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Challenging International Development's Response to Disability

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Challenging International Development's Response to Disability

Abstract

[Excerpt] This article argues that developing countries are often portrayed as being backward in appreciating the importance of inclusion. In addition the stigma attached to disability is thought to be greater in the Developing World. This article acknowledges the implications scarce resources have on inclusivity but argues that this does not necessarily reflect deeper prejudice in regard to disability. The development discourse has constructed a category of *underdeveloped Other* which is used to depict all marginalised people. This label fails to acknowledge and appreciate the different experiences and needs of people living with impairments. This article then goes on to highlight the support networks that are indigenous to many societies and suggests that development interventions should build on these rather than transplant a western model of inclusion. The article will develop these arguments through a case study documenting the life experiences of a rural poor, low caste Indian family of four. The wife and two daughters are blind. The sighted husband is the primary carer and cannot work because of the level of support required by his wife and two daughters. In the absence of a state welfare system this family is supported by families within the community who belong to the same social caste. The UK NGO working in the area uses images of this family to highlight extreme suffering and discrimination; it does not seek to appreciate how they cope with everyday life. The argument stressed throughout this article states that outside agencies must be motivated by a desire to *know* and understand the experiences of those living with impairments if their interventions are to be effective.

Keywords

development, inclusion, disability, prejudice, international comparison, discrimination, public policy

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les sujets concernant l'infirmité. Est aussi englobé sont les rapports ethniques au niveau national et international où la conduite de ce procès devant incombée aux handicapés afghans.

Resumen: Este artículo tematiza la discriminación que conviven las Personas Discapacitadas como miembros de una minoría étnica en Afganistán. Aunque se ha mejorado la situación después de la caída del régimen de los Talibán en el año 2001, las Personas con Discapacidad de estos grupos están todavía marginadas en todas las áreas de la vida social, económica y política. Entre ellos hay tres grupos donde la discriminación es más alta: niños, mujeres y personas de mayor edad. Lo más necesario son actividades coordinadas y concertadas de concientización, incluyendo investigaciones y discusiones sobre los temas de la discapacidad y relaciones étnicas.

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Challenging International Development's Response to Disability

Tamsin Bradley

This article argues that developing countries are often portrayed as being backward in appreciating the importance of inclusion. In addition the stigma attached to disability is thought to be greater in the Developing World. This article acknowledges the implications scarce resources have on inclusivity but argues that this does not necessarily reflect deeper prejudice in regard to disability. The development discourse has constructed a category of *underdeveloped Other* which is used to depict all marginalised people. This label fails to acknowledge and appreciate the different experiences and needs of people living with impairments. This article then goes on to highlight the support networks that are indigenous to many societies and suggests that development interventions should build on these rather than transplant a western model of inclusion. The article will develop these arguments through a case study documenting the life experiences of a rural poor, low caste Indian family of four. The wife and two daughters are blind. The sighted husband is the primary carer and cannot work because of the level of support required by his wife and two daughters. In the absence of a state welfare system this family is supported by families within the community who belong to the same social caste. The UK NGO working in the area uses images of this family to highlight extreme suffering and discrimination; it does not seek to appreciate how they cope with everyday life. The argument stressed throughout this article states that outside agencies must be motivated by a desire to *know* and understand the experiences of those living with impairments if their interventions are to be effective.

Introduction

This article argues that the voices of disabled people have been systematically excluded from international development agendas because a homogenous image of an underdeveloped Other continues to influence development practice and policy. When depicted the disabled body is presented as an example of extreme and desperate human suffering. Whilst the link between poverty and disability is affirmed by this article the oppressive impact of using broad labels and images to describe the experiences of others is critiqued. If the complexities of exclusion and social marginalisation experienced by disabled people in the Developing World are to be fully appreciated and responded to then the voices of people living with impairments must be listened to.

This article supports a right-based social model of disability. This defines disability as the loss or

limitation of opportunities to take part in everyday life of the community on an equal level with others due to physical and social barriers. The term *impairment* is used as defined by Barnes (1991) as a functional limitation within the individual caused by physical, mental or sensory impairment. My view expressed throughout this article (and shared by many) is that impairment need not lead to exclusion and inequality if inclusive policies are implemented. This article argues that at present this view is not shaping development policy on disability. The relatively few interventions directed at disabled people stress the need for medical solutions rather than societal.

A common critique directed at development interventions claims that insufficient attention is given to understanding local knowledge and little attempt is made to understand the life experiences of those aid is targeted towards (Chambers 1996, Pottier 1993, Gardener and Lewis 1996, Hobart

1993, Mosse 2005). Furthermore an assumption is made that the West has got it right. Western models of social inclusion enshrined in legislation are propounded as the *way forward* in the quest for greater social equality for disabled people. This article begins by critiquing the work of development agencies on disability through an analysis of the approach taken by many agencies. Focus will be placed on how these goals translate into development practice. The primary argument states that such approaches fail to acknowledge the agency of disabled people and do not seek to acquire deeper knowledge and insight into the experiences of disabled people across the Developing World. This article emphasises the importance of dialogue between agents of change (disabled people) and agents of development (NGOs). This dialogue involves a disruption of the usual power relation between recipient and givers of aid. In a development relationship it is usual for the recipient to be in the weaker or subordinate position. The giver (of aid) holds power over the Other (recipient of aid) and can bypass the experiences of others in deciding what is best for them. This process marginalises disabled people further and fails to acknowledge and respect the agency of each individual person whose desires and needs may be very different from others.

The starting point for any intervention must be the acknowledgment that disabled people as individuals have voices. As individuals they should be listened to as they articulate their experiences of marginalisation. Development interventions must be designed through a dialogue between all parties and must be open and constant. This dialogue must build upon existing support networks rather than implant western constructed models of *ideal social inclusion*. Policy and practice must influence each other in a constant and ongoing manner (Mosse 2005). This process should be mediated by the experiences of those it is intended to help.

This article uses ethnographic research techniques in presenting a case study of one family's experiences of living with impairments. The case study focuses on a family of four, three of whom are visually impaired. The family are from a low caste and live in rural Rajasthan. I visited this family in January 2002 with a Gandhian NGO and their western donor agency. The experience of visiting this family provoked many feelings and reactions in me which I feel should also be documented in this article. These experiences have allowed me to think about disability and international development with a certain openness and reflexivity which should be an integral part of the development process. I am an outsider and in my attempt to understand the experi-

ences of others I must be open in exposing my own prejudices and the impact of my western culture on my perceptions of social exclusion in rural Rajasthan. I spent six months living in the same area of Rajasthan as this family. I visited them on a few occasions and learnt of their progress through the local Gandhian NGO. It was clear that although there are limits in terms of life opportunities open to this mother and her young daughters they are supported by a caring community who firmly believe they have a right to a secure subsistence. As with all ethnography the account of this family represents a story, my story which I very much hope is also theirs.

Critique of Development Practice in Regard to Disability

The image of a physically disabled person living in extreme poverty is often used by NGOs. The use of such an image assumes that to be disabled in the Developing World means you are acutely poor. This link between disability and poverty then conjures up many more assumptions of extreme hopelessness and desperation. In using this image the notion of disability and poverty as the worse case of human suffering is asserted. Beresford (1996) points out that an analysis of disability based solely on poverty is both inaccurate and misleading. Clearly disabled people are presented as specimens of truly oppressed victims of backward societies in need of salvation.¹ Although it is true that disabled people are among the poorest in the Developing World (Kauppinen 1995) the constant use of extreme images of impairment and poverty homogenises disabled people into a single category of *underdeveloped*. The result of this homogenisation is highly oppressive. Berresford states: "There has been a tendency to isolate and lump people together indiscriminately as poor, without examining the different causes of their social and economic exclusion, and to stereotype them as dangerous or dependent. The effect has been to obscure both people's differences and their shared oppressions." (1996:554-5)

The labels of *poor* and *disabled* are highly stigmatising and an unhelpful basis for action. To be poor and disabled is not just about a low standard of material comfort and subsistence but is also about a denial of rights. In addition such labels fail to allow individual disabled people to articulate their different experiences of both poverty and living with impairment. These experiences are often excluded and systematically ignored by development policy. Instead a larger image of an *underdeveloped* Other is used by the international community towards which policy and aid is directed. This overarching image of an underdeveloped person cannot respond to the

huge variants of marginalisation and is the reason disability has been consistently ignored by international development agendas.

The term *underdeveloped*² is used to denote those whom the West sees as in need of enlightenment (Esteva 1993). According to Hobart (1996), development practice is in reality a strategy for the maintenance of western sovereignty through transforming the underdeveloped in order for them to fit into a vision that reflects the way the dominant powers (West) would like the world to be (Sachs 1992, Escobar 1988, Chambers 1996). Gramsci (1971) anticipates this argument when he describes how modernisation theory sees society or culture as the obstacle and the element that must be changed if hegemonic values are to be imposed and western power assert its control. Through this process of transformation the underdeveloped Other is encouraged to strive for the status of a developed person: "the knowledges of the peoples being developed are ignored or treated as mere obstacles to rational progress." (Hobart 1993:2) In fact, the individuals who are supposed to be the recipients of improved lives are rendered passive. Agency is identified only with changes in the economic or political structures of a country, and western knowledge, through the process of development, consequently embeds itself in the political culture of underdeveloped countries.

Those that are placed in the category of underdeveloped are considered ignorant and in need of the continued presence of western NGOs. If a project fails development practitioners will often blame the lack of appropriate knowledge of the local community (Mamdani 1972). Local knowledge is thereby impoverished by the development discourse (Richards 1993). Those targeted to receive aid are not involved in the decisionmaking (Black 1991); instead western constructions of knowledge determine who is qualified to know and act and who is not. The discourse creates the development expert (typically white, middle/upper-class and educated), the only one who possesses the wisdom to effect positive and lasting change (Parpart 1999). This *expert* designs the development policies which through their micro focus hide a macro level political agenda which is detached from the daily realities of the poor.

An Other has been created to symbolically represent the supposed needs of the Developing World, but because this Other has been constructed by the development discourse it blocks access to real people and real needs. The huge budgets that development agencies command contrasted with the limited success their interventions achieve clearly suggests that something is going wrong. De Sousa Santos (1999) states: "Suffice it to recall how the great promises of modernity remain

unfulfilled or how their fulfilment has turned out to have perverse effects." (1999:30) De Sousa Santos lists statistics that reveal an ever-widening gap between the rich and the poor. Further evidence to support the claim that development is failing to deliver on its promise of global equality can be found in the numerous analyses of failed development projects (Gardener and Lewis 1996, Crewe and Harrison 2000, Marchand and Parpart 1999, Mosse 1994, Hobart 1993). A main reason for a project's lack of success is often identified by the authors of case studies as being inadequate consultation with members of the target community. NGOs' actions suggest that they believe that consultation between NGO workers and the recipients of aid is not needed because NGOs believe they already *know* the focus of their compassion. However, if they really knew what their recipients needed than surely the success rate would be higher? The effects of NGOs will continue to be limiting for as long as they are focused on this symbolic Other rather than the lived realities of others. Hobart (1993), Escobar (1988), Esteva (1993:90), Mosely (1987:21), Hayter (1971) and Sobhan (1989) all describe how the overarching discourse of development functions to prevent reality from emerging through its repressive homogenisation of whole populations into this image of a poverty stricken Subject (or Other).

Yeo and Moore (2003) and Masset and White (2004) state that disability has been systematically ignored by development agencies, this is clear by the fact that it rarely appears as a separate issue on international development agendas. Until this overarching notion of an underdeveloped Other is eradicated there exists little chance of a space opening up for meaningful dialogue based on a respect for individual rights. Such a space requires, not just an appreciation of difference, but a consensus over the rights that have been so far denied to disabled people. Attitude change alone cannot achieve inclusion of disability in the development discourse. A dramatic shift must occur that depassifies the disabled body by acknowledging the voices of people living with impairments. The current impulse dominating the development industry in which the diversity of voices are ignored must be replaced with a desire to know and understand the needs of others.

At present the development discourse believes that there is only one path for human progression, which involves the transformation from *underdeveloped to developed*. In relation to disability this process utilises medical intervention to rectify the perceived damage of the disabled body (Coleridge 1993). Although disabled people living in the Developing World do need money, this money must be channelled through a dialogue that wishes to hear

and respond to their specific experiences of marginalisation. In other words, if the social model of disability is to work effectively in the Developing World it must be founded on a shift in how disabled people are viewed by development agencies.

The biggest barrier to the implementation of a rights-based social model of disability is that at present power is exercised through money, and those who want donor aid must conform to the dominant rationality of the *giving* institution (Hulme and Edwards 1997). According to Hulme and Edwards (1997) and Edwards and Hulme (1992) NGO workers insist on certain conditionalities (which have often been set by larger donor agencies) that determine the specific nature of the projects implemented. These conditions remove the possibility of dialogue through which projects can be constructed in partnership with local communities. Individuals within target communities are therefore treated as passive subjects and are denied the agency to shape their own futures. This imposed subjectivity contradicts the stated objectives of development practice as it serves to limit human freedom rather than increase it. Escobar (2002) and Sachs (1992) go as far as to describe this process as violent. This oppression is hidden within development because of the objective of alleviating suffering. It is not the stated desire to rid the Developing World of poverty that is the problem but rather the way in which this suffering is symbolised within the boundary of a subject projected as the *underdeveloped Other*. This symbol acts as a camouflage, and as long as this suffering subject exists it requires a second subject who presents itself as possessing the potential to liberate. However, rather than liberate, the second subject dominates and dictates how the Other should live. Until this relationship of dominance at the heart of the aid industry is challenged the experiences of disabled people will continue to be ignored. Furthermore the increased levels of poverty and global inequality will continue. A shift in power must therefore occur that allows for both parties in the aid relationship to be regarded equally. In such a relationship Fagan (1999) argues that local people should be perceived as agents of development rather than as passive recipients. The giver of aid merely facilitates and supports the actions and desires of the person living with impairment.

Deconstructing the Passive Subject

The answer to overcoming this hegemony is not the withdrawal of western assistance from the Developing World. It is not acceptable for NGOs just to disappear from the lives of others for fear of being accused of dominating and suppressing them

(as Hobart 1993, Bloch 1983, Hayter 1971, Escobar 1995 and Sobhan 1989 seem to suggest). Di Leonard rejects such an outcome, arguing that "post-modern cultural relativism falls into politicised irresponsibility." (1991:24) Theory falling in the category of "post development" (Parfitt 2002) can certainly be accused of this. Fagan similarly argues: "adopting the privilege of being antidevelopment is not in my view politically or morally viable when sitting in an 'overdeveloped' social and individual location." (1999: 180) Instead the challenge to the macro level power structure must come from the grass roots; the lived experiences and agency of those this symbolic order wishes to maintain as passive subjects. Images of disabled people living in acute poverty must be replaced by a plurality of voices talking about their life experiences and dreams.

Listening and responding to others

The relationship between others or specifically between NGO workers and agents of development must be founded in respect between others and a desire to understand their differences. The work of Luce Irigaray is useful in understanding the qualities that must be present in a relationship that is free from power. Irigaray (2000) states that the space between subjects must be transformed from one in which power is contested to one shaped by peace and tranquillity. In such a space listening to the other does not involve the destruction of the other. Irigaray claims that an equal and harmonious relationship with an other is worth striving for since it offers the possible of reciprocity from which both parties can benefit. She states that it is through a relationship with an other that you should come to know yourself. There is a reflexive dimension in the dialogue with the other. "As I know you I let you see what I know of you; in return you allow me insight into what you know of me." (Irigaray 2000:32) This dialogue relies upon the determination of each party to know the other and in doing so facilitate the other in their own personal development.

Irigaray describes a relationship based on a perfectly reciprocal dialogue in which both beings reflect what they have learnt of each other. *Silence* is a vital component in this discourse; without it reflection is not possible. Without *silence* the voice of the other cannot be heard. According to Irigaray, if such relationships comprised society, then the arms of the state would operate to preserve and respect individuality rather than to master it and acquire supremacy. If such a dialogue founded development practice then the present tendency in development practice to dominate the Developing World through replicating western values and models would cease.

NGO workers must acknowledge their positioning within the binary opposition Developed/Underdeveloped and move towards a reciprocal relationship as outlined above. However, if reciprocity is to be achieved then the NGO worker has to allow her/himself the possibility to change as a result of interacting with agents of development. If change is acknowledged as a benefit of such a relationship the power imbalance caused by the presence of donor money can be reduced. Although the agent of development will not give money back to the NGO worker they can at least give them the chance to see themselves in a new way. If aid were to be conceived of in terms of a reciprocal gift which all parties benefit from the power embedded in the term *aid* could be replaced with a sense of equality. Stirrat and Henkel (1997) state that as it currently stands, there is nothing reciprocal about the act of giving in development. "Here, the act of receiving is hedged with conditionality at best, while at worst the gift may become a form of patronage and a means of control." (1997:72) Aid is a vehicle through which the giver can attain dominance over an Other. The concept of *gift* could be reciprocal if the giver could let go of the desire to transform the Other and realise the potential for their own growth through dialogue with others. To be open to what the other can give you driven by a concern to express love and respect holds powerful potential to restructure the relationship between NGO workers and agents of development.

The case study presented below represents my attempt to gain an understanding of how others live and experience their specific impairments. My informants have raised provocative questions that challenged assumptions that the Developing World possesses the most *backward* and prejudicial of attitudes towards disabled people. Whilst Yeo and Moore's (2003) article can leave us in no doubt that disabled people in the Developing World are marginalised by societal factors these case studies suggest that more ethnographic research is needed documenting how different communities respond and react to living with people who have impairments.

Case Study: Blind family in Rajasthan North India

Neela is a blind forty-three year old mother of two daughters. Both daughters – Prem who is twenty, and Shobila who is twenty-four – are also blind. The father's name is Krishnam, he is fifty-five and is the only sighted member of the family. This family is from a low caste known as Kumhar which translates as potters. It is traditional for Kumhar families to make their living making and selling clay pots.

These pots are used to fetch and carry, and store water. Krishnam is unable to work because he must remain at home to look after his wife and daughters. Because this family is so poor they do not have access to technology and life is hard. Cooking is done over a fire which requires wood to be collected. The process of collecting, laying and lighting a fire is complex and virtually impossible without sight. The process of collecting and carrying water from the village well is also complicated when you have no sight. Neela, Prem and Shobila cannot go out unguided.

I first visited this family in January 2001, it was a fleeting trip and I was with a group of representatives from a UK donor agency. It was a strange and uncomfortable experience. We visited this family in the pitch black. The family's home has no light mostly because of the cost of electricity. Suddenly flashes started going off from cameras. I caught glimpses of Neela, Prem and Shobila, in the split seconds as the flashes went, obviously they could not see me. Others in my group were keen to capture this family on camera, keen to expose, reveal what could not be seen in the darkest of the night. I later saw the photos of that night and felt uneasy. The camera had been pointed straight at their eyes. The eyes captured in this shot clearly belonged to someone who had a severe visual impairment. The pictures were then used on a display board to promote the work of the NGO. This family was used as an example of disadvantage and extreme poverty much in need of western help. Whilst Krishnam, Neela, Prem and Shobila did need help, what was not told in that picture or elsewhere was the extent to which they were being supported. I asked them on another visit how they coped with everyday life. Krishnam described how family friends came each day with food and helped with household chores.

In Krishnam's own family it was only his younger brother and his wife who came to help. Krishnam's family was poor and not seen as a good match. Neela's family were keen to marry her to someone who would look after her. The only family willing to take her was Krishnam's. The financial drain Neela was thought to bring was too great for other more wealthy families. The difficulties Neela found in getting married highlights her social exclusion. Harris-White (1999) documents the difficulties disabled people in Tamil Nadu face in getting married and argues these experiences point to an unequal access to rights of passage. Despite this level of exclusion Neela and her daughters have been supported by families belonging to the same caste. This support was maintained throughout long spells of heavy drought. This sense of responsibility towards them expressed by their community is perhaps linked to notions of caste identity. Both Zene (2004) and

Leslie (2004) explore notions of collective caste identity, which they argue unites families and individuals regardless of levels of poverty, gender and disability.

The experiences Neela and her daughters have of living with an impairment were not appreciated by the donor NGO. The photographer ceased a photo opportunity. The image provided him with evidence of extreme poverty and suffering. This NGO did not attempt to access the specific needs of this family but used their image to further create a category of an underdeveloped Other. If effective strategies to ease the marginalisation of this family are to be implemented they must be founded on an understanding of what support already exists and appreciation of what kind of life Neela and her daughters would like to lead. This information can only be gathered through open and empathetic dialogue.

Conclusion

Although a rights-based approach is needed in terms of addressing the lack of resources given to disabled people in many developing societies the mechanism through which these rights are to be delivered also needs to be examined more closely. At present the aid industry has not adopted a methodology that is reflexive enough to allow for the experiences and voices of others to be heard. Until a more effective model is formulated and adopted it is unlikely a social model of disability will ever be successfully implemented in the Developing World.

Anmerkungen

- 1 De Groot makes a similar argument in relation to women. She describes how women in this discourse are understood to be "exotic specimens, as oppressed victims, as sex objects or as the most ignorant and backward members of 'backward' societies." (1991:115) Women are portrayed as a weak Other contrasted against the strong liberated women of the West.
- 2 Bloch and Bloch (1980:127) discuss the binary opposition inherent in the development discourse, which separates the North (civilised) from the South (uncivilised).
- 3 "The advanced capitalist countries, amounting to 21 per cent of the world's population, control 78 per cent of the world production of goods and services and consume 75 per cent of all the energy produced. Textile or electronics workers in the Third World earn twenty times less than workers in Europe and North America doing the same jobs with the same productivity. Since the debt crisis emerged in the early eighties, Third World countries in debt have been contributing to the

wealth of developed countries in liquid terms, by paying each year an average of \$30 billion more than what they get in new loans. During the same period, available food in Third World countries decreased by about 30 per cent." (de Sousa Santos 1999:30)

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Zusammenfassung: Entwicklungsländer werden häufig als rückständig in Bezug auf die Wertschätzung von Inklusion dargestellt. Das Stigma, das der Behinderung anhaftet, scheint dort größer als in den Industrieländern zu sein. Die Autorin gesteht ein, dass knappe Ressourcen die Inklusion beeinträchtigen, betont jedoch, dass dies nicht unbedingt tiefere Vorurteile gegenüber Behinderten widerspiegelt. Der Entwicklungsdiskurs hat die Kategorie des unterentwickelten Anderen geschaffen, in der alle marginalisierten Menschen zusammenfasst werden. Diese Bezeichnung ist jedoch ungeeignet, die verschiedenen Erfahrungen und Bedürfnisse von Menschen mit Beeinträchtigungen abzubilden. Die Autorin stellt traditionelle Unterstützungsnetzwerke vor, die in vielen Gesellschaften existieren, und schlägt vor, dass Entwicklungsprojekte auf diesen aufbauen sollten, anstatt westliche Modelle von Inklusion zu exportieren.

Résumé: Cet article montre que les pays en voie de développement sont fréquemment décrits comme étant arriérés en ce qui concerne l'appréciation de l'inclusion. De plus, le stigmata, inhérent à l'infirmité, semble y être plus important que dans les pays industrialisés. L'auteur admet que des ressources rares entravent l'inclusion, mais cependant souligne que cela ne reflète pas forcément les préjugés profonds concernant l'infirmité. Le discours du développement a créé une catégorie des autres sous développés dans laquelle sont groupées toutes les personnes marginalisées. Cette étiquette est cependant inappropriée pour reproduire les divers besoins et expériences de personnes ayant des entraves. L'auteur présente des réseaux de soutien traditionnels qui existent dans beaucoup de sociétés et propose que les projets de développement devraient être construits sur ces réseaux au lieu d'exporter des modèles occidentaux d'inclusion.

Resumen: Los países en vías de desarrollo muchas veces son vistos como países subdesarrollados con respecto a la inclusión. El discurso del desarrollo ha creado la categoría del Otro Subdesarrollado, la cual contiene todos los seres humanos marginados. Pero esta categoría es inadecuada para dar un imagen de los diferentes experiencias y necesidades de las Personas con Discapacidad. El autor constata, que principalmente los pocos recursos en estos países frenan a la inclusión, mucho más que los prejuicios existentes, y él presenta redes de apoyo tradicionales y propone, que los proyectos de desarrollo se orienten más en ellos, en vez de exportar modelos de inclusión occidentales.

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