Mental Health of Children & Adolescents with 22q11.2DS

Prevalence of disorders, available Irish mental health services & recommendations

Presented to the annual 22q11 Ireland Conference 2015
by Lorna Kerin, BA, H.Dip (Psych.), MCAT
Child & Adolescent Mental Health Research Consultant
LoveKnowledge Consultancy, Dublin

LOVE KNOWLEDGE CONSULTANCY

Guidelines for best psychiatric care for mother and baby during pregnancy

Fung et al (2015): Practical Guidelines for Managing Adults with 22q11.2 DS)

1. Ensure provision of genetic counselling during pregnancy

- (Including both partners, as well as other guardians/caregivers, as appropriate)
- Discussion of (i) recurrence risk (50% chance of having a child with 22q11.2DS),
- (ii) unpredictable intrafamilial variability in expression,
- (iii) potential impact of maternal morbidities and associated treatments on maternal–fetal health, and (iv) challenges in caring for a child with (or without) 22q11.2DS

2. Optimize psychiatric care for mother and fetus, as well as partner, if necessary

- Confirm medication safety (e.g., at http://www.motherrisk.org) and necessity, and modify medications only as required
- Monitor for signs of peri- and postpartum mood and psychotic disorders

3. Provide and reinforce general recommendations during pregnancy

- Maintain good nutrition and physical activity
- Standard preconception folate/vitamin supplementation
- Avoid smoking, alcohol, and street drugs
- Avoid known teratogens (e.g., retinoic acid)

What is 22q11.DS?

- 22q11 deletion syndrome is a rare genetic disorder caused by the deletion of a small piece of chromosome 22 resulting in the loss of up to 40 genes. 22q11DS is used as an umbrella term to describe various clinical presentations of a common genetic cause.
- Prevalence is around 1 in every 2000 live births (Fung et al, 2015) but is clinically under-recognised so may be higher.
- 22q11DS as a disorder can affect many organs and systems, affecting the health and quality of life from birth through infancy, childhood to adult life.
- Children can experience a range of physical health issues (e.g cardiac anomalies, weakened immune systems and malformations of the head, neck and palate) & developmental delays (e.g. delayed growth and speech development)
- Children also may experience intellectual or learning disabilities. The most common is borderline intellectual function (IQ of 70-75) to low average.

LOVE KNOWLEDGE CONSULTANCY

How does 22q11.DS affect childhood & adolescence?

- Developmental delays and conditions can affect communication and social interaction e.g speech & language disorders, autism spectrum disorders.
- Learning difficulties are very common during pre-school and primary school aged children. The mathematic ability is usually weak, and attention difficulties, visual spatial abnormalities, and impaired executive function are also common. (memory and verbal abilities are often good)
- Children and adolescents can characteristically experience significant anxiety and appear socially awkward.
- Children and adolescents also may experience neuropsychiatric issues including attention-deficit/hyperactivity disorders, anxiety disorders, depression, autism spectrum disorders and psychosis.
- The variety of presentations often leads to clinical confusion, diagnostic delay and frustration for children/caregivers /service providers (Hacıhamdioğlu et al.,2015)

LOVE KNOWLEDGE CONSULTANCY

A Shared Understanding of Mental Health

What is 'mental health'?

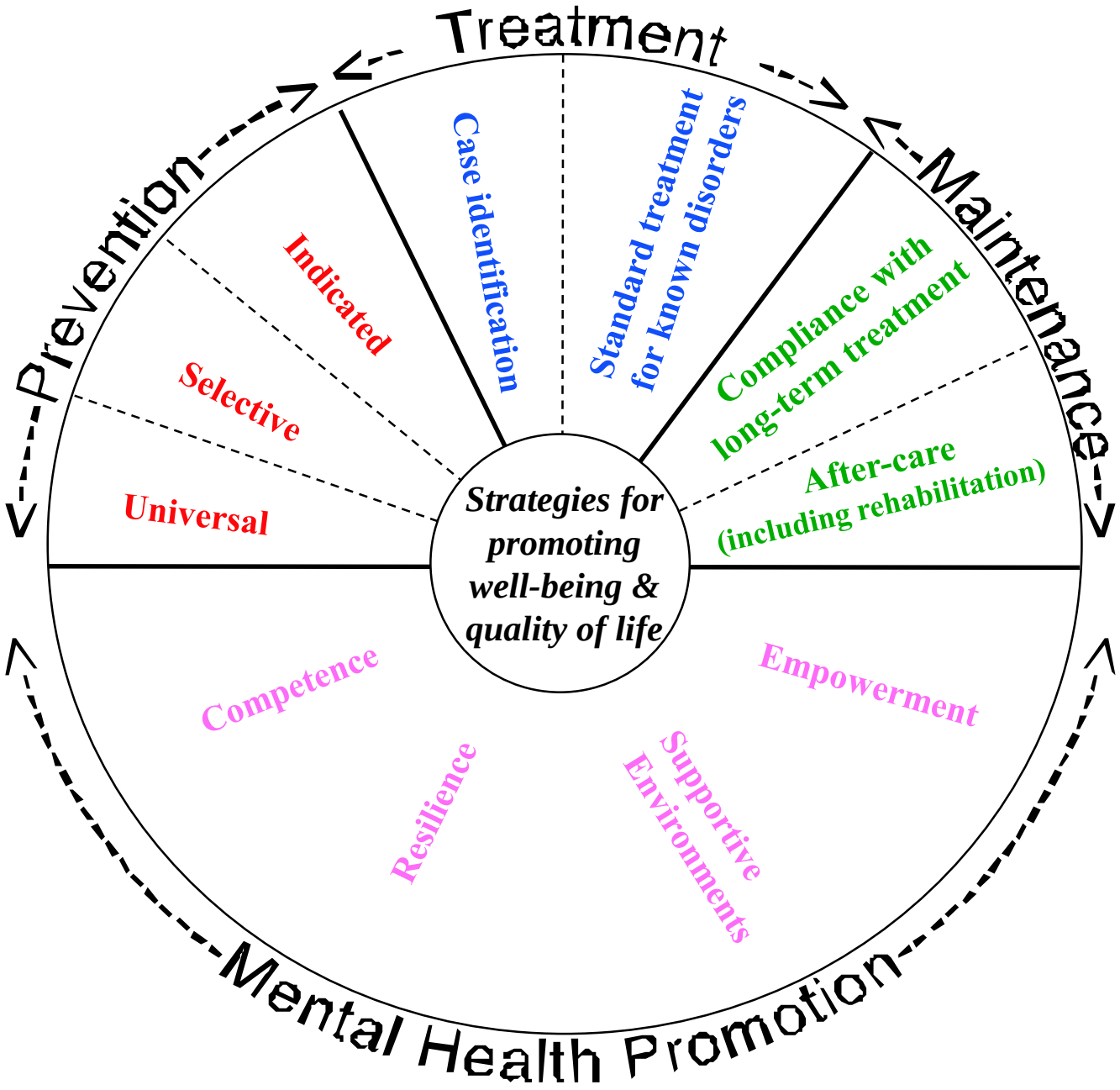
- Mental health is often defined as;

  "*a state of emotional and social well-being in which the individual realises his or her own abilities, can manage the normal stresses of life, can work effectively, and is able to play a role in his or her community*" (World Health Organisation, 1999)

What are 'mental disorders and symptoms'?

- Emotional and behavioural symptoms (signs) that may be experienced by individuals with 22q11DS are diverse, and affect each individual in a unique way.
- Mental diagnosis are clusters of symptoms known as 'disorders'
- Mental health and mental illness is not fixed over the lifespan of someone with 22q11.2DS -symptoms and diagnoses can and do change (Schneider et al, 2014)
- Global research evidence is that mental health promotion, prevention, early intervention & access to evidence based treatment can be effective in reducing mental health distress, and/or even preventing most disorders.

LOVE KNOWLEDGE CONSULTANCY



Barry, M.M. (2001) International Journal of Mental Health Promotion, 3(1) 25-34.

Categories of Child/Adolescent Mental Health Disorders

- **Neurodevelopmental Disorders**
  - Autism Spectrum Disorder*
  - Attention Deficit Hyperactivity Disorder*
- **Depressive and Bipolar Disorders**
  - Major Depressive Disorder*
  - Persistent Depressive Disorder (Dysthymia)
  - Bipolar Disorder
  - Disruptive Mood Dysregulation Disorder
- **Anxiety Disorders**
  - Selective Mutism, Specific Phobia, Separation Anxiety*, Social Anxiety*, Panic Disorder, Agoraphobia, Generalized Anxiety
- **Disruptive, Impulse Control, and Conduct Disorders**
  - Oppositional Defiant Disorder*
  - Intermittent Explosive Disorder
  - Conduct Disorder*
- **Trauma and Stressor-Related Disorders**
  - Reactive Attachment Disorder
  - Disinhibited Social Engagement Disorder
  - Posttraumatic Stress Disorder
- **Feeding and Eating Disorders**
  - Anorexia Nervosa
  - Bulimia Nervosa
  - Binge-Eating Disorder

LOVE KNOWLEDGE CONSULTANCY

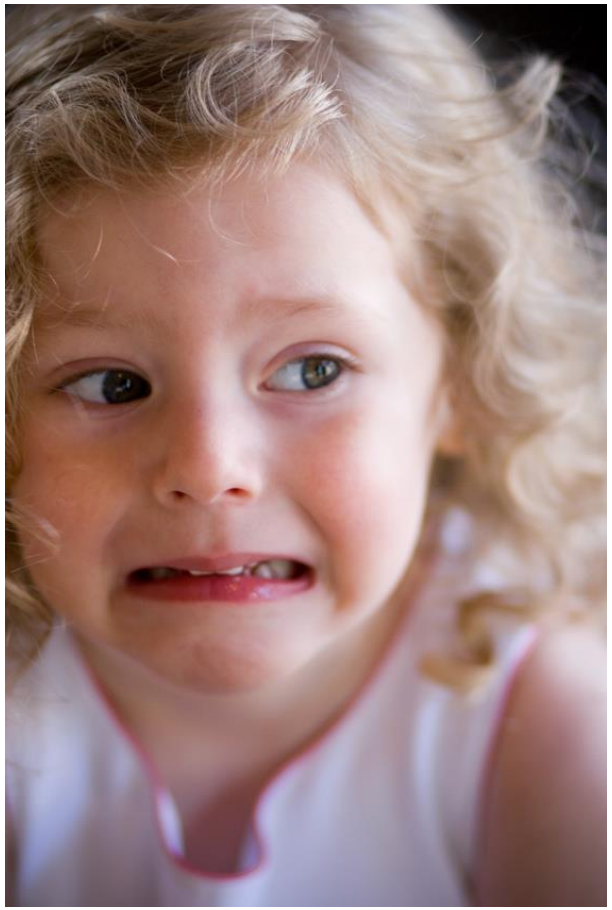
Anxiety Disorders & 22q11.2DS:

Anxiety disorders are characterised by

1. Excessive fear (emotional response to real or perceived imminent threat)
2. Anxiety (anticipation of future threat)
3. Behavioral responses (fight, flight, freeze)

Between 40% -61% of children with 22q11.2DS experience some type of anxiety disorder -Why?

- Early negative life experiences increases risk of anxiety.
- Stress associated with serious medical complications, or repeated medical procedures or poor sense of control over one's body can predispose children to anxiety disorders.
- Prolonged stress can cause physiological changes via cortisol leading to changes in the brain, behaviour and stress response which can result in anxiety disorders
- Poor interpretation of environmental and social cues can affect daily functioning and limits ability to interact and learn from the environment, causing anxiety.



LOVE KNOWLEDGE CONSULTANCY

Anxiety Disorder Types & 22q11.2DS:

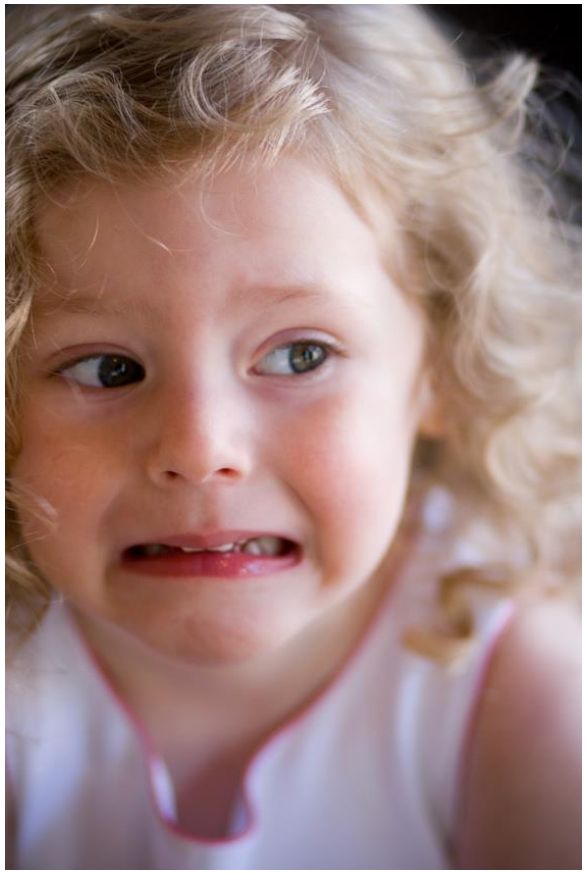
Specific phobias are most common in children with 22q, followed by generalized anxiety disorder, separation anxiety, and obsessive compulsive disorder.

Specific Phobia (SP) – is a marked, persistent and unreasonable fear towards a thing or event. The fear and a response of anxiety may be triggered by either anticipation or exposure to the stimulus.

- Most children with 22q11DS who had a specific phobia had fear of the dark, fears of the natural environment type (fear of lightning/thunder) and fear of the animal type. (Antshel et al, 2006)
- Children do not recognise that the fear is excessive or unreasonable and will try to either avoid the stimulus or endure it with distress and anxiety.
- GAD in general population: **8.7%.** (Kessler et al)

  GAD in 22q11.2 population: **23% to 61%** (Antshel et al, 2006)

These high anxiety rates are specific to 22q and not to the general Intellectual Disability population. This indicates the high need for preventative/early intervention support for children with 22q.



LOVE KNOWLEDGE CONSULTANCY

Anxiety Disorders & 22q11.2DS:

2. **Generalized Anxiety Disorder (GAD)** – excessive worry that's difficult to control & impairs functioning

Symptoms- restless, sleep disturbance, irritability, easily fatigued, muscle tension, mind going blank or difficulty concentrating

Prevalence of GAD in general population: **3.1%** (Kessler et al)

Prevalence of GAD in Ireland, **5.1%** (11-13 yrs) and **11%** (19-24 yrs) (Cannon et al, 2014)

Prevalence of GAD in 22q11.2 population: Between 29% and **40%** **(**Augustiri et al, 2012)

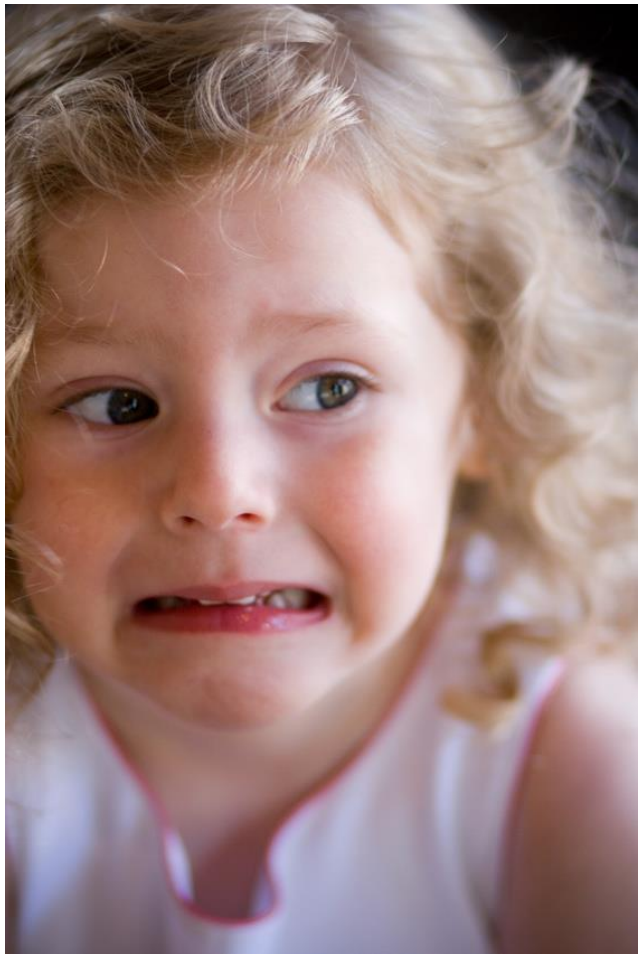
3. **Social anxiety disorder (Social Phobia)-**excessive self-consciousness that goes beyond common shyness.

Symptoms –very worried about being judged negatively by others, of doing or saying anything that may cause humiliation, may avoid eye contact, school avoidance, headaches/stomach aches, etc.

Social Phobia**: 4.7%** in Irish adolescents (Cannon et al, 2014)

22q: Social Phobia: 57.7% (Augustiri et al, 2012)

Study of 55 children indicated excessive shyness/social withdrawal may be a predictor of psychosis (Schonherz, 2014)

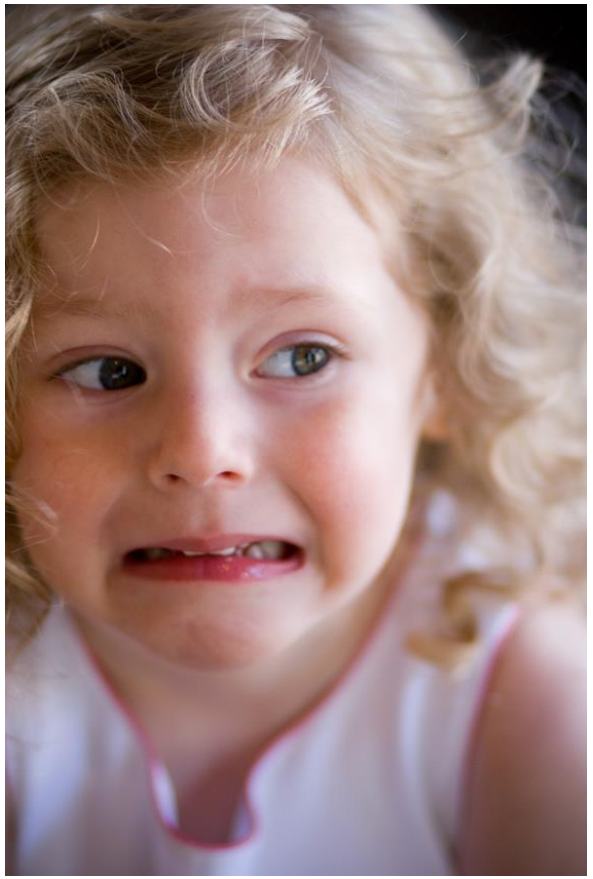


LOVE KNOWLEDGE CONSULTANCY

Study of Anxiety Disorders, Intelligence & Daily Functioning:

Study of 78 children with 22q11.2DS (Angkustsiri et al, 2012)

- 60% of children had fear based anxieties (separation anxiety, fear of physical injury) compared to 20% of obsessive-compulsive or panic-agoraphobia symptoms
- the presence of anxiety disorders, but not intelligence levels, is negatively correlated with adaptive function and impacts daily living skills
- Specific subtypes of anxiety may predict lower adaptive functioning, including panic-agoraphobia, physical injury, and obsessive-compulsive disorder.
- Anxiety disorders had a nearly significant relationship with schizophrenia spectrum disorders, maybe predictive factor but currently unknown
- 1/3 of participants with an anxiety disorder qualified for multiple anxiety disorders
- 19% had prior diagnosis but 58% had elevated, significant anxiety scores - **Anxiety is under-identified in children with 22q11.2DS,** and is more frequent in children than adults (Angustsiri et al, 2012)



LOVE KNOWLEDGE CONSULTANCY

Treatment for risk of/anxiety disorders

- Mental health screening important to identify difficulties early and to access treatment
- Evidence based interventions, both behavioral and pharmacologic, to reduce anxiety may improve adaptive functioning and quality of life in the immediate future. (Schneider et al, 2014)
- Behavioral techniques can teach useful coping skills, encourage positive environmental interactions, support performance to the maximum of cognitive potential, encourage independent functioning and improve relationships.
- Emerging evidence that exercise, yoga, mediation/mindfulness and nutrition can have a protective effect and/or reduce stress and anxiety
- Possible that early anxiety reduction and attainment of coping skills could protect against the development of serious psychopathology later in life (Gothelf et al, 2007)

LOVE KNOWLEDGE CONSULTANCY

Attention Deficit Disorder (ADD)

ADD or ADHD is a pattern of inattention, impulsivity and/or hyperactivity that is persistent, severe and which can affect a child's ability to learn and to get along with others.

Children and adolescents with 22q11DS and ADHD are more likely to exhibit the following symptoms: (Antshel et al, 2007)

- fail to give close attention to details and make careless mistakes in schoolwork
- not seem to listen when spoken to directly
- not follow through on instructions and fail to finish schoolwork or chores
- avoid, dislike, or are reluctant to engage in tasks that require sustained mental effort.
- to interrupt or intrude on others
- to fidget with hands or feet or squirm in his or her seat

In **adolescence** ADD can present as difficulties analysing a task, planning how to address a task, organising the steps need to carry out the task, developing timelines to complete the task, adjusting the steps if needed and completing the task in a timely way

LOVE KNOWLEDGE CONSULTANCY

Prevalence & Specifics of ADHD in 22q11.2DS

- Prevalence of ADHD between 8% to 12% worldwide in the general population (Palanczyk et al, 2007).
- Irish Prevalence 5.1% (11-13 yrs) (Cannon et al, 2014)
- In 22q11DS ADHD ranges **between 30% and 46%.** (Antshel, 2007)
- The '**Inattentive type' (ADD)** seems to be more prevalent in 22q, especially academic inattention
- No gender difference, girls and boys appear equally at risk (Antshel, 2007)
- Children with 22q have a different profile – they have significantly higher scores on the Child Behaviour Checklist scales of somatisation, social problems, thought problems and internalising problems (Antshel et al, 2007)
- Children with comorbid intellectual disability + ADHD had more significant behavioral problems, externalizing and internalizing, than children with intellectual disability only

LOVE KNOWLEDGE CONSULTANCY

Attention Deficit Disorder (ADD)

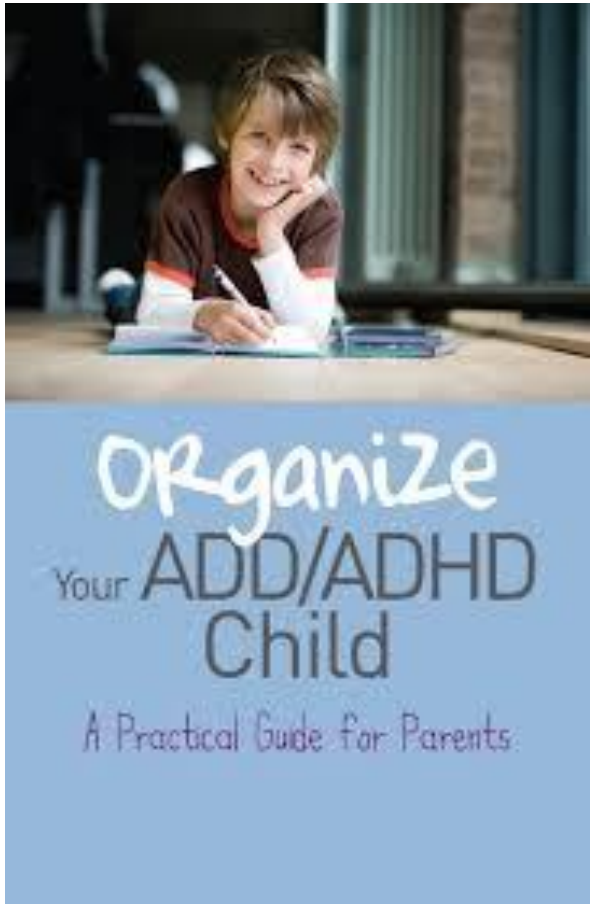
Accurate diagnosis to avoid 'diagnostic overshadowing' where problematic behaviours assumed to be due to intellectual disability and vice versa, where 22q symptoms are misdiagnosed as ADD

- Appropriate diagnostic tools such as broadband checklists (e.g. CBCL) may need to be used with mental age, rather than chronological age

Evidence based treatments for ADHD include

- Behaviourally orientated psychosocial interventions (behaviour therapy, behaviour modification)
- Behavioural parent training (Evidence based programmes in Ireland include Incredible Years, Parents Plus programmes, Triple P, ADD specific programmes include 'Parent to Parent' see CHADD.org)
- Stimulant medication

More research is needed on ADHD in children with low IQ- generally excluded from research if medical disability or intellectual disability



LOVE KNOWLEDGE CONSULTANCY

Psychosis & 22q11.2DS:

- **Psychosis** is a symptom of mental illness rather than the name of a medical condition itself. Broadly speaking, it means a loss of contact with reality
- Generally the types of psychiatric disorder that produce psychotic symptoms are: Psychotic Disorder Not Otherwise Specified, Schizophrenia, Schizoaffective Disorder and mood disorders such as Bipolar Disorder
- **General Irish population rate: 22.6%** report psychotic symptoms (age 11-13 yrs) and **10%** (age 19-24 yrs) (Cannon et al 2013). International rate is around **17%** adolescents
- **22q11,** up to **50% of adolescents** have developed brief, transient positive **psychotic symptoms** that are not perceived as highly distressing (Baker & Skuse, 2005), or attenuated positive psychotic symptoms (Stoddard et al, 2010).
- Psychotic symptoms can appear commonly in 22qDS during childhood and adolescence (Gothelf et al, 2007; Jolin et al, 2009, Stoddard et al, 2010).
- Frequently children and young people report both psychotic symptoms and anxiety (Stachon & De Souza, 2011).

LOVE KNOWLEDGE CONSULTANCY

Psychotic Disorders & 22q11.2DS:

General Irish population rate: 0% diagnosed psychotic disorder (Cannon et al, 2013) International rate: 1% (Schneider et al, 2014)

22q11, largest study of psychiatric morbidity found **10% of adolescents** studied who qualified for a diagnosis of a **psychotic disorder -** Mean onset in adolescence: 17.7 years (**Schneider et al, 2014)**

- This indicates that early-onset psychosis is relatively common in individuals with 22q11.2 deletion syndrome who are referred for psychiatric research studies
- Psychotic disorder not otherwise specified was a somewhat more common diagnosis in children and adolescents than was schizophrenia.
- May be because some young people do not meet the duration and/or severity criteria for a schizophrenia diagnosis and/or because of some reluctance to diagnose children with schizophrenia.
- 22q11.2DS is one of the strongest risk factors for psychosis with studies finding between **25% to 41% of adults meeting diagnostic criteria** for a psychotic disorder (Baker et al, 2003)

LOVE KNOWLEDGE CONSULTANCY

Psychosis & Non specific early signs:

- earliest change described as having more difficulty screening out distracting information and sensations.
- may have difficulty focusing or understanding what they are hearing.
- Visual experiences may become brighter or sounds louder.
- may feel overloaded or find it harder to keep track of what they are thinking and what others are saying.
- may feel more and more disconnected or just want to be alone.
- Gradually, may become confused about what is real and what is not real, mistrustful, even panicky.
- Depressed mood, anxiety, Sleep disturbance
- Problems with handling everyday stress

LOVE KNOWLEDGE CONSULTANCY

Attenuated (mild) psychotic symptoms

- **Suspiciousness**
  (e.g., Feeling increasingly uneasy around friends, family, or teachers without knowing why)
- **Odd beliefs or magical thinking**
  (e.g., Feeling confused about whether a dream actually happened; Wondering whether other people might be able to read your mind; Finding meaningful connections between unrelated events; Clear and frequent déjà vu experiences or experiences of unreality)
- **Unusual perceptual experiences**
  (e.g., Sounds seeming louder than usual; Seeing shadows that look like people or vague figures out of the corner of the eye; Finding that everyday noises sound like words or have special meaning)
- **Tangential/circumstantial speech**
  (e.g., Going off track while speaking; Using odd combinations of words)
- (Symptoms as described by www.cedarclinic.org)

LOVE KNOWLEDGE CONSULTANCY

Treatment of Psychosis & 22q11.2DS:

- Early intervention has the potential to delay or ultimately prevent the onset of psychosis, and to improve the outcome of those who do develop a disorder
- Some patients with 22qDS who present with psychotic symptoms do not develop a psychotic disorder; therefore, the use of antipsychotics for every child or adolescent with 22qDS who experience psychotic symptoms is debatable.
- Initial studies of treatments for people at clinical risk for psychosis have suggested that both psychological and low-dose medication treatments can be helpful.
- Effective psychological treatments can include cognitive behavioral therapy, reducing daily stress, and family support and education
- Most people with psychosis experience a moderate to good recovery with treatment, especially when it is caught early.

- Long-term follow-up, phenomenological and treatment efficacy studies in larger samples are needed to determine optimal treatment of psychotic symptoms in children and adolescents with 22qDS.

LOVE KNOWLEDGE CONSULTANCY

Mood Disorders – Depression, Dysthymia

- Symptoms: low mood • loss of interest in daily activities • loss of energy • tearfulness • poor concentration and memory •low self-esteem and negative view of the future
- Biological features, include disturbed sleep, poor appetite and mood variation
- treatable depression may be missed as mislabelled part of learning disability
- General Irish population rate: 1.7% (age 11-13 yrs) and **4.8%** (age 19-24 yrs) (Cannon et al 2013)
- 22q11.2DS rate: **12.5%** (Jolin et al, 2009)
- The frequency of major depressive disorder in 22q significantly increased with age, whereas dysthymia peaked in emerging adults (Schneider et al, 2014)

LOVE KNOWLEDGE CONSULTANCY

Clinical Treatment of Depression

- Comprehensive guidelines on evidence based treatment of childhood depression are available via NICE guideline on depression in children and young people https://www.nice.org.uk/guidance/cg28/evidence/cg28-depression-in-children-and-young-people-full-guideline-2
- Cognitive– behavioural therapies can be helpful in initial episodes of mild to moderate depression
- If unsuccessful, a cautious trial of medication should be considered,(such as SSRI's, SNRI's, NDRI's) in combination with cognitive–behavioural therapeutic work.
- Exercise & nutrition also need to be considered as key prevention and/or treatment elements (Rao et al, 2008)

LOVE KNOWLEDGE CONSULTANCY

Where can children with 22q get mental health treatment in Ireland?

- *"Since the main delays are related to learning disability, speech development and autism, they 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, child mental health researcher

Child and Adolescent Mental Health Services

LOVE KNOWLEDGE CONSULTANCY

Location of ID Consultants in CAMHS in Ireland (2015), 4.7 whole-time posts, 3.5 vacant posts

CHO	Area	Pop	CAMHS MHID Consultant	Comment
Area 1	Donegal	389, 048	0	
	Sligo/Leitrim		0	
	Cav/Mon		(1)[1]	
Area 2	Galway/Rosc	445, 356	(1)[1]	
	Mayo		0.8	
Area 3	Limerick/Clare/NTipp	379, 327	0.7	
Area 4	Cork	664, 533	0.5	
	Kerry		0.1	
Area 5	CKST	497, 578	1	
	Waterford/Wex			
Area 6	Wicklow/DSE	364, 464	0.2	Part of Dublin South City covered by St Michael's House
Area 7	DSCW	647, 071	0.4	Cheeverstown House
	Kildare		0	
Area 8	L/O	592, 388	(1)[1]	
	Long/W'meath			
	Louth/Meath[1]		See Cav/Mon	
Area 9	Dublin N City	581, 486	0.5[2]	Daughters of Charity 0.5 child
	North Dublin		1.0	St Michael's House 1.2 (also covers part of CH06)

HSE: PROPOSED ALLOCATION TODEVELOP MENTAL HEALTH ID 2015

CHO	Area	Child	Adult	Rationale
1	Donegal	0.5 Cons, 1 CNS,1 Psychologist	1 Psychol (s)	Develop team for children
	Sligo/Leitrim	0.5 Cons, 1 CNS, 1 Psychologist		Develop team for children
2	Mayo	1 Psychologist, 1 CNS	1 SW, 1 OT	Develop teams
	Galway/ Roscommon	1 Social Worker	1 OT, 1 SW, 1 CNS	Further develop services for both
3	Limerick/Clare/North Tipp	1 Psych, 2 CNS,1 Admin (GIV)	1 Cons, 1 Psychologist, 2 CNS, 1 Admin (GIV)	Develop teams for adults and children
4	North Lee		1 Admin (GIV)	Complete Team
	Kerry	1 CNS,1 Psychologist	1 OT, 1 Admin (GIV)	Start child team,Develop adult
5	Wexford	--	1 Cons, 1 CNS, 1 Psychologist 1 Admin, 1 OT	Start service in Wexford
6	South Dublin	1 Consultant, 1 CNS, 1 Psycholog	1 Consultant[1], 1 CNS 1 Psychologist	CAMHS - ID will cover South Dublin and Wicklow
7		0.6 Consultant, 1 CNS 1 Psychologist,1 SW	2 SW 2 Admin (GIV)	Cheeverstown 0.4 WTE CAMHS ID consultant returning Sept 2015. Combine

What are Community Child & Adolescent Mental Health Services (HSE CAMHS) in Ireland?

- Multidisciplinary team - a consultant child and adolescent psychiatrist, registrar, clinical psychologist, clinical nurse specialist, social worker, speech and language therapist, occupational therapist and administrative staff.
- Services - individual work, family work, art and play therapy, cognitive behavioural therapy, group work, parenting courses, social skills groups, medication.
- Referral to specialist CAMHS only through GP-so important to brief your GP on mental health aspects of 22q11.2DS

Challenges in CAMHS (CMHC review, 2015)

- Difficult to access due to lack of information restrictive referral criteria and pathway, lengthy waiting periods and a lack of out of hours/crisis service
- Lack of evidence based treatment as standard
- Lack of standardized outcome monitoring
- Lack of published, service quality guidelines
- Lack of inclusion of child/young person/caregiver in care planning
- Lack of consistent support transitioning into adult mental health care

LOVE KNOWLEDGE CONSULTANCY

What do good practise CAMH services for children & adolescents look like?

1. Needs based, timely referral, assessment and access procedures
2. Locally based services with multi-agency collaboration & referral
3. Evidence informed practise and evidence based treatment options
4. Alternative CAMH services to meet complex mental health needs including out of hours service
5. Participation of child/young person and family in service & care plan development & evaluation
6. Relationship building valued, consistent staff
7. Outcome monitoring & accountability
8. Confidentiality and privacy

LOVE KNOWLEDGE CONSULTANCY

What does good practise CAMH services for children & adolescents with learning disabilities look like?

Specific CAMH care pathway (Quality Standards for Mental Health Care Pathways for Children & Young People with Learning Disabilities, UK, 2007)

Six quality standards include:

1. **Pre-referral** -clear criteria & processes so no bouncing between services
2. **Referral** -with caregivers & referrer in normal setting
3. **Assessment** -holistic, suited to developmental level, age & culture
4. **Interventions** individually tailored, effective interagency coordination
5. **Discharge** – clearly coordinated between agencies using existing review procedures
6. **Re-referral** –clear definition of agency roles in relation to new concerns

Team management of the transition from CAMHS to adult mental health care

LOVE KNOWLEDGE CONSULTANCY

Irish research with parents of children with 22q (Flood & Sweeney, 2011)

- Parent's main reported concern was lack of care coordination.

"As there is no coordinated approach to children with 22q11, we feel that very few of the doctors we attend are taking account of the 'big picture'. The result is that parents have to constantly navigate their way forwards and backwards through the system own their own."

- The majority of parents felt that felt that information provided at diagnosis was inadequate and awareness among professionals about 22q11 symptoms was generally low

"We have to go searching for doctors that know about 22q11DS and try to find out where they are. The information is very poor and we've only found information through parents of children with the same condition."

- Mental health was the second greatest concern of parents for the future (29.8%)

29.7% (n=14) of children have behavioral problems and 36.1% (n=17) have emotional problems yet **80.5% (n=33) have never seen a psychiatrist and 40.5% (n=17) have never seen a clinical psychologist** for assessment.

This indicates a large detection and mental health service provision gap.

LOVE KNOWLEDGE CONSULTANCY

Irish research with parents of children with 22q (Flood & Sweeney, 2011)

- The majority of parents (70%, n=35) have never been given an ongoing individualized treatment plan for their child.
- Need for a multidisciplinary 22q11.2 clinic *"I would love to be able to bring her to 22q11 clinic where they would be able to assess all her problems and help her where needed."*
- According to parental views, there is a need for improvement in the current provision of services in Ireland

Recommendations from report 2011

- Awareness among health care professionals of the range of possible symptoms,
- clear need for established care guidelines and coordination of care.
- Assigning a key worker at time of diagnosis could be valuable
- Further in-depth research using interviews and/or focus-groups is recommended

LOVE KNOWLEDGE CONSULTANCY

Advocacy suggestions to support mental health

Primary Care & Universal Services:

✓ Develop awareness; Professional Development Training; Evidence based preventative & early intervention programmes

Statutory CAMHS:

Advocate that best practise guidelines are adopted or adapated for Irish context. Consider for example:

- Towards a safety net for management of 22q11.2 DS: guidelines for our times; Habel et al, 2014;
- International Guidelines Practical Guidelines for Managing Patients with 22q11.2DS (Bassett et al, 2015)
- Fung, W. et al. (2015). Practical guidelines for managing adults with 22q11.2 deletion syndrome.
- Schneider et al, 2014 Psychiatric Disorders From Childhood to Adulthood in 22q11.2 Deletion Syndrome: Results From the International Consortium on Brain and Behavior in 22q11.2 Deletion Syndrome
- UK CAMHS service provision for children and young people with learning disabilities

LOVE KNOWLEDGE CONSULTANCY

Advocacy suggestions to support mental health

- ✓Appoint case worker to family/child on diagnosis
- ✓Ready access to a psychologist and psychiatrist at all ages, assessment to determine the intervention
- ✓Screen and follow preschool and school-aged children with 22q11DS for neurocognitive and psychiatric problems.
- ✓Provide early support and treatment for indicated or diagnosed individuals.
- ✓Prioritise appointment of intellectual disability teams in CAMHS as per Vision of Change policy
- ✓Facilitate access to consultations to ID CAMHS/specialist clinic/ by professionals and parents

LOVE KNOWLEDGE CONSULTANCY

Advocacy suggestions to support mental health

22q Ireland to seek funding/partnerships to collaborate to:

- Develop evidence-informed training materials for parents, children & young people and professionals on mental health and 22q
- Access evidence based psychosocial prevention & early intervention mental health programmes
- Conduct research on prevalence and treatment efficacy in Ireland
- Build capacity of young people and their parents to advocate for right to service provision to meet their needs
- Lobby for implementation of policy on children & young people's rights e.g. 'A Vision for Change'; 'Healthy Ireland'; 'Better outcomes, Brighter Futures'; 'Wellbeing in Schools: Guidelines for Mental Health & Wellbeing'; 'National Rare Disease Plan for Ireland'

LOVE KNOWLEDGE CONSULTANCY

Over to you as parents & experts by experience to inform the briefing report…

- Have you experience of your child experiencing mental health difficulties?
- What support have you been able to access?
- What has been your experience of child & adolescent mental health services (CAMHS) in Ireland?
- What has been your experience of Disability Services supporting your child's mental health?
- What would you like to see happen in Ireland to improve the mental health and wellbeing of children and adolescents with 221.11.2DS?

LOVE KNOWLEDGE CONSULTANCY