De-fusing and re-fusing face-to-face encounters involving autistic persons in Hong Kong

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Abstract

Purpose – *This article documents accounts of the tactics parents and siblings of autistic persons in Hong Kong deploy in order to manage social encounters. The article considers the impact of such tactics and their enmeshment with factors that combine to limit satisfactory outcomes and outlines a project intent upon contriving dialogue between persons.*

Design/methodology/approach – *This qualitative project elicited stories and accounts (or narratives) produced by persons involved in encounters involving autistic persons. This project also intervened in these encounters.*

Findings – *Persons involved in social encounters are de-fused, in the sense of being disconnected. The emotions persons experience through these encounters (e.g., and especially anxiety) remain hidden. Dialogue has the capacity to re-fuse, not only reconnecting but also rejecting unsatisfactory arrangements.*

Originality – *The dialogue produced in the article may extend beyond the specific circumstances and persons considered, potentially reducing the barriers and distances between autistic persons and others.*

Keywords – *Hong Kong, autistic persons, face-to-face encounters, performance, stigma, de-fusing/re-fusing, narrative, dialogue*

Introduction

Encounters between persons whom Goffman provocatively describes as ‘normals’ and ‘stigmatized’ constitute ‘one of the primal scenes of sociology’ (1963, p.13). The term ‘primal scene’ was borrowed from Sigmund Freud and refers to formative traumatic encounters like a child witnessing his/her parents having sex. As Titchkosky explains, Goffman repeatedly returns

sociologists to such primal scenes—as Freud returned his patients to their traumatic encounters—'in order to unwrap the mystery of the genesis of social identity and difference' (2009, p.44). Goffman (1963) continues to influence understandings of stigma not only as a consequence of his microscopic accounts of the elements that constitute face-to-face interactions but also by virtue of his careful attempts to map and explore the ways persons try to manage stigma through such tactics as passing, concealment and refusal and his recognition of how stigma extends to persons associated with stigmatized persons through 'courtesy stigma'. More recent accounts have recognised the structural forces that shape stigma in general (e.g., Tyler and Slater, 2018) and notions of disability in particular (e.g., Gleeson, 1999). Other accounts have attended to how disability manifests *through* social encounters while recognising the wider discursive cultures and repertoires that shape and sustain disabling practice (Cockain, 2014, 2018). Scholars have also examined how stigma extends to persons like the parents and associates of autistic persons (e.g., Farrugia, 2009), in both 'western' and 'Asian' cultures (e.g., Yang 2015) while developing rich and nuanced languages with which to conceptualise stigmas.

This article seeks to contribute to such understandings of social encounters, especially those involving autistic persons, particularly by supporting persons to critically reflect upon, and then narrate, social encounters in which they had been involved. The focus is not upon autistic persons themselves but, instead, their parents, siblings and those seemingly 'normal' persons (e.g., onlookers, passersby, etc.) they 'meet' in public places. In this article, such encounters are conceptualised as performances, a term which may broadly refer to activities, events and interactions which are replete with, and shaped by, cultural codes. I will argue that the tactics persons use to manage interactions (with varying degrees of success) are performed and practiced in contexts in which persons are 'de-fused', in the sense of being set apart and cut adrift; considerations that compel attempts to 're-fuse'. Such interactions illustrate failed performances, namely 'those in which the actor, whether individual or collective, has been unable to sew back

together the elements of performance to make them seem connected seamlessly' (Alexander, 2004, p. 529).

This article not only describes such failure but also, and especially, seeks to intervene in de-fused relations and failed communications by contriving dialogue between persons. Attending to the narratives persons produce may be destabilising. However, the dialogue these combine to produce has the potential to re-fuse—in the sense of repair and rejection—relations that may otherwise remain de-fused. Dialogue may not only re-fuse the particular persons involved in this article but also may provide texts and maps that other persons can use to navigate encounters of their own. The narratives and dialogues presented and contrived in this article may both highlight and intervene in circumstances resembling those Milton (2012) has called 'the double empathy problem', namely the struggle to empathise that persons with different experiences of the world have when they interact. These 'lacks' in insight are not the property of particular autistic or non-autistic actors but, instead, extend to *all* persons. It is, accordingly, vital to pay attention to 'what lies between ... encounters with others', highlighting, as Titchkosky (2012, p.89) goes on to explain, 'the actual work we are involved in, work that makes up the meaning of people'. Stigma may then be seen to arise in specific circumstances where individuals and social structures meet.

Methodology matters

The 'data' to which this article refers was produced as part of a larger project. This sought to elicit the experiences and responses of disabled persons and their families to social exclusion in Hong Kong. In 2019 three phases of semi-structured interviews were conducted with five groups. Each group contained between three and five persons. Some of these groups contained persons with a variety of different impairments. However, this article refers only to persons who were either a sibling or parent to autistic persons. Although autistic persons participated in two of the groups, their voices are absent in this article. This is partly a consequence of my reliance upon interviews

to collect data. This restricted access to persons who could not communicate through orthodox language may inadvertently contribute to the silencing of autistic persons (Milton 2012). However, I intend to include their contribution using visual methods in future work.

Interviews frequently focused upon disabling dimensions of the social encounter. Goodley's (2014) efforts to elicit stories about non-disabled people's reactions to disability, most of which were from disabled persons and non-disabled allies, suggested ways to intervene in such disabling communications. As well as eliciting the accounts of siblings and parents to autistic persons I also sought written accounts from non-disabled students. Later, students were invited to recruit further participants from within their personal networks. These persons then produced narratives of their own, albeit only after being made clear of the scope and intentions of the project. Then, I circulated narratives so persons could read and respond to each other's accounts in ways that contrived the conversation, or dialogue, to which this article refers.

Approval of the project was gained from the Human Subjects Ethics Sub-Committee of my university department. At both the start of each interview and while inviting participants to produce written accounts, I gave a short, relatively accessible description of the scope and intentions of the project i.e., to disseminate disabling stories to a wide audience and to facilitate critical reflection upon and perhaps contesting of the stories. All persons to which this article refers gave their written consent to involvement and were eager to participate. All participants are referred to pseudonymously.

All interviews were transcribed and analysed in conjunction with the written 'data'. Particular attention is paid to how participants portray, construct and impose order upon their experiences of the social encounter in ways that are typical of narrative analysis, or inquiry (e.g., Riessman, 2002). Because narrative analysis explores such subjective construction, texts are examined as

wholes that preserve the ‘flow’ of stories rather than being ‘broken’ into discrete parts or codes (Riessman, 2002).

De-fusing tensions and other outcomes: everyday tactics and their limits

During group interviews, participants produced many accounts of disabling face-to-face interactions. These occurred in a variety of settings like local trains, restaurants and the apparently communal areas in the housing estate in which some participants lived. Participants deployed a range of tactics to defuse these experiences. For example, they routinely either avoided or, more commonly, rationed their presence in these settings. They also produced zones in spaces like restaurants, for example, booking and occupying private rooms, so they could avoid the potentially stigmatising gazes of customers and staff. Meanwhile, participants practised forms of emotion work. These included efforts to actively alter (i.e., manage) the nature and intensity of the feelings they and their presence seemed to produce in not only themselves but also those whom they encountered. For example, they deployed humour and other forms of discourse to ‘signpost’ they were with an autistic person and regularly apologised when things went awry. Such practice is intent upon defusing antagonisms, both actual and anticipated, by making situations less tense or dangerous. Ho-Man’s tactics sometimes seemed capable of transforming encounters:

> ‘After I apologise and tell people my son “has issues”, people will understand. They’ll say it is fine. Some even become helpful. I’ve learned to become more skillful’.

Ho-Man also distinguished her own ‘indirect’ practice from that of a friend with an autistic child who apparently ‘challenged head on’ other persons’ ‘offensive looks’. Ho-Man said she had learned to understand persons’ ‘confusion’ and to see her own role as that of an educator who ‘taught’, often through humour:

> ‘Once I was filling up my car with petrol. We heard a “woof-woof” noise. I was amused as I knew it was my son. The staff there looked confused. “Is that a dog?” the man asked. “No, it’s my son”, I said to which the man replied “how interesting” and a conversation ensued in which the man disclosed he had an autistic relative’.

Such emotional control was not only capable of producing effects ‘outside’ but also shaping outcomes ‘inside’ participants themselves:

> ‘My friend who has an autistic son is always unhappy’, explained Yuk-Wah. ‘She always confronts people. Her husband had a stroke too. I just laugh things off. You know people are just curious.’

Managing such social encounters was stressful for participants. They were, effectively, trying to manage a melee of emotions: their own, those of their autistic child or sibling and those of persons like onlookers. Man-Yee, mother to an autistic son, summed this up, saying she felt like she was ‘walking on a tightrope’; a figure of speech which seems to illustrate not only the precariousness and perhaps even jeopardy of the social encounter but also her feelings of being on display.

However, neither apologies nor humour inevitably produced satisfactory outcomes as Chih-Yun explained with regard to events in which her 30-year-old autistic son had been implicated. Her son would often ‘jump up and down and swing his hands’, actions that seemed to make residents in the housing estate in which they lived ‘step out of the way’ if they saw him approaching. On one occasion, Chih-Yun explained how he touched the back of an elderly lady, after which Chih-Yun immediately apologised and disclosed her son had learning difficulties:

> '"So what", the lady replied before shouting at us for a long time. "You should not take this kind of person out. He's aggressive. You should keep him at home"'.

Despite seeming disturbed by her recollection of such events, Chih-Yun, nevertheless, saw matters from the perspective of others, in ways that may further indicate the complexity of the emotion work that she was practising. 'Wouldn't *you* walk away if you witnessed violence?' she asked, seemingly rhetorically, when explaining instances in which her son required restraint in public places. 'Discrimination happens a lot', she said, 'but I can't blame them if they're scared'.

This example illustrates how efforts to actively manage encounters can have unpredictable results. Put differently, social encounters develop in ways that go beyond the intentions of their participants (or authors) as Derrida registers (e.g., 1981). As Titchkosky (2012, p.92) explains, the 'meaning of bodies, minds and senses are formed from our relations—from the in-betweens of histories, politics, and cultures through and against which we perceive each other'. Additionally, contributing to such a complex enmeshment of factors are the ways in which individual characteristics, like those sometimes associated with autism (e.g., biting, shouting, etc.) enter into the world. They erupt into such mundane spaces as train compartments and cafes in ways that invite the gazes of onlookers (Murray, 2008) and, because autism is an 'invisible disability' (Brewin *et al.,* 2008) there is no mark to forewarn (e.g., a scar, a wheelchair, etc.).

However, it is not merely impairment effects (e.g., Thomas, 2007) that produce 'failed performances' (Alexander, 2004). Instead, these result from contemporary constructions of autistic persons as, for example, 'emotionally cut-off', or 'Rain Man like savants' (Humphrey and Lewis 2008, p.32). Such inaccurate or hyperreal representations circulate and accumulate meanings between persons, even entering into the ostensibly mundane places to which this article refers. Consequently, the aforementioned tactics may only defuse, in the sense of

preventing something from exploding, while failing to refuse (in the sense of both repairing connections and resisting unsatisfactory circumstances) defused relations.

Narrative work and contriving dialogue

Participants seemed frustrated by the kinds of situations described above. In fact, in several cases, this is what initially compelled them to take part in group interviews. Participants felt, in short, that they were not understood by members of the general public and they were anxious to find ways to get their message out and their voices heard. In one meeting, participants brainstormed ideas about what they would like persons to do and not do when encountering them in public places. My intention was to construct a co-narrated guide, or manifesto, for successful place-based encounters involving autistic persons modelled upon those published elsewhere, albeit populated by their particular suggestions about what to do and not to do.

However, during and between group interviews in various WhatsApp group discussions, participants became storytellers of their own inclusionary and exclusionary experiences and listeners to those accounts produced by others. I am cautious not to exaggerate the efficacy of such practice. However, such telling and listening seemed to offer participants not only a means to vent but also derive feelings like reinforcement and camaraderie by virtue of the shared qualities of the experiences they recounted and were told about.

Nevertheless, because persons taking part in these group interviews resembled those Goffman (1963, p.28), calls ‘the wise’, namely persons who are familiar and sympathetic with issues affecting stigmatised persons, such dialogue was perceived of limited usefulness. Put simply, participants wanted me to act as a conduit for their experiences and to extend them to a wider audience.

Accordingly, I sought ways to enable other persons to hear the narratives participants produced while also eliciting further narratives from persons with no direct or immediate experiences of learning disabilities. The aim was to contrive a dialogue between the two groups that might positively impact upon all participants. Consider, for example, the following fragments of this manufactured dialogue.

Sau-Lan, a middle-aged woman whose sister has learning disabilities, produced commentary documenting strains and tensions:

> 'Before I was so scared when people looked at me. 20 or 30 years ago, I wished I could just get off the bus. I just did not want to be seen. However, later I said to myself if I do not take persons with intellectual disability out, they will never be seen. People do not understand our situation; how difficult it is to care for someone, and we have to handle that. Sometimes people are unsympathetic, they say "what a bad kid", and so on. They say "I am so sorry for you" but really they mean, "Don't bother me" ... You know, my sister … she has many temper tantrums, and hits her head. It is usual. However, I said to myself, I have to let her be seen. I have to have courage to take her on public transport so people understand. Nowadays, when I am on a bus, or on the train, people will say, "oh please, sit down." I have to let them know she is one of us too. She has every right to live in our community, to share with us. Of course, I am grateful to people who offer their seats and even smile. It does not matter; just a little gesture may help to encourage me to do better ... We have to step outside, to let ourselves to be seen, to be heard. So people will understand.'

Meanwhile, I asked students to document their own feelings when witnessing persons displaying symptoms suggestive of autistic spectrum conditions and to recruit participants from within their

personal networks, asking them to record their own narratives about similar social encounters. Participants expressed emotions like fear, anxiety, sympathy, or pity that coincide closely with those claimed by Hughes (2012) to populate the emotional infrastructure of ableism. Despite such complicated emotions, participants often either retreated or said nothing sometimes simultaneously:

> ‘If someone is making a “strange” noise, even if another person is looking after them, to be honest, I will silently move to somewhere far away from them. I am scared about staying close by since I have no idea if the person will do something dangerous that might hurt others’ (Xiaolu, 19 years old, female, from Shanghai).

> ‘I would imagine the different reasons and scenarios that caused their situation. I will then picture what their life is like ... I sympathise with them, and I will bless them in my heart. I will hope they can adapt ... and hope it [their life] will become better ... I also hope they will continue receiving support from others in the future. However, I usually won't say anything to them since he/she is a stranger to me. I am afraid that they will misunderstand my intention of talking to them as “mocking”. So all the things are done in my heart, there is no real action involved’ (Chun-Kit, 19 years old, male, from Hong Kong).

> ‘If I see a person making “strange” noises, I will find them weird and will try to get away as soon as possible’ (Lai-Ka, 18 years old, female, from Hong Kong).

Later I showed Sau-Lan, as well as other parents and siblings of autistic persons, the narratives produced by Xiaolu, Chun-Kit and Lai-Ka, asking them how they felt when reading these words and what, if anything, they would like to say to them. I also showed Xiaolu, Chun-Kit and Lai-Ka

the narrative Sau-Lan produced, asking them how Sau-Lan's words made them feel and what, if anything, they might like to say to her. Fragments of this discourse appear below.

Destabilising encounters and re-fusing relations

These dialogues are instructive in and of themselves. Prior to dialogue, it may be contended that persons do not even meet each other, given a symbolic interactionist definition of an encounter as a 'joint act between … persons where the interactants are maintaining … contact' (Denzin, 1974, p.270). Rather, both parties seemed to withdraw in ways that accomplish the art of 'mis-meeting' (Bauman, 1993, p.153), a skill which must be 'mastered if one is to live among strangers' (Davidson, 2003, p.116). This sense of being cut adrift also reflects the previously mentioned (mis)representations of autistic persons which, even if distorted, form autism for persons who encounter such depictions.

Following dialogue, through which private and personal becomes public, there seems more chance of a real encounter as persons open up to each other. For example, Xiaolu, responding to Sau-Lan's discourse, said:

> 'After reading her words, I feel I understand her feelings ... In today's society, we do not want to have too much contact with strangers. We don't want them to disturb our lives. This is even more so with persons with intellectual disabilities ... [She] showed us her inner thoughts ... Only when we know the hidden story can we better understand and accept'.

Persons appear to each other through dialogue as multi-layered and multi-faceted: composed of both core and shell (Bakhtin, 1981, p.136). Such depths that surface, even from fragments of discourse, contrast markedly with how persons normally appear to each other in contemporary conditions of possibility. Central to persons' complex, rich and hitherto inner emotional landscapes,

at least as they appear in the aforementioned narratives, is fear and fragility. By addressing such fears and naming them, persons begin to confront them in a manner which may permit more expansive views of both self and other in ways that might, consequently, permit openness and solidarity across differences. Fear is not a guarantee of solidarity, to be sure. However, the troubled positions that Sau-Lan, Xiaolu and Chun-Kit all seem to occupy may not only help to identify common ground but also stimulate questioning of the cultural expectations influencing their various behaviours. Furthermore, as persons glimpse the other, in no matter how rudimentary a way, binaries of oppressor/oppressed, abled/disabled, normal/abnormal begin to dissolve. What emerges, instead, are persons like Xiaolu trying, and often failing, to make sense of the world and the persons therein, without necessarily possessing a map with which to successfully navigate.

Not all dialogue results in as sudden a reversal in perspective as Xiaolu's commentary suggests. Put differently, dialogue does not magic a fusion of horizons between persons. For example, Yuyan, a student, not only seemed to justify persons' detached stances with regard to persons like Sau-Lan and her sister but also doubted her capacity to feel empathy, despite being witness to Sau-Lan's account that she claimed she was inspired by:

> 'It is not that people look down on you, people's life rhythms are fast. They just don't have time to walk into other persons' lives so they can't put themselves in other people's shoes. Just because people show their understanding, does it mean they really understand you,' she asked, before seeming to answer the question she had posed in ways that implicated herself in a spirit of self-confrontation. 'I am a typical person who says "I'm sorry for you" but I am really thinking "don't bother me". I know this is ugly, but it's the real me. I disagree that people will gradually understand. Persons have time to say words of comfort but they do not have sufficient energy to really care.'

Although perhaps less evident, Yuyan was questioning herself and listening to Sau-Lan, albeit without necessarily agreeing with her in ways that create intersecting viewpoints. In any event, as Shields (2007, p.77) explains, not all dialogical interactions result in dramatic turnarounds and in fact this is not even necessarily the goal of living dialogically. Nevertheless, dialogue opens up possibilities for change as persons encounter others who might otherwise be set apart and concealed. Dialogue, put differently, permits persons to see more varied perspectives and, while this may be destabilizing, it provides possibilities for persons to re-fuse. Moreover, by virtue of how dialogue permits persons to grasp 'something of another's life, however precariously or provisionally … something new can come out of the encounter—new understandings, fresh creative efforts, or novel ways of relating to others' (Desjarlais, 2011, p.74).

To be sure, although the dialogue to which this article has referred has re-fusing potential, it is no cure-all remedy, especially because words, and the discourse they combine to produce, acquire meaning within particular structural, systemic and symbolic circumstances. Words cannot singlehandedly create inclusive encounters. Despite such restrictions, words may propel action by virtue of starting conversations among persons who might not otherwise have them. Words, and the thinking they help to promote, might even be regarded as a 'kind of action … [that may lead to questioning] … accepted rules of conduct [and] unexamined prejudgments which prevent thinking by suggesting that we know where we not only don't know but cannot know' (Arendt, 2003, pp.174, 188).

Even those fragments of discourse this article has disclosed may combine with other utterances to intervene in flawed mappings of autism and local productions of disablement. They may also make conscious what is otherwise easy to avoid or ignore. Once expressed, they may encourage other persons to extend and propagate fresh perspectives so the already powerful words of

persons like Sau-Lan may gain more influence. Drawing attention to the actions and inactions of particular persons, and the dialogue they combine to produce, should not conceal the structural and systemic elements which produce and maintain exclusions. However, dialogue discloses how disablement is produced between persons and how blame—for want of a better word—is not the property of discrete, self-contained, actors but is, instead, diffuse; in the spaces between people. Such a statement should not be regarded as a surreptitious apology for ableist and disablist practice. Instead, this acknowledges and attends to how exclusions are not results of irresistible social forces but actualities produced and accomplished between persons in particular circumstances. This is why it is vital to think about what 'lies between our encounters with others' (Titchkosky, 2012, p.89) in ways that bring us back to where we started, hopefully with more resources with which to map and re-imagine our dialogues.

Concluding thoughts

This article has introduced the disabling social encounters which autistic persons in Hong Kong and their families experience and the latter's tactics for coping with such interactions. Such tactics (e.g., humour, apologising, taking the blame for 'disturbances', etc.) may sometimes succeed in de-fusing awkward, and perhaps even dangerous, encounters. However, they neither address the underlying conditions in which such encounters take place, thereby leaving relations fundamentally de-fused, nor question them, in ways that allow unsatisfactory circumstances to remain unchallenged. Nevertheless, participants' individualised tactics produce unintended outcomes. This is not solely a consequence of the larger social, economic and political factors that shape personal encounters. Instead, this is a result of how the meanings of people, the world and stigma in particular are produced between persons in seemingly mundane milieu in ways that not only register but also generate certain conditions of possibility. Crucially, as these meanings are made, or accomplished, between people so they may be re/un/made between persons.

This article has presented narratives, and especially the way they may combine to form dialogues, as a way of intervening in 'failed performances' (Alexander, 2004) and as re-fusing persons and relations that may otherwise remain de-fused. These narratives provide insights into persons' emotions while in situ, especially the anxieties that mark the social encounter. Dialogues, even when contrived, may enable different parties to understand the other more richly and lead to broader, and sometimes changed, perspectives.

Admittedly, the narratives and dialogues to which this article has referred may merely constitute droplets in seas of negative, or inaccurate, representations and exclusionary practice. It is, therefore, vital not only to keep such conversations going but also, and especially, to expand them. Thus although the dialogue in this article is confined to Hong Kong, it is intended this be a template, or model, which may be emulated, extended, reproduced and added to by other persons implicated in similar encounters. With this in mind, I invite readers to contact me and to share narratives that I promise to collate, curate, circulate and use to contrive conversation and dialogue. In this way it may be possible to have a greater influence both on what happens and how it is discussed, thereby contributing to processes of re-fusing, in the double sense of resisting and bringing together.

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