Building Resilience, Enhancing Social Support: What research tells us

Children’s Research Network for Ireland and Northern Ireland 5th Annual Conference
6th December 2016
Research Dialogue
Mental Health Resilience

Facilitator
David Kenefick
Research Dialogue
Building Mental Health Resilience in Children and Young People with Rare Genetic Disorders

Collaborators:

• Prof Fiona McNicholas (UCD Child & Adolescent Psychiatry)
  • Lorna Kerin (Love Knowledge Consultancy)
  • Anne Lawlor (22q Ireland)

Emma Brady (22q Youth Experts by Experience Panel)
22q11DS

• A ‘rare’ genetic disorder
  – Generally sporadic
  – Prevalence 1 / 2-4000 live births (Fung et al, 2015)
    • Clinically under-recognised
  – Second most common genetic disorder behind Down's Syndrome
  – Most frequent cause of palatal defects
  – Found in 1 of 68 children born with heart defects

‘The most common 'rare' syndrome you've never heard of.“ Michelle Breedlove Sells,
Small deletion C22

• Loss of up to 40 genes.
  – Variable deletion, so varied unique presentations, making recognition & detection difficult

• Affects many organs and systems
  – Differential expression from childhood through adulthood
Synonyms

- DiGeorge syndrome (endocrinologist/Ca).
- Shprintzen syndrome (SALT).
- Velo-cardio-facial syndrome (VCFS)
- Autosomal dominant Opitz G/BBB syndrome.
- Cayler cardio-facial syndrome.
- Cono-truncal anomaly face syndrome.

Donna McGlin 1997
Near sighted vets, each describing accurately the bit they were looking at...
Multi-systems involvement

- Cardio-vascular
- Cleft palate
- Feeding difficulties
- Immunization problems
- Growth hormone deficiencies
- Delayed neurological and psychological developments
- Mental Health Problems
- Speech problems
- Renal abnormalities
MH Difficulties

- Anxiety
- ADHD
- Autism
- Bipolar affective disorder
- Depression
- Schizophrenia
- OCD
- Phobias

MH problems are a main concern expressed by parents

22q11.2DS is one of the strongest risk factors for psychosis - 25% to 41% of adults met diagnostic criteria for a psychotic disorder (Baker et al, 2003)
Physical illness & MH wellbeing and adjustment

• Impact on child:
  – Biological effect of illness, disease process esp if affecting brain, treatment
  – Age at diagnosis, eg epilepsy, IDDM
  – Functional impairment (days off school, pain, physical limitations, level of dependence, QOL etc)
  – Physical appearance
  – Speech articulation difficulties
  – Hope for recovery

• Impact on family:
  – Parental Responsibility for treatment
  – Parents reaction to illness
  – Relationships past and present
  – Financial
  – Blame and guilt if heritable
  – Concern re future risks

22Q numerous medical problems
Who should be involved?

- Cardiology
- Endocrinology
- Immunology
- Speech & Language
- Psychiatry
- Plastic Surgery
- ENT/Audiology
- Gastroenterology/Feeding Team
- Orthopaedics
- Ophthalmology
- General Surgery
- Dentistry
- Rheumatology
- Neurology
- Hematology
- Urology/Nephrology
Research Rationale

- Lit review 2014 revealed dominantly biomedical quantitative data on 22q11 & exclusion of ‘first person perspectives’ of both adults and children with learning or intellectual disabilities (Jurkowski & Paul-Ward 2007; Kirby et al 2015).
- Parents frustrated by lack of Irish mental health service for mild ID/learning disability. **Identified need for voice of young people and parents to inform services & policy**
- Opportunity for narrative research to illuminate unique perspective of young people as patients/service users/citizens on their mental health experience and needs.

“Since the main delays are related to learning disability, speech development and autism (children with 22q) are seen by the HSE Early Intervention Services and ID services run by the voluntary organisations (where relevant). Where such children have a comorbid mental problem, if they have a learning disability they should be seen by the MHID CAMHS Service. **If no or only mild learning disability, they would be seen by the generic CAMHS service.**” Paul Braham, Senior Operations Manager, Mental Health Division, HSE email reply 25/09/2015 to Lorna Kerin
Research Question, Design & Participants

• Collaboration between 22q Ireland family support organisation, Love Knowledge Consultancy and UCD Child & Adolescent Psychiatry resulted in joint application to the IRC New Foundations

• Research Question (1) - ‘What the Irish Youth Experts by Experience Panel (YEEP!) say about mental health needs of young people w/22q.’

• Study Design: 4 preparatory groups and 4 focus groups held with over the course of 6 months. Focus group topics to emerge from preparatory group discussion so participant led.

• Participants: 6 young women aged 18-35 living with 22q in Ireland
Participatory Action Research (PAR) methodology

- **Somatic methods** to decrease anxiety (body awareness, mindfulness, breathing techniques, progressive relaxation)
- **Narrative, arts based methods** to increase group cohesion and creative expression (body mapping, lifeline, photo collage, creative writing)
- **Photovoice methods** to facilitate voice (Freire-‘pedagogy of the oppressed’; Feminism- Faith ‘resistance to invisibility & silencing’; Documentary Video)
- **Digital storytelling methods** to disseminate key messages (MDT clinic video targeted at clinicians & policy makers, mental health discussion targeted at parents)
Finding: Key themes arising from YEEP discussions on mental health and wellbeing

Six key themes identified by YEEP relevant to their mental health experience of living with 22q11

• (1) Acceptance of having 22q
• (2) Anxiety – how to manage it
• (3) Communication
• (4) Friendship and Relationships
• (5) Mental Resilience
• (6) Telling Other People about 22q.
Emerging findings

1. Enhanced protective factor of mental health awareness & normalised communication about mental health
   - ‘Being in a group helped me talk about how I feel. For example we talked about thoughts and feelings and mental health which usually we don’t talk about every day. We need to talk about mental health more.’ (Ai)
   - ‘I learned we all experience anxiety and feeling stress and down from time to time.’ (E)
   - ‘Anxiety... is common for everyone with 22q and the doctors should know how to help me to cope with anxiety and big groups. Sometimes I hear sounds and voices like ghosts and I think doctors should be able to help.’ (K)
   - ‘Talking can help us feel better, share problems and thoughts’ (E)
Emerging findings

2. Enhanced protective factors of belonging & confidence and lessened risk factors of social isolation & stigma

- ‘It was a nice feeling being in the same room as other people who have the same condition as you, and not being under pressure to have to fit in.’ (AL)

- ‘It has made me feel more confident with having 22q as I didn’t really like to talk about it with anyone else. But when your in a group with people that have it, it makes it so much easier and it takes the stress off you because they know how you understand and feel about it.’ (A)

- ‘Growing up I always thought I was the only one who had this syndrome, I thought wrong. I used to feel lonely and afraid. But then I met these lovely ladies who now I call friends for life’ (AL)
Emerging findings

3. Enhanced understanding of shared similarities and difference within the experience of living with 22q

- ‘I liked listening to others as I didn’t realise we all have the same feelings and some have the same stories too! It’s nice to know because then you don’t feel as if you’re on your own’ (Ai)
- ‘I understand now that everyone is different with 22q even though it’s the same syndrome.’ (S)
- ‘I learned that we are very different and sometimes that it hurts me but it something that I am learning to accept that we are all different but with the same deletion.’ (E)
- ‘I learned that we are the only ones that understand about us like nobody else.’ (E)

www.childrensresearchnetwork.org
4. Recognition of need for parental and self acceptance:

• ‘Acceptance is important. Parents are afraid of it, but once they learn acceptance, their child or adult will too.’ (Ai)
• ‘Focus on what they (your child) can do not so much on what they can’t do.’ (E)
• ‘Accept them as they are. 22q doesn’t leave you, you grow with it.’ (Ai)
• ‘I found the group very worthwhile, it helped me accept my condition more.’ (E)
• ‘Yes it has changed because now I don’t really care that I have 22q11 it’s not going to stop me from doing my own thing every day.’ (N)
5. Recognition of value of 22q peer support at all ages

- ‘My advice for parents with young children that have 22q is that to get to know people that are around the same age as them. It helps because then they know they are not alone and they have someone to talk to and understand how they are feeling as parents can only do so much.’ (A)
- (My advice to other young people with 22q is) ‘Make a friend who has the same or similar condition as you & keep in contact’ (A)
- ‘I some times found difficult talking about 22q11 cause I am still learning about it but by going to the YEEP group and hearing other people stories I have learned more about 22q11.’ (N)
Questions for dialogue

1. What value can you see in this participatory, creative and narrative approach to engaging with young people with rare disorders and/or learning difficulties?

1. What messages might you have for policy makers and service providers based on your brief encounter with this research with the 22q Young Experts by Experience Panel?

www.childrensresearchnetwork.org
Emma’s story

• My name is Emma Brady and I am 30 years old. I was diagnosed with 22q11 in 2002 at the age of 15.
• I was born with a Congenital Heart Defect, VSD/Pulmonary Sstenosis
• Dislocated Hips
• Enlarged Liver
• Sub mucus Cleft Palate
Emma - Early Years 1 – 5

- Corrective Surgeries
- Numerous Chest and ear infections
- MMR vaccines (3in1) resulted in hospitalisation as my immune system was unable to cope with live vaccines.
- Slight developmental delays
- Fine Motor Skills poorly developed.
- Hearing effected as a result of numerous infections
- Glasses prescribed for eye sight.
Emma - Primary School
5 – 12 years

• Happy to be on my own and play on my own
• In school I played with younger children or older children
• Dependent on younger siblings for company and friendship
• Learning was difficult, struggled with maths.
• Had support for English, Irish and Maths.
• Sports was not an options, as I was clumsy.
Emma - Secondary School
13 - 17 yrs

- Most stressful period of my life
- More teachers and subjects to adjust to.
- As a result my anxiety heightened.
- Difficulty getting learning support and retaining learning support.
- It was during this period I was diagnosed with 22q11.
- Trying to deal with a medical condition I did not understand and I could not explain to my peers it made me feel more isolated and different.
- Stopped looking after myself, lost interest in my appearance and the first signs of severe stress began to develop.
- Began to believe that I smelled of a bad odour.
- I managed to complete school and pass my leaving certificate.
Emma - Early Adulthood 18 – 30

I completed a number of courses including

• Office Administration and Computer Skills
• Childcare QQI Level 5
• Social Studies QQI Level 5
• Healthcare Studies QQI Level 5

• I successfully completed college courses but working in the chosen careers proved very difficult for me.
• I attended the National Learning Network so that they could assist me in further training and work support.
• I learned to drive.
• My anxiety heightened. I attended counselling sessions.
These days...

- I have no confidence or belief in myself.
- I struggle daily with anxiety.
- To manage my life I practice meditation. I do colour therapy and walk with my dog.
- I found CBT, Cognitive Behavioural Therapy and I put the skills I have learned into practice every day.
- I now attend Kerry Mental Health Services and I take medication for anxiety.
Emma - What I need to support my mental health resilience

• Understanding the complexities of 22q11 and educating myself is important to me.

• ‘I found the YEEP group very worthwhile, it helped me accept my condition more.

• I learned that we are the only ones that understand about us like nobody else.

• I feel a bit more confident since being part of the group because I am surrounded by people who are going through the same things as me and it helps that I have someone to turn to.’

• I want to be able to live independently and manage my life as best I can. I do realise I will need some form of support. But most frustrating for me of all is accessing the supports I need.
What would help mental health resilience for children & young people with 22q

• We really need a multidisciplinary clinic with doctors and people who understand about 22q.
• We also need free psychological therapies like CBT and things that help with stress like yoga and mediation.
• Most of us are on disability allowance & can’t afford private therapists or classes.
• We also would like the YEEP group to get funding to continue so children and younger people can learn from our experience.
Questions for dialogue

• Thank you for listening to my experience of 22q and to the YEEP group.
• Do you have any comments or questions for me?
Anne Lawlor - parent

22q Ireland – small but mighty!

• Parent of a now 33yr old adult women with 22qDS

• Chairperson of 22q11 Ireland since 2006.

• “Like a three-legged stool, mental health consultation works best when all three parties – families, providers, and consultants – are equal partners with a shared purpose and coordinated effort”.

www.ecmhc.org
How to support resilience of children & young people with 22q

- Support the parents. Mothers usually are the care coordinators/intereters/researchers etc.
- Provide parent with psycho-educational /advocacy training.
- Challenge the double-edged reality of a ‘mild’/‘invisible’ diagnosis. To access supports child has to be consistently & relentlessly described in terms of deficits. What long term effect?
- Provide appropriate treatment and management of child’s complex and ongoing health issues in appropriate ways: i.e. an MDT clinic / baseline psychiatric assessment / lifespan psychological support
- Educate the educators – need an in-depth knowledge of the syndrome and in particular the cognitive profile: executive functioning skills
Feedback from Irish parents on hearing the voice of the Young Experts by Experience Panel with 22q

**Feedback from Conference forms**
- “The YEEP group were fab!” (Parent)
- “We would like the 22q children and young adults to get to know each other and possibly form friendships” (Parent)
- “Would like to see construction of the YEEP group for the next generation of young adults or a similar group”
- “We would like a lot more interaction with the YEEP group” (Parent)
- ‘We received a lot of informal feedback from (conference) attendees. Many expressed how emotional they found the YEEP group’s presentation and how inspiring they were especially to those who have young children. The group gave them great hope for their children and for what they could achieve!’ (Volunteer with 22q Ireland)

**Parents:** seek to have some idea of what the future will hold for their children. Hearing young people with 22q give voice to their life experiences has a two-fold impact.

1. Parents get an insight into the interior life of what life is like for child/adolescent with 22q and can adjust expectations accordingly.
2. Hearing YP with 22q helps parents develop a more optimistic attitude of mind and a greater expectation of positive outcomes for their own children.
Observations on giving voice to young people with 22q

- **Young People**: Before the young person gains their own voice the parent/mother is the channel for the child’s voice / advocate.
- The process of giving voice to young people directly is just that, a process and can take years.
- The value of participatory research in giving young people their voice is immense.
- Importantly their sense of isolation decreases and their self-confidence increases. They become self-advocates.

Conference feedback on YEEP

- ‘Perhaps the most important thing that I personally have observed are the benefits that the YEEP group themselves have reaped. I have watched them grow in confidence and strength. They have formed a bond with one another, a unique sharing with one another of what life is like being a young adult with 22q11.2 DS and this in turn has empowered them to share their experiences with the rest of us. They are teaching us!!’
  (Volunteer with 22q Ireland)
Questions for dialogue

1. How do you think we can better support parents of children and young people with 22q in Ireland?
2. How can the physical & mental health of children with 22q be managed better?
3. What can be done to gain better insights and knowledge (not theory) of 22qDS?
4. Please write post-it note message to policy makers about what you now think could or should be done to support children and young people with 22q and their parents!
THANK YOU FOR YOUR PARTICIPATION!

22q YEEP project contact details:
Lorna Kerin, Lorna@loveknowledge.ie
Dr Fiona McNicholas, Fiona.mcnicholas@ucd.ie
Anne Lawlor, alawlor4@gmail.com
For discussion

1. Implications arising from presentations
2. Next steps for policy development/practice improvement/research
3. How can CRN support this?
   a. Is there scope and interest for establishing a special interest group to further build on today’s dialogue?
   b. Publishing a resource, policy brief
   c. Holding a training event
   d. Other