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## **Complexity Embodied: Using Body Mapping to Understand Complex Support Needs**

*Angela Dew, Louisa Smith, Susan Collings & Isabella Dillon Savage*

**Key words:** body mapping; embodiment; arts-based; visual methods; participatory research; qualitative research; complex support needs; planning; transitions

**Abstract:** Arts-based methods reduce reliance on verbal communication. This makes them particularly useful for exploring sensitive and controversial topics, which can often be difficult to articulate verbally, and capturing the experiences and insights of marginalised groups including people with complex support needs. The visual arts-based method of body mapping provides an alternative way for participants to express their views and experiences through non-verbal storytelling. In this article, we report on the adaptation of body mapping to conduct research with two disadvantaged groups: adults with cognitive disability and complex support needs; and young people with complex support needs. We identify the potential of the method to promote participants' choice and control over the research process and the onus on researchers to create and maintain a mutually safe and supportive environment. Body mapping is also identified as a useful practical tool for use by individuals and their supporters. Arts-based methods, including body mapping, have the potential to empower people with complex support needs to engage more fully in research, which provides a greater understanding of their experiences, views, and feelings.

### **Table of Contents**

- [1. Introduction](#)
- [2. Doing Body Mapping Research](#)
  - [2.1 Participants](#)
  - [2.2 Research personnel](#)
  - [2.3 Materials and spaces](#)
  - [2.4 Adapting the body mapping method to the group](#)
    - [2.4.1 Study 1: Planning with people with cognitive disability and complex support needs](#)
    - [2.4.2 Study 2: Life transitions with young people with complex support needs](#)
  - [2.5 Analytic approach](#)
- [3. Lessons Learnt From Using Body Mapping](#)
  - [3.1 Choice and control over the map](#)
  - [3.2 Creating and maintaining a mutually safe and supportive research environment](#)
  - [3.3 Body mapping as a useful practical tool](#)
- [4. Conclusion](#)
- [Acknowledgements](#)
- [References](#)
- [Authors](#)
- [Citation](#)

## 1. Introduction

Visual and arts-based methods are increasingly recognised by social science researchers as offering new ways to engage with participants on a more equal footing, thereby promoting participant engagement and empowerment (BOYDELL, GLADSTONE, VOLPE, ALLEMANG & STASIULIS, 2012; LYON & CARABELLI, 2016; NOTORA & ROBINSON, 2013). By engaging in creative encounters, researchers and participants can produce "rich and contextual information" (SENIOR & CHENHALL, 2017, p.96). Using a variety of genres, arts-based methods reduce reliance on verbal communication, making them particularly useful for exploring sensitive and controversial topics, which can often be difficult to articulate verbally (SENIOR & CHENHALL, 2017), and capturing the experiences and insights of marginalised groups (ALDRIDGE, 2012; ORCHARD, 2017). One such group is people with complex support needs. [1]

RANKIN and REGAN (2004) noted that complex support needs are typified by both a breadth and depth of needs across multiple life domains. This may include such factors as co-occurring disability, mental illness, and substance misuse coupled with, for example, homelessness, trauma, violence, and involvement in child protection or criminal justice systems (DOWSE, CUMMING, STRNADOVÁ, LEE & TROFIMOV, 2014). Gender, ethnicity and indigeneity are also associated with complexity (TROFIMOV & DOWSE, 2014). Due to the presence of overlapping needs, people with complex support needs often interact with a range of agencies and are expected to navigate vastly different service contexts. The absence of holistic support has been shown to exacerbate complexity (KEENE, 2001; MADDEN, FORTUNE, COLLINGS & MADDEN, 2014). Complex support needs, then, are produced in the interaction between an individual and the support services and systems that they encounter (COLLINGS, DEW & DOWSE, 2016). [2]

People with complex support needs are socially marginalised and often experience discrimination and disadvantage throughout their lives, with their views and experiences hidden and untold (DOWSE & DEW, 2016). For example, people with cognitive disability may have complex communication needs and many lack the opportunities and confidence to express themselves (IACONO, 2014; McDONALD, SCHWARTZ, GIBBONS & OLICK, 2015). Individuals who have experienced lifelong and entrenched disadvantage may similarly lack the confidence and skills to articulate their views and experiences (CLIFT, 2014). People who engage—often unwillingly or unsuccessfully—with multiple systems report fatigue and frustration at being asked to recount their life histories to many different service providers (MENDES, SNOW & BAIDAWI, 2014). The consequence of these unmet needs and ineffective service responses is that people with complex support needs have traditionally either been excluded from or unwilling to participate in research (ALDRIDGE, 2012; GOODLEY & MOORE, 2000). [3]

Conventional qualitative research methods such as interviews and focus groups rely on the person having the verbal proficiency and confidence to share their

perspectives (ALDRIDGE, 2012). In addition, as BAGNOLI (2009, p.547) reminds us, "not all knowledge is reducible to language". Visual methods provide an alternative way for participants to express their views and experiences through non-verbal storytelling across a range of diverse issues (ALDRIDGE, 2012; ORCHARD, 2017). For example, TARR and THOMAS (2011) used three-dimensional body scans to map dancers' embodied experience of pain and injury, and VACCHELLI (2017) used collage-making with migrant, refugee and asylum-seeking women to depict their experiences. [4]

One increasingly popular visual method is body mapping. Body mapping involves a participant tracing a life-sized outline of their body and then populating this space with visual representations, symbols, and words related to the experience under investigation (DE JAGER, TEWSON, LUDLOW & BOYDELL, 2016). [5]

Body mapping as a form of storytelling stimulates imagination and creativity, permitting participants to reflect on thoughts and feelings in a multi-modal way: physically (through lying on the page and making the artwork), visually (through art making), verbally (through describing the artwork) and relationally (through dialogue and interaction with the researcher). The core element of body mapping—the outline of a person's body—provides a structure for participants to visually depict both the internal and external influences on their lives; working directly on the body shape connects the participants to past experiences as lived by their body and stored in memories. According to ORCHARD (2017, p.2) using body mapping as a research method can "guide participants in the artful communication about their embodied life experiences in ways that are safe and supportive". This multi-modal, safe and embodied approach to storytelling has the potential to express the lived experience of complexity by capturing in one place the interaction between the depth (internal influences) and the breadth (external influences) of a person's support needs (LAW & MOL, 2002; RANKIN & REGAN, 2004). [6]

Early accounts of body mapping emerged three decades ago with its use in explorations of rural fertility rates in Jamaica (MacCORMACK & DRAPER, 1987) and living with HIV/AIDS in South Africa (SOLOMON, 2002). The therapeutic and community development use of body mapping is now widespread but, according to a recent literature review, its use in research is less established (DE JAGER et al., 2016). The review identified 19 studies meeting the criteria of including full body maps and describing the meaning-making process undertaken by participants. Of these 19 studies, six were related to HIV/AIDS and the remainder involved a range of health-related topics such as sexual health, child health, pain, trauma, grief, and domestic violence. Adele DE JAGER and colleagues reported that body mapping had permitted a deeper reflection on the topic, which elicited novel information from participants. To date, however, no direct comparison of body mapping and interviews has been undertaken to test this assertion. [7]

While body mapping has been used in research with marginalised young people, its use has been restricted to health-related topics, such as sexual health and decision making by Aboriginal young people in Australia (CHENHALL, DAVISON,

FITZ, PEARSE & SENIOR, 2013). To our knowledge, body mapping has not been used in research with people with cognitive disability. In this article, we report on the novel use of body mapping in two studies: one about planning by adults with cognitive disability and the other on life transitions for vulnerable young people with complex support needs. We begin with a description of how we adapted the body mapping methodology to suit the participant groups (Section 2). We follow this with a discussion of the lessons we learnt through our application of body mapping with the two groups (Section 3). We conclude with our reflections on the potential of body mapping to creatively engage marginalised groups who may otherwise be excluded from research (Section 4). [8]

## **2. Doing Body Mapping Research**

We are engaged in research with people with complex support needs. In Study 1, the authors AD, SC and IDS used body mapping with adults with cognitive disability and complex support needs (e.g., mental illness, sensory impairment, autism spectrum disorder, and contact with child protection and/or criminal justice systems) to explore experiences of support planning. In Study 2, author LS used body mapping with young people (aged 16 to 26) with complex support needs (e.g., mental illness, out of home care, drug and alcohol misuse) to explore a life transition and the supports that they received during this time of change. The substantive findings of both projects will be reported elsewhere, with the focus of this article being the use of body mapping as a data collection method with vulnerable populations. Both research projects were approved by the University of New South Wales, Sydney, Australia. All participants provided written consent to participate. [9]

### **2.1 Participants**

Using a purposive sampling method (PATTON, 2002), participants for both studies were recruited with the assistance of organisations providing support and advocacy to people with cognitive disability (Study 1) or young people with complex support needs (Study 2). Inclusion criteria for Study 1 were: being over 18 years, having a cognitive disability, having complex support needs, and living in a metropolitan, regional or rural area of New South Wales (NSW), Australia. Inclusion criteria for Study 2 were: being 16-26 years, having complex support needs, living in a metropolitan, regional or rural area in NSW, Queensland or Victoria, Australia and being in an ongoing relationship with a support service. A limitation of recruiting through services was that those who do not access services (arguably the most marginalised), were not represented in our studies. [10]

Participants were asked to choose a pseudonym by which they would be known in all research reporting. In recognition of their time and contribution, participants were given a \$A50 gift voucher per day. Table 1 provides details of participant recruitment and body mapping session set up for each study. [11]

## 2.2 Research personnel

As shown in Table 1, body mapping is a time and personnel intensive research method, particularly when working with people who require one-to-one support to complete the task. A high level of engagement with participants is needed irrespective of whether mapping is done in a group, as in Study 1, or individually, as in Study 2. [12]

Study 1 engaged an arts therapist to work with the research team. This person, who had previous experience working with people with cognitive disability, provided advice to participants about ways to visually represent their experiences and feelings and helped them to overcome concerns about their artistic ability. [13]

The researchers also requested one staff member from each recruiting organisation to act as a facilitator in each session of both studies. In Study 1, the facilitator assisted with participant recruitment and logistics of attendance (e.g., transportation), venue booking and set up, and catering arrangements. At the beginning of each session, the facilitator introduced the researchers and, where participant numbers required additional personnel, the facilitator was briefed by the researchers to work one-to-one with a participant to create their body map using a proforma as a prompt. As a person known to group members, facilitators also served as a reassuring presence for participants, and their familiarity with participants' communication styles meant they could ascertain when individuals were feeling anxious or overwhelmed and, if necessary, suggest a break. In addition to each group's facilitator, some participants came with a support worker. Reflective of the nature of disability support, some workers knew the person better than others and so some merely accompanied the individual and did not participate in the body map creation; others worked with the individual to complete their map alongside a researcher or facilitator. Participants who came with a support worker tended to have more significant cognitive disability or additional needs (e.g., visual impairment, autism spectrum disorder, mental ill-health). [14]

In Study 2, LS was usually the sole researcher, which meant that she needed the facilitators and support workers to play a more active role in the group-based sessions. LS developed information materials for the facilitators and support workers about how to conduct body mapping, the history and process of body mapping, and the differences in body mapping for research compared to therapy. The facilitator and any other support workers who planned to attend were given pre-session training so that they could take an active role and support the participants to develop the body maps, if necessary. In some cases, this training was delivered in a two-hour workshop in which facilitators and support workers had an opportunity to create a group body map. In other cases, training was delivered remotely (by phone, Skype or PowerPoint presentation). The training, which included discussion on how to support rather than intrude on participant storytelling, built facilitator and support worker expertise and confidence to work with the young people in a body mapping session. [15]

In both studies, having paid workers accompany participants to the session appeared to help facilitate some participants' active engagement in the task. In a few cases, the presence of a worker proved problematic when individual workers over-reached their support role to impose their views or images onto a participant's map. In these cases, we reminded workers about how to assist rather than control the engagement of the participant. Following training, Study 2 workers appeared better prepared than those involved in Study 1. The level of cognitive disability of Study 1 participants may also have meant that workers were more likely to impose their views than workers in Study 2 where the participants did not have cognitive disability. The positive and negative engagement of workers was reported on in our field notes which formed part of the analysis data set. Table 1 includes details of the research personnel engaged in each study.

	<b>Study 1</b>	<b>Study 2</b>
Participants	29 adults with cognitive disability and complex support needs	13 young adults with complex support needs
Body mapping set up	6 groups 3-6 participants per group 12 x 3 hour workshops (2 consecutive days per group)	3 groups, 3 individual 2-7 participants per group 3 x 2 hour workshops 3 x 2 hour sessions with individuals 3 x 2 hour training of support staff
Personnel	3 x research staff 1 x arts therapist 1 x honours student (attended two groups) 6 x facilitators (1 per group) Support staff (varied by group)	1 x research staff 1 x participant investigator from research partner Support staff (varied by group and young people preference)

Table 1: Body mapping comparative procedures [16]

### 2.3 Materials and spaces

High quality arts paper was cut into 1.8 metre lengths for the body maps. Art materials such as crayons, textas, glitter pens, magazines, coloured paper, post-it notes, fabric, ribbon, and beads were made available to participants. Participants could choose to work on a table or on the floor. Other researchers have noted the need for enough space to allow participants to work on their map without being self-conscious about the presence of others in the room (GASTALDO, MAGALHÃES, CARRASCO & DAVY, 2012). A large space was required in these two studies due to paper size and arts materials, and this was particularly the

case for Study 1 where the sessions involved up to six participants and six researchers/workers. At the completion of each session, body maps were marked with the participant's pseudonym and group identifier and photographed. This ensured data integrity and record keeping accuracy. Original body maps were stored in a secure location in line with approved data protection protocols, and digital reproductions used for analytic purposes. Illustration 1 shows a researcher creating a body map outline with a participant.



Illustration 1: Creating body map outline [17]

## 2.4 Adapting the body mapping method to the group

Both studies based the body mapping procedure on a guide developed by SOLOMON (2002), also described by GASTALDO and colleagues (2012). This procedure included three key elements: 1. creation of a visual body map; 2. short first-person narrative ("testimonia") describing the elements / experiences depicted on the map; and 3. a key to interpret the symbols and slogans used on the map. Each study adapted the method to suit the particular population, as described below. [18]

### 2.4.1 Study 1: Planning with people with cognitive disability and complex support needs

The project involved participants creating two maps. The first was based on an actual experience of planning (e.g., moving out of home, going on a trip, or studying). For the second, participants were asked to map an "ideal" plan—something they would like to plan for in the future (e.g., getting a driver's licence, an overseas holiday, reconnecting with family). We decided that, with a short project timeframe and considerable investment of researcher time and personnel,



body mapping would take place in small groups. Organisations engaged in recruitment confirmed this approach as appropriate, and felt it would also create a social atmosphere for participants to relax and enjoy themselves. Given the research topic concerned planning, the risk of emotional distress and disclosure of sensitive information was considered minimal. [19]

Due to the nature of cognitive disability and its impact on memory, concentration, auditory processing, and abstraction, adaptations were required to tailor the SOLOMAN (2002) format to the population. Each session was no longer than three hours and sessions were held over two consecutive days rather than the four days recommended by SOLOMAN. The format was trialled with a pilot group prior to conducting subsequent groups. The pilot comprised six people with cognitive disability and complex support needs who already knew each other through involvement in a self-advocacy organisation. We had previously worked with the organisation's facilitator and were confident that she would recruit participants who could respond to the emergent nature of the method and provide feedback. [20]

A second adaptation to the method proposed by SOLOMAN concerned the timing of the testimonia and key used to interpret the symbols. During Day 1 of the pilot group, we realised that many participants would have difficulty recollecting and reflecting on their body maps two weeks later. Therefore, an on the spot decision was made to complete the testimonia in situ during the body mapping session rather than at a later stage. Following the pilot group, a proforma was developed for this purpose and used in subsequent sessions (available from first author on request). [21]

At the conclusion of the two-day pilot group, we sought feedback on the content, format and timing of the session from the facilitator and participants. This confirmed that two half day sessions were preferable to a single longer day. Some felt that too long was spent in group discussion before the body mapping began and that people became bored and distracted. As a result, in subsequent groups the introductory session was shortened and made more interactive. [22]

In the introductory session and in order to orient participants to the body mapping activity, AD and SC shared a personal planning scenario (a planned and emergency hospital admission), which the arts therapist mapped onto a pre-prepared body outline while eliciting input from participants. This helped participants to understand what was expected of them, including how they might visually represent their own experiences and feelings using symbols, pictures, colours, and placement within and outside the body outline. We recognised that in providing an example, there was a danger that participants may be influenced to reproduce either the topic or depictions of the topic on their own maps. None of the Study 1 participants chose to map hospital admissions. Some images drawn by the arts therapist were used by participants on their own maps tailored to their specific topic and experiences. [23]

To minimise intrusion into the body mapping process and for practical reasons due to background noise working with groups in a single space, we did not record the conversations but instead asked participants a series of prompt questions during the mapping exercise and recorded the answers on the purpose-designed proforma. We then converted the notes from the template into a third person narrative "testimonia" format as soon as possible after the session to preserve recall. The third person pronoun was used in recognition that this was a co-construction, told by the participant to the researcher, who then constructed a narrative. We also took field notes during and after the sessions which noted, for example, non-verbal communication during the body mapping activity, interactions between the participants and their support worker (when present), and our reflections on working with the person. Table 2 outlines the daily agenda and activities for Study 1.

<b>Study 1, Day 1</b>	<b>Study 1, Day 2</b>
Welcome, introductions	Welcome back and recap from yesterday
Project explanation	
Information and consent protocol	Reminder about consent
Preparing to body map	Preparing to body map
<ul style="list-style-type: none"> <li>Worked example of planning (experience of going to hospital)</li> </ul>	<ul style="list-style-type: none"> <li>Worked example of future planning (moving back from overseas)</li> </ul>
Group brain storming session	Group brain storming session
<ul style="list-style-type: none"> <li>Past experiences of planning</li> <li>Good and bad</li> <li>Who helped?</li> </ul>	<ul style="list-style-type: none"> <li>Future/ideal planning experience</li> <li>What might an "ideal" planning experience be?</li> </ul>
What are we going to do today?	What are we going to do today?
<ul style="list-style-type: none"> <li>Explain body mapping and why using it</li> <li>Ways to represent—drawing, writing, collage</li> </ul>	<ul style="list-style-type: none"> <li>Ways to represent—drawing, writing, collage</li> </ul>
Relaxation activity	Relaxation activity
Setting up the body mapping	Setting up the body mapping
<ul style="list-style-type: none"> <li>Drawing outlines onto paper</li> <li>Familiarising with materials</li> </ul>	<ul style="list-style-type: none"> <li>Drawing outlines onto paper</li> <li>Familiarising with materials</li> </ul>
Body mapping session	Body mapping session
<ul style="list-style-type: none"> <li>Individually identify an example of planning to map</li> <li>Researcher/support worker uses proforma to guide discussion and mapping</li> <li>Assist person (if needed) to decide how to represent ideas on their body map</li> </ul>	<ul style="list-style-type: none"> <li>Individually identify an "ideal" example of planning to map</li> <li>Researcher/support worker uses proforma to guide discussion and mapping</li> <li>Assist person (if needed) to decide how to represent ideas on their body map</li> </ul>

Study 1, Day 1	Study 1, Day 2
Large group	Large group
<ul style="list-style-type: none"> <li>• Debrief—what was making the body map like?</li> <li>• Should we do anything differently tomorrow?</li> <li>• A\$50 voucher given</li> </ul>	<ul style="list-style-type: none"> <li>• Debrief—how was Day 2?</li> <li>• What should we do differently with future groups?</li> <li>• What happens now?</li> <li>• A\$50 voucher given</li> </ul>
LUNCH	LUNCH

Table 2: Study 1, body mapping workshop agenda [24]

#### 2.4.2 Study 2: Life transitions with young people with complex support needs

Study 2 was designed in consultation with an advisory group comprised of seven young people who were experts by virtue of their lived experience of complex transitions and with whom LS had been engaged for a year and had an ongoing relationship, as well as two facilitators who supported the advisory group. This group formed the pilot group for Study 2. With the advisory/pilot group, LS adapted processes used in Study 1, such as the introductory relaxation activity and demonstration of body mapping, and use of a proforma to gather information. The pilot group reflected on the process, with the discussion audio recorded and transcribed. The group agreed that the inclusion of a worked example by LS was important and that the body mapping process was a helpful way to communicate transition experiences. The pilot group advised against the use of the proforma on the basis that it constrained freedom of expression. Group members reflected that having someone scribe their words and actions reminded them of therapeutic encounters, which was off-putting. LS and facilitators also felt that they could miss important information shared by a young person if they were focused on completing the proforma. As a result, the Study 2 body mapping sessions were audio recorded and the recording was used to create the testimonia at a later time. The group also advised LS that young people who participated in the study should be given choices about how they engaged with the research process. This included how they took part in the research (either in a group or one-on-one), the stories they told, and how they shared them. In line with this, the facilitator for each service venue discussed the project with the potential participants and those who consented to take part then decided whether they preferred to work one-on-one or in a group, and whether they wanted to create a body map, be interviewed, or make a life line (the latter two options are not discussed in this article). The facilitator advised LS of the choices made by participants. If a young person chose the body map, s/he was asked to think about a specific life transition, such as leaving school or home. In all but two cases participants selected to do the body mapping process one-on-one with LS. During a two-hour session, participants shared their experience of a transition and created a body map to depict their transition (e.g., becoming homeless, pregnant, moving from/to foster care placement, a death in the family, or starting a new support program). [25]

The scope of the topic (life transitions) and the short time available to complete the body maps necessitated some adaptation to the approach suggested by SOLOMON (2002). First, in both the group and one-on-one body mapping sessions LS and the participant spent time discussing what life transitions meant, so as to clarify that it referred to significant life changes. In a group setting, the researchers, workers, and young people shared major life transitions from their own lives. [26]

Following this initial discussion, LS described and drew an example body map based on a personal experience of transition. LS chose which example transition to map in consultation with the facilitator. This choice was often based on choosing a transition from LS's life which was relevant to the group of young people. In two of the three cases where LS provided an example, this involved body mapping her experience of becoming a mother and having postnatal depression. In both cases, the groups were very engaged with the example as reflected in LS's field notes: "they both asked questions as I went, adding in to my discussion of my feelings as I drew, nodding all the time". Two participants said that the choice of the example helped them to choose their own transition (both choosing to body map transitions related to mental health), and gave them ideas about how to represent certain embodied experiences. For example, both of these participants used the same squiggly line to obscure the outline of the body that LS had used to represent how blurry and unclear your place in the world is when depressed. In one-on-one sessions, LS showed the participant photos of body maps made by other participants and explained the significance of body position, symbols, and placement of images inside or outside the body. [27]

Following the example, an informal one-on-one discussion of up to an hour duration was held about the participant's chosen life transition. The discussion was audio recorded, and was used in three ways: first, to help build rapport with the participant; second, to give the researcher/worker some personal context and background that was used to prompt the person during the body mapping process; and third, to write the testimonia. [28]

Each participant then worked with LS, or a facilitator/support worker for the individual body mapping process. In both groups and one-on-one body maps, participants chose the support worker they would like to work with or have present during the process, in all cases this was someone who had been supporting the young person for over a year and who they trusted. While a proforma was not used to collect the data about transitions, LS, and/or support workers used a proforma for structuring field notes. This proforma included prompts around the participants' feelings towards body mapping, relationships between young people during group sessions, and changes in the approach over time. Table 3 outlines the daily agenda and activities for Study 2.

Welcome, introductions

Project explanation

Information and consent protocol

- A\$50 voucher given

What are we going to do today?

- Explain body mapping and why using it

Group discussion around the circle

- Past experiences of transitions
- What supported these changes?
- Who made the changes difficult?

Body mapping example

- Worked example of transition (transition to motherhood or migration)
- Introducing ways of representing; drawing, writing, collage
- Familiarising self with material

Relaxation activity

Body mapping session (one-on-one)

- Audio recorded discussion to identify an example of transition to map
- Researcher/support worker questions in the proforma to guide discussion and mapping
- Assist person (if needed) to decide how to depict/represent ideas on their body map

Debrief (one-on-one)

- What was it like making a body map?
  - What would have made it easier?
  - What we'll be doing with the body map
- 

Table 3: Study 2, body mapping workshop agenda [29]

## 2.5 Analytic approach

To date, analytic approaches to interpreting body maps remain undeveloped. As Treena ORCHARD (2017, p.43) explained, "[t]he divergent processes and outcomes associated with this method are its key strengths but they can make the systematic analysis of the findings challenging". Similarly, GASTALDO et al. (2012) described moving beyond description to a critical interpretation as a challenge of the body mapping method. BAGNOLI (2009, p.568) argued, however, that analysis of the visual and textual contribute equally to results since the researcher can "interrogate the data on multiple levels". [30]

For both projects reported here, three data sources were analysed: the visual images (photos of the body maps) and accompanying symbol interpretation keys; the written testimonia; and the researcher field notes. All data sources were

imported into NVivo (Version 11), a qualitative data management software package. Initial data analysis was undertaken as soon as possible after each group to preserve recall. [31]

As a first step, each visual image was coded using the symbol interpretation keys and written descriptions (on the proforma used in Study 1 and transcripts of audio recording in Study 2). An NVivo function was used to plot the grid references of each image and note the placement of symbols. Following this, as a second step, the written testimonia data and researchers' field notes were analysed using the well-established qualitative methods of thematic analysis and constant comparison (BRAUN & CLARKE, 2006). Codes were allocated to each line of data with some data being placed under multiple codes. The codes captured the nature of the experience portrayed by each participant and the development of common and divergent themes across all participants. [32]

In Study 1, AD, SC and IDS met after each body mapping session to conduct the visual and textual analysis. Once data for all participant groups had been coded, we worked together to remove repetition by amalgamating codes and deleting redundancies. The process was repeated on two occasions until we agreed on the final categories and themes. The results of thematic analysis will be reported elsewhere. [33]

In a third analytic step in Study 1, we applied the "axial embodiment" approach developed by ORCHARD (2017). Axial embodiment quantifies textual and symbolic representations across the different layers of the body map. In Study 1 this included: *on the map* (the background space), and *on the body* (the physical outline). Following ORCHARD's method, each image, collage, word or phrase that expressed a single idea was counted across the different layers of the maps. After tabulating the diverse representations, there was no apparent gender difference in the use of text versus images. Female participants averaged 19 text representations and males 17. An average of 34 image representations were used by both female and male participants, meaning images were used almost twice as often as textual representations (see Table 4). This emphasis on visual representations reinforces the argument that arts-based methods are likely to be well-suited to engaging participants who experience difficulty articulating their experiences verbally and/or in writing, such as people with cognitive disability.

Table 4: Axial embodiment coding of Study 1 body maps. Click [here](#) to download the PDF file [34]

During data analysis for Study 1, we also explored a possible pattern in the placement of images and text on the maps across the data set, however, no relationship between support types and placement on maps was found. Some participants deliberately drew support people inside their bodies to symbolise the significance of the relationship while others placed figures and services seemingly at random on the background of their maps. Similarly, representations of what we considered "internal supports" such as resilience or knowledge were

often drawn internally although many participants wrote or symbolised such concepts external to the body. [35]

Despite being unable to show a pattern in the placement of supports, there were commonalities in the visual representations used by Study 1 participants. For example, feelings were almost always represented on the body in the same areas (the head and stomach) or by swirling lines drawn throughout the entire body to represent emotions such as excitement, anxiety or uncertainty. Images were often placed at the feet, which participants described as representing grounding or the foundations of a new activity in her/his life as explained in this testimonia excerpt and depicted in Illustration 2.

"Barbara's family come from a small country town ... she has very fond memories of staying on the family farm with her grandparents as a child. The family grew wheat on the farm and Barbara created a collage of the wheat fields by cutting out strips of coloured paper—black for the soil, brown for the stalks, and yellow for the heads of wheat. She placed these images at her feet as her country roots are where she feels grounded—it's her background."

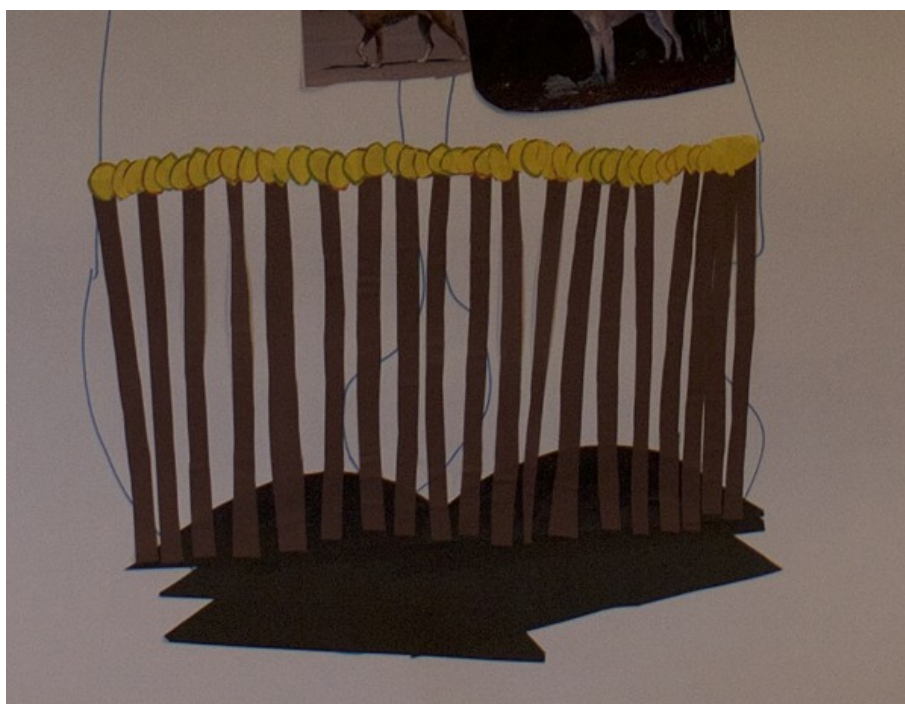


Illustration 2: Depiction of grounding [36]

Despite the absence of a clear pattern in placement of text and images across the group, some participants did use placement to symbolically represent their experiences. For example, one participant drew two eyes in the shoulder area to represent her sense that she was under surveillance by child protection authorities and fear about her child being removed from her care. Another participant placed an image of a house in the heart area to reflect that moving out of the family home was her "heart's desire" (testimonia). Coding the symbolic

representations of participants' experiences, expressed both visually on the map and in a narrative form in the accompanying testimonia, enabled us to identify themes across the data. Despite the varied pictorial expressions of planning experiences, specific emotions, types of supports and mechanisms that impeded, or facilitated opportunity, consistently occurred throughout the data. The resultant overarching themes (reported elsewhere) provided an in-depth insight into the perceptions of people with cognitive disability regarding their experiences of planning. [37]

For several reasons, a different approach to analysis was needed in Study 2. First, in contrast to Study 1, only LS analysed data from Study 2, so no dual coding was undertaken. Second, since the majority of participants in Study 2 did not have cognitive disability, they tended to readily combine visual and verbal storytelling. Third, as previously reported in research using visual mapping with young people (see, for example, CHENHALL et al., 2013; NOTARA & ROBINSON, 2013), the process of making the body maps and the visual representations themselves, shaped the interactions between groups of young people and with the researcher. Such diversity across the Study 2 body mapping sessions produced rich data but resulted in a less uniform approach than that used in Study 1, which meant that a different analytic approach was needed. [38]

Preliminary thematic analysis of testimonia and field notes was undertaken in Study 2, following the approach taken in Study 1 (BRAUN & CLARKE, 2006). However, the topic being explored by Study 2 participants around major and often traumatic life transitions, meant that during the analysis process LS became concerned that the complex interplay of written, visual and relational content evident during the body mapping sessions was being lost. For this reason, LS created individual narratives using the techniques of "thick description" (ORTNER, 2006, p.43) from ethnography, to combine the field notes, researcher reflections, descriptions of body mapping process and interactions around it, and sections of participants' transcripts. The individual narratives helped to articulate how complexity is embodied in and through time and relationships both in the lives of the participants and in the real time of the body mapping session, and how these meanings come to settle in the body maps in particular ways. For example, one participant initially drew a light grey cloud to represent difficult transitions and barriers to moving forward but, over the course of creating her body map, she painted these clouds bigger and blacker, returning to them to illustrate the impact of different violent events on her life transitions. Illustration 3 shows the depiction of these clouds.





Illustration 3: Depiction of clouds [39]

The individual narratives helped to elucidate the depth, multiplicity and complexity of transition experiences in ways that could be obscured by cross-sectional thematic analysis (HAGGIS, 2008). In Study 2, these individual narratives and the accompanying body maps were then thematically analysed to illustrate the intersections and the complexity of the themes within embodied lived experience. In the following section, we identify and discuss methodological and practice lessons learnt from using body mapping with people with complex support needs based on the two studies presented. [40]

### 3. Lessons Learnt From Using Body Mapping

#### 3.1 Choice and control over the map

Body mapping, with its reduced reliance on verbal communication, was particularly useful for eliciting the experiences and feelings of people with complex communication needs and those who were uncomfortable telling their story verbally (BAGNOLI, 2009). In both studies, participants reported enjoying the act of drawing a body outline and then filling it with pictures, words, and symbols to represent their experience. As for SENIOR and CHENHALL (2017), we found this process yielded rich contextual information, and in line with BAGNOLI (2009), we found that body mapping shifted the power balance between researcher and participant by putting the participant in control of the images they used and where they positioned them on the map. ORCHARD (2017, p.66) described this as "the transfer of creative license and power from researchers to participants, whose work not only captures their lived experiences but is considered of equal value alongside other kinds of data". [41]

In both our studies, participants chose the example (of planning or transition) which they wished to map. In making this choice, participants could decide not only *how* they "spoke" about the topic (as happens in an interview), but *which* topic they "spoke" about (i.e., the experience they chose to map). In making this choice, participants established themselves as the expert on the topic and the researcher became the conduit. We often then assumed the role of assistant, cutting out magazine images as directed by the participant, supplying glue sticks, and getting cups of tea. While we were asking questions of the participants throughout the body mapping process, this was done as part of the activity and through casual conversation rather than a more formal interview setting. This meant we were often taken to surprising places that may not have arisen in an interview. Participants used images to reveal aspects of cultural heritage and sexual orientation that had not come up during conversation. For example, one transsexual young woman in Study 2 was uncomfortable with the body mapping process until she covered her incorrectly gendered body with another piece of paper upon which she could recreate and redraw her body as she wished. [42]

Some participants expressed that the process was cathartic, whereas others were surprised by where the body mapping process took their stories. In Study 2, one young person who mapped becoming homeless, reflected that "I'm really surprised about how it really took me back there ... I probably should have chosen an easier one [transition]." This insight reinforced the importance of ensuring that support from the organisation involved was made available to participants afterwards. [43]

The role of facilitators and support workers during the process must be carefully considered to ensure that they facilitate rather than lead the person's body mapping experience. The training provided in Study 2 provided more comprehensive preparation for workers than was given in Study 1 and is likely to have provided them with a greater understanding of their role. In Study 1, and reflective of way services for people with cognitive disability are staffed, different support workers accompanied a participant on each day creating challenges for researchers in ensuring consistent support in the body mapping process for participants. [44]

In Study 1, at the end of Day 1, participants were told that on Day 2 they would map an 'ideal' planning experience. Having reflected on this overnight some participants returned on Day 2 with the intention of extending or re-imagining the plan they had made on Day 1. For example, one participant who had mapped her experience of moving out of home on Day 1, decided that she really wanted to move from her current home to a place where she could have pets. The testimonia records:

"Hovi's ideal planning experience is to have animals living with her because they make her feel good. Currently, Hovi's rental contract does not allow animals. She has four mice but is worried that the mice will die and she'll be lonely again. Hovi feels like living somewhere with animals means she will have more control over her life." [45]

Other participants took the opportunity to imagine a very different future. For example, one participant revealed that he wanted to become an author like JK Rowling and filled his entire body map with writing; another expressed a desire to become a policeman and filled in his body outline with images of what he would need to achieve this aim: "Belt, gun, handcuffs, boots, shirt, uniform, hat, stripes, tie. I watched a lot of cop shows when I was a kid and found out a lot about it." [46]

Body mapping is not a method that suits everyone. It is essential to recruit participants who can engage in a level of abstraction and reflection that enables them to provide a considered account of their views, feelings and thoughts on a body map. We found that Study 1 participants with more significant cognitive impairment struggled to engage in the process and, while it does not necessarily mean the method is unsuitable for all such individuals, it does mean that researchers need to find different ways to present the activity to them. In Study 2, one participant whom the recruiting service provider identified as suitable for body mapping was wary of strangers and anything that resembled therapy. When the researcher invited him to join the body mapping session, his body language indicated reluctance, so a co-researcher played basketball with him and, after an hour, he volunteered to participate in an interview instead. This experience emphasised the usefulness of having other methods available for those participants who choose not to take part in body mapping. [47]

### **3.2 Creating and maintaining a mutually safe and supportive research environment**

As previously described, body mapping requires participants to reflect on their personal experiences about the topic under investigation and then visually represent the thoughts and feelings that were invoked by that experience. The body mapping literature warns that the embodied nature of this process can provoke an emotional response for some participants and recommends that strategies be put in place to mitigate this risk (DE JAGER et al., 2016; ORCHARD, 2017). An important way in which participant safety was protected in our studies was by recruiting through service providers so that support could be embedded in existing relationships. Most groups included participants who knew each other, and the facilitator and support workers. This made it more likely that participants felt relaxed and ensured that follow-up support was available, if required. In Study 2, LS made a follow up phone call to each facilitator one week after the body mapping session to remind them to check on participants' wellbeing. [48]

In Study 1, a brief relaxation exercise at the beginning of each session was used to help participants become aware of their physical responses during the body mapping. Depending on their personal preference, some but not all, Study 2 participants took part in a relaxation exercise. In both studies, having a member of the research team, a facilitator, or a support worker assigned to or chosen by individual participants meant that every person's comfort with the process could be closely monitored. At the end of each group session, participants were given the opportunity to de-brief on their feelings about the experience of body mapping

in a group discussion or, if they preferred, privately with a research team member. [49]

Prior to our first body mapping sessions, we had speculated that lying down on the floor and having someone draw around their body might be threatening for some participants. All participants were given the option of using a pre-drawn outline instead, however, very few participants in either study chose this option. The majority enjoyed the process of adopting a pose and seeing their own body outlined on the paper. [50]

The body is a cultural as well as a physical object and varied cultural norms and sensitivities circulate around bodies including taboos around being touched by a non-relative, sharing personal space, and maintaining privacy. This meant that some people chose to trace the researcher or free draw their bodies instead of lying on the page and being traced. An example of cultural specificity was when a young Muslim woman who participated in Study 2 chose to draw her own life size body outline (rather than having her outline traced) and then included a detailed sketch of her hijab on the map as shown in Illustration 4.



Illustration 4: Depiction of hijab [51]

As discussed in Section 2.4, in both studies researchers shared and body mapped stories from their own life experiences. While this approach was largely to model the body mapping as a process and form of storytelling, this also created a safe, secure and reciprocal place for storytelling. One of the Study 2 participants who had used some of the symbols from LS's model to represent his own depression said of the process: "I [usually] feel like people listen but they don't understand ... you need to have experience yourself to understand. Like you [LS] ... you can have empathy without asking questions because you know what it's like" (from transcript of audio recording). [52]

Given that both studies involved vulnerable populations, we were conscious of the potential that participants might be identifiable. Pseudonyms were used in both studies and identifying information such as names and personal references on the body maps or in the testimonia were removed (GASTALDO et al., 2012). In Study 2, an ethical concern was the potential for young people who had experienced trauma to be emotionally distressed by using an embodied method. As is typically the case when researching sensitive issues with young people, this risk was in part addressed by giving young people a choice about the transition they mapped, allowing them to "tell as much or as little of their story as they chose" (CHENHALL et al., 2013, p.129). In both studies we tried to mitigate a risk of emotional distress by involving facilitators and support workers in the sessions so that someone who understood the participants' history and potentially triggering subjects was available to provide support during and after the sessions. [53]

As recommended by GASTALDO and colleagues (2012), we established formal and informal de-briefing opportunities for ourselves, such as talking to a vicarious trauma expert or another research team member if we felt unsettled after a body mapping session. As described earlier, we also prepared for the possibility of participant distress (ORCHARD, 2017). This preparation was essential since, in both studies, there were participants who depicted traumatic life experiences in visually graphic ways that disturbed both the participant and us as we worked alongside them. [54]

### **3.3 Body mapping as a useful practical tool**

An unanticipated consequence was the discovery in Study 1 that participants and support workers saw body mapping as a useful tool for future planning within service settings. Participants explained that drawing on the body map had encouraged them to think in new ways about the people and activities that helped them plan. Support workers said the method was beneficial for placing the person with cognitive disability central to the planning process. Study 1 was undertaken to develop a practical planning resource and, based on this feedback, a body outline was used throughout the resource to encourage users to engage in both a visual and written way. [55]

Similarly, in Study 2 the training for facilitators and support workers that was offered prior to the body mapping sessions was seen as a valuable source of professional development. This was particularly the case in the group training session where case workers, support workers and social workers together created a collective body map of their experience supporting a young person going through complex transitions. In the process of making the body maps together teams discussed, brainstormed and reflected on their professional practice and their strategies. One group took their map out to the car park and drove over it a few times to show not only the distance they travel but how sometimes you can feel flattened by the work. [56]

Body mapping involves a substantial investment of time and energy and this may reduce its broader application to qualitative research environments with limited

resources. The significant logistical issues that were encountered in bringing participants together indicates that, for some marginalised groups, it may be best to engage on an individual basis, as was done in Study 2. [57]

#### **4. Conclusion**

The studies reported in this article demonstrate that body mapping required adaptation and presented challenges, but was found to be a useful method for facilitating the engagement in research of marginalised groups such as people with complex support needs related to cognitive disability and disadvantaged young people. Our studies add to the literature on the use of body mapping with diverse populations and exploring a range of research areas (DE JAGER et al., 2016). The guide developed by SOLOMON (2002) offered a useful foundation for the design of our body mapping sessions, from which we made adaptations around timing and format to accommodate the particular needs of our study participants and research areas (ORCHARD, 2017). ORCHARD provided a guide for visual analysis of the body maps, which was used in Study 1, but not found to be a useful approach in Study 2. With this emerging methodology, identifying suitable analytic frameworks remains a consideration for future researchers. [58]

The first three authors are skilled qualitative researchers with over twenty-five combined years of experience conducting interviews and focus groups. We found that body mapping fostered a different engagement with participants, one that facilitated a deeper level of personal reflection (BAGNOLI, 2009) and insights into participants' worlds, which would have been unlikely to arise using interviews alone (ORCHARD, 2017). In particular, the use of body outlines focused participants' thoughts on both internal (as depicted on the body) and external (placed outside the body) factors that influenced them in relation to the topic (ibid.). Working with such a diverse range of participants also demanded flexibility and creativity of us as researchers, an ability to "think on our feet" and have multiple strategies on hand to respond to whatever arose during the sessions. We think of this as a "tool kit" approach for conducting arts-based research with people with complex support needs. [59]

Arts-based methods including body mapping have the potential to empower people with complex support needs so as to engage more fully in research in order to provide a greater understanding of their experiences, views, and feelings. In their discussion of complexity, LAW and MOL (2002, p.1) stated that while there is no argument that complexity exists, it is very hard to 'attend' to it. The visual structure of a body map provides a concrete framework for attending to the depth and breadth of embodied experience, which RANKIN and REGAN (2004) defined as typifying complex support needs. The multi-modal approach offers a wide range of ways in which participants and researchers can engage with body mapping. However, the potential vulnerabilities of people with complex support needs also means that researchers need to be flexible in the way that they use body mapping, and allow the method to evolve throughout the research process (CHENHALL et al., 2013). [60]

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