



Participation – the key to personalised healthcare

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Emma Brady – Young Expert by Experience

Anne Lawlor – 22q Family Support Group

Saint John of God's Annual Research Day, Dublin, 12 November 2019

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Lorna Kerin, Love Knowledge Consultancy

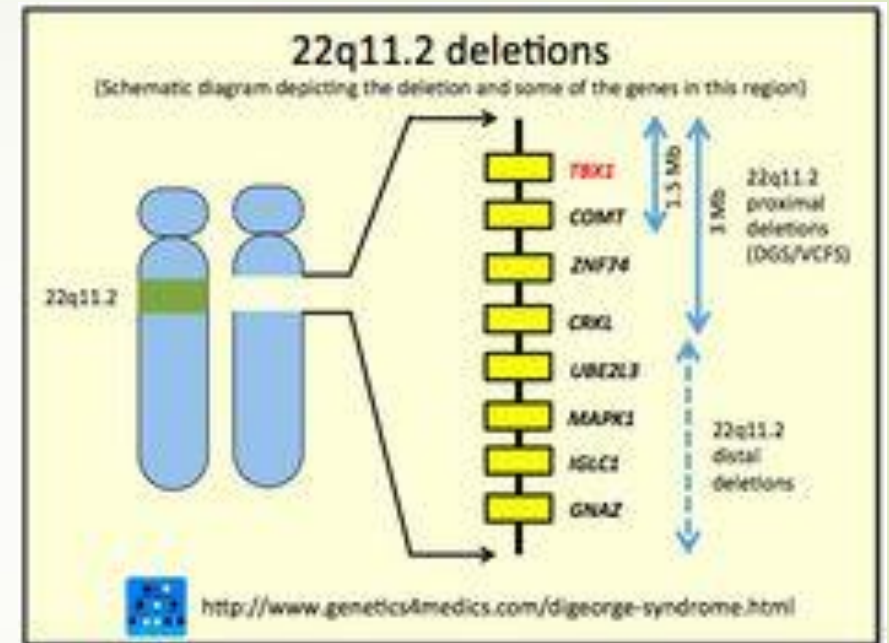
Emma Brady, Young Expert by Experience

Anne Lawlor, 22q Ireland Family Support Group

Presentation at St John of God's Annual Research Day – 12th November 2019

What is 22q11.2 Deletion Syndrome?

- A rare genetic disorder caused by a micro-deletion of a chromosome resulting in the loss of up to 200 genes.
- The name of the syndrome refers to the missing piece of chromosome 22. It is located at a place on that chromosome called q11.2.
- It is the 'most common' rare disease. Prevalence is greatly under recognized & under diagnosed but is between **1 in every 2000** and 1 in every 4000 live births
- This disorder affects many organs and systems.
- Many children & young people with 22q11.2DS have significant **medical, psychiatric, and learning difficulties**
- The variety of presentations often leads to **clinical confusion, diagnostic delay and frustration** for children/carergivers /service providers



2014 Lit review on mental health prevalence rates for 22q Ireland

Mental Health Disorder	Irish general population prevalence rates	International general population prevalence rates	22q11.2DS population prevalence rates
Attention Deficit Disorder	5% of Irish aged 11-13 years (Cannon et al, 2013)	5.3% worldwide (Palanczyk et al, 2007)	37.1% (Schneider et al, 2014)
Autism Spectrum Disorders	1% Irish (Staines et al, 2014)	0.75% (or one in 132 persons, Baxter et al, 2015)	14% to 50%.(Antshel, 2007)
Social anxiety disorder	4.7% Irish adolescents (Cannon et al, 2013)	8.2% (12 mth prevalence adolescents USA, Kessler et al, 2012)	57.7% (Angkustsiri K, 2012)
Psychotic symptoms	10% Irish young adults (19-24 yrs) (Cannon et al, 2013)	9 -14 % (Bartels-Velthuis AA et al, 2010)	50% of adolescents (Stoddard et al, 2010)
Psychotic disorders	0.1 % Irish young adults (age 19-24 yrs) (Cannon et al, 2013)	0.4% (4 in every 1000 UK adults, Kirkbride et al)	10% of adolescents to 25% of adults (Schneider et al, 2014)

Research Rationale

- Lit review revealed **dominantly biomedical quantitative data on 22q11.2ds** & exclusion of 'first person perspectives' of both adults & 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 **Participatory Action Research** to illuminate unique perspective of young people on their mental health experience and support needs in an empowering way.
- PAR is an iterative cycle of research, action and reflection; often targeted on the needs of a particular group; challenges inequality; seeks to empower participants to have a greater awareness of their situation in order to take action



Research Question, Design & Participants

Collaborative application to the **IRC New Foundations funding** stream –UCD/22q Ireland

- Research Question- '**What the Irish Youth Experts by Experience Panel (YEPP!) 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.
- Participants: 6 young women aged 18-35 living with 22q in Ireland
- **Arts based, narrative methods** (body map drawings, lifelines and photo-voice) employed to elicit qualitative themes with a 'Young Experts by Experience Panel' (YEPP).
- Subsequent **Focus Groups** explored these themes
- -**Digital story** methodology informed a short video highlighting the YEPP's experience & recommendations to inform action





Video clip from 2017 YEEP on mental health & support needs



Participatory Action Research findings

- Enhanced protective factor of mental health awareness & **normalised communication about mental health** *“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)*
- Enhanced **protective factors of belonging & confidence** and lessened risk factors of social isolation & stigma *“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 you're in a group with people that have it, it makes it so much easier”*
- Identified the **‘transition gap’ communication challenges** experienced by young people with healthcare providers
- Identified the **systemic issue of uncoordinated service provision negatively impacting on service access and health outcomes** for children and young people with 22q (Flood, L. & Sweeney T. 2011 ; Alugo, T., McNicholas, F. et al, 2017; Kerin, L., Lawlor, A. & McNicholas, F., 2016)



Led to further IRC funded research on Transitions (2017-2018) & development of a pragmatic communication tool by and for young people with 22q to personalize communication & care

WHO AM I ?

Hi, my name is _____. I live at _____. These are the important people in my life:

Name: _____ Relationship: _____
 Name: _____ Relationship: _____
 Name: _____ Relationship: _____
 Name: _____ Relationship: _____

I am diagnosed with 22q11.2DS (22q11.2 Deletion Syndrome) [pronounced **one-one**], but I call it **22q** for short! I got this diagnosis when I was ____ years old. This means that on the q arm (long arm) of my 22nd Chromosome, at position number 11.2; some of the genes are missing; there is a 'micro-deletion'.

This syndrome used to be called Velo-Cardio-Facial Syndrome (VCFS), Sphrintzen Syndrome, CATCH22, DiGeorge Syndrome, or Conotruncal Anomaly Face Syndrome. You may not have heard of 22q11, but have heard of one of these other names. It is thought that 22q11 affects about 1 in every 4,000 people, and presents differently for everyone.

Below are some common problems for people with 22q, but there are many more:

Congenital Heart Disease	Malformed Feet/Toes	
Cleft Palate/Insufficiency	Vision Problems	
Learning Difficulties	Hearing Problems	
Low Immunity	Dental Problems	
Speech/Language Difficulties	Oedema (Swelling)	
Mental Health Problems		
Muscle Problems (+Ca2+)		Add your own!

I am here today to talk about...



UCD School of Medicine and Medical Science
 Excellence in Teaching & Research

Contact Details of my GP

Name: _____
 Address: _____
 Phone Number: _____

My Contact Details

Name: _____
 Address: _____
 Phone Number: _____

Emergency Contact Details

Name #1: _____ Name #2: _____
 Relationship: _____ Relationship: _____
 Address: _____ Address: _____
 Phone Number: _____ Phone Number: _____

PAST MEDICAL HISTORY

MEDICATIONS

Name: _____ Dose: _____ Time(s) of the Day: _____ Are you still on this?: <input type="checkbox"/> Yes <input type="checkbox"/> No	Name: _____ Dose: _____ Time(s) of the Day: _____ Are you still on this?: <input type="checkbox"/> Yes <input type="checkbox"/> No
Name: _____ Dose: _____ Time(s) of the Day: _____ Are you still on this?: <input type="checkbox"/> Yes <input type="checkbox"/> No	Name: _____ Dose: _____ Time(s) of the Day: _____ Are you still on this?: <input type="checkbox"/> Yes <input type="checkbox"/> No
Name: _____ Dose: _____ Time(s) of the Day: _____ Are you still on this?: <input type="checkbox"/> Yes <input type="checkbox"/> No	Name: _____ Dose: _____ Time(s) of the Day: _____ Are you still on this?: <input type="checkbox"/> Yes <input type="checkbox"/> No
Name: _____ Dose: _____ Time(s) of the Day: _____ Are you still on this?: <input type="checkbox"/> Yes <input type="checkbox"/> No	Name: _____ Dose: _____ Time(s) of the Day: _____ Are you still on this?: <input type="checkbox"/> Yes <input type="checkbox"/> No

Do you have any Allergies?

FOR DOCTOR'S USE - GIVE TO PATIENT

You came to see me today about your

I did the following:

I found out that:

The plan is

Tests:

Medication:

Referrals:



Next Appointment

Time: _____
 Place: _____
 Doctor: _____
 Need to Bring: _____

Please remember to add the next appointment to my calendar!!

Led to development & delivery of 'PEEP' Psycho-Educational Programme for parents of children with 22q by Prof Fiona McNicholas

- 4 full one-day MH
- Pre-school, child, adolescent and Young Adult
- Topics:
 - Common mental health disorders
 - Parenting & Managing difficult behaviours
 - Optimise communication and socialisation
 - Manage their own parental stress
 - Know where to go for help
- Evaluation:
 - N=24 attended
 - Videod for future use
 - Well received
 - Practical suggestions



A Peep into PEEP: Designing and Delivering a psycho-educational programme for parents and carers of children with 22q11DS

Coake L.F.¹, Gannon A.², Lawlor A.J., Crotty R.F.³, Kelly L.F.⁴, Gavin D.⁵ & McNicholas F.^{1,2,3,4,5}

¹UCD Department of Child and Adolescent Psychiatry, ²Our Lady's Children's Hospital, Dublin, ³Lusana Child Services, Rathgar, Dublin, ⁴22Q11 Ireland Association, ⁵Department of Psychiatry, Mater/Matercorcora University Hospital, ⁶Love Knowledge Research Consultancy

BACKGROUND LITERATURE

22q11.2 deletion syndrome is a rare genetic condition with a micro-deletion on the arm of chromosome 22 that persons with many medical difficulties, often from early life, and has an increased risk of the development of psychiatric disorders throughout life – such as ADHD, schizophrenia, anxiety disorders and ASD. (Schneider et al., 2014).

Parents often feel that they are not appropriately prepared for the mental health implications of 22q11DS as they are for the possible medical complications. (Hart et al., 2020). Poor mental health, parental stress, poor family functioning and increased child-related stress all have a strong link to the risk of psychiatric symptoms and other mental health disorders. (McConkey et al., 2008). However, family psycho-education has been found to impact families positively and reduce relapse rates and rates of hospitalisations in individuals with mental health problems. Parenting programmes aimed at early recognition and focused intervention exist for parents of children with Autism, and have been evaluated and linked with the prevention and reduction of behavioural problems and reduced parental anxiety. (Hilley et al., 2011)

In a previous project (Aluja et al., 2017), 22q11DS Ireland and UCD department of Child and Adolescent Psychiatry worked collaboratively to establish the evidence base to support the development of a psycho-educational mental health parenting programme (PEEP) specific to 22q11DS. This is the implementation study focusing on delivering the planned PEEP day to parents and carers of children with 22q11DS.

RESULTS

There were 24 parents involved in this study, 4 in the infant group, 8 in the child group, and 8 in each of the Adolescent and Young Adult groups. Although parental stress levels were high, this did not correlate with parental fulfillment (Spearman's $\rho = -0.09$, $p = 0.25$), which was also not highly Parental Stress scale (Table 2) reflect changes of stress over time, and therefore the results at the moment just show the current levels of stress previous to PEEP day. Table 3 shows the excellent feedback from the teaching days.

Table 2 Study specific questionnaire data regarding family stress and parent reported stress and fulfillment on a 5 point Likert-type scale

Group	Parental Stress (Mean)	Parental Fulfillment (Mean)
Infants	4.0	3.0
Children	4.0	3.0
Adolescents	4.0	3.0
Young Adults	4.0	3.0

Table 3 Parental Stress Index (range 0-100)

Group	Stress	Parental Fulfillment
Infants	47	33%
Child	42.5	32%
Adolescents	46.5	32%
Young Adults	45	37%
Total	45.5	33%

Table 4 Client Satisfaction Questionnaire rating the PEEP day on a 5 point Likert-type scale (2 point = excellent)

Group	Very Satisfied	Satisfied	Not Satisfied	Very Dissatisfied
Infants	0	0	0	0
Child	0	0	0	0
Adolescents	0	0	0	0
Young Adults	0	0	0	0
Total	0	0	0	0

AIM OF STUDY

The aim of the project was to design and deliver 4 full one-day mental health psycho-educational programmes for parents and carers of children with 22q11DS (PEEP) for the age groups Infant, Child, Adolescent and Young Adults. This programme was to provide methods to identify common mental health disorders in their children, manage difficult behaviours as a prevention tool, optimise communication and socialisation and also manage their own parental stress.

DISCUSSION & CONCLUSION

Most children/young adults with 22q11 had complex medical, mental health and learning difficulties. The study specific questionnaire (Table 1) showed very high levels of self-reported stress. Rating on the Parental Stress (PS) was average, presumably as the scale includes parental stress, but whether the parent enjoys their child and has fulfillment from them. Fulfillment in the 22q11 children can be seen as a protective factor against parental stress.

Although fewer adolescents had medical problems they were more likely to have mental health difficulties, which correlates with previous finding by the group that 50% of adolescents are one of the parents biggest concern in their child (Aluja et al., 2017).

The psycho-educational days were very well received by attendees, with overall high ratings on the CSQ. These ratings were felt to be relevant to their needs. Suggestions for improvement included taking place later in the day (it commenced at 9am), more time spent on group discussions and less on didactic presentations and more focus on the identification of specific mental health disorders, likewise, in their children. There was strong endorsement by the group to repeat the days annually (either just for 22q11 or with parents whose children had other conditions). From an organisational perspective the program will be 'packaged' in folders containing checklists, Smalltalks, instructions how to replicate the day, and powerpoint presentation data from the previous PEEP days. A video taken each day will be edited ensuring confidentiality, and making it available to the 22q11 support group or clinicians/professionals working with 22q11, and interested in understanding the MH risk. The feedback from the parents will be incorporated into the next delivery.

METHOD

Following approval from the ethical committee of Our Lady's Children's Hospital, parents were recruited through '22q11 Ireland' support group. All parents were sent information about the PEEP days, and they could opt in if they wished to participate. Psychoeducational days were run by senior clinicians from a multi-disciplinary background, covering topics such as communication, infant attachment, behaviour and mental health difficulties and parental well-being. Sessions were run using both didactic group based discussion and reflective practice.

Each parent was given an ID to ensure anonymity. Baseline measures included a study specific questionnaire capturing demographics and family composition. Parents discussed their teaching day goals. They also rated their own stress and fulfillment on a 5 point Likert-type scale, along with the parental stress index (PS). This consisted of 18 questions examining positive and negative aspects of parenting using a 5 point scale (Bony, 1995).

LITERATURE

Aluja J, Gannon A, Lawlor A, Crotty R, Kelly L, Gavin D, McNicholas F (2017) A Peep into PEEP: Designing and Delivering a psycho-educational programme for parents and carers of children with 22q11DS. *Journal of Child Psychology and Psychiatry*, 58(12), pp. 2291-2300.

Aluja J, Gannon A, Lawlor A, Crotty R, Kelly L, Gavin D, McNicholas F (2017) A Peep into PEEP: Designing and Delivering a psycho-educational programme for parents and carers of children with 22q11DS. *Journal of Child Psychology and Psychiatry*, 58(12), pp. 2291-2300.

Aluja J, Gannon A, Lawlor A, Crotty R, Kelly L, Gavin D, McNicholas F (2017) A Peep into PEEP: Designing and Delivering a psycho-educational programme for parents and carers of children with 22q11DS. *Journal of Child Psychology and Psychiatry*, 58(12), pp. 2291-2300.

Led to development of '22q CARA' – Clinical & Research Advocates for 22q11.2DS

- **-Professional Development Events** (Dr Anne Swillen; Prof Donna McDonald-McGinn; Dr Tabib Dabir)
- **-Multidisciplinary Clinician meetings** to initiate planning for a clinic (June 2016)
- **-Submission of a Business Plan to the HSE & Minister for Disability** for Integrated Care Clinic (Dec 2016)
- **-Provision of dedicated clinic days** (Prof Fiona McNicholas; Dr Suzanne Kelleher; Dr David Orr; Dr Ronan Leahy)
- **-Multidisciplinary Care Pathway Planning Day** (Feb 2017) – Immunology, Genetics, Paediatrics, Plastic Surgery, Speech & Language, Psychology, Child & Adolescent Psychiatry
- **-Interdisciplinary Poster** for International Integrated Care Conference (May 2017)
- HRB Applied Partnership Award application (2018)
- **Co-Production Transition clinic planning** (2019)
- **SPARK Hospital Consultant Award** (Nov 2019)



Led to the 'PEERS' social skills programme 2019

12 The 22q YEEP clearly told us that social skills can be more challenging for young people with 22q

- ❖ Piloted the 'PEERS' social skills programme in 2019, a **structured evidence-based programme from UCLA** to develop and build social skills such as:
 - ✓ Conversational skills (entering/exiting individual and group conversations)
 - ✓ Identifying where and how to find friends
 - ✓ Using humour appropriately
 - ✓ Organising social get togethers
 - ✓ Dating etiquette – Letting someone know that you like them, Asking someone on a date, Dating do's & don't
 - ✓ Handling disagreements
 - ✓ Handling direct and indirect bullying
- **Parents group facilitated by Prof Fiona McNicholas, young adults group facilitated by Lorna Kerin**



Led to national & international dissemination events to increase awareness

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- National Children's Research Network Ireland & N. Ireland (Nov. 2016 & Nov 2017);
- 7th World Congress on Women's Mental Health Conference (2017);
- International Integrated Care Conference (May 2017)
- European Society of Child & Adolescent Psychiatry (June 2017);
- International Youth Mental Health Conference (Sept. 2017);
- 22q European Alliance Conference (Oct 2017 & Nov 2019)
- -Patient Public Initiative Conference, HRB (April 2018)
- 23rd World Congress of the IACAPAP (July 2018)
- Irish 22q Ireland Family Support conference (Nov 2017 & 2018)
- St John of God's Annual Research Conference (Nov 2019)



So has participation in action research had an impact on young people's individual mental health & access to personalised healthcare services?

- Engaged in a safe space & facilitated process to reflect on and voice mental health experience & support needs
- Reported improvements in mental health literacy, self advocacy in healthcare; decrease in stigma re: diagnosis & related issues
- Reported decrease in social isolation; increase in peer support; increase in confidence
- Access to a communication tool to improve individualized healthcare communication
- Parents have benefited from an individualised psycho-social parenting programme
- Young adults have benefited from an evidence based social skills programme
- Professionals have benefited from professional development events that increase their ability to personalize their healthcare service for 22q
- Children now have access to specialty pediatric clinic in OLCHC since 2018
- Adolescents will have access to a specialty transition clinic in St James in 2019



Young Expert by Experience Perspective – Emma Brady

- My name is Emma Brady. I am 33 years old and I am the eldest of 3 children in my family.
- I was born in Holles Street hospital October 1986 with a congenital heart defect, dislocated hips, enlarged liver, sub mucus cleft palate and low immune system.
- I have attended a lot of hospitals and seen a lot of consultants. They all took very good care of me, but no connection was ever investigated.
- At 14 years I had genetic testing and only then was I diagnosed with 22q11 deletion. All my family was tested but I was the only one with it.



Young Expert by Experience Perspective – Emma Brady

- The diagnosis gave me some answers but it was very hard to understand and even harder to explain.
- I look normal so it is hard to see the disability.
- As I grew into my teenage years, anxiety took over.
- Finding a consultant to deal with my heart, hips etc was easy enough. Finding a consultant to deal with my anxiety was a lot more difficult. My family doctor was slow to refer me. Maybe because I was a teenager.
- The number of times I would have being told that it was all in my head and it would pass.



Young Expert by Experience Perspective – Emma Brady

- Eventually when the stress got to bad for me I was put on medication.
- For the last number of years. I am also under the care of the Mental Health care team. I see a psychiatrist every 3 months and the mental health nurse once a month.
- But putting this in place was a long and difficult process. Most of the time the professionals spoke with my parents but didn't try to include me.
- I couldn't understand my illness. I couldn't explain how I felt and the doctors I was attending were not including me in the care.
- They spoke through my parents. It made me feel worse and isolated.

Young Expert by Experience Perspective – Emma Brady

- I was very lucky to become part of 22q11 Ireland support group.
- The YEEP group has been a lifeline for me.
- Being with my peers and others who have the condition has given me a confidence boost.
- So much so I was able to tell my boss that I had the deletion.



Young Expert by Experience Perspective – Emma Brady

- The projects I have been taking part in with Lorna and other 22q11 deletion warriors has helped me to understand myself better.
- We are all very different but with the one deletion.



Young Expert by Experience Perspective – Emma Brady

- I am now at the stage that I can speak out not only for myself but also for others with 22q.
- I have been invited to be the Young Expert by Experience Panel representative on the new planning group for the 22q Transition clinic in St James.



Young Expert by Experience Perspective – Emma Brady

- I hope sharing my personal experience will help lot of young people with 22q who like me suffer with anxiety
- I hope that mental health professionals will talk to them, not about them.
- Special thanks to Fiona McNicholas and Anne Lawlor who have supported and encouraged our YEOP with Lorna since the start!



Parent Perspective – Anne Lawlor, Chairperson 22q Ireland

- **Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community – World Health Organisation**



The benefits of participation in action research according to Irish Parents of young women with 22q

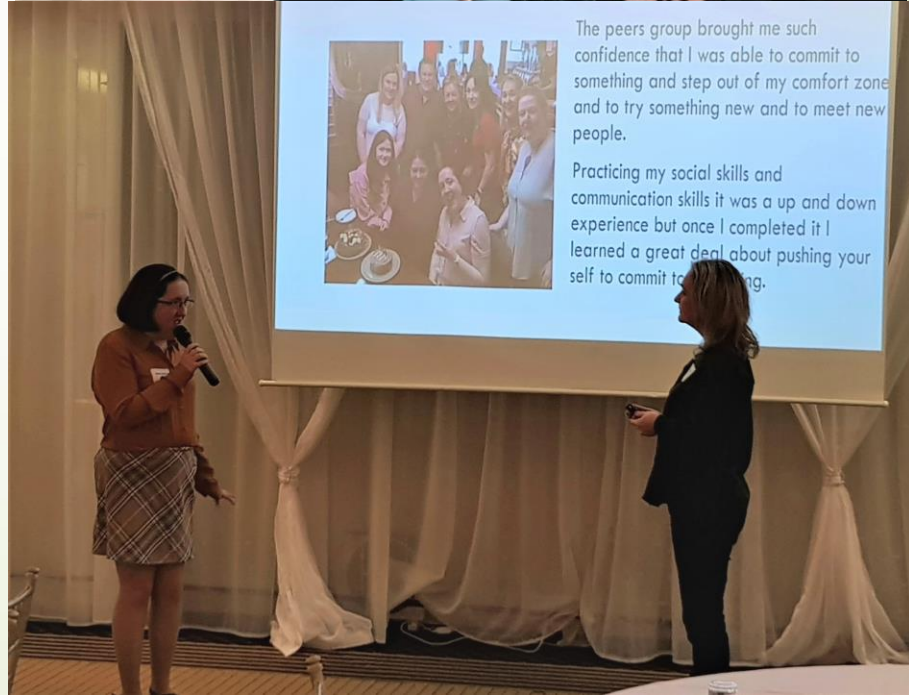
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- ▶ 'Before the young person gains their own voice the parent/mother is the channel for the child's voice / advocate.'
- ▶ 'The process of giving voice to young people directly is just that, a process and can take years.'
- ▶ 'The value of participatory research in giving young people their voice is immense. Importantly their sense of isolation decreases and their self-confidence increases. They become self-advocates.'
- ▶ '*Perhaps the most important thing that I personally have observed are the benefits that the YEOP 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!*' (Irish 22q Ireland conference feedback 2016)



Participation' in the YEEP participatory action research has increase our daughters' abilities to advocate for personalised healthcare

- Confidence
- Voice (in group, at home, vlog, conferences)
- Independent living skills (travel, time, social skills)
- Self-advocacy & other advocacy
- Peer mentoring younger people with 22q
- Access to a specialist mental health professional & a therapeutically trained researcher
- Group has helped destigmatise mental health issues, normalising challenges
- *'If you want to travel fast, travel alone. If you want to travel far, travel together'* – African proverb



Participation of Parent Association in clinical developments & research increases personalized healthcare

- Research funding applications, projects & presentations (IRC; HRB; HSE; DoH)
- Professional development events (for clinicians)
- European & international conferences (with researchers & clinicians)
- Irish 22q Paediatric clinic (supported by parental presence)
- Irish 22q Transition clinic (co-produced with parents & young experts by experience)
- Advocacy for service improvement to policy makers (with clinicians & researchers)



Supportive policy context for Participation approaches

“We will listen to the views and opinions of our patients and service users and consider them in how we plan and deliver our services” (CAMHS SOP)

- ➔ United Nations Convention of the Rights of the Child (**UNCRC** Art. 12)
- ➔ Lundy Model of Participation (2007)
- ➔ **National Strategy on Children and Young People’s Participation** in Decision-Making 2015-202 (DCYA)
- ➔ **Co-Production in Practice Guidance** Document: 2018 - 2020 Supporting the Implementation of ‘A National Framework for Recovery in Mental Health 2018-2020’ (HSE)
- ➔ **Public Patient Initiative (PPI) in Research** – HRB Strategy ‘Research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them’ (INVOLVE)



Questions or comments welcome!





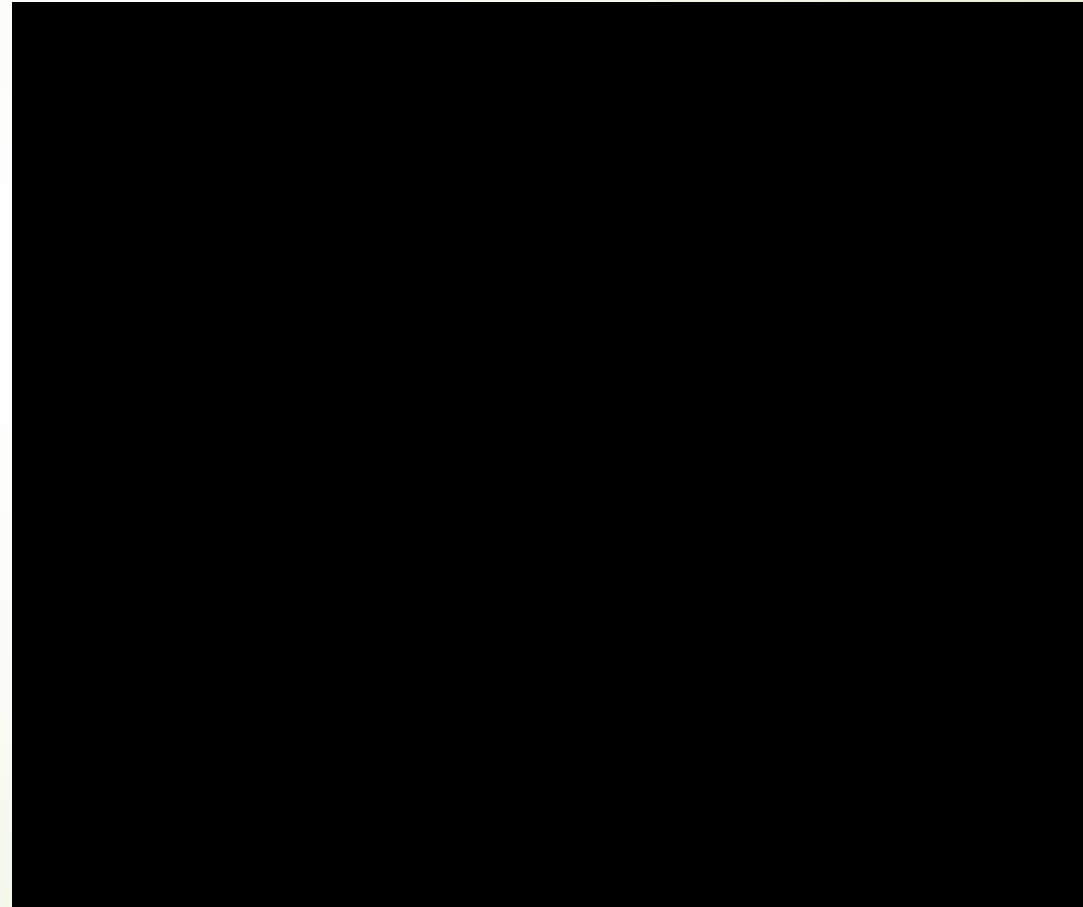
Back up slides



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

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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

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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

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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)



Emerging findings

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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)



Emerging findings

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)

