

Heroic or Stoic: why do we try so hard or give up so easily in helping with autism?

Key words

Relational intelligence, cognitive analytic therapy, heroic therapy, supporting the autistic person's social context.

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Introduction

Autism has distinctive features that are challenging for people in the helper's role. Helpers can become frustrated, dismissive, heroic or numb. It is easy to become either too rigidly protocol adherent or dismissively sceptical in response to the autistic person's unique way of being in the world. In a companion paper entitled 'The Neurological Outsider', we explored linking quite unconnected theories of autism via our concept of relational intelligence (Lloyd & Potter 2009). Our interest in this paper is to use relational intelligence to consider how helpers can step back and see more versatile ways of responding to autism especially when the helping relationship gets stuck.

We move the focus of understanding to the helping relationship and away from the mind of the autistic person. This framework encourages helpers to think relationally about the way to discuss, describe, manage and help. In particular, we think it allows the practitioner, regardless of profession or role, to be more versatile in how they handle difficulties. In using relational intelligence, it introduces a clinical approach using the ideas and methods of Cognitive Analytic Therapy (CAT) and other relational therapies.

This paper is aimed mainly at practitioners working in the field of learning disabilities, mental health and education. It is equally part of a wish to be in dialogue with individuals and families experiencing the distinctive world of autism.

Therapists, heroic therapy and learning disabilities

Why do some people choose to become helpers? Common themes are about liking working with people, wanting to make the world a better place, relieve suffering, and understand self and others. A common denominator is a wish to be in a relationship - though we shouldn't rule out the possibility that the attraction of the therapist role is in keeping people at a distance.

Some therapists specifically like trying to build relationships with people who have learning disabilities. There are many attractions, such as having more straightforward relationships as often with such a client group what you see is what you get; feeling accepted and not judged badly, including working with people who functionless well than ourselves, helping us feel better about ourselves. When wanting to help people whose lives are so impoverished almost anything a helper offers could improve things, even if only in the present as these moments are likely to be soon forgotten. Working with people with learning disabilities expresses sympathy with people who have a raw deal because their cognitive and social capacity to cope with the complexities of life is limited. However, for sociable and relationally minded helpers and therapists, this wish can be severely challenged by people with autism. The helper's own fears of being out of contact with the world and not being understood or held in mind might be triggered.

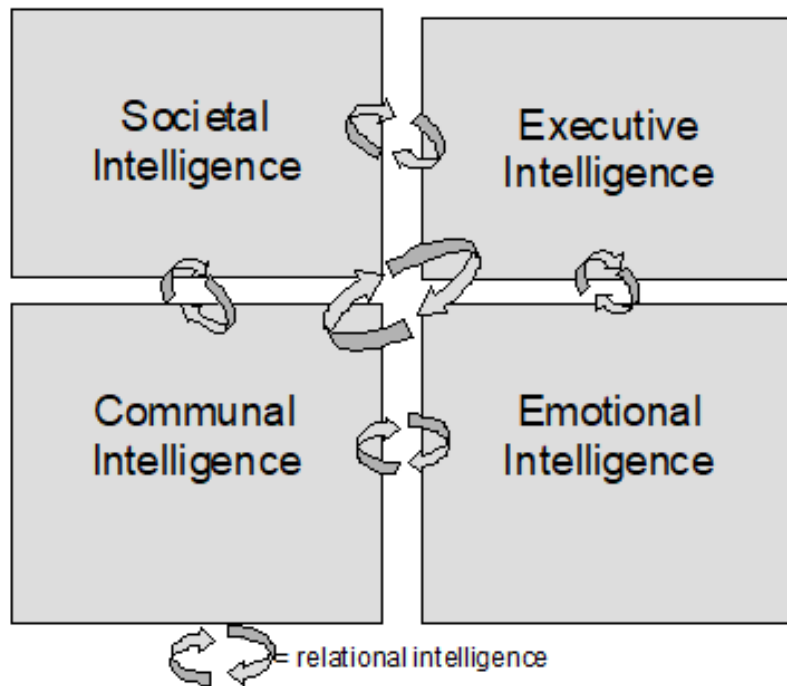
We have a natural investment in mutual exchanges and moments of shared understanding (Stern, 1998), which we take for granted, but in autism, a lack of a clear theoretical and clinical understanding often leads to mutual bewilderment. In under-resourced and 'Cinderella' services, thinking time is less available. Autistic

clients may be experienced as hard to help and tend to evoke heroic attempts at 'intelligent' relating from helpers, carers and therapists wishing to fill the relational gap against all odds. Such heroic work may be a way of coping with the other possibility of feeling overwhelmed by, being dismissive, rejecting and abandoning towards the client. If we are not being heroic, we can struggle on in stoic ways denying our own feelings and distancing ourselves from the person with whom we are working and end up feeling numb to ward off our own hurt.

Relational intelligence

The diagram below builds on the description elaborated in our companion paper 'The Neurological Outsider' of four sources of intelligence, which we posit are needed to relate adequately to ourselves and between ourselves and other people intelligently. The quality of ordinary everyday relational intelligence is characterised by a versatility and richness of overlapping ways of relating and moving towards, or away, with or against, hotting up or cooling down interactions.

Figure 1. Relational intelligence is the orchestration and integration of multiple intelligences through interaction with self and others



Everyday intelligence is relational and combines in our view four sources of intelligence: the society, the communal group of our origins and home, our executive

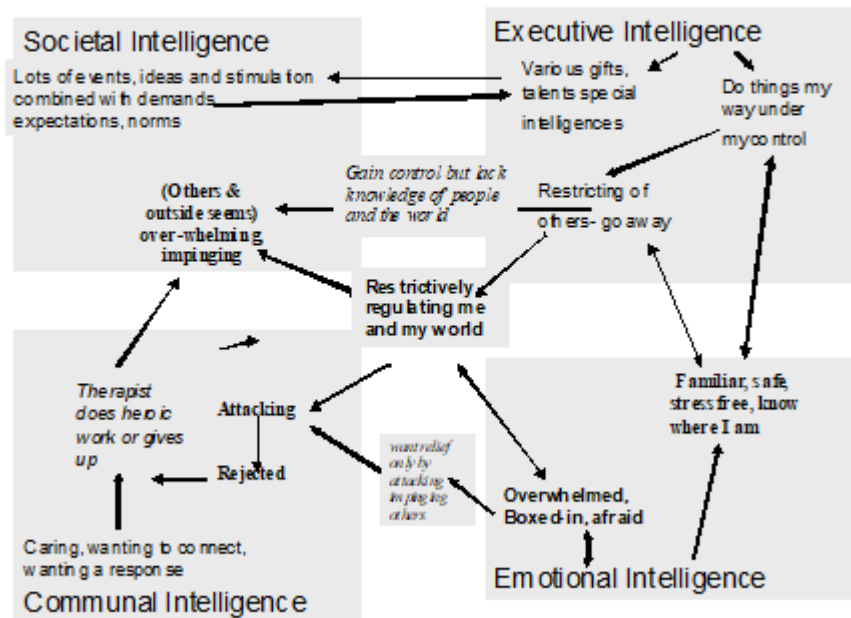
activities and our emotional understanding and skills. We have contrasted these as four interacting sources of intelligence contributing to any particular activity. We describe intelligence by its use rather than as an individual attribute. We also think some of what contributes to intelligent activity is explicit and deliberative and some of it is implicit and out of consciousness. A key feature of these interacting sources of intelligences is their multiplicity and their function in throwing out many hooks for connecting with others. This is, in our view, an indication of the central importance of relating and connecting continuously moment by moment in adaptive ways in order to survive.

We see these intelligences as operating a bit like a network between us and within us combining feeling, thinking and interpersonal negotiating skills. These multiple intelligences are motivated by our basic need to share experience and meaning. Group functioning is central to individual survival. The use of multiple intelligences whilst embracing another, shopping, on the street, is a joint activity between community, group and society on the one hand and the individual and his or her feelings and thoughts on the other. People with Autism make powerful statements about themselves, which reach us, and we respond. They narrow this multiplicity down to often a single dimension of relating. The response from the person with normal relational antennae looking for lots of hooks to connect, is often to feel bewildered and then to cope in similarly restrictive ways.

There is a dreaded state for the autistic person of being overwhelmed and afraid. Others, and the outside world are seen as overwhelming and impinging. The person's autistic way of gaining relief from this is to seek control in familiar if narrow ways. In stark contrast to the dreaded state, there is a desired state of executive intelligence operating to control emotional experience and secure interaction with society with familiar, but highly controlled, bits of societal knowledge or intelligence. This state sometimes involves unwittingly pushing others away by restricting them

and attacking them. Helpers or therapists are likely to be routinely exposed to feeling dismissed and hurt because of this. Figure 2 describes these issues.

Map of some of the limiting interactions between helper and autistic person using the idea of four sources of relational intelligence



Using Cognitive Analytic Therapy

In working with autistic people, Cognitive Analytic Therapy (CAT) has attracted growing interest among clinical psychologists and nursing staff. CAT was developed in the past three decades by Ryle in the NHS in the UK in the context of hard to help patients whose complex clinical needs were not being met by traditional methods. In response to autism, CAT offers a framework for working directly to highlight ways of preventing and avoiding unhelpfulness, collusion or retaliation. CAT has a way of describing unhelpful patterns of interaction by use of the idea of reciprocal role procedures. From a CAT perspective, a lot of our interactions with ourselves and the world of people and things is coloured by trying to get out of dreaded positions or states of mind and get to more desirable or manageable ones. Reciprocal roles such as being caring in relation to feeling cared for or being neglecting and hurting in relation to feeling neglected and hurt, are learnt and replayed repeatedly in one guise

or another from early on in life. These reciprocal roles may be experienced in quite restrictive ways and elicit a powerfully fixed mood or state of mind. These then become familiar places or positions from which we experience and handle ourselves and ultimately how we come to know ourselves. Reciprocal roles can be used to describe different interactions between the various sources of relational intelligence.

Seeing just how hard working with people with autism can be, it is inevitable that many helpers can end up by either heroically seeking to make a familiar relationship but impinging on the autistic person or risk themselves becoming restricting, dismissive and attacking. By restricting others so as to gain control for self, the autistic person does miss out on a spontaneous important aspect of social and emotional knowledge and some sense of this absence may keep perpetuating the heroic efforts of carers and helpers to connect in the way humans usually do. A vicious circle can be set up in which interactions are impoverished as others abandon trying to get into dialogue, because dialogue takes two playing whole heartedly and mutually together. In most neuro-typical interchange between carers and infants there is a surprisingly rich multi-modal interaction, which is distressingly absent in the case of autism. The helper may then stoically struggle on, seeking a relationship but within these limiting and painful options. Such parents often learn how they must temper their expression, controlling and hiding it as they see how easily overwhelmed the autistic child can become. It is as if the child with autism has not been able to learn how to manage their parents' feelings.

As workers, because we are usually unable to tune in alongside autistic individuals, we tend to fill in the void through our own relationships. Conducting a functional assessment of a man with autism and very severe learning disability, the client approached the psychologist. She said and signalled 'hello' using an exaggerated waving arm movement. To her astonishment he copied the movement and so, for a split moment, delighted at having 'broken through'; she joyfully repeated her arm movement. At the point when her arm was furthest away from her trunk, he grabbed

and pulled off a button on her cardigan and put it in his mouth! The psychologist had wanted him to copy her movement, attributing relational intentions to him, whilst he saw his chance to grab the button he wanted. The psychologist was taking for granted this relationally rich mix of interactive awareness that wasn't being reciprocated.

Autism services offer the challenge to become familiar with indirect working to map meanings with the team of helpers. Staff referred to the psychologist, a severely learning-disabled woman with autism who kept screaming, behaviour which had a ripple effect by distressing other clients who were also being neglected as staff had to focus their attention on the screaming woman, trying to quieten her. Staff were able to reduce her screaming by offering her a more fulfilling sensory environment, but the authors of this paper wondered if staff had then slipped into ritualised care routines doing caring things to her, in a way that did not offer an opportunity for closer and more mutual interaction that might need more subtle step by step negotiations to build up. Several hour-long workshops for the staff team explored ideas about how to widen a dialogic zone with her and during these workshops ideas developed about joint activities including painting each other's nails, turn taking games with a parachute, and squiggle drawing (Winnicott 1968 in Abram 2007) helping to build a more intimate and mutual relationship.

For example, Pat, who has no speech and spends all her time standing rooted to one spot at a distance from the group, does respond to a brief game of 'Round and Round the Garden' on her hand (with no tickling) and to her psychologist's surprise makes eye contact and then copies the game on the psychologist's hand, (surprise because people with autism do not usually copy and also avoid eye contact). However, the door is slammed shut when after a tantalising glimpse at a meeting of minds and bodies, Pat physically pushes her away to get rid of her. The beginnings of dialogue were overwhelming, and she could only stand a little contact. The

psychologist refrained from chasing after Pat who can tolerate a silent passive proximity, sitting side by side whilst the psychologist attends to others.

The therapist may long to inculcate in the person with autism a sense of curiosity and a wish to be relational. This can lead to a sustaining fantasy for the therapist that at times they have broken through to the client with severe autism and for a tantalising moment there was true dialogue. Maybe the belief is that to be significant, dialogue has to be sustained. In the case of the woman who used to scream, she quieted down when she and the psychologist painted each other's nails, and they both enjoyed this experience of doing *with* rather than doing *to*. Although the psychologist's reward was thinking to herself, "We are doing dialogue", we cannot say that the client felt the same, although she might have. A CAT relational perspective might point to how the fantasy of a relationship for the psychologist then promotes providing good experiences for the person with autism. One view might regard this as a problem, especially if our fantasised relationship is damaging, but it can also be an asset. The perception of a momentary relationship may only be in the eye of the therapist, as the person with autism may hold to an instrumental rather than relational purpose, but where both are happy such, an illusion harmlessly meets the needs of the relational therapist.

We know the world can be a wonderful place with interesting people; the distress for the therapist is seeing the client with autism not knowing this, and not wanting to find it out either, as they do not want to relate to people or novel stimuli. At the level of direct intervention, if the person with autism is safely engaged in one of their rituals, the therapist is able to make a choice about whether to leave them alone, or join in and by taking part in their rituals trying to make it a relational moment

People with autism may be portrayed as hiding their real self, a self that is lost, estranged or feral with the hope that the passionately heroic therapist will break through, releasing the human being from their prison. The therapist may respond by searching heroically to lift the level of dialogue hunting for delight and interpersonal

curiosity, hoping to make an impact through a live relationship, only to be pushed out repeatedly.

There are a number of tools aimed at teaching a person who does not wish to communicate that dialogue results in rewards, emphasising Functional Communication. For example, the Picture Exchange Communication System (PECS) is a highly structured attempt to foster dialogue, using rewards to reinforce desired behaviours, errorless learning, and formal techniques for extinguishing errors. Augmented Interaction, taking as its model infant – parent proto ‘conversations’, encourages the worker to join in the client’s stereotypies, bit by bit developing these routines playfully into more of a turn taking interaction.

As it is the behavioural learning that matters in autism, our theory of change is associational. Applied Behavioural Analysis and specific applications such as PECS are criticised as reducing people with autism to the status of Pavlovian dogs yet remain the most effective approach in terms of teaching basic communication skills. But these behavioural techniques can work better when staff and parents can hold in mind the relational issues of working with people with autism, otherwise interventions can be dehumanised and lose a sense of authentic reality.

The ‘autistic’ therapist

The therapist, who has chosen this line of work, may identify with some of their client’s autism, recognising their own wish at times to be left to get on with life, or to escape from being overwhelmed, hiding in detail and not having to try to see the bigger picture. Many therapists working with people with autism try to learn how to reduce the amount their own autism impacts on them, as is evidenced by the typical banter in Community Learning Disability Teams in which colleagues describe certain other colleagues or their specific behaviours as “autistic”, and perhaps by becoming vigilant at spotting when these tendencies occur in themselves.

Knowing autistic solutions have their place, means using Relational Intelligence to recognise the futility of spending an entire life like that. Relational intelligence is an

interactive experience as the name implies and depends upon shared processes of response and engagement. There are many ways in which society, organisations or interpersonal relationships can produce the equivalent of limiting interactions characteristic of autism. These can arise through trauma and violence, and it goes without saying that people with autism can also have their relational intelligence limited by neglectful and careless experience.

The heroic therapist

In autism, the push to be heroic comes from three sources: professional theory and aspirations, the client, and ourselves. But this push rebounds in unwanted ways, as the therapist is touched. Psychological researchers view understanding autism as a chance to learn about why nurture and connection matters in human development and what happens when it goes wrong. This huge responsibility placed on professional shoulders means that successes in therapy are also desperately sought to validate the accuracy of psychological explanation. However, in autism, the therapist's dream to transcend such severe relational limitations is brought back to earth with a bump by interactions that preserve these limitations.

The therapist longingly and the client unwittingly create a relational environment which is dissociated. The need to treat the split team becomes pressing. The heroic therapist 'can see what is needed'. They are going to improve the system, run psycho-educational workshops for the staff who just need a bit of guidance and meanwhile be the client's, caring, insightful, reliable, advocate and helper. Surprise and disappoint results when clients reject such overtures and therapists become unpopular with staff who discard the therapist's sensible advice. Similarly, referrals can be made from one agency to another or from families to agencies in which a catalogue of repeated failures are described and the demand is that 'they' get their act together and fix it. Receipt of such referrals can induce righteous indignation, guilt, determination to be the one to fix it, resentful concern, or compassionate but stoic resignation.

When things fail to improve, therapists may feel their own inadequacy, blameworthiness and sense of being overwhelmed. Seeing client's predicament from a position of a defeated therapeutic hero, therapists may enact the abandoning other pole of the borderline procedure and try to keep their heads down. Statements about autism having a terrible behavioural phenotype for which little can be done, leads to hopes the individual will be taken away to somewhere that is better resourced. A few referrals are made together with sympathy, helplessly disparaging 'care in the community' and 'inadequate resources' as bruised support workers are left to cope. A common response to such unresponsiveness in the client can be cast as a dilemma of either heroically striving to give care, in a way idealised by the therapist, which leads to disappointment, or cold indifference so as not to be disappointed.

It is also easy to fall into a heroic therapist position by default. Trying to not play hero or vanquished, a therapist may seek to work as effectively and efficiently as possible by judicious selection of achievable goals, in a timed intervention, presented in carefully graded steps towards an integrated service. However, just as they begin to be effective, others bow out knowing the client is safe in their expert hands, expecting them to be able to manage each crisis so they steadily become isolated, ground down and resentful. People with autism may find themselves in a 'borderline' world as carers alternate between striving to give ideal care and then being abandoning or indifferent.

The Stoic Therapist

When working with people with autism, so often nothing seems to change, and daily care becomes tedious, so bored workers or therapists can elaborate and 'beef up' their perception of what is happening in ways that might render the work more 'heroic'. A psychologist was asked to conduct a functional assessment on a non-verbal woman with severe learning disabilities who constantly and insistently sat on

top of other people if they were sitting or lying down. Staff gave an elaborate account of the motives behind whom the client selected to sit on, but 16 hours of minute-by-minute detailed observation showed the woman's choice was entirely based on availability and no other distinguishing characteristic. Perhaps their elaboration had been an attempt to enrich the barren and empty reality of the relational experience.

Whereas when working with people with a personality disorder there is a notion of multiple transferences and highly charged enactments of the need to relate, in working with autism there is only the real relationship, i.e., what the person with autism wants, (Clarkson 1995). People like knowing where they truly are with others and hence may be particularly attracted by these relationships in which what you see, at face value, is how it is. There is no layering or illusions built out of projection or rehearsal of desires. There is physical violence, and challenging behaviour, including behaviours that the therapist may find revolting, such as being alongside clients who spit or injure themselves. The therapist may feel helpless or furious when their attempts to soothe a self-injuring client does nothing. Walking onto an autism unit, the helper or therapist may have that sinking feeling of being useless. Pushing out such disturbing feelings, staff soldier on, throwing energy into areas in which help them to be comfortable with being paid, such as focusing on the client's physical condition.

Workers may dismiss the idea of breaking through to the client, as the person with autism remains relentlessly the same. On the one hand non-reciprocation hurts and frustrates, but on the other hand, accepting the narcissistic wound of non-reciprocation in autism as replicating how life is, autism feels true, honest and reality based. The helper's own characteristic transferences are highly exposed, as the person with autism does not dance to the helper's tunes. We are confronted with a dilemma; either being hurt because invisible or being real because life (i.e., early

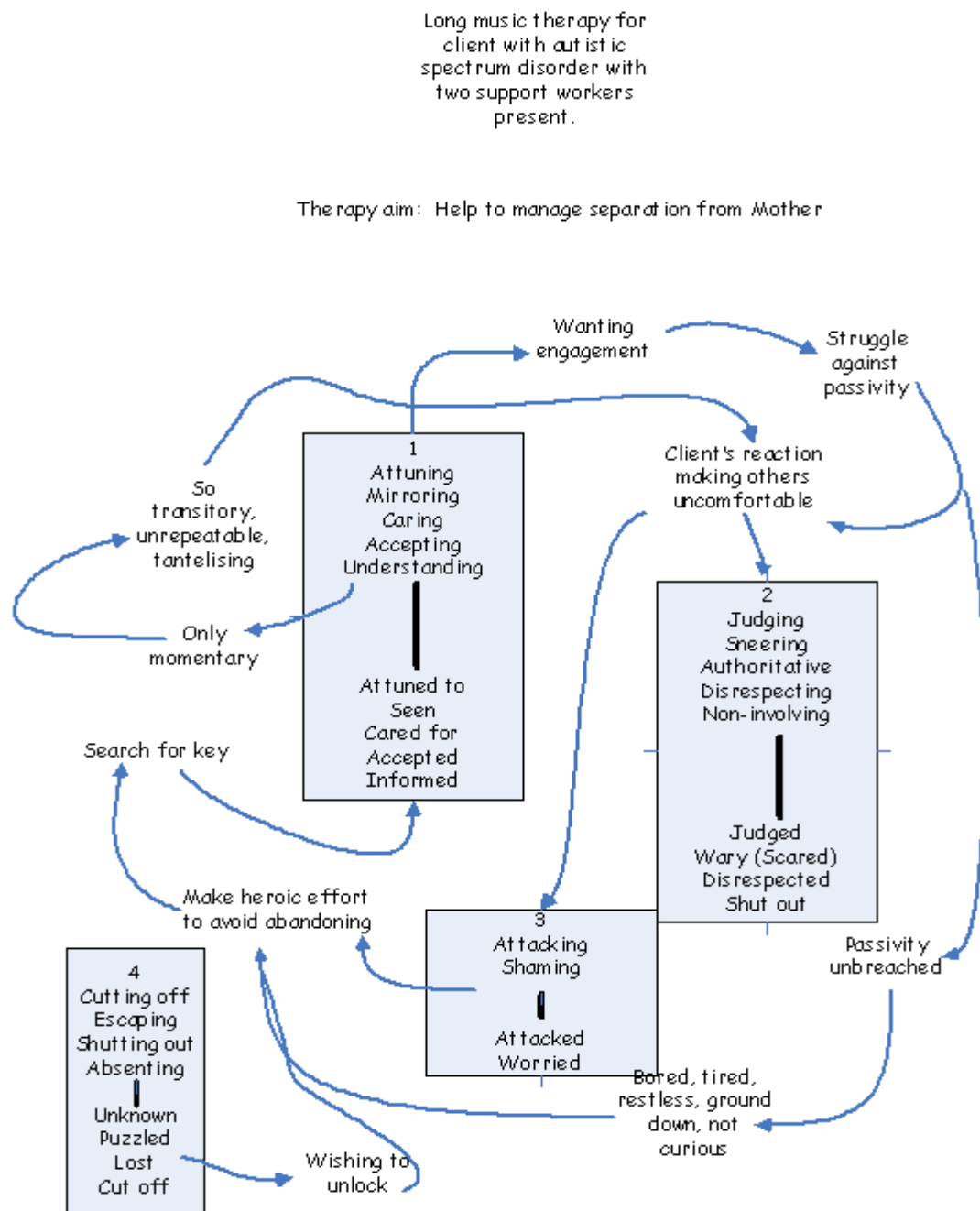
infant wounding) is like that. In autism the worker may at best enjoy and at worst accept resignedly that autistic experiences confirm what their own early life had taught them.

Clinical example of heroic stoicism

A music therapist received a referral for a young woman with severe autism who had recently moved from living with her mother into supported living. The aim was to give her an opportunity to process this change. Owing to her challenging behaviour, the therapist saw her always accompanied by two carers. When the therapist considered having two carers present was unnecessary and suggested that one carer could remain outside the music therapy room, the carer refused, saying she would get bored. During sessions, the carers would text other people and express their disdain and contempt for the therapist's work by raising their eyebrows and pulling faces at each other. The client remained difficult to engage and did not show spontaneous or non-ritualised behaviour. The therapist wanted times when she and the client could experience being together. Her aim was: searching to find the person and to be 'person to person' (Clarkson, op cit), but she felt the support workers prevented her, sabotaging her attempts to build a therapeutic relationship. She had created the space in her mind to relate, but this could only happen if either the support workers would join as allies or leave. They seemed accomplices to the client's inability to be in dialogue. The therapist was trying to be authentic, and the support workers were trying to maintain expressing their own view of the therapy. When she brought the situation to a case discussion group, she realised that she was actually seeking permission to discharge, and she felt concerned about why she had stuck with it for so long with minimal progress. She had not addressed how the client's presentation had caused splits in the staff team.

Methods of describing reciprocal patterns in the plain language of the staff team have proved useful for jointly mapping and tracking problematic ways of relating to self and others. The activity of making a map is in-itself a powerfully therapeutic experience,

as the staff team and therapist discover together how the various problems, symptoms and experiences they encounter interact in self-limiting or self-perpetuating way. A diagram, which might help map the interactions described by the music therapist was developed with her and described below and detailed in figure 3. The map offers a likely guide to the interactions and possible difficult moments for the team in working with the person with autism, and the development of more relationally intelligent self-reflection and self-management.



In the first reciprocal role (RR); 1 in the diagram, the music therapist described how music therapy operates at a relational level through attunement and mirroring, so she sought to engage with her but was almost always confronted by her client's extreme passivity. The client was far better at remaining passive than was possible for anyone with her. She would try to engage her, but often aware of the attitudes of the support workers, she remained unassertive, as she described in the second RR. This made her feel very judged, but she also wondered if the support workers felt uncomfortable with how a therapeutic relationship is different from a supportive relationship. She described how the support workers wanted to sing jolly songs with the client, without understanding the aim of expressing difficult feelings in therapy. She said how the atmosphere in the sessions felt uncomfortable and she felt that her efforts were being attacked (RR3). She also recognised that she felt cross with the support workers, but she felt unable to tackle this (RR4). Her way of coping as we recognised in the consultation and supervision session was to feel she had to redouble her efforts. Mostly her client remained cut off, as were the support workers and she did not know what to do (RR4). However, there were a few isolated moments when she felt there was a brief rapport between herself and the client via their music (feeding the desire to redouble her efforts), but she could never recapture those moments. She said how she sensed that the support workers felt uncomfortable when these moments of rapport occurred, as they were so unexpected, which would lead them to RR2.

After jointly constructing this diagram with one of the authors (Lloyd), the music therapist recognised that nothing was being achieved and she felt the client seemed to dislike music therapy. She gave the client 10 session's notice. However, perhaps replicating the original reason for the referral, the support workers sabotaged the client's opportunity to process this ending and separation by finding they were just unable, for one stated reason after another, to bring her to any of these final sessions. In thinking from the point of view of needing to develop a more intelligent

way of relating and using CAT methods in consultation, this example seemed to fit a familiar pattern of a therapist's heartfelt and heroic, but thwarted, search for meaningful connection and reciprocation. The wider relationship with the support workers' manager had needed addressing.

Describing typical interactions when working in autism services

Traditional understandings of autism fail to take full account of this complexity and how easy it is for any of us, despite our best intentions to be drawn into heroic work with limited results. By searching for a breakthrough, the heroic therapist is faced with the gulf between her longing for a more mutually creative and expansive interaction and the timeless quality of stereotyped repetition. Autistically restricting behaviour (arising as we suggest out of an executive intelligence which is cut off from the other intelligences) depends on the therapist being untouched and unmoved and does not acknowledge (indeed an impaired Theory of Mind concludes, 'cannot acknowledge') that the therapist has their own unique, individual and unpredicted reactions which are different from how the client perceives them to be. The client with autism insists the only effect they have on the therapist is the only reaction that could exist and becomes demandingly outraged at variation, pushing away the existence of other options. Such restrictiveness by the client can reduce the therapist's sense of their own agency, leaving the therapist feeling anxiously stuck as their own ability to make a difference ebbs away. The autistic client or child tends to push the therapist or parent, into behaving out of character or more extremely than they would normally, testing patience, and troubling the mind as instead of being submissive or rebellious, they do not offer any reciprocation. Heroic therapists lose their capacity to be versatile. Presumably changes of treatment or care plan need to be very carefully negotiated in the case of autism.

Supporting the autistic person's social context using CAT

If capacity to relate is absent in the autistic person's interaction with the world, then we, the authors, suggest the intervention of the therapist has to be to the system of

care and support, with a view to reducing the risk of unhelpful helpfulness of trying to make the autistic person do relational dances of which they are not capable. The relational thinking available to individuals and teams working with autistic people helps in the following ways. It allows the workers space to think about the patterns they may be falling into. It can help formulate a plan of support, which is more relationally intelligent. It can soften and help adjust those tendencies to want to recast the autistic person's particular patterns into ones more characteristic of empathic relating.

Thinking in terms of a limiting or narrow pattern of relational intelligence helps thinking about our dependency on its abundant, routine availability in daily interactions and the difficulty of helping someone without such a basic, shared human resource. It is an unfortunate temptation to blame and pathologise the client. We have explored how heroic work locates the gap in intelligence or its wilful absence, in the person, and we suggest it is better understood as an absence that needs working on in the specific and changing context of the person's daily life. In the life of the autistic person, it is a systemic gap rather than an interpersonal or developmental one. The 'client' of therapy in work with an autistic person should be seen as that person's social system. We have argued that a borderline system analogous to a borderline personality is easily produced in the relational world of the autistic person. Accordingly, the focus of therapy is the integration of the system of support for the autistic person rather than upon the integration of their personality or temperament.

A care team consulted a psychologist following an outburst of challenging behaviour from a woman with severe autism who screamed at a bus driver and passengers because the bus was unexpectedly late (impinging, overwhelming). The client was initially given a brief break from going on buses, (perhaps a communally and emotionally intelligent response; familiar and safe but limited) whilst a letter

explaining autism was sent by the home manager to the bus company (socially intelligent). The home manager also boarded the bus at the time the client normally went on it in order to talk to a passenger who had burst into tears when the client had screamed abuse at her. The client rehearsed a Social Story script with the psychologist about why buses may be late and how to handle this tension and staff now practice this with her whilst waiting together at the bus stop until the bus arrives.

Since the autistic person cannot mediate or construct their states of mind in relationally intelligent ways, staff must hold such work. To the extent that the relational gap is genetically structured, it cannot be filled by the heroic longing of the therapist. Understanding our impulsive, heroic or rejecting reactions and determining how far, how fast and by what means dialogue maybe established is the key professional skill. An indirect intervention is needed where the therapist, as consultant, creates a well-attuned compensatory and complementary, relationally intelligent environment. This work needs the therapist to establish an agreement on the possible and necessary limits of the work, agreeing role differentiations. In this way they can hold in dialogue the severely autistic person, themselves and society.

The investment in the special education, welfare and treatment of autism needs to build this in. Similarly, although we are describing here experience of working with people on the autistic continuum, some of these observations may not be restricted to that and apply more widely. In this respect, autism challenges us to think more about what it means to be human and connected with society in relationally intelligent ways.

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