

# "I TELL THEM, I TELL THEM NOT": DISCLOSING ONE'S IMPAIRMENT IN HIGHER EDUCATION

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# ABSTRACT

Besides dealing with architectural and attitudinal barriers in higher education, disabled students also have to go through their identity formation as having some form of impairment resulting in their actions whether to disclose or not to disclose such information within various aspects of campus life. This article explores factors that influence one's decision to disclose his or her impairment in higher education setting. We collect qualitative data from two groups of research participant. The first group consists of first year university students with various impairment at a public higher learning institution in Klang Valley, whereas the second group comprises of members of a Facebook group known as 'Jalinan Mahasiswa OKU Malaysia'. Through qualitative comparative analysis, we uncover ten factors that influence one's decision for impairment disclosure. Those factors are study course suitability, meritocracy, feeling towards one's limitation, risk of discrimination, fulfilling one's rights, risk of manipulation, facilities provision, responsibility, priority and thoughtfulness. These factors produce a complex matrix that needs to be managed effectively. We debate several issues arise relating to these factors. Our debate calls for critical interrogation of issues such as disability conception, individuals' capabilities and the need for re-operationalizing the term 'human rights'. We also advocate for further research on this matrix in different contexts of disabled people's life such as during applying for a job, applying to participate in an event or training, and during applying for services or assistance schemes.

**Keywords:** Disabled people, higher education, impairment disclosure, factorial matrix, qualitative comparative analysis.

# **INTRODUCTION**

It is very easy for us, those who research disabled people's struggles in higher education setting, to overlook psychosocial dimension of these persons. One issue in particular is their identity development, which they have to make peace with their impairment as part of their identity, or in some cases, rejecting that part of identity altogether. Failure to reconcile with this aspect of oneself may result in negative outcome. For every year a disabled student fail to disclose his or her impairment, it will affect his or her graduation for almost a semester (Hudson, 2013).

Be that as it may, it is not easy for one to accept and adjust his or her self-concept, especially for those who just recently acquired or being diagnosed to have some form of impairment or those who never really see themselves as 'impaired' or 'disabled'. As Kerschbaum, Eisenman and Jones (2017) state, disclosing one's impairment is a process that continuously happens within various settings and contexts involving questions such as process, what to disclose and not to disclose, its benefits and risks, as well as its repercussions to individual's and collective experience.

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This paper attempts to explore local disabled people's perception, attitude and factors to consider when disclosing impairment in higher education setting based on discussion with two groups of research participants. We start by reviewing past literature relating to our research topic. Next, we explain our methodological framework for the present study. Finally, we present our findings and confabulate on the few issues and questions arise.

# LITERATURE REVIEW

De Cesarei (2014) proposes one's attitude towards disclosing his or her impairment may be influenced by social support, self-efficacy and metacognitive skills. The work of Cawthon and Cole (2010) provides the evidence that students with learning disabilities generally know the implications of their impairment which end up using the same resources that they use during their secondary education, resulting in lack of university resources usage to the fullest extent. The findings suggest that disabled persons develop their impairment conceptual and identity throughout their schooling years and bring such conceptual and identity along when they pursue postsecondary studies. This may be true for those who receive education in special schools or integrated programme or inclusive schools that provide special facilities and services. However, the same process may not happen for those who go through general schooling system either due to their mild level of impairment or lack of access to accessible schools in their living area.

In re-examining the association of institutional distance education goals with the frequency in which the disabled students request accommodations in courses offered, Barnard-Brak and Sulak's (2012) work reveal a positive and significant relationship between institutional distance education goals and the frequency of requests for accommodations in online courses among disabled students. Their work indicates that institutional distance education goals, which reflect the policy and practices can facilitate positive effects of impairment disclosure which the disabled students feel comfortable to request accommodations. This finding opens up a possibility to extend such aspiration to traditional postsecondary education setting.

Though disclosing one's impairment can result in receiving good support throughout his or her studies, bringing the identity of having an impairment into employment sector and even when applying for practical training produces negative effect (Riddell & Weedon, 2011). Such effects or risks become more complicated because disclosure of one's status as a disabled person intersects between multiple identities (e.g. race, gender, and sexuality), locations, and assumptions which reflect conditions of social power relationships (Samuels, 2017), hence envelop into a politics of disclosure (Carter, Catania, Schmitt, & Swenson, 2017). Alshammari (2017) shares her experience as a middle-eastern woman living with multiple sclerosis that she has to live a hybridised academic identity since her invisible illness causes her to be in a position between the juncture of able/disabled and healthy/sick, as well as other factors such as shame, family support, social construction of gender, and cultural values towards living with an impairment/chronic illness.

Sharing personal lived experience including disclosing one's impairment can satisfy curiosity which non-disabled people have and make oneself more confident afterword despite it is emotionally taxing and make one expose to backlashes and criticisms (Knight, 2017). Telling others about one's own impairment and experience living with it can nurture an open

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and frank discussion which then act as tool in combating stigma and discriminatory attitude. However, it may be different for those who have invisible impairment or illness. In another study by Wood (2017), she discovers that disabled students are actively negotiate their identities and the choices they make illustrate continuous tension between medical model of disability and embodied experience, the clash of oppressive structural forces, and the need for community and connection to develop positive identification with impairment.

It is also worthy to caution that disclosure processes which guided by guidelines, parameters, and policies can unintentionally cause a hassling process due to institutional bureaucratic structures (Carroll-Miranda, 2017). Even after disclose one's impairment, there exists obstacles in accommodating one's needs because of lack of system in place for faculty accommodation, lack of awareness on disability, and difficulty to practically translate some legal terms into reality (Kerschbaum, O'Shea, Price, & Salzer, 2017).

# **RESEARCH METHODOLOGY**

We employ qualitative research design for this study because we want to understand subjective perception of our research participants toward disclosing their impairment within higher education context. We gather data through group discussion with two sample groups. The first group consists of eight disabled first year university students at a public higher learning institution in Klang Valley. Within this first group, four of them have visual impairment, three of them have physical impairment and one research participant has learning disabilities. The number of male and female research participants in the first group are equal, with four male and four female. We use cluster sampling for disabled first year university students with the help of officer in charge of disabled students' affairs in that particular university.

We conduct the discussion with the university students in Malay language. We develop a semi-structured questions to guide our discussion. The discussion is recorded using first author's audio recording device. Afterword, second author transcribe the discussion audio recording and we analyse the transcript together.

The second group of research participants comprise of eight member of a Facebook group, known as 'Jalinan Mahasiswa OKU Malaysia' (presently they rename the group to 'Jalinan Belia & Mahasiswa OKU Malaysia'). This Facebook group was established to provide a dedicated space for disabled local university students and alumni. We post a couple of questions and ask the members of the this Facebook group to give their feedback. Then, we copy all of their responses into a word document file for analysis. Since some of the members use their real names as Facebook ID, we change all research participants' name in this group, representing them by a code name 'ODM' (online discussion member) following by a number to differentiate each participant.

For clarity, we refer to the first sample group as Group A, whereas the second sample group as Group B. We analyse data from these groups using qualitative comparative analysis. We conduct the analysis process manually without using qualitative data analysis software.



## **RESEARCH FINDINGS**

For this section, we present findings gathered from the two groups of sample. As such, this section is divided into two subsections with each subsection presenting data from each group. The next section follows up with critical interrogation of the research findings.

# *i)* Findings from Group A

Two patterns of response emerge from Group A, which are 'need to disclose' and 'need to disclose in certain conditions'. Amongst the reasons that need for impairment disclosure is when determining a suitable degree course.

*"Need. So the management knows. For course determination."* (Safi, 20 September 2017) Another research participant has the same opinion.

"So they know how to assist. So they [the university] ready for us. If they say disabled person cannot take this course, understandable. No hustle to us, nor to them. Understandable. Some people say, oh you enter [university] because you are disabled. But I have other disabled friends unable to enter..." (Balqiz, 20 September 2017)

During application process, one may disclose his or her impairment to make sure he or she is being enrolled into a suitable degree course. Balqiz's response above also poses a risk to encounter negative societal attitude and the need for appropriate assistance. Furthermore, her response also portrays her effort to not burdening herself and others. Borhan, one of the research participant also shows the same emotion.

"I feel we need [to disclose]. I feel it is needed because if we do not tell them, for example there are university programmes and we cannot do, they will not know. Plus, when we say we are disabled, we can get exemption, not to burden ourselves and others." (Borhan, 20 September 2017)

The response above illustrates the intersection between one's perception towards his or her own limitation and failure in support system. On the other hand, though one needs to disclose his or her impairment, Tasha is still concern with the risk of discrimination and meritocracy.

"Need... I feel there is a need because the system will soak through [the application]. On their part, they have no problem. But for us, they know we are disabled, how much the system can take the disabled in a session. But, there is also a risk. The risk of rejection. Because we are disabled. Our pointer are high but our batch many of them have low pointer than us but because we are disabled, the system will not accept. They accept the sighted first. Finally then we find someone with high pointer among the disabled. There is a possibility." (Tasha, 20 September 2017)

One may view Tasha's response as ridiculous accusation. Her response above maybe a product of negative cues or experience which the disabled community repeatedly share and consume (Nasir & Hussain, 2016). In this case, we need to examine policy and admission process at different level; the government, the public higher learning institutions and the faculties. According to the information provided on the Department of Information Malaysia's website, there is a special channel for disabled students' admission to higher education, which they are not competing with non-disabled applicants, using minimal qualification and the placement is made according to facilities provided and course offered at a higher learning



institution ("Faedah OKU Berdaftar dengan JKM," 2019). However, the questions remain on what the 'special channel' really means and how many disabled persons have benefited from it.

On contrary, two members of Group A assert the need for impairment disclosure only in certain conditions.

"I feel that... disclosing impairment, is not needed. Because when disclose it will give opportunity to the university to discriminate. Because even though we the disabled are qualified to choose the course that we want and the university should not reject on basis of impairment. On UPU [the online application system] they look at academic and co-curriculum qualification. So, impairment, to me, is not a factor. Actually, [disclosing impairment] it is needed after enrolled into the university." (Isaac, 20 September 2017)

"Needed in certain condition. Not needed in certain condition. Need for us to avoid from unsuitable course. Not needed because they [the university] will give excuse that this course is not suitable for you the disabled." (Sheyla, 20 September 2017)

Besides noting meritocracy in Isaac's statement above, both of them point out the risk of discrimination when one disclose his or her impairment. As Sheyla and few other have stated, though disclosing one's impairment may work in their favour (i.e. getting a suitable course), but at the same time may also be used as discriminatory tool. Interestingly, Isaac views impairment disclosure is only needed after the student successfully enrolled into the university. This reasoning may relate to opinions voiced out in the next section.

### *ii)* Findings from Group B

Majority of research participants in Group B agree on impairment disclosure in order to fulfil one's rights and to get appropriate facilities or services.

**ODM01**: I need to disclose.. So that I can get facilities provided for disabled student.. like special parking space, room at ground floor and so on.

**ODM02**: In my opinion, must disclose our status because: 1. To receive necessary facilities. 2. To avoid any problem arising from not disclosing impairment when something happen.

**ODM03**: For me it is needed. This is to facilitate university management in disseminating related information to disabled student in a higher learning institution. Like me in the past, receiving residential service throughout my studies, get extra time in final examination every semester.

**ODM04**: In my opinion, it is needed to register / disclose as disabled student. Rationale : 1. Fulfilling the rights as disabled students as provided, can distribute accordingly (scholarship, disabled-friendly facilities, extra time, and so forth). 2. To fulfil the quota of disabled students enrollment in public or private higher learning institutions in Malaysia. 3. Evidence or documentation in black and white if something unexpected to occur.

**ODM05**: Need to get facilities provided by university or college for one's benefit.

**ODM06:** Disclosure is needed so the management know current needs of disabled student ..., we must show to the society that disabled people is not a symbol of sympathy... We are the same. **ODM04:** Disclosing as disabled student is needed to prevent misunderstanding and to obtain appropriate special facilities according to the limitation we have.

The importance of impairment disclosure is also to prevent any risk of manipulation by those who are not eligible to receive support as those who are disabled.

**ODM07**: 1. Disclosing impairment in public higher learning institution is important. To me, the question of its importance is more important than it is needed or not. It is important to avoid non-disabled takes advantage. For example, a disabled student who studied in public higher learning institution together with his or her non-disabled friends and non-disabled cousin or



non-disabled twin, it does not mean that disabled student has no need to disclose because a lot of people can become his or her support system. So, a disabled student must disclose impairment in public higher learning institution although many supporting individuals, even though the disabled student can provide support system on his or her own. Thus, it is important to avoid risk of taking advantage.

Although one may disclose his or her impairment to obtain necessary support, there are also matters of responsibility, priority and thoughtfulness.

**ODM08**: 1. Disclosure is needed to facilitate university in assisting in any needs. 2. Must also see on the needs because disabled persons consist of many categories, for example if one may not in need of special room, give that opportunity to those who greatly need it. Must have thoughtfulness.

**ODM04**: Disclosing impairment is indeed needed in any aspects so appropriate facilities can be provided to related disabled persons. I am also supporting the view that points out tolerance or thoughtfulness, must evaluate and analyze those who are really in need since disabled persons comprise of many categories from mild to severe ... rights as provided will be fulfilled according to priority of needs among disabled people ... It is the authority's duty in determining. As above-mentioned by members of Group A, one member in Group B also repeats the

same theme on risk of discrimination from impairment disclosure.

**ODM04**: Actually negative effects from impairment disclosure exist due to societal perception. It is inevitable in life. Among many implication usually voiced out include the difficulty to get enrolled in public or private higher learning institutions, besides the difficulty to gain job opportunity based on one's qualification.

### DISCUSSION

Our discussion with the two sample groups reveal ten factors that influence one's decision either to disclose his or her impairment or not. Those factors are study course suitability, meritocracy, feeling towards one's limitation, risk of discrimination, fulfilling one's rights, risk of manipulation, facilities provision, responsibility, priority and thoughtfulness. These factors produce a complex, seemingly misfit matrix. In this section, we reflect upon this matrix and make known of some of the questions arise from it. What we discuss here is not definite since we too are very much still searching for the truth. Yet, we hope to encourage critical interrogation on this issue for future research and policy making.

The first factor, which is the study course suitability, may indirectly relates to one's feelings toward his or her limitation. Few members in Group A assert that impairment disclosure may facilitate the matching process of degree programme according to one's impairment. Our question is whether certain impairment really limits those who have it to enter certain fields. To our knowledge, there is still no research that actually investigate this claim. This may very well be just assumption or so-called logical conclusion on certain biological dysfunction. If this is truly just assumption, we must examine it because it may bring negative precedence to disabled community.

Taking one step further, we question whether we should conduct the modification process on disabled persons in order for them to be eligible and able to undertake certain fields, or should we modify the course to suit disabled persons' capabilities as well as providing appropriate support system. The former classically reflect the medical model of disability, while the latter translate the social model of disability. Notwithstanding such breakthrough thinking is highly commendable, we still need to do a lot of reconstruction, both in material and philosophical aspects, to achieve the latter. Not saying that material reconstruction is not



important, but here we are more concern with philosophical reconstruction as it demands for paradigm shift from old thoughts and cultures.

We must reconstruct, for example, concept of blindness and vision and its functional relations or accommodation in the fields which previously utilize sense of sight such as arts, media and so on. Moreover, philosophical reconstruction has to provide answers to a number of controversial questions. One may ask whether if a person with impairment and/or chronic illness can only perform certain tasks or unable to learn certain parts of a discipline, does it degrade the status of that particular discipline? Plus, reconstruction efforts must not decline to becoming reverse patronization.

The second factor is meritocracy. We problematize the issue of meritocracy and its position within human rights context elsewhere (Nasir & Efendi 2019b). Current debates on education in many countries, including our own, focus on how to measure one's gain in education, either performance or growth. Merit can definitely measure one's performance, however may not reflect overall growth, potential and capabilities. It is also interesting to ponder whether impairment disclosure amplifies positive response towards one's good grades or can serve as uplifting factor to be enrolled in a degree course. Again, we must critically interrogate the concept of merit and its effects on disabled individuals within higher education context.

The first two factors above overlap with one's feelings toward one's limitation and risk of discrimination. The former exist in oneself, whereas the latter is a product of negative societal response. Feelings such as not wanting to burden others due to the impairment that one has may result in weak self-concept development and self-stigmatization. This may also be a product of ableist culture which still consider as dominant way of thinking in our society. To overcome this oppression, we must break away from the fixation on causal relation between disability and impairment.

We also wonder whether there is a possibility to create and nurture a space for negotiation when one is applying for a degree programme even though he or she is not eligible based on the prerequisite conditions set forth for that particular programme. We are not trying to promote naïve thinking or idealistic fallacy. Instead, we want to challenge the current notion on impairment effects and individuals' capabilities in relation to their unsuitability in certain degree programmes.

Another factor is risk of manipulation. It is important to ensure a mechanism is in place to avoid such risk in order to have fair distribution to those in need which more often than not relies on limited resources. Though this favour impairment disclosure, there are few individuals understandably have concern when disclosing their impairment usually relating to labelling. Here, it is vital to examine how disabled persons react and construct relationship towards the label which they may receive upon impairment disclosure. Label not only exists in interactional form, such as the phrase 'disabled persons', but also include material symbols commonly associated with the disabled-friendly facilities, special quota and so forth.

One is also considering the factor of facilities provision when disclosing his or her impairment. Impairment identification facilitates the provision of appropriate facilities and services to disabled persons according to their needs. Hence, they are able to meaningfully enjoy their rights. In other words, facilities provision and fulfilling one's rights are interdependent. However, it gives rise to several questions:



- i. Does one has greater rights than others only because he or she has exigent needs?
- ii. Are those who do not disclose their impairment are not eligible to acquire facilities and services even though they rely on such provisions?
- iii. Does impairment disclosure give effects in degrading or upholding one's dignity?

To answer the first question above, we must look back at three remaining factors which are responsibility, priority and thoughtfulness. These three factors complement and bring balance to other factors in this matrix. These factors also encourage collective and relational effort within the disabled community in a higher learning institution. On the other hand, university administration must also equip themselves with related knowledge and skills to manage priorities efficiently. In addition, university administration at different levels must have clear and non-discriminatory understanding of impairment and the role and costs of impairment disclosure.

For the second question, we have to effectively manage between the risk of manipulation, responsibility and thoughtfulness as well as ensuring fairness and protecting one's dignity. In our opinion, the framework of universal design for learning offers a comprehensive tool in resolving this dilemma. Further research on the usage of this concept within local setting is needed to understand its benefits, supporting measures and appropriate accommodation. Producing inclusive environment does not mean adopting philosophy of 'one size fits all' or only providing special facilities to meet special circumstances. Rather, we argue that inclusivity requires both translation of universal design philosophy as furthest as we possibly can and at the same time providing special services and equipment to those who have specific needs as integral part of the environment.

Finally, the third question comes back to one's conceptualization of impairment and its effects. We advocate for neo-biopsychosocial understanding of disability which defines disability as barriers and risks of barriers produced from negative relationships between self, society and environment that based on inaccurate episteme (Nasir & Efendi, 2018). When a male student perceive negatively towards his impairment and then firmly believe that perception to be true (episteme is then established), he may view his impairment as abnormal, not masculine, feel that his identity is being threatened and agree to ableist notion of a typical man.

We hypothesise all of the aforementioned factors may not interact simultaneously and some factors may arise later throughout one's life course based on his or her experience, maturity and contexts. We also hypothesise that few factors may dominate over others in one's decision to disclose or not to disclose. It is obviously clear that we are only able to scratch the surface, therefore further investigation is definitely in order.

Furthermore, looking at this matrix and trying to make sense of the new dynamics between its factors, we come to a realization that we need to redefine the term human rights. There are many scholars discuss human rights from different perspectives (Boot, 2017; Gregg, 2012; Osiatynski, 2009; Snyder, Hopgood & Vinjamuri, 2017), as well as discussion which focusing on disabled people's rights (Riddle, 2017) and even disabled people's rights in higher education (Barfield, Bennett, Folio & Killman, 2007; Konur, 2000; Nasir & Efendi, 2019b). We propose that the new definition must reflect on the issues arise from this matrix as well as inclusive of individuals' needs, capabilities and dignity. The new definition, in our opinion, must also link individuals' experience to wider social and political setting.

In addition to four values of human rights (dignity, autonomy, equality, and solidarity), we propose an extension of the philosophy of human rights to also integrate individualised-



communal adjustments, shared responsibilities, and multidimensionality (Nasir & Efendi 2019a). The extension, in our opinion, recognizes and re-engage with the issue of multi-relational components in our lives. Researching factors to one's impairment disclosure testifies for the application and further exploration of the neo-biopsychosocial model of disability.

# CONCLUSION

In deciding whether to disclose or not to disclose one's impairment in higher education setting, one must take into consideration various factors such as study course suitability, meritocracy, feeling towards one's own limitation, risk of discrimination, risk of manipulation, fulfilling one's rights, facilities provision, responsibility, priority and thoughtfulness. We raise up several questions toward these factors, calling for critical reflection on disability conception, individuals' capabilities and re-interpretation of human rights. We realise the factorial matrix opens up to more questions that need for deeper investigation, contemplating within philosophical, ethical, psychological and methodological realm. Moreover, further research is needed within different contexts of disabled people's life such as during application for a job, participating in an event or programme, and during application of services or assistance schemes.

We also recommend for future research to investigate this topic from other parties' perspective such as university management, administrative staffs, and lecturers. Different actors at different level and in different setting may have different perception and tendencies. Such information can help us to understand better and map the ecology of local higher education sector which the disabled students are part of, whether it positively supports or negatively discourages impairment disclosure. Nonetheless, the endeavour must depart from medicalisation of one's impairment and/or chronic illness, instead must employ critical ontology as Hughes (2007) advocates and use human rights framework.

Findings from this study demand for the government of Malaysia, especially the Ministry of Education, to take three forms of action. Those actions are empowering disabled school leavers who will continue their studies, continuing public awareness especially among parents and campus community, and improving higher education policy and system for disabled persons. Better understanding of the diverse group of disabled persons and their needs as well as valuing their individual capabilities must be nurtured among the public and explicitly incorporated into the admission policy and process. The findings from this study also make us radically think about campus diversity and coming up with solutions to achieve inclusive campus environment which include disabled persons' psycho-emotional and social adjustment. For these actions to be successful, the Ministry of Education must practice multi-sectoral collaboration and continuous engagement, especially with the disabled individuals in the higher learning environment.

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