to each other, but they both hurt people and continue to do so. And both examples show that the exhibition *TOUCHDOWN* has contributed to a change in the way we remember and debate the historical and present living conditions of disabled people in Germany.

During the interview with HG, he said that for him the exhibition was transdisciplinary in yet another sense. Whilst it seemed to be about the 'otherness' of people with Down's syndrome, for him, one of the exhibition's 'overtones' evoked – or 'transcended' to – something larger than just 'the other' personified by people with Down's syndrome. It evoked a feeling that, despite all differences, we are all one. HG said, 'There is no otherness, only wholeness' (HG, interview), because wholeness for him incorporates otherness. 'We are all one in the acceptance of our diversity' (HG on 30 August 2023).[44] The given realities in mind, KB strongly countered this notion in the interview I conducted with her and AL: 'We are not one. The mix is what matters.' Diversity is what rules. Interestingly, this indirect conversation between HG and KB in two separate interviews sounds like a description of the twofold understanding of transdisciplinarity in a nutshell. Are we aiming at a universal body of knowledge (and joint rules such as human rights) or is the specialization and acceptance of diversity sparking more innovative ideas and better solutions for the big questions we are facing as human beings? Both notions seem convincing in their own rights.

This exhibition has been a major accomplishment, but it turned out to be very difficult to repeat it in its integrative quality and depth, mostly for institutional reasons. The two following case studies will speak of these obstacles.

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[42] Quoted from: https://de.wikipedia.org/wiki/Natalie_Dedreux (last accessed 11 July 2023).

[43] See https://www.bundestag.de/dokumente/textarchiv/2017/kw04-de-gedenkstunde-490478 (last accessed 11 July 2023).

[44] HG asked for a further conversation after reading the interview transcript. This conversation took place on 30 August 2023.