

Institution: University of Dundee

Unit of Assessment: UoA 23 Education

Title of case study: Giving voice to people with additional support needs through artsbased approaches

Period when the underpinning research was undertaken: 2000-present

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Divya Jindal-Snape	Professor of Education, Inclusion and Life Transitions, School of Education and Social Work	1998-present
Anna Robb	Lecturer, Arts Education, School of Education and Social Work	2012-present

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Interdisciplinary research has brought together work in the fields of education, creativity and arts, and comics studies to address issues of inclusion for people with additional support needs. The research forms the foundation for a process of co-design that has led to the creation of a suite of educational comics. The resulting comics have given voice to those who have been marginalised or silenced and have enhanced engagement of professionals and organisations working with marginalised or vulnerable groups, through the provision of new educational resources and the development of new practices. The comics have reached international audiences of 13,904 people in 91 countries, leading to improved awareness of poorly understood conditions.

2. Underpinning research

This case study is underpinned by interdisciplinary research related to the inclusion of people with additional support needs; it draws on research in the area of arts-based approaches as potential routes to empowerment and inclusion for those with additional support needs. In educational terms, additional support needs are defined as relating to those who need additional or different support for learning to that which is provided to others of the same age. The reasons underlying additional support needs are diverse and can be complex, ranging from disability and chronic health conditions to abuse or caring responsibilities. Additional support needs differ from the definition of special education needs (SEN) applied in England, in that it acknowledges the role of the learning environment and family circumstances as well as social and emotional factors such as bereavement, as factors frequently associated with a need for additional support. In 2019, the Scottish Government Pupil census identified 215,897 children and young people (30.9% of all school pupils) as having additional support needs, thus highlighting the importance of better understanding the challenges of associated policy and practice.

Professor Jindal-Snape's research in the area of inclusion, has identified enduring themes in relation to those with additional support needs, in particular the negative narrative surrounding issues of inclusion, especially where the underlying causes are invisible or poorly understood **[R1]**. Her research has demonstrated that this predominantly negative discourse is exacerbated by a lack of understanding in the general public and by professionals about additional support needs, and that those with additional support needs are silenced with no real voice in society **[R2]**.



Further, longitudinal research conducted with a large sample of Finnish special education teachers between 2010-2016 demonstrated that inadequacy in pupil–teacher relationships predicted special education teachers' exhaustion, cynicism towards the wider teacher community and inadequacy in pupil–teacher relationships five years later. This stress was compounded by the reliance of other teachers on special education teachers in mainstream schools for support with building an inclusive pedagogical culture **[R3]**.

The studies **[R1, R3]** have highlighted the importance of good pupil-teacher relationships and emphasised the need for teachers to be able to work effectively with *all* children/young people. They have further demonstrated that, in order for this to happen, teachers and other professionals needed a better understanding of the lived experiences of those with additional support needs and that these had to be communicated through engaging and accessible educational resources for time-poor professionals **[R3]**.

Together, the findings informed the exploration of a creative and arts-based programme of research led by Robb and Jindal-Snape **[R2, R4, R5]**. The arts-based approaches were proven effective in providing inclusive spaces for those with additional support needs **[R2]**, creating opportunities for empowerment and voice, and in enabling the development of mutually respectful and trusting relationships that could be adopted in pedagogical approaches, to the benefit of children, families, professionals and other stakeholders **[R2]**.

The insights from the programmes of research led to an interdisciplinary collaboration with Murray (Professor of Comics Studies, UoA27) and Nabizadeh (Lecturer Comic Studies, UoA27) and the development of a participatory practice-research methodology entitled 'Comics Jam' [R6] that drew on the combined expertise of the group in education and practice-methodology. This partnership brought together people with additional support needs, beyond the context of school and school-aged pupils, to actively engage with professionals and organisations in collaboration with artists and academics and resulted in the creation of a suite of six educational comics focused on issues connected to a range of additional support needs.

3. References to the research

[R1] Boyle, C., Topping, K. J., & **Jindal-Snape**, **D.** (2012). Teachers' attitudes towards inclusion in high schools. *Teachers and Teaching: Theory and Practice*, 19(5), pp.527-542. DOI: <u>10.1080/13540602.2013.827361</u>

[R2] Levy, S., **Robb, A. J.**, & **Jindal-Snape, D.** (2017). Disability, Personalisation and Community Arts: exploring the spatial dynamics of children with disabilities participating in inclusive music classes. *Disability & Society*, *32*(2), pp. 254-268. DOI: <u>10.1080/09687599.2016.1276433</u>

[R3] Soini, T., Pietarinen, J., Pyhalto, K., Haverinen, K., **Jindal-Snape, D.**, & Kontu, E. (2019). Special education teachers' experienced burnout and perceived fit with the professional community: A 5-year follow-up study. *British Educational Research Journal*, *45*(3), pp. 622-639. DOI: <u>10.1002/berj.3516</u>

[R4] Davies, D., **Jindal-Snape, D.**, Collier, C., Digby, R., Hay, P., & Howe, A. (2013). Creative learning environments in education-A systematic literature review. *Thinking Skills and Creativity*, *8*(1), pp. 80-91. DOI: <u>10.1016/j.tsc.2012.07.004</u>

[R5] Jindal-Snape, D., Davies, D., *Murray, C*., Scott, R., **Robb, A.**, & Harkins, C. (2018). Impact of arts participation on children's achievement: A systematic literature review. *Thinking Skills and Creativity*, 29, pp. 59-70. DOI: <u>10.1016/j.tsc.2018.06.003</u>



[R6] Herd, D., **Jindal-Snape, D.**, *Murray, C.*, & Sinclair, M. (2020). Comics Jam: Creating healthcare and science communication comics: Sprint co-design methodology. *Studies in Comics*, 11(1), pp. 167-192. DOI: <u>10.1386/stic 00020 1</u>

Quality of underpinning research:

R1-R6 have all been subject to peer review.

Funding:

- (i) **DJ-S** PI, GBP 35,000 from Glasgow Centre for Population Health, 2014;
- (ii) **AR, DJ-S** CIs, GBP 5,000 SFC Innovation scheme with Paragon (music charity working with autistic children), 2016;
- (iii) Robb PI, GBP 2695, Carnegie Trust, creative practice of teachers, 2018-2019;
- (iv) DJ-S and *Murray* CI with *Nabizadeh* PI, and University of Strathclyde and charities, GBP 18,000 from Scottish Universities Insights Institute's knowledge exchange funding, 2019 [When people die comic].

4. Details of the impact

Impacts from the comics have reached multiple communities, benefitting those with additional support needs as well as the families and professionals supporting them. Benefits have been realised both through the participatory process of creation and through the provision of new resources that have been, and continue to be, used by multiple communities. Impacts from two of the titles are discussed here.

Impacts on the bereaved and their support networks

According to Winston's Wish, 45,000 UK school children experience the death of a parent or sibling every year; approximately 112 children are bereaved every day and 41% of young offenders experienced bereavement as a child, yet their needs are often overlooked following bereavement **[E1]**.

The comic 'When people die: Stories from young people' was co-created using the Comics Jam approach by children and young people receiving support following bereavement, and articulates their stories using their own words and images. The finished comics have given a voice to this vulnerable group, providing a much-needed resource for the bereaved and those providing support to them **[E1-E4]**. One organisation involved in the comic's creation confirms the value of the process in providing a safe environment for young people to "*tell their stories exactly as it was and is for them*" as well as to the resulting comic as an *"invaluable resource"* that can be used to promote healthy and therapeutic conversations about bereavement **[E1]**. Another describes their involvement in the project as "*very beneficial*" noting "*the importance and impact of bereavement… especially those who may already be vulnerable or marginalised*", as well as the usefulness of the comic in supporting professionals **[E2]**.

The impact of the comic extends beyond those directly involved in its creation. The Children and Young People's Commissioner for Scotland highlighted its "*pivotal role*" in enabling an understanding of the experiences of bereaved children and their families, describing it as a "*powerful tool*" for him, his team and other professionals at a time when many more families than usual are likely to experience bereavement due to COVID-19 **[E3]**. When people die is also being used by Golden Charter, a UK-wide provider of funeral plans working with independent funeral directors. The comic has been shared through their network and recognised as "*a powerful way*" to acknowledge grief; it has been a much-welcomed resource by parents and guardians as well as funeral directors, many of whom "are not trained bereavement counsellors and can find it challenging to offer emotional support" **[E4]**.

Since its launch (Dec 2019) *When people die* has had 1227 downloads in 30 countries and 2000 print copies have been distributed. The comic has been made available in the Glasgow Children's Hospital and is listed as a recommended resource by the Glasgow Psychological

Impact case study (REF3)



Service [collated in **E7**]; in West Dunbartonshire a link to the online resource forms part of a trauma toolkit for teachers working with bereaved children **[E1]**. The comic was due to be showcased at the Scottish Parliament's Good Death Week in May 2020 (cancelled due to COVID-19, **E4**).

Raising awareness and giving voice to those with chronic health conditions

Those with additional support needs caused by chronic health conditions frequently find themselves marginalised by poor awareness or understanding of their needs; fibromyalgia is one such condition. The National Fibromyalgia Association estimates as many as 200-400 million people (3-6% of the world population) suffer from the condition, yet awareness of the condition is low and it is poorly understood, managed and supported. Co-created at the request of a pain clinic psychologist who identified a lack of awareness amongst professionals, the comic '*Fibromyalgia and Us: Living with fibromyalgia*' is based on the lived experiences of those who have fibromyalgia, their families and professionals.

For those involved in the development of the comic, it has afforded them a voice, providing important validation, often after years of health-related issues. One project participant wrote *"It was a moment of pure catharsis... all the years of health-related anger and holding health-related information in my head, were gone. Instead, when I saw the finished comic, I felt incredibly proud... Seeing it allowed me to offload years of baggage"* **[E5]**.

The comic's significance has also been felt by readers, with many commenting on the relief of finally having something that validated their experiences "*it's so easy to doubt what you're experiencing, and that's the scariest part, let alone explaining it to anyone*" and how it has opened opportunities for different conversations "... *people not understanding us or believing us is the worst thing, still to this day my friends and family think I'm lazy. I'm going to show them this amazing animation of our illness*". Another reader in their 70s, whose diagnosis took some 25 years, said "*It is so hard to explain even to well-meaning people, what fibromyalgia is and how it affects me… I tend to hold most of my symptoms inside, even when I am close to tears, because I don't look sick… This comic is amazing"* [E6].

The title has gained traction internationally with coverage across print, broadcast and social media [collated in **E7**]; it has been downloaded 12,627 times across 86 countries (November 2017-December 2020), over 2000 paper copies have been distributed and it has been translated to Spanish on request. Its inclusion in an article on *The Mighty* (a digital health community with over 2 million registered users) generated nearly 30,000 views overnight, overwhelming the website as noted by the editor *"As soon as we shared our article on social media, it became clear our readers loved the comic — in fact, the following day… the link to download the comic wasn't working because the site had crashed from too many people clicking on it…"* **[E8]**. The tremendous response led to Jindal-Snape's inclusion in *The Mighty's* 2017 list of 11 people who changed the perception of chronic illnesses. In March 2019 the comic was distributed to MPs as part of a fibromyalgia awareness campaign and received cross-party support in an Early Day Motion in the UK Parliament **[E9]**.

Fibromyalgia and Us has been endorsed by the Clinical Deputy Director **of** NHS Tayside **[E10]** and made available at all 64 GP surgeries in three local authorities (Angus, the City of Dundee, Perth and Kinross), providing much needed information as one person observed: "*My mother suffers from fibromyalgia, but I learned more about the condition and its impact through this comic than my experience at home. It exposes real patient insights/thoughts – they're 'raw' and moving...*", with another suggesting "*it should be mandatory reading for all GPs*" **[E6]**.



5. Sources to corroborate the impact

[E1] Testimonial letter from Family Social Worker, Children's Hospice Across Scotland (CHAS)

- [E2] Testimonial letter from Children and Young People's Centre for Justice (CYCJ)
- [E3] Testimonial letter from the Children and Young People's Commissioner Scotland
- [E4] Testimonial letter from Golden Charter
- [E5] Testimonial from Fibromyalgia and Us project participant
- [E6] Compilation of feedback from Fibromyalgia and Us readers
- [E7] Compilation of media coverage and download figures
- [E8] Testimonial from *The Mighty*

[E9] Early Day Motion: EDM 2135 Fibromyalgia and Us, <u>https://edm.parliament.uk/early-day-motion/52638/fibromyalgia-and-us</u>

[E10] Email communication – NHS Tayside Clinical Deputy Director