'*And that, Damian, is what I call life-changing*': findings from an action research project involving autistic adults in an on-line sociology study group

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Editorial comment

Damian Milton is currently studying for a doctorate with the Autism Centre for Education and Research (ACER) at the University of Birmingham. He is a member of the ACER steering group and a member of the Programme Board for the Autism Education Trust. Damian holds a number of academic qualifications in a range of subjects (sociology, psychology, philosophy and education) (MA, PGCert, BA (Hons), Dip (conv), PGCE, Mifl, MBPsS) and has a number of years' experience as a Lecturer in both further and higher education. Damian's interest in autism began when his son was diagnosed in 2005 as on the autism spectrum at the age of two. Damian was also diagnosed as being on the autism spectrum in 2009 at the age of 36.

Lyte Moon is a dual professional: a practising artist with a parallel career in education. She has a BA (Hons) Degree, CFET Stage 2 (PTTLS), IDHP Dip. Facilitator Styles and MIfL). She is neuro-divergent and is emerging as an insider voice with a particular interest in bringing new perspectives to bear both within the field of education and in wider contexts. Sociology has thus proven a powerful tool within an eclectic and extensive set of interests: sufficiently so as to lead to a personal conclusion that it should be a mainstream subject in all schooling.

In this paper, the authors refer to the power imbalance which generally exists between the researcher and the researched and suggest that action research is a means to lessen the power often held by the researcher. The paper reports on how a group of 9 autistic adults got together to talk on-line about sociology and the issues that this method of working created and raised for some of the participants and the group as a whole. It is often said that autistic adults are likely to find Internet discussion groups easier than face-to-face interactions, and this was the case. After that, however, learners had different needs in terms of their time available, the type of structure that worked and their degree of exposure anxiety. Comparisons are made between the positive effects of this on-line learning experience and the often negative effects of the

participants' experiences of mainstream education, the latter frequently being very disabling, leading to low self esteem and self doubt. Exploring and discussing sociology on-line for some participants was liberating and life changing, as presentation of self, identity, alienation and feelings of 'other' are key concepts within the discipline – and there are important lessons within this paper for teaching staff and professionals from other disciplines too.

Introduction

This project involves a small group of participants (currently nine, including the authors of this paper), all of whom self-identify as being on the autism spectrum, studying and discussing the subject of Sociology in an on-line format. The group was originally formed through a discussion on an on-line autism chat list, and the group members agreed from its inception that the experience could be utilised as an action research project, and that the group was for the use of anyone on the autism spectrum whether formally studying the subject or not. It was agreed at this early stage that all participants in the group were to have an equal 'voice' in deciding how the project developed, although this has been difficult to achieve in practice. The aim of the group is to help enable collaborative learning experiences between its participants, with one of the participants taking on a 'facilitator' role regarding the subject area being studied. This group however, has no time frame constraints, no formal assessments of learning, and an ethos of collaboration in the construction of learning materials. The project has been running for several months, thus there has been ample opportunity to analyse the various learning styles, strategies, materials, and barriers, that impact upon this group of learners.

Rationale

Action research originated with the work of Lewin (1946, cited Robson, 2002), where it first referred to learning about organisations by trying to change them. This approach to research has become popular in the field of education, with practitioners in a position of 'active researchers'. There are three general aims in the usage of research in terms of the attainment of knowledge: improvements in practice, in understanding practice through a dynamic process, and understanding the context within which practice occurs (Robson, 2002). Action research tends to reduce the primacy of the researcher's role in the research process, instead emphasising collaboration and the value of groups of

practitioners investigating their own working contexts (Carr & Kemmis, 1986).

Robson (2002) argues that the close relationship between the researcher and participants fits well with other qualitative methodologies, yet is at odds with the aims of positivism. Action research combines inductive and deductive reasoning, in order to build a 'cycle' of reasoning. This traditionally involves: planning a change, acting upon this plan, observing the consequences of changes, reflecting upon the processes and consequences, and then planning future action, and so on. It is a mistake however, according to McTaggart (1996) to regard the utilisation of the 'research spiral' as constituting 'doing action research'. McTaggart (1996) warns researchers from applying the 'cycle of reasoning' in terms of a dogmatic application of a model, and thus slipping into a bureaucratic way of processing data. One of the limitations of action research, according to Robson (2002) is the loss of 'control' over data collection for the researcher. This democratisation of the research process is seen here however as a strength of such a method, in terms of diminishing the power relationship between researcher and researched. Adelman (1989, cited Robson, 2002) argued that much action research carried out by practitioners is 'inward looking', 'ahistorical', and generally of a poor quality. Bogdan and Biklen (1992) however view action research as linked to traditions of community organisation, activism and action, with the practitioner actively involved in the 'cause' for which the research is being conducted.

Robson (2002) states that action research can be seen as an alternative research paradigm and as a democratising force, where changes in practice can be informed from the 'bottom-up'. Such research styles have also been used by feminists and minority groups for the purposes of empowering participants (Reinharz, 1992), and such uses can be seen as having an 'emancipatory' aim where both collaboration (and

improving practices) are seen as of central importance. In this project, the group members have active participation in the progress of the study, and in the interpretation of data produced, so that the research has a wider sense of 'ownership' than just the researchers'.

Gramsci (1971) argued that all people were 'philosophers' or 'organic intellectuals', with regard to their own life experiences, and in terms of using such understandings to address problems in society. Similar views can be found regarding 'everyday lived experience' and the skills of social actors in achieving social reality (Garfinkel, 1967; Milton, 2011a), and how such discourses of experience relate to wider historically situated discourses (Foucault, 1973). All these approaches, as well as the action research used by feminists (Reinharz, 1992), view investigating 'experiences' as epistemologically valid, methodologies which are argued here and elsewhere (Milton 2011a, 2011b, 2011c), that are needed in order to generate a more in-depth understanding of autistic people and 'neuro-diverse' culture.

For O'Brien (2001), the 'radical stream' of action research influenced by Gramsci (1971), has as its foundation Marxian concepts of 'dialectical materialism' and 'praxis', which has a strong emphasis upon 'emancipation' and the reduction of power imbalances and inequalities. Such research O'Brien (2001) states, strives to transform social situations via advocacy for marginalised groups in society.

Winter (1996, cited Robson, 2002) lists a number of ethical principles to attend to when conducting action research, as follows:

• that all participants should be able to influence the work

• those who do not wish to participate must be respected

• the development of the work must be visible and open to suggestions from participants

• permission must be granted for the use of such work

• the researcher must maintain confidentiality.

O'Brien (2001) suggests:

• that the direction of the research should be collectively agreed

• that the nature of the research process is explicit from the beginning, including biases and personal interests

• that there is an equal access to data generated.

All these principles have been, and will be followed in this project, although it is interesting to note that many of the participants have asked to be cited by name in order to give value to their contribution and 'voice'.

This project is being conducted following the advice of the British Educational Research Association (2010) and the British Psychological Society's guidelines for research with human participants (2009) of informed consent, right to withdraw, anonymity and use of data.

Data analysis

Initial investigations into how the study group has progressed include quotes from on-line discussions, the joint production of resources, and collaboration in the analysis of the group's development and the writing of this article.

Time constraints

Many lessons have been learnt already in the process of conducting this project. One of the most pertinent difficulties encountered being how to access willing participants who had enough time and energy to participate.

> '*Hi folks, just to say I really want to join in with this but am extremely busy with other matters at the moment so have no time to do so.*' (Busy Mum)

> '*You have got my interest. However, you haven't got (much of) my time yet.*' (Kalen)

> '*Although I'm not contributing myself at present, that's only temporary.*' (Ava-Ruth)

Due to the group's open format for discussions and contributions, participants have been able to 'dip in and out' of the study group activities, although this has only alleviated difficulties caused by time constraints to a limited extent.

On-line learning formats and styles

It has become clear that technology such as the Internet has vastly increased opportunities for a researcher to access a sample population. It has also become evident from the autistic people that have taken part in this pilot research, that face-to-face interactions can be more difficult to navigate due to geographical distance between people, and that many feel that they can clearly express their opinions in written format on-line. With this particular population, it seems appropriate to offer a variety of pathways for individuals to participate in their learning. Indeed, one of the striking issues encountered has been the differential learning needs of the participants, even within a small study group.

'More different modes would work better for me. Eg video, audio, real time chat, articles, PowerPoint style presentations, *and* discussion (e-mail or message board if necessary).' (Kalen)

An increasingly obvious difficulty is with the issue of 'structure' and how it is implemented. It is often assumed that autistic people are 'rigid' and need 'routine'. What is more the case is that autistic people have a need to learn and live in a way which suits them, and find a semblance of structure for themselves. The imposition of arbitrary structures will be likely to be met with resistance and/or confusion. In the construction of workable 'structures' for an autistic student, it is therefore recommended here that these be produced on a mutual basis, drawing upon the strengths of both the practitioner and the autistic person. Autistic learning styles can also contain major strengths in negotiating academic work, but also challenges, particularly given the current structures imposed upon them.

Lyte's perspective on the workings of the on-line group

This particular subject demands a somewhat different emphasis from my creative work where I learn through experimentation, experiential and kinaesthetic exploration alongside the academic rigours of the subject. In an abstract subject such as sociology, I needed to get a good grasp of the theories before I had any chance of applying them.

I was highly motivated by the opportunity to be an active, genuine, interactive 'researcher' of my own learning as well as being part of a pioneering and innovative project which I felt I was co-founding. I think

this is very much a 'work in progress' as the group explores new models of learning together. For example, at the beginning of the learning process, Damian chose the title for the group, thus giving me a strong message that it was 'his course'. In contrast, one of the most powerful experiences to come later in the process has been the opportunity to collaborate in the group's development and in the writing of this paper, and the resultant dialogue about the roles and power held by members of the group.

Damian's perspective on the workings of the on-line group

One of the more pleasing aspects of such a study group was the mass of knowledge that each participant had regarding different aspects of social life. Some in the group had previous experience in the subject, and added in interesting links to relevant theorists, increasing the learning opportunities of the group as a whole:

'Well never mind Durkheim or Marx, it is something that to me goes back before those times to the notions of "natural law" and the "social contract" on which all civil society is said to be built.' (Larry)

Of particular interest was how such discussions turned to analysis of issues concerning the lived experience of autistic people:

'The other classic so far as this [group] is concerned is Stanley Cohen's 'Folk Devils and Moral panics' … very relevant to autism too considering the … moral panic over the "autism epidemic".' (Larry)

Psycho-emotional disablism

At the start of the formation of the group however, there was much discussion needed for people to feel confident in accessing the group in the way they wished. It was found that group members had a largely negative view of mainstream education, yet saw participation in the group as an opportunity to learn without the attached 'psycho-emotional disablism' (Reeve, 2011) that they had felt whilst attending mainstream educational establishments, often commenting of the impact of having to 'pass' in a 'neuro-typical' environment and culture.

Lyte's perspective on education

Yes, I wrote that my experience of education had been one of 'dismissal'. My needs were effectively 'invisiblised'

and I internalised this treatment, resulting in a field of distress hampering and countermanding my attempts to learn. I left school with little sense of self-worth or my potential. In my need for learning, belonging and thriving, with few means to achieve these other than the prescribed judgements of authority figures and with fear driving all my actions as a result of having learned that I would not be seen, understood or supported, I remain beset with self-doubt. Yet, remarkably, there is more hope now as there are more like-minded advocates amongst us. Paradoxically I am more who I am as I become more aware of my voice within an extraordinary process and with extraordinary people, none of whom seem at all interested in limiting my potential in any way. On the contrary, the room to grow is exquisite, and the mistakes are both real and wonderful.

> *'Merely to acquire information or knowledge is not to learn. Learning implies the love of understanding and the love of doing a thing for itself. Learning is possible only when there is no coercion of any kind. And coercion takes many forms, does it not? There is coercion through influence, through attachment or threat, through persuasive encouragement or subtle forms of reward.'* (Krishnamurti, 2005, p 3)

Sociology is no mere subject, it is a way of examining one's values, one's assumptions, and those of others – but isn't that what real learning is all about? It can be unnerving, moving beyond the 'rules' and developing increasing ability to critique and to question intelligently, yet being unnerved is not disabling in a space where I experience learning as fun.

Owning the learning process
Damian's perspective

Fullen (1982, cited Robson, 2002) suggested that there can be great ambiguity and uncertainty engendered in participants of action research regarding changes in practices that occur. One would think that this is particularly pertinent to autistic participants. However, it has been found thus far, that the group members have greatly appreciated the ability to 'own' their own learning environment, and being able to learn at their own pace and not that of an imposed structure placed upon them. One of the most positive aspects of the group has also been how participants have contributed to the development of learning materials, particularly by Lyte (see *Figures 1 and 2*). These figures were created by Lyte from scribbles and discussions with Damian. The first is based on a figure by George Ritzer (1996) from his book on 'Sociological Theory' (p 49) and the second
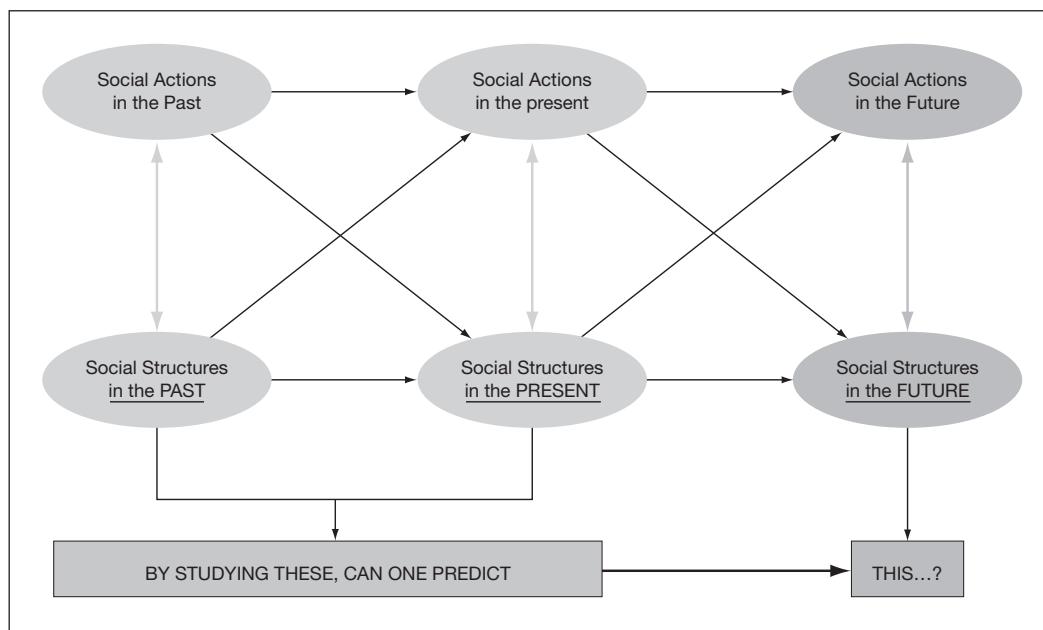

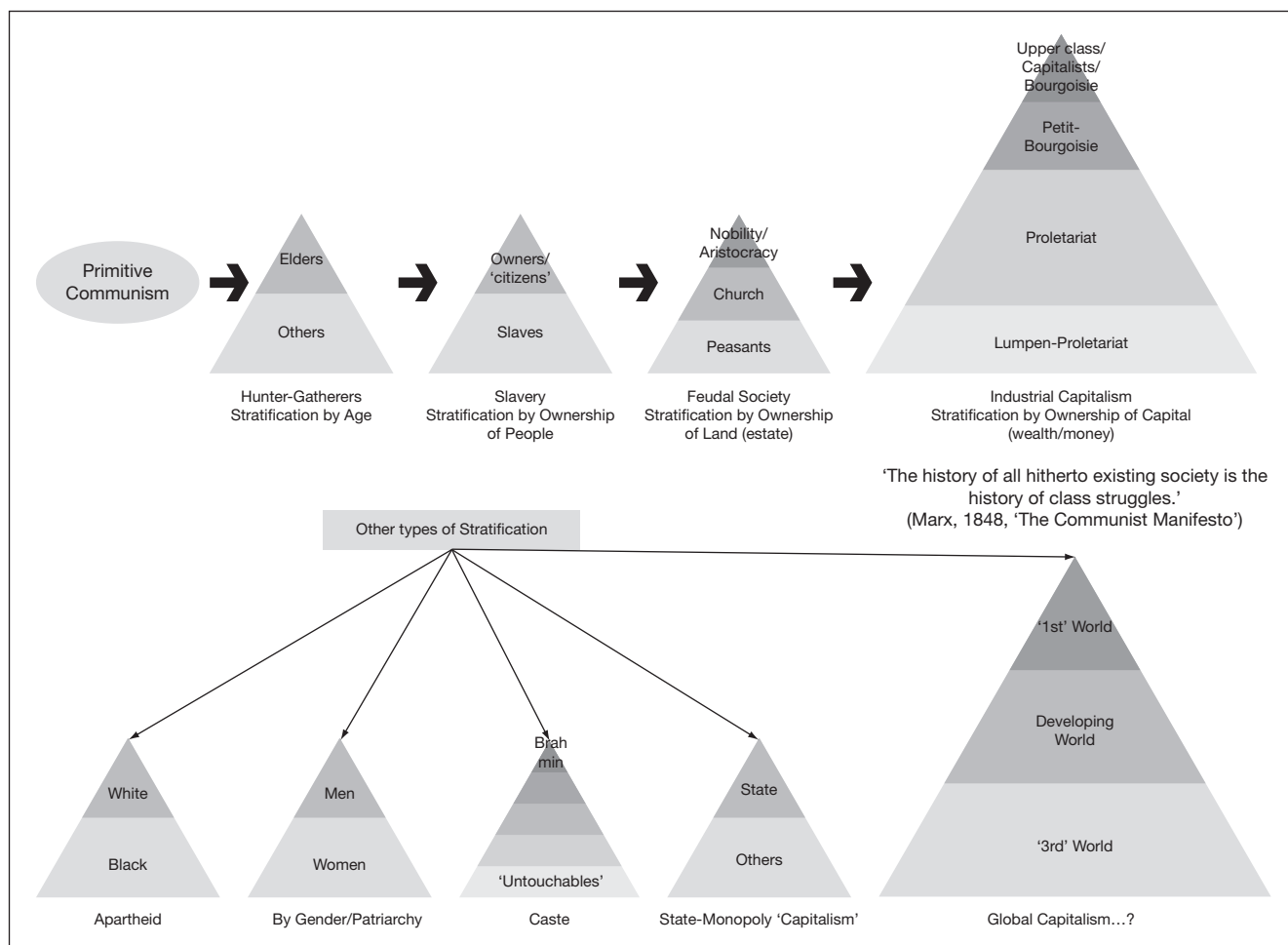**Figure 1:** Marx on the Structure vs Agency debate

Figure 2: The changing mode of production

was created by Lyte from Damian's ideas gleaned from other works on class systems.

Lyte's perspective
The acceptance of my contribution was important and validating to me, as I wrote at the time:

> *'I am seeing something emerging that is more than mere "learning" – it is fulfilling on a more 'need' level of basic human need.'* (Lyte)

However, when the research aspect initially came to the fore, and I saw the first drafts, I felt 'fishbowled'. This was an intense, visceral and disturbing experience. My reportage of the experience and the way it mirrored the general life experiences of being 'a subject' for others to ponder over, has led to a re-evaluation of how this paper may be written and to the development of a different and immeasurably more empowering, collaborative approach.

The building of 'simpatico' relationships

An interesting aspect of the group was the level of recognition the participants had for one another – evidence to support the 'double-empathy problem' previously theorised by Milton (2011a, 2011b, 2011c), and the potential for autistic people to learn from one another.

> *'I find that in some ways you and I think very similarly.'* (Selina)

The relative success of this group is in no doubt in part due to the relevant skills of both the facilitator and the group members, however all of these people (including the facilitator) had at some point or another struggled in further or higher educational establishments. The potential for autistic people to learn from one another has been an area totally underdeveloped, and at times in previous years indeed frowned upon (Lovaas et al, 1987).

Lyte's perspective

At times I wanted to ask for reassurance that my work would be fully respected as my own, but I could not avoid coming to the conclusion that I could be plagiarised due to my open engagement and my enthusiasm for dialogue as part of my learning process. Laister and Kober (2012) recognise that gaining the 'active participation' of all the members of a new e-learning group is not easy. Nevertheless this would have increased my learning and my enjoyment: I was of course aware that others were 'dipping in' or may be witnessing my own learning process and as a participant I felt somewhat unnerved and vulnerable. This exposure anxiety (EA) may be an issue that holds others back from being so vocal (Williams, 2003) even though they may learn a great deal from the input of others. It is certainly an area ripe for further exploration and one on which there is a need for teachers to be very sensitive. The issue of EA and how deeply one feels the experience of being watched, heard, seen, even acknowledged, is all too real for me. It is ever present and may be so for others in the group. Some means of addressing this would be useful, and certainly the freedom to engage or not, is the right start. Having engaged, it can be excruciating to continue and whilst Williams (2003) talks of indirect approaches, balancing this in a 'verbal' (ie written email) direct environment can be a challenge. A slightly larger group may mitigate this problem by allowing more diversity in learner-input, to which responses may be invited. However, I suspect that teachers who are able to tune themselves to, or even have our experiences, may be more likely to reduce the stress of EA, and that suggests a need for choice of both teacher and learning environment.

> *'… it has been great to do learning the way I want to and not at all like the "teachers" seemed to think I should … and there is so much more I will do as I set myself free to start learning the way I CAN and not the way I CANT! And with your gentle and steady support as you guide the subjects and check my work and have the patience to even look at my dizzy-making "answer" to the question.'* (Lyte)

Our enthusiasm for the project is clear, but as I suggest above, there is always more to learn: I re-discovered a longing to have my learning checked by being questioned further, and there were times when I was given too much additional new information before I had had time to process earlier information or construct a scaffold for it. I need to 're-group' once some learning has taken place and to own the learning process at each step. I trip over my own eagerness! However, I also experience this issue with mainstream teacher interactions: the difference here is twofold - firstly that because Damian is recognisable to me as being 'like me', and secondly the response I receive is different from mainstream, where I am regularly informed to 'ignore' additional information, told 'I don't need it' even when it has been given, or just 'that I am doing fine and not to worry so much' (really!). I have not in my mainstream education succeeded in communicating that I would like the teacher to go at my pace and closer to my style rather than vice versa in order that I may indeed learn. This comes to psycho-emotional disablism (Reeve, 2011) in the form of: 'teacher knows best what we need', even when teacher has little insight into how our minds work, and is keen to stick to their own ideas of how our minds 'should' work or be made to work, thus reducing our learning potential and disrespecting our autonomy and own insight, our own relation to self becomes further disabled, affecting all learning in all aspects of life.

Progression in learning

Damian's perspective

Without doubt, the participant who has progressed most in their learning during the initial stages of this project has been Lyte, who has been able to make some quite astounding gains in newfound sociological knowledge, followed by a rise in confidence in terms of what Lyte feels capable of in academia more generally:

> *'I find it astonishing that I should be capable of this degree of analysis/observation in so short a time!'* (Lyte)

Lately, this confidence has been evident in Lyte's understanding of sociological theorists and the application of these (after just a few months of participation), in the case below, Merton's 'Strain theory':

> *Damian: 'Well – even if one wanted said success – there may be "innovative" ways in which to grasp them – but one is disallowed/blocked from following such "deviant" paths.'*
>
> *'Do you see the reference to a sociologist here …?'*
>
> *Lyte: 'I certainly do … and that was where I was directing my challenge …'*
>
> *Damian: 'You rebel!'*

Empowerment

The group has also led to discussions of the setting-up of external projects that highlight a growing confidence in the ability of 'neurodiverse politics' to achieve positive change for others:

> *'Yes, I like the idea of the book very much, too. Not in a position to contribute at this stage, but maybe as things develop …'* (Selina)

> *'We need autistics making work about ourselves, though not necessarily of the "oh poor me, isn't life haaaard" type.'* (Busy Mum)

Future developments

It is envisaged that the study group will expand to include an increasing subject base of Psychology, Philosophy, 'Academic Skills' and 'Autism Studies', yet further expansion would be dependent upon the recruitment of further facilitators, with the skills to monitor discussion forums and the development of resources. However, there is a growing number of autistic people who wish to be actively involved in the education of other autistic people, and members of the study group are already growing in confidence, with one participant suggesting topics that they could facilitate in future. Such an expansion would be empowering to autistic individuals and the 'neuro-diverse' community as a whole.

> *'And when I have learned more, I was thinking earlier today that I will not be "limited" by the sociological way of seeing things. Being me, I will be able to contrast that point of view with others … and be able to see things in many different ways, and will KNOW that I am doing so, and will be able to choose at any one time which perspective/ viewpoint I will be taking.'*

> *'And that, Damian, is what I call life-changing.'* (Lyte)

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