# A Young Disabled LGBT+ Researchers Group: Working collaboratively to explore the lives of young autistic LGBT+ persons.

**Alex Toft**

Nottingham Trent University, UK

0000-0003-3734-2242

**Beth Ward**

Independent Researcher, Birmingham, UK

**Anonymous author**

## Abstract

This article explores setting up a research group and outlines how we work together. The goal of the research group is to work collaboratively to conduct research on aspects of life for young disabled LGBT+ people that we think need more research. We hope to outline the aim of the group and what we want to achieve. It will also discuss our research principles and how we have conducted research together. We hope that the article provides insight on how to set up collaborative groups, how to work together and what such groups can achieve. This article has been written collaboratively and this is reflected throughout.

## Key Words

Sexuality, gender, autism, disability, LGBT+, youth, collaborative research methods.

## Corresponding author details

Alex Toft
School of Social Sciences
Nottingham Trent University
Chaucer Building
Goldsmith Street
Nottingham NG1 5LT UK
Alex.toft@ntu.ac.uk

## Introduction

This article explores setting up a research group and outlines how we work together. The goal of the research group is to work together to conduct research on aspects of life that we think need more research.

We have written this article together. We hope it is clear and accessible. The sections are short and precise, and we thank the editors for allowing us to do this.

The overall purpose of this article is to outline the aim of the group and what we want to achieve. It will also discuss our research principles and how we have conducted research together. We hope that the reader will gain insight into how to set up collaborative groups, how to work together and what such groups can achieve.

This is a collaboratively written article. There are three people's voices here to be read. At times, Alex has pulled separate ideas together and revised the text to create a unified voice. He has also added references when appropriate. Co-writing took the form of sharing online spaces for writing sessions or working individually offline. This was a very long process as we wanted to make sure this article was a group response. We worked flexibly and to each other's strengths. Alex, for example works best with lists, whereas Anon[1] prefers answering short questions. We all preferred to work in text. It is important to note that this article is not written in the style of traditional article as a result of this approach.

The two members of the Group who co-authored this article are aged between 18-25 and are autistic and LGBT+. We wanted to write this article because we hoped that our experiences could help others conducting similar research. We also feel there is a need to include autistic voices in autistic research and acknowledge what 'that there is a relationship between involving autistic

---

[1] The third author wishes to remain anonymous due to issues of privacy and personal safety.

people in autism research and lower odds of ableist cues in researchers narratives about autistic people' (Botha and Cage 2022:42).

The research group currently consists of 10 young people (16-25) who have worked together to construct a research project (discussed later). However, this article was written by Alex who set up the group, and Beth and Anon who are part of the group. Future work may involve different members. No-one has to be involved in the group at all times. Everything the group does is flexible and individuals only take part in the activities they want to.

This article is not a guide to conducting research online. It is an outline of the group and its purpose, how we work together and what we hope to achieve.

## Ethical statement

All the group activities and emerging research work has been approved by Nottingham Trent University School of Business, Law and Social Sciences Research Ethics Committee.

## The Structure of this article

In this article we will outline three things:

1- The purpose of the group.

2- How we work together.

3- What we hope to achieve.

Having done this, we will offer some concluding remarks. The concluding remarks include why we think this article is important and the lessons we have learnt. We hope that overall, this will provide an insight into working collaboratively and managing this process.

## The Purpose of the Group

In this section we will outline what the group is and what the purpose of the group is.

## What is the group?

The group was set-up to work together to develop ideas for conducting research. We wanted to do research together. Too much research, particularly on autism, is done without asking autistic people about their experiences (Evans, 2013; Bölte, 2017; Chown et al, 2017; Cusack, 2017). Young people are sometimes included as advisors, but we did not think that this was enough. The group was set-up to work on all aspects of research, from the initial idea to telling people about the results.

Members of the group were recruited using existing networks and gatekeepers that Alex had worked with previously. Advertisements were also placed on community and group pages (Facebook). Key organisations were also helpful in spreading the word (e.g., Stonewall, REGARD, SPARK+). All adverts focussed on describing the project as a collaborative research group, with flexible levels of involvement. Participation required the young people to be aged 16-25 and identify as LGBT+ and disabled. There were no specific recruitment issues, most likely due to the flexibility of the involvement in the group.

## What is the purpose of the group?

The purpose of the group is to create a space where young people who identify as LGBT+ and disabled can work together on research. We agreed that research that compares disabled people or comes from the position that there is something strange about disabled people's sexuality/gender identity should not be the focus.

We aim to give voice to those who are rarely heard and bring these voices into a research world that is often exclusory. The group hopes to redress this balance and show how research should be conducted by those who it affects. Importantly, those who conduct the research should have knowledge of the lives of those being researched.

## How we work together.

In this section we will outline how we work together as a group. This relates to our Research Principles and Working Online.

## What are our research principles?

After clarifying the purpose of the group, we tried to understand how we could conduct research together. We held group or individual meetings online using Facebook group messaging. We started by discussing what we would like the research process to feel like. We also read some important previous research, which will be highlighted in this section. As a result, we produced three guiding principles:

1- To be respectful of difference.

2- To listen and acknowledge all lived experiences.

3- To work to understand barriers and how lives can be improved.

Our principles were guided by key terms that were repeated through our discussions. It was hoped that we could work in an inclusive fashion and make the research welcoming and safe. The group repeatedly noted that need to focus upon being human. We also found the 12 principles proposed by Henrickson et al (2020) useful whilst thinking about doing research. Their focus upon not making assumptions about research participants was particularly important.

As noted, we want to make sure that the participants voices are the most important. This approach is evident in research focussing upon the rights of disabled children and young people (Franklin and Sloper, 2009; Brady and Franklin, 2019; Toft and Franklin, 2020). The overall message of Askins (2018) was similar to our view here. Participants are the experts and by focussing upon diverse voices, change is possible.


## How do we work online?

Here we outline why the decision to work online was made.

As a result of the Coronavirus pandemic all group activities have taken place online. The group was originally intended to be a group who met physically. We have found that there are advantages to working online only. Online working can increase accessibility due to technological advancements. Software is available that means for some people working online in beneficial. Working online is often seen as more flexible and convenient (Song et al, 2004) and people can take their time to respond (Vonderwell, 2003; Kirtman, 2009). Also, interacting digitally means that people can communicate in a number of ways (video, text, audio etc.)

There are disadvantages of working online. Not everyone will have access to the internet or a computer (Chaney, 2001). There are also potential security/privacy issues particularly if households share computers (Malecki, 2020).

We found an article by Shapka et al (2016) useful in thinking about how we will conduct research online. The article also addressed some concerns we had about the move away from face-to-face interviews. The authors found that although online interviews take longer to complete and produce less information, they reveal the same type of information.

# What we hope to achieve

In this section we will outline what we hope to achieve. We will focus on what the current project is and how it was constructed.

## What is the Current Project?

The current project explores the experiences of young people who are autistic and LGBT+. It is called the 'Under the Double Rainbow' project. It is hoped that this will help to develop a better understanding of what it means to be autistic and LGBT+. This will improve lives by educating the wider public, particularly with regards to misplaced stereotypes and changing perceptions.

The project focuses upon: identity, relationships, sensory experiences, perceptions and how to improve young people's lives. The group saw these as the most important everyday issues. The title, focus, construction, and dissemination of the project was decided upon by the Group.

## How was the project constructed?

The group worked together to develop and conduct all aspects of the project. This specifically relates to: the title of the research, the focus, aims and objectives, advertisements and information sheets, research questions, data collection methods and tools, interview schedules, analysis, dissemination and anything else related to the research process. Nothing was produced for the project outside of the group.

Over several months the group met online to discuss their lives as young people who are disabled and LGBT+. These chats were open but guided in order to explore everyday experience, challenges and positive experiences. Online text-based chats emerged as one of the best methods to conduct chats. They were easy to engage with. They were also less reliant on social cues that some of the group found difficult. Some of the group noted how being autistic meant that they had difficulty reading facial expressions or using facial expressions themselves. Using text only bypassed this.

Following these initial chats, the group worked to pull these experiences together. The decision to focus upon autism was made early on due to the majority of the group being autistic. These sessions resembled physical group work but were less demanding. Members could leave chats and re-join when suited them. Of course, attendance is always optional. Key decisions were made in group meetings and then fine-tuned in emails or in one-on-one chats.

Identities and relationships were noted as being important everyday negotiations, particularly in terms of how they are impacted by sensory experiences. The relationship between autism and LGBT+ identities was highlighted throughout. The group reported experiences of people assuming their identities were a symptom of being autistic or that being autistic was too much work for others. It was clear that the young people in the group faced additional barriers due to a lack of understanding, support or accessibility. It is important to find out how these barriers affect people's lives and what can be done about them.

Having developed the focus, we moved to think about how to collect the stories. Informal online chats and diaries were highlighted as being potentially the most useful. Online video chats were noted as useful and also instant messaging chats because written communication is sometimes preferred to the pressures of face-to-face meetings. It allows for the opportunity to give more complete answers than face-to-face meetings. Diaries would allow participants to answer questions and reflect on their experiences in their own time, with whatever support that they may need. It also reduces the number of social interactions for those who might not want to talk to people. However, it was noted that diaries mean that questions cannot be adapted, and it is not always possible to seek clarification. We worked to develop a diary guide which clearly laid out what was expected.

The interview questions were constructed via one-to-one online chats or via email conversation. This was viewed as being preferable to group messages so that we could spend time exploring individual questions and approaches to data collection. Once the most relevant areas were decided upon, individual questions were drafted for the interview schedule. The questions were then written together to ensure that they were as clear as possible. We took our time thinking how we would ask the questions in the most autistic friendly way. It was particularly important to ask direct questions

as indirect or open-ended questions would not be useful. However, we worked to make sure that even when the questions were clear and direct, they were never closed. As a result, questions needed rewording and checking multiple times until they could be officially set. Language was also changed in some of them to aid in inclusivity which is a massive part of the project. This would have looked silly to ignore considering the themes and aims.

## How have we completed the project?

We have conducted 15 interviews and collected 10 diaries. Alex conducted all the interviews as the group did not want to be involved in this aspect of the project. However, we have worked together on making sense of the stories and diaries. Once we had transcriptions of the interviews we worked online in three stages. All activities took place over a number of online meetings and emails.

1- Sorting the information.

This took a long time because we had a lot of information. We focussed on organising the stories into the five areas of research: identity, relationships, sensory experiences, perceptions and how to improve young people's lives. Alex added text into the online chat (or email), and we talked about what part of the research it was talking about.

At the end of the process, we had a record of all the information organised into research areas.

2- Making sense of the information.

We took the organised information and then discussed what we thought it meant. During meetings we explored quotations and talked about what they meant in relation to the person's life and also our own lives. Whilst talking Alex made notes and highlighted where patterns started to emerge. This stage was important because we could talk about any misunderstandings and differences of opinion.

At the end of the process, we had a commentary on quotations and emerging patterns.

3- Creating patterns or themes.

The final stage of our online analysis was to decide on the most important patterns we saw. We took the information from stage 2 and tried to see what ideas were repeated. This resulted in creating lists of 'ideas' (or themes) with quotations and commentaries next to them.

At the end of the process, we had a list of what the key issues for the people who took part, quotations and commentaries.

## Concluding Remarks

This short article has outlined how we constructed a research project together. It has focussed upon the principles of the group, how we work together and what we will hope to achieve. The article has been written by three people. Although this was a lengthy process (over 12 months), we felt that it was important to have authentic voices due to the collaborative nature of the project. The group have now finished the data collection and analysis and are working on how to disseminate the findings.

We hope that the article has been beneficial for others striving to work in a more collaborative fashion. The article has attempted to offer insight into how groups can be set up, how they work together and what can be achieved. We strongly feel that working so closely together has meant that the project is closer to what we planned. We also feel that it has been conducted in a more appropriate fashion as all the research materials have been created by autistic people. However, we have also learnt a number of lessons which will be of interest to those conducting similar work. Conducting an online project where all decisions and all materials are co-produced takes a lot of time. We feel that this was entirely necessary but for projects with strict deadlines this will be difficult. Writing collaboratively also takes time. Although, we felt it was important to hear authentic voices in this article, the process of pulling three narratives together took time. Perhaps, the most important lesson was discovering our own working styles. Each member of the Group works slightly differently (lists, emails, one-to-one chats, videos etc.) and it took a while to negotiate this. It would be beneficial to understand this early in the process and to work to support this. Alongside this, the lead author has learnt that as the organiser of the majority of research activities, communicating clearly and concisely is always important. It is important to be organised and plan activities ahead of time. However, as with the issues that relate to time, flexibility is often the key.

## Acknowledgements

Thank you to all the members of the Young Disabled LGBT+ Researchers Group and for the young people who have shared their stories so far.

## Funding

## References

Askins K (2018) Feminist geographies and participatory action research: Co-producing narratives with people and place. *Gender, Place & Culture* 25(9): 1277-1294.

Bölte S (2017) Autism-Europe international congress 2016 – autism research and practice in Europe 2016. *Autism* 21: 3–4.

Brady G and Franklin A (2019) Challenging dominant notions of participation and protection through a co-led disabled young researcher study. *Journal of Children's Services* 14(3): 174-185.

Botha M and Cage E (2022) Autism Research is in Crisis: A mixed method study of researcher's constructions of autistic people and autism research. Epub ahead of print 14 June 2011. DOI: 10.31219/osf.io/w4389

Chaney EG (2001) Web-based instruction in a Rural High School: A Collaborative Inquiry into Its Effectiveness and Desirability. *NASSP Bulletin* 85(628): 20-35.

Chown N, Robinson J, Beardon L, Downing J, Hughes L, Leatherland J, Fox K, Hickman L and MacGregor D (2017) Improving research about us, with us: A draft framework for inclusive autism research. *Disability & society* 32(5): 720-734.

Cusack J (2017) Participation and the gradual path to a better life for autistic people. *Autism* 21: 131–132.

Evans B (2013) How autism became autism: The radical transformation of a central concept of child development in Britain. *History of the human sciences* 26(3): 3-31.

Franklin A and Sloper P (2009) Supporting the participation of disabled children and young people in decision-making. *Children & Society* 23(1): 3-15.

Franklin A and Toft A (2020) Centring the voices of disabled LGBT+ young people in research: ethical and methodological considerations. In Toft A and Franklin A (eds) *Young, Disabled and LGBT+: Voices, Identities and Intersections.* London: Routledge, pp. 73-87.

Henrickson M, Giwa S, Hafford-Letchfield T, Cocker C, Mulé NJ, Schaub J, and Baril, A (2020) Research ethics with gender and sexually diverse persons. *International Journal of Environmental Research and Public Health* 17(18): 6615.

Kirtman L (2009) Online versus in-class courses: An examination of differences in learning outcomes. *Issues in Teacher Education* 18(2): 103-116.

Malecki F (2020) Overcoming the security risks of remote working. *Computer fraud & security* (7): 10-12.

Shapka JD, Domene JF, Khan S and Yang LM (2016) Online versus in-person interviews with adolescents: An exploration of data equivalence. *Computers in human behavior* (58): 361-367.

Song L, Singleton E, Hill JR and Koh MH (2004) Improving online learning: Student perceptions of useful and challenging characteristics. *Internet and Higher Education* 7(1): 59-70.

Vonderwell S (2003) An examination of asynchronous communication experiences and perspectives of students in an online course: A case study. *Internet and Higher Education* 6(1): 77-90.

## Author Biographies

*Alex Toft*

Alex Toft is a Research Fellow in the Nottingham Centre for Children, Young People and Families at Nottingham Trent University. His research focuses upon sexuality, gender, disability, spirituality and identity theory. His work includes Bisexuality and Spirituality: Critical Perspectives (2020, with Andrew Yip), and Young, Disabled and LGBT+: Voices, Identities and Intersections (2020, with Anita Franklin) and has published in journals including Sexualities and Journal of LGBT Youth. He has worked on projects funded by organisations such as NSPCC and the Fundamental Rights Agency (EU),and received British Academy funding to conduct research exploring the negotiation of identity in the lives of young disabled LGBT+ people. He currently works with the Young Disabled LGBT+ Researchers Group exploring the lived experiences of young people who are autistic and LGBT+.

*Beth Ward*

I'm Beth ward, I am a 22-year-old autistic and gay female.

I'm a freelance artist and work with birds of prey at a children's farm a couple of times each week.

My favourite things are dogs, birds and art.

*Anonymous*

The third author is also a member of the Young Disabled LGBT+ Researchers Group but would like to stay anonymous throughout the process.