‘Staff would be whispering’: Exploring employment related stigma experienced by women with intellectual disabilities in Ireland.

**Background:** Individuals with intellectual disabilities are particularly vulnerable to stigma and continue to face inequality as a result of the attitudes and beliefs of others. This puts them at risk of social exclusion and can affect their employment opportunities resulting in varying degrees of stigma around the concept of work.

**Objectives:** This research is in the context of a larger qualitative study. It aims to explore employment related stigma experienced by women with intellectual disabilities in Ireland and identify the main barriers to employment.

**Methods:** A qualitative research method was chosen for this study and a critical disability theory was used to guide it. Semi-structured interviews had already been carried out and transcribed by previous research students. The experiences of twelve female participants with intellectual disabilities aged 30 -65 were analysed thematically using ATLAS.ti software.

**Results:** Three key concepts emerged from the data. “Employment participation” explored participants work in the context of day centres and sheltered workshops. “Range of opportunity” revealed the scale of employment opportunities available to participants and “Experience of discrimination” exposed participants employment related stigma experiences.

**Conclusions:** Women with intellectual disabilities are at risk of employment related stigma when exposed to a range of employment opportunities. Occupational therapy has the potential to play an important role in bridging the gap between sheltered workshops and the employment market by providing support and educating employers and co-workers to minimise stigma experiences in Ireland.
Introduction

Stigma refers to the prejudice and discrimination that a person experiences as a result of having a certain characteristic that is deemed flawed by society’s standards (Goffman 1963). Stigma is a challenge faced by people with disabilities (Stuart 2006, Ali et al 2012) and is perceived as the biggest barrier to employment (Scheid 2005). The National Intellectual Disability Database found that only 5% of working age adults with intellectual disabilities were employed in Ireland (Health Research Board 2011). This study aims to explore employment related stigma experienced by women with intellectual disabilities in Ireland and identify the main barriers to employment derived from these experiences.

Literature Review

The benefits of working are abundant, some of which include earning a wage (Judge et al 2010), improved self-worth, independence and social inclusion (Carew et al 2010); and many people with intellectual disabilities do not get the opportunity to experience these benefits. Many would like to work (McConkey and Mezza 2001) and get a chance to give back to their community (Brown et al 2009). The Disability Act (2005) defines disability as a “substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment” (The Disability Act 2005). In Ireland, section 9(a) of the Equality Act 2004 requires employers to provide accommodations for people with disabilities so that they can access, participate and advance in employment (Employment Equality Act 1998, 2004). Although most employers are aware of these policies and legislations they do not always apply them to practice (O’Neill and Urquhart 2011). There are many challenges during the hiring process for people with disabilities, such as the stereotype that people with disabilities are less capable of getting work, doing work and staying in the workforce (Goldberg et al 2005, Baldwin and Marcus 2006, Kaye et al 2011). These stereotypical attitudes correlate with Link and Phelans (2001) stigmatisation process which builds on Goffman’s idea of stigma and suggests that it occurs as a consequence of labeling, stereotyping, separating, status loss and discrimination. This conceptualization of stigma links with the literature presented because the stigma and stereotyping of people with disabilities stems from the knowledge, attitudes and behaviour of other people (Thornicroft 2007).
The prejudices, stereotypes and discrimination experienced by people with disabilities have resulted in the feeling of stigma across many cultures (Kock 2012). The purpose of Article 27 in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is to prevent discrimination around employment; unfortunately Ireland is still waiting for this to be ratified. The odds of experiencing employment related stigma in Ireland are twice as likely for persons with intellectual disabilities compared to a physical disability (Watson et al 2010). A concern about the added cost of disability accommodations, the lack of experience working with people with disabilities (Burge 2007), and the fear of a potential lawsuit are among the top concerns of employers when considering hiring a person with a disability (Kaye et al 2011).

Prejudicial attitudes such as those stated can force a person to question disclosure of their disability (Joachim and Acorn 2000; Goldberg et al 2005; Jans et al 2012). Disclosure is a very complex thought process for disabled persons’ seeking employment (Dalgin and Bellini 2008). It can be influenced by many factors; the attitude of the employer, how visible or invisible their disability is (Jans et al 2012) and their own disabled identity (Brown et al 2009). Not every person with a disability has the opportunity to consider disclosure; people attending activation day services, sheltered workshops and supported employment are already known to have a disability. A sheltered workshop or day service is an employment programme for people with intellectual disabilities as an alternative to working in the open labor market (Migliore 2010). The principle behind sheltered workshops is to gain valuable skills through training, empowerment and rehabilitation, which assist in the transition to supported employment (Cimera 2011; Holmqvist 2010; O’Hara and O’Shaughnessy 2004). Unfortunately this is not always the case (Gill 2005; Cimera 2011) with a transition rate between 1 and 5% (Beyer et al 2002; Hoffman 2013). Sheltered workshops have been controversially compared to “sweatshops” (Gill 2005), a place of isolation and exploitation with little or no opportunity to progress to actual employment (Cimera 2011; Hoffman 2013). This consolidates the attitude that people with disabilities should be hidden away from society (Scheid 2005).

Cimera (2011) also found that attending a sheltered workshop did not increase the chances of finding supported employment anymore than not attending. In addition to this, people in sheltered workshops earn significantly less than people in supported employment, work fewer hours and cost more in services received from vocational rehabilitation than people in supported
employment (Cimera 2011). A study on employment issues for people with intellectual disabilities in Ireland found that out of 753 participants, 6.6% were in some form of paid employment, 7.4% perceived they were in employment when attending activation day centres, and 12% attended sheltered workshops where the average weekly wage was €26.90 (McGlinchey et al 2013).

Wave 2 of the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA) reported that 4 out of 5 people attending day services reported being happy with the services (IDS-TILDA 2014). However, Health Information and Quality Authority (HIQA) reports were explored, and many of the disability services inspected were deemed non-compliant with day service regulations and service users did not have the choice or the opportunity to participate in activities that were meaningful to them (HIQA 2016). Every individual, regardless of disability has the occupational right to make choices, participate in occupations that are meaningful to them and be included in society (Hammell 2008). If these rights are violated then occupational injustice has occurred (Townsend and Wilcock 2004). The majority of literature reviewed focused on both genders. There was little research on employment related stigma experienced by women with intellectual disabilities in Ireland. This study intends to build on the research and focus solely on women in Ireland, aged between 30 and 65 years.

Methodology

Critical Disability Theory guided this study (Pothier and Devlin 2011), it focused on the participant’s experiences of stigma using qualitative interviews and explored disability oppression. It guided the analysis of stigma, by exploring the social model of disability and how it affects autonomy, inclusion and participation in society for people with disabilities, rather than focusing solely on a person’s disability (Hosking 2008). Using this perspective the study examines the occupational injustices encountered by the participants and explores how these injustices limit opportunity to participate in meaningful occupations, something that is crucial for social inclusion, health and wellbeing (Townsend and Wilcock 2004).
Data Collection

The experiences of twelve female participants with intellectual disabilities aged between 30 and 65 were explored for this study. A qualitative methodological design was used as part of a larger study. This method was selected because it allowed the researchers to capture the participant’s personal experiences of stigma; something a quantitative design would have found difficult (Yin 2011). The researchers did not use an ethnographic approach but were guided by ethnographic principles (Hammersley and Atkinson 2007).

The semi-structured interviews were audio-recorded and carried out in a place familiar to the participant for example; a private room in a day service, sheltered workshop or at the participant’s home. The key content of the interviews were around daily routines, activities and then experiences of discrimination. This study employed a thematic analysis method for data collection and analysis as described by Braun and Clarke. There were six stages; the initial stage began with familiarising oneself with the dataset by transcribing the audio recordings and subsequently reading the transcripts (Braun and Clarke 2006). Following this, recurrent patterns were identified from the data and organised into codes using qualitative analysis software ATLAS.ti. The codes were then explored and key concepts emerged which were arranged into a concept map. The key concepts were further reviewed and subsequently refined. Queries were run on ATLAS.ti to generate quotations and from there the initial findings were established and finally reported.
Trustworthiness

To ensure trustworthiness the study strived to meet specific criteria; confirmability, transferability, credibility and dependability (Shenton 2004). Confirmability was assured by keeping an analytical memo to document thoughts so that the researcher was reflexive, thoughtful and self-aware of the participant’s perspectives and not their own (Curtin and Fossey 2007, Finlay 2008). A thick description of the participant’s experiences of stigma will ensure that the project is transferable to other contexts (Shenton 2004). The researchers were thorough when coding the transcripts and analysing the data to ensure overall Credibility (Curtain et al 2007). Dependability was established by using ATLAS.ti to run queries to ensure that any concern identified in the data was expressed by many participants; not just one (Sinkovics et al 2008). The use of a reflective journal also improved dependability and transparency throughout the study (Houghton et al 2013). To ensure reflexivity and to address any potential preconceptions, the researcher attended shared supervision meetings, submitted a draft for feedback and

Participant Table

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<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Employment</th>
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<tbody>
<tr>
<td>P2</td>
<td>31</td>
<td>Part-time employment in retail</td>
</tr>
<tr>
<td>P35</td>
<td>43</td>
<td>Part-time employment in office</td>
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<tr>
<td>P37</td>
<td>44</td>
<td>Full time sheltered workshop</td>
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<tr>
<td>P38</td>
<td>35</td>
<td>Full time sheltered workshop</td>
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<td>P39</td>
<td>41</td>
<td>Full time Day Service</td>
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<td>P41</td>
<td>34</td>
<td>Full time Day Service</td>
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<tr>
<td>P42</td>
<td>40</td>
<td>Full time Day Service</td>
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<td>P43</td>
<td>Late 40's</td>
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<td>P44</td>
<td>39</td>
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<td>P46</td>
<td>53</td>
<td>Full time Day Service</td>
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<tr>
<td>P62</td>
<td>47</td>
<td>Full time sheltered workshop</td>
</tr>
<tr>
<td>P71</td>
<td>44</td>
<td>Part time in retail/part time in workshop</td>
</tr>
</tbody>
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presented a preliminary analysis to an audience who were unfamiliar with the research (Finlay 2008).

**Ethical Considerations**

Ethical approval for this research project was obtained from the University of Limerick Education and Health Science Research Ethics Committee, The Health Service Executive (HSE) and the Daughters of Charity. Ethical guidelines from the 2008 HSE National Framework were adhered to and the key ethical concerns such as informed consent, anonymity and confidentiality were discussed with participants (HSE Research Ethics Committee 2008; HSE National Consent Policy 2014). Careful consideration was given to explain informed consent to the participants as it was of utmost importance to the study (Emerson et al 2004; Iacono 2006). Research students had access to the dataset already transcribed and each participant was assigned a number to ensure anonymity (Flick 2015). For confidentiality purposes the principal investigator has safely stored the data in the Clinical Therapies Department in the University of Limerick where it will reside until the duration of the project (King and Horrocks 2010).

**Findings**

From the data, three key concepts emerged. “Employment participation” outlines the participant’s work and the context in which it takes place. “Range of opportunity” reveals the scale of employment opportunities available to the participants from day services to mainstream employment and highlights the risk of stigma associated with such exposure. “Experience of discrimination” exposes the varying degrees of employment related stigma experienced by participants.

**Employment Participation**

Many of the participants attended day services or sheltered workshops and perceived this as their job. Some reported receiving a small wage, while others particularly in the day centres did not:

> I work inside the [training centre], it isn’t paid work... But I’d like to get paid for it

Many understood that it was not paid work but still considered it their job. Both services offered activities and projects throughout the day. Many of the participants reported that they did not
choose the activities that they engaged in daily. P62 was describing a typical day in the sheltered workshop, working on various projects. Her current project was making a paper Mache Easter bunny. When asked the purpose of the project she replied:

Oh, I don’t know what they’re doing it for. I just do it. I’m just working away with it.

The lack of choice or purpose behind the activities did not seem to faze some of the participants. They passively participated in whatever project was given to them. It was considered the “norm” to be told what to do at work and they simply did it. The purpose of the activities in some of these services was to keep people busy and not about offering them a choice or meaningful, purposeful activities. A small number of participants reported a different experience. P42 attended a day service fulltime and in comparison to some of the other participants, she had the opportunity to choose which activities she wanted to participate in: “The staff said it’s up to myself to choose...Use your own imagination”. She explained that she was knitting a scarf for someone and making Christmas calendars for others. She seemed to enjoy the various activities because she selected them herself, which meant that they were meaningful to her. Most of the participants attended these services for many years and there were limited mainstream employment opportunities available to them outside the service.

Range of opportunity

The participants’ employment opportunities ranged from attending day services to part-time supported employment. Some participants were given the opportunity to try work experience in the community. For example, P46 attended a full time day service and had been on work experience in the past. Here she described her duties while on work experience:

I do the photocopying, I does the cleaning and I goes for drives with [the manager], go out for hot chocolate...I feel happy when I’m doing work experience.

Working is important as it allows a person to develop their occupational role and become a valued member of society. P46 only worked for five weeks, yet she experienced the positive effects of working and having responsibilities which enhanced her sense of self-worth. Securing work experience could be long process and participants relied on a job coach to organise this, which could take months or years. P38 expressed a strong interest in trying work experience. She
notified her manager in the sheltered workshop and he organised an interview with a job coach who had not yet managed to source suitable work experience for her:

*None has ever been found...so em... I'm waiting...They haven’t found anybody and sometimes they’re busy*

P38 had been attending the sheltered workshop for many years and was never offered the opportunity for work experience. This was similar to some of the other participant’s experiences. Only three participants in the study participated in mainstream employment. P35 was many years in her current job in an office. She described her everyday role:

*I just do typing, well I do very little typing I do mostly shredding papers and I do going to the bank and the courthouse. Cause before I used do full days but they had recession and cut backs about five years ago.*

She reported that she enjoyed the experience of working and receiving a small but substantial wage. She respected her employer and this appeared to be mutual.

Some of the participants engaged in voluntary work outside of their day service or sheltered workshop. Both P62 and P71 volunteered with a retired ladies club during the week: *“We feel good. It’s great to help them out. It’s great, they enjoy it”*. They had taken on a caring role and enjoyed the responsibility of helping others. They were reaping the benefits of working in addition to challenging societal norms and attitudes towards people with intellectual disabilities. However; with this range of opportunity came the added risk of exposure to employment related stigma, which stemmed from societal attitudes of disability.

*Experience of discrimination*

Not every participant in the study experienced employment related stigma, however many did. Experiences ranged from not having a choice of activities, being treated differently to others, receiving low pay and being underestimated in terms of their ability. P62 was asked if people with disabilities received the same employment opportunities and got the same treatment as people without disabilities:
Not really, some people don’t... I think some people with disabilities are told to go there, they don’t... they’re just put there... in the (day service) they’re just put there they don’t have any choice... they should be out in the community.

P62 as well as some other participants felt that people with disabilities had less choice in terms of opportunities compared to people without a disability. P42 had previous work experience in a hospital environment; however it was not a positive experience for her:

They’d be roaring at me and they said P42 do this, P42 to that, P42 there’s no tissue in the toilet.

Other participants experienced similar situations where they were treated unfairly or accused of something which they strongly denied. Here P2 recalled a past experience of employment related stigma, where an employer underestimated her ability to work in an office environment simply because of her disability:

They think that you wouldn’t be able to do it and they wouldn’t give you the chance... in one place I tried office work and they thought it was too hard for me, but then I did the European Computer Driving License course and it is good.

She demonstrated her competence to work in the office by completing a course to improve her skills and ultimately proved them wrong by challenging their attitudes about disabilities. P2 was in a volunteer post and was working in part time supported employment for many years. She recalled how her co-workers in the shop treated her differently when she first started and how their attitude towards her had changed as of late:

It's probably getting a bit better now... people understand what your ability is and not your disability.

Some participants reported similar experiences to P2. The more employers were aware of the capability of participants, the less stigma was present. However, the general consensus from participants with a heightened awareness of their disability was that there was a divide between people without disabilities and them. Here P42 discusses the difference between securing a job with a disability and without:
They get them; they get jobs straight away d’know? They get in straight away and like I can’t now….you know I’m waiting and waiting trying to get into the hairdressers.

P42 along with many other participants must rely on a job coach to secure employment while people without a disability can fast track a job by sourcing their own work. The job coach usually discloses participants’ disability to potential employers. The subject of disclosure was reflected on by some of the participants. Here P42 discussed her disability and whether she openly discloses it to others:

I try to hide it…Yeah I don’t (show) it, embarrassing saying it, I wouldn’t say nothing, I’d be embarrassed saying I have a disability, it’s not nice.

Unfortunately the stigma surrounding people with disabilities and the discriminatory attitudes of others made some participants feel different and some yearned to be “normal”. Others had difficulty understanding the terms disability and stigma and were unaware of their own disabled identity, and thus did not report experiencing employment related stigma

Discussion

This research provided a window into the working lives of woman with intellectual disabilities in Ireland and their experiences of employment related stigma. The literature reviewed highlighted the challenges faced by people with disabilities around the concept of work as a result of discriminatory attitudes and the stereotype that they are not capable of working efficiently (Kaye et al 2011).

Sheltered

The range of employment opportunities offered to participants with intellectual disabilities was minimal. It began with day centres and sheltered workshops, which were just that, a place to shelter people with intellectual disabilities away from society. This strongly correlates with the literature reviewed, in particular Cimera (2011) and Hoffman (2013) who described them as institutions of isolation. However, this form of sheltering failed to protect participants from society’s preconceptions of disability (Scior 2011; Burge 2007) as they were required to endure meaningless activities while attending these services and on occasion a job coach sourced suitable work experience. Most were unaware how occupationally unjust this was and that
everybody regardless of a disability has the right to participate in meaningful and purposeful occupations (Hammell 2008). The findings suggest that the risk of exposure to stigma from the ‘outside world’ further increased in mainstream employment. It was here that participants were open to the elements so to speak, the elements being societal attitudes towards people with intellectual disabilities. Supported employment, which notably was a rare occurrence for participants in this study, was seldom attained after work experience. It must also be noted that there were no reports of employment related stigma by participants in their current supported employment, only when first starting. Experiences of discrimination occurred for many of the participants while attending work experience, which suggests that the short time frame of work experience did not allow people with intellectual disabilities to adequately showcase their ability to employers and co-workers. (Migliore et al 2007; Jahoda 2008).

*Perceived employment*

Many of the participants in this study perceived attending sheltered workshops and day services as their job; however they received little or no wages for doing the job. Allowing people to perceive that they are working if they are not receiving working benefits is occupationally unjust and is reflected in the literature (McGlinchey et al 2013). If these services are to continue, changes should to be made to enhance opportunities for social inclusion in line with the UNCRPD (Quinn 2009). In 2002 a draft ”Code of practice for the operation of sheltered occupational services” was developed by the National Disability Authority and the Equality Authority among others, to address the legal status of people who attend sheltered workshops (NDA 2002). This was never implemented. The code of practice would have sought to rule that individuals who attend sheltered workshops would be considered workers and not service users. This would have entitled them to the minimum working wage and the same rights as other workers in Ireland, moving towards a more occupationally just society (Townsend and Wilcock 2004).

*Barriers to employment*

Gender inequality is still an issue in the Irish workforce and women with intellectual disabilities are doubly disadvantaged when seeking employment (Kavanagh 2007; O’Hara 2008). The barriers to employment stem from society’s preconceptions about people with intellectual
disabilities (Burge 2007), which echoes the findings and is affirmed in the literature that they are viewed as incapable of working efficiently (Kaye et al 2011; Scior 2011). This had an effect on some participant’s view of their own disabled identity and in turn resulted in a barrier to employment.

Ireland is still a predominantly catholic nation and continues to cling to the concept of institutions as a way of supporting people with intellectual disabilities (Fleming et al 2016). The purpose of establishments such as day services and sheltered workshops was to provide the necessary skills to enhance employment opportunities and social inclusion for people with disabilities (Cimera 2011; Holmqvist 2010; O’Hara and O’Shaughnessy 2004); however the findings of this research contradict this ethos. Many of the participants who attended day services and sheltered workshops were found to engage in meaningless activities that did not enhance employment opportunities or promote social inclusion, and this was a further barrier to employment.

**Limitations**

The main limitation of this research study was that the researchers were working from an already existing dataset where the interviews were previously carried out by past research students and experienced researchers. This prevented the researcher and the participant s from building any type of rapport which may have provided the researcher with richer information for the project (Leavy 2014). A further limitation to this study was the inexperience of one of the researchers; however this was counter balanced by the principal researcher who had many years’ experience carrying out research.

**Implications for occupational therapy practice**

Currently, employment support services for people with disabilities in Ireland do not receive occupational therapy input. An occupational therapy programme could assist with the transition from sheltered employment or day services to supported employment in the mainstream working market (Jang et al 2014). The aim of the programme would be to secure appropriate employment for the client, by offering them the opportunity to participate in meaningful and purposeful activates, in the hope of developing skills, enhancing quality of life, overall health and wellbeing (Clark et al 2001).
Many participants reported that employers had underestimated their ability to carry out the job, which mirrors the literature outlining employers concerns when hiring a person with a disability (Goldberg et al 2005; Baldwin and Marcus 2006; Kaye et al 2011). Current opportunities of work experience offer a ‘quick fix’ of a number of weeks work and then individuals re-enter the sheltered workshop with little opportunity to progress to supported employment (Cimera 2011). Educating employers on the ability of the client with a view to permanent employment will work towards minimising stigma and breaking down barriers. A transition programme would promote essential skills for optimum function at work, workers strengths and abilities would be highlighted and the employer’s needs would be met to maintain successful employment. This would be in line with Article 8 and 27 in the UN convention of rights for persons with disabilities which strives to promote awareness of the capabilities of people with disabilities, and ensure the right to participate in meaningful employment (United Nations 2006). These are vital components for the successful development of a worker role (Kennedy-Jones et al 2005).

Moreover it will ultimately break down barriers to employment for women with intellectual disabilities and further improve the transition rate from sheltered employment to supported employment (Beyer et al 2002; Hoffman 2013).

Further Research

This research was culturally specific in that it was based in Ireland and focused on women’s experiences of employment related stigma. The findings of this study cannot be generalised across other countries. The interviews took place outside of the participant’s place of work and no observations were carried out in the work or home environment. An ethnographic study around how people with intellectual disabilities in different countries function on a daily basis in their home and work environment would make for interesting future research. Additionally, a gendered analysis of the employment related stigma experiences of men from the same dataset would be beneficial to better understand similarities and differences between both genders.

Conclusion

Preconceptions concerning people with disabilities can be a barrier to employment and women with intellectual disabilities continue to experience stigma and be underrepresented in the employment market (Synder et al 2010; McGlinchey et al 2013). Based on the findings of this
study, the range of employment opportunities available to women with intellectual disabilities can expose them to varying degrees of stigma. The gap between sheltered workshops and supported employment in Ireland must be bridged and occupational therapy can play an important part in this successful transition. If provided with the necessary skills and supports, people with intellectual disabilities can thrive in the employment market (Suzuki et al 2008). However, this must be combined with cooperation from both employers and co-workers and the only way this can be achieved is by educating them on the capabilities of people with intellectual disabilities to minimise stigma. Further public education and campaigns around the issue of disability could help reduce prejudicial attitudes towards people with disabilities in the future (Li 2004). This study has the potential to inform and guide Occupational Therapy practice to support occupation in employment for women with intellectual disabilities in Ireland.
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