

Mental health in a children's hospital - detection and access to effective care – with some examples from epilepsy

Isobel Heyman MBBS PhD FRCPsych

Palermo May 2019 6th MAUDSLEY MEDITERRANEAN FORUM

Summary

- **Mental health needs of children with long term health problems are elevated:**
 - Common psychiatric disorders are even more common in this population
- **We have to be creative and flexible about how we detect and treat these mental health problems**
 - Some research examples with potentials for community roll-out

Some tips along the way of how to do research as a full-time clinician and have fun.....



WELLBEING

ADJUSTMENT

PROCEDURAL FEARS

**EMOTIONAL AND
BEHAVIOURAL SYMPTOMS**

MENTAL ILL HEALTH

Tip 1

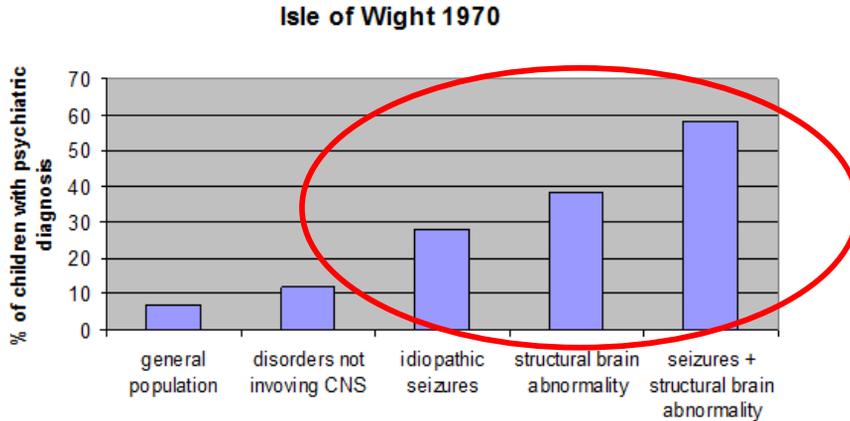
- Find great mentors





Background: Isle of Wight, 1970

- Epilepsy and CNS disorders are major risk factors for psychiatric disorders.



Developmental Medicine and Child Neurology 2003, 45: 292–295

A population survey of mental health problems in children with epilepsy

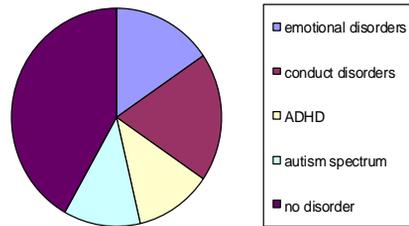
Sharon Davies MBBS MRCPsych, Specialist Registrar, Great Ormond Street Hospital;

Isobel Heyman* MBBS PhD MRCPsych, Consultant Child and Adolescent Psychiatrist;

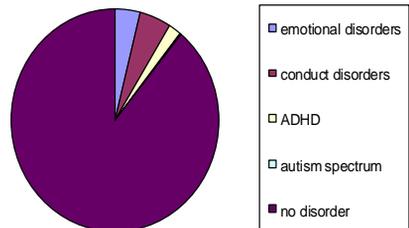
Robert Goodman MBBS PhD FRCPsych, Professor of Brain and Behavioural Medicine, Department of Child and Adolescent Psychiatry, Institute of Psychiatry, King's College London and Maudsley Hospital, London, UK.

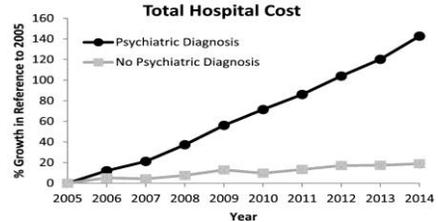
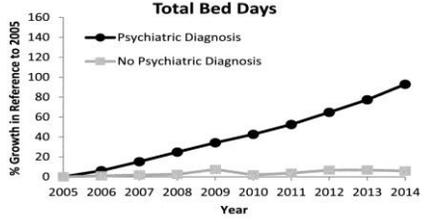
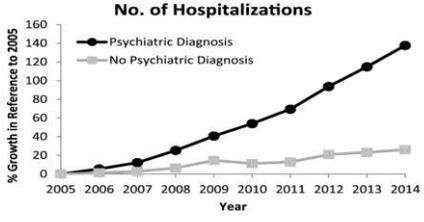
*Correspondence to second author at Department of Child and Adolescent Psychiatry, Institute of Psychiatry, King's College London and Maudsley Hospital, London SE5 8AZ, UK. E-mail: i.heyman@iop.kcl.ac.uk

complicated epilepsy



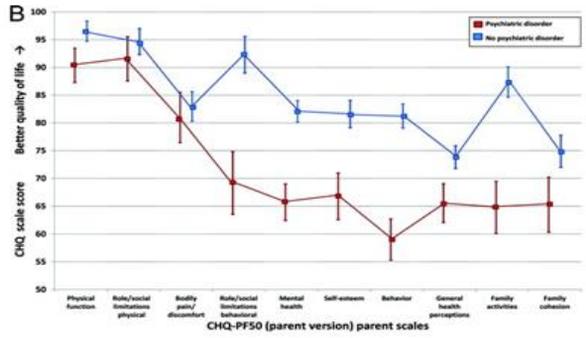
controls



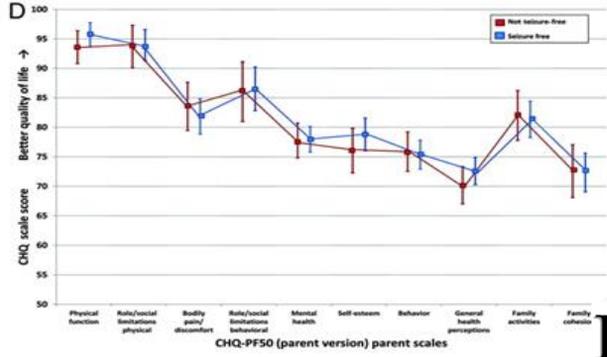


Zima, B. T., Rodean, J., Hall, M., Bardach, N. S., Coker, T. R., & Berry, J. G. (2016). **Psychiatric Disorders and Trends in Resource Use in Pediatric Hospitals.** *Pediatrics*, 138(5),

'The 10-year rise in pediatric hospitalizations in US children's hospitals is 5 times greater for children with versus without a psychiatric diagnosis. Strategic planning to meet the rising demand for psychiatric care in tertiary care children's hospitals should place high priority on the needs of children with a primary medical condition and cooccurring psychiatric disorders.'



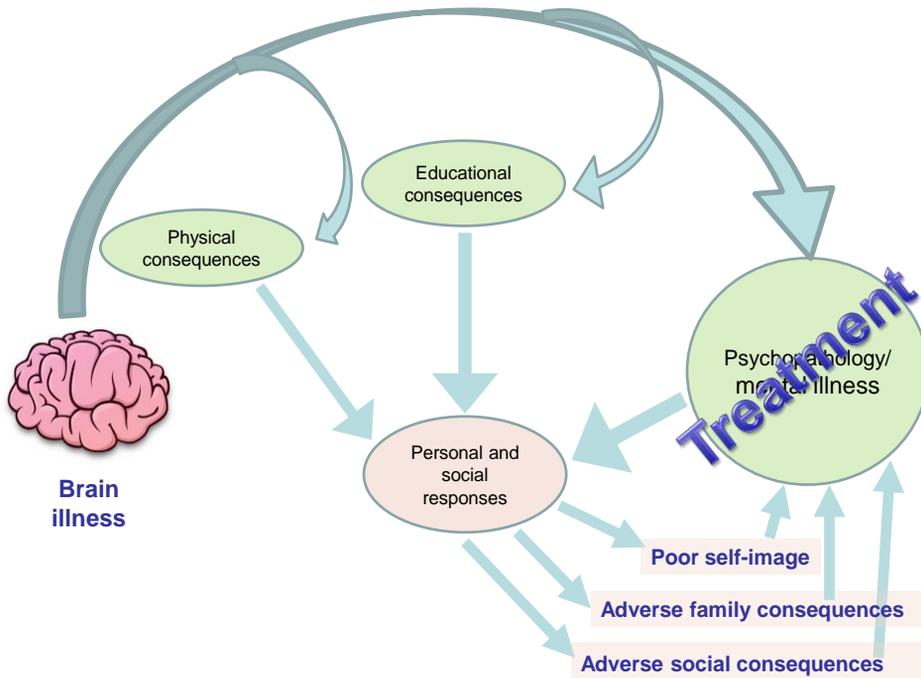
Presence of a psychiatric disorder at 5 year follow-up associated with reduced quality of life



Presence of seizures not associated with reduced quality of life

Baca C B et al. *Pediatrics* 2011; 128:1532-1543





Tip 2

- Find a focus – but don't be scared of changing
- You will have interesting groups of patients who will give you ideas and can help you discover things

Psychopathology in children with epilepsy before and after temporal lobe resection

A McLellan* MRCPsych, S Davies MRCPSych, I Heyman PhD, B Harding PhD, W Harkness PhD, D Taylor FRCPsych, B G R Neville PhD, J H Cross PhD
 UCL Institute of Child Health and Great Ormond Street Hospital, London, UK

*Correspondence to first author at Department of Paediatric Neurosciences, Royal Hospital for Sick Children, Edinburgh EH9 1LF, Scotland, UK.
 E-mail: mclellanailsa@doctors.org.uk

Children with epilepsy are at an increased risk of psychopathology when compared with the general population. This is a chronic illness that affects the central nervous system (CNS). Rutter et al. (1984) conducted a 10-year follow-up study of 100 children with temporal lobe epilepsy (TLE) who had undergone surgery. They found that 40% of children had a psychiatric diagnosis pre-operatively, and 41% had one or more psychiatric diagnoses post-operatively. Some children lost a diagnosis, while others gained one. The study also found that children with TLE were more likely to have a psychiatric diagnosis than children with other types of epilepsy. The authors concluded that the high rates of psychiatric problems in children with TLE are likely to be related to the underlying brain pathology and not just to the effects of surgery. This finding is important because it suggests that children with TLE should be monitored for psychiatric problems both before and after surgery. Early detection and treatment of these problems can help to improve the quality of life for these children and their families.

41/57 (72%)
 post-operatively-
 some gained
 and some lost a
 diagnosis

40/60 (67%)
 children had
 one or more
 psychiatric
 diagnosis
 pre-operatively

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

ORIGINAL ARTICLE

Psychopathology in children before and after surgery for extratemporal lobe epilepsy

M CHIARA COLONNELLI^{1,2} | J HELEN CROSS^{1,2} | SHARON DAVIES³ | LUIGI D'ARGENZIO^{1,2} | ROSA C SCOTT¹ | ANDREW PICKLES⁴ | SIOBHAN HANNAN¹ | WILLIAM HARKNESS⁵ | ISOBEL HEYMAN^{1,6}

¹ Neuroscience Department, UCL Institute of Child Health & Great Ormond Street Hospital for Children, London, UK; ² NHS Foundation Trust, London, UK; ³ Maudsley Hospital, London, UK; ⁴ King's College London Institute of Psychiatry, London, UK; ⁵ UCL Institute of Child Health, London, UK; ⁶ UCL Institute of Child Health, London, UK

This article is commented on by Besag on page 486 of this issue.

31/71 (44%)
 children had
 one more
 psychiatric
 diagnosis
 pre-operatively

32/71 (45%)
 post-operatively

<p>PUBLICATION DATA Accepted for publication 4th January 2012 Published online 14 April 2012</p> <p>ABBREVIATIONS ADHD Attention deficit hyperactivity disorder ASD Autism spectrum disorder DBD(NOS) Disruptive behaviour disorder (not otherwise specified) DSM-IV Diagnostic and Statistical Manual of Mental Disorders (4th edition) ODD/CD Oppositional defiant disorder/conduct disorder</p>	<p>AIM To establish the rates and types of psychiatric disorder in children before and after surgery for extratemporal epilepsy. Relationships between psychiatric morbidity and demographic/clinical variables were examined.</p> <p>METHOD A retrospective case note review of 71 children undergoing extratemporal focal resection epilepsy in a specialist epilepsy surgery programme between 1997 and 2007. Psychiatric diagnoses were derived from pre- and postoperative assessments according to DSM-IV criteria.</p> <p>RESULTS Seventy-one children (38 males, 33 females) were eligible for this study. Mean age (SD) at surgery was 9.6 (3.0) years. Frontal resections were performed in 73% of the children, parietal in 17%, and occipital in 10%. Mental health problems were present in 37 of 71 (52%) children pre- and/or post-operatively. A similar proportion of children had psychiatric diagnoses pre- and post-operatively: 31 of 71 (44%) and 32 of 71 (45%) respectively.</p> <p>INTERPRETATION Psychopathology is common in children with extratemporal epilepsy. In this sample, the impact of surgery on psychiatric symptoms was not predictable: some children were unchanged, others improved, and others acquired new psychiatric diagnoses postoperatively. Given the high rates of psychiatric disorder in this group of patients, detection and treatment of mental health needs may be important.</p>
---	---

Mental health disorders in children and young people with epilepsy:

Identification and treatment



The context

Prevalence estimates of mental health disorders in children and young people with neurological conditions are 50% or greater compared with the general population (Thapar et al., 2016)

“The psychological needs of young people with epilepsy should always be considered”

Psychological problems can impact more on physical health problems

Physical health problems may impact upon psychological health problem itself (e.g. Thapar et al., 2005)

NICE National Institute for Health and Care Excellence
Epilepsies: diagnosis and management
Clinical guideline
Published 11 January 2012
CG127

what is I have a Fit instant of people?
I hope
What
what is I have a Fit instant of people?
who I am.
things like
you from
is
who I am.
Etc

The background of this slide is a complex collage. On the left, there is a close-up of a woman's face with green hair and dark eye makeup. The rest of the background is filled with various handwritten notes and text in different colors and fonts, some of which are repeated. The text includes phrases like "what is I have a Fit instant of people?", "I hope", "What", "who I am.", "things like", "you from", "is", "Etc", and "what is I have a Fit instant of people?".

The problem

- ‘Contemporary standards of practice fail to integrate screening and treatment of the comorbidities into routine clinical care’ (Asato, Caplan & Hermann, 2014)
- Mental health disorders in the context of neurological illnesses often remain undiagnosed and under-treated (e.g. Ott et al., 2003)
 - Community epilepsy sample
 - 60% had DSM-IV diagnoses
 - >60% received no mental health treatment
- Paediatricians are said to ‘despair’ at accessing psychological therapies (Smpokou et al., 2015) despite such interventions being paramount to optimising outcomes

And...

- There are no strong evidence-based interventions for mental health disorders in this group of young people
- There are only 10 studies in children with mental health disorders and physical illnesses
- Only 2 of which were with children with neurological conditions (epilepsy)

Original article

Psychological interventions for mental health disorders in children with chronic physical illness: a systematic review

Sophie Bennett,¹ Roz Shafiq,¹ Anna Coughtrey,² Susan Walker,^{1,2} Isobel Heyman^{1,2}

ABSTRACT Children with chronic physical illness are significantly more likely to develop common psychiatric symptoms than otherwise healthy children. These children
Chronic Disease Prevention,^{1,2} similarly includes an objective to develop strategies for integrating mental health and mental illness and public health systems. There are highly effective evidence-based
Background: Despite recognition that psychosocial interventions can improve quality of life and mental health, there continues to be a lack of clarity and guidance around effective psychosocial interventions for children and young people with epilepsy. This review utilizes specific quality criteria to systematically identify and appraise the evidence for the effectiveness of psychosocial interventions for children and young people with

Contents lists available at ScienceDirect
Epilepsy & Behavior
journal homepage: www.elsevier.com/locate/yebeh

Review
A systematic review of psychosocial interventions for children and young people with epilepsy
Fiona M. Corrigan^a, Helen Broome^{a,b}, Liam Dorris^{a,b,*}
^a Institute of Mental Health and Wellbeing, University of Glasgow, Glasgow G12 0XJ, Scotland, UK
^b Pediatric Neurosciences Research Group, Royal Hospital for Children, Glasgow G11 4JZ, Scotland, UK

ARTICLE INFO
Article history:
Received 26 September 2015
Revised 21 January 2016
Accepted 4 January 2016

OPEN ACCESS

Additional material is published online with this article. To view please visit the journal online (http://dx.doi.org/10.1016/j.yebeh.2016.01.014).

© 2016 Elsevier B.V. All rights reserved.

Tip 3

- You have identified a problem from your clinical work
- It can be a long road to design and implement a research plan.....
-find great colleagues and get some money

Acknowledgements

Roz Shafran
 Sophie Bennett
 Anna Coughtrey
 Helen Cross
 Sophia Varadkar
 Colin Reilly

Daniel Stark
 Maria Hadji-Michael
 Fiona McFarlane
 Eve McAllister
 Chloe Taylor

- **Funding from**
 - Great Ormond Street Hospital Children's Charity
 - Epilepsy Action
 - NIHR
 - Beverley Alexander Charity


 National Institute for
 Health Research

 epilepsy action

 Great
 Ormond
 Street
 Hospital
 Charity

The solution?

No reason to assume that standard evidence based protocols won't work

So start with these.....



Start with a case series to determine feasibility/acceptability



Progress to pilot trial



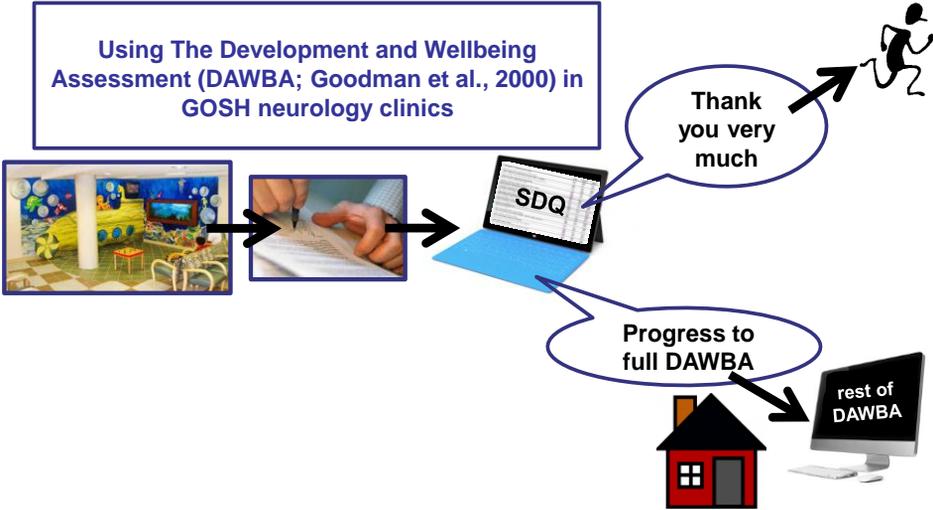
Then full RCT

Automation.....





How do we identify them? A modernised screening process



What is the DAWBA?

- DAWBA = Development and Well-Being Assessment
- Standardised assessment of mental health and well-being
- Incorporates an emotional and behavioural symptom screen: the Strengths and Difficulties Questionnaire (SDQ)
- Generates DSM and ICD psychiatric diagnoses
- Validated in epidemiological and clinical settings
- www.dawba.info
for a demonstration of the online DAWBA system

Searchable database of DAWBA publications

343 publications from 29 countries:

<http://dawba.info/py/dawbainfo/e0.py>

Main findings

- High rate of uptake for screening 639 SDQs were completed



- 353 (55%) of these met criteria for continuation to the full online mental health diagnostic assessment (DAWBA)

Progress to full DAWBA

- In those who progressed to the DAWBA:
69% had at least one mental health disorder
- 170 DAWBAs were completed
(48% of those eligible)



Tip 4

- Don't give up on getting published

Leading article

Assessing feasibility of routine identification tools for mental health disorder in neurology clinics

Sophie D Bennett,¹ Isobel Heyman,^{1,2} Anna E Coughtrey,^{1,2} Marta Buszewicz,³ Sarah Byford,⁴ Caroline J Dore,⁵ Peter Fonagy,⁶ Tamsin Ford,⁷ Rona Moss-Morris,⁸ Terence Stephenson,¹ Sophia Varadkar,^{1,2} Erin Walker,⁹ Roz Shafran¹

INTRODUCTION
Common childhood mental health disorders are up to five times more frequent in children with neurological conditions than in those without a chronic illness, yet 'contemporary standards of practice fail to integrate screening and treatment of the comorbidities into routine clinical care' and there is a high unmet need for treatment.¹ This situation is not unique to neurological conditions; up to 80% of those with a chronic illness and symptoms of a mental health disorder are not in contact with child and adolescent mental health services.²⁻⁴ Left untreated, mental health disorders seriously impact social

and another that general practitioners (GP) have difficulty identifying mental health needs in children.¹¹ Physical health specialists may also not have the time to ask about and/or assess mental health; mental health discussions can take up a significant proportion of clinic time^{12, 13} and clinicians may not wish to 'uncover a can of worms' that will warrant a significant amount of extra work.

One solution to the challenges in identifying mental health disorders is to embed mental health specialists within paediatric teams.^{14, 15} However, many paediatric centres do not have access to embedded

line with the National Institute for Health Research (NIHR) guidance on feasibility studies,¹¹ the specific objectives were to determine the:

- ▶ Numbers of families who consented to screening.
- ▶ Numbers of families who completed screening measures.
- ▶ Proportion with a mental health disorder.
- ▶ Overall acceptability to families and clinicians.

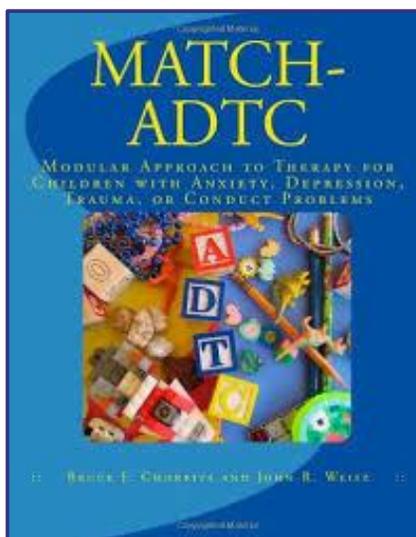
The first study established initial feasibility in a neurology service within a specialist paediatric hospital. The second study built on this by offering the screening programme within both the specialist hospital and several paediatric epilepsy clinics in general hospitals.

METHODS
Materials
Strengths and Difficulties Questionnaire
This is a commonly used and psychometrically robust measure to identify mental health difficulties, including both emotional and behavioural difficulties. It consists of 25 items, divided into five scales (emotional symptoms, conduct problems, hyperactivity/inattention, peer relation-

Arch Dis Child first published as 10.1136/archdischild-2018-016696 on 11 May 2019

Treatment

- Evidence-based protocols with clinical judgment using an empirically derived algorithm
- Designed to be adapted for a diverse range of children and problems and has a modular design
- Suitable for guided self-help



Guided self-help

- Easier for families who already have a lot of medical appointments
- Economical and increases access (Williams & Martinez, 2008)
- With guidance, as efficacious as face-to-face therapy for anxiety and depression (Cuijpers et al., 2010)
- Effective in adults with physical illnesses (Cuijpers et al., 2008)



Help for Parents

One-on-One Time

Getting Started

1. You can either schedule a regular time together each day, or just try to find a time each day when your child seems to be enjoying a play activity alone. If scheduling one-on-one time, start by asking your child what he or she would like to do together. If one-on-one time is unscheduled, wait until you notice your child playing in a positive way.
2. Next, join in the child's play. Do not try to do one-on-one time when you are upset, busy with something else, or planning to leave the house soon for an errand or trip, as your mind will be preoccupied, and the quality of your attention to your child will be poor.
3. No other children should be involved in one-on-one time. If you have other children in your family, either have another caregiver look after these children while you play with your child or choose a time when the other children are not likely to disturb your one-on-one time with this child.
4. Relax! Casually watch what your child is doing for a few minutes, and then start some positive interactions (see **What to Do**, below) when your child seems to have noticed you and seems open to your attention. The main idea is to have fun with your child.



What to Do

1. After watching your child's play, begin to describe out loud what your child is doing. In other words, narrate your child's play in a way that shows your child that you find his or her play interesting. You can think of yourself almost as a sportscaster describing a baseball or football game over the radio. Try to make your tone of voice exciting and action-oriented, not dull or flat.
2. Now and then, you can also provide your child with positive statements of praise, approval, or positive feedback about what you like about his or her play. Be accurate and honest, not excessively flattering. For instance, you might make comments like "I like it when we play quietly like this," or "I really enjoy our one-on-one time together," or "Look how nicely you've built that!" Try to be very specific about what you like.
3. Try to be as immediate as possible with your approval when you notice something good.
4. If your child begins to misbehave, simply turn away and look elsewhere for a few moments. If the misbehavior continues, then calmly tell your child that one-on-one time is over and leave the room. Tell your child you will play with him or her later when he or she can behave nicely. If the child becomes extremely disruptive, destructive, or abusive during play, use the other skills that you would typically use at those times.

What Not to Do

Do not ask questions. Do not give instructions. Do not criticize. One-on-one time is not the time to teach your child anything new, like how to build something higher or draw something better. If you just pay attention and provide lot of description or praise, your child will be learning a lot. It is never a good idea to give backhanded compliments like, "I see that your construction is the lines. Why couldn't you do that more often?"

Sticking with It

This skill is easy to read about, but it is not always easy to do, especially at first. Many parents make mistakes during the first few playtimes, usually by giving too many instructions, asking too many questions, or not making enough positive comments to the child. Don't worry about making such mistakes. Just try again the next time. If possible, each parent should spend 15 minutes with the child in one-on-one time. During the first week, try to do this every day or at least 5 times a week. This may sound like a lot, but it will get the best results and be the most rewarding in the long run. After the first week, try to have one-on-one time 3 to 4 times each week. You may want to spend one-on-one time with the other children in your family once you feel things are going well with this child. One-on-one time should become a part of your natural routine—you shouldn't ever have to stop once you start doing this together, and over time, you probably won't want to.



Examples of Ways to Show Approval

NONVERBAL	VERBAL
Hug	"I like it when you ..."
Pat on the head or shoulder	"It's nice when you ..."
Affectionate rubbing of hair	"That was terrific the way you ..."
Placing arm around child	"Great job!"
Smiling	"Nice going!"
Giving a "thumbs-up" sign	"Terrific!"
A wink	"Super!"
High five	"Fantastic!"
	"Wow, I never knew you could do that!"
	"Beautiful!"
	"Wow!"
	"What a nice thing to do."
	"You did that all by yourself. Way to go!"
	"I am very proud of you when you ..."
	"I always enjoy it when we ... like this."

Case 1

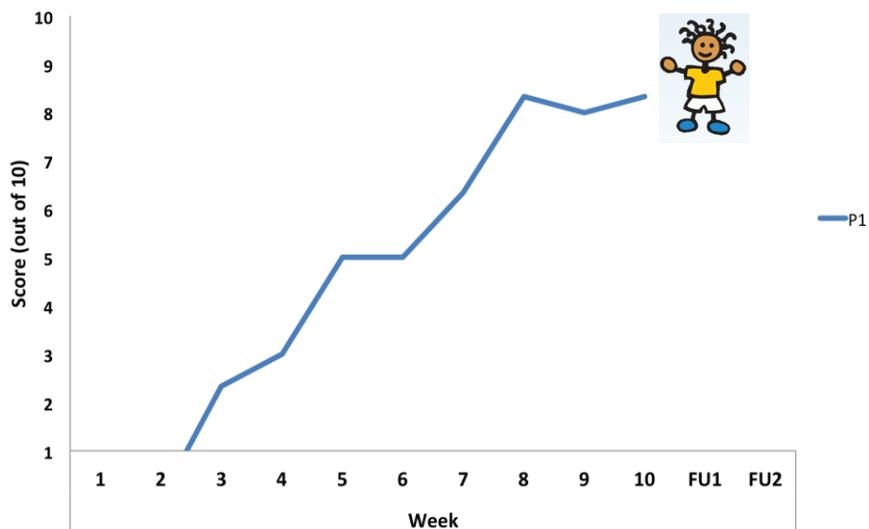


- 12 year old boy. Focal epilepsy. Autism spectrum disorder

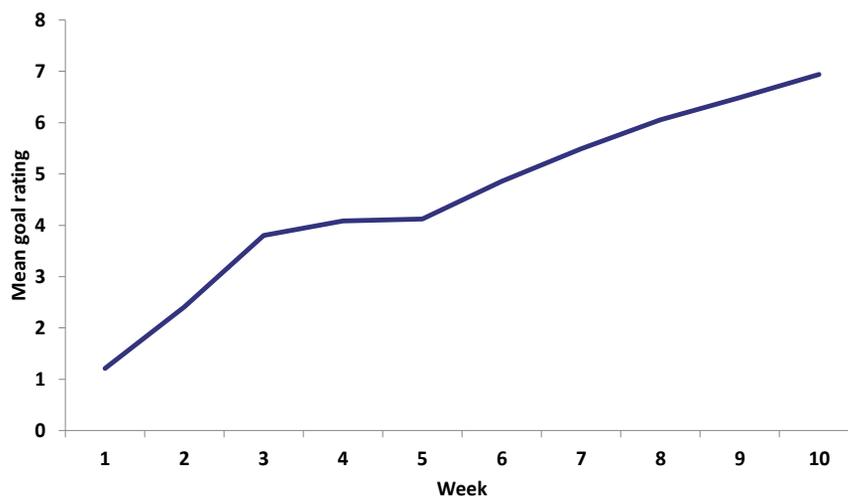
<p style="text-align: center;">1. Not having a tantrum or being able to accept when you say no</p>	<p style="text-align: center;">2. Being able to stop things mid-routine without having a tantrum/getting upset</p>	<p style="text-align: center;">3. Being able to choose food or have food chosen) from a menu at a restaurant without getting upset</p>
--	--	--

- **Strategies:**
 - Behaviour

Results: Goal Based Outcomes



Impact of intervention on goals (n=28)



Qualitative results (n=27 interviews)



Summary so far...

- **Standard psychological/behavioural interventions have beneficial impact on diagnosis, goals and symptoms**
- **No need for major adaptation of standard evidence based treatments and families considered the strategies to be suitable**
- **These methods are adaptable to the specific needs in even a severe epilepsy surgery group**
- **5yr year NIHR Programme Grant**

The MICE Study (Mental health Intervention for Children with Epilepsy)

- As a result of pilot: intervention telephone based but fully integrated within epilepsy services
- Who can deliver the intervention and knows about epilepsy?
- As not previously trained in mental health intervention, need to make tailoring to epilepsy explicit – epilepsy specific module/examples



Design

- 4 phases:
 - 1. Development of epilepsy-specific module
 - 2. Training services to deliver the intervention
 - 3. Randomised Controlled Trial, with quantitative and health economic evaluation
 - 4. Qualitative outcome and process evaluation



Development informed by...

- Theory/literature, Patient and Public Involvement Research Advisory Groups, Health Professionals Advisory Groups, Qualitative interviews



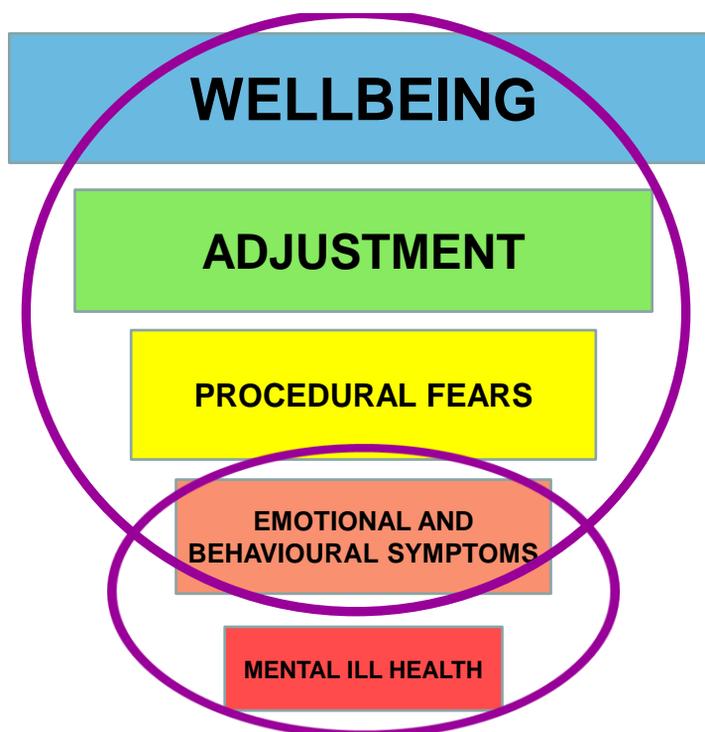
Tip 6

- Make as many friends as you can along the way – but don't occasionally be afraid of being bloody-minded.....

Psychological Wellbeing and Mental Health Drop-In Centre at Great Ormond Street Hospital for Children

Research project funded by
Beryl Alexander Trust





BACKGROUND



AIMS

- Evaluate the usefulness of a Psychological Wellbeing and Mental Health Drop-In Centre at GOSH
- Evidence-based interventions for emotional and behavioural difficulties
- Children, siblings, parents and carers at GOSH only

BACKGROUND



FOCUS:

- Early intervention
- Subthreshold cases
- ‘Low intensity’ evidence-based, stepped care
- Liaison and referral
- Integration with existing services not duplication of involvement

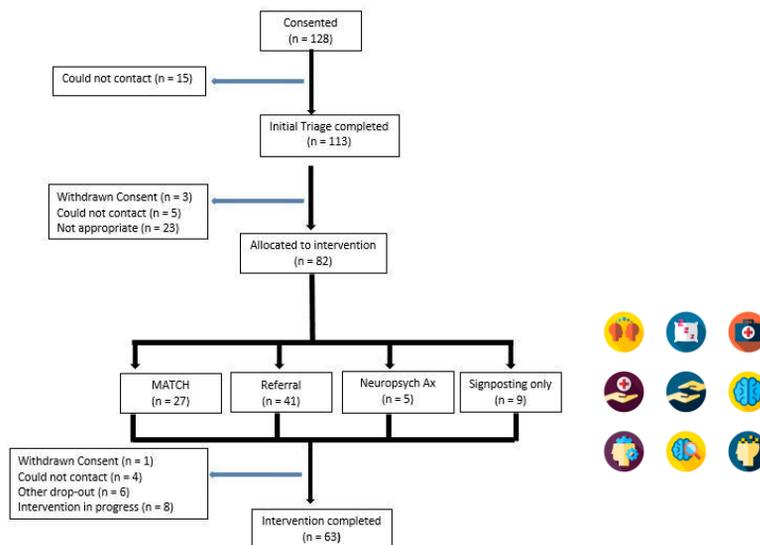


Progress: evaluation of need cont.

- Symptom severity: *Booth purchased*
 - 75% young people in clinical range on SDQ
 - 50% parents – caseness for anxiety
 - 30% parents – caseness for depression
- Conclusions:
 - Unmet need
 - Common mental health difficulties (*anxiety, sleep, behaviour*)
 - Potential for low-intensity interventions



Progress: total numbers for phase 1



Progress

- <https://gopsychmed.wixsite.com/drop-in-centre>

Official Project Launch

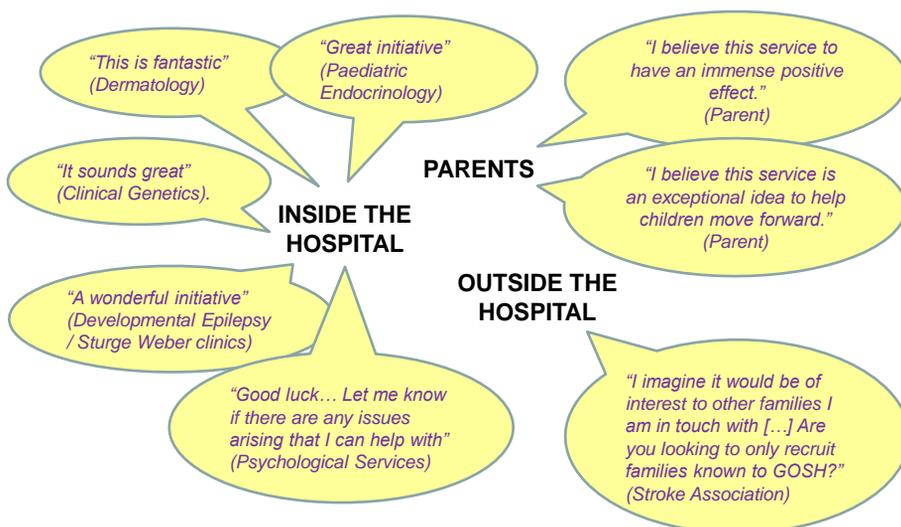
On the 22nd January we officially launched the Lucy Booth Drop-In Centre with a grand opening in the reception of GOSH.



Tip 6

- Have fun

Progress: feedback to date



Present focus: main phase of study

- Treatment outcomes
- Impact on mental and physical health
- Participant satisfaction
- Cost-effectiveness



2018

Psychiatric team of the year - children and adolescents: Psychological Medicine Team, Great Ormond Street Hospital



This team puts 'No Health Without Mental Health' into practice by fully integrating physical and mental health care in a children's hospital. Early detection and effective treatment of mental ill-health in children with physical illness is also the subject of their clinical research programs. Accessible, cost-effective and flexible stepped care models are evaluated with the aim of wide dissemination.



The judges said, "Although we had a number of truly excellent submissions this year, the judges were unanimous in their decision regarding this winner. This application was judged to have outstanding contributions in all domains. This is a model team, exceptionally led and productive both clinically and academically. We were impressed by the teams commitment to providing accessible, effective, evidence-based treatments for improving the mental health of children and young people with physical health problems with a number of innovative projects and research studies.

For example, the Lucy Project was set up as a self-referral Mental Health and Psychological Wellbeing Drop in Centre at Great Ormond Street Children's Hospital, an excellent example of breaking down barriers and increasing access to help for children and families."

Conclusions

- **Integrating physical and mental health care optimises early detection and intervention**
 - Emotional & behavioural problems are common
 - Mental health problems contribute to overall level of disability
 - All children must have easy access to effective, evidence based treatments for psychiatric disorder
 - Preliminary evidence suggests detection and integrated treatment in childhood improves prognosis
 - Need for further research and treatment trials

