

**Institution:** University of East London (UEL)

Unit of Assessment: 20 Social Work and Social Policy

Title of case study: The RIX Wiki; Multimedia advocacy for young people with learning

disabilities

Period when the underpinning research was undertaken: 2008 - 2020

Details of staff conducting the underpinning research from the submitting unit:

Name(s): Role(s) (e.g. job title): Period(s) employed by submitting HEI:

Professor Andrew Minnion Director, RIX 1994 – present

Research and Media Centre (RIX) at UEL

Period when the claimed impact occurred: 2014 – 2020

Is this case study continued from a case study submitted in 2014? No

## **1. Summary of the impact** (indicative maximum 100 words)

People with learning disabilities (LD) in the UK experience exceptional social exclusion and inequality. In 2017, the Equality and Human Rights Commission reported that in terms of education, standards of living, health and social care, and participation, people with disabilities achieve poorer outcomes than their non-disabled peers.

Minnion and the RIX Centre team, has pioneered multi-media advocacy via "The RIX Wiki" software tool, which directly addresses inequalities faced by people with LD. This has benefited people with LD in the UK by enabling them to communicate their views, wishes, aspirations and preferences to ensure improvements in the services they receive.

# 2. Underpinning research (indicative maximum 500 words)

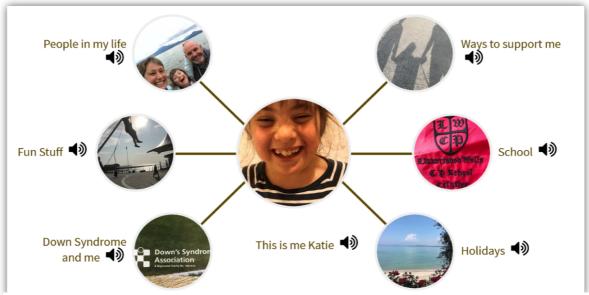


Figure 1. RIX Wiki software

The RIX Centre was founded in 2004 and utilises person-centred approaches to promote self-advocacy for people with disabilities (**R3**, **R4**). The RIX Centre has successfully developed ways of using emerging techologies to transform the lives of those with learning disabilities (LD),

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particularly for those who do not use speech-based communication (**R2**, **R5**). This is known as multimedia advocacy. Minnion and team developed the "RIK WIKI, a software tool, where portfolios of media content are developed to enable children, young people and adults with LD to self-advocate and communicate their choices, needs and aspirations, as they plan their futures, and engage with a wide range of professionals (**R1**, **R3**).

#### The RIX Wiki software

Multi-media advocacy practices and The RIX Wiki software has been used to improve:

- 1. The education and advocacy of young people with LD in transitions
- 2. Accessibility of services
- 3. Delivery of care services during Covid19

#### **Education and transition**

Minnion developed accessible personal Wiki software for young people with LD to plan and self-advocate their transition to adulthood (R3, R5, G4). Minnion's team co-developed training resources with professionals and carers to ensure young people's needs and wishes were more effectively communicated to ensure *person-centred planning* support for their transition (R3).

Pilot trials that took place between 2013-2016, with 14 UK local authorities and 11,550 young people and their families on the SEND Pathfinder programme, researched and developed the RIX Wiki software solution. Minnion hosted an active and inclusive 'community of practice' for disabled people and carers to develop multimedia advocacy with support staff, professionals and service-provider organisations (R3). The use of the RIX Wiki addresses the issue of *poor information sharing across services* (R3, R4). RIX developed easy-to-use multimedia Learning Portfolios and Platforms in approximately 40 schools with Mencap (G1) and UK Specialist College Network (G2)

### **Accessible services**

Work with **the Social Care Institute for Excellence** addressed the need for easy-to-understand information about community services for adults with LD (**R6**). A group of experts by experience reviewed services and shared their findings with peers, using The RIX Wiki. This resulted in the development of accessible websites for 6 London councils (**R6**, **G3**). Additionally, commissioned research with NHS Trusts and health and social care teams enhanced the RIX Software for use in Health and Care Plans, Hospital Passports, Mental Health Wellbeing Plans and a multimedia 'NHS Family & Friends Test' for Primary Care (**G5**, **G6**).

#### Delivery of care services during Covid19

Work with the **London Borough of Redbridge** and 3 care provider organisations introduced a RIX Wiki toolkit for people with LD receiving community-based care services to help reduce social isolation and maintain links with professionals during periods of lockdown and the closure of community services (**R1**, **G8**).

Minnion researched best practice models for adoption, implementation and long-term use of multimedia advocacy across education, health and social care sectors and focused on developing strategic implementation tools and workforce-training resources to accompany RIX Wiki Software (R3, G7).

#### 3. References to the research (indicative maximum of six references)

R1. Minnon, A., Kwiatkowska, G., Watts, P., Finch, J., Wilkes, C. 2020. *The RIX Multi Me toolkit: RIX research & media feasibility report*. RIX Research & Media, University of East London. https://repository.uel.ac.uk/item/88v8q



**R2.** Minnion, A., Kwiatkowska, G., Sharpe, D. 2017. *RIX Wiki evaluation toolkit.* Institute for Health and Human Development, University of East London. https://repository.uel.ac.uk/item/88v88

**R3.** Kwitakowska, G. and Minnion. A. 2013. *Multimedia advocacy for person-centred planning, pilot report*. RIX Research & Media, University of East London. https://repository.uel.ac.uk/item/88v8

**R4.** Saward C., Minnion A., Kwiatkowska, G. 2013. *W2ID – Web 2.0 for people with Intellectual disabilities. E*ducation, Audiovisual and Culture Executive Agency, European Commission <a href="https://repository.uel.ac.uk/item/88vvy">https://repository.uel.ac.uk/item/88vvy</a>

**R5.** Bunning, K. Heath, B., Minnion A. 2009. Communication and empowerment: a place for rich and multiple media? *Journal of Applied Research in intellectual Disabilities*, 22(4), 370-379. https://doi.org/10.1111/j.1468-3148.2008.00472.x

**R6.** Minnion, A. 2008. *Beyond the road ahead- project report*. The RIX Centre with Social Care Institute for Excellence Rix Centre, University of East London. <a href="https://repository.uel.ac.uk/item/88v7v">https://repository.uel.ac.uk/item/88v7v</a>

- G1. Andrew Minnion, 'Project @pple', ESRC/EPSRC/DTI 'PACCIT', 2002-2004, GBP370,000.
- G2. Andrew Minnion, 'Infolio', JISC TechDis, 2008-2011, GBP105,000.
- G3. Andrew Minnion, 'Beyond the Road Ahead', SCIE, 2005-2006, GBP150,000.
- **G4.** Andrew Minnion, 'ClickStart', Learning and Skills Council, 2008-2010, GBP335,000.
- **G5.** Andrew Minnion, 'ICICLE', NIACE, 2012-2014, GBP50,000.
- G6. Andrew Minnion, 'My Health, My Say, My Way', NHS England, 2014, GBP100,000.
- **G7.** Andrew Minnion, 'SEND Pathfinders Co-Production Trials', DfE Innovation funds, 2012-2016, GBP350,000.
- **G8.** Andrew Minnion, NHSxTechforce19 Competition, 2020, GBP65,000.

# **4. Details of the impact** (indicative maximum 750 words)

People with LD are structurally disadvantaged in terms of their human rights. In 2001, the Valuing People report noted poor community-based service provision and planning processes at key transitions, lack of choice and control over their own lives, unmet health-care needs, limited housing and employment opportunities, and significant digital exclusion.



Figure 2 Nurse assists with advocacy

# Multimedia advocacy for children and young people

The Children and Families
Act 2014 promoted the inclusion of the voice of the young person and engagement of all agencies in a single "Education, Health and Care Plan" (EHCP) - a directive that RIX's software solution was particularly well suited to address. (S1)

Since 2014, the use of the RIX Wiki in 65 UK schools and colleges has resulted in 2,890 learners engaged in the personcentred planning process. Evaluation has evidenced significant improvement in communicating individuals' views and

wishes, better communication between home, schools and professional services such as NHS therapies and social work and improved provision of local information to support their journey to

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adult life in the community (**S2**). The use of the RIK Wiki in schools and colleges has therefore significantly developed the "pupil voice" and informed self-advocacy for those with LD (**S3**). Parents and carers have reported improved communication, for example:

"It eases the ever-heavy challenge of coordinating all professionals and family and communicating real-life detail on behalf of a non-verbal child - helping improve my daughter's quality of life by providing a tool for quality communication." (**S4**)

# **Employability**

Inclusive education for employability, independent-living and social inclusion has also been a focus on 5 large-scale EU projects undertaken by RIX since 2014 that have engaged 1200 learners with LD in face-to-face workshops and reached thousands more via these projects' accessible multimedia learning resources. These resources have been translated into 7 languages and are distributed freely online. School and college leavers' employability has been improved through production of personal multimedia CVs that help prospective employers understand learners' support needs, **alongside** their skills and abilities. (**\$5**)

## Multi-media advocacy for Adults

The Care Act 2014, England has a number of guiding principles including, but not limited to, valuing people's experience and knowledge of their own needs, involving users in decision making and that actions taken to support individuals should have minimal impact on rights and freedoms (Feldon, 2017). The RIX Wiki therefore was ideally placed to realise the underlying principles of this Act and the principle enshrined in the Valuing People report (2001) with its endorsement of accessible, easy to understand information and engagement with the voice of the service-user in person centred planning. (**\$6**)

Minnion's action research has resulted in 20,000 annual RIX Wiki accounts for use with adults, with training and consultancy across 20 UK local authorities, NHS services and social care providers. 6,019 professionals and parent/carers have completed training over this period, with 75% provided via face-to-face provision. This work has transformed traditional care and support practices, pioneering use of digital person-centred tools for the first time for 88% of trainee participants. This has driven culture-change for organisations struggling to adopt personalised care provision over legacy paper-based processes that interpreted assessment as a one-off service-led process that failed to engage effectively with the voice of young people and their carers. Use of RIX software positively engages parents and carers (\$7), which local authorities report has helped reduce adversarial meetings and costly tribunals, saving public-costs.



Figure 3 RIX in Times Square, New York



#### **Digital innovation**

Minnion's research on "My Health My Say" won the Patient Experience Network (PEN) National Awards, in the Access to Information category in 2015. RIX software is adopted as a demonstrator by NHS Digital who have affirmed that Minnion's R&D "aligns with the current thinking and innovation" and "will make a significant contribution to the development of new and improved care for people with disabilities in the UK" (S8).

The RIX Wiki is one of 11 innovations chosen in March 2020 via a rigorous multi-stage selection process for the NHS Innovation Accelerator to support adoption of the software into the NHS (**S9**). It is one of just 2 innovations selected from 1,643 applications to progress to Phase2 of the NHS x 'TechForce19' challenge with funding to address risks for vulnerable people facing isolation due to Covid19. RIX software rolled out for 1,050 at-risk people with LD and their carers during 2020 lockdowns and improved social connectivity, bettered support and reduced risk of mental health issues through deployment of a RIX Wiki-based online support-network (**R1**).

# **5. Sources to corroborate the impact** (indicative maximum of 10 references)

**S1.** UK Government, Department of Health and Department of Education. 2015. *Special educational needs and disability code of practice: 0 to 25 years.* Department of Health and Department of Education. Particularly, 19-59.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/398815/SEND\_Code\_of\_Practice\_January\_2015.pdf

- **S2.** Camden Council, Resources Easy read information | Cindex
- **S3.** Annie Grant, Multimedia Advocacy, *Special Children* 217,14 February 2014, 40-42. http://www.atomicmediaproductions.com/wp/blog-4/page/3/
- **S4.** Emma Townsend, Parent/Carer, Westfield School,

Herefordshire, from the Herefordshire multimedia advocacy implementation pilot, interim report to Herefordshire County Council, April

2019. <a href="https://www.herefordshire.gov.uk/downloads/file/18768/wikime\_herefordshire\_interim\_eval\_uation\_report\_april\_2019.pdf">https://www.herefordshire.gov.uk/downloads/file/18768/wikime\_herefordshire\_interim\_eval\_uation\_report\_april\_2019.pdf</a>

- **\$5.** Social inclusion of learner's project, EU Erasmus+ project website and learning platform. <a href="http://www.soil-project.eu/en/About-SOIL/">http://www.soil-project.eu/en/About-SOIL/</a>
- **S6.** Minnion, A. 2014. Multimediale Selbstvertretung Von Menschen mit Geistiger Behinderung Neue elementare Kompetenzen fur

die Erwachsenenbildung. Grenzenlose Kommunikation. Behinderte Menschen 3/2014, 8-19.

## Translation:

Minnion, A. 2014 Multimedia self-representation of people with intellectual disabilities - new elementary competencies for adult education, Grenzenlose Kommunikation. Behinderte Menschen (Translation: Boundless Communication. Disabled people) 3/2014, 8-19. **S7.** Tania Tirraoro (founder and co-director Special Needs Jungle Ltd), 'One Page Profiles and EHC plans the Wiki way. Special Needs Jungle, 17 February 2016. https://www.specialneedsjungle.com/one-page-profiles-and-ehc-plans-the-wiki-way/

- **S8.** Testimonial from Keith Strahan, Principal Clinical Lead, NHS Digital Social Care Programme 'Integrated Care'. He presented the RIX wiki in the 'Care Showcase 2019' NHS Digital.
- **S9.** Minnion's selection for 2020 NHS Innovation Accelerator Fellowship, New NHS Innovation Accelerator Fellows announced for 2020! NIA (nhsaccelerator.com)
- **\$10**. M. McKean, NIA Communications Manager, NHS Innovation Accelerator COVID-19 Response Website. *Innovative solutions for the future of the NHS*. Published 23<sup>rd</sup>Sep 2020. https://covid19.nhsaccelerator.com/?biro-theme=5#filters