Supporting children and families: How does co-design invite us to think differently?

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Summary

This paper focuses on a series of reflective questions that invite practitioners to think differently about their work with children and families, especially those living in complex environments:

- Where should we focus?
- Who holds the power?
- Who gets to speak?
- What should we share?
- Who is allowed to struggle?

These questions emerged as the three authors – a lived experience consultant, a practitioner, and a researcher – engaged in a co-design process to develop this paper together. While these reflective questions were central to the co-design process itself, they simultaneously speak to some of the most challenging dilemmas facing practitioners in the field.

Our intention was to develop a resource that represents a genuine coming-together of lived experience, practice wisdom, and research knowledge. In this paper, the lived experience voice is represented by Jason Tyndale, the practitioner voice by Jackie Amos, and the research voice by Rhys Price-Robertson. To support a true meeting of these different perspectives, we developed this paper using a co-design approach (which is described more fully below and in Appendix 1).

A central requirement of co-design is that all participants attempt to relinquish control of the outcome, trusting a deeply collaborative process. This allows for the emergence of things new and unexpected. As we worked together to develop this paper on supporting families living in complex environments, a series of unplanned reflective questions emerged:

- Where should we focus?
- Who holds the power?
- Who gets to speak?
- What should we share?
- Who is allowed to struggle?

This paper is for practitioners who work with children and families, especially those living in complex environments. Rather than provide concrete practice advice, it encourages readers to reflect on broad themes — including power, inclusion, and suffering — that are often obscured by the high demands of day-to-day practice. We hope that reading and thinking about these themes creates space for self-reflection, ethical inquiry, new ideas, and rich conversations.
Initially, we asked these questions of ourselves as a team of co-authors; yet we quickly realised that they also pointed directly at dilemmas many practitioners grapple with — often with limited support — in their work with children and families. We decided that these questions would comprise the backbone of our paper. The co-design approach invited us to think differently about how to develop a written resource, and we in turn invite you to think differently about your own practice.

This paper is part of a suite of Emerging Minds resources on supporting families in complex environments ('families with complex needs').

What is co-design?

Co-design is a methodology designed to include people with relevant lived experiences (e.g. living with a mental health condition) as equal partners with professionals in the conceptualisation, design, and development of projects or organisational processes. Co-design builds on engagement processes such as social democracy and community development, in which all critical stakeholders, from professional experts to end users, are encouraged to participate equally in the design of services and products (NSW Council of Social Services, 2017).

In the co-design process, power is shared. People with lived experience often begin the process feeling there is a power imbalance between professionals and themselves. Professionals must make explicit efforts to address perceived and real imbalances in power, knowledge, and resources. Such efforts require high levels of staff expertise, organisational resources, and time.

Done well, the co-design process ensures that all participants enjoy true participation, not tokenistic or exploitative involvement. This would normally involve providing financial compensation and reimbursement of expenses to people with lived experience in acknowledgment of their expertise.

For further information on the co-design methodology and how it is used by Emerging Minds, see the Child and Family Partnerships Toolkit. For more detailed information on the specific co-design processes used in the production of this practice paper, see Appendix 1.

The structure of this paper

Following the introduction, each author introduces themselves, writing briefly about personal and professional experiences that are relevant to this paper.

This paper is then divided into five main sections, each focusing on one of the reflective questions that emerged from the co-design process. These sections all begin with the voice of Jason, the lived experience consultant. You are invited to pause after reading each of Jason's sections, taking time to reflect on your response to his writing, identifying any reactions (including defensiveness), and considering the implications for your own practice of really hearing his voice.

You are then encouraged to read the sections written by Jackie and Rhys, as well as Jason's responses to these sections. A series of 'practice reflections' at the end of each section is designed to prompt you to consider specific aspects of your work with children and families.

This paper includes two appendices. Appendix 1 provides additional detail on how we developed this paper using a co-design methodology. Appendix 2 provides space for all involved in the production of this paper to reflect on the learnings we have taken from engaging in this co-design experiment.

Introducing the authors

Jason

‘To say I live in a complex environment would be an understatement. At 52 years of age, I have a family that consists of four children and a supportive partner. I have a lived experience of mental health challenges, which has included a stay in the hospital, a struggle with finding the right therapies and medications, and the demands of finding the right services and organisations to help me in a regional area.

‘Growing up was difficult. I lived in a home where my father was working hard during the day, and my mother worked night shifts. My mother was quite abusive: physically, emotionally, and verbally. My sister and I grew up scared by threats of being sent away to live with a cult or admitted to an asylum if we turned out “queer”. This latter threat had a significant impact on me, as I was born female, but knew from very early on that I was in the wrong body. Being transgendered in the 1970s was not acceptable to anyone, let alone my parents.

‘I got married and had a baby. This was a horrifying experience for me, but one I dealt with out of pure love for my son. I got divorced, then met my life-partner and began to realise that I could be happy and stop living a lie.

‘My father died of cancer when I was 27, six months after I’d secretly started to transition. I couldn’t tell him because I didn’t want to break his heart. I waited another 12 months to tell my mother. She was abusive and unsupportive. Transitioning at work had its consequences too. I was ridiculed, shamed, and bullied until I quit my job. At that time, Queensland’s anti-discrimination laws didn’t cover transgendered individuals, so I had no legal recourse. It triggered my first breakdown. During this time, my partner and I came
out to her parents. Her family were so supportive, it was surreal.

‘My partner and I moved to Tasmania to start fresh. By now, we had my son and a new, six-month-old son that we brought into the world through IVF. My partner and I decided to have another baby, again through IVF.

We ended up with twins this time around, a daughter and another son. They were diagnosed early on with autism. Our house was far too small. My mother-in-law had moved in with us after my father-in-law passed suddenly.

‘We had to renovate our small house; clean it up, put it up for sale, then seek out a larger house. This led to me becoming unwell shortly after moving into our new home. I was hospitalised and experienced psychosis while under the care of doctors. For five years, I languished in bed. Once I found the right doctor and medication, I began my recovery journey.

‘Today, I feel valued, loved, and respected. The challenges are still here, but my tenacity to succeed is stronger.’

Jackie

‘I joined the team conceptualising and writing this paper as a mental health clinician. My training is in Gestalt psychotherapy and child and adolescent psychiatry. I have worked, in a psychotherapeutically-informed way, in both adult-focused and child, adolescent, and family mental health services for close to 30 years. I also have experience in academic research. When invited to be a part of this project, I jumped at the chance.

‘Over the course of my working life, there have been increasing calls for accountability in mental health services. This initially resulted in an increasing reliance on evidence-based interventions, with a subsequent boom in “brand-name” therapies. The integration of evidence into practice is an admirable and necessary challenge. However, my mental health challenges are similar to my co-authors; I feel that a single designation — “researcher” — fails to adequately capture my experience and understanding of the themes that run through this paper.

‘There are many aspects of this project that excite and inspire me. I feel particularly enlivened by the power of co-design to break down the often-unnecessary walls we build between one another. And I feel particularly inspired by the courage of the lived experience consultants who engage in co-design processes, including Jason and his family. Their voices challenge me to bring more of myself to my work.’

Where should we focus?

Jason

‘Our household is a busy one: we run a small business, we home-school, we’re writing a novel, and until recently I was regularly volunteering. On top of this, I struggle with anxiety, post-traumatic stress disorder (PTSD), bipolar, and borderline personality disorder. These are all serious challenges. However, my mental health challenges are only 1/1000th of me. They don’t define who I am.

‘There’s so much going on, both internally and externally, when one is experiencing mental health difficulties. When I was severely unwell, health professionals didn’t seem to take this into account.

‘During my hospital stay in 2007, I “escaped” and made my way home. While experiencing psychosis, I was under the distinct impression that my wife was struggling and needed help with the twins, who were around six months old. For me, it was imperative that I go home and help her. When my wife took me back to the hospital, the ward staff were angry at me and made me feel bad for going home.

‘Part of the problem is I’m seen as a patient and not as a husband and father. Due to my own trauma history, I’ve placed great emphasis on raising my children in a
happy and safe environment. Even in periods of illness, I still highly value the parenting role. My happiness is my family.

‘My wife is often seen as a carer, yet she has her own set of challenges in raising four neurodivergent children with high anxieties. Again, health professionals weren’t looking at the impact that my illness was having on the family, particularly my wife. There wasn’t any support for her. She was placed in the stressful position of being a full-time carer, making sure I was safe and taking my medication.

‘This caused me to become more unwell, as I was acutely aware of the stress my wife was under, and I couldn’t help. Health professionals weren’t asking either of us the right questions and were not providing us with any helpful solutions.

‘Perhaps health professionals need to shift the focus onto the family unit, and not just on the individual that is sitting in front of them as “the patient”. In my experience, the health professional who did a thorough investigation was the one to make the most significant breakthrough and put me onto the road to recovery.’

Jackie

‘In my experience, there is a tendency for practitioners in adult-focused services to think about individuals. There may be a number of reasons for this. In our training we learn about distorted cognitions, emotional dysregulation, internal object relations, or even attachment styles, as attributes of an individual: an attitude referred to as “the myth of the isolated mind” (Stolorow and Atwood, 1992).

This way of thinking also exists in child-focused services. Talking about child-centred practice is a useful reminder for services to always keep children in mind. Yet what this can unintentionally create in some contexts is a false dichotomy, where the needs of parent and child are seen as mutually exclusive. For example, practitioners in dedicated children’s services who engage meaningfully with parents around their “individual” struggles can be seen as losing their child focus, or to be “doing work that should be done by adult services”.

‘I am passionate both as a practitioner and a researcher about understanding how families can find themselves caught in vicious cycles of interactions where members’ interests seem pitted against one another, and their attempts to foster joyful connection end in disappointment, even though family is often the most important source of profound meaning, connection and belonging. What seems clear to me is that the desire for loving relationships with family is hard to extinguish.

‘If we (practitioners) focus on contexts rather than individuals, we will automatically bring a holistic lens into each treatment environment. We can still explore the internal context that a person brings to their life. For example, it is crucial to understand how contextually-activated, internal models of the self, others, and the world, forged in early traumatic caregiving relationships, can lead people to confuse past and present, and contribute to distressing and repetitive patterns. But contexts also include present-day families, workplaces, and the many communities that a person may belong to. As Jason powerfully reminds us, a person’s identity as a parent might give strength, courage, and a compelling reason to strive for recovery. On the other hand, worry about how a spouse is coping may impede recovery, if not considered and addressed. In Jason’s story, his concern for his family may have been contributing to his psychosis. His concern is also evidence of his connection to family and, if noticed and valued, may promote healing.’

Rhys

‘I find it unsurprising that Jason would like health professionals to shift their focus to the family unit, or that in her training Jackie was encouraged to think about individuals rather than contexts. It is unsurprising because we live in a deeply individualistic society. The most obvious manifestations of this individualism are cultural: our society emphasises the values of personal achievement and self-sufficiency; we celebrate “self-made” men and women; we conceive of healthy development as a movement from the dependence of childhood to the independence of adulthood (Adenpole, Whitley & Kirmayer, 2012). Yet underlying these obvious cultural manifestations is a more insidious form of individualism, a dualistic philosophical doctrine that sees peoples’ subjective experiences as fundamentally separate from the social and material contexts of which they are a part (Orange, 2010). This is the “myth of the isolated mind” (Stolorow & Atwood, 1992) to which Jackie refers.

‘It would be ideal if individualistic myths remained confined to philosophy textbooks or academic debates, but they do not; they remain embedded in many of our health and welfare disciplines (Orange, 2010). Psychology is an obvious example, as its basic unit of analysis is the individual. This would not necessarily be a problem in itself, except that many of the tools and frameworks that this discipline uses to understand peoples’ distress and impairment actively obscure the social determinants of health (e.g. poverty, marginalisation, discrimination), and inadequately account for people’s current and historical relational contexts (e.g. trauma, attachment difficulties, abuse and neglect) (Dignam, Parry, & Berk, 2010; Parry & Levin, 2012; Watt, 2017). For example, although the Diagnostic and Statistical Manual of Mental Disorders (DSM) has long claimed to be “atheoretical,” numerous authors have argued that its symptoms-based “checklist” approach actually relies on a strongly individualistic worldview, one that largely precludes understandings that account for environmental and historical influences (e.g. Castiglioni & Laudisa, 2015; Timimi, 2014).’
‘I see the question, “Where should we focus?” as one of the most pressing questions for contemporary health and welfare practice. Do we focus on individuals? Or their brains? Or their attachment relationships? Or their family systems? Or the broader ecological system of which they are but a part? Or all of the above, depending on the circumstances? These are highly complex questions. Which is why, I believe, we must exercise caution around myths that provide easy and global answers.’

Jason’s response

‘Jackie is correct when she speaks about the connection to family; on reflection, concern for my family was feeding into my psychosis. In looking back on that time, it was quite obvious that my anxiety and depression fed into my paranoia. This was picked up by the last psychiatrist and we worked together towards recovery. He invited my wife Kate to sit in on my sessions and often consulted with her in regards to my recovery processes and medication reviews. This was the first time a mental health professional included Kate as part of the solution. It was refreshing and assisted greatly in my successful recovery.

‘In the last paragraph, Rhys asks questions relating to where one would focus. Instead of a one-size-fits-all approach, people and circumstances, particularly where families are involved, should be taken into consideration.’

Practice reflections

- In your work, do you predominantly support individuals, families, or a combination of the two? What has informed your choices around this?
- Does your treatment framework support you to primarily focus on the private, internalised world of bodily sensation, emotion and cognition, or the external world of relationships and socio-cultural influences?
- What adversities do you think Jason’s family may have been experiencing in the period described above? What do you imagine Jason’s children would have been seeing, hearing, and feeling?
- How could you support people with complex family needs, such as Jason and his family members, within the parameters of your role? How could you take the entire family dynamic into consideration?
- What are the barriers to working with whole families in your role, if this is not central to your current practice?
- Have you considered the role that family plays in the recovery of your client? Could you find a way to include other family members in collaborative conversations with your client? What other strategies could you use to include the family in the recovery of your client?

Who holds the power?

Jason

‘As a family that has neurodiverse children, we found that the younger children, particularly, had a great deal of anxiety. We chose to have the children see a psychologist. Both Kyle (12 years) and Karen (12 years) are on the autism spectrum. Kyle saw the psychologist to try and minimise his meltdowns and Karen saw the same psychologist for her high anxieties. We were about to embark on a holiday which would require the children to be in close proximity for two weeks and thought this would help them adapt. We split the sessions over two 10-week periods.

‘Kyle didn’t need to go back for the second period because he had worked hard and there was a significant improvement, and after a discussion with the psychologist, he didn’t require ongoing treatment. While the psychologist worked wonders with Kyle, the same could not be said for Karen’s experience. She found the male psychologist made her feel uncomfortable and upset. She was hiding under his desk and didn’t feel comfortable with him looking at her. In fact, she made a point of saying that she found him “patronising and condescending” and that his questioning made her feel...
uncomfortable. The psychologist was trying his hardest to connect with Karen through her interests in Harry Potter and other popular topics.

‘Karen relayed to her mother that she didn’t want to continue seeing the psychologist because she felt that he didn’t take her feelings seriously. After a conversation between us, Kate and I decided that perhaps we should talk to the psychologist and seek his opinion. He wanted to continue, but Karen didn’t want to. After another discussion, we put it to Karen to decide whether or not she wanted to go back, and she chose not to, opting instead to try another psychologist. The problem with being in a regional area is that it is not easy to just find another health professional. It took us two years to find a suitable psychologist that was able to work with an autistic child, and one that Karen would feel comfortable with (i.e. a female).

‘Sometimes it’s about the right tools for the job; the right person for the situation. We felt we made a difficult decision that was proactive and allowed our child to have a voice instead of making decisions for her without consultation.’

**Jackie**

‘If I were facing this situation, I imagine that I would have many responses. On one hand, the young person and their family’s views must be central in decision-making. On the other, I have an obligation to offer my responses to the situation for the family to consider in their decision-making process.

‘Part of my job is to wonder what might be going on when a young person has an intense response to meeting me. Has this young person had difficult experiences in the past that have been activated by our meeting? Am I contributing to this in some way? Does this response relate to me also seeing their sibling? If so, does this young person experience this as a threat to their individual identity? Does this young person often react intensely to certain sorts of people, such as those in authority? Is gender a factor? How is this related to the young person’s stage of development? These are a few of the thoughts that might occur to me. If relevant, understanding and working through them with me might be useful.

‘However, there are other considerations. Is the reaction so strong that the young person will not be able to work with me? If the parents encourage the child to work with me, will this undermine this young person’s trust that their parent will listen to them? Does this parent need to find a way to value their own authority in the face of this young person’s constant demands? To what extent does my desire to explore these ideas override the young person and their family’s autonomy? Overriding a family’s autonomy is almost certainly going to be counterproductive.

**Rhys**

‘The French philosopher and historian Michel Foucault (1980, 1998) is perhaps the most famous theorist of power. In his understanding, power is intimately bound up with knowledge. Indeed, rather than speaking of power and knowledge as separate concepts, he introduced the idea of power/knowledge to convey what he saw as an inextricable connection.

‘Foucault was particularly interested in the ways in which systems of knowledge — or what he called discourses — influence people’s identities and social practices. He spoke of power as a discursive force that shapes how people understand their own experience, how they make sense of their difficulties, and how they work towards changing their lives. Take psychiatric discourse as an example—that is, the concepts, frameworks, tools, and practices that our society uses to distinguish “normal” and “abnormal” thoughts and behaviours. Psychiatric discourse exerts a potent force in many people’s lives, shaping their self-understanding, the ways in which others understand and relate to them, and, indeed, the very ways in which their symptoms manifest.

‘For Foucault, there is nothing inherently wrong with power/knowledge, as it can be a productive as well as an oppressive force. However, he does stress that dominant discourses tend to exclude other ways of knowing and understanding the world, which can lead to a limited understanding of particular issues, and which can constitute a form of injustice for those whose viewpoints are suppressed. One way of understanding Karen’s refusal to continue seeing her psychologist is to see her actions as a resistance against the power/knowledge that can so easily be imposed onto clients by health and
welfare professionals. As a young person on the autism spectrum, I imagine it would be very easy for Karen's understanding of herself and her world to be devalued. The fact that she felt patronised, condescended to, and that her feelings were not being taken seriously, suggests that this may have been the case with her psychologist, despite what sound like genuine attempts on the part of this professional to engage with her.

‘Both Jason’s and Jackie’s responses invite Karen to be included as a legitimate participant in the production of knowledge about her own life. Jackie, in particular, is in a position where she could unintentionally act to reinforce the power of psychiatric discourse by uncritically imposing this discipline's knowledge on others. Yet her desire for “genuinely cooperative dialogue” sees her question the presumptions and categorisations of her own discipline, and invites young people into a form of relating that undermines existing power relations. There is no point in trying to be free from all power/knowledge relations—Foucault is clear that this is not possible. Yet as professionals, it is within our power to resist the excesses of dominant professional discourses, and to create space for other ways of knowing.’

Jason’s response

‘I totally understand Jackie’s point of view, I feel that it’s important to discuss all options before making a crucial decision. I wonder if the psychologist actually had a chance to think about some of those questions himself. I imagine he struggled a bit to find ways of connecting with Karen. It was evident when he tried to encourage her to continue seeing him, and I realise that his job was very difficult. It is no bad reflection on his work as a psychologist, it just wasn’t a good fit for Karen. In fact, having now found a psychologist to work with Karen — a young woman — we have seen much growth in our daughter. Again, we have found a practitioner that allows us to sit in on sessions (at Karen's request) and who looks at all aspects of the family dynamic. This has been a positive and educational experience.

‘In his last sentence, I feel that Rhys nails the point. Creating space means that things are not set in stone and that individuals’ needs can be met through exploring other avenues.’

Who gets to speak?

Jason

‘Our family and our circumstances are complicated. Because of this, I believe it’s essential to allow the children to have a voice. Too often children are overlooked and pushed to the side. In conversations with other families, the parents seem to control what goes on with little thought as to how the children are feeling, or even what they might be thinking. The children are dismissed as being too young or not capable of making decisions.

‘I believe it’s vitally important that children are allowed to express their thoughts and opinions. Their insights sometimes focus on what adults seem to miss or overlook. We try to do our best, but I feel that by allowing children to have their voices heard, we’re helping them grow and learn and feel included within the family. It’s my personal belief that it leads to better mental and emotional health for everyone if discussions between family members are open and inclusive.

‘When I was unwell, the children were very young. As a result, they didn’t get much say in who their carers were, or in making any family-based decisions. The older boys did not get to speak to any of the service providers that I accessed; their opinion was apparently not something that was required by the health professionals, although I feel that perhaps it may have been beneficial for both them and myself.'
'As for the home front, once the children were old enough to voice their opinions, Kate and I felt quite comfortable engaging them in conversations about their care, seeking their opinions and their thoughts. The children felt that being able to have a voice meant that they were being taken seriously and that their words and ideas were valued. 

'Ultimately, I feel that it’s essential to allow the children to express their thoughts and feelings in a safe and inclusive environment. While parents must have their say, I feel there’s a strong argument for involving children in day-to-day decision making. Their words and actions can make a big difference in how we approach challenges and make decisions that inevitably affect the entire family unit.'

**Jason’s children speak**

Children's voices matter. We wanted to explicitly include the voices of Jason's children in this paper. Three of his four children were interested. We invited them to tell us what their ideal practitioner would look like. We didn’t offer any further guidelines, but let the children have free reign to say what they thought in conversation with Jason. The children and Jason were paid for their time doing this work.

**Kyle (12)**

‘My perfect psychologist would be able to understand my feelings even when I’m not showing them my true feelings. They’d be able to understand everything I say, even when I’m being obscure. I don’t have a gender preference, I don’t mind their age, so long as they are a good psychologist.

‘They have to be a good listener, and they should be careful not to hurt my feelings. I want them to be able to clearly tell me things without being aggressive. They need to be calm and have a sense of humour. I want them to be reasonable and very knowledgeable about everything.’

**Matthew (15)**

‘Someone who is nice and straightforward and good at their job. I don’t have a gender preference. I would prefer a psychologist who is more focused on me, rather than on themselves. They would need to talk to me on my level, not as a child, but as an adult. I would like someone who takes their time and doesn’t jump to conclusions. It would be good if they listened to me.’

**Karen (12)**

‘I would prefer a woman as my doctor. I don’t feel comfortable with a man, I feel that most young girls don’t. I would like her to be nice; someone who listens to my problems and doesn’t disregard them. I feel like a lot of people disregard my problems because I’m 12. I’d like her to speak to me on a level that is equal. I’d like if she would understand what I’m thinking instead of jumping to conclusions based on my age and gender. I feel that I’d prefer her not to make eye contact with me because that makes me feel uncomfortable.’

**Jackie**

‘What Jason’s children have shared is that they want to be respected as individuals in their own right, not as extensions of their adult caregivers. They want the opportunity to voice their concerns and have these taken seriously, by someone who values their unique and distinctive perspectives. Jason and his wife choose to allow their children to participate in decision-making around issues that are of concern to them, which is a choice that supports their children to develop a robust sense of themselves as valued individuals with agency in their lives. Hearing a child’s unique voice, and understanding the world from their point of view, is absolutely essential to facilitate this process.

‘As I reflect on Jason’s children’s words, I realise that many of the families that I work with are not as able as Jason’s family to hear and consider everyone’s voices. I wonder about the role of shame in making this difficult. Hearing a child’s voice may sometimes entail hearing that you (therapist or parent) have been hurtful, insensitive, and caused the child distress. Where a parent feels fragile and uncertain of their worth as a parent, they may feel shamed by the child. Shame can be paralysing, but it is also often at the root of angry, retaliatory responses, responses that then shame the child. In these situations, there is a real risk that a clinician seeing a child alone will leave the parent wondering how they are being represented to the clinician, which can further undermine them in their parenting role.

‘When families bring their children for treatment, I want to balance my desire to meet a child and young person fully and respectfully, with an unwavering appreciation for the deep interconnections between all family members. Everything that happens in a family has an impact on everyone else. If this is overlooked, there is the risk of differentiation becoming separation and isolation. When all of the voices can be heard and family members can lean into painful conversations, new and creative solutions to problems can emerge.

‘Perhaps in adult-focused services we need the corrective of hearing the children’s voices, but the opposite may be needed in child-focused services. We ignore the interaction of multiple voices at our peril, and risk alienating families rather than helping them to draw closer to one another in the face of adversity.’

**Rhys**

‘As I read the words of Jason, Kyle, Matthew, Karen, and Jackie, I am reminded that the inclusion of children’s and families’ voices serves two purposes.
The first purpose is instrumental: when we listen to what children have to say, there will often be some form of benefit. If, like Jason, we include children in decisions that affect them, we are more likely to make good decisions, and less likely to be met by children’s resistance. If, like Jackie, we draw on both children’s and parents’ perspectives, our interventions are likely to be more effective, if for no other reason than we will have strengthened practitioner-client relationships. And if we include the voices of children and families in our research and policy projects, the chances are better that our words, concepts, and frameworks will actually map onto the complex realities to which they refer.

The second purpose is intrinsic: to include children’s and families’ voices is to show respect for them as autonomous human beings. People have the right to be heard, especially in decisions and discussions that affect them. Article 12 of the United Nations Convention on the Rights of the Child (1989, p.5) aims to,

“assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”

‘Like all human rights, the right to be heard does not need to be justified by appeals to benefits. Rather, it emerges from the idea that everyone enjoys certain fundamental rights, simply because they are people.’

**Jason’s response**

‘Jackie’s observation about the role shame can play in a situation makes sense. No parent wants to hear that they’re doing a bad job. I’ve experienced this in the past, and it was unpleasant. Adults tend to be reactionary, and getting feedback on their parenting could lead to further complications.

‘However, if this is introduced in a way that both adults and children can understand, it could lead to a successful outcome. In my experience, hearing from my children that my loud voice often scares them, even when I am laughing, resulted in mixed feelings: shame and embarrassment. However, it was a catalyst to assist me in coming up with solutions that have had positive outcomes. Sometimes, as adults, we have to realise that we’re far more emotionally developed than our children and it’s up to us to make the necessary changes, even if we feel uncomfortable.

‘I also can see how receiving feedback could bring concern and weigh on the mind of a healthcare professional. Going back to the example of Karen’s psychologist, I wonder how he felt when he was told he was patronising and condescending. Though he laughed it off, I often wonder how he felt in that situation.’

**Practice reflections**

- What are your experiences of speaking and being heard? Do you feel heard in your professional role? Do you think that others feel heard by you?
- What are your experiences of listening? How could you improve your listening skills?
- What reactions did you have when reading the words of Jason’s children? Where might such reactions come from?
- Can you think of ways to give children more of a voice in your practice? How might your strategies differ across age ranges (i.e. babies and toddlers, pre-schoolers, primary school-aged, and high school-aged)?
- Shame is often referred to as the hidden emotion. Do you know what form your shame-driven responses take?
- How do you habitually respond when your worth as a practitioner is called into question?

**What should we share?**

**Jason**

‘Sharing my experience over the years has been an exercise in trial and error and patience. In the first instance, my initial breakdown was so sudden and extreme that I quit my job. It involved bullying in my workplace (over my transition), no anti-discrimination laws to protect me in Queensland, and an ex who would say and do anything to gain custody of our son.

‘In many respects, it was because of those last two reasons that I failed to approach a mental health professional of any kind. I was worried (perhaps irrationally) that I’d lose my son, so I cut myself off from the world for the following 13 years. I was terrified that a doctor would see me as mentally unstable and somehow remove my son from my care. He was in no danger; I was just unwell and found it hard to cope with the loss of my job. (This came on the tail of losing my father to cancer, my mother practically disowning me, and my friends abandoning me after I came out.)

‘Fear is a powerful emotion that triggers paranoia and other feelings that lead to irrational thought. I feel sad that I couldn’t trust a mental health professional at the time. Having access to a diagnosis at the time would have possibly made my life a lot different.

‘I’ve struggled with a practitioner oversharing their personal experiences, in what I assume was their way of trying to connect with me. However, relating stories of globetrotting to places I’ll never likely go doesn’t
sit well with me. In my opinion, a therapist is there to offer solutions to my lived experience, using tools and resources applicable to that situation. Making me feel miserable because I can never afford to go to Paris is unhelpful.

‘A positive experience I’ve had with a psychiatrist, though, allowed me to share safely and confidently. He was always genuinely concerned with my progress. He listened to me and always asked me questions, which made me realise he was there to help me to the best of his ability. In my experience, however, he is the only mental health professional in the last 12 years to show any kind of compassion, concern, and interest in my recovery, and I have seen over 15 people in that time.’

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**Jackie**

‘Working out what to share can be complicated. Jason reminds us that fear is a powerful barrier to people sharing their painful struggles with professional helpers. For Jason, and many others, help-seeking is made impossible by fears of invalidation, humiliation, being harmed instead of helped, and being treated as a problem to be solved rather than a person to be understood.

‘As clinicians, it is vitally important to remain sensitive to how what we share, and what we choose not to share, affects an individual’s experience of reaching out for help. Experiences like those described by Jason—discrimination (both real and feared) and loss of valued relationships and employment—can strip an individual of their sense of inherent worth, or dignity. If these barriers are sensitively negotiated, a therapeutic connection can begin to restore an individual’s dignity: in their suffering, and as they recover.

‘Jason underlines how important it is for professional helpers to be genuinely interested, and emotionally invested, in the lives of the people with whom we work. It is sobering to hear that, in Jason’s experience, only one in 15 professionals effectively demonstrated their care and concern for Jason.

‘As a Gestalt therapist, a commitment to dialogue is central to my practice, which involves participating fully in the therapeutic relationship. Jason highlights the potential pitfalls with this. An important distinction can be made between transparency and self-disclosure. When I am transparent, I share, in a considered way, my responses to what the person I am with is bringing to our meeting. The sole purpose is to help us develop a shared understanding of the suffering that they are facing. The hope is that we will discover, together, a pathway towards a more satisfying future.

‘An example of transparency would be sharing a dilemma that I might have when wanting to recognise and support a suicidal individual’s autonomy, whilst also being very scared for their safety. Self-disclosure would happen if I shared information about how I live my life in a day-to-day sense; where I shop for food, take holidays, plan to buy a new car, the ways in which I am satisfied or dissatisfied with my life, and so on.

‘A way to test whether I am straying into the territory of self-disclosure or being genuinely transparent, is to ask, “How is what I am about to share going to support this person who is seeking my help to take the next step in their journey?” If I am unable to work this out, then I am cautious and err on the side of not sharing. For me, not sharing is better than over-sharing.’

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**Rhys**

“What should we share?” The answer to this question will depend on many factors. An important factor is the social position we occupy in a given situation. The three social positions the authors of this paper occupy — a lived experience consultant, a practitioner, and a researcher — each come with different expectations and norms about what and how much should be shared.

‘As a service user and lived experience consultant, there is an expectation that Jason will reveal personal information about his life. In the right circumstances — such as with a trusted and skilled professional — sharing one’s stories, and having those stories received and held, is often at the heart of healing. Yet, as Jason’s experiences indicate, many interactions between practitioners and those they support do not provide the right conditions for healing. For example, people may be required to repeat highly personal and distressing information about their lives whenever they access a new practitioner or service.

‘As a practitioner, Jackie has more choice about what she shares and when she shares it. Indeed, many practitioners struggle with this choice, not knowing how much of themselves to reveal in their work. It does not help that there are marked differences in how various professions, and the many schools or approaches within these professions, view self-disclosure. Indeed, as Yalom (1995) observed in the field of psychotherapy, “more than any other single characteristic, the nature and degree of therapist self-disclosure differentiate the various schools of… therapy” (p. 202).

‘Transparency and self-disclosure in professional practice are ambiguous and complex issues. Ultimately, each practitioner must find ways of navigating these issues that: feel personally appropriate and sustainable; adhere to ethical, professional, and organisational guidelines; and, most importantly, are of benefit to the families with whom they work (Peterson, 2002).

‘In my role as a social researcher, there is pressure on me to avoid self-revelation. Many areas of research are still underpinned by the positivist assumption that genuine knowledge is always objective and quantifiable. To write of your own experiences, beliefs, motivations,
and feelings is seen by many as less credible than citing statistics and avoiding personal pronouns.

‘Of course, there is nothing wrong with striving for a degree of objectivity in research. I simply believe that the research norms that forbid self-revelation can serve to deepen the existing gulfs between lived experience, practice wisdom, and research knowledge.’

**Jason’s response**

‘Jackie mentions developing “a shared understanding” and I feel she completely understands the idea of how to go about building a rapport with the person accessing services. Her last paragraph, where she asks the question of relevance and reflects on the answer, is encouraging.

‘Rhys’ observation that people can be “required to repeat highly personal and distressing information about their lives whenever they access a new practitioner or service” resonates deeply with me. I always found this to be difficult, and in some cases frustrating. While sharing information is paramount in a new situation, there are often reports that go along with the person being seen. It becomes difficult when one has to continually refer back to hurtful or difficult situations. It seems to be the standard practice. So, I wonder if this is something clinicians actually take into consideration when seeing a new person.’

**Practice reflections**

- How much of yourself do you share in your professional practice? Could sharing more of yourself benefit your clients and colleagues? How do you decide what is worth sharing and what is not?

- How do you imagine it felt for Jason to balance his need for seeking support services with his fear that sharing his story might result in the removal of his child? What might you say to someone who was struggling with such a dilemma?

- How do you think people feel when having to retell their story each time they access a new practitioner? How can you honour all aspects of a person’s story when they tell it to you? What do you think compels practitioners to want clients and families to repeat information that has already been given to colleagues?

- Have you ever thought of experimenting with not asking any questions during a session with a client or family? While impractical in every encounter, it can be a useful way to investigate the balance of listening versus leading that characterises your practice.

**Who is allowed to struggle?**

**Jason**

‘While it was a trial for myself navigating mental health services and trying to get by one day at a time, there were other struggles going on that were just as important: my wife was under pressure to hold everything together. With two newborns, a two-year-old, and a 14-year-old in the house, plus her ageing mother, she was attempting to run the household because I was bed-bound and physically incapable of assisting. The children struggled with carers, because of the high rotation rate, which meant that people they were attached to were coming and going.

‘Overwhelmed and exhausted, Kate had to go on anti-depressants to help her cope. She felt left out by the mental health professionals treating me, and she felt they were treating her as if she were part of the problem and not part of the solution for my recovery.

‘It took five years for us to get to a point where we realised that we could take more control of the situation we were in. Kate found a counsellor who gave her a list of good psychologists, one of which, although it was not his responsibility, suggested some medications that might be beneficial, because the psychiatrist I was seeing had no intention of listening to what it was either of us had to say. It was empowering for her when she told the psychiatrist that she wanted to change my medication; that feeling grew when she felt that we were no longer trapped in the system. Once I was on the road to recovery, it gave us more energy to take control of my recovery ourselves.

‘Reading The Happiness Trap by Dr Russ Harris led to us making contact with Aspire (now Wellways, a mental health and community care organisation), which led to involvement with Flourish (a mental health advocacy organisation) and the beginning of advocating for myself.’

**Jackie**

‘These words are heart-wrenching to read: both Jason’s experience of disempowerment, and Kate’s feeling of being seen as part of the problem. What Jason seems to be describing are multiple experiences not being seen fully or accurately by professionals. Perhaps our own hidden struggles sometimes obscure the view?'
'Although I was the person who advocated strongly for including this question, I have found this the most difficult section to write. I am used to my struggles being shared privately with trusted colleagues, rather than publicly and in print.

Most days I experience doubts about my ability to meet a family’s needs, and concerns about whether I am engaging authentically and skilfully with families. When I feel helpless, I am tempted to take control and offer advice, to relieve my discomfort. Sometimes I fill an awkward silence too quickly, closing down an opportunity to approach a difficult subject, or I avoid saying something that I think may be important in case I make someone in a family uncomfortable. I want to avoid censure and may allow the views of colleagues or the requirements of my professional body to dictate rather than inform my practice. In those times, I am guilty of limiting therapeutic possibilities. These are the everyday struggles that I try to embrace in order to be thoughtful and considered in my work.

‘In addition to this, I, like all therapists, encounter adversity: family illnesses, loss and grief after death, times of compromised physical or mental health, relationship stresses or breakdown, the ongoing impact of personal traumas, to name a few. There is no place in therapy for a family to be burdened by a therapist’s personal struggles. At these times, the onus is on the therapist to make considered choices about their ability to work.

‘Earlier in this discussion, Jason spoke about “escaping” hospital and making his way home, driven by his intense desire to help Kate with their six-month-old twins and their two other children. When Kate took Jason back to the hospital, staff were angry. I wonder if the anger shielded ward staff from a full awareness of their more vulnerable feelings about not noticing that Jason had left and about what could have happened to him. If these vulnerable responses were welcomed and discussed, could staff have responded to Jason with curiosity and kindness rather than defensive anger?’

Rhys

‘The question “Who’s allowed to struggle?” circles us back around to the first reflective question in this paper, “Where should we focus?” Do we simply focus on the struggles of the client who is presenting to a service? Or do we expand our view to look at the ways in which one person’s struggles are most often held within a broader network of relationships, which can include many people who are struggling in their own ways?

‘It seems that many of the services that Jason has been in contact with over the years have focused solely on his mental health concerns, while neglecting both Kate’s struggles and the central role she has played in Jason’s recovery. Fortunately, there are alternatives to such individualistic approaches. For example, while the mental health recovery model tends to be quite individualistic (Price-Robertson, et al., 2017), a number of authors have developed models of “family recovery” (e.g. Nicholson, 2014; Wyder & Bland, 2014). In outlining her family recovery model, which was developed for mothers with severe mental illness (but is also applicable to fathers), Nicholson observed:

Clearly, women who are mothers are not living in a vacuum. The context of their lives is often defined by family parameters. Families are commonly understood as systems in which members are engaged in reciprocal relationships (i.e. family members affect each other) and events are multiply determined by forces operating within and external to the family. For mothers living with mental illnesses, recovery is a dynamic process that contributes to and is influenced by family life, family experiences, and the wellbeing and functioning of other family members. (pp. 6–7)

‘I am left to wonder about how different Jason’s and Kate’s experiences could have been had their service providers adopted such an expansive approach to mental health treatment; one that highlights the interdependence of different family members’ struggles and triumphs.

‘Jackie then gives us an important reminder: it is not just clients and family members who struggle, but clinicians too. Many health and welfare disciplines promote the idea that clinicians’ personal struggles can undermine the objectivity or professionalism required to provide effective treatment. In such disciplines, clinicians tend to be trained to see problems as “out there” and are offered little guidance on understanding their own struggles as a way to strengthen their work with clients.

‘Yet, as Jackie points out, such a splitting can be detrimental to clients. Indeed, some therapeutic traditions (e.g. psychoanalysis, Gestalt therapy) insist on clinicians undergoing their own extensive therapy because it is recognised that those in touch with their own struggles—their shame, fear, doubt, sadness, and confusion—tend to be better able to understand, empathise with, and safely contain others’ struggles.’

Jason’s response

‘As someone who has volunteered in the mental health sector, and who has friends who work in clinical roles, I understand that clinicians indeed struggle. For a long time, prior to meeting these people, and during my worst years of being unwell, I often felt that the clinicians I was engaging with seemed uncaring and, quite frankly, cold. Cultural and personality differences aside, I wondered if these people just couldn’t care less.

‘However, by coming into contact with clinicians on a personal level, and getting to know Jackie through this project, I have come to understand that it’s indeed...
a difficult situation for many. It matters to me that clinicians struggle, in that it allows me to see them as human beings and not just professionals. I’ve taken to thinking about these things when talking to my health professionals. I see now that most of them seem to struggle (although I hold my reservations for some who seem very staid and hyper-focused on their own importance). It allows me to be more objective and to cut them some slack.’

Practice reflections

- Are you allowed to share your struggles in your professional role? How would you feel if any constraints on your capacity to share were lifted?
- As a professional, what are your thoughts about the need to be intimate with your own struggles in order to be most effective with clients?
- How would you investigate whether sharing your humanity is self-serving, rather than in the service of the client’s healing?
- Do you share with clients your doubts or dilemmas about how best to help them? If not, what do you gain from keeping these doubts hidden?
- What strategies do you have in place to deal with any struggles that might arise for you personally during your consultation with a client?
- How might you recognise and support the struggles of family members who are not your primary client?

Conclusion

The co-design methodology invited us to think differently about developing a written resource for practitioners who support children and families. This methodology led us to explicitly confront a series of questions — dilemmas involving power, inclusion, and suffering — that underpin almost every social activity, including writing practice papers and providing professional support to families. Whether we acknowledge it or not, our professional lives are defined by how we relate to the questions touched on in this paper.

Our decision to retain three distinct voices in one paper challenged our habitual ways of thinking, writing, and relating. It can feel like there is a gravitational pull towards the well-rehearsed and the already-known. Anything else feels risky. Habitudated practices can provide us, and those around us, with a sense of confidence. Yet they can also undermine the vitality that animates important work — work that makes a difference to people — whether it is writing a paper or supporting a family. We are not in a position to judge whether this paper makes a difference to you. We are sure, though, that stepping outside of our comfort zones made a difference to each of us. In Appendix 2, we each speak about the learnings we have taken from this co-design experiment.

We hope that this paper encourages you to think differently about your work with children and families. The people you support need you to ask the reflective questions posed in this paper, not just once, but over and over, in every new context. The point is not to try to answer the questions. Rather, the point is to let the questions guide your practice, and to find the courage to keep asking them if they lead you beyond your comfort zone. As the poet Ranier Maria Rilke (1934, p. 34) advises,

“Live the questions now. Perhaps then, someday far in the future, you will gradually, without even noticing it, live your way into the answer.”

Continuing the conversation

We invite feedback and ongoing discussions related to this paper and the co-design process at codesignauthors@emergingminds.com.au

Authors and acknowledgements

Jason Tyndale is a lived experience consultant for Emerging Minds. Jackie Amos is a child and adolescent psychiatrist at Centacare, and an adjunct research fellow with the Health Economics and Social Policy Group, University of South Australia. Rhys Price-Robertson is a workforce development manager at the Australian Institute of Family Studies.

Views expressed in this publication are those of the individual authors and may not reflect those of Centacare, the University of South Australia, the Australian Institute of Family Studies, or the Australian Government.

Our heartfelt thanks go to Lydia Trowse, without whom this paper would not have been written. We also thank the following people for their contributions, advice, and feedback: Kate Tyndale, Matthew Tyndale, Kyle Tyndale, Karen Tyndale, Tamika Perrott, Helen Francis, Morwynne Carlow, Louise Salmon, Kerry Hawkins, Amy Watson, Brad Morgan, and Dan Moss.

References


This resource was co-produced with:

Emerging minds.

The National Workforce Centre for Child Mental Health (NWC) is funded by the Australian Government Department of Health under the National Support for Child and Youth Mental Health Program.
Appendix 1: How we developed this paper

This paper reflects the collective efforts of four people: the three authors and Lydia Trowse, who is Emerging Minds’ child and family partnership coordinator.

Lydia is responsible for facilitating the inclusion of lived experience consultants in Emerging Minds’ work, and was involved in this paper from conceptualisation to publication. Her role centred around a strong, trusting relationship with Jason and included providing support to him as he co-authored the paper, and checking in throughout the process, especially after he wrote sections of the paper that were particularly emotive for him and his family.

Lydia’s role also included explicit attempts to facilitate an authentic co-design process, ensuring Jason’s voice was centred and that power imbalances between the authors were equalised. Her role also extended to conversations around Jason’s family; how the process was impacting them, and ways to include the voices of Kate and the children in the paper.

Finally, Lydia ensured that Jason (and his wife and children when appropriate) were remunerated for their work. Remuneration (and reimbursement of expenses) is an important aspect of acknowledging the individual strengths and unique expertise of children and families; it helps to show respect for their time, knowledge, and, often, personal emotional cost. Lydia’s facilitation role was integral to building an effective, supportive, collaborative co-design environment, honouring the process of people bringing their lived experience into this work.

After some provisional planning discussions between Lydia and Rhys, Jason and Jackie were invited to be part of the team. At this point we met via video-link to generate initial ideas about the scope of the project.

We then spent two days together discussing and planning the paper. This occurred in a relaxed environment, with few trappings of corporate, academic, or clinical environments. A conscious choice was made to dedicate a significant amount of this shared time to personal introductions and free conversation. Co-design only works effectively when participants develop a high level of interpersonal safety and trust, as professional participants traditionally hold more power than those with lived experience.

We agreed to enhance the conversation by attending to the quality of our presence; to participate fully and unreservedly in the conversations, to respect differences, and to recognise, explore, and move beyond defensiveness.

An invitation was also extended for all of us to monitor and “call out” constraining actions by other members of the co-design team. The aim of this intensive process was to build emotional safety and the interpersonal trust required for genuine co-design.

We then wrote the paper over a number of months. In order to embody, as fully as possible, our desire to subvert traditional power structures, the lived experience voice was given priority in this process. Initially, Jason provided responses to each of the reflective questions generated in the two-day workshop. Jackie then responded to these words. After this, Rhys responded to both. Finally, Jason was offered the chance to briefly respond to what Jackie and Rhys had written. In practice, this meant that the professional voices were always responding to, and contained by, the lived experience voice.

The team hoped, in this way, to ensure that the writing addressed the concerns of our lived experience consultant, modeling a process of true partnership whereby the voice of the person seeking help can be given priority in a clinical setting. This was our attempt to remain true to our goals of avoiding tokenism and challenging the prevailing distributions of power in health and welfare service provision.

Throughout the writing process, we also communicated via email and met a number of times via video link. Towards the end of the writing process, we invited independent reviewers to provide feedback.
Appendix 2: What we learned from the co-design process

Jason

‘When I was first asked to join this project, I was quite nervous. It was a project that would challenge my perceptions and bring new understanding to aspects of co-design that I had not encountered before.

‘Initially, I was not familiar with Jackie and had only met Rhys briefly. I was uncertain as to how the project would pan out. My main cause for concern was how we could share the power and how powerful the sharing might be. Would my voice be lost amongst two very professional individuals? And how would they react to my contribution as a child and family partner? How would I react to two professionals who had extensive training in psychology? And how would I get around my bias against mental health practitioners, who I’ve come to be wary of due to past negative experiences?

‘There was no cause for alarm. Within a few minutes of meeting together in person, I felt very relaxed and comfortable. Jackie was a wonderful and simply lovely individual. Her caring nature and her enthusiasm for the project allowed me to feel a positive connection straight away. Rhys was amazing. He was very respectful and asked several times if it was okay if he took the lead on writing things down. I felt that we established a camaraderie from the start of the project.

‘Our roles, while completely different, marked each one of us as professionals in our fields of expertise. My trepidation around mental health practitioners completely dissipated. I feel both Jackie and Rhys respected me; and, of course, I highly respect them for their knowledge, their compassion, and their willingness to share part of their own stories in a safe and confidential environment.

‘Overall, the project and the outcomes we hoped to achieve are apparent to me. It was both successful and enjoyable, and I truly believe that this paper and the co-design process will be of benefit to anyone wishing to implement the strategies and challenge themselves with the questions that we asked ourselves.

‘I’ve learned so much through working on this project. Through the co-design process, I’ve come to understand that it’s possible for lived experience consultants to have their voices heard in a way that matters. I’ve learned that working with health professionals and researchers can be a great way to gain a better understanding of how we can all work together to implement changes to a system that is desperate for change. I have a deep respect for Jackie and Rhys and their contributions, and for the fact that they gave me an equal voice in this project from the start.’

Jackie

‘On the morning of our first Zoom meeting, I was both nervous and excited. The excitement was easy to make sense of. I enjoy new projects and this project would introduce me to a completely new process, that of co-design. With the benefit of hindsight, I think I was anxious about how I would be received by Jason, Lydia, and Rhys. I know that I can have strong opinions, and in an effort to not impose on the process I was in danger of being overly tentative.

‘Within the first hour of our face-to-face workshop, I relaxed. I realised that our shared humanity would be more powerful than our different roles. I also realised that my anxiety that I could overpower others with my voice underestimated the eloquence and expertise of my colleagues. Rhys and Jason introduced themselves in full-hearted ways, which inspired me to do the same.

‘As a Gestalt therapist and child and adolescent psychiatrist, I have tried to straddle two very different worlds, with different norms and values. Many years ago, a psychoanalytically-trained colleague questioned my emphasis on transparency in the therapeutic relationship. I had not until that point understood the gulf that existed at that time between my therapeutic orientation and some other approaches to psychotherapy. This left me very confused.

‘I have spent years reading about psychotherapy in an attempt to resolve my discomfort. One of the most powerful outcomes of being involved in this co-design process has been that my doubts about the value of the radically-relational approaches to therapy have finally resolved. I have been inspired to lean evermore rigorously into my Gestalt roots, trusting fully that genuine dialogue will support the emergence of unique and creative ways for families and therapists to respond to complex environments.’
Rhys

‘I normally start a research or writing project with quite a clear idea of how I would like the process to unfold and what I would like the final outputs to be. If I look honestly, I see that when I have worked with others, I have tended to treat them as consultants: people who can offer valuable assistance and advice, but who are unlikely to fundamentally shift my basic ideas.

‘This co–design process has disrupted my usual way of working. I have been challenged to step back, really listen, and cultivate space for other perspectives. I have been asked to soften the tight grip I have on my own agenda and my own ways of working—to move from consultation to collaboration. I cannot claim to have always been successful at this, but this project has highlighted the value in at least aiming for true collaboration.

‘I finish this project wondering how I might allow the lessons learned from this co-design process to inform other areas of my professional life. Most of the work I produce is more traditional, in both process and form, than this co-design project. For example, I am often required to meet pre–determined objectives, and seldom do I have the budget to employ a lived experience consultant as a project partner. Yet the qualities that true collaboration demands—humility, flexibility, openness, presence, generosity—are ones that I hope will steer all of my work, no matter what form it takes.’

Lydia Trowse, Emerging Minds’ child and family partnership coordinator

‘It is important to me that the work produced by Emerging Minds includes genuine and authentic attempts at co-design. Our work concerns the lives of human beings, of families and children. We owe it to families to produce the best work possible, and to do this we need to work in partnership with them.

The co-design process can be slow, it can cost more money, and the resultant change families may wish to see in the real world can also be frustratingly slow. However, it remains a vital process for us to learn, to practice, and to eventually excel at.

‘This paper began as an exciting opportunity for a group of us to do something none of us had done before: to be involved in the creation of a truly co–designed paper. My role was not as an author, but as a facilitator of the process. I am honoured to have been involved in the creation of this unique paper and have learned a lot along the way. I would like to offer the following three reflective points as key factors to the success of this co-design process:

• The importance of relationship: Our relationships are both professional and personal, and share knowledge and power.

• Trusting in the process: When we started on this journey, we did not know what we were going to create. The process and the outcome are different to what we expected, but also more rewarding and worthwhile for us and others.

• Opening to input from others: We sought input from outside of the co-design team, which helped us to see things that from the inside we hadn’t been aware of, and which allowed us to refine the paper into what it is today.'