

# The balancing act: Performing stories of our practice within systems of the state

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## Abstract

Funding for arts therapy services through the National Disability Insurance Scheme (NDIS) has changed the way that Australian arts therapists can work. While facilitating increased access to arts therapy, the NDIS raises challenges for arts therapists who experience pressure to conform to deficit-focused reporting practices. We invite arts therapists to reflect on the values performed by the documents we produce, and to resist the influence of institutional and systemic practices that can disempower and stigmatise. We offer the possibility of humanising, collaborative and empowering approaches that are more in keeping with the values underpinning arts therapy practice.

## Keywords

Arts therapy, collaborative reporting, complex systems, ethics, evidence, language, NDIS, values.



Figure 1. Alisoun Neville, *Within the walls*, soft pastels on paper, 420 x 297mm.

## Introduction

The National Disability Insurance Scheme (NDIS) provides support to people who are assessed as having a permanent and significant disability. Within Australia, NDIS has given national recognition to arts therapists through unprecedented access to Commonwealth Government funding. It is overseen by the National Disability Insurance Agency (NDIA). Of those arts therapists who are able to make a living in private practice alone, many are doing so through NDIS funding.

As arts therapists, we are likely to work in private or semi-private businesses and institutions, or in social agencies. In each of these contexts we may mediate, represent and/or reproduce state commitments and interests (Goldberg, 2002, p.7). We often find ourselves working within institutions and systems that require us to write reports about the people we work with, and are expected to engage in mainstream reporting practices that seem clinical, deficit-focused and dehumanising. This creates tensions for arts therapists, who experience

conflict between our professional value set and the requirements of organisations and funding systems.

We, Carla and Alisoun, are engaged in conversations about these tensions. We have both been consulted by other practitioners and developed professional development training in response, addressing some of the dilemmas faced by arts therapists. Carla's training emphasises findings from her doctoral research (van Laar, 2020) and her practitioner experiences of using arts-based practices for collaborative goal-setting and therapeutic reviews. Alisoun's training covers the process of becoming an NDIS provider, in which she encourages a critical and values-based lens on working within the NDIS system. We have attended each other's training and through our shared concerns decided to collaborate by writing this article.

The Australian, New Zealand and Asian Creative Arts Therapies Association (ANZACATA)'s code of ethical conduct states:

Creative arts therapists have a primary responsibility to respect and honour client confidentiality and to safeguard all written, taped, digitally (or analogue) recorded, and visual, work, or information produced during the course of therapy. (ANZACATA, 2018, p.5)

We have asked ourselves, how do we enact this principle when the state asks us to share confidential information about the people we work with?

Foucault's (1991) notion of governmentality is useful in understanding 'the state' as an elaborate network of relations and a continuous relation between various forms of power. Our power as therapists within this network extends beyond our face-to-face practice, or ethical considerations about participation in research. The power of the therapist's voice is also palpable in phone calls with family members, case managers or funders, in the discretions and blind spots that shape our case notes, and in the writing of deeply personal narratives on the 'progress' of the persons with whom we are working.

In this article, we explore the complexity of finding a balance between ethics and reporting, and look to relevant discussions in the literature that examine context, risk and values, themes that are crucial when facilitating the seeing, viewing, witnessing or audiencing of artworks (van Laar, 2020). We discuss classification systems as forms of

violence that are enacted through the law, science and bureaucracy (Neville, 2005). This paper draws on our earlier work, offers an overview of ideas that inform our current situation, and provides examples of our attempts to respond through practices that are congruent with our personal and professional values.

## Context, risk and values in arts therapy

Being client-centred, using arts-based practices, and drawing on narrative-informed principles are inherent to the authors' professional value systems. We engage with genuine positive regard for the people we work with, believing in the transformative power of empathic witnessing, being seen and being heard, and trusting in creative and organic processes. We work to subvert oppressive power dynamics, making spaces for alternative stories to be shared, respected, celebrated, made public, given voice and acknowledged. The contexts that we work in can make these values more, or less, difficult to perform.

Some arts therapists explore how organisational contexts impact on the way that art therapy is practised (Gilroy, 2008), including an acute psychiatric ward (Luzzatto, 1997), Tate Britain (Huet, 2011), public healthcare (Broderick, 2011; Huet, 2012), rural district hospitals (Ndziesi et al., 2013) and a museum (Salom, 2015). These discussions consider the qualities of the institutional culture that can be addressed by or contribute to the introduction of art therapy, such as the "cold climate" (Huet, 2012, p.25) of a healthcare setting or the "safe holding environment" (Salom, 2015, p.47) of a museum. Gilroy (2008) urges us to be aware of the values and dominant discourses within allied health settings, and how we may inadvertently be recruited into, reinforce, or consciously respond to these through our art therapy practices. There is a real risk that arts therapists can find ourselves performing stories of expert knowledge that conform to and maintain the status quo of patriarchal and colonial systems that our values tell us we should strive to subvert.

Other discussions prompt us to reflect on how we conceive of 'risks' associated with arts-based experiencing, and the risks of adopting discursive habits that perpetuate unimaginative and disempowering practices. Jensen (2014) discusses risks unique to arts-based practice, recommending that the 'first, do no harm' principle in arts and health projects includes "signing up to a code of conduct"

(p.336), assessment of participants' compatibility with the project, briefing participants about potential risks, awareness training for facilitators and ongoing supervision or mentoring of the artist facilitator. Springham (2008) focuses on a court case in which he had been called as an expert witness. He describes the legal process in which an organisation providing an addiction rehabilitation program was found to have been negligent in the way an art program was conducted. Specifically, a participant injured himself while experiencing a strong reaction to his artwork, head-butting his artwork while it was on a concrete floor. Springham's (2008) opinion was that the facilitator of the art process "had exceeded his competence" (p.71) in two areas:

1. General psychological: evaluating the claimant's tolerance to unwanted feeling states;
2. Art therapeutic: a specialist assessment of the effect of the art on the participant. (p.71)

Linnell (2012) revisits Springham's article to explore "risk discourse in art therapy" (p.34). She argues that "Springham's paper can be seen as a performance of expert knowledge, rather than simply a description of events" (p.34), and that this itself poses risks within the field of arts and health. Linnell (2012) invites us to reconsider the facilitator from an approach informed by narrative therapy:

I have wondered whether he, as well as his even more unfortunate client, was to some extent an unlucky individual upon whom a widespread preoccupation in the world of psychotherapy with lack, negativity and the confessional mode, combined with stretched resources and inadequate/inconsistent protocols within an agency, rebounded with devastating consequences. (p.37)

Linnell (2012) posits that Springham "discursively reinforces and performs a set of hierarchical binaries" (p.37) such as "the expert responsabilised art therapist / the vulnerable and needy client" (p.37). She sees this tendency as a disadvantage of risk discourse in art therapy. She reminds us that art therapy has the capacity to subvert disempowering discourses, and urges us to continue taking risks such as mindfully questioning the values that can be imbedded in performing normative narratives of professional expertise in regard to risk management. She suggests that complete risk aversion would be a great loss for art therapy.

Normative narratives are similarly at play when we create stories to provide evidence of efficacy. The ways in which evidence is sought and evaluated is a critical part of the context in which arts therapy is practised and funded. For example, Patterson et al. (2011) examined a randomised controlled trial as a normative culture in research. In response to "the findings of a pragmatic randomised controlled trial testing the addition of group-based art therapy to standard care for people diagnosed with schizophrenia" (p.28), they critique the implications of this research culture. In concluding, they say that, "the infinite variability of art therapy is a key strength of the approach", and that "a fundamentally different kind of evidence is needed to inform provision to individuals" (p.36). This kind of fundamental difference requires a cultural shift towards arts-based inquiry and evidence in arts therapy evaluation, research and reporting.

Art therapists referring to the work of post-structural feminists (Hogan, 1997; Joyce, 1997; Lupton, 1997) describe overbearing discourses as holding rigid assumptions and claims of truth and normality. Normality is seen to be the perspective of a white, able-bodied, adult, middle class, heterosexual male (Joyce, 2012). This perspective constitutes the 'real world', and all other perspectives are perceived as not-normal, other, and delusional or untrue. This generates alienating dissonance for people who are excluded from the dominant discourse. This dissonance can be experienced by art therapists striving to work towards empowerment within a disempowering context.

In the social climate of 2020, public outrage against racism and police violence has increased social awareness of issues including privilege and intersectionality. Kuri (2017) has highlighted:

the ongoing need to apply an intersectional framework to art therapy practice in a manner that acknowledges power, reflexivity, and the social construction of meaning. Intersectionality is a way to understand how marginalized, intragroup identity differences simultaneously intersect to create and exacerbate experiences of oppression. (p.1)

ANZACATA (2018) formalises an understanding of intersectionality as a core ethical guideline for the practice of arts therapies. For instance, they advise creative arts therapists to consider diverse genders

and sexual orientations “within the context of other significant intersections of lived experience among LGBTQIA+ such as diverse ability, age, culture, ethnicity and religious beliefs” (p.3).

The contexts of our work as arts therapists include our personal life histories, the institutions we engage with, the culture of societies that we live and work in, and the histories of our art-making practices. Being mindful of these multiple influences broadens the ways in which we can consciously create contexts that support ourselves and others to safely share stories through art, enabling art to be a meeting place, and contributing to the making of cultural contexts that are increasingly consistent with our values. Moon (2002) encourages us:

If our art making and art therapy practice occur in a socially engaged way, there is no distinct division between the personal and the political. Our most personal revelations are given meaning within the context of our social reality. (p.283)

Finley (2003) refers to the impact of theorists such as Denzin, who encouraged us to move “from the personal (the reflexive relational) into the political (reflexive activist), not in a disconnected way but by employing emotional critique to political action” (p.287; see also Denzin, 1999, 2000). It is exactly this kind of emotional critique that we seek to inspire in arts therapists. The discomfort we experience when performing discourses that are incongruent with our values can, in this way, become a call to action. Our authentic voices can tell different, more empowering stories about our work and the people we work with.

### Alisoun’s voice

I first acknowledge the collective and diverse experiences of peoples living with disabilities. I also acknowledge and am thankful for the work of the advocates and activists who have made my life today possible. I identify (provisionally) as a person with disabilities, though I do not like this language. I see myself as one of the lucky ones and have a degree of choice about when, whether and how much of this I reveal to others.

I introduce myself simultaneously as a new/emerging arts therapist. Qualifying in late 2018, I launched directly into private practice as a registered NDIS provider. A few years prior, as the NDIS was first rolled out, I worked with Aboriginal health services in Victoria, supporting Aboriginal

community-controlled organisations as they grappled with the new model and funding scheme. Intersectional inequality for Aboriginal and Torres Strait Islander peoples with disability is acute and pervasive (Avery, 2016), compounded by the inability of public sector systems to respond from a meaningful cultural framework.

McNiff (2000) tells us that research can be directed towards “the need to experience, to inspire, and to collectively build a profession” (p.35). While I am new to this sector and have much to learn, I am guided by McNiff’s visions for our work. I also believe the NDIS offers a critical turning point for our profession in Australia.

### Carla’s voice

Over the years I have noticed that I can feel disheartened and sometimes incensed when the context of my work does not reflect the values that inform my practices. I have come to recognise these feelings more quickly than I did a decade ago, and I now describe this familiar discomfort as a ‘paradigm clash’. This paradigm clash occurs when there is a dissonance between my values and the systemic context of my work.

In my own practice I consciously work to cultivate my capacity as a witness to participants’ descriptions of their lived experiencing. I seek to disrupt therapeutic practices such as those that Linnell (2012) describes as having “the authority of normative psychological practice and of psychoanalysis” (p.37) by using people’s own words when I am writing any report.

Twenty years ago I faced a dilemma as a beginning arts therapist. This is mirrored in the current issues, power dynamics and ethical tensions faced by arts therapists providing private services for NDIS participants whose access to funding similarly relies on arts therapists’ compliance in writing reports for a paternalistic state funding system. We navigate these dilemmas in an ongoing way. A consideration of ethics and power challenges us to examine the stories we may create and the values we may perform, in the process of documenting our work.

### Dilemmas old and new – what is this dynamic I am working in?

It is the year 2000. Nell (not her real name) is 14. She attends an alternative school and her father has agreed to pay for some private

arts therapy sessions at the suggestion of the school well-being coordinator. I am a young arts therapist and I travel to the school weekly to see her. Nell uses the sessions to make art through which she explores and shares vulnerable aspects of her inner world. Her father happens to be a medical doctor. He insists that I provide him with a report each week about Nell's sessions.

I am conflicted. I feel as though I have been drawn into a controlling power dynamic between Nell and her father. I am concerned that Nell will not feel safe with me if she is worried that I am going to report on the content of our private sessions to her father. And yet he is paying the bill. I am also apprehensive that if I don't write the report that I won't be able to keep seeing Nell.

After some soul searching and supervision, I decide to have a conversation with Nell about this dilemma. I ask her if she wants our sessions to continue, and she does. She can see that wanting a weekly report is in keeping with her father's usual tendency to oversee her healthcare.

Together, we come up with a unique solution. Each week, we spend the last ten minutes reviewing our work together, and we co-create the weekly report that I then pass on to her father.

## A dilemma from today – what is this NDIS system?

The NDIS started in most Australian states and territories in July 2016, following three years of pilots in selected sites. It aspires to a person-centred, lifelong and strengths-based approach that aims to invest in people with disability earlier, to build their capacity to reach greater outcomes later in life. The NDIS is underpinned by the concepts of choice and control in the provision of individually tailored packages of funding for services and equipment to eligible people. It is designed to provide flexibility to each person to use the funds that have been allocated to support them (ANZACATA, 2020).

While arts therapists have welcomed recognition and broader access to our services via NDIS funding, it is clear to those of us who encounter it that this new system gives rise to some significant dilemmas

for arts therapy practitioners. In this section, we focus on the requirement that each therapist must supply a 'progress report' that demonstrates the 'outcomes' achieved in their work with the person. This report is submitted, usually once a year, as part of the person's NDIS plan review process, through which the allocation of funding for the next period is decided.

NDIS funding for 'therapeutic supports' is categorised in the person's NDIS plan as 'capacity building' and 'improved daily living'. As a result, the funding is conditional on the therapist's ability to facilitate 'functional improvement' with/for the person. Many allied health practitioners, including some arts therapists, use rating scales and other psychometric testing to assess and monitor functional change.

In contrast, Lett's (2011) notion of "preferred ways of being" (pp.4-5) focuses on process and holds within itself the promise of changes we may choose or aspire to. It seems consistent with the foundational philosophy of the NDIS, as the goals were intended to reflect the dreams and aspirations of the person, putting them 'in the driver's seat' regarding the funded supports they use to achieve them.

The design and implementation of bureaucratic categories in practice (for example, capacity building) has created a system in which the emphasis is on the 'deficits' of the person. The person is asked to 'improve' herself, 'build her capacity' and achieve 'outcomes' in relation to what are often deeply personal matters – intimate and social relationships, ability to manage emotional responses or pay bills on time. This occurs after submitting assessments and practitioner reports (in the application process) establishing the 'permanency' of her condition and her inability to 'function' as others do.

There is merit in therapists holding ourselves accountable for making a difference in the lives of the people we work with. While we can and often do look to science for an understanding of what those differences may be, this cannot replace attending to the lived experiences, perspectives and voice of each person themselves. We also note the absence in the NDIS reporting process of any requirement to take account of the cultural lens and needs of the person. It relies instead on models and assumptions of 'expertise' inherited specifically through the intellectual traditions of Western modernity and imperialism (Neville, 2005).

Bowker and Star (2000) point out that “categories perceived as real become real in their consequences” (p.53). The very word ‘disability’ remains contested by those of us subjected to it, tied as it is to historical and contemporary impacts of hyper-normative assumptions and social prescriptions for who and how we may be. We can reject it, along with the biomedical models, assessments and classifications it carries in its wake, but we are asked to forfeit access to necessary and life-enhancing supports when we do so. It can mean risking our survival.

As practitioners, we tend to hold the concept of change lightly, as a possibility not an imposition. Mandating change within an emergent, person-centred context is philosophically and ethically fraught. Change in the therapy field can also imply causality – “one person changing another or a person changing from one thing to another” (Anderson, 2007, p.10) – when causality is not possible. Yet it remains easier to focus on individual change – i.e., ‘the person’ – rather than structural inequalities and poverty as the root cause of a person’s circumstances (Morgan, 2016, p.180).

A focus on deficits is pragmatic; however, it has consequences. Experiences on the receiving end are often painful, even when consensual. Without “reflection and analysis about the ‘bigger picture’ [and]... without identifying and inquiring about complex sources of harm, we may risk interpreting one’s struggle as a failure on their part” (Sajani & Kaplan, 2012, p.165).

Proponents of NDIS and its founding philosophies could argue that the change is driven by the person, as the intended author of their own NDIS goals, which reflect their aspirations for their daily lives. We allow space for this; however, we cannot overlook the complex systems and power relationships through which these goals are crafted in practice, often on repeat: *I want to manage the impact of my mental health on my daily life; I want to increase my social relationships and connections to the community; Jasmine (caregiver) wants Andrew (child) to develop his emotional regulation.*

## What are our choices?

An NDIS progress report can reveal some of the most complex “forms of tyranny that are embedded in representational practices” (Lincoln & Guba, 2000, p.184). If we do not adopt language from the NDIS framework (working towards participant goals,

building capacity) the person can miss out on funding and access to the supports they are asking for.

Jeynes (2006) encourages us to practise “reflecting ‘on the go’ from within the immediacy of experiencing. It is here that discernment takes place and decisions are made whilst we are in the midst of doing” (p.76). We can pay attention to the embodied dissonances that emerge for us through the report-writing process. This may include our concerns and decisions about how to take account of power, engaging reflexively with these questions on an intellectual and action level.

In the NDIA guide for progress reporting, we are asked to advise whether there were any risks identified to the participant or others (NDIA, 2020). The very question encourages us to provide the NDIA with everything they have asked for, without regard for the legal or ethical relationship/s between this report, our obligations to the person and our professional practice guidelines.

We can think about identifications of risks within our practice, obligations to manage and/or avoid risk *and* whether the NDIS report is the best way to do this. Does the NDIS need to know? This is not to say we will not report on risks – we have both done so where we have felt it pertinent and within our obligations – but rather to question the assumption that the agency is *entitled* to this information through our practice. We also think about, and report on, systemic risks to the person, not risks *from* the person. Are they at risk of homelessness, or behaviours that make them vulnerable to others, if they do not have access to housing or other supports? What are the NDIA’s accountabilities in managing these risks?

The NDIS application and reporting processes are placing unprecedented levels of personal information on the public record. The implications of this are yet unknown. We know that accessing a mental health care plan through your GP could compromise your future access to income protection or other insurances. What will it mean if/when the record contains information about your problematic drug use, family violence, your last suicide attempt or self-harm, what you do when you first get up in the morning, your relationships with friends, lovers and family members, your workplace?

For many people (for example, in Aboriginal and Torres Strait Islander communities, or in the criminal justice or child protection systems) the consequences

of being subjected to the interpretation and power of your government records are at once familiar and catastrophic. With the introduction of NDIS, another half a million files will join the existing (often intergenerational) archives of personal lives and stories narrated in bureaucratic form.

Many NDIS planners are accustomed to reports that use validated assessment tools, with numeric measures of success. For many of us, this is not consistent with our arts therapy practitioner training, practice values or philosophical approach. However, as noted above, if we do not persuasively demonstrate ‘improvements in functional capacity’ the participant will miss out on future funding.

If arts therapists reject the use of validated assessment tools and rating scales, then the NDIA may see us as providing ‘insufficient evidence’ of effectiveness and reject the use of arts therapy. The sources we use are likely to be ranked and weighted according to a “hierarchy of credibility” (Becker, 1967) that upholds ‘objectivity’ as the holy grail. This of course parallels broader debates about constructions of truth and their ethical implications. As McClintock (1995) reminds us, empiricism is “a mode of ordering past experience according to certain rhetorical and disciplinary conventions”, a notion can be upheld only “by radically depoliticizing the dynamics of power” (p.306).

The National Disability Insurance Scheme (Supports for Participants) Rules 2013 (hereafter NDIS Rules) require us to submit “evidence” but do not require us to be positivist in our methods or orientation (Federal Register of Legislation, 2013). We are required to establish that our ongoing support will be “effective or beneficial for the participant, having regard for current good practice”:

You can provide evidence of the effectiveness of the support for others in like circumstances. That evidence may include: (a) published and refereed literature and any consensus of expert opinion; (b) the lived experience of the participant or their carers; or (c) anything the Agency has learnt through delivery of the NDIS. (Federal Register of Legislation, 2013, rule 3.2)

The rules “do not limit the kind of evidence that may be relevant [or] suggest that more weight should be given to any kind of evidence over another” (NDIA, 2019b, para 30). The NDIS Rules state simply that

“expert opinion” is to be *taken into account* (Federal Register of Legislation, 2013, rule 3.3, emphasis ours).

The NDIS Operational Guidelines effectively narrow the scope, arguing that lived experience “will inevitably be subjective” and the weight it is given will depend on whether it is consistent with “reliable, relevant, independent evidence” (NDIA, 2019b, para 31).

It is important to think strategically about how we provide alternative forms of evidence *and* make it clear to the NDIS planner that we are meeting their requirements. They may not like the way we have written it, but they will not want to give us grounds for an internal review or external appeal of their decision. NDIA have already been held to account in the Administrative Appeals Tribunal for some of their decisions to override the training and knowledge of allied health practitioners (see, for example, Administrative Appeals Tribunal, 2015; see also Gingold, 2019).

The ambivalence and complexity of this situation makes it very tempting for practitioners to adopt discourses of expertise and all-knowing authority over the persons we are working with. In this environment, while we are committed to authenticity in what we write, we also draw pragmatically on terms and rhetoric with which we are not always comfortable, to ensure that NDIS can see that its requirements are mirrored in each report. At times the rhetoric can stray too far, motivated by eagerness to ‘make the system work’ and secure the funding for the participant, meaning, also, more funded work for the therapist.

Heilbrun (1989) contends that “power is the ability to take one’s part in whatever discourse is essential to action and the right to have one’s part matter” (p.18). We have faith that a power-sharing participatory process through the report-writing and research process can “generate knowledge not obtainable in other ways” and strengthen the capacity of people “to discover better ways to meet their needs and impact their reality” (Kapitan et al., 2011, p.72).

Jacobi (2011) acknowledges complicity and compromise, but nevertheless encourages creative strategies that support “participation in self-expression and larger movements toward social change” (p.49). We believe deeply in the collective possibilities of the multimodal and creative arts therapies, including enabling the voices of people

who may otherwise be silenced to be heard. We long for more – and new – opportunities for persons ‘with disability’ to shape the community’s understanding of our needs and aspirations.

We are inspired by stories from a former disability worker on Ngaanyatjarra country, in which the person, their family members and/or friends were co-authors of reports and explicitly acknowledged as such. Following discussions arising through the drafting of this paper, Alisoun has offered a co-authoring approach to a number of people she is working with, with great feedback from the participants, tangible outcomes through the funders, and invaluable – mostly unanticipated – insights to inform ongoing practice.

## Conclusion

As a growing field of practitioners, arts therapists have a current and urgent opportunity to co-create our own socio-cultural context that supports and nurtures the emergence of a strong professional identity. Diligence is required to persistently examine and destabilise the power dynamics and systems of oppression we may unwittingly participate in through our compliance with organisations and structures that can masquerade as safety measures or governance.

We can do this by valuing our own arts-based ways of knowing, our pedagogies, our practices,

and by developing our own arts-informed methods, approaches, evidence and reporting styles that challenge and subvert dominant cultures and discourses. Being a strong community, sharing our ideas, and turning to each other in rigorous dialogue and with deep respect, is paramount to our success in these efforts to establish our unique professional identity, through which we can resist disempowering practices and find our creative voices.

As arts therapists we can contribute strategically to the meanings attributed to what happens in our sessions, under the banner of NDIS and within other institutions. This opens new and potentially transformative possibilities for our work. If, collectively, arts therapists can be intentional in our rejection of the roles of narrative expert and demonstrate instead the efficacy of collaboration through participatory and dialogical process, we might begin to hear some new voices, and co-create some new and safer spaces.

The access to funding through NDIS has changed the way that arts therapists practise. While this has increased access to arts therapy for people living with a disability, it raises questions for practitioners who feel under pressure to conform to clinical and deficit-focused reporting practices. This article has presented an invitation for arts therapists to discursively reflect on the values performed by the

documents we produce, and to resist the influence of institutional and systemic practices that serve to disempower and stigmatise. We have suggested alternative ways of reporting that are more in keeping with the values that underpin arts therapy practice, and perform stories that are humanising, collaborative and empowering.



Figure 2. Carla van Laar, *Looking up*, pastel, ink and house paint on board, 900 x 900mm.



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