Stress, adversity, COVID; caring for children with an intellectual disability

The *sixth* of ACAMH’s Adverse Childhood Experiences (ACEs) Special Interest Group Monthly seminars.

**17.00**  Welcome to the event & introduction - Dr Arnon Bentovim, Child and Family Psychiatrist and Director of Child and Family Training

**17.20**  Stress, adversity, COVID; caring for children with an intellectual disability –  
Dr Jeanne Wolstencroft, Research Fellow at the Great Ormond Street UCL Population, Policy and Practice Dept

**18.20**  Q&A, Led by Dr Arnon Bentovim, Child and Family Psychiatrist and Director of Child and Family Training

**18.45**  Close - Dr Arnon Bentovim, Child and Family Psychiatrist and Director of Child and Family Training

www.acamh.org
Stress, adversity, COVID; caring for children with an intellectual disability

Dr Jeanne Wolstencroft
Research Fellow
j.wolstencroft@ucl.ac.uk

28th March 2023, ACAMH
Agenda

- Setting the scene: IMAGINE
Agenda

• Setting the scene: IMAGINE
• Interview study during Covid-19
Agenda

• Setting the scene: IMAGINE
• Interview study during Covid-19
• Impact of Covid-19 on IMAGINE cohort
What is IMAGINE?
UNIVERSITY OF CAMBRIDGE

IMAGINE PROGRAMME

Funded by Medical Research Council & Medical Research Foundation

IMAGINE-1: 2014 - 2019
IMAGINE-2: 2020 - 2024

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD
IMAGINE ID Cohort
2,809 children

Children aged 4 – 19
learning disability or developmental delay
Pathogenic CNV or SNV
NHS Regional Genetic Centre recruitment

Online Assessment Completion
2,397 CHILDREN

56% male

Type of genetic condition:
- CNV 74%
- SNV 26%

Inheritance of change:
- de novo 39%
- Familial 27%
- Unknown 34%
Physical health

94% 1+ significant physical health problem
30% history of seizures
65% disturbed sleep
What are the mental health needs of children with learning disability?
Strengths and Difficulties Questionnaire

- Average: 17%
- Above Average: 14%
- High: 16%
- Very High: 53%

English norms

- Average: 80%
- Above Average: 10%
- High: 5%
- Very High: 5%
Mental health conditions

1 in 10  Anxiety
1 in 10  Behavioural problems
1 in 5   ADHD
1 in 3   Autism

Neuropsychiatric risk in children with intellectual disability of genetic origin: IMAGINE, a UK national cohort study
The Lancet Psychiatry
Covid-19 Interview Study
Timeline

- **23 March**: PM announces lockdown in England ordering people to "stay at home".
- **1 June**: Phased re-opening of schools in England.
- **15 June**: Non-essential shops reopen in England.
- **23 June**: PM says UK’s "national hibernation" coming to an end – announces relaxing of restrictions and 2m social distancing rule.

- **July 2020**: Interview Study 1
- **July 2021**: Interview Study 2

**IMAGINE 1**

**IMAGINE 2**
AIMS

Explore the experiences of parents of children with an Intellectual and Developmental Disability (IDD) and a rare genetic disorder during the COVID-19 pandemic.
PARTICIPANTS

- IMAGINE Study Participants
- 23 mothers
- 14 boys and 9 girls aged 5–15 years

METHODS

- Mixed methods: Online survey + Telephone interviews
- Thematic analysis
Online Survey (n=23)

Coronavirus Health and Impact Survey (CRISIS)
Family circumstances, distress and resilience during the pandemic (parent report)
39% reported that the pandemic had reduced their ability to earn money

87% reported that restrictions on leaving home had been stressful for their child

83% reported the family had difficulty following the government recommendations

61% reported that their child’s school had been closed
PARENT MENTAL HEALTH

A quarter of parents reported anxiety symptoms

CHILD WORRIES

65% of children were reported to be worried about getting infected with COVID-19

35% were concerned about their physical health

UNEXPECTED POSITIVES

74% families reported at least one positive change as a result of the pandemic
Telephone Interviews
Thematic Analysis

1. Transcribe
2. Code
3. Identify themes
I am tall, single (widowed), easy going, honest, good listener with a good sense of humour. Being a handyperson I keep busy working around the house, I also like to follow my favourite hockey team on TV or spoiling my two granddaughters when I get the chance!! I enjoy most music except Rap! I keep fit by jogging, walking and bicycling(at least three times a week). I have travelled to many places and RVd the South West U.S., but I would now like to find that special travel partner to do more travel to warm and interesting countries. I now feel its time to meet a nice, kind, honest woman who has some of same interests as I do; to share the happy times, quiet times and adventures together.
## Thematic Analysis

<table>
<thead>
<tr>
<th>Physical description</th>
<th>Widowed</th>
<th>Positive qualities</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am tall, single (widowed), easy going, honest, good listener with a good sense of humour. Being a handy person I keep busy working around the house, I also like to follow my favorite hockey team on TV or spoiling my two granddaughters when I get the chance!! I enjoy most music except Rap! I keep fit by jogging, walking and bicycling (at least three times a week). I have travelled to many places and RV'd the SouthWest U.S., but I would now like to find that special travel partner to do more travel to warm and interesting countries. I now feel its time to meet a nice, kind, honest woman who has some of same interests as I do; to share the happy times, quiet times and adventures together.</td>
<td>Keep busy</td>
<td>Hobbies</td>
</tr>
<tr>
<td>Family</td>
<td>Future plans</td>
<td>Active</td>
</tr>
<tr>
<td>Music</td>
<td>Future plans</td>
<td>Future plans</td>
</tr>
<tr>
<td>Travel</td>
<td></td>
<td>Partner qualities</td>
</tr>
</tbody>
</table>
Thematic Analysis

- Positive Qualities
  - Personal
    - Unique
    - Physical
    - Family/Friends
  - Humour
  - Values

- Potential Partner

- Keep Busy
  - Travel
  - Active
  - Hobbies
  - Music

- Future Plans
Main themes

“you just feel like our life was so different to other people’s”

“just being able to have that support bubble, rather than being locked in your own four walls”

“The pandemic was nice but really hard”
SOCIAL DISTANCING IS THE NORM
“We’ve been in lock down since he was born”

LEFT BEHIND
“I feel like they just left people who are vulnerable behind for two months.”

MANAGING PRE-EXISTING CHALLENGES

PLANNING FOR COMPLEX NEEDS
“there’s a lot more things that I needed to do than the average sort of family”

EXPLAINING COVID CHANGING
“How do you explain a pandemic?”

FEWER RESOURCES, BUT BEHAVIOURAL ISSUES ARE THE SAME
HAPPY AT HOME
“Everyone’s keeping distance from me and that’s how I like it”

SPENDING TIME TOGETHER AND SLOWING DOWN
“It brought us a lot closer together”

MIXED EMOTIONS

DESPERATE FOR HUGS
“I don’t like lockdown because I want snuggles with my nanny”

STRAINED RELATIONSHIPS
“Being constantly 24/7 together definitely did build up pressure”
TRANSITION TO TELEHEALTH
“I don’t think you can replace face to face with a telephone”

CHECKING IN
“just being able to have that support bubble, rather than being locked in your own four walls”

SUPPORT MATTERS

EQUALITY THROUGH ACCESS TO TECHNOLOGY
“I think the first thing to do is make sure everyone is able to access what they’re providing”

EQUITY OF ACCESS LAGGING BEHIND AS ADAPTATIONS AREN’T ALWAYS APPROPRIATE
“That is very difficult to do when you have special needs”
SUPPORT MATTERS

TRANSITION TO TELEHEALTH
“I don’t think you can replace face to face with a telephone”

CHECKING IN
“just being able to have that support bubble, rather than being locked in your own four walls”

EQUALITY THROUGH ACCESS TO TECHNOLOGY
“I think the first thing to do is make sure everyone is able to access what they’re providing”

EQUITY OF ACCESS LAGGING BEHIND AS ADAPTATIONS AREN’T ALWAYS APPROPRIATE
“That is very difficult to do when you have special needs”
Timeline

23 March PM announces lockdown in th ordering peopl "stay at home"

23 June PM says UK’s “national hibernation” coming to an end – announces relaxing of restrictions and 2m social distancing rule

15 June Non-essential shops reopen in England

14 September ‘Rule of six’ – Indoor and outdoor social gatherings above six banned in England

14 September ‘Stay at home’ order remains in place.

19 July: Step 4 Most legal limits on social contact removed in England, and the final closed sectors of the economy reopened (e.g. nightclubs).

8 March: Step 1 Schools in England reopen for primary and secondary school students.

Recreation in an outdoor public spaces will be allowed between two people.

July 2020 Qualitative Study 1

July 2021 Qualitative Study 2

IMAGINE 1

2019 2020 2021

IMAGINE 2
July 2021: New themes

Anxiety returning to school
“He was really anxious to start off. He was getting upset every morning because (...) he had to go to school“

Functional and social skills concerns
“He hasn’t got any siblings, so he regressed for things like sharing and waiting. I think the saving grace for us was when he went back to school.”

Academic concerns
“Undoubtedly there will have been impacts on his learning, there will gaps that I have nowhere near filled.”
Mental health and behaviour

- Parental distress & resilience
- Unexpected positives
- Varied impact on children
- Change in concerns over time:
  Complex behaviour -> emotional wellbeing & development
School and healthcare

- Short but regular check-ins
- Digital equity
- Tele-medicine as complementary care delivery
IMAGINE 2: Online Survey

- Changes in mental health?
- Impact of Covid-19?
Timeline

- 1 June: Phased re-opening of schools in England
- 15 June: Non-essential shops reopen in England
- 23 March: PM announces lockdown in England, ordering people to "stay at home"
- 23 June: PM says UK's "national hibernation" coming to an end – announces relaxing of restrictions and 2m social distancing rule
- 14 September: 'Rule of six' – indoor and outdoor social gatherings above six banned in England
- 22 September: PM announces new restrictions in England, including a return to working from home and 10pm curfew for hospitality sector
- 8 March: Step 1 - Schools in England reopen for primary and secondary school students.
  - Recreation in outdoor public spaces will be allowed between two people.
  - 'Stay at home' order remains in place.
- 19 July: Step 4 - Most legal limits on social contact removed in England, and the final closed sectors of the economy reopened (e.g. nightclubs).

2019

IMAGINE 1

2020

July 2020: Qualitative Study 1

2021

July 2021: Qualitative Study 2

IMAGINE 2
<table>
<thead>
<tr>
<th>Strengths and Difficulties Questionnaire (SDQ)</th>
<th>Coronavirus Health and Impact Survey (CRISIS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child emotional and behavioural adjustment (parent report)</td>
<td>Family circumstances, distress and resilience during the pandemic (parent report)</td>
</tr>
</tbody>
</table>
Strengths and Difficulties Questionnaire

**Before pandemic 2014-2019**

- **Average**: 17%
- **Above Average**: 14%
- **High**: 16%
- **Very High**: 53%

**After lockdown 2021**

- **Average**: 20%
- **Above Average**: 15%
- **High**: 15%
- **Very High**: 50%
Strengths and Difficulties Questionnaire

Before pandemic
2014-2019

After lockdown
2021
41% of families were shielding

47% reported that the pandemic had reduced their ability to earn money

48% families reported at least one positive change as a result of the pandemic
Biggest challenge

- Social distancing: 24%
- Anxiety: 21%
- Other: 19%
- No change: 16%
- Loneliness: 14%
- Low mood: 7%
Practical implications

• Care co-ordination
  Brief check-ins
  Support the parent to support the child
• Tele-medicine has a role to play
Strengths and limitations

• Biases
• Confirms previous observations
• New insights:
  - use of technology during the pandemic for schooling and healthcare
  - need for regular check-ins
Thank you for listening!

https://imagine-id.org/news/coronavirus-experiences-study-findings/

https://bmjopen.bmj.com/

Questions:

j.wolstencroft@ucl.ac.uk
Questions?