



An Exploration of Audience Responses to Stay Up Late's (un)Ordinary Conference

Social Care professionals' responses to a conference where ALL the speakers had learning disabilities and shared how they are living 'ordinary lives.'

A Research Report By

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May 21st 2019



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EXECUTIVE SUMMARY

1.1 Overview

Stay Up Late is a registered charity in England and Wales that promotes full and active social lives for people with learning disabilities. Since the launch of the The Stay Up Late campaign in Brighton in 2006, the team has continued to advocate for people with learning disabilities to choose how they live their lives. The charity was set up to ensure that person centred planning for people with learning disabilities and autism meant that it truly reflected what an individual wanted to do in their life. Stay Up Late are involved in many community projects that enable everyone to lead active social lives. Stay Up Late organized the (un) Ordinary conference in March of 2019, which was an event where all the speakers had learning disabilities and shared stories about how they are leading 'ordinary' lives. Audience members included a variety of social care professionals, policy coordinators and other support staff and members of related fields.



Stay Up Late's principal objective is to promote full and active social lives for people with learning disabilities.

1.2. Major Achievements

The **purpose** of this study was to explore the responses of social care professionals to the March conference, with a particular focus on the potential impact of this conference on their work. The audience responses outlined a number of different ideas, from which three key areas of exploration were identified to help answer the research questions.

Three key areas of exploration and corresponding research questions:

- **Attitudes:** How the conference has shaped the thinking of the social care professionals.
- **Strengths and challenges:** How this conference will make social care professionals listen more to people with learning disabilities.
- **The Future:** How social care professionals will respond and make practical changes.

1.3. Recommendations

A number of audience recommendations were suggested about the future of individuals who have learning disabilities. Participants emphasized four crucial areas that should be focused on within our communities, that will ensure that people with learning disabilities lead healthier and more full lives: Support, inclusivity & accessibility, greater opportunity to share their voices, and public advocacy.

INTRODUCTION

2.1 Current knowledge about attitudes toward individuals with learning disabilities

Mencap is a UK charity for people with a learning disability. A learning disability, as defined by Mencap, is a reduced intellectual ability and difficulty with everyday activities – for example socialising, household tasks, or managing money – which affects someone for their whole life (Rix, 2006). Previous research has been compiled on attitudes toward people with learning disabilities. The shift from institutional care to person-centered care is viewed by majority of support staff as a positive change that allows for more choice and more time spent building relationships with residents with learning disabilities (Salmon et al., 2014). Moreover, health care providers pro-inclusion attitudes toward people with intellectual disabilities as compared to attitudes of the general population seem to suggest that in addition to offering knowledge regarding the specific health care needs of individuals with intellectual disabilities, training programmes need to promote increased interaction with individuals with intellectual disabilities as well (Morin et al., 2018). Additionally, inclusion in school and community settings was found to create opportunity for integration and exposure between the mainstream population and those with intellectual and developmental disability (Keith et al., 2015). The findings further emphasize how contact can positively impact attitudes towards those with learning disabilities. Information presented in this report about present attitudes towards individuals with learning disabilities may

allow for future studies to find ways to decrease prejudice and foster the development of positive attitudes in society.

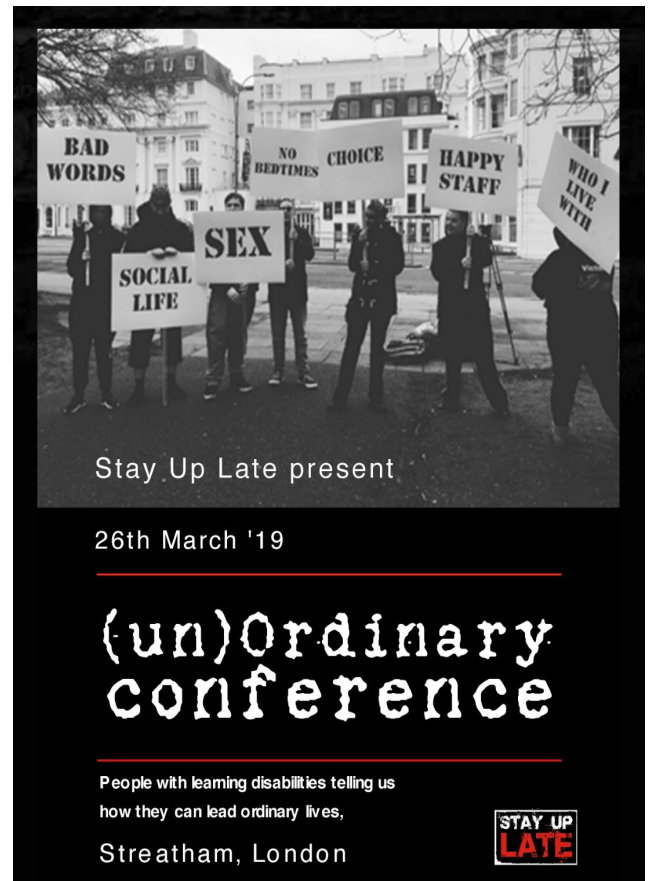
Person-centred day opportunities and supported lifestyle service place service users at the heart of their local communities. Many strongly believe everyone has the right to be in their community, and person-centered support focused on social inclusion for people with learning disabilities, takes into consideration that some people need extra help to make sure this happens (Carnaby et al., 2011). Services should be based on what people like to do and be given the support they need to do things safely. Staff working in services should all work together whatever their role is, to make sure *all* people with learning disabilities get what they need (ibid).

Though attitudes about learning disabilities have evolved over the last several decades fostering more widespread acceptance, not all cultures or countries hold positive attitudes towards individuals with learning disabilities. People from a collectivist culture hold less favourable attitudes towards people with learning disabilities than those from an individualist culture (Benomir et al., 2016). Studies of attitudes in collectivist cultures provide a basis for developing interventions that will further improve attitudes towards individuals with intellectual disabilities throughout the world.



2.2 About Stay Up Late

Stay Up Late is a registered charity in England and Wales that promotes full and active social lives for people with learning disabilities. Since the launch of the The Stay Up Late campaign in Brighton in 2006, the team has continued to advocate for people with learning disabilities to choose how they live their lives. Stay Up Late coordinate events and participate in community projects that enrich the lives of individuals with learning disabilities. Stay Up Late was created because many fans of the punk band Heavy Load who had learning disabilities, were getting increasingly frustrated that they weren't getting to see 'gigs' due to support staff working inflexible shifts. The story of the formation of Stay Up Late is one about trying to create mainstream opportunities for people with learning disabilities through music. Over a decade later, music is still a large part of Stay Up Late. Gig Buddies is a Stay Up Late project that pairs up adults who have a learning disability with a volunteer who has similar interests and they go to events together such as concerts, museums, and festivals. Stay Up Late is a unique organization and continues to support its members and advocate for people with learning disabilities to choose how to live their lives.



2.3 Research focus

Stay Up Late was set up to ensure that person centred planning for people with learning disabilities and autism meant that it truly reflected what an individual wanted to do in their life. Stay Up Late are involved in many community projects that enable everyone to lead active social lives. Stay Up Late organized the (un) Ordinary conference in March of 2019, which was an event where all the speakers had learning disabilities and shared stories about how they are leading 'ordinary' lives. Audience members included a variety of social care professionals, policy coordinators and other support staff and members of related fields.

RATIONALE AND METHODS

3.1 Purpose of the study

The research was carried out by a graduate student from the School of Applied Social Science at the University of Brighton who attended the conference. The purpose of this study was to explore the responses of social care professionals to the March conference, with a particular focus on the potential impact of this conference on their work.

The aims were three-fold

- **To explore** how the conference has shaped the thinking of the social care professionals.
- **To investigate** how this conference will make social care professionals listen more to people with learning disabilities.
- **To consider** how social care professionals will respond and make practical changes.

3.2 Participants and methods

Following the conference, in March and April of 2019, online questionnaires with both closed and open ended questions were completed by social care professionals as well as other support staff and delegates who had attended the Stay Up Late (un) Ordinary conference.

There were a total of 24 responses confidentially completed, nearly half of which provided contact details for follow-up phone interviews. In total, 8 phone interviews were conducted and focused on topics surrounding the conference that related to the research aims. The qualitative information obtained from the open ended questionnaire questions as well as phone interviews, was supplemented by the other quantitative data gathered via the questionnaire.

Although the topic of the research centered around what is ethically considered a more vulnerable population, the research itself focused on audience response and thus no direct data collection of anyone with learning disabilities took place. This research was given a favorable ethical opinion by the School of Applied Social Science Research Ethics Committee.

3.3 Data analysis

Thematic analysis was used to analyse the open ended responses and phone interviews. Thematic analysis is a method for identifying and reporting patterns within data as well as interpreting various aspects of the research topic (Braun & Clarke, 2006). Using themes involves categorizing, reorganizing, and summarizing data in relation to research questions. The similarities between responses create themes that can be used to address the research questions.

THE CURRENT PROJECT

4.1 Findings and Discussion

The quantitative data revealed respondents were between the ages of 25 and 64. While just over half (54.2%) of respondents strongly agreed the conference had an impact on the way they will work in the future, all respondents (100%) indicated that overall they found attending the conference to be worthwhile. The overwhelming positive response to the conference is an indicator that more events of this kind are highly desired. In addition, majority of respondents (83.3%) expressed the conference was very valuable in advancing one's understanding of the needs of the those with learning disabilities. Community-based approaches to mental health center on principles relating to social justice and are focused on supporting communities to respond to their own needs (Prilleltensky, 2001). Listening to and valuing the needs of the those with learning disabilities is crucial, and from the data above it is clear better understanding is achieved when those with learning disabilities are directly involved, encouraged to participate, share, and contribute their voice.

When asked if the conference changed the way they think about their job, some participants (29.2%) strongly agreed, nearly half of participants (41.7%) agreed, and of the remaining participants, some (25%) neither agree nor disagree and very few (4.1%) disagreed. Similarly, when asked if they were

likely to make changes in the way they do their job in response to having attended the conference, some participants (29.2 %) strongly agreed, and just under half of participants (45.8%) agreed, they were likely to make changes. The remaining participants (25%) reported they neither agree nor disagree. The results suggest an openness to reflection and a willingness to reevaluate how support staff work and are trained. The large amount of respondents (83.3%) who deemed the (un)Ordinary conference 'very valuable' in advancing one's understanding of the needs of the those with learning disabilities, is an indication that much can be gleaned from asking those with learning disabilities directly about their wants and needs. The core values underpinning community psychology relating to social justice, stewardship, and community must be applied to the inclusion and understanding of those with learning disabilities, if the focus is truly to be on the wants and needs of those with learning disabilities as articulated by them. If community-based approaches to mental health are to be strengthened, clinical training programs must be more inclusive of this paradigm as to develop more capacity for social action (Rhodes. & Langtiw, 2018).



4.2 Key Themes

Thematic analysis was used to analyse the qualitative data: open ended questionnaire responses and phone interviews about delegates' experiences at the conference. Three key themes emerged which were attitudes, strengths and challenges, and ideas about the future.

Attitudes

Participant responses about features of the conference they found to be most successful, revealed similarities in attitudes, many of which focused on the importance of hearing directly from speakers with learning disabilities. Some participants felt the 'motivation and intent of the conference' were aspects that made the event a success, while others focused on the diversity, the themes, and the real stories. The positive reception of the speakers from the audience is an indication more events of this nature should take place. It further highlights the importance of service providers talking directly to those with learning disabilities about how they would like to live (Deguara et al., 2012).



Attitudes

Respondents discussed the success of the conference.

"I loved that this was a conference solely led by experts, rather than what can feel like tokenism with co-production."

"Hearing stories of individuals and how the right support helped them fulfil exactly what they wanted to achieve- very **empowering**."

"Hearing real stories from people who live with a disability."

"I loved that people with learning disabilities were able to contribute their thoughts and ideas."

"**Powerful stories** from people with learning disabilities, promoting and standing up for their rights."

"Very **positive** day and great to hear learning disabled and autistic people speaking for themselves rather than being spoken about."

"Heading directly from speakers with learning disabilities and autism set the whole tone of the event and made it so **positive** and **celebratory**, as well as more challenging to people's assumptions."

"I thought hearing directly from people about their battles, but also their hopes and interests and what made them happy was **enormously valuable**."

Strengths and Challenges

Participant responses highlighted what they viewed as strengths of those who have learning disabilities as well as the challenges facing this community. Strengths of those with learning disabilities included, individuality, confidence, and the ability to engage, enthuse, and influence. Challenges of those with learning disabilities included vulnerability, lack of respect, deprivation, and lack of support. Individuals with learning disabilities do not surrender their need for growth and development, for personal relationships, or for anything else because they presents a challenge to services. Individuals with learning disabilities have the same human and civil rights as anyone else (Carnaby et al., 2011). It is interesting to note the strengths articulated revolve around the unique positive contributions those with learning disabilities bring to our communities and to society. The challenges however, revolve more around the issues society has with learning disabilities. Audience ideas about strengths and challenges point more to systemic societal problems than anything else.



Strengths

Respondents detailed perceived strengths and challenges of those with learning disabilities.

“The greatest strength is their **eternal optimism** and their ability to be completely honest.”

“Having the **confidence** and encouragement to speak out.”

“Greatest strength is being human with qualities and frailties like all of us.”

“Giving to society in a **positive** non-judgemental manner.”

“Greatest strength- ability to see things from a different angle, and **honesty**.”

Challenges

“My greatest concern is adults not being able to fulfil their potential and have the life they want, due to **lack of support** or the wrong kind of support.”

“Greatest concern is not being treated and respected as an individual and fellow human.”

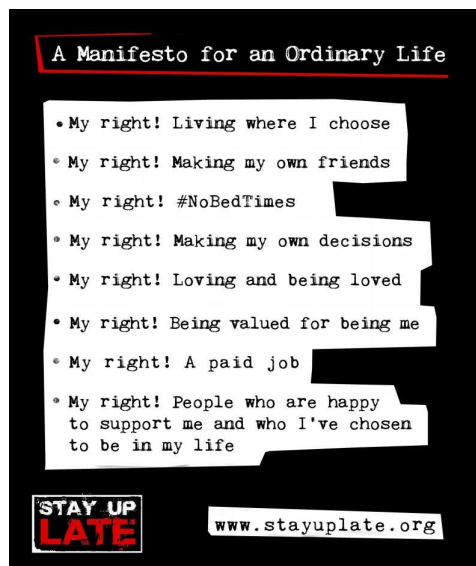
“Greatest concern would be not being within the community and living life to the full.”

“That people with a learning disability or autism are taught from a young age that they can't do things that they clearly can, which prevents them from standing up for themselves.”

“That with **discriminatory** attitudes, practices, and behaviors from the general public and decision-makers, people with learning disabilities will experience a **marginalized** existence.”

The Future

Participant responses about the future for individuals who have learning disabilities, strongly advocate for new project ideas, new ways of working as well as for personal resolutions toward change. The vision for people with learning disabilities is the same as for everyone: inclusion and participation in all areas of community life, including living independently and having paid work (Carnaby et al., 2011). Participants highlighted the need for better exposure and more awareness within the general population about how important individuals with learning disabilities are to the community. Responses also focused on promoting employment, inclusion, and increased interaction for community members with learning disabilities. There was an emphasis on collectively working together to ensure that people with learning disabilities lead healthier, more full lives.



The Future

Respondents ideas about the future for individuals with learning disabilities based on the conference.

“Want to re-evaluate how we employ staff in supported living etc. Think the whole interview process needs to be changed to ensure staff give adults with a learning disability **a choice and a voice.**”

“Encourage them, interact with them, appreciate them.”

“It has reinforced my commitment to being alongside people with learning disabilities and autistic people as individuals who deserve to be taken seriously and be given the **support and space** they need to **thrive.**”

“Greater opportunities for people to tell their stories and express their needs/ wants in a straightforward way- then we all recognise the commonality between us.”

“Challenging/ **correcting language** that is not respectful, etc.”

“**Fundraise** specifically to ensure we can be more inclusive.”

“Making sure we translate these amazing ideas and energy into practical and sustainable projects.”

“It has made me reflect on the way that we all **work together**, and that by listening and **collaborating** we can produce something better than we could have achieved alone.”

CONCLUDING REMARKS

5.1 Highlights of Stay Up Late conference

Stay Up Late is a unique organization that promotes full and active lives for people with learning disabilities. The (un) Ordinary conference was a chance to radically shift the power dynamic between people who need support and 'experts' who support them. This event was the first of its kind for many participants, who felt it was refreshing to be part of a conference where the tables were turned and all the speakers had learning disabilities. The collaborative nature of the conference allowed for many voices to come together to share issues, find solutions, and strategize about the future. The conference theater venue held around 100 audience members and it was a packed house. The audience was incredibly supportive with many cheers and moments of joyous laughter. There were musical elements as well as comedic moments, and an overall feeling of genuine support and encouragement. The speakers with learning disabilities spoke candidly about their lives -both their struggles and their triumphs- and all came across as humble and capable. Participatory action research (PAR) is a framework for creating knowledge based on the belief that those most impacted by research should be the ones to frame the questions, the design, the methods, and the analysis, and determine what actions might be the most useful

in effecting change (Torre, 2009). Community psychologists seek to enhance quality of life for communities, individuals, and society through collaborative research and action (Dalton et al., 2007). There needs to be continued advocacy for and promotion of these types of events that focus on the wants and needs of those with learning disabilities as articulated by them. PAR allows marginalized populations to become empowered with more control and autonomy over their lives. PAR is a beneficial tool committed to action, fighting inequalities, and promoting social justice and should continue to be explored further in the future.

5.2 Barriers

It is important to consider that audience members who attended the un(Ordinary) conference consisted of delegates who already have a connection to the learning disabled community, and are thus already more receptive of ideas about inclusion, support, and advocacy. There are still many barriers that face individuals with learning disabilities such as the social justice system, funding and commissioning issues, policy stagnation, and public perceptions about learning disabilities. Another barrier to living an ordinary life is an institutional approach to care, exemplified by staff shifts ending too early to take people to evening events. Moving forward, decision makers who commission and run care services must rethink their priorities if the ultimate focus is to become helping people lead healthier, happier, and more full lives.

5.3 Recommendations

There were a number of participant responses regarding recommendations about the future of individuals who have learning disabilities. In addition to new project ideas, new ways of working and personal resolutions toward change, participants emphasized four crucial areas that should be focused on within our communities, that will ensure that people with learning disabilities lead healthier and more full lives.

- **Support** - Many audience members emphasized the importance of finding the right support for each individual. Some examples included ideas relating to:

- *Supporting individuals with learning disabilities to take more measured risks to enable development and fun.*

- *Greater emphasis on fostering connections, being respectful and building rapport between support staff and clients.*

- *More listening and collaborating, less telling people what to do or how to live.*

- **Inclusivity & Accessibility** - Audience members highlighted the value of inclusivity within the community as well as better accessibility to enable greater participation within society. Some examples included ideas relating to:

- *Making all events more accessible.*

- *Better employment opportunities.*

- *Challenging the accepted ways of doing things.*

- *Making all creative and cultural events more inclusive.*

- *Designing engagement events more around the people being supported by asking in a way that is engaging and meaningful to their lives.*

- **Greater opportunity to share their voices** - Delegates expressed a desire for more opportunities to see people tell their stories and express their needs and wants in a straightforward way. Some examples included ideas relating to:

- *Offering individuals with learning disabilities the space to speak their own stories, rather than speaking for them.*

- *More positive exposure in the media*

- *Monthly focus groups with parents, careers, and those being supported.*

- *Incorporating personal stories into training events, conferences, and social media.*

- **Public Advocacy** - Audience participants underscored a need for greater public advocacy. Some examples included ideas relating to:

- *More opportunity for interaction within the general public.*

- *An increase in the amount of Stay Up Late ambassadors locally, and in cities all over the country.*

- *Having people with lived experience at training events for staff of all levels.*

- *Leading by example: More events like the (un) Ordinary conference to try to influence public thinking about learning disabilities.*

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APPENDIX

Stay Up Late (un)Ordinary Conference Questionnaire

Conference questionnaire for social care professions. This may include those working in commissioning teams, local authorities, the NHS and supported housing.

For each question please tick only one bubble.

1. What is your age group?

- 18-24 25-34 35-44 45-54 55-64 65+

2. What is your job title?

3. This conference has had an impact on the way I will work in the future.

- Strongly Agree Agree Neither agree nor disagree
 Disagree Strongly disagree

4. This conference has changed the way I think about my job.

- Strongly Agree Agree Neither agree nor disagree
 Disagree Strongly disagree

5. I am likely to make changes in the way I do my job in response to having attended this conference.

- Strongly Agree Agree Neither agree nor disagree
 Disagree Strongly disagree

6. Overall did you find attending the conference to be worthwhile?

- Yes No Other _____

7. Would you recommend a similar event to others?

- Yes No Other _____

8. What features of the conference were most successful?

9. Could the conference have been improved in any way?

10. How valuable was the conference in advancing your understanding of the needs of those with learning disabilities?

- Very valuable Somewhat valuable Not valuable at all

11. To what extent has your participation at this conference increased your willingness to make practical changes in how you work with individuals with learning disabilities?

- Greatly increased Somewhat increased No change at all

12. What (if any) are your follow up plans in terms of implementing occupational changes in response to this conference?

13. What aspect of the conference did you enjoy most?

- Speeches Break-out workshops Bedspread graffiti
 Other _____

14. What do you see as the greatest strength of this community (those with learning disabilities) and what is your greatest concern for this community?

15. How do you view individuals with learning disabilities?

- As peers As colleagues As individuals in need As clients As friends
 Other _____

16. Has this conference inspired any new project ideas, new ways of working, or personal resolutions? If yes, please specify below.

17. If you are happy to receive a brief follow up phone call about the conference, please provide your contact details in the space below. Phone interviews will be carried out by Amanda Fleg of University of Brighton, working in conjunction with Stay Up Late and I hereby consent to being contacted.

Thank you for your time.