

Relaying of Learning in Autism and Intellectual Disability Services (RELAIDS): How services for people with Autism and/or Intellectual Disability have developed during the COVID-19 Pandemic



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What was this project about?



The project was initiated and coordinated through the North West **Learning Disability and Autism Operation Delivery Network (ODN)**.

We wanted to find out how services **changed** to cope with the covid-19 pandemic and how they **continued** to support people during lockdowns and the rule changes, and what **positive learning** could be taken forward.



Who were asked to participate?

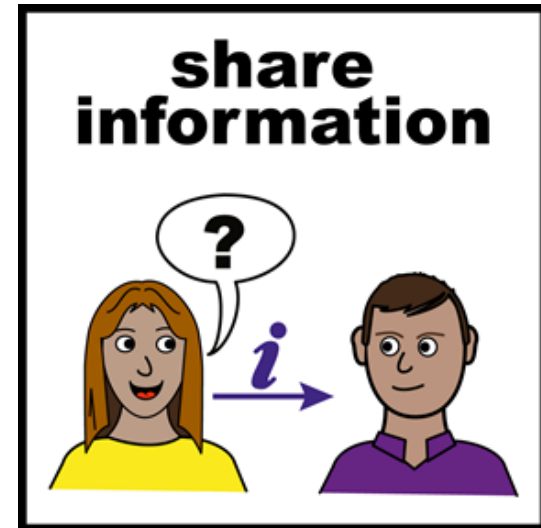
Organisations that supported adults with autism and/or a learning disability across the North West of England through initial contact with lead nurses, organisational/team leads and regional networking opportunities.



Self-advocates, families and carers through engagement in different forums, such as Confirm and Challenge and the regional Family Forum.

Requests for information were structured around three basic questions:

1. What problem were you trying to solve?
2. What did you do?
3. How did it go?



Who responded?

- A range of services and teams responded (N=18) with a number of services providing multiple examples within the submission (N=32).
- Sources of submission across the North West included:
 - Acute Hospitals and Hospital Trusts
 - Community Learning Disability Teams
 - Autism Diagnostic Services
 - Self-advocates
 - Independent providers
 - Autism Support Services
 - Supported living and respite services

Deriving themes

- Two independent focus groups were established, comprised of AP's and TCP's and tasked to independently identify themes and sub-themes emerging from responses to each area of questioning
- These identified theme sets were then merged by the core research team and mapped against submissions
- This identified a final set of:
 - 8 base themes
 - 33 sub-themes
 - 36 sub-sub-themes (note that not every sub-theme was comprised of sub-sub-themes)

Some initial points

- The diversity of theme areas was broad and demonstrated a huge range and scope of work that had been undertaken across and within services
- There were potential areas of overlap between some sub-theme (ST) and sub-sub-theme (SST) areas, but coding decisions were made on the basis of the initiating Theme area (e.g. whilst improved information sharing was identified as a positive element of Collaborative Working, references to this being made easier during commentary on Utilising Virtual Platforms were coded here, as an SST to the linked ST Benefits/Positive Feedback)

Some initial points

- Many responses indicated a rapid application of change, some of which had been thought about for some time but needed a nudge to implement, some that from a best practice perspective should have already been enacted, and others that had never been actively considered – some knowns, some known knowns, some unknown unknowns
- There was clear contextual reference to the perceptions of fear and heightened risk, particularly at the outset of the pandemic



Emergent themes, sub-themes and sub-sub-themes

Base theme	Number of sub-themes (Overall number of sub-sub-themes in parentheses)
Concerns regarding COVID	2 (2)
Risk	2 (7)
Collaborative working	10 (0)
Utilising virtual platform	4 (19)
Reasonable adjustments	5 (3)
Resources and education	2 (5)
Evaluation	5 (0)
Continuity of care	3 (0)

Concerns regarding COVID

- Responses highlighted aspects of uncertainty, fear and isolation (ST1) experienced by self-advocates, families and professionals and concerns regarding response to the interpretation and application of Government guidance (ST2)
- Responses were balanced against a need to provision services and support whilst mitigating risks as far as was possible without fully withdrawing or withholding services and support
- This created a distressing state of dissonance between a need for action and paralysis in respect to delivery and access to support

Concerns regarding COVID

- *“Local learning disability care providers were unwilling in some cases to send care staff to support patients due to the perceived risk of staff contracting covid” (anon)*
- *“Making sure that people felt safe, protected, informed and supported to the best of our abilities” (Wigan Link)*
- *“Where patients at Red on the covid risk register, a face-to-face visit offered (adhering to all covid restrictions and guidance)” (Blackpool Teaching Hospitals NHS FT)*
- *“We set out 3 steps that GPs would follow allowing a staged process to be undertaken depending on the changes in local R numbers” (St Helens & Knowsley CLDT)*

Risk (and mitigation)

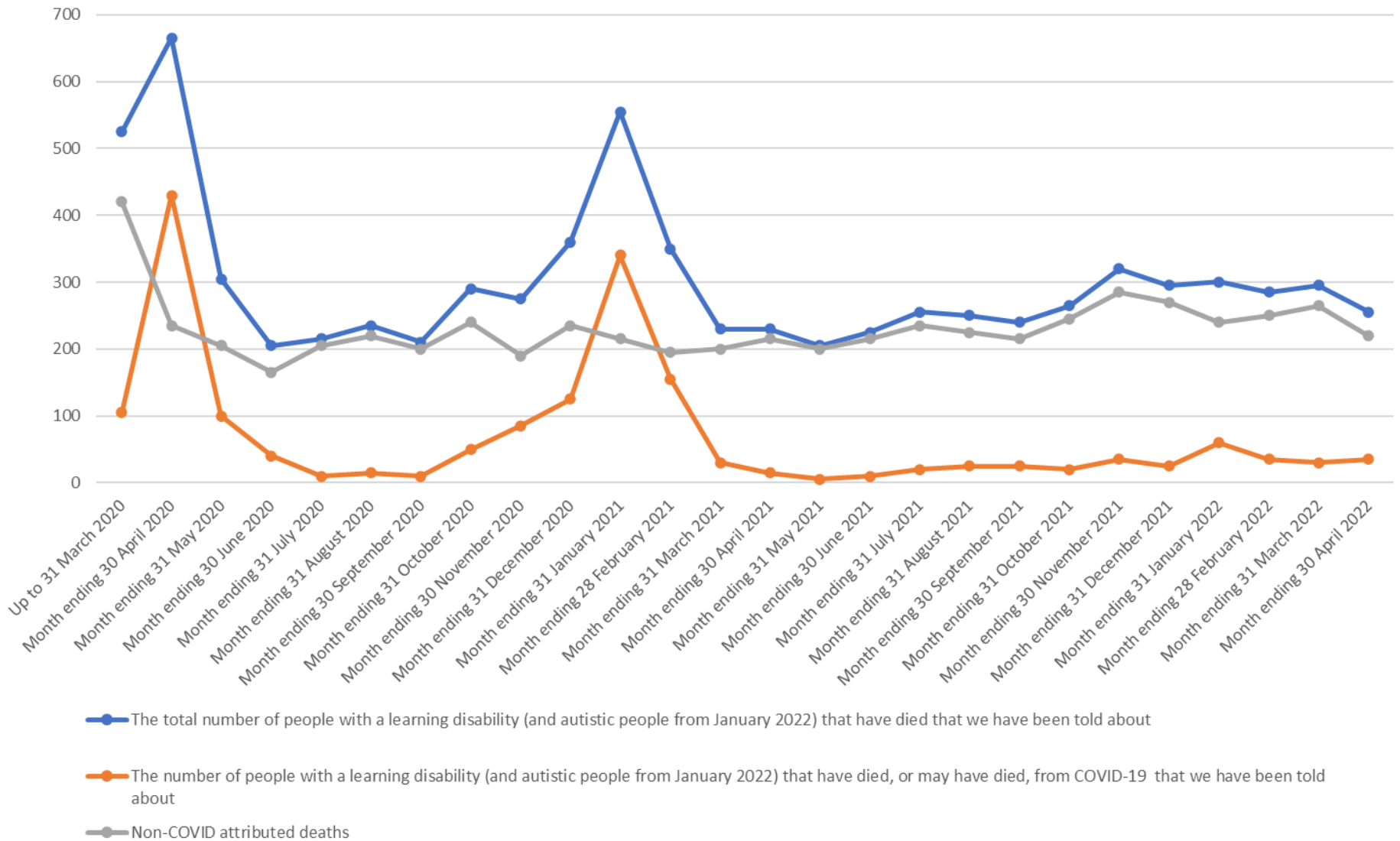
- Concerns regarding augmented vulnerability of LD/ASC cohorts (ST1) were evident in identified concerns and need for a service response in three main areas (SSTs):
 - i. increased safeguarding concerns
 - ii. physical risk factors
 - iii. prevention of crisis
- Concerns for increased service demands and continuation of care (ST2) were also identified across four core areas (SSTs) recognising the impact of:
 - i. delays
 - ii. cancellations
 - iii. redeployments
 - iv. prioritisation

COVID Risk: The context

“England death rate up to 6 times higher from coronavirus during the first wave of the pandemic than the general population” for people with a learning disability

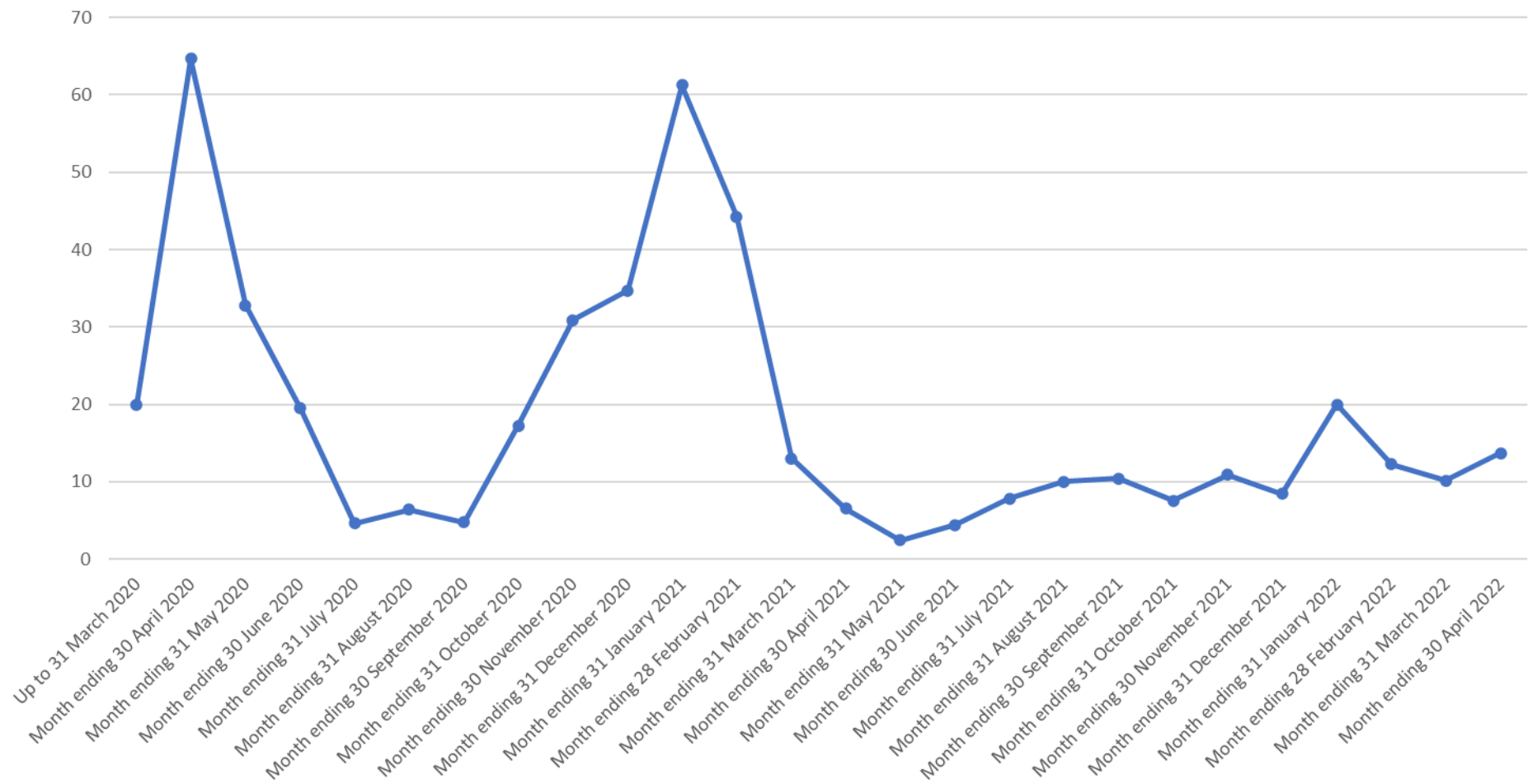
<https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19>

Number of deaths reported to LeDeR



<https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/> (accessed 20/09/2022)

Percentage of LD deaths attributed to COVID



<https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/> (accessed 20/09/2022)

Risk – Response areas included:

- Awareness of direct and immediate impact of support systems at home and need to provision urgent guidance and support at source for behavioural presentation of distress – restructured delivery of services
- Introduction of COVID Care Plans
- Introduction of rapid triage monitoring and response processes to prioritise alternative provision of psychological care
- Use of LD flags on systems
- Ongoing stratification on Dynamic Support Databases/Registers
- Advanced healthcare planning
- Introduction of O2 monitors
- Attempts to maintain workforce for this vulnerable population

Collaborative working

Interestingly, key sub-themes here (n=10) were not just about innovation, but about quality of information shared and completed within existing processes (e.g. care plans, risk plans, dissemination) and accessibility of information across the system (services, self-advocates, support teams, etc.)

- *“support to local hubs and third sector providers, to help them continue to function and support their members and have enhanced this over the pandemic so they feel supported” (CWP Autism Service)*
- *“We worked closely with the local authority to identify creative ways in which people could be supported at home, in partnership with day centres and day support” (Wigan Link)*
- *“Good communication and documentation” (Local Provider in Wigan)*

Utilising virtual platforms

- It was evident that there were clear differences in experiences reported between adult learning disability and autism services into the successes and levels of support required in respect to use of these different platforms
- Sub-themes here (n=4) were:
 - Challenges (incl. access and connectivity, knowledge, poverty of technology and resources)
 - Benefits and positive feedback (incl. travel, choice, reduced anxiety)
 - Speed of mobilisation (incl. loaning of equipment, sharing of resources, preparation)
 - Continuation beyond pandemic (incl. online resources, maintaining access options, retaining positive elements)

Utilising virtual platforms

- *“To start it was a little challenging, with lots of learning that needed to take place (on my part), and supporting families to use this new platform” (CWP Autism Service)*
- *“Young people and their families really valued the continued support using ...[platforms] as they did not wish to visit the hospital unless absolutely necessary, due to their fear of the COVID virus” (Transition Lead, Alder Hey Children's Hospital, Liverpool)*
- *“The resources highlighted the importance of having up-to-date information that can be accessed online and has led to the ongoing development of other areas of our website” (Mid-Mersey ASC Service)*
- *“In some circumstances it is not always possible for relatives to attend hospital so to help loved ones and patients we have offered a virtual visit” (Liverpool University Hospitals NHS Foundation Trust)*

Reasonable adjustments

- Responses here – with five key ST areas – primarily reflected reasonable adjustments made to support the national programme in regard to swabbing and testing in addition to aspects of vaccination
- This including adjustments made in respect to information delivery, identification of those in higher risk categories, and actual delivery of the vaccination where existing challenges regarding health delivery were evident
- However, it also required services to reinforce the message that there was a moral and legal obligation to ensure reasonable adjustments were applied across the system to provision support (e.g. virtual platforms were not the panacea for continued delivery of mental health services, particularly for self-advocates with a learning disability)

Reasonable adjustments

- *“Reasonable adjustment care plans were shared with service providers so that adjustments required could be identified, documented and sent in with the patient” (East Cheshire NHS Trust, patient experience team)*
- *“...recognised the need to provide our client group with reliable and concise information regarding COVID, which was clear, jargon free and easy to understand” (Mid-Mersey ASC Service)*
- *“...offer a Vaccine pathway to implement desensitisation programme, liaison with the patient, carers, vaccine coordinators and GP’s across the 7 primary care networks in Wigan ” (Wigan CLDT)*

Resources and Education

The development and of online training courses and resources, and transition from face-to-face classroom-based teaching boomed over this period. This included greater engagement and support for of self-advocates in the development and delivery of training materials, resources, groups and other areas of support.

- *“we needed to find a way to transfer knowledge and expertise to the people immediately involved with those cases so that they might better manage themselves” (GM, Lancs and S.Cumbria SST)*
- *“We also offered and delivered bespoke training sessions to specialist services and staff groups, such as IAPT/Think Wellbeing, Eating Disorder Service, CAMHS and Pharmacy and Occupational Therapy” (Mid-Mersey Autism Service)*
- *“...led to an increase in other peer-led activities such as an in person social group, a Skype social group, autism and art sessions, autism and meditation sessions, and an in-person arts and crafts group, and a peer led Facebook group and we have supported where necessary” (CWP Autism Service)*

Evaluation

It was clear that many services had planned to evaluate the efficacy of the changes initiated, or already embarked on an evaluation of developments and changed practices, to determine the value of maintaining change

- *“For this evaluation, for all workshops, participants reported it to be a positive experience” (GM, Lancs and S.Cumbria SST)*
- *“Demand grew, and then we undertook a survey to gather information, followed by a focus group to look at how to improve hub sessions” (CWP Autism Service)*
- *“130 specialist consultations have been provided and a 100% rate of positive evaluations received” (Mid-Mersey ASC Service)*
- *“We will continue to trial online options and monitor outcomes” (St Helens/Knowsley CLDT)*

Continuity of care

Responses here really displayed the positive outcomes experienced by services and self-advocates in overcoming the challenges faced over the COVID pandemic, and provided examples where necessary change actually resulted in continued positive outcomes that had not been anticipated

- *“I have a job list that I do everyday now I even feed my neighbours birds for him. I like helping people and I even help the staff now” (Self-advocate)*
- *“As difficult as the last 2 years have been and the fact we are still going through it, what has got us through is the relationships we have with the people we support, team members and family members which is present at all times with or without covid, it is what we pride ourselves on – recognising people’s needs and wants and making sure we meet those needs in the best way possible” (Wigan Link)*

Conclusions

- The period of COVID restrictions demonstrated that rapid change in service delivery is possible and changes made through adversity can bring about positive outcomes for self-advocates, staff and systems
- A range of creative and innovative adaptations were implemented across the system with mostly positive but variable levels of success and acceptance by self-advocates and families, support teams, and broader services
- We just need to ensure that the system of which we are all a part continues to recognise the need for proactive reasonable adjustments to support the equitable provision of support for self-advocates with a learning disability and/or Autistic people