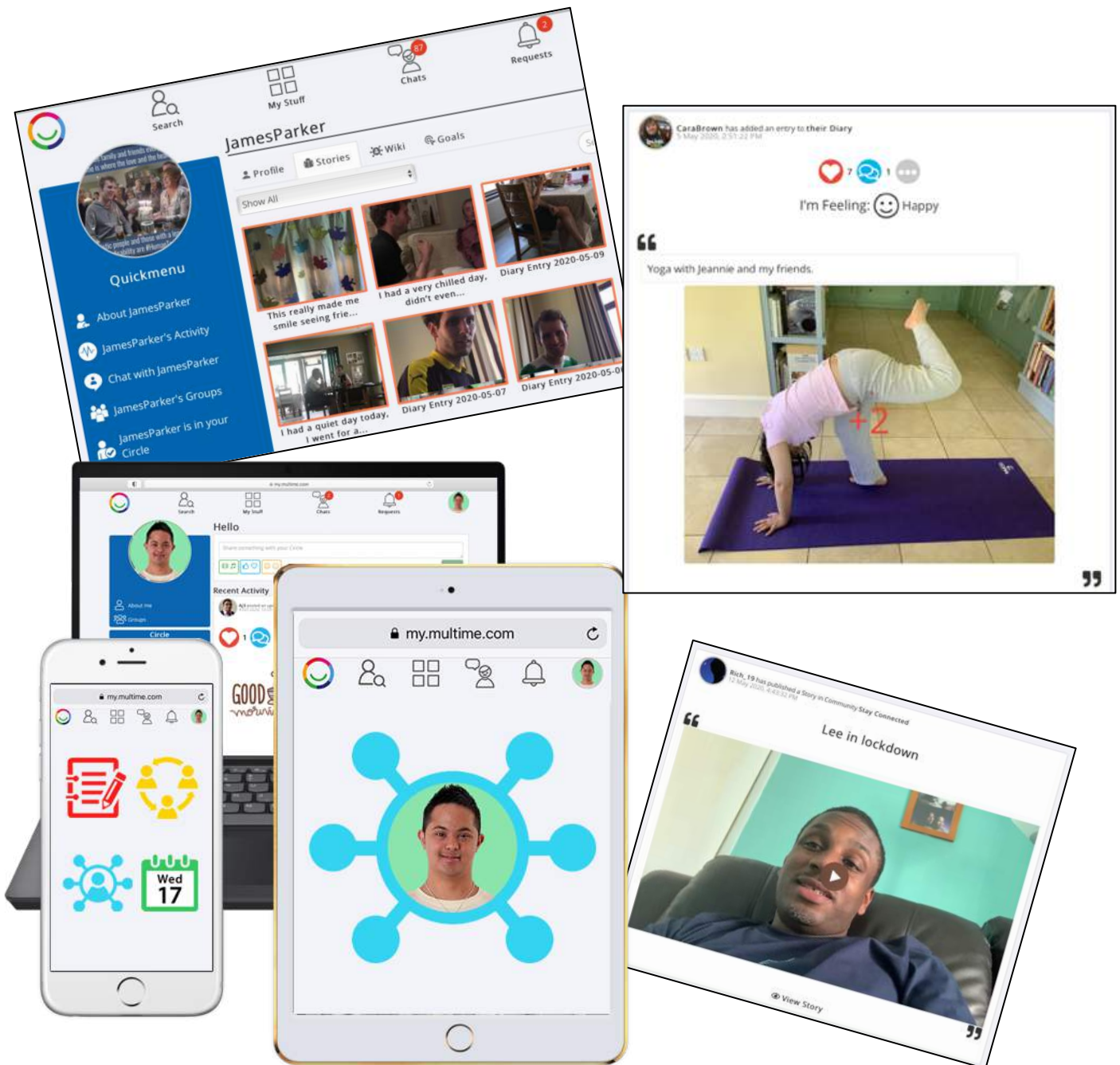


The RIX Multi Me Toolkit 'Stay Connected' Project

Evaluation Report - May 2021



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Table of Contents

Introduction and Executive Summary	3
Background to the RIX Multi Me Toolkit ‘Stay Connected’ Project.....	5
TechForce 19 (TF19) Brief and RIX response	5
People with learning disabilities (LD) and autism – health inequalities and COVID-19 risks	5
Current service provision	6
Risk of COVID-19 for people with LD and autism	6
The RIX Multi Me Toolkit Solution.....	7
The Project Approach	8
Project structure and resources	8
Phase 2 Project - Aims and Objectives	9
Methodology	9
Data Analysis	10
Deployment – Organisational and Supported User profiles.....	11
Findings	11
Data analytics	12
Baseline surveys analysis.....	14
End of project findings	16
Discussions and conclusions.....	26
References.....	29
Appendices	30
<i>Stay Connected case study Amy.....</i>	<i>32</i>
<i>Stay Connected case study Kai.....</i>	<i>33</i>
<i>Stay Connected case study Jessie</i>	<i>35</i>
<i>Stay Connected case study Keshan.....</i>	<i>35</i>
<i>Stay Connected case study vignettes.....</i>	<i>37</i>

Introduction and Executive Summary

People with Learning Disabilities (LD) face significant health inequalities that are demonstrated in mortality statistics. Those identified with a learning disability aged 0 to 74 years were found to be between 3.9 and 4.2 times more likely to die in the period 2015-18 than would be expected for people with broadly the same characteristics in the general population (NHS Digital, Sep 2019). Evaluation of the causes of this health inequality have pointed to a poor understanding of people with learning disabilities by health and care professionals and poor communication with them and their carers about their individual needs and how best to support them (Six Lives Report DoH 2009.)

Changes due to COVID-19 distanced carers from patients and care service-users with closure of group care facilities and community-based centres. Facing isolation without their usual hands-on support and face to face interventions, people with learning disabilities suddenly lost their usual routines, their usual social interactions and their regular care interventions and experienced increased risk from anxiety, loneliness and deterioration of mental health amongst others.

RIX Multi Me Toolkit software provides a secure and highly accessible social network that serves as a support network for people with LD disconnected from their usual care in the community. It supports interventions by restoring and replicating contact and communication capability normally provided face-to-face by social care and healthcare workers. Additional multimedia advocacy tools enable users to organise and communicate their thoughts, needs and choices, enabling improved self-advocacy for people often poorly understood by those who work with them.

This report presents the findings of the RIX Multi Me Toolkit software implementation as part of the 'Stay Connected Project' funded by NHSx through the TechForce19 Competition in two phases between April 2020 and May 2021. The evaluation was conducted by RIX Research and Media with the social care, education and health provider services that participated in the use of RIX Multi Me Toolkit during the COVID-19 Pandemic. The final evaluation took place in March 2021.

Six organisations registered to participate on Phase 2 of the project in September 2020; two London-based local authorities, three supported living organisations in North London, Surrey and Cornwall, and one Special Education School in Herefordshire. The total number of users registered on the system was 938. This is made up of 363 Supported Users (people with LD & Autism in receipt of services); 468 Buddies (Nominated staff and informal carers responsible for safeguarding of Supported Users on the RIX Multi Me platform) and 107 General Users (Support staff, professionals and informal carers and friends registered, but without Buddy responsibility for Supported Users on the platform).

Qualitative insights came from the Stay Connected project user feedback collected via interviews, focus groups and surveys. Quantitative insights were generated from the RIX Multi Me System usage, data collected by RIX Multi Me toolkit and Google Analytics. Data covered the period between October 2020 and 27 April 2021. Two surveys were distributed; one at the beginning of the project (October- November 2020) and one at the end (March 2021). Three focus groups were held with supported users, front line staff and managers from five social care organisations during March 2021. Interviews were held with eight staff and seven supported users.

Project findings and recommendations

- Where access to devices, infrastructure and support was achieved, evaluation suggests that the use of Rix Multi me Toolkit software assisted significantly in providing digital care and support for people with learning disabilities and autism during lockdowns.
- The key barrier adversely impacting take-up of the software reported and observed on the project was the lack of access to suitable devices, internet connectivity and skilled support for service-users with disabilities and their families to benefit from digital systems.
- Alongside the clear impacts of staff shortages and crisis management factors effecting adoption, it was noted that, with closure of schools, colleges and day opportunity services, the pandemic rapidly highlighted the structural issues of technology and internet access inequality faced in the community, particularly in regions with higher incidence of poverty.
- Limited digital skills of support staff, parents and carers in individuals' homes was seen to be a significant factor in the poor take-up of the intervention.
- The use of the software complemented emergency telephone support and compensated for severely limited face-to-face contact to positively impact on individuals' mental wellbeing and confidence and improve their self-advocacy and independent living capability.
- The intervention enabled organisations to deliver better person-centred care, strengthened supportive social and community networks and enhanced relationships between individuals, staff and their families in a crisis situation.
- Where organisations had digital communications channels at least partially established with service users and their carers before the pandemic, they showed markedly better outcomes on the project as a result.
- Identified facilitators of successful implementation included the simplicity of the RIX Multi Me software's accessible multimedia tools and availability of staffed online training for the induction of new users, alongside streamed video tutorials and easy-read instructions.

In summary, the Project evaluation and data analysis evidenced the positive impact of a digital person-centred intervention to help provide care for people with LD and autism and their families and carers facing the challenges of the public health emergency. It also demonstrated the significant adverse impacts of digital exclusion for this population, particularly in less affluent communities. These conclusions were repeatedly reinforced in our dialogue with service-providers and users who saw the health and care inequalities exposed by the pandemic matched and frequently aligned to the poor digital readiness of services and digital exclusion experienced by users of services. While services have started to recover, the perceived need to tackle this inequality has not diminished. Services are reduced and frequently still require internet connectivity to be accessed.

Recommendations

Together, the project team, its participants and researchers have proposed the following recommendations as a result of taking part in the TechDForce19 programme on the Stay Connected project:

- Access to suitably easy-to-use, personally owned and mobile devices and internet connectivity for citizens and carers are a critical dimension for the effective support of people with LD & autism in the face of a pandemic
- Support staff require core digital skills and capability to support service users in the set up and use of digital technologies is essential to our health & care services as these are 'built back'

- Integrated care teams need to restore services in ways that blend face-to-face and remote care to connect together health and care service providers so that a person's support circle can effectively work together effectively
- Standards and guidelines are required for use of digital technology for remote, blended and face-to-face care to help steer and strengthen good practice in this rapidly evolving market
- Change management support needs to accompany new tools and training to help health and care organisations to embrace new, more inclusive technology-enabled systems if health inequalities for people with LD and autism are to be addressed
- Capture and sharing of diverse examples of effective use of digital tools to illustrate their benefits will help suppliers and adopters in the rapidly emerging digital sector
- Clear communication about new technology initiatives demands close work with staff, service managers and commissioners. Front line staff team leadership endorsement is critical to staff and service users' adoption of the new roles and ways of working that come with new technologies.

The RIX Multi Me toolkit's trial implementation as a scaled solution for maintaining person-centred support of people with learning disabilities and autism has demonstrated the extraordinary potential benefits for today's personal and social media tools in the new environment we occupy since the Pandemic. At the same time, the project has helped to identify the significant barriers in place, and the behavioural and organisational changes required, if such potential is to be realised. Recent events have exposed the requirement to prepare our care systems for an unpredictable and potentially challenging future in which distancing and lockdowns may continue to be a regular occurrence. A pro-actively *blended* model of remote and face-to-face care provision can provide the resilience that future models of integrated care demand. This must however address technical skills training and provision of infrastructure and devices as an essential requirement.

Background to the RIX Multi Me Toolkit 'Stay Connected' Project

TechForce 19 (TF19) Brief and RIX response

The RIX Multi Me Toolkit 'Stay Connected' project was funded through the TF19' Competition organised by NHSx with the AHSN Network and supported by the Government Digital Service, the Department of Culture, Media and Sport, and the Ministry of Housing, Communities and Local Government. The mission of the TF19 competition was to identify, support and make available to communities at scale innovative new technologies that 'can help support the vulnerable, elderly and self-isolating as COVID-19 continues to spread.'

RIX responded with a proposed digital social care network solution to assist isolated people with mild and moderate LD and with dual diagnosis of LD and autism, who are normally supported to live in their communities, receiving domiciliary social care. This cohort included adults with learning disability and autism living with family, parents and carers alongside those in residential care and nursing homes.

People with learning disabilities (LD) and autism – health inequalities and COVID-19 risks

Approximately 2.2% of the UK population are believed to have a LD, which maps to over 5,500 people per the average sized population that is covered by a single CCG of 250,000. National statistics have indicated that the majority of people with a LD known to local authorities live in one of three types of accommodation: with family and friends (38%), in a registered care home (22%) or in supported accommodation (16%). 12% of people with LD live as tenants in accommodation provided by a local authority or housing association and 3% as tenants in privately rented accommodation.

Current service provision

Adults with LDs and autism are supported by care teams to enable them to live in their communities. They normally rely on a weekly timetable of activities, meetings and appointments with services to maintain their health, safety and wellbeing:

- Social care appointments and drop-ins.
- Supported learning for independence.
- Organised social activities.
- Therapeutic & outpatient healthcare.
- Community & voluntary groups.

Their personalised care packages provide stable and regular social connectivity alongside social care, therapeutic services and clinical healthcare. Their weekly timetables facilitate active engagement in the local community, so that they can live a supported lifestyle with an effective health and care network in place that will underpin individuals' mental wellbeing as well as their capacity to live safely and as independently as possible.

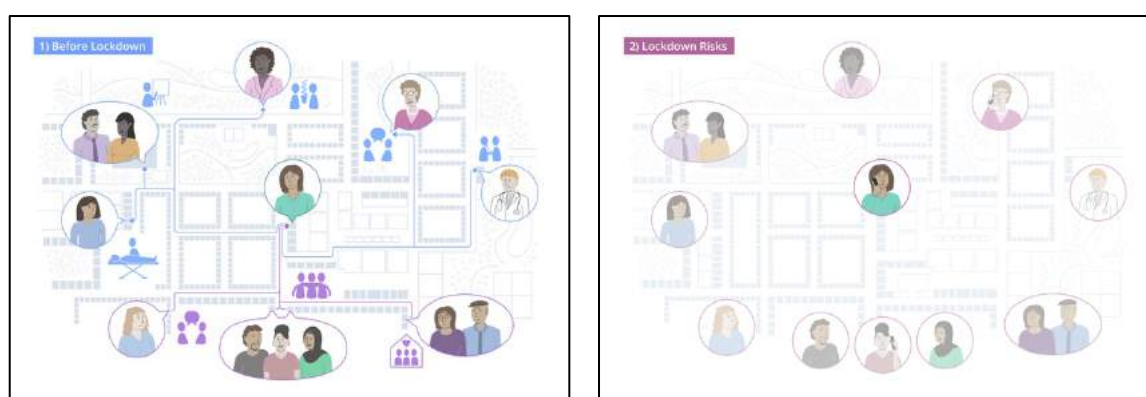


Figure 1 Connectivity models before and during lockdowns

Risk of COVID-19 for people with LD and autism

Changes due to COVID-19 distanced carers from patients and care service-users with closure of group care facilities and community-based centres. Facing isolation without their usual hands-on support and face to face interventions, people with LD suddenly lost their usual routines, their usual social interactions and their regular care interventions and experienced increased risk from:

- Anxiety, loneliness and deterioration of mental health.
- Loss of hard-won life skills, confidence and independence.
- Diminished capacity to self-manage their health and wellbeing.
- Less effective monitoring of their wellbeing and behaviour by professionals.
- Loss of personal and social support networks with peers, families, neighbours.
- Lack of access to accurate and easy-to-understand information and guidance.
- Potential crisis events that may lead to hospital admissions, police emergencies, and the breakdown of supported living arrangements in the community.

All of these risks carry significant and costly long-term consequences and critically, this vulnerable populations' mental health is at risk in ways that may not be visible to a remote care team.

Research directly before the pandemic evidenced that disabled people (including those with LD and autism) experience the lowest feelings of happiness, worthwhileness, life satisfaction and the highest levels of anxiety (Jones 2019). These feelings have been found to have been significantly exacerbated

for many people with disabilities during the pandemic. Increased feelings of isolation and loneliness were evidenced, with reduced access to care and support, loss of face-to-face activities and day opportunities. Resulting limitation of peoples' access to technologies was notably also evidenced as a contributing factor to the deterioration of morale (Disability Rights UK, 2020).

The cumulative effect of these factors in the UK is that the pandemic has been shown to have had a disproportionate impact on disabled people who make up six out of ten COVID-19 related deaths. According to The Office for National Statistics (2021) the figures '...clearly show that current measures to protect disabled people are not enough and that there is an urgent need for more and better support.' The Health Foundation has additionally highlighted how the mental health from Pandemic restrictions posed extra challenges for this population,

'...as well as protecting disabled people from exposure to the virus, measures must account for the potential negative effects of lockdown and shielding. A significant number report that, due to lockdown, their health care needs are not being fully met or that they had treatment cancelled or delayed. Further action should include careful review of the support that is available to disabled people so they can access the care and essential services they need at home.'(The Health Foundation, 2021).

One UK study showed that 42% of respondents with LD reported that their mental health was "much worse" during lockdown due to a variety of factors including lack of access to resources (Kavanaugh, 2021). Similar to the national findings, isolation and social regression were major themes highlighted in the study performed by Theis et al. (2021)

The RIX Multi Me Toolkit Solution

- Secure and accessible social and support network platform.
- Multimedia content creation tools for self-advocacy.
- Wellbeing monitoring and usage insight dashboard for remote support staff.
- Diary, calendar and goal-setting and Tracking tools.
- Training & support - by video conference, video, worksheets.
- Platform to complement phone and video meetings.
- Online community of formal and informal support.

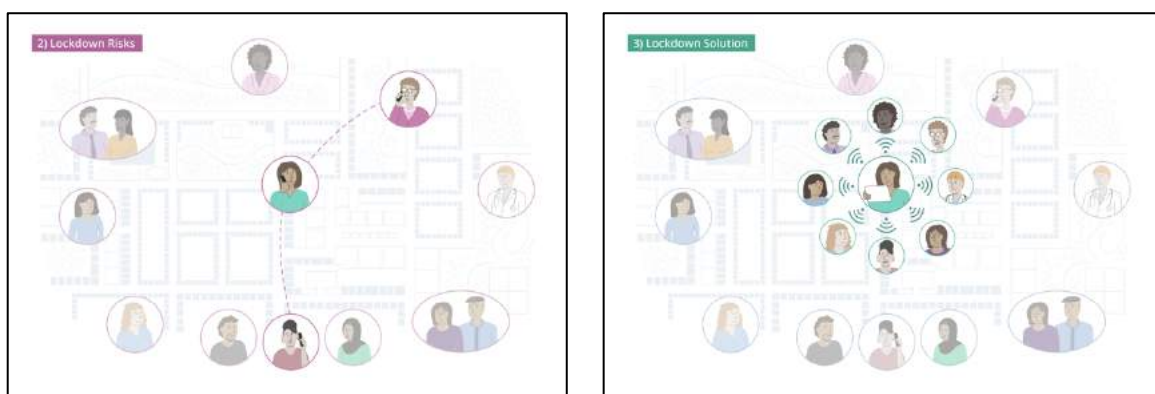


Figure 2 Lockdown risks and digital system solution

The software provides a secure and highly accessible social network that serves as a support network for people with LD disconnected from their usual care in the community. It supports interventions by restoring and replicating contact and communication capability normally provided face-to-face by social care and healthcare workers. Additional multimedia advocacy tools enable users to organise

and communicate their thoughts, needs and choices, facilitating improved self-advocacy for people often poorly understood by those who work with them.

Supported users are provided with easy-to-use photo and video authoring tools with which they can document and plan their daily lives, share what they are doing, report on how they feel and raise issues or concerns. Rich media tools widen the accessibility and potential engagement of disabled service users. Photos, video and sound clips can capture communications that are not word-based, meeting accessibility needs of those who do not read and enabling and capturing the self-advocacy of 'non-verbal' service users.

Support staff can monitor their wellbeing by directly accessing this self-reported information, and can respond, support and advise, or raise alerts where required. The system can additionally help individuals to connect with and mobilise wider informal support networks of peers, friends, family, neighbours and volunteers.

The RIX Multi Me software also facilitates potential enhancement of interaction with circles of support for patients or service-users, with improved understanding of their communication and their health and wellbeing made possible for professionals and care and support staff.

The Project Approach

Project structure and resources

Two phases of the project were funded by TechForce19 (TF19), a three-week proof of concept Pilot Project between April-May 2020 and a second Scaled Implementation phase from October 2020 to March 2021. Software with basic user-support was also provided pre and post the project and across the four-month period between the TF19-funded phases. This helped to ensure that potential benefit for supported users, their support circles and services was sustained.

The first TF19-funded Phase 1 - Pilot Project took the form of a rapid trial. This was designed to help understand the challenges faced by these communities more fully and to test and affirm the efficacy of the solution proposed by the implementation of the RIX Multi Me Toolkit.

Following the pilot trials and a review of their findings, TF19 focused its support on specific groups of vulnerable or isolated people highlighted by the programme. People with LD and autism were one of the user groups identified who were seen to face challenges, exacerbated in the pandemic around the withdrawal of services, increased isolation and mental wellbeing. Based on the evidence generated in the Pilot, RIX won a further tranche of funds from the programme in October 2020 to undertake Stay Connected Phase 2 – Scaled implementation Project.

The second phase of the project was organised in four phases.

- Phase 1 – Recruitment.
- Phase 2 – Onboarding.
- Phase 3 – Training and implementation.
- Phase 4 – Evaluation and reporting.

As part of the Stay Connected phase 2 project, a suite of communication and learning resources and training and support sessions were developed for staff and supported users. The delivery of training sessions for Supported Users was repeated four days a week, giving them opportunity to choose their preferred slot. Staff sessions were provided on a weekly basis and a daily drop-in support sessions

were made available to all users. All training sessions were video recorded and made available subsequently on the RIX Multi Me platform users to access as required. A staffed telephone user-support desk was available during business hours as well as a single-click access to online help.

Phase 2 Project - Aims and Objectives

The aims defined for Phase 2 of the TF19 programme were:

- To further explore and develop the software innovation and help accelerate its potential deployment at scale.
- To build wider and transferable insight that could be shared to help prepare for expected challenges from further waves of the COVID-19 infection levels in the UK.

The RIX Centre's proposal identified five specific objectives to meet these aims in a second phase of proactive implementation of the RIX Multi Me software, training and support solution through the 'Stay Connected' project:

- To implement and further evaluate impacts of use of the software and its implementation for 1,000 people with LD and autism, their carers and their support services.
- To develop the scaling capability of the software intervention with refinement of the RIX Multi Me 'Stay Connected' package and its remote adoption and implementation tools.
- To identify the facilitators and the barriers that affect adoption and implementation the solution.
- To develop transferable, evidence-based insight on the design, delivery and benefit potential of digital person-centred care solutions for public health emergency situations.
- To capture and disseminate learning on strategy and good-practice from the project, and contribute to professional guidance and standards for digital person-centred care.

Methodology

The project's evaluation methodology included the following tools: baseline and end of project evaluation surveys, end of the project focus groups, interviews, capture of representative case studies and analysis of usage data from the technical system.

Ethics

As part of ethical considerations, accessible information sheets and draft letters about the project for different audiences were developed. Consent forms were also created and provided for participating organisations, staff, supported users and allied professionals to enable all to make an informed decision on whether or not to participate in the project. Information events were held at different times to give an opportunity for each potential participant to attend. All members of RIX and Multi Me staff had valid clear and recent enhanced DBS certificates.

Baseline and post project surveys

Baseline surveys were distributed at the beginning of the project in October 2020. The aim of the surveys was to capture demographic, geographic and behavioural information including: gender, age, ethnic background, employment status, living arrangements, activities and behavioural characteristics such as use of social media, use of technologies and the availability of access to the internet and technologies for participants.

The post project surveys were distributed during March 2021. The aim of the surveys was firstly to evaluate users' experience of the software features and functionality, and the RIX Multi Me onboarding, training and support solutions. Subsequently, the surveys were designed to help understand emerging patterns of use of the tools during different phases of the project and to

evaluate the value and impact of various applications of the system on digital care and support delivery.

User interviews and focus groups

Semi structured interviews with users and focus groups were conducted during March 2021 and lasted between 45-60 minutes each. Three focus groups were organised: for supported users, for frontline staff and thirdly for project managers. Twelve interviews were conducted to expand on some of the initial findings. Five case studies were subsequently developed. All consultations were undertaken on video calls using MS Teams or Zoom. The sessions were recorded, transcribed, anonymised and processed thematically.

The aims of the focus groups, user interviews and case studies were:

- to capture general experiences of different users taking part in the project and using the software to gain insight on the potential and actual benefits for those taking part.
- to identify barriers and facilitators that influence successful adoption and implementation of the RIX Multi Me Toolkit by organisations, staff and supported users.
- to explore the usability and accessibility of the software and accompanying services and examine methods used to onboard, train and support deployment of the system for different groups of participants.
- to identify examples of effective practices and different strategic approaches to deployment and implementation of the toolkit.

Data Analysis

Usage data for RIX Multi Me Toolkit was extracted from software analytics at server level and the Toolkit's own 'Insights Tool', which provides metrics on use and simple content trends for managers and administrators as a back-office feature within the system. The software data accessed covers user numbers, their identity and their activity on the system and a 'Wellbeing Dashboard' feature is available to present a rapid view of users' recent posts relating to their moods and emotions.

Information is presented according to organisation and registered user roles. Roles of system users on the RIX Multi Me toolkit are differentiated as:

- 'Supported Users' - the service recipients who are people with LD and autism.
- 'Buddies' - the primary supporters of supported users, who are the registered guardians of the supported users on the software system.
- 'General account holders' – staff and professionals registered on the system without 'buddy' roles and 'informal carers' in supported users' support circles. The latter are typically, family, friends and peers chosen to join the individual's social and support network on the system.

The Insights Tool shows quantity and genres of posts with direct access to Supported Users' content enabled for authorised buddies and administrators. Information is provided on the Supported Users' uploaded media, posts, comments, chat and diary entries. A simple artificial intelligence feature filters key words and emoticons in diary posts to provide up-to-date monitoring of Supported Users' self-reports on how they feel. This enables Support Staff to keep track of individuals' wellbeing remotely via the Insights tool and swiftly respond and provide additional support when required.

Users can also be organised into categories for monitoring purposes according to the scope and scale of their engagement providing an overview of users' routines and level of activity:

- Super Users – post more than 100 x per month.
- Frequent Users – post between 21 – 10 x per month.
- Medium users - post between 6 – 20 x per month.
- Low Users - post between 0-5 per month.

Infrequency of posts does not necessarily correlate with a lack of engagement or benefit for users as low users were frequently identified as so-called ‘lurkers’ who do not share information but frequently view other people’s posts. This group was seen to be a significant cohort which nonetheless could gain from a sense of passive connectivity with friends, peers and support staff.

The data presented covers RIX Multi Me Toolkit use between 14 April 2020 and 26 March 2021.

Deployment – Organisational and Supported User profiles

Participating organisations shared the aspiration as they engaged with the project to integrate the use of RIX Multi Me Toolkit across the majority of their services. Change to participant organisations occurred over the interim period between the two funded phases. A large national care provider organisation that participated in the pilot subsequently elected to withdraw from the second Phase of the project. This was in consideration of the extra pressures that their frontline staff were already experiencing at the frontline as a result of the pandemic. The decision to withdraw was also influenced by insight gained in the pilot phase that the organisation’s more able service users, many of whom had support needs but no diagnosis of LD, preferred to use mainstream social media and saw the Stay Connected software as too simple and ill-suited to their established social media habits and capabilities. A second London local authority was subsequently enlisted and the number of prospective Supported User participants identified by participating organisations during the inter-project phase between May - October 2020 totalled 1,400.

Six organisations were ultimately registered and primed to participate on Phase 2 of the project in September 2020:

- Two London-based local authorities (O3, O6).
- Three supported living organisations in North London, Surrey and Cornwall (O1, O2, O4).
- One Special Education School in Herefordshire (O5).

The profile of the living arrangements of Supported Users differed from Phases 1 to 2 of the project as a result of the changing composition of the organisations taking part. A lower proportion of young people in shared supported-living accommodation were subsequently involved in Phase 2 of the project. Larger numbers of people were directly supported by local authority domiciliary care teams and the second phase of the project featured a larger cohort of older adult service-users who lived with their families.

The living arrangements of the resultant Supported User cohort on the implementation Phase comprised: 57% living with their families; 29% in supported living; 5% living independently; 5% in residential care and 4% ‘other’. A small but significant number (est. 5%) had returned from supported independent-living accommodation to temporarily living with parents as a chosen response to the risks and fears associated with the pandemic.

Findings

In this section we will first present the initial findings from data analysis, surveys, interviews and focus groups. Secondly, we will present the analysis organised in the following themes: access, patterns of use, training, barriers and benefits.

Data analytics

1. Registrations

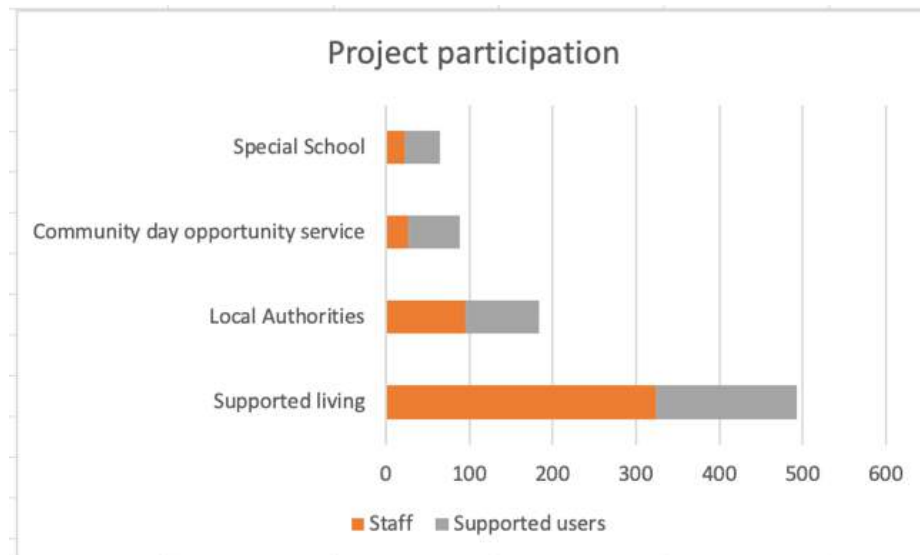


Figure 3 Project participants organised by type of organisation and user ratios

Six organisations successfully registered and used the system during the pilot. The total number users registered on the system is 938. This is made up of 363 Supported Users, 468 Buddies and 107 General Users.

Phase Two RIX Multi Me Users

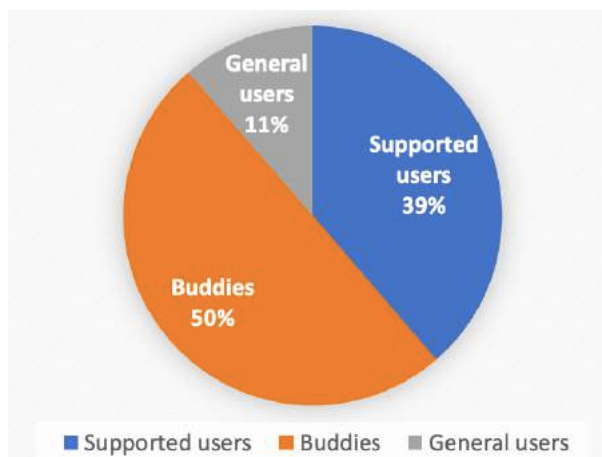


Figure 4 RIX Multi Me Toolkit users

Supported users – are individuals with LD and/or autism.

Buddies – are family or staff members who act as a guardian of the individual.

General Users - are made up of invited family members, education, health and social care professionals invited to joining the online social/support 'Circles' of supported users.

The proportion of Supported Users and staff differed across different settings (Figure 3). The largest proportion of participants came from supported living organisations, with just under 500 users. The ration between staff and supported users was quite high, roughly two-thirds were staff members and one third Supported Users. That is representative of the organisational structures where a large number of staff in supported living settings are engaged in the delivery of care providing a 24-hour

service. In comparison, local authority owned care settings feature staff and supported users' ratio of approximately 50:50 indicating a lower ratio of staff involved in the delivery of care. The staff and supported users' ratio is further changing in the community day opportunity service where we observed one third are staff and two thirds Supported Users with a much smaller ratio of staff to supported users. With the smaller staff/Supported Users' ratio the continuity of care for the community day opportunities service would be much more difficult to deliver remotely with Supported Users dispersed in different locations and settings such as homes, residential or supported living settings. We observed a similar picture in the special school where the staff to Supported Users' ratio is 1:3.

2. Activity

The level of user activity is indicated by the totals and average quantity of comments and posts made, mapped to the Project Phases and the inter-project period between the two funded project interventions.

Project Phase 1 was delivered between 14 April and 18 May 2020. The total number of posts in the 34 days period of this phase was 8,650, with the average of posts per day 254.

The inter project phase dated between 19 May and 19 October 2020. During the 154 days period of this phase, the total number of posts was 19,430, with the average of 126 posts per day.

Project Phase 2 was delivered between 20 October 2020 and 26 March 2021. The total number of posts with the 158 days of the project phase was 35,439, with the average of 224 posts per day.

This pattern of user activity on the Stay Connected system, when mapped to the wider pandemic environment on a timeline (Figure 5), shows correlation between user engagement and the wider severity of the UK pandemic environment. The figure below indicates the gravity of the public health emergency over time, indicated by changing COVID-19 related mortality rates and the periodic imposition of lockdowns. User engagement is shown to persist and only slowly diminish in the inter-project phase, when provision of pro-active support was minimal and activity levels are shown to have sustained since the end of the Second Phase of the project. Activity by Super Users (those posting over 100 x per month) was shown to significantly correlate to the extent of infections with its attendant risk. Activity levels also consistently showed a dip during periods when lockdowns ceased.

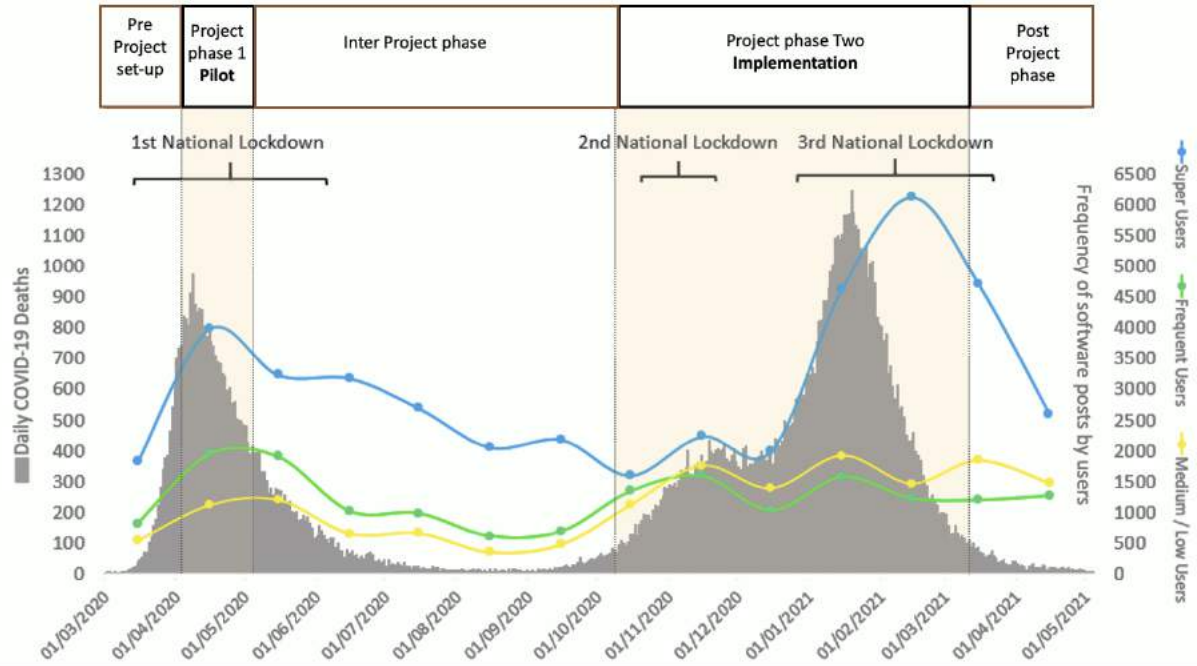


Figure 5 Patterns of RIX Multi Me system use mapped to wider pandemic timeline.

Baseline surveys analysis

Surveys were used at the beginning and the end of the project to find out the initial feelings, technology usage patterns, demographics of all project participants and their experiences of the participation in the project and impact it had on their daily lives, wellbeing and experience of support. Surveys were designed to be easy to read and understand using PhotoSymbols and the RIX Easy Survey tool to maximise accessibility for the participants with LD and autism.

1. Demographics

Sixty-five Supported Users completed the baseline assessment. A wide range of ages were represented from 15 to 70 year-olds, with the largest proportion of adults in their 30s and 40s (Figure 6).

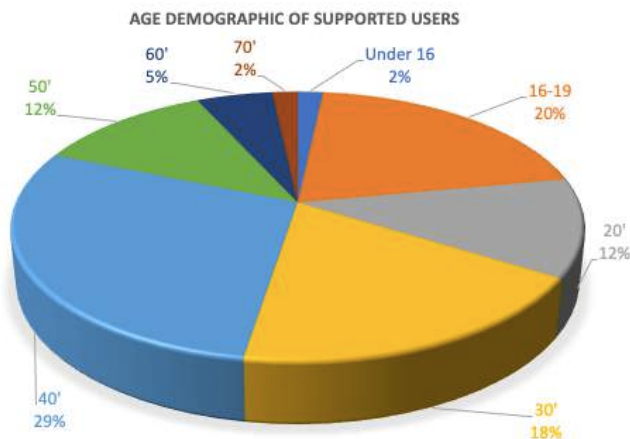


Figure 6 Age demographic of Supported Users

2. Wellbeing

Surveys addressed the feelings and emotions experienced by Supported Users prior to their participation on the Stay Connected project. Only 12% of supported users reported feeling confident at the beginning of the project. The remainder reported feeling scared, frustrated, bored and/or worried. 28% of participants felt well supported and the remainder 72% affirmed that more support was needed at that time. 32% of supported users also reported that connecting with staff over the previous two weeks prior to the pilot was difficult. The negative feelings were expressed equally across different living arrangements, we have however noticed the correlation between age, our findings showing that the negative feelings were mostly expressed by under 20s where 83% of participants expressed one or more negative feeling. People in their 20s demonstrated equally negative and positive feelings. The negative feelings were however increasingly growing in the population between 31 – 74(Figure 7).

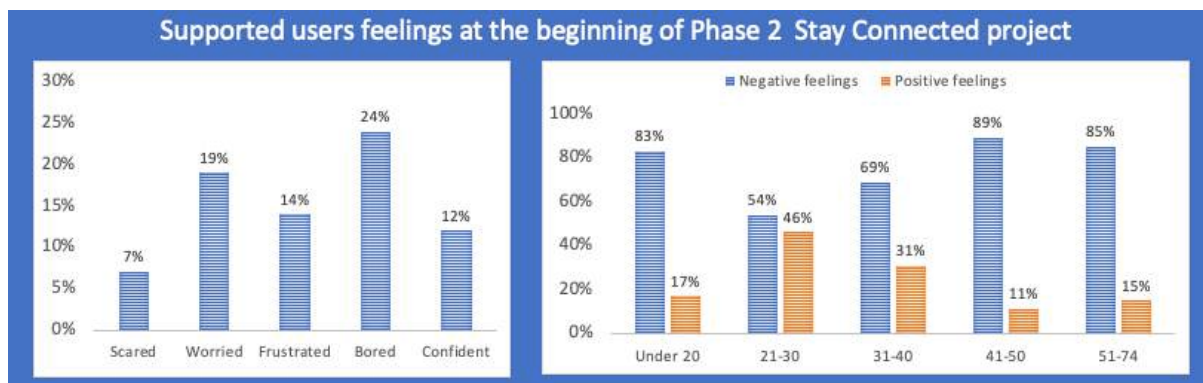


Figure 7 Supported Users' feelings at the beginning of Phase 2 Stay Connected project

The above findings should not be too surprising. Research shows that people with LD have less opportunities to socialise with their peers and as a result have fewer friends (Mencap 2021). Loneliness is not a new phenomenon caused recently by the pandemic; it was already an issue for people with LD prior to lockdown with one in three young people with a LD spending less than one hour outside their home on a typical Saturday (Mencap 2021). Our findings are very much in line with previous findings by Sense, who reported that 77% of those aged 18-34 were feeling lonely (Sense 2017).

3. Access to technologies

Stay Connected project participants were asked about their access to technology at the beginning of the project. The survey was answered by 147 staff and found that only 40% had access to a smart phone and 1.3% used a phone without internet connectivity. However, all respondents reported accessing the internet for personal use daily, using either personal phone (40%), laptop computers (31%), tablets (19%) and PCs (8%). At the start of the project staff reported that the primary support to service users to compensate for significantly reduced face-to-face support was via regular telephone calls and occasional meetings and messaging via Zoom, MS Teams and WhatsApp.

Access to technologies reported by 165 Supported User respondents was significantly below levels recorded for the wider population. A small number of Supported Users (8%) had access to a phone without internet connectivity, 39% accessed tablets, 31% reported access to a smartphone, 12% had access to laptops and 10% accessed a desktop computer. Access to these devices did not reflect ownership or sustained access devices. A minority 35% of Supported Users affirmed their ownership of the devices they used. Access was otherwise shown to be via shared devices at home or at day services. Although 89% Supported Users recorded access to the internet daily, this was mainly achieved via shared devices in day services, school or at home.

End of project findings

End of project surveys, focus groups, interviews and case studies provided a rich and detailed account of the beneficial impacts of the Stay Connected project and its scaled implementation of the RIX Multi Me software. This consultative evaluation also provided further insights on the barriers and facilitators that effect access to technologies, the skills training and support required to optimise the benefits for people with learning disabilities and autism that digital technology can provide. In this section we will first report of the usage of RIX Multi Me Toolkit and individual tools. Secondly, we will examine the patterns of use across different organisation. Next, we will discuss different barriers and facilitators that stop or enable the wide scale adoption of our software. Finally, we will discuss the benefits of the use of the software during the pandemic.

1. RIX Multi Me Toolkit usage

The usability and usage of the RIX Multi Me software was evaluated using the end of the project surveys, interviews and focus groups. 95% of supported users and 90% of staff found the RIX Multi Me Toolkit easy to use and affirmed that they liked using the system on a regular basis.

The Multi Me Toolkit comprises of five distinct tools and the preferred choice of tool to use varied between staff and supported users (Figure 8). Staff reported using all of the tools within the toolkit equally. 53% of staff reported using the system daily, 21% weekly, 5% monthly and 21% less often.

The intensity of use was firstly determined by the role staff played in Supported Users support circles. Buddies would be expected to use the system daily or weekly as part of their one-to-one support role. Managers would typically use the system monthly or less often. The pattern of different usage would also be determined by whether the individual could access a day service or receive support in person at all. Where just remote support was in place, daily use was standard and when this changed to blended support, use of the RIX Multi Me Toolkit diminished as a result.

Supported Users engaged with the system and the social networking apps in particular, enabling them to keep in touch with their peers and staff members from their established day centres. The tool most frequently used by Supported Users was the Chat function aligned with users' Circles with 38% of supported users using this daily. This helped users to stay connected and provided remote access to staff for continuity of care, and support.

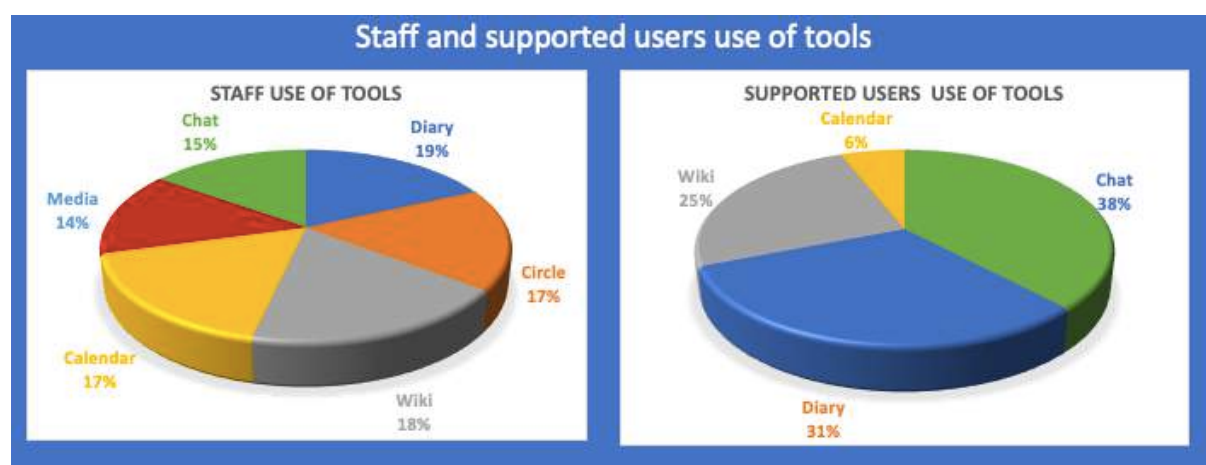


Figure 8 Supported users and staff use of tool

The second highest scoring tool was the Diary with 31% of supported users adding entries to their diaries on a daily basis. The Diary tool enabled supported users to document their activities, share

their experiences and feelings, their stories and ideas. Supported Users using this function liked the idea of sharing and receiving 'comments' and 'likes' from other users from the Stay Connected community group. Supported Users reported that this helped them to broaden their friendship circles, managing them to expand their social and support networks despite the socially distanced circumstances.

The use of the Wiki tools was the third most popular tool amongst Supported Users, of whom 25% reported using the RIX Wiki tool on a daily basis. The Wiki enabled people to capture their new daily routines, and organise their media files, pictures, video clips into separate sections and annotate or caption their media. They also used Wikis to capture their goals and wishes for the future, defining outcomes to scaffold their support longer term.

The Calendar tool was the least favourite tool for the Supported Users, who mostly used it simply to access online activities. It was therefore seen by them as a tool to which they had not added content and only 6% of users reported using it on a daily basis. Notably Staff highlighted the usefulness of this tool to schedule online events in an accessible form, complete with links to Zoom or Teams meetings that Supported Users could access with a single click. This significantly improved punctual attendance and direct engagement for Service Users with online activities.

2. Patterns of use

Insight from the various participating organisations and their differing systems, processes and dynamics were shared and these are summarised below with analysis of how they shaped their respective experiences of putting the RIX Multi Me toolkit into use during the second Phase of the Project over the second and third waves of the COVID-19 Pandemic.

The Supported Living Service based in London (O1) originally intended to engage 113 Supported Users, however during the recruitment phase it became apparent that this level of engagement would be problematic. In addition to the wider pressures of the pandemic, poor internet connection in some of the settings, a lack of access to devices and poor technical skills of support staff were all issues that obstructed potential participants from registering on the system and engaging with the project activities. However, 27 supported users and 20 staff members were engaged from three supported living settings within this organisation. Five of the staff members (representatives from each of the settings) and four Supported Users attended all of the training sessions provided. Two managers attended weekly project management meetings, addressing any issues and reporting on the project progress within settings. The most significant barriers for the organisation were poor internet connectivity and absence of up-to-date devices.

Staff and Service Users' resilience and commitment to take part in the project in the face of extraordinary challenges was demonstrated at one of the supported living homes taking part. At one point 13 members of staff and all of the Supported Users attached to a single setting were ill with COVID-19. The strongest member of staff who experienced mild COVID symptoms, remained on site to support the infected residents who were socially distanced in their bedrooms. Regular teas and take away meals were provided and communication with the residents was achieved using a combination of WhatsApp and the RIX Multi Me software's Chat and Diary tools. The participants created a 'COVID-19 club' on the Stay Connected system to keep up the morale of the residents who were feeling depressed and unwell, isolated in their rooms. They reported use the RIX Multi Me software and online activity with the Club helped everyone to stay connected and improved their morale and their wellbeing.

'COVID -19 brought a lot of changes to our residents' lives. We had a number of people going to hospitals, being there completely on their own. We had no means of contacting them. They were in a strange place not knowing where they were and what was happening to them. The use of digital devices become compulsory as most of the medical appointment were happening online. Honestly, this was the worst week of my working life.' PM

A service from this organisation used the Wiki tools to capture Supported Users' personal information in preparation for a GP consultation. They reported that Annual Health Checks were overdue for Supported Users and that phone calls with GP practices had failed to effectively engage the supported individuals. Contact was made with the local GP Practice, where there was positive interest in registering on the System to access person-centred information from the individuals' Wikis. GPs welcomed the invitation and saw the positive potential of remotely accessing information prepared with support by the person themselves as part of preparation for the Annual Health Check by both parties. Despite agreement in principle to take part, the Practice was obliged to prioritise its vaccination work and plans to put this approach into practice for Annual Health Checks are on hold until the pressures of the pandemic are reduced. This organisation remains at the early adoption stage but has firm commitment to continue to develop this use of the toolkit to improve liaison with Primary Care services around Annual Health Checks in particular.

The Supported Living Provider in Cornwall (O2) engaged 239 members of staff and 104 supported users. 13 staff attended training that was tailored to an organisational plan for adoption, which principally deployed the software's Diary tool to record case management notes alongside photos of daily activity with Supported Users on the system. The key aim was for the system to provide a person-centred way to keep abreast of isolated and distanced service users who would normally have had regular face-to-face visits before the pandemic. The system enabled improved monitoring of Supported Users' wellbeing and encouragement to pursue daily activities and share achievements. Staff reported use of the system to maintain and monitor progress on outcomes-based care plans that were developed using a Person-Centred-Planning template on the system's Wiki tool. This organisation had clear vision for deployment of the software within their care service that they were able to follow throughout the project with clear messaging to staff and Supported Users. They achieved a full integrated adoption of the software across the service led by trained support staff and built around remote case reporting that could be managed through a blend of online and face-to-face activity with their service users. The organisation's leadership reported that the tool proved indispensable as part of their response to the challenges of the pandemic.

'I couldn't say there was no one who has struggled during COVID, but I think what we have managed to do is identify those struggles and put in support much faster. Without being able to connect remotely we may not have been able to identify them. I think the system has not been a resolution to COVID but it has made the journey so much easier.' -SM

The Large London Local Authority (O3) had participated in the first phase of the Stay Connected project and wanted to maximise the systems potential impact and roll it out across their services. They thus targeted engagement of over 800 Supported User participants for Phase 2 of the Stay Connected project. However, planned registration and onboarding of users coincided with the second wave of the pandemic and subsequent lockdown. This series of events led to day services and school facilities closing and transfer to remote working. In these circumstances team leaders and service directors were cautious about engagement on a new project that entailed introduction of new software systems and processes. Organisations felt overwhelmed and wanted to protect their staff from any additional pressures. This resulted in only eight services seeing through their planned engagement on the project through day opportunities, residential and supported living settings and significantly, a large cohort of schools were unable to adopt as intended. Overall, 96 members of staff

and 137 Supported Users registered on the system throughout the project. The local authority actively engaged with the project, despite the pitfalls and tasked the Borough's Assistive Technology Project Management Team with the coordination of engagement across the organisations taking part. This centralised Team engaged systematically with the project's activities, attended weekly management and review meetings and progressively expanded the integrated adoption of the software with people with learning disabilities and autism across the borough through the duration of the project. The Borough undertook its own evaluation of the impacts of engagement, which evidenced positive improvement to provision and wellbeing impacts for service users as well as for parents, carers and support staff teams. The local authority has subsequently committed funding to sustain the provision of the software and has co-developed a strategic plan for the incremental adoption of the RIX Multi Me software across integrated care and education services, with the goal to achieve scaled implementation.

The case studies that have emerged from this local authority include a young man who joined the Stay Connected project and engaged with the additional training session offered. This young man used the software to organise his thoughts and capture his aspirations and personal plans using the software's Wiki tool. This was in preparation for his participation in an upcoming education, health and care planning meeting that was organised to occur over a Teams call with education and health services. During the call he used his Wiki to frame his contribution to the process, effectively chairing his 'About Me' session. The response from the professionals taking part was very positive:

'I have done a lot of annual reviews over the past three or four years and I've got to say that without a shadow of a doubt this one has been the best and it's absolutely amazing. I think the learner worked really well and the presentation of it has been fantastic. It gave me a massive insight into the learner's likes and dislikes now, how he is feeling and his aspirations. Fantastic! I liked it as it was visual and colourful. It's amazing. I think all our learners should use it.' EHC Co-ordinator

The Supported Living Service in Surrey (O4) provides 13 homes and engaged 65 members of staff and 38 Supported Users from across its service settings. Three customised training sessions were provided and attended by 20 members of staff. The service used the RIX Multi Me Toolkit to maintain social connectivity between the people they support and their peers and support workers across their various homes and day opportunity centres. Users reported that the software enabled continuity of connectivity and helped to improve morale and wellbeing for service users who were frustrated by isolation in their homes and missing contact with the wider social circles usually in place across settings. Senior staff who were missing their previous frequent contact with staff and service users across the 13 settings found the multimedia messaging capability valuable to keep up with staff teams and service users and the greater security and usability of the toolkit over conventional social media was welcomed.

The shortfall in take-up from the intended targets across this organisation was largely attributed to lack of devices, staff shortages and the crisis management that was in place as a result. However, management reported a further factor influencing poor adoption which was described as the 'software fatigue' shared by frontline staff who had previously been required to implement two new case management and reporting packages over the six-month period immediately prior to the pandemic.

'It has made us understand and see that we didn't really push the use of technology within our services properly for the people we supported, actually they were very behind even just on smartphones. At the moment we are doing strategic planning for the next three years and one of the big factors that's come up is that we need to improve on the use of technology, so it generally fits into that.' – SM

'I think we have probably done too many systems too quickly. Staff are just getting to grips on the other two or three systems we got in place and now we put another system on their laps. I think between the pandemic and having to focus on keeping people safe, people haven't really focused on it as much as we like. I don't think the staff have picked it up and run with it but I think as an organization there is a bit of a lack of communication and direct access to staff.' - SM

The Special Education School in Herefordshire (O5) had just 13 accounts for their staff and learners in place at the start of the pandemic and rapidly scaled adoption as the second lockdown was introduced, registering a total of 23 staff and 42 of their 65 students. They engaged with the system on a daily basis for school-home communication and peer-to-peer networking to help maintain learners' morale and wellbeing. This immediately extended to additional use of the system for distance learning and interventions to progress work on learners' education, health and care planning and the monitoring of pupils' progress on their defined outcomes. The school did not require any additional training and the learning guides and video clips available enabled staff to get onboard and engage with the functionality of the software intuitively. Over the period of the pilot, the school has successfully integrated the software within their workflows and are particularly interested in the benefits that this will present as they cautiously transition to face-to-face and blended teaching provision.

'The staff wanted to engage in it more because of lockdown. So, they can communicate more with the pupils whilst they are home-learning... I think with regards to the curriculum and the safeguarding and the PSHE [Personal, social, health & economic education], it's been very, very beneficial to enable our young people who are turning into young adults to develop hopefully safer practice within chat rooms etc.' – Teacher

'I think some people are a little bit scared of the technology. But communication-wise it's so much easier for our parents to just put little notes when they are on it rather than writing the home school diary. Longer term you know, theoretically every child in our school could have an education, health and care plan [on the system], if we can coordinate it. I think the onerous part would be converting from paper records of achievement to the multimedia one.' – Head Teacher

The second London local authority (O6) that took part in the project initially committed to 150 participants but struggled to meet this target as immediately their day provision across multiple sites and local further education college were obliged to close. The local authority leadership managed to engage 25 members of staff and 15 supported users from six services across the borough on the project, in negotiation with commissioned provider organisations. 14 members of staff firstly attended staff training sessions but only three supported users subsequently took part in just four of the six inclusive training sessions provided. Despite the fact that participating organisations were committed to a large-scale adoption at the onboarding phase of the project, they subsequently experienced particularly significant surges in illness and staff and service-user absences as the second COVID-19 wave started in the autumn, which led to participants' scaling down their ambitions for adoption. However, the dominant factor obstructing adoption repeatedly reported by service providers was the lack of access to suitable devices and internet connectivity available to the people they support and their families. One service provider reported that just seven out of their 20 service users could access the required technology from their homes and that use of digital tools was strictly encountered by most of their service-users as a timetabled part of the day care service's activity programme.

This local authority was already committed to actively addressing the issue of digital exclusion as a priority prior to the pandemic and a funded evaluation and pilot programme was in place. The

pandemic rapidly highlighted and exacerbated the structural issues of technology and internet access faced locally and the particular inequalities faced by the local learning disability community. While the borough's various providers were willing to participate in the project in principle this was frustrated by the shortage of structured provision of personal access to digital tools and networks for supported people outside of timetabled sessions in day centres and residential settings. Additionally, the skills levels of support staff from centres and from parents and carers in individuals' homes was seen to be a significant factor in the poor take-up in this borough.

'It was contradictory to everything shutting down due to COVID and we kept wondering if we can do this new thing in the same time frame. It was not the best approach as people were going off sick as well as service-users going off sick. The time frame and asking people to move quickly when we had so many stakeholders involved was a challenge because things do move slowly in the council.

It would have been a different story if we had face-to-face engagement with about 30-50 service users coming in and providing our staff encouragement to use it rather than trying to engage remotely with their parents, carers, and then themselves...' - SM

3. Barriers and facilitators

During the COVID-19 Pandemic and lockdowns there were extraordinary pressures put on education, health and social care personnel, which was reported and recognised on the national level (Seale, 2020). Our study experienced these challenges as a significant factor for organisations and individuals that took part in the Stay Connected project and our targets for adoption and deployment at scale fell short as a result of these exceptional challenges.

The project suffered from lower-than-expected engagement by organisations at setting level, often despite numerous efforts to onboard, train and engage support teams. Staff from organisations reported having to deal with a considerable set of issues that were directly caused by the pandemic including staff absences, sickness of clients and increased frequency of health and social care emergencies. Project recruitment and active engagement with the software tools suffered as a result.

Additionally legacy issues that were highlighted, rather than directly caused by the pandemic, presented significant further obstacles to active participation. These included poor internet connectivity, lack of access to devices, poor availability of face-to-face support for users to set up their devices, access networks and log into the system. Lastly, a relatively low level of digital skills and experience of social media was noted as a factor amongst support staff as well as the service-users.

'The technology problem is that now more people are jumping onto one business line now that everyone is remote. We have had lots of issues with lack of devices, poor internet etc.' - O4

'Technology barriers, people not knowing how to use technology... were relevant to what they needed... Some people are more technological than others and that was a main barrier. But a majority of the time, after explanation, they enjoy and are interested' - FLS1.

'We want to teach managers and staff how to use the tools effectively' - SM2

New learning materials, guides and video tutorials were developed and staff training and support sessions were refined throughout the project as part of the objective to streamline and accelerate the software's deployment at scale. Six weekly training workshops introduced each of the system's key

features and tools, accompanied by daily drop-in sessions that were offered to buddies and other support staff. The use of system's support resources and the training offer was evaluated at the end of the project to assess the utility of the materials for staff and service users. Overall, the training offered and the accompanying learning materials were highly valued by staff who commented on their usefulness, flexibility and high quality. Findings show the majority of staff (75%) opted for training and used accompanying learning materials to gain confidence in use of the system. The most popular learning materials used were video tutorials, which were accessed by 22% of staff and the face-to-face training sessions attended by 23%. The use of PDF tutorials (12%), User Guides (11%) and peer-support (15%) were also popular with staff. Only 6% of staff reported receiving additional bespoke training during the project. The remaining 25% of staff did not access training resources and reported learning how to use the system simply by exploration and use, without instruction or guidance.

'I really appreciate that there's been a flexibility around training I think that's made the difference. Being able to offer these evening sessions to those who can't attend in the day being able to do a bit of a fast-track training for people who are more confident using IT. I think that really made a difference. I think as well the summary sheets that you've done are really helpful with the videos' - SM

The existing training materials were received extremely positively. The most popular resources were video tutorials that could be accessed in people's own time after training sessions and the sharing of case studies during training.

Do you know, I definitely found the agenda really helpful [with] the Wednesday sessions, because it keeps me on task, I remember the things I have to come back to' - FLS

The project's second phase start time unfortunately coincided with an already rising second wave of COVID infections that particularly effected the London local authority areas involved in the trial. Local people with LD and autism and their support circle faced immediate challenges around their safeguarding and emergency support service delivery, that understandably took priority over our project agenda. The introduction of the RIX Multi Me tools demanded new online working approaches and required devices and infrastructure to be configured. In the exceptional prevailing circumstances, project participation proved too much of a challenge for a significant number of selected service teams, whose managers and team leaders chose to protect their over-stretched frontline workers and delay or postpone their participation in the project. Organisations persistently maintained positive intent to take part in the project despite the false starts. Onboarding sessions with staff and service users were re-scheduled around the anticipated easing of restrictions, for example when day centres, schools and colleges were due to re-open after the winter break, but such loosening of the constraints did not materialise. The number of project participants who could actively use the software was reduced and so the project cohort diminished. This prevented the implementation of the RIX Multi Me solution at the intended scale.

'I think between the pandemic and having to focus on keeping people safe, people haven't really focused on it as much as we like. I don't think the staff have picked it up and run with it but I think as an organization there is a bit of a lack of communication and direct access to staff. Anything I am encouraging, it goes through the manager then they have to pass it on, and that communication line breaks often. I think the pandemic actually has been a hard time to implement something new as managers are run off their feet.' - SM

4. Benefits

The benefits from use of the software highlighted by project participants included:

- Improved connectivity and wellbeing.
- Improved access to and participation in activities.
- Acquisition of new digital skills by both staff and Supported Users.
- Improved self-advocacy and development of these skills.
- Improved quality of care and support provision.

4.1 Connectivity and wellbeing

Research shows that social connections are very important for our wellbeing (Ortiz-Ospina & Roser 2020). Connectivity was one of the themes that emerged from our focus groups and interviews and was seen as one of the biggest benefits. Many Supported Users and staff commented how important the access to the software was in terms of maintaining connections between and amongst supported users, their families and staff. It was felt by all participants that the software provided a genuine platform for staying in touch.

'It has been really lovely; it has given service users a way to stay in contact with staff. Especially during lockdown, where no contact makes you feel lonely.'- SU

Research also shows that having support is important for our happiness and health, and it is fundamental for our ability to share information and learn from each other (Ortiz-Ospina & Roser 2020). The toolkit enabled participants to continue their connections and communications remotely particularly using the Chat and Circle tools, which helped Supported Users, staff and families to restore and strengthen connections sharing photos and video clips alongside text and emoticons, which eased isolation improved feelings of wellbeing.

'I would like to see every single care home to be involved in this project, using this social media platform. I want to see all residents in supported care homes to be connected online and recruit their friends to join. The more you reach out the better it is for society at large because it ...will benefit everyone who decides to participate. We want to encourage people to use it as frequently as possible as it will help their mental health and afford them opportunities to reach out to people.'- SM

Access to technology and support to use the RIX Multi Me toolkit to communicate and share information with other people from different settings helped to address issues of loneliness during lockdowns and to restore the important social dimension of day service provision for users who reported that they met people during training and activity sessions on the software and developed established new friendships.

'With changes to our day opportunities and limited face-to-face engagement it has supported us to reconnect with each other. I am based in another unit and being able to connect with colleagues and service users I would usually see day-to-day, has reignited our community.' – FLS

4.2 Participation in remote activities

Participation in leisure activities is closely related to improved quality of life, wellbeing, development of skills, confidence and friendships (Wilson et al., 2017). According to Mencap, people with learning disabilities take part in fewer leisure activities than people without a disability (Mencap 2021).

Organisations involved in the project were keen to ensure that regular scheduled leisure activities were available for supported users to access remotely. The Calendar tool helped to provide an easy-to-understand timetable and access point for frequent zoom activities, significantly reducing obstacles for supported users to join those sessions. Staff added direct links to the Calendar to enable Supported Users to join with a single click of a button. Those sessions brought Supported Users closer together, joining sessions from their rooms when isolating for example, sharing the supported

cooking session that could be less frequently be offered in shared kitchens, joining Zumba sessions from their living rooms, art sessions at the dining table etc. Access online to peoples' personal and home spaces gave support staff additional insight into individuals' environments and opportunity to monitor their wellbeing.

Regular activities help to maintain the lost routines that typically help people with LD and autism feel calm and secure. They scaffolded the remote support offer that support staff were able to maintain using the RIX Multi Me tools. Supported Users were encouraged to keep a daily photo record of activities, add them to their Diaries and share with their Circles. This in turn framed continuing informal online exchanges between peers, carers and support staff within secure circles of support in which friendships could be safely consolidated and new skills acquired.

'it's brilliant as I can be connected with friends and staff plus [the organisation] is adding all new activities that they are putting up on Multi Me.'- SU

'I've run out of photos and videos to post. It made me feel great, it's quite nice to know that people are liking and commenting, it feels nice.'- SU

4.3 Self-Advocacy Skills

The RIX Multi Me software is designed to use multimedia authoring to facilitate the self-advocacy of people across a spectrum of ability, with a diverse range of communication preferences and needs. The use of pictures and videos gives supported users who are less verbal or non-verbal a means to communicate more effectively with wider circles of support on the secure system. Supported Users reported that the software was accessible and easy to use and they gained confidence in using the network independently, which helped develop their safe social media skills within a safe space, boosting their confidence and improving their self-advocacy.

'Made me feel so brilliant, amazing. I was comforted by how to do all sorts of things, such as upload my photos or videos on there I could just write it right on there.'- SU

'I personally loved the software regardless of the pandemic, the people we support could use it themselves and it was aimed directly at them self-advocating for themselves. I just loved the collection of the tools - not just one tool - and the fact it was a technology they could own and use.'- O4

Improved self-advocacy skills were evidenced for a participating young man with speech impairment who deployed the Wiki tool for a remote annual education, health and care review meeting. The improved confidence of the young man's presentation and communication skills was noted by attendees. Prior to this meeting he was not vocal in planning meetings and his mother would speak on his behalf. On this occasion, he had reflected and created content using his Wiki on the toolkit beforehand and he was able to speak up on his own behalf. He had prepared an account of his personal aspirations, on what he felt was working well and not working well in his life and how he could best be supported to pursue his aspirations. His multimedia skills were excellent and he was able to demonstrate his strengths and capacity for independence throughout of the meeting.

'We found it really useful. When we first started, I was a bit unsure and a bit reluctant, but it was really good to breakdown his goals, his targets, make him understand and take responsibility for his own things. It also really helps him with his organisational skills.' Mother

'I like that I can invite my teachers and they can see how you are feeling each day. They can see your aspirations - and get a good understanding of me.' Young Person

4.4 Digital skills acquisition

The Stay Connected project gave social care staff and people with LD of all ages an opportunity to acquire and develop their digital skills. Some service managers were surprised that so many staff and supported users positively welcomed the use of new technologies and showed enthusiasm to learn new skills. They were also surprised at how capable some of the Supported Users were when using new technologies.

'The biggest surprise was the staff team and how keen they were to get moving on this.' - SM4

'I was impressed with how the service users can be resourceful in learning from staff and go home and then use it.' -SM4

'I have put my gardening stuff on Multi Me and my baking and art. I have learnt a lot on Multi Me. I was pleased with myself and grateful to those who commented and liked it.' - SU

The project provided a variety of learning materials and study options to fit a wide range of learner ability and to accommodate different preferred learning styles. Acquisition of new digital skills also requires extra time for learning and practice. Increased levels of motivation and satisfaction were reported by staff who were actively assigned time to dedicate to the project. Services where time slots were not actively provided for support staff were significantly less successful in their implementation of the software. Consistent staff engagement and resource allocation to the project were noted as key factors for successful adoption. One of the managers in their 1:1 interview commented on the fact that training alone is not enough and that giving people time to learn new skills is also an important factor:

'I do think the lesson plans were really useful especially during the first bit of logging on. I think some people logged on, had a look and ran away and didn't touch it. I think lesson plans are good but also a time management plan would be really good, so; Monday you log on and you update your picture; Wednesday you put an hour aside and do this...' just so there is consistent use otherwise people just drop it and forget their logins.' - SM

Lack of digital skills, like other barriers to adoption of digital technologies, can be mitigated through application of time and resource. Strategically this was seen to be understood and addressed by organisations where leaders recognised that the adoption of person-centred digital tools disrupted standard practices in place and understood that this represented a transformation project for their organisation. One of our successful large-scale providers (O4) approached the implementation of the RIX Multi Me software as a change project, they sent clear communications to all staff and assigned time and resource, so facing little resistance.

'Staff never liked change, the thought of the transfer was almost a dark cloud over Multi Me, but as soon as people understood the system and what it meant for them and how much easier it was going to be for them it was OK... Through the 12 months, I have not had a person not engaged with Multi Me, which is really rare for a system change, but nothing negative.' - O4

4.5 Care and support

Traditionally, front line staff providing care and support share care notes with each other using paper via shared files, communication books and diaries, accompanied by telephone conversation. With the introduction of the RIX Multi Me toolkit some of these communications started to be recorded on the system and shared appropriately with consent between carers across the service. This information

sharing was reported to directly improve care provision. One example involved an elderly lady, 'Jessie' who attends a day services three times a week and spends the rest of the week with her family carer. Jessie started using the RIX Multi Me system at the day centre in October 2020. Her key worker introduced the system to the main carer, who provided consent and helped to establish her online circle of support using the Circle Tool, with permissions in place for different members of the circle depending on their roles. The key worker adopted the chat tool to communicate directly with the main carer instead of using written communication book. In the Diary she included pictures and video clips documenting activities, including snack and lunch times. The exchange of these notes, images and videos highlighted an issue with high sugar intake and the associated behavioural challenges caused by increased blood sugar levels. This triggered discussion between the service and the family and a dietary plan was put in place to monitor sugar intake between home and the service. The Toolkit is subsequently in use to further develop Jessie's person-centred support plan, which is now routinely used by the service (Appendix 1- Jessie's Case Study).

Sharing accurate 'About Me' information is an important part of delivering good care and the project evidenced that the RIX Multi Me system can assist organisations to do so in an efficient and timely manner.

'From a support worker perspective providing direct care, the system is so much more streamlined, quicker and easier. It saves some time and they also receive positive feedback. If I'm a support worker, for example [with] the woman I spoke to last week, I can look into the system and I can get a whole overview.' - SM

'Overall, the Stay Connected project has given us the ability to support individuals remotely which we couldn't do before and have real oversight when you can't have physical presence and without having that people would have been at risk of mental health breakdowns. A lot of individuals have struggled with mental health issues, for the people we provide support to, it has been influential and I know contact is often overlooked. From conversations with staff and people who use our services they say they feel more communicated with and feel that we have a stronger presence as a senior team than we have ever had before! The last 12 months, my visits to services have been so much less. However, the time it takes me to travel - all that has now been used to speak to people, even though remotely. Before COVID, in my working week I would spend 15 hours in the car, so I applied the same amount of time to my working day at home, so the organization has gained about 15 extra hours of my time!' - SM

The use of the Insights tool further enabled front line staff and managers to monitor Supported Users' progress and their self-reported mood status, and so provide better person-centred care as a result. Several participants talked about the use of this feature and the benefits of having access to this kind of information. Although it was agreed that use of the Insight Tool on its own was not necessarily an accurate measure of a person's wellbeing it was seen to usefully complement other indicators used by organisations to monitor service-users' emotional status and vulnerability.

'Multi Me gives us a simplified version of a medical record. Very person centred. Monitoring service users progress which assists with our daily care plans and mood monitoring.' – FLS

Discussions and conclusions

We started the phase 2 of Stay Connected project in October 2020 as the COVID-19 related death toll was significantly increasing. The recruited organisations had to divert their priorities to keep both frontline staff and supported people safe, secure and protected, whilst ensuring the continuity of

care. The adoption of RIX Multi Me Toolkit was largely recognised as a transformational project, but despite the challenging environment, this was placed high on services' agenda. The commitment, determination and resilience of managers, front line staff and the supported users was notable and the challenges presented by the pandemic contributed to their stronger appreciation of the added value that online technologies could provide for social care.

Barriers to wide adoption emerged from the beginning of the project, with the first lockdown already underway. Organisations immediately realised how few of their service-users had access to technologies and good internet connection,

'Having access to technology is like having electricity and water, we need to address this issue. Out of 20 people only seven had access to devices.' - SM

These barriers could be partially addressed by some organisations, where resources were available to arrange the rapid issue of tablets and dongles to their service-users and support staff. However, technology alone was seen to only go part of the way to address digital exclusion challenges. A lack of suitably skilled basis technical support was a significant factor that influenced whether or not supported users could access the system from home. Adult service-users in supported living who withdrew to the parent or family homes during the pandemic, were susceptible to poor connectivity and device access. Organisations providing access to new devices, found it difficult to take Supported Users successfully through the registration and login process remotely. People did not have digitally capable support in their homes to assist with these endeavours and support staff found themselves setting up devices and logging in for online browser-use on behalf of their service users on their doorsteps, which mostly succeeded only for temporary periods.

Experience on the Stay Connected project thus demonstrated that digital inclusion for this population requires the combination of device and internet access with appropriate basic digital skills that must be learned and provided by support staff. It was additionally noted that for these to be in place organisations needed to apply workforce development and strategic approaches at organisation and commissioning levels.

Most front-line staff had basic IT skills and experience of technologies for personal use such as browsing the internet and online shopping, but little experience of using technologies in the social care work place. Front-line staff positively embraced the use of technologies, attended training sessions and supported each other to use the range of tools for different aspects of care and support. As the project progressed their understanding of how different tools could assist with different elements of care broadened and the software's potential direct benefits for various processes and routines were identified. The collection and sharing of these case studies across the project's community of practice in open Teams meetings helped staff to explore, define and share the potential of the tools to address different care and support processes.

The Insights dashboard feature was developed as an added software feature as part of the project, in consultation with users and served to improve and enable the remote monitoring of health and wellbeing of service-users. This tool enabled staff to quickly recognise individuals' moods and monitor changes or patterns of self-reporting that highlighted additional risk. This enabled staff to prioritise those who required support urgently and helped to avoid the escalation of incidents. The Insights Dashboard was being seen as a useful care delivery tool. In some places it duplicated the core functionality of other case management tools in place, but it was shown to strengthen the service-users' own input to the wellbeing process with the ease of use of its self-reporting aspect. This highlights the complexity of different tools that are increasingly available in the emerging digital care market. The combination of various software will inevitably be a part of a tech-enabled service

ecosystem and the capacity for tools to securely interoperate for safe sharing of data and communication between systems will increasingly be a key concern. The consultation process behind the addition of the Multi Me Insights tool highlighted a need for clear guidance to help provider organisations to navigate this evolving landscape. Experience of working across organisations and systems on the project emphasised the importance for the sector to provide leadership and co-develop professional standards and best practice guidance to achieve effective digitisation of person-centred services.

Our findings have evidenced that to achieve scalable adoption of technologies within social care, access, support, training and infrastructure must be in place. The circumstances of the public health crisis has prompted an active shift towards the use of online technologies within education, health and social care. We have noted more positive and open-minded attitudes from education and social care staff towards digital take-up than that which is previously recorded (Thakur et al.,2012). Potential scalability of the particularly person-centred solutions provided by the Stay Connected project for education and integrated care was shown to be achievable. Each organisation however was seen to bring their own culture and adopting environment, which demands further work on the development of strategic training, support and change-management tools and approaches to support this transformation project.

In conclusion the project has demonstrated that a combination of diverse factors affect the wide scale adoption and implementation of software solutions such as the RIX Multi Me toolkit. The project has foregrounded a set of requirements for the readiness of service provider and technology supplier organisations:

- Access to suitably easy-to-use devices and internet connectivity are critical for support staff and service user.
- Supported Users require personally owned and mobile tools to optimise their benefit from today's digital technologies.
- Availability of support staff with core digital skills and capability to support service users in the use of new technologies is essential.
- Mobility of support teams is required to work across differing environments that include remote, blended and face-to-face arrangements and various public and private settings that may include homes, schools and colleges, community health, care and learning facilities.
- Partnership working practices are essential to enable the various agents that make up a person's professional and informal support circle to work together effectively.
- Digital networks can facilitate this when accompanied by consciously applied collaboration practices.
- Leadership from local authorities and place-based integrated care systems can scaffold and facilitate the required joint-working approaches across sectors and disciplines.
- Standards and guidelines are required for use of digital technology for remote, blended and face-to-face care to help steer and strengthen good practice in this rapidly evolving market.
- System vendors and training providers need an understanding of commissioning organisations' processes to identify how new tools can best assist the continuity of care and support in challenging conditions and sustain through unpredictable and changing times.
- Project management assistance, training and support from vendors helps organisations to overcome the change issues that are encountered with adoption of new technology-enabled systems.

- Case studies that profile diverse examples of simple applications of the tools and explain the processes they can facilitate help adopters to position how to use the software as an effective intervention in their own settings.
- Clear communication about new technology initiatives demands close work with and service managers as well as commissioning leadership in an organisation. Front line staff team leadership endorsement is critical to staff and service users' adoption of new roles and ways of working that come with new technologies.

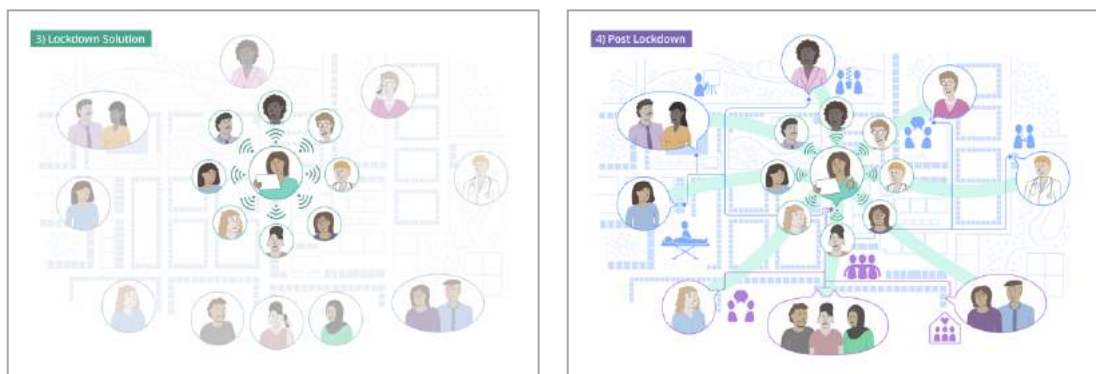


Figure 2 Lockdown risks and digital system solution

The RIX Multi Me toolkit's trial implementation as a scaled solution for maintaining person-centred support of people with LD and autism has demonstrated the extraordinary potential benefits for today's personal and social media tools in the new environment we occupy since the pandemic's arrival. At the same time, the project has helped to identify the significant barriers in place, and the cultural changes required if such potential is to be realised. Recent events have exposed the requirement to prepare our care systems for an unpredictable and potentially challenging future in which distancing and lockdowns may continue to be a regular occurrence.

The RIX Multi Me team is taking the scaled adoption of our software system forwards in partnership with the organisations with which we have undertaken the Stay Connected project. Each organisation has specified a similar but different strategy for long term use of the system with continuing ambition to sustain use of the software at scale. The RIX Multi Me team has similarly refined the specification of the toolset required to optimise its effective deployment as a solution for isolated people in lockdown situations. Further software simplification and the development of refined App-based systems, coupled with the technical and skilling requirements listed above, can provide an effective and sustaining model of person-centred care. Working together both parties have realised significant benefits from the system's use as an emergency pandemic solution as well as gaining an understanding of how an inclusive support network with self-advocacy tools for people with learning disabilities and autism can provide an enduring and sustainable digital foundation for their care across whatever different and changing circumstances prevail. As our services regroup and transform post COVID in the context of emerging place-based and ntegrated care solutions, the learning from this extraordinary project can contribute to the urgent mission to make our systems more effectively inclusive, person-centred and connected across our communities.

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Appendices

Case studies

- [Amy case study](#)
- [Kai case study](#)
- [Jessie case study](#)

- [Keshan case study](#)

Vignettes

- Day opportunities
- Supported living
- Residential services

Stay Connected case study | Amy

Overview

Amy is an 11-year-old girl with physical and learning disabilities. Amy goes to school but, like most children during the pandemic, has been stuck at home doing online learning with the help of video calls from her teachers. Amy's adoptive mother, Emma, says this has not been easy as Amy tends to sway away whenever she is not interested in what is happening on screen.

Journey

Emma has been using Multi Me to support Amy's education, care, and wellbeing and says the software has been easy to use and has saved her a lot of time, energy and extra work. Amy cannot use the platform herself but benefits directly from the software's support networking features. Emma says that it took Amy's school a long time to 'come onboard' as they had concerns around confidentiality and the sharing of information. Amy's circle of support would not be able to access certain information if the school chose not to upload it to the platform.

Being a visual learner, Emma has found it particularly useful to have been able to track Amy's development through photos and videos. She has been impressed by how others have taken the time to join in and be present in her daughter's life:

"Every day I see someone has looked in even though she has not been at school, but they are totally engaged with her and her journey."

Emma has been using Multi Me to:

- transcribe information from Amy's school.
- ensure consistency in terms of communication and quality assurance.
- talk to professionals in Amy's circle of support using the Chat feature.
- store and keep track of Amy's Education, Health and Care Planning documents.
- agree targets with school and use the Goals feature to monitor and evaluate these.
- share letters, reports and other information by using the Diary and Circle features.
- use video to record and monitor progress and store these safely in the media folder.
- save time and energy by streamlining communication and avoiding the need for repetition.

Feedback

Multi Me and the Stay Connected project have reinforced a means of communication for Amy and she does take a great interest in the vibrant, colourful platform - we know this because when she is not interested, "things get swiped away." It has made the pandemic more bearable and helped strengthen links between home and school. Professionals involved in Amy's care were sceptical about the platform at first, due to potential breaches of confidentiality, but this has now changed. Most importantly of all, the RIX Multi Me software has made a real difference to the quality of Amy's life by giving people the opportunity to understand her more, witness her ability and, as a result, not underestimate her potential.

Stay Connected case study | Kai

Overview

Kai is an 18-year-old male with lived experience of LD and autism who attends mainstream college.

Kai is interested in engineering and, in particular, metalwork in the field of military hardware and armour. He applied for an Army internship but was unsuccessful and decided to go to college to study English, Maths and Metalwork.

Kai initially contacted the Stay Connected project to offer his services as a peer support trainer. He has excellent IT skills and had no difficulty in using the RIX Multi Me software. Kai did not see himself as a Supported User and was not interested in engaging with the Stay Connected project in that way, preferring to be identified as a trainer, “like Ajay”. *[Ajay is a self-advocate and trainer who works for the RIX Centre].*

Journey

Kai and his mum worked with RIX support once a week and they started by using Kai’s Wiki to capture his hopes and dreams. He found it hard to identify aspirations for himself but when encouraged to share his hopes and dreams he talked about the army, military technology and armour. He also started using the Diary, Calendar and Goals tools as well as the Wiki.

By working on his Wiki, Kai and his mum were able to identify some key issues:

- Kai missed out on having an EHCP meeting last year.
- He did not receive a timetable for the college’s online learning provision.
- He failed his English course.
- Virtual metalwork classes are not possible.

Working on his Wiki and using the other RIX Multi Me software tools has helped him reinforce memory and organise his thinking and this enabled him to communicate more effectively with others. Kai was able to contact the college and use his Wiki to explain his situation and how he feels about it.

Feedback

Kai really enjoyed the one-to-one person-centred planning session, noting how positive they were. He likes the fact that all the tools are in one place in the Stay Connected environment and he particularly enjoys making diary entries. He says that Wikis are great and he now feels prepared and ready to communicate with staff.

Kai’s mum manages a small residential provider service and had been approached regarding taking part in the Stay Connected project. At the time she could not see the benefit of taking on what looked like extra work. However, when her son became involved in Stay Connected, she soon realised the potential of the project and decided to try it out in the residential setting she manages. And as a lovely footnote to his Stay Connected journey, Kai now has a job, 10am-2pm every Sunday, training residents and staff in the use of the RIX Multi Me software.

“I have done a lot of annual reviews over the past three or four years and I’ve got to say that without a shadow of a doubt this one has been the best and it’s absolutely amazing. I think the learner worked

really well and the presentation of it has been fantastic. It gave me a massive insight into the learner's likes and dislikes now, how he is feeling and his aspirations. Fantastic!' I liked it as it was visual and colourful. It's amazing. I think all our learners should use it." Education, Health and Care Co-ordinator

"We found it really useful, when we first started, I was a bit not sure and a bit reluctant, but, it's really good to breakdown his goals, his targets, make him understand and take responsibility for his own things and it also really helps him with his organisational skills." Mum

"I like that I can invite my teachers and they can see how you are feeling each day. They can see your aspirations and get a good understanding of me." Kai

Stay Connected case study | Jessie

Overview

Jessie is an older woman living with dementia who lives with her daughter Jane, who is also her primary carer. Jessie attends a local day care service for the elderly and vulnerable and is supported there by Zelia, a new member of staff who transferred there from a care home a few months ago. Jessie is active and engaged and enjoys taking part in activities but she also needs a space to stay safe when she is distressed.

Journey

Jessie and Zelia learned about Multi Me together and soon realised that the Stay Connected platform would be a great way of celebrating and sharing Jessie's love of making pictures. Jessie could make the picture and Zelia could then take a photo with her smartphone and upload it, adding it to Jessie's diary. Staff who were already using Multi Me began to recognise her from her posts and would welcome her to the centre by name.

They were also able to use the Calendar tool to invite Jessie to Zoom sessions on the days that she wasn't attending. On days that she was attending, Zelia used Multi Me to monitor Jessie's health and wellbeing. For example, she was able to add pictures of the meals Jessie was eating as a way of sharing this information with Jane, who was monitoring her mother's diet following a pre-pandemic diagnosis of diabetes.

Jane thought about Jessie's life story and how this could inform the coping strategies used by staff for when she is distressed. She identified a particular song from Jessie's past that seemed to have a positive effect on her mood and shared this with Zelia. Staff were then able to record themselves singing the song to Jessie and share this back with Jane via the Stay Connected platform.

Feedback

Both Jane and Zelia said that they now have a new communication channel for sharing information about Jessie and how her day at the centre is going. Zelia, being new to the service, was keen to learn and excited to be using the new tools: 'I learned a lot, I wanted to learn more about Jessie. We of course have a folder but being involved [in Stay Connected] was more positive.'

Jane hopes to use the platform to stay in regular contact with the centre and share more about Jessie's life so that her support continues to become more personalised.

And a final reflection from Zelia: 'This is the future definitely. For our communication, it has had an impact.'

Stay Connected case study | Keshan

Overview

Keshan is a young man with autism who attends sixth form where he is working towards his BTEC in Business Studies.

Journey

Keshan was supported by his father to attend regular training sessions with the Stay Connected project team where he could learn in detail about the various features of the RIX Multi Me software with the help of video activity sheets. His IT skills meant that he was soon up and running, exploring the different tools and how he might use them. He learnt how to upload media that he could then add to his Wiki and Diary and his father helped him to adapt to the new social environment as he began communicating with others taking part in Stay Connected.

Keshan found the Goals tool particularly useful, both to identify goals and to set specific targets that could then be checked and evaluated over time. Keshan's first goals focused on:

- managing the coursework for his BTEC in Business Studies.
- developing his confidence in communication both in and outside school.
- making new friends and forming new relationships.

Keshan has become an active user of the RIX Multi Me platform, making frequent diary entries and sharing how he's doing today by using the Add Feeling feature. He has a separate Multi Me diary for school and this, along with the Goals tool, helps him stay organised and keep some separation between home and school. Other members of the Stay Connected community give him positive feedback and these interactions have made him feel welcome and connected.

Feedback

Being able to connect with other people has meant a lot to Keshan and given him the opportunity to develop his communication skills in a friendly and safe environment:

"It makes me feel more comfortable when I am talking to other people and showing more confidence."

He has made new friends and has enjoyed the validation he gets from other people recognising his competence in IT. He believes he would do even better if his teachers could agree to join him on the platform to support him with his schoolwork and step in when he finds something hard to understand.

Taking part in Stay Connected during the lockdown has been helpful, productive and informative for Keshan, enabling him to develop his communication skills and make new friends.

Stay Connected case study | vignettes

Day Opportunities

Staff at the day service loved the fact that they could use the Calendar to look up and join training sessions. Having everything in one place meant they did not have to keep referring back to emails and other documents to keep up with the project and progress through the training programme. If people were struggling with the software or needed a knowledge refresh, all the training videos were also available in people's Media folders for catch-up sessions.

Residential living

David and Scott used their smartphones to add content to Stay Connected. They would take photos and upload them to the Diary so that other people could see how they were doing. They said it was fun, they liked Multi Me and they enjoyed seeing pictures of themselves on the platform.

Supported living

Glenn and Roger live in a supported living home where all the support staff had contracted COVID and many were unable to work. A member of staff called David was the last man standing and with the virus all around them they started a COVID 19 Club. With David's support, they used WhatsApp to communicate and The Multi Me Diary to document what was happening.