

Changing the World for Children with Complex Feeding Difficulties: Cultural-Historical Analyses of Transformative Agency

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How to bring about positive change is a key concern in cultural-historical theory. There is an urgent imperative to address questions of transformation at the nexus of the individual and the social. One way to approach this is through the concept of agency, the means through which people go beyond coping with problems or adapting to the status quo, instead striving to make the future that ought to be a reality. This paper takes up ideas from Stetsenko's transformative activist stance (TAS), Sannino's transformative agency by double stimulation (TADS), and Edwards' relational agency, tracing the emergence and enactment of agency among parents of children with complex feeding difficulties. These children were unable to eat orally, instead using a tube to feed. Each family strived towards, and realised, futures where their child was able to feed orally, without a tube. Parents acted agentially in ways that were contingent upon relevant cultural tools. Such tools are key to futures that are more inclusive, equitable and nurturing for all children and their families. The paper highlights the value of contemporary cultural-historical approaches to agency in understanding and provoking transformation at the nexus of the individual and social.

Keywords: agency, transformation, cultural tools; parenting, feeding, Vygotsky, tube-weaning, tube-feeding dependency, enteral feeding, health consumer engagement.

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Introduction

How to bring about positive change is a key concern in cultural-historical theory. A focus on the dynamics of change is a hallmark of cultural-historical approaches [5]. Stetsenko [53] critiques the domestication of Vygotsky to suit politics-neutral approaches, arguing that Vygotsky, in the footsteps of Marx, advocated world-changing scholarship committed to activist agendas. Vygotsky's early work can be seen in this activist light, an unapologetic orientation to so-

cial justice, equality, liberation of the oppressed, and social transformation through equal access to education [52]. Instead of 'banal biscuit-box' readings of Vygotsky, Stetsenko [52] suggests Vygotsky's work belongs alongside other radical movements including Freire's critical pedagogy.

These currents are clearly visible in contemporary cultural-historical research, including that of Mariane Hedegaard [22], Finnish work on Change Laboratories and enacted utopias [39], Indigenous learning laboratories tackling historical racism in schools [2; 3], Edwards

and colleagues' project reducing social exclusion of children in the UK [15], and Edwards' work with young people with autism [16]. There are many other examples of cultural-historical scholars upholding an ethico-political approach to research. Stetsenko [51] urges for theory in general, Vygotsky in particular, to be made 'dangerous again', meaning useful and put to use in the struggle for a better world, for cultural-historical research to be (or go back to being) flagrantly partisan [43].

The concept of agency is central to this. However, dualistic thinking that pits individual agency against social structure embroils the concept in precisely a rift between persons and the world that cultural historical activity theory (CHAT) seeks to overcome [51]. Unsurprisingly, CHAT scholars have been wary of agency. Stetsenko suggests researchers within and beyond CHAT have, in debunking the myth(ology) of isolated individuals, thrown out important concepts — including the person, subjectivity and agency. These concepts need not imply dualistic thinking. One of today's major challenges in theorising human development and mind is...

"... how to conceptualize human agency yet not slip into the pitfalls of traditional approaches premised on assumptions about agency as an autonomous, solipsistic achievement of isolated individuals understood either as "free-will" subjects or, on another spectrum of views, as puppets of extraneous influences at the whim of powerful forces outside of one's control and even awareness." [51, p. 5].

Agency can be conceptualised dialectically such that the gulf between persons and society disappears [8; 51]. A dialectic view enables us to see 'the adaptive and innovative opportunities that humans create through agentic projects with each other and the natural world, rather than as against each other and the world' [8, p. 283]. Agency can and should be taken up in CHAT, in non-individualistic ways [10; 33; 34]. Agency manifests in CHAT scholars' interest in identity development [23], collaboration at sites of intersecting practices [13; 14], double stimulation [34; 39], mediation in breaking away from given frames [19; 21; 28; 56], breaching social order [20], collaborative change [30; 31], civic participation [11], and *pouvoir d'agir* or power to act [6]. Vygotsky's work can itself be read for more than glimpses of agency, including through children's active deployment of tools [1], creative sense-making [7; 9], and idea that actions are not dependent on an immediate need or situation, but are rather directed toward the future [51].

These examples reflect a recent surge of interest in agency [48]. If we commit to transforming the status quo, not just adapting to it, then we need concepts that allow for agentic action at the intersection of individual and social dimensions [50]. This paper takes up three contemporary approaches to agency within CHAT: Stetsenko's [45–54] transformative activist stance (TAS); Sannino's [35–41] transformative agency by double stimulation (TADS); and Edwards' work on relational agency [13–17]. Each of these will now be outlined.

Contemporary cultural-historical views of agency

Stetsenko's transformative activist stance (TAS) incorporates agency as a central feature of a wider, unified ethico-ontepistemology [50; 51]. This offers a notion of the 'collective' [42], which transcends social/individual divides. Personal becoming is contingent on how one comes to matter in social processes, and social practices are contingent on individual contributions [51]. This shifts from a focus on *participation* to a concern with *contribution*: each person 'not only enters social practices, but agentively realises them while making a difference to them' [49 p. 10]. TAS combines standpoints (who is speaking, acting) with endpoints, the future towards which people strive. Actions are world-making, with agency a matter of moving beyond the status quo rather than adapting to it, infused with activism as opposed to political quietism.

"Paraphrasing Kohn, I would say—show me a conception of agency that operates with the notion of responding to the world and stays away from politics, and I will show you a conceptual terrain tacitly defined by behaviorism and neoliberalism" [48, p. 11].

Nardi [32] concurs with Stetsenko's [45] efforts to (re)direct CHAT towards understanding what enables us to transform our circumstances, acknowledging that this will require a readiness to deal with individual agency without losing sight of the social. Individuals strive towards the future that ought to be, while doing so is contingent on access to relevant cultural tools, and always unfolds within social practices. TAS is not about solipsistic acts of heroism; it reclaims agency at the intersection or nexus of individual and collective.

Sannino [35–41] approaches agency through the concept of double stimulation. Transformative agency by double stimulation (TADS) links double stimulation, volitional action, and transformative agency. TADS refers closely to Vygotsky's writing, was further developed through experiments [37; 41], and analysis of efforts to eradicate homelessness [38–40]. TADS foregrounds intentionality in agency, focusing on situations where there are conflicts of motives. Double stimulation is elevated from an epistemological principle of formative intervention (as in change laboratories), to a core principle of agency:

"Transformative agency built on double stimulation transpires in a problematic, polymotivated situation in which people evaluate and interpret the circumstances, make decisions according to the interpretations and act upon these decisions" [35, p. 2].

Key to TADS is the use of artefacts as auxiliary stimuli connected to auxiliary motives that provide a new frame, a way out from the dilemma through new modes of action. TADS can capture the emergence of agency whether focusing more on how individuals escape from conflicted situations [26; 27; 39], or at diffuse, city-wide scales [39]. It does so without evacuating the social in the former, or individual contributions in the latter. Recent expansions of TADS incorporate the concept of warping or anchoring forward [40]:

“Forward anchoring involves the formation of novel representations emerging through personal sense-making, social interaction and experimentation embedded in the materiality of a problem situation... Second stimuli understood as forward-oriented kedge anchors are instrumental in the elaboration of new meaning which may be stabilised to the point of supporting transformative actions in problem situations for which there are no known solutions” [40, p. 4].

The individual and social are also equally present without being separated in Edwards' work on relational agency. This comprises three concepts: relational agency, relational expertise, and common knowledge [13]. Relational agency refers to how two or more people work with different object motives while tackling the same complex object of activity, such as a child's trajectory [14]. This involves joint expansion of the object, revealing its complexity in ways that a person working alone could not do. This expansion, opening up new possibilities for action, depends on relational expertise, a 'capacity to elicit and hear what matters for other practitioners or the family and to be explicit about what matters for themselves as professionals and to be able to draw on these understandings when needed' [14 p. 2]. The links between people working relationally in this way are built through what Edwards calls common knowledge. This refers to knowledge of each other's motive orientations, which ...

“... can then become a resource that can mediate responsive collaborations on complex problems. In this sense, common knowledge is what Vygotskians would recognise as a second stimulus... a resource that is constructed and reconstructed in use on problems while it mediates actions on the problems.” [13 p. 9].

Here we see an auxiliary stimulus arising through collaborative work. Edwards links common knowledge with asking and giving reasons, revealing specific values and motives so that people can recognise what matters to others, articulate what matters to them, and align their responses [13]. As with TAS and TADS, Edwards' advocates work that is 'deeply ethical as it allows for creative responses which stem from what is important for each individual, at the same time connecting people dialogically to each other and to a common good' [13, p. 2].

Complex feeding difficulties in childhood

Feeding difficulties affect many children. They can vary in severity and duration, from fussy or picky eating, to life-long difficulties associated with chronic disease or disability. Feeding difficulties affect around half of otherwise healthy children (with parents identifying more cases than are recognised clinically), with a much higher figure of around 80% for children with developmental delays [4].

In severe cases, children are unable to feed orally. This is common in prematurely born babies, recovery after surgery or cancer treatment, and is associated with hundreds of conditions, such as cerebral palsy, autism spectrum disorder, cleft palate, and some genetic condi-

tions [29]. Where oral feeding is not possible, a tube is often used. This is called enteral feeding, and commonly begins with a nasogastric (NG) tube, which passes up the nose then down into the stomach. A surgically emplaced tube may be used if tube-feeding extends beyond a few months, including a percutaneous endoscopic gastrostomy (PEG), passes from near the naval through the skin and into the stomach or intestines. Data on tube-feeding prevalence are patchy and incomplete, with estimates pointing to between 1 and 92 children per 100,000 [29].

Tube-feeding can solve the problem of nutritional intake, providing a safe and reliable of delivering food to the body. However, tube-feeding can also create problems, including biomedical side effects (such as excessive vomiting), and feeding-tube dependency, meaning that children who *could* feed orally do not because continued use of a tube inhibits their learning and ability to do so [57]. Tube-feeding impacts all aspects of home life, and can also cause distress, anxiety and social isolation among families, challenged by the logistical and material complexities of tube feeding, and feeling stigmatized and subject to the critical gaze of others [24].

Given these difficulties, what matters to many parents is a transition to a future where their children thrive without being negatively impacted by the tube. For some, this means long-term tube-feeding, however most hope to transition to oral feeding, removing the tube completely. However, the healthcare system is not always adequately set up to make such transitions happen. Tube-feeding helps ensure children gain weight, which is a key indicator of 'thriving', while the untoward problems that tube-feeding can trigger are often out of clinicians' sight. Failure to plan for eventual tube-weaning can cause additional anxiety in families, lead to feeding-tube dependency, and unnecessarily delay transition to oral feeding [18]. Tube-weaning should be part of the discussion and planning from the day tube-feeding starts, for all children who are expected to be able to feed orally at some point [55]. This was not the case for the parents whose agentic actions are the focus of this paper. They each describe significant struggles in accomplishing tube-weaning. In these struggles they both challenged the status quo in the healthcare system, and were assisted by healthcare services and professionals. We need to better understand how parents have been able to realise tube-free futures for their children, and the challenges they have faced in doing so.

Narratives of change from an unfolding, collaborative activist study

This paper considers data from a larger collaborative activist project called the SUCCEED Child Feeding Alliance, which strives to foster better futures for children with complex feeding difficulties and their families. The SUCCEED team includes a paediatrician, speech pathologist, parents, an artist, and academics from education and business. The project co-created the childfeeding.org website, which curates parents' knowledge, sharing practical strategies that help families of children who tube-

feed go from just surviving, to situations where everyone is thriving. The website aims to ensure tube-feeding is no longer a barrier to inclusion in developmental opportunities for children, enjoyment in family mealtimes, and wider social activities for siblings and parents. This was based on a cultural-historical analysis of the tools that parents develop and use in their everyday life to help get out of the house, manage care responsibilities, and resist stigmatising practices [24]. The website is a unique resource not constrained by geography and timing (clinic locations and opening hours), nor by a prescribed relationship to the child (available to wider relatives, friends, professionals and others usually not present in clinic appointments).

Guided by parents, SUCCEED took on new forms of activism, including arranging Australia’s first tube-feeding picnic in 2019 (featured on national news television), and an online version in 2020 (due to the Covid-19 pandemic). An art installation was co-developed with parents and artist Kate Disher-Quill, presenting a series of photographs of parents, children, and tube-feeding equipment, exhibited at a number of locations across Sydney. The images share the challenges of parenting children who tube-feed, while celebrating courage, and children as playful, happy, nurtured, loved and accepted [12]. Another thread in this activist work involves advocacy for change in healthcare, co-writing an agenda for research and care improvement, co-authored with parents and clinicians [27]. Central to this is improving care by addressing the tube-feeding life-cycle, from tube initiation to tube-weaning (or for those for whom weaning is not possible, transitioning to long-term tube-feeding). This paper extends the tube-weaning agenda by examining how parents enable their children to transition to oral feeding – through agentic practices that shed critical light on ways the healthcare system can create tube-weaning as a site of greater struggle than it needs to be – while also playing a crucial role in successful weaning.

The analysis focuses on three mothers’ narratives of tube-weaning. Transitions to oral feeding were accomplished in different ways in each family. The mothers were asked to tell the story of tube-weaning from wherever they felt it started, up until the present day. The researcher probed for additional detail or confirmation, but otherwise, the narratives were free-flowing and unfolded as each mother chose to tell the story. Table 1 outlines the three cases.

In the analysis, a timeline was constructed, placing each action in unfolding historical context. Then, relationships between the mother, child and others were mapped to anchor the analysis in the nexus between individual and social. Next, specific attention was paid to mediating tools, conflicting motives, common knowledge, and future orientations. Through this, a distinct character emerged for each of the three cases. The cases are presented below, beginning with a summary narrative in the first person that foregrounds each mother’s contribution to the transformations from tube- to oral feeding. These are discussed with reference to the cultural-historical concepts of agency outlined above, emphasising aspects that are particularly resonant in each case. This is a diffraction for analytical purposes, and in reality each case displayed aspects of agency highlighted in the other.

Kate, Jessica, and family

Jessica’s first feeding tube was placed the day she was born, even before I got to first properly hold her. Tube-feeding was life-saving, but then became a problem when she was physically able to eat orally, but have become tube-feeding dependent.

Jessica’s tube-weaning story began 16 months later, on the beach. A family came up to us and said, “Oh your baby’s tube-fed. Our niece was tube-fed and she’s just done a rapid tube wean at the Royal Children’s in Melbourne and they got her off her feeding tube.” We said, “Tell us more!” I rang the mother. She’d done a net-coaching rapid tube wean with the Graz Children’s Hospital Austria, supported by the Royal Children’s Hospital (RCH) Melbourne. We did our research and connected with other families who had used this approach. It felt legitimate and safe because RCH Melbourne had been involved. But I wanted to be sure. I read articles and made phone calls. Family stories on the Graz website were really important, as was the opinion of a dietician whom I trusted and felt knew and trusted Jessica. We connected with another family who had actually travelled to Graz for their rapid tube-wean.

We made our decision using a BRAN test, which we had learnt from another parent: What are the Benefits, Risks, Alternatives and N is for No thank-you. We knew our child and our instincts were that Jessica could eat orally, but she

Table 1

Overview of tube-weaning cases*

Mother	Child	Tube-feeding history	Approach to tube-weaning	Key theoretical insights about agency
Kate	Jessica	Birth to 16 months	Rapid tube-wean led by overseas hospital, based on hunger	Relational agency, building a coalition of professionals to overcome inertia in the healthcare system
Elena	Izzie	Birth to 14 months	Puppets, hunger, learning to chew and swallow, giving Izzie control	Diverse cultural tools of agency, collective, relational agency
Irene	Connor	NG tube from birth to 10 months, then PEG for just over 2 years	Developing interest in food while tube-feeding; cessation of tube-use during ‘testing’ period before final removal	TADS, use of auxiliary motives to resolve conflicts of motives; anchoring forward

* Parents chose the names to be used for them and their children.

was not hungry from the constant tube-feeding, and had so many negative experiences around food and tubes and equipment around her mouth that she was not motivated to eat.

I really had to sell the idea to Jessica's paediatrician, presenting our research and finally the pitch that if kids in Melbourne are able to do rapid tube-weaning, then Brisbane kids should also be able to. Thankfully, Jessica's paediatrician engaged. We connected with the hospital paediatric child psychiatrist, and she knew the lead consultant involved at RCH Melbourne and made contact. The rapid tube-wean was on! But we still had to get the wider feeding team on board. Now we had two consultants supporting us and the connected care nursing team. The speech pathologist and occupational therapist who were concerned by Jessica's lack of feeding skills. With the consultants' endorsement they got on board. Eventually we persuaded the hospital legal team, and finally we could go ahead.

We started the wean following a feed reduction schedule from the Graz team in Austria, overseen by Jessica's paediatrician. We had daily play picnics with three other families, including one from Brisbane who had been to Graz. Seeing the quick progress made by one 6-month old in our group really helped keep us going.

Progress was initially slow and hard going. We were sending daily videos and updates to Graz. The professor was always very positive and confident, saying "She's close! You see what she's not doing. We see what she is doing". They were noticing subtleties that I now realise are massive milestones for a child regaining interest in food. Jessica was losing weight as expected, but the messages from Graz and our local team's support gave us confidence to keep going.

Day 17 – Jessica started eating! We were brainstorming with all of the team (clinicians, nursing, allied health, and mum) after one play picnic and the complex care nurse said, "She loves the bath, try feeding in the bath". We tried later that day and Jessica ate some puree off her Dad's fingers!

Jessica had to feel hungry and learn that food was the solution to that hunger. We had to make food and eating fun and follow her cues, her pace and her timing. We transitioned Jessica from feeding in the bath to the dining table, with a bucket of water beside her for play. After a few days we no longer needed to do this. Jessica was happily eating puree off a spoon with no distractions.

Three months later our feeding-tube dependent child was completely orally fed. It has still been a lot of work to get Jessica to eat age appropriately. We found a speech pathologist who helped enormously teaching Jessica to chew and grind food with different textures. Now we go out and order food for Jessica straight off any menu. To see her enjoy food and mealtimes just like any other child brings us the greatest joy. Tube weaning truly transformed Jessica's and our whole family's lives.

The relational aspects of agency in this case are clear, in the sense associated with Edwards' [14] concept. This was not a matter of one mother taking on the health system. Rather, Kate built coalitions of people, each of whom contributed something crucial to the process. This required acts of advocacy and persuading others to advocate, as

when the consultants brought the wider team on board, who in turn helped convince the legal team. The many healthcare professionals involved each brought their own object motives, while tackling the same complex object of helping Jessica feed orally. Not only were different professionals involved, but the collaboration spanned Australia and Austria. Kate recognised and addressed the demands of bringing the healthcare for Jessica into alignment with her motive for a tube-free future [17].

Common knowledge [13] was key to how these alliances were built. In Edwards' [13] vocabulary, it was a process that depended on asking and giving reasons, revealing values, and recognising what matters to others. Kate had to learn what mattered to the legal team, the consultants recognised what mattered to their more hesitant colleagues. Relational expertise underpinned coming to know the motive orientations of others, reaching joint interpretations of the problem in order to develop a joint response. Over time, the object (how Jessica could feed orally) expanded – including noticing Jessica enjoyed the bath, and the possibility that this could be used to help her feeding. While the idea was a particular contribution of the nurse, this inspiration was possible because of all the information and insight that had been shared, including by Kate, about how Jessica was at home. These collaborations enabled the transition to oral feeding, but were also the focus of agency themselves. The coalitions were not a given, and were themselves sites of struggle, contestation and power differentials.

Also noteworthy are the many cultural tools that mediated this process. These included the BRAN analysis (recommended by another parent), creative adaptation of a bucket to bring bath-time to meal-times, stories provided by other parents on the Graz website, and the presentation of an achievable future horizon through the co-presence of a child who was thriving having recently completed a rapid-wean. This highlights the social contingency of the whole transformation. Kate was able to act agentically because some tools were available, yet at the same time agency was required in making other tools available. Kate's social environment was not simply saturated with all the necessary tools simply at hand.

Kate's standpoint, her positioning in wider social relations, cannot be ignored as a factor making this possible, including chance encounters on a beach, living in an urban area close to relevant healthcare services, and the fact she had a friend who could help her understand how to persuade the legal team. The healthcare system presented huge inertia, favouring the status quo of continued tube-feeding, but the tube-wean would not have been accomplished without it. Believing in Jessica, and buttressed by stories from others, weight given to professional opinion and institutional standing, Kate took a stand, fiercely committed to the endpoint of Jessica feeding orally.

Elena, Izzie, and family

When Izzie was 13 months, she'd had her surgery and I felt we could start to address her feeding (she used an NG tube). We were attending a clinic, but we weren't get-

ting anywhere. They were happy with her weight gain, and when they offered her food or a bottle, Izzie didn't want it. They just said "You're doing a good job Elena, keep it up. See you next month".

My mother-in-law pushed it. She happened to meet someone through her work whose son had feeding issues and had weaned off his tube. She asked for the details of their speech therapist, Sarah, and passed them onto me, I thought I'd try her out, get a second opinion. Sarah saw us after a few weeks. My mother-in-law came with me, because I felt I couldn't think straight right then, I needed someone with an honest opinion to help me out. She's the best person for that.

We went to the appointment. I've never seen anything like it! Within 10 minutes, Izzie was holding food. That was 'oh my god!' because Izzie had never had that relationship with food. Sarah had a Cookie Monster puppet, and started singing to Izzie, singing "Everybody eating, eating". She started feeding these biscuits to the puppet. There's mess everywhere but he's eating. Izzie grabbed the food and started to feed the puppet. Me and my mother-in-law were like "Am I seeing this?! Are we dreaming?!"

Then Sarah was asking us about Izzie's story, and we noticed Izzie grabbed a biscuit and put it in her mouth. That was it! I knew I had to see Sarah. Within six weeks, Izzie was off her tube.

We'd go each week, and she reduced Izzie's formula bit by bit, replacing it with water so Izzie had to eat: she was hungry. She had to get comfortable with her mouth, chewing — she didn't know how to use those mouth muscles. Sarah would give me a list each week, what we could and couldn't offer. Like the pouch food, that was great because it was high in fat, so it kept her going and made her feel full. We needed her to associate that feeling with food.

We let Izzie have her say. Izzie's personality is she wants to do things her way, so we always started with the tube, and gave her the option afterwards. Gradually, more water meant more hunger for Izzie, and soon she was eating solids.

Within six weeks, we were hardly using the tube, and Sarah said "Today is the day. Take that tube out of Izzie's nose". I didn't know if I could do it. Sarah said "No, you have to do it. She's ready, this is good". She made me physically throw it in the bin. I'd replaced her tube heaps of times. This was different. This was like 'this is it'.

When I got home, before I even went inside, I rang my husband, saying "You'll never believe this. We have no tube". He said "Are you kidding?" I said "No. I had to throw it out". I took pictures of Izzie in the back seat of the car, a big smile on her face. I sent it to everyone. We were all crying. It was a great moment. It was anniversary of my Dad passing away. I thought 'that's him'. So now we truly celebrate that day.

We kept seeing Sarah, introducing different textures, homemade cooking and things like that. Izzie had always been part of our mealtimes, sitting with us, watching us put food in our mouths. That was our time for bonding, but it also really helped when it came to the weaning. Any meal, Izzie was always part of it.

Below is an extract from a speech Elena gave at a tube-feeding picnic event

Pretty much from the day Izzie was born, up until just before Christmas, she was with a feeding tube. [crying] Um, it gets a bit emotional, as you all know. It was the hardest point in our lives. [children's entertainer comes over to hug her] Thank you! It was super-hard, but we're super proud of what we achieved. [applause] Our main focus was we hoped to get her off that feeding tube. I think the message is really that for the majority of us it is only temporary and that's what we have to think about. There is the light at the end of the tunnel. We put our heart and soul and everything into it. With patience and a lot of strength from family and friends supporting us as well, and our intuition of what our child needed, we followed that through. And since just before Christmas she hasn't had a feeding tube. She's been eating everything. I'm super-proud to be a part of this picnic. We should be super-proud that we are leading the way, doing things like this where we can all get together — talk to the people next to you, get their stories, and see you next year!

Elena's story highlights a number of everyday items that became significant as tools of agency. This often involved repurposing towards the endpoint of Izzie weaning off the tube: a children's puppet was a tool to link food and play; food pouches were a means to make oral ingestion of food safe; the dustbin became a material and symbolic artefact, accentuating both the significance and finality of Elena's action in removing the tube. Finally, Elena took up the platform of the picnic, drawing on cultural conventions of speech-giving, contributing to making the cultural tools of agency visible and available to others.

Like with Kate and Jessica, the process for Elena and Izzie started with a chance encounter. Elena's story points to the risks of getting trapped in a clinical acquiescence, where tube-feeding is perpetuated because those involved settle for the status quo of sufficient weight gain. The 'given' future was not one where Izzie was feeding by mouth.

Elena foregrounds the contributions of others in making Izzie's tube-free future possible. However, Elena's own contributions do not disappear. Elena acted with relational agency in taking her mother-in-law to the first appointment, using their special relationship as a means to exert control over her own behaviour (having the courage to attend), and to delegate when she felt unable to think clearly herself. What might appear to be surrenders to others are not that at all. Elena followed Sarah's advice, but according to her instincts of what would work for Izzie — not pushing her (here we see acts of resistance against the past). Although it was hard to do, it was *Elena* who pulled the NG tube out for the last time and threw it away. Sarah was instrumental in making this possible. From her clinical standpoint, she stood for the same endpoint, sharing a belief in Izzie and a readiness to take steps towards her tube-free future.

In her speech at the tube-feeding picnic, Elena publicly claimed her accomplishments. Her language (our, we, us) tells a story of a shared journey, of multiple contributors, whilst acknowledging her own instincts, efforts, and the difficulties she faced.

Elena narrates a truly 'collective' [42] account of transformation for Izzie. The mention of others (friends,

wider family, her father in spirit) does not come at the expense of her own contribution. This is precisely how the dynamics of agency worked in Izzie's tube-weaning, where the effects of diverse cultural tools (cookie monsters, feeding pouches, diluting practices, the symbolism and materiality of the bin) were amplified by individual actions connecting with the actions of others. This nexus of the personal and social manifests in Elena's envisioned future actions in a wider public sphere, joining others in solidarity, 'leading the way' for families with children who tube-feed, now an expanded, collective, endpoint.

Irene, Connor, and family

When he was 10 months old, Connor had several surgeries coming up, so we made the decision to have his NG tube changed to a PEG. We initially thought it might be for months, but it turned out to be for two years. We understood he needs it, it's there for nutrition, so what are we going to do as parents for him to develop an interest in food and to establish oral feeding?

We knew we had to tick off the medical boxes, ensuring he was safe. I relied on his medical team for that. For instance, his cardiology team to tell me they are happy with his heart function, his cleft team to say we need to leave it a while longer because there's surgeries coming up. Our plan forward was to keep offering him food, to help him have a positive relationship with food.

Intellectually I knew the tube has its purpose, but emotionally I couldn't wait until it came out. I felt that type of thinking was focusing on something unproductive. To get the tube removed, whenever the time comes, we need A, B and C in place. My job was to get those steps done. We can't remove the tube until he has proven he can eat a full diet, that he's hydrated orally. Can we give him his medicine orally? Has he suffered an illness and we haven't used the tube? Do his medical team support it? Are there no surgeries on the horizon? The professionals deal with his medical stuff, the rest is up to me. Realising that was when I felt empowered.

Our journey has been a collaboration between our paediatrician and his team, my husband and how we operate as a family, my research, networking, blogs, and talking to other parents. That's how I found out other children with cleft palate can still eat a full diet without a tube. I knew there's nothing stopping him to eat, it's simply a lack of practice and instruction. So we had to get him knowing what to do with food, touching food and more importantly, swallowing safely.

Yes, we had access to feeding clinics, but he was with me 24/7, and I had the power to cultivate a positive relationship with food. We set him up to thrive, not to fail. We made it fun, gave him the foods he enjoys, let him lead that. We made sure the foods supported him in terms of how his mouth was for instance he handled solid whole foods much better than purée. We all sat down together for meals. At morning tea, I'd pack a few extra snacks — making adjustments like that to expose Connor to the idea that this is eating, this is a social thing, this is what we do. Taking him to coffee shops and restaurants so he could see

others eating. Our other children got on board, emphasise their chewing and theatrics "Ooh yummy this is going in my mouth". He was captivated. The kids didn't feel silly. That was our intensive therapy! He started grabbing food or opening his mouth and letting us feed him. Even if most of the time he wasn't eating, it was exposure, and it was his choice. I wasn't concentrating on getting rid of the tube, just on taking the pressure off and providing him positive experiences.

Eighteen months after his PEG was put in, the cleft team said they didn't want to do any surgery for at least a year or more. This gave us a window — one of the things on my list, tick! By this time, he was eating a full diet, but we were still using the tube occasionally. I said, right, let's shut it down and pretend it's not there, and see if we can really show he's eating a full diet, he's empowered making choices about his food, we are listening to him.

I said let's try for 3 months. I taped the tube down. It was a real personal restraint for me not to use it because it is convenient, it does guarantee your child is getting everything they need nutritionally. I had to say, "Irene when things get tough, you've got to resist the temptation to use the tube." Three months was a realistic timeframe for me, without adding any pressure. Six weeks wasn't enough data for me to feel comfortable removing it.

Those three months we did really well, but he hadn't gotten sick, so I didn't feel it was time to remove the tube. From then we went on a monthly basis. Let's assess the data and Connor's progress each month. Two months later he got croup, and his appetite dropped but he was still drinking water. He had a slight fever and we were able to squirt some Panadol in his mouth, and he swallowed it. Tick! He recovered and went right back to eating grapes, watermelon, biscuits and so on. There's my data, there's my evidence.

We got to six months since we taped over his tube. I felt he was ready. I was just waiting for when I felt comfortable. I didn't want to have any regret, I knew I had to feel 100%. I had my tube removal kit ready, the medical team told me how to do it. People were saying "He's not using the tube, you should take it out". My sister-in-law is a doctor and thought it posed a risk of infection. I noted the information but really had to minimise external opinions and pressures. It was a personal thing. As a mother when you feel it is right, that's when it is right.

The 24th November was a day no different from any other. Connor was asleep. We went to bed. It was 10.15pm. I said "It's time. We're going to take it out." I had everything ready, I felt empowered. It felt right. I had everything on hand. It took 90 seconds. It was a good time — he was asleep, relaxed and as his body had overnight time to close off the site. Next day, he ate normally and we've never looked back.

Transformative agency by double stimulation (TADS) [35–37] is especially helpful in understanding the agency involved in Connor coming to feed orally. Irene's story strongly highlights conflicts of motives. Most fundamental was a conflict between wanting to remove the tube and wanting to ensure Connor got all the nutrition he needed. Irene's solution to this was guided by an auxiliary motive to work on establishing the conditions for even-

tual removal, part of which involved developing a positive relationship with food for Connor. When so many other aspects of Connor's medical difficulties were beyond her control, this was described by Irene as 'empowering'. These conditions were a combination of criteria she delegated to others (the professionals), and those she developed and applied herself (his not needing the tube when he got sick, and her own feelings of being ready).

This motive set up new modes of action Irene could undertake every day, in a process of warping [38]. She anchored forward by taking Connor to cafes, offering him food. Each instance of these practices pulled the family towards those conditions. In Stetsenko's [45] language, Irene found a way to commit to a desired (tube-free) future, despite the current necessity of the tube. The primary tool of agency here was Irene's checklist.

When Connor was feeding without the tube, new 'kegde anchors' were placed in the form of additional tests that would produce the 'data' Irene needed. Tests when Connor got croup and fever provided means to pull forward again. During this period, Irene resolved a different conflict of motives: the motive to feed orally versus the motive to use the tube because it made things easy. Her solution here was to tape over the tube, the tape acting as a physical barrier, and a symbolic one, reminding her to resist the temptation to use the tube. Irene also used fixed time periods as auxiliary tools in what was otherwise an open-ended and temporally ambiguous process – initially three months, then a monthly data-check. There are echoes of the waiting experiment here, where a clock is used to make decisions in a situation with no clear temporal end [37; 41].

The final conflict of motives came when others thought it was time to remove the tube, and Irene felt the need to wait. The auxiliary motive here was one of finding the moment when all doubt was gone for Irene. This had no temporal anchor, but involved Irene having everything ready for when the moment arose.

Irene was central to the process as mother and primary caregiver, and she determined the moment of the tube's final removal. However, her story repeatedly highlights the importance of others – her family, Connor's medical team, members of the public in cafes, children excitedly modelling chewing, and the blogs and parent networks which gave Irene the confidence to remove the tube before Connor's palate surgery was finished. Connor himself was highly involved, with Irene letting Connor lead aspects of the process, especially around what, how and how much to eat.

Conclusion

Agency is a potent concept to understand transformative change, continuing the spirit of Vygotsky and his colleagues in contributing towards more equitable and just futures. Contemporary Vygotskian ideas enable agency to be understood in connection with change at a nexus of the individual and social, transcending the concept's unfortunate association with individualism. This paper has taken up Stetsenko's transformative activist

stance (TAS) [42–53], Sannino's transformative agency by double stimulation (TADS) [35–41]; and Edwards' relational agency [13–17]. Three cases were analysed, in which parents of children with feeding difficulties rejected the status quo of enduring tube-feeding, instead committing to and realising a future in which their child could feed orally, without a tube.

The analysis highlights how valuable the three approaches to agency are in understanding the dynamics of transformation in everyday life. Each upholds the dynamic hallmarks of cultural-historical theory, showing how it is possible to recognise the inherently social nature of change without erasing each mother's contributions. Analysis of Kate's story revealed the importance of relational agency, building coalitions of professionals and others in order to overcome inertia in the health-care system, where the given future was one of indefinite tube-feeding for Jessica. Elena's story highlights the diverse forms that cultural tools of agency can take, showing how the contingency on such tools renders similar change for other families precarious, given their availability is not guaranteed to all. Irene's story highlights how conflicts of motives can be overcome through auxiliary motives and processes of anchoring forward.

These are not stories of solipsistic heroes. The agentic contributions of the three mothers were enabled and amplified by the involvement of others. They were also contingent on these families' positioning in wider social structures through which particular social connections were available, so that alliances could be forged, support from extended family, friends and community to be activated. The three cultural-historical frameworks each reveal how agency arose through actions mediated by cultural tools. Agency belongs in this active realm, not a possession of the three mothers. At the same time, agency depended on Kate's, Elena's and Irene's commitment to *realise* (ie. make real) the future that ought to be. The cases embody commitment precisely as Stetsenko outlines:

What the notion of commitment suggests is that a person not so much expects or anticipates the future, but rather, *actively works* to bring this future into reality through one's own deeds, often against the odds, that is, even if a particular version of what is to come in the future is not anticipated as likely and instead, requires struggle and striving to achieve it. This applies in cases when a person struggles for one's vision of 'what ought to be' in spite of the powerful forces that might be pulling in other directions [42, p. 19].

These parents were not responding to or adapting *under* given circumstances [48]. Their actions were not defined by a response to the tube. They involved taking a stand, acting towards an end. Stetsenko's [42] concept of the collectividual is helpful in holding onto the importance of individual contributions without negating the social contingency of these actions and the tools that mediate them.

Cultural-historical theory helps us to identify the means through which more equitable and inclusive futures for children with feeding difficulties might be realised. These cases of accomplished transformation are presented as a call to action, highlighting struggles that

do not, and should not need to be. Each shows how transformation to oral feeding can be possible in situations where there were many forces holding a tube-fed a status quo in place. These include: understandable but entrapping risk-avoidance in healthcare; a sense that because the tube enables weight gain, the problem is solved; a reliance on serendipity; and patchy availability of relevant tools of agency. Consistent with Vygotsky's pioneering thinking about disability and difference, this analysis is not about fixing a deficit in the child, but about social deficits, the struggles families engage in despite them, and the need for wider social action to address these deficits. It is also about courage, transgressive visions of

the future, and the means people use to progress towards desired futures.

Theory can play a role in bringing about more desirable futures by pointing to the need for change, signposting a world in which sites of struggle against the status quo are refashioned into sites where transformation is envisioned, collectively committed to, and actions towards it taken. By revealing struggles such as those of Kate, Elena and Irene, and elucidating the tools of agency deployed in striving that produces positive change, cultural historical theory can be taken up as Stetsenko [43] says is needed: made dangerous again in the struggle for a better world.

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Изменяя мир для детей с нарушениями приема пищи: культурно-исторический анализ трансформирующей субъектности

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Как добиться позитивных изменений — ключевая задача культурно-исторической концепции. Остается актуальной важность рассмотрения изменений сквозь призму переплетения индивидуального и социального. Определенные возможности для этого открывает концепция субъектности/агентности (agency), средства, с помощью которого люди могут не просто справляться с проблемами или адаптироваться к текущему положению вещей, но прилагать усилия к тому, чтобы создавать будущее, которое должно стать реальностью. Данная работа опирается на идеи трансформирующей позиции активизма (TAS) А. Стеценко, трансформирующей субъектности посредством метода двойной стимуляции (TADS) А. Саннино и социальной субъектности (relational agency) А. Эдвардс, прослеживая возникновение и проигрывание субъектности у родителей детей с нарушениями приёма пищи. Это дети, которые не в состоянии питаться самостоятельно, через рот, поэтому для их кормления необходимо прибегать к специальной трубке (зонду). Каждая семья усиленно конструировала, а затем воплощала в жизнь будущее, в котором их ребенок мог есть самостоятельно, без трубки. Родители действовали из позиции субъектности и руководствовались теми способами, которые согласовывались со значимыми культурными средствами. Эти средства — краеугольный камень будущего, в котором есть больше пространства для инклюзии, равенства и заботы, как для детей, так и для их родителей. В статье подчёркивается значимость современных культурно-исторических подходов к субъектности для понимания и инициирования изменений на стыке индивидуального и социального.

Ключевые слова: субъектность (agency), трансформация, культурные средства, родительство, кормление, Выготский, отучение от трубки, зависимость от кормления через трубку, зондовое питание, вовлечение потребителей медицинских услуг в принятие решений (health consumer engagement).

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