

COMMUNITY CHECK-IN NOTES

Tuesday 19 January: The CoIN Study

Organisations represented:

- Alex TLC
- Behcet's UK
- Duchenne Family Support Group
- Nerve Tumours UK
- Pitt Hopkins UK
- PKD Charity
- Rett UK
- Spinal Muscular Atrophy UK
- Smith-Magenis Syndrome Foundation
- Unique
- Wolfram Syndrome UK

Genetic Alliance UK staff attending:

- Jayne Spink, Chief Executive
- Nick Meade, Director of Policy
- Amy Hunter, Director of Research
- Isabel Rundle, Engagement and Support Officer
- Natalie Frankish, Policy and Engagement Manager - Scotland
- Emma Hughes, Policy and Engagement Manager - Wales

Jayne Spink welcomes everyone to the meeting and introduces special guests (Dr Charlotte Tye and Jessica Martin). Amy Hunter will chair the meeting.

Amy Hunter:

- Director of Research at Genetic Alliance UK
- Introducing Charlotte Tye – researching the impact of the pandemic on the wellbeing of families with rare diseases. Thank you for supporting us.

Genetic Alliance UK

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www.geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

Charlotte Tye – presentation:

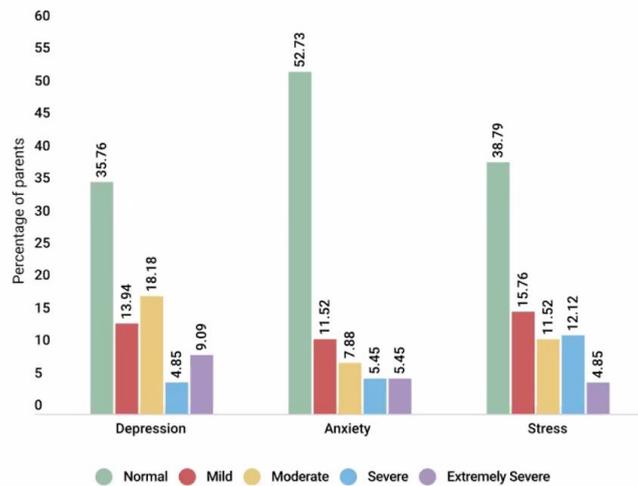
- Lecturer and research fellow and King's college London – aims to identify predictors of neurodevelopmental disorders. Jessica Martin – research assistant of CoIN study. Summary of presentation – present research findings and what's next.
- What do we know? Children with rare neurogenetic disorders have learning disabilities, challenging behaviours, sleep problems, ADHD, autism – combination of physical and mental health problems. Families of individuals with rare disorders report experiencing stress and low mood. Learning disability associated with poor parental mental health and wellbeing
- What about during the pandemic? Major disruptions to daily lives with impact on mental health in the general population and particularly vulnerable groups e.g. those with young children and children 5-16. Parents of children with special education needs reported fewer problems during the pandemic.
- What about rare disorders? Children with rare disorders need to access a range of medical specialists, which have changed or been removed during pandemic. Sudden change in stability, isolation and shielding due to higher risk of covid-19. Do these factors exacerbate mental health problems or trigger new ones? and are they overlooked by national surveys?
- CoIN study aims to: identify the specific challenges compared to other populations, short and long term impact of pandemic on mental wellbeing, explore associations between parental mental health and child behaviour during pandemic, and disseminate findings to families, charities and support organisations.
- Invited parents/carers of children aged 0-16 with rare neurodevelopmental and/or genetic disorders across the UK – recruited through charities, existing research studies, schools and social media.
- Families were asked to complete an initial survey, and then a monthly follow-up, then a final survey. Optional for families to follow up, but good to identify changes over time.
- Similar questions to match other large-scale UK studies e.g. Cospace Oxford. Surveys were completed online.
- Initial survey – demographics, housing, diagnosis and disability of child, family's experience with covid-19, focus on parent's mental health and child behaviour, how they've coped, as well as support/resources they've accessed
- Timeline of key events – launched study in May 2020, taking part in monthly follow-ups. Capturing phases of pandemic e.g. lockdowns, school closing/opening.
- Will launch the final survey in a few months' time. Emerging findings focus on mental health but other findings will be available as digests in the website.
- 90% of parents/carers were female, 59% were employed, 61% self-isolating and 73% of children had learning disabilities.
- Current stressors – top 5 are related to child – future, wellbeing, education, behaviour, and the parent's future plans. Other stressors were related to work, screen time and family/friends outside of the household.

- Depression, anxiety and stress scale – negative emotions state, measures levels of emotional wellbeing. Describe the graph below.

Parental Mental Health

Depression, Anxiety and Stress Scale – 21 items (DASS-21)

→ Significantly increased levels of negative emotional states compared to general population during the pandemic (www.cospaceoxford.org)



“Lack of interaction with usual support networks has had a massive impact on emotions”

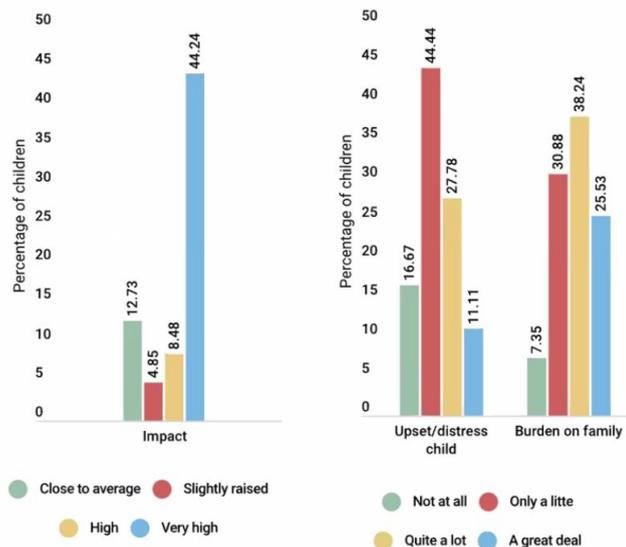
“It’s been a very isolating experience and I feel that the support has been lacking”

- Levels significantly increased compared to the general population during pandemic. Parents highlight lack of support. What are the predictors of more severe levels of negative emotions?
- Perceived impact – how much parents think that impact of a child's difficulties – over half of parents said it was high or very high – significantly increased compared to the general population.
- Describes the graph below.

Child Behaviour

Strengths & Difficulties Questionnaire (SDQ)

→ Significantly increased perceived impact of child behavioural difficulties compared to general population during the pandemic (ONS MHCYP 2020)



“Struggling with changes & missing routine”

“Enjoyed being at home”

“New negative behaviours”

“Happier and less anxious”

- Families noting some positive elements e.g. children enjoyed being at home, felt happier and less anxious.
- Coping and resources – ¾ of parents said they’d benefit from more support.
- Top 3 areas – manage child’s education, behaviour and emotions, access to healthcare

- How would they want to receive support? online written materials, support groups, webinars/podcasts.
- Sharing resources and producing online videos to disseminate findings/resources
- Positive elements – more quality time, less running around, go outside a bit more, increased online accessibility to platforms
- Summary – parent worries focused on child, experienced poorer mental health, behavioural difficulties have impact on daily life, investigate predictors of parental mental health and digests will be available on website

Jessica Martin – presentation:

- Invited parents to complete interviews – 15 parents/carers. Interviews allow discussion in more detail and ask questions that are more sensitive, and allow parents to discuss their own insights without limitations of survey. In the process of recruiting families
- Engage and involve the community – members of the CoIN community to shape the surveys. Community feedback – all parents found it really easy to use, flow and could understand questions, good length. Outlet for parents to understand what they were feeling – both positive and negative feedback.
- Will continue to involve community in research and disseminate findings with community groups and patient organisations
- Thank all participants and families, as well as Baily Thomas charitable fund, as well as other charities / support organisations. Still recruiting.

Discussion:

- Participant in the chat – were you able to include offline recruitment?
- Charlotte – no, but would be possible if that was easier.
- Participant in the chat – what about families without access to online resources? How can we address them?
- Charlotte – difficult to reach them.
- Unique participant – people in digital poverty are the most stressed and least resilient, with different ethnic backgrounds and language difficulties, would need a different approach.
- Charlotte – questionnaire itself would limit ethnic diversity.
- Jess – over 90% white British.
- Charlotte – offer to do the questionnaire on the phone.
- Amy – difficult to access through routes e.g. schools, which would've allowed to pick up those. Can slides be shared? Brief digests will be available in the website.

- Charlotte – will also post on social media when the digests are available.
- Amy – CoIN study website www.coinstudy.co.uk
- Participant – findings match what she’s found through her helpline, in touch about further recruitment.
- Participant – Autistic society has completed research with similar results.
- Amy – any other questions? Next stage is to determine predictors, can you give us any hunches?
- Charlotte – age of child is a key predictor, and also more specific challenges e.g. lack of access, access to education, removal of care.
- Rett UK participant – parents suffering from survey overload, so may not be picking up the most stressed families
- Behcet’s UK participant – people tired of looking at news because of negativity. Wondering how much research has been done into this sort of thing previously? What background research there is on these suggestions (from questionnaire questions) influence behaviours?
- Charlotte – not sure about background research, trying to balance out by also asking positive experiences.
- Jessica – important to focus on positive experiences and lessons learnt.
- Amy – thank you for the presentation and members for attending.

Jayne Spink:

- Thank you.
- Next week – how vaccines are developed and #ValuingVaccines campaign, and how to get involved.
- Week after next – increase engagement around Rare Disease Day 2021.

Discussion:

- Jayne Spink – Any concerns about vaccine rollout in your community?
- SW-UK participant – children’s lead medic is leading a webinar this Friday on different types of vaccines and where on the priority list WS-UK affected people and their carers are.
- Unique participant – priority order lists people with severe learning difficulties. Push with moderate learning difficulties, because there is evidence they are more susceptible. Anyone from your community got the vaccine?
- Jayne – No. What about under 16s? Question for next week’s meeting.
- Participant in chat – son was due vaccine on 25 January as care home resident but delayed to new guidance from Scottish government as yet unpublished.
- Participant – when are we getting it? Some over 80s haven’t got it.

- SWAN UK participant – hearing children’s carers have appointments for vaccines but not parent carers.
- Unique participant – have to be registered with GP as a carer to be prioritised.
- Rett UK participant – group 4 for carers, trying to boost adults with learning difficulties for higher priority due to higher vulnerability letter for Matt Hancock. Parents of carers are getting the vaccine and now it’s being revised.
- Jayne Spink – what disruptions?
- Participant – won’t put some posts back up e.g. neuromuscular. If surgeries are not done that will have life limiting consequences.
- Jayne Spink – no coherent plan for reinstatement of service, important to highlight that.
- Participant – all carers are now entitled to the vaccine.
- Participant – can update Covid-19 hub.
- Participant – GA-UK is running 12 weeks of Rare Resilience, great talk and useful, looking forward to following sessions.

Jayne Spink thanks everyone for attending and closes the meeting.