

Chapter X

“The kitchen is my favrote place in the house”: A world worth living in for children with feeding difficulties and their families

Nick Hopwood, Henry Gowans, Jessica Gowans, Kate Disher-Quill, and Chris Elliot

Abstract We cannot live well without food. However, a significant number of children experience medical issues that impact their feeding, in some cases requiring feeding via a tube. The SUCCEED Child Feeding Alliance recognises the challenges that tube-feeding presents, and collaborates with parents, healthcare providers and others to take steps towards a world in which all children who tube-feed thrive, experiencing the full joys of childhood, and agenticly pursuing the futures of their own making. This chapter is inspired by Henry, who despite an ongoing need to tube-feed, has a passion for cooking, and wants to be a chef when he is older. We explore the challenges and praxis of tube-feeding, and different responsibilities and opportunities we have as adults in promoting positive change – from perspectives as parent, clinician, artist, and researcher. This dialogue is infused with theoretical insights from the theory of practice architectures, and Stetsenko’s transformative, activist stance, which draws our attention to ways in which we contribute individually and collectively to the future that ought to be. We conclude by presenting one of Chef Henry’s own recipes.

Keywords. Agency, transformation, feeding, activism, childhood; praxis

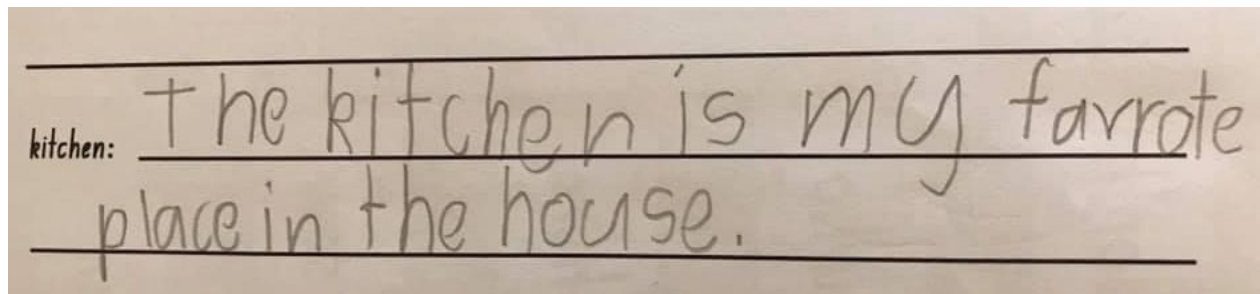
X.1 Introduction

We cannot live well without food. This applies to the biological necessity of food as well as the shared joys of eating together: feeding nourishes us in many ways. Feeding practices are sites of togetherness in everyday routines, moments of celebration, and rites of passage. Feeding relationships with parents underpin children’s emotional development and parents’ experiences of caregiving, shaping wider family identity (Wilken, 2012). In this chapter, we conceptualise feeding not only as of nutritional significance, but as of relational, social and transformational significance. As a parent (Jess), clinician (Chris), artist (Kate) and researcher (Nick), members of a collaborative project called the SUCCEED Child Feeding Alliance, we explore what it means to live well when a child feeds using a feeding tube. We are joined by Jess’ son Henry, who spent time with Kate, and gave Nick a cooking lesson.

Food and mealtimes vary around the world. However, there is a significant group of people, especially children, who have in common medical issues impacting their feeding. Within this group, the most seriously affected require feeding via a tube. Even though there over 350 medical conditions requiring tube-feeding (Feeding Tube Awareness Foundation, 2016), it is overlooked in the everyday discourses of health systems, and artistic expression (Hopwood et al., 2021). Our title quotes Henry, who like his sister Rosie, has a metabolic disease that requires tube-feeding. Henry has tube-fed since birth. When he was two and a

half years old, he began to drink a special formula through a bottle. Now seven years old, Henry can ingest some foods orally, but chewing and swallowing can be difficult, so his bottle formula and a tube-feed using a pump overnight remain needed. His comment in his Year 1 school workbook is significant. Given the ways tube-feeding can create barriers to inclusion in feeding and other practices, it is remarkable and wonderful that he wrote what he did (Figure 1).

Figure X.1 Henry's words



SUCCEED began with an aim to improve the lives of children with feeding disorders. We started by creating a website (childfeeding.org) that plugged gaps in resources available to help parents with everyday life aspects of tube-feeding their children. We conducted interviews and focus groups with over twenty families whose children had tube-fed, guided by our Parent Advisory Group, which led us to create opportunities first and foremost for parents to tell their tube-feeding story. We draw on excerpts from these discussions in the dialogue between us below.

Following Vygotsky, SUCCEED rejects deficit models of disability, and chronic and temporary illness (all of which can require tube-feeding). Where stigma and barriers to participation arise, the 'defect' lies in society, not in a physical quality of the child (Stetsenko & Selau, 2018; Stetsenko 2020e). Our task is not to change children who tube-feed, but to re-educate the majority who feed orally, and transform the practices that produce unnecessary difficulty and exclusion. Vygotsky linked the topic of disability and difference with social action: our commitment to action is not to compensate for biological difficulties, but social ones (Stetsenko & Selau, 2018). The deficit we address is a 'secondary one' (see Sannino, 2018), one that is socially produced and perpetuated.

An important feature of the SUCCEED website involved images that challenge stereotypical, negative views of children who tube-feed as fragile and sick. Parents wanted pictures to reflect the way they saw their children: as happy, playful and above all, as *children*. This became an explicit focus in subsequent arts-based collaboration with Kate called *The HIVE*. *The HIVE* was an immersive art installation at the Partnerships for Better Health 2019 International Symposium (International Convention Centre Sydney), involving collaboration between artists, academics, health professionals, health service consumers, and carers. Kate produced a series of black and white images relating to tube-feeding, called *Be Not Afraid of my Body* (Disher-Quill, 2019). Kate's exhibition was installed at Sydney Children's Hospital in 2021.

This series of portraits aims to share the challenges and vulnerabilities of these mothers while celebrating the courage and resilience that I witnessed. It also gives a voice to these children, who just like any other child, need to be nurtured, loved and accepted. (Disher-Quill, 2019)

One of the images that was displayed was of Henry, shown in Figure 2. This, along with Henry's statement about the kitchen (Figure 1), are taken up as key foci in the dialogue between us as co-authors of this chapter.

We take tube-feeding as a site to explore and reflect on the practices, practice architectures and critical praxis (Kemmis & Grootenboer, 2008) of a world worth living in *for all*, and the transformative activist stance (Stetsenko, 2017) required to make that world a reality for all children and their families, regardless of how they feed.

Figure X.2 Kate's photograph of Henry



X.2 Transformative activism and critical praxis

We use theory critically to probe how just and inclusive practices, which *realise* better futures, become possible. This brings us to questions of in whose interests, in solidarity with whom, and towards what future we struggle (Kemmis, 2019). Building on resonances outlined by Hopwood (2021), we draw on the theory of practice architectures (Kemmis & Grootenboer, 2008; Kemmis & Smith, 2008; Kemmis, 2019) and Stetsenko's (2017, 2020a-e) transformative activist stance.

We focus on practical and emancipatory aspects of the theory of practice architectures. The former concerns acting wisely and prudently for the good of humankind, through *praxis* which is history-making and self-forming at the same time. Emancipatory aspects concern *critical praxis*, interrogating and transforming existing ways of doing things where they have untoward consequences (Kemmis, 2019; Kemmis & Smith, 2008). Through the theory of practice architectures, we are interested in the sayings, doings and relating that form complexes of actions around tube-feeding, and the cultural-discursive, material-economic and social-political arrangements that make practices – especially those of critical praxis – possible.

Stetsenko's transformative activist stance (TAS) revives and reinvigorates Marxist philosophy, extends insights from Vygotsky's work, and draws on theories of resistance including critical pedagogies (Freire) (Stetsenko, 2020e). In TAS,

acts of being-doing-knowing are non-neutral, transformative processes that produce the world, its history and also people themselves, all realized in the process of taking up the world, rather than passively copying it or coping with it. (Stetsenko, 2020e, p. 1)

In the struggle to create a world in which everyone lives well, TAS pivots away from an ethos of adaptation and political quietism, instead striving for social transformation guided by principles of social justice and equality (Stetsenko, 2020e). Here we find resonance with critical praxis. In TAS, human beings are agentic, contributing through actions oriented towards sought-after futures as they envision, imagine and commit to those futures. We take up Stetsenko's (2020d) call to make theories 'dangerous again' – that is, useful and used in the struggle for a better world.

TAS maintains individual agency without falling into traps of individualism. Individual|social dichotomies are eschewed in a view that social reality is contingent on each and every individual human being, and is changed every time individuals act (Stetsenko, 2019a). Agentic actions are contingent on access to cultural tools that are provided by society and agentially taken up by individuals (Stetsenko, 2019b). TAS shares with the theory of practice architectures a grounding in critical theory, Marxist dialectics, strong materiality, and an explicit reference to the philosophy of practice (Stetsenko, 2020a).

In both frameworks, the future is up for grabs, dependent on agentic individuals whose agency relies on what society provides. Both pull scholarship towards active engagement in co-making the future rather than passive by-standing and observing a world that already is. On this basis, we explore tube-feeding in childhood from a transformative activist stance, interrogating the status quo, co-producing cultural tools of agency in solidarity with others. Despite our different backgrounds and *standpoints* as young person, parent, artist, clinician and researcher, we share a commitment to an *endpoint* that involves alternative futures (Stetsenko, 2015): not a naïve utopia, but a precise-yet-open vision of a world in which all children who tube-feed are able to thrive and live well, as fully and joyfully as their peers who feed orally.

X.3 Feeding difficulties and tube-feeding

For all their vitality, feeding practices are often challenging. Clinical measures suggest a quarter of children have feeding problems (Aldridge et al., 2010), although when parents are asked, the figure is closer to half (Borowitz & Borowitz, 2018). The prevalence of feeding difficulties reflects the fact that feeding reflects biophysical, family, social, and environmental factors (Aldridge et al., 2010):

Feeding is a complex, dynamic process requiring not only well-integrated movement and coordination among muscles but also effective interaction with caregivers and the environment, globally defined. (Kerwin, 1999, p. 193)

Chewing and swallowing are not possible or safe for all children. When children are not able to eat orally, tube-feeding is an alternative. Tube-feeding can be needed because of premature birth, congenital heart disease, cerebral palsy, neurodevelopmental disabilities, metabolic disorder and cleft palate. Estimating the prevalence of tube-feeding in childhood is difficult, however, because little data is collected systematically (Hopwood et al., 2021).

Figures suggest between 1 and 4 per 100,000 children tube-feed at some point, but some evidence points to a figure closer to one percent (Krom et al., 2019). As children who tube-feed, Henry and Rosie are far from alone, but too little research attention has been paid to what it means – and what it takes – to live well as a young person who tube-feeds.

Commonly, children are first given a nasogastric (NG) tube, which is inserted through the nose and continues down to the stomach, with the external tube taped along the cheekbone. The insertion of an NG is uncomfortable, an NG can be pulled out relatively easily, and is highly visible to others. For longer-term tube-feeding, surgically emplaced tubes are used. A common form of this is a percutaneous endoscopic gastrostomy or G-tube, a small plastic button to which a longer tube is attached when feeding (see Figure 2). Henry used an NG from birth until 11 months, since when he has used a G-tube.

From the perspective of the health-care system, tube-feeding tends to be regarded as a solution to the problem of nutritional intake, ensuring children gain weight as they would if they were able to eat orally. Adequate nutrition is necessary to thriving, but does not guarantee children will live well. A feeding tube solves the problem of delivering food to the body, but does not address social practices of feeding (Craig et al., 2003). In this chapter, we shift the focus away from calorific nutrition and towards other ways in which children are nourished: through love, joy and connection with others. In what follows, we consider the challenges to living well that society's response to tube-feeding presents, what it means to live well while tube-feeding. We consider Henry's words (Figure 1), the photograph of him that Kate produced (Figure 2), and how parents, clinicians, artists and young people themselves can contribute to transformations that make living well more, and more equally available, to children who tube-feed and their families.

X.4 What are the challenges to children living well while tube-feeding?

Our dialogue begins by exploring the challenges to living well that arise through tube-feeding and the way society responds to it. First, we hear from Jess, as a parent:

Jess: I think the first thing is tube-feeding isn't something that is very well known, so there's a lot of confusion about what tube-feeding actually is. To me it is the thing that keeps my children alive. It doesn't just give them nutrition, it manages their ability to get through the day. When you see pictures of someone who's tube-fed it is in the context of being severely unwell. It's challenging because people generally don't understand and haven't had those experiences in their own lives... I went around so many preschool centres. They weren't all equally open to Henry attending, even ones that had an inclusion sign on the door.

Jess points to social-political practice architectures that separate those who experience tube-feeding from those who don't. This manifests as an institutional separation preventing access to preschool and an epistemic one, in which social understandings of tube-feeding are narrow and, in parents' eyes, incorrect. This is something Kate learned from her time as an artist working with families:

Kate: A lot of it comes down to stigma, what do people think of me and my family if they see my child with a tube. I saw a huge challenge being the perceptions of others, how parents and children perhaps feel judged. I think people relate the tube to sickness because of images we see: tubes are used to represent a sick child.

Association with sickness leads to views of tube-feeding as *life-saving*, while Jess sees the tubes as *life-enabling*. Cultural-discursive architectures in which imagery of tubes and sickness are embedded reinforce a sense of deficit in the child, simultaneously producing and reproducing the secondary deficit in wider society. This manifests when families are out and about. One mother commented in a focus group:

Everybody stares. When you walk with the pram, somebody runs back and says “What’s wrong with your child?” I’ve had that.

This resonates with other accounts of ‘living life on the margins’ (Hewetson & Singh, 2009, p. 325) and stigmatisation of the child, and of the parent who (in the eyes of others) fails to meet normative expectations of ‘good mothering’ (Craig & Scambler, 2006, p. 1116). Negative associations with tube-feeding can also manifest within families, particularly around photographs of children. Several parents explained to us how they had resisted requests from grandparents to have photographs of the child without the tube:

Why can’t she have photos in the house with the tube? Because that’s her story.

Again, we see practice architectures of separation and othering. The materialities of visible tubes and their depiction in photographs collide with discourses of normalcy and sickness, unsettling relationships and creating dividing lines.

Chris, a paediatrician, expanded our reflection on challenges relating to tube-feeding:

Chris: Many parents tell me that it’s hard when you have to feed using medical formulas, because otherwise you would be preparing food from your heart, as an expression of love for your child. From the healthcare point of view, we don’t focus enough on tube-feeding. We focus on the serious, life-threatening condition [that creates the need for tube feeding]. The tube-feeding just gets done in a pragmatic, ‘move on’ kind of way. Nutrition is of course key, but that’s where most people stop with tubes.

The materialities of tube-feeding may disrupt the expression of parental love through preparation of food and feeding. This connection between nutrition, food and love is often missed in healthcare, where a focus on nutrition can compound a medicalisation of both the child and parenting. The child’s needs are framed around nutrition and weight gain, and the parent’s role is viewed as one of enacting prescribed feeding routines. The architectures of healthcare practices focus on materialities (volume, pace, frequency, and content of feeds) through discourses of weight gain. These often do not align with the social architectures of parenting, which foreground loving relationships with the child. Morrow et al. (2008) found a contrast between health professionals’ concern for weight gain and parents’ concern that their child feels loved. An overly biomedical focus can amplify a sense of loss and disempowerment in parents as their role is reduced to one of compliance with medical instructions (Hewetson & Singh, 2009; Pahsini, 2018).

Difficulty arises not from the child or failings in caregiving, but from what happens around tube-feeding. In the language of TAS (Stetsenko, 2020a-e), a significant part of parents’ struggle and striving is not tube-related, but around the relationship between tube-feeding and society. The architectures that shape and uphold everyday practices and healthcare practices create separation and perpetuate framings of tube-feeding around sickness, when, in Chris’ words, the multiple complexities of tube-feeding ‘don’t preclude you from having a life filled with wellbeing and joy’. It is to this form of life that our dialogue now turns.

X.5 What does living well with tube-feeding mean?

Jess: I think living well means having similar opportunities and choices to the people around us, enjoying life. Being joyful and having nice things to look forward to. It would be nice to live in a society where tube-feeding is accepted, because it is a basic need for people who do have a feeding tube. Tubes can be life-enabling not just life-saving. I really believe that because I see it in my own children. If they didn't have a feeding tube they wouldn't be able to access all those opportunities [picnics, preschool, school, play], and have all the choices in life I would like them to have.

Kate: I think to live well is to feel accepted, to feel you don't have to change a part of you. You're accepted for who you are and you have the support you need around you, to fulfil all those aspects of who you are and who you want to be.

Living well is something that becomes possible *because* of feeding tubes not *despite* them. From Jess' perspective, Henry's and Rosie's feeding tubes have been what has opened doors to the joys of childhood and their empowerment to make choices in and about their lives. This shows clearly how it is not the tubes in themselves, or the underlying medical issue that creates barriers: these barriers unquestionably are an effect of the 'secondary' deficit (Sannino, 2018). Living well as a child who tube-feeds is no different from living well as a child who feeds orally: having the opportunity to fully realise oneself – in the moment and towards projected future selves.

Chris frames living well in terms of linking nutrition with love and joy:

Chris: I see living well as depending on confident, well-informed healthcare professionals who have a family-centred understanding of what tube-feeding means, and can adapt to individual circumstances. That then enables taking joy in the child, in mealtimes, and in going out and about. The child is at a centre of a family who loves them, who feels happy and confident; they're receiving the nutrition they need, but in a way that's joyous.

Healthcare practices that make living well possible require architectures that enable care that attunes to specific circumstances based on holistic rather than narrowly nutritional understandings of tube-feeding and thriving. Nutrition is not just a precursor to a joyous life or feeling loved, but can be an enactment of these things: nutrition can be delivered joyfully and as an expression of love when tube-feeding.

These expressions point to what the sought-after future looks like, outlining the *endpoints* (Stetsenko, 2020e) that we and others commit to, from our different standpoints. Significantly, these endpoints are not about 'fixing' children, or measurable in terms of weight gain, but about a different society, a society that enables children who tube-feed to fully realise themselves, joyful, accepted and loved.

X.6 Henry's comment about the kitchen

Henry writing that the kitchen is his preferred, 'favrote' room in the house struck us all in a way that we wanted to explore further. But first, Henry's perspective.

Henry: I looooooove fooooooooooooooooood!

This was one of the first things Henry said when he met Nick for the first time on Zoom. Subsequently, Jess invited Nick to their home so Henry could give him a cooking lesson. Henry improvised a recipe for a chocolate pudding (see below), and while it was cooling down, Henry sat on the small steps he uses to reach the kitchen bench, and in between sips of his formula, talked to Nick about his love for cooking (Figure 3A). He mentioned his grandmother frequently as an inspiration. During the cooking lesson, it was clear that Henry loves measuring out foods precisely, taking great care and pride in filling the scoops so the flour was level. He said he likes to make his own recipes. While he had a basic plan for the chocolate pudding, new elements were added as he went. One of these was a caramel icing, which he decided he wanted to insert into the middle of the pudding. He came up with the idea of using one of the syringes from his feeding kit, which worked perfectly, and which he had never done before (Figure 3B). Decorations were added before the puddings were served up, including portions for Rosie and Jess. Cooking with Henry gives a clear sense of the many ways he finds and expresses joy in food – measuring, stirring, mess, texture, creativity, being with others, and doing something for others.

Henry's use of the syringe is a striking example of his agency. A device so wound up with his feeding difficulties is appropriated into something that furthers his passion, a solution to a creative problem in a moment of joy. This all seems so natural when you're with Henry. However, Henry's passion for cooking and food has developed despite considerable challenges and conditions that might well have led to food being a source of negativity and frustration.

Chris: What gets me in my heart is – without knowing what and how they did it – that his family gave him this gift of joy in the kitchen, when the medical system and his own health have provided an almost indescribable number of barriers to that.

Figure X.3 Cooking with Henry: (A) A chat while the pudding cools; (B) using the syringe



Chris' comment attests to the fact that reality for children who tube-feed is not a 'given'. It is 'taken' by them and the people caring for them. The barriers that appeared to be given did not determine Henry's relationship with food, his relationships with others through food, or his visions for his future, as Jess explains.

Jess: When I read [Henry's comment], I was really shocked. I just sat there and I stared at it. I'm tearing up now talking about it. I think I'm going to frame it. It means so much to me because it means we've been able to give Henry those nice experiences, a nice relationship with food and cooking food, rather than him think it's hard work or a point of difference. It's a celebration of all the things we've done with in those seven years with him. He loves the kitchen. He loves cooking food. He wants to be a chef when he grows up. In kindergarten, they had a dress-up day and he went as a chef. He loves recipes, being creative and experimenting and putting different things together. He just loves making food, giving people food and serving them things. You can see that joy, that creativity, and that love. Food is involved in a lot of social situations. He's able to celebrate those and be involved by making food, even if he's not always able to eat it.

For all that tube-feeding often leads to exclusion, for Henry food has become a means through which he creatively, with joy and love, *contributes* to his own life and lives of others. This has been made possible, taken as his reality, through agentive actions of Jess, her husband, and Henry and his sister Rosie. It also reflects practice architectures: materialities which enable his physical doings in preparing food; relatings in which he is included not just within family food preparation, but in wider settings such as birthday parties; and cultural-discursive architectures in which food is a subject of talk focused on exploration, experimentation, and hoped-for futures. This is the discursive space that gave rise to Henry's words about the kitchen, which Chris notes "are the absolute endorsement of the difference between feeding and meals. Nutrition is nutrition: materially, emotionally and substantively different in every way from a meal with a family".

X.7 Kate's photograph of Henry

As discussed above, visual representations of children who tube-feed form part of public discourses associating tube-feeding with sickness, and can be sites of more private struggle within families when a tube's presence in images celebrating children is contested. Part of the secondary deficit that creates and perpetuates difficulties is therefore in cultural-discursive practices architectures. These are upheld by everyday imagery of childhood, as well as campaigns which can exacerbate negative connotations as well as an othering of children who tube-feed. Kate's photograph of Henry (Figure 2) is part of a body of work seeking to disrupt these architectures, mobilising artistic expression to transcend the status quo. The endpoint is not the production of the image, but the transformation that the images can forge in those who view it.

Kate: Henry and Rosie were running around, playing, doing their thing. I was just taking his photo and he lifted his shirt up. He was being really playful and silly. I felt he was covering his face to be cheeky. I can't see that image without seeing his actual face. He's such a hilarious, funny child, always smiling or laughing. I see a confident, cheeky boy. He's covered his face, so it could be anyone. So in a way it is kind of an anonymous image. The fact it could be any child, helps our aim to make tube-feeding everybody's business. I feel like it is a strong image in that any parent with a kid who is tube fed could see that and think, 'Oh, that's my child' you know? They probably can

relate to that kind of image. I wasn't aware that these PEGs exist. You wonder how many others are there that we just don't know about?

Chris also reflected on the anonymity of the image being what makes it so disarming and transgressive. While typical images invoke a sense of someone else's (sick) child, this image could be any child, your child, my child, and it invites a connection of joy, of contact and togetherness, radically upsetting the distance and separation that so many other images produce:

Chris: It's a breathtaking portrait. The gastrostomy tube is so visible, but because he's got his t-shirt over his head, he's sort of anonymous. Clearly a child, but it could be any child. There's a really universal aspect to it... It makes you want to give him and all children a big hug and just tell them they're loved.

A point that we discussed was whether Henry was being confident or shy in hiding his face. Was he, perhaps, in the act of concealing himself, revealing the thing (the tube) that he most wanted to hide? Jess' reflections helped us explore this ambiguity:

Jess: It's my son, it means a lot to me. Henry is really embarrassed about his feeding tube. He doesn't like showing it or talking about it, but on that day, it was all about him and Rosie and how wonderful they are. He was actually really proud to show Kate, but he chose to hide his face. I think he was still a bit embarrassed. But you can see under his shirt he has his massive smile. You can see that joy there. He's so cheeky. We just let them play. Kate was sharing stories and I was sharing stories about other families we've met with feeding tubes. He's cheeky. This is what we're talking about, celebrating the joy, allowing it to be there, he's like 'Okay, well look at my tube, but I'm going to hide my face'.

Through Jess we can understand Henry's dual confidence and embarrassment, and the social conditions in which his act unfolded, where adults were naming the feeding tube as part of their being wonderful, and he was able to be the cheeky child he is through his play, and then his pose for the photo. This environment was one of relationships that gave space for the playful doings of childhood, sayings that did not shirk away from the tube, but which elevated it as part of celebrating who he is.

As one image from a body of work – *Be not afraid of my body* (Disher-Quill, 2019), we can see how Figure 2 embodies the contribution that the arts can make to transcending the status quo. Images *can* reshape the ways people understand tube-feeding and connect with it. They can replace distance, separation, othering and pity with proximity, connection, togetherness and joy. As such they form powerful cultural tools of agency (Stetsenko, 2017), making Henry's agency as a cheeky boy contagious, challenging the viewer not to be brought into his world, a cheeky world of play. By being brought into his world, viewers become complicit contributors to a different world, bringing us closer to the future that ought to be.

X.8 Conclusion: Contributing to a world worth living in for all, and a dangerous proposition

Stetsenko (2017, 2020a-e) challenges us to reject bystander scholarship and the acquiescent political quietism that is bound up with it. Instead, she calls for a 'flagrantly partisan' (2015, p. 113, borrowing Dewey's expression) scholarship, where research, theory, social practice and realising the future are all part of collective, committed actions. This is the spirit that

SUCCEED aspires to. Therefore, in conclusion, we reflect on our roles as parents, clinicians, artists and researchers in contributing to alternative and futures that transgress the (false) givenness of the status quo. As a prelude to this, we first acknowledge Henry's contribution – it is with his permission that we reproduce his words and image here. In preparing food for others, in dressing up as a chef, in aspiring to work as a chef, and in being cheeky in play with his sister, Henry is not merely participating, he is already agentially contributing to his own world and the world of others. As are all children who tube-feed and do what children do.

Henry's agency does not arise in a vacuum; like all expressions of agency, it is contingent on what is made available to him socially and through culture. Key in this have been the (equally agentic) actions of his parents.

Jess: We had to create our own opportunities and choices when they weren't there. We've shown them they can enjoy their lives by going to preschool and playgroups and trying things other children their age would try. We've created those spaces. We might go out for a picnic, taking food the kids can eat and having our tube-feeding equipment with us. We're still experiencing the picnic, but we're doing it in a way that made it possible for us.

Jess eventually found a preschool that was ready to work with her to make Henry's attendance possible. Henry was the first, but since then other children who tube-feed have attended. Others have followed in Henry's wake at his school, too. In their commitment to Henry, Jess and her family are also clearing the path for others.

As a paediatrician, Chris sees different responsibilities and opportunities to contribute. These range from changes in his own work with families, to becoming a voice advocating for deeper and wider changes:

Chris: The challenge is to recognise that being nourished isn't sufficient. You need your heart and your mind, and your family nourished as well. That comes through mealtimes. Mealtimes happen at home, not in clinics. We need to get better at that hard work of figuring out what works for each family. At the same time, we need *less* variation in care in the sense that all families should get the same options and level of support whichever health district they live in... You think about guide dogs – there's legislation allowing them onto trains. There's ramps for people who use wheelchairs. We're a long way from those kind of legislative and structural aspects for tube-feeding. Things like tube-friendly cafes. Finding ways so that families don't get asked 'When is your child going to die?'. As a doctor I feel responsible for the healthcare elements. But I also have an opportunity to bring families' voices into the mix and join them in engaging with and understanding what matters to children and their families.

Sharing the same endpoint, Kate considers the contribution that can be made through the arts:

Kate: I think art can play a very powerful role in making an issue that is taboo or sits in a medical space, bringing it into a space that is celebrated and appreciated and valued. That's what art is, something people love and appreciate. So, when you bring that other world that people might have quite negative feelings towards into that positive art space, it suddenly changes their perception of it, perhaps their own feelings towards their own relationship with that issue.

The arts offer a rich basis for cultural tools of agency that enable children who tube-feed to live well. Not by safeguarding their nutritional intake, but by addressing the secondary social deficit. The spaces and values of artistic expression can address not only epistemic issues

around understandings of tube-feeding, but affective and relational ones too, creating joy and connection, helping to make tube-feeding everybody's business.

Reflecting on the scope for contribution through research, Nick draws on Stetsenko (2019b, 2020c) and Bierria (2014).

Nick: Through SUCCEED I've recognised that I do not only have an opportunity to be committed to a better future in research, but an obligation – ethically, epistemologically and ontologically. We are making our reality whether we like it or not, and as researchers we can stand for the status quo and uphold hegemony, or we can act insurgently, transgressively. We can accept the world as it is, or we can come to know it as it is changing, and become part of that change. I have come to understand my role as one – always in collaboration and solidarity with others – of discovering the cultural tools of agency already in use, developing new ones, and reshaping practice architectures so they become more equitably available.

We thus imagine research as a form of critical praxis, co-creating a world worth living in by interrogating the status quo, seeking inequality and injustice and the means to rectify them (Kemmis & Grootenboer, 2008; Kemmis 2019). Theory, including the theory of practice architectures and the transformative activist stance, play a crucial role, but only if we work with them 'dangerously', that is 'useful in the struggle for a better world' (Stetsenko, 2020c, p. 7). In terms of tube-feeding, the world that ought to be requires looking outwards, to society, for the change that is needed, for it is there where the challenges to living well are born. A group of students from UTS called the Neu Collective collaborated with SUCCEED and parents, developing this expression, which captures this crucial but often forgotten point, now our axiom, to be put to use dangerously in the struggle for the world in which all children who tube-feed can live well:

The tube fills stomachs
But sharing a meal fills hearts.

And finally, as an expression of Henry's agentic contribution, making his world, his future, and the worlds and futures of others, we offer his recipe for the meal he made with Nick. This is our contribution to and extension of his critical praxis. The recipe represents the sayings, doings and relatings that Henry employs in his own emancipation. When Henry, Rosie and Nick sat and ate the pudding, Nick explained the intention to write about the cooking lesson and to publish his recipe. At which point, while chewing slowly on his own creation, and with sprinkles beautifully scattered on his lips (Figure 4), he made the following comment, asserting in his own words how, for him, food can be part of his contribution to the world, his refusal to accept the given future, and his charting of a path towards a future of his own making, with others:

Henry: Oh that would be wonderful! Now I can be famous for my recipe!

Figure X.4 Henry eats his creation



X.9 Chef Henry's Choc Pudding

Scored 1,000,000 out of 10 by Chef Henry (later revised to 7.94 / 10, then 8.57, finalised at 9.24 / 10).

Ingredients for 2-4 servings:

Coconut spray (to grease ramekins)
1 ½ cups plain flour
1/2 cup white sugar, then another 1/3 cup
1 egg
250ml unsweetened almond milk
Ground cinnamon
Ground nutmeg
Chocolate syrup to taste (Henry suggests a generous helping)
1/3 cup pure icing sugar
Gourmet caramel syrup to taste (Henry suggests an equally generous serving)
Coloured sprinkles
Edible smiley faces

A 60ml syringe is needed to inject the caramel icing mixture into the pudding.

Instructions:

Mix the flour and sugar in a bowl, and add the egg. Add the almond milk and stir. Sprinkle the cinnamon and nutmeg, then pour chocolate syrup into the mixture and stir until evenly

mixed in. Scoop the mixture into pre-greased ramekins (two for a larger portion, four for a smaller portion). Microwave individually on high for two and a half minutes. Allow to cool.

While the puddings are cooling, mix the icing sugar with the caramel syrup. Use the handle of a teaspoon to drill a hole down the middle of the pudding, then syringe 20mls of the caramel mix to fill the hole, allowing extra to spread over the top. Decorate with sprinkles, and use spare caramel mix as glue for the smiley faces.

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