



# Improving Healthcare for Children and Young People with Intellectual and Developmental Disability

Reflections into the past, present and envisioning the future

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Senior Staff Specialist  
Child Development Unit  
Former Team Lead  
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Sydney Children's Hospitals Network

Have you ever encountered a healthcare experience with your child or young person where safety or quality of care was a concern?





**Acknowledging our working group  
Intellectual Disability Education Academic and Liaison Team**



# Pioneer in Patient Safety



# Complex Adaptive System

Braithwaite J 2018: BMJ (Health Foundation QI Series)

60% Level 1 evidence 30% Waste 10% Adverse Events

Reductionist approaches have not worked

Batalden and Davidoff (2007) - change is dynamic, needs to be intrinsic, informed by co-production

Jorm, C., Iedema, R., Piper, D., Goodwin, N., & Searles, A. (2021) "Slow science" - "meeting clinicians at the front line"

# Intellectual Disability Health: Challenges

Iacono et al. *BMC Health Services Research* 2014, **14**:505  
<http://www.biomedcentral.com/1472-6963/14/505>



RESEARCH ARTICLE

Open Access

## A systematic review of hospital experiences of people with intellectual disability

Teresa Iacono<sup>1\*</sup>, Christine Bigby<sup>2</sup>, Carolyn Unsworth<sup>3</sup>, Jacinta Douglas<sup>4</sup> and Petya Fitzpatrick<sup>2</sup>

### Abstract

**Background:** People with intellectual disability are at risk of poor hospital experiences and outcomes. The aims were to conduct a content and quality review of research into the acute hospital experiences of both people with intellectual disabilities and their carers, and to identify research gaps.

**Method:** A systematic search was conducted of primary research between 2009 and 2013 that addressed the experiences of the target group in general acute care hospitals. Quality appraisal tools yielded scores for quantitative and qualitative studies, and overarching themes across studies were sought.

**Results:** Sixteen studies met inclusion criteria. Quality scores were 6/8 for a survey, and 2/11-9/11 (mean =5.25) for qualitative studies/components. Content analysis revealed seven over-arching themes covering individuals' fear of hospital encounters, carer responsibilities, and problems with delivery of care in hospitals including staff knowledge, skills and attitudes.

**Conclusions:** Our review of eligible papers revealed that despite 20 years of research and government initiatives, people with intellectual disability continue to have poor hospital experiences. The need for research to identify and investigate care at specific points of encounter across a hospital journey (such as admission, diagnostic testing, placement on a ward, and discharge) as well as to include people with a diversity of disabilities is discussed in terms of potential to influence policy and practice across health and disability sectors.



# Children Intellectual Disability & Healthcare

## Inequities in quality and safety outcomes for hospitalized children with intellectual disability

LAUREL MIMMO<sup>1,2</sup>  | REEMA HARRISON<sup>3</sup>  | JOANNE TRAVAGLIA<sup>4</sup>  | NAN HU<sup>5</sup>  | SUSAN WOOLFENDEN<sup>5,6</sup> 

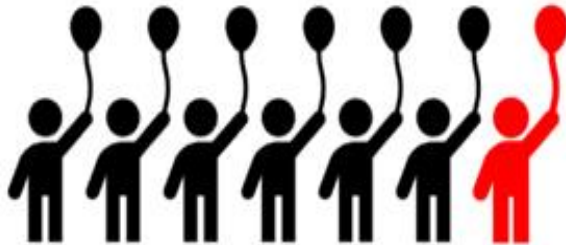
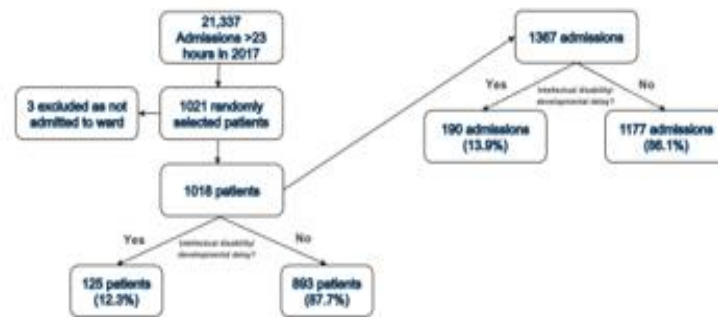
**1** School of Population Health, Faculty of Medicine, University of New South Wales, Sydney, New South Wales; **2** Clinical Governance Unit, The Sydney Children's Hospitals Network, Sydney, New South Wales; **3** Health Management Programs, Faculty of Medicine, School of Population Health, University of New South Wales, Sydney, New South Wales; **4** Faculty of Health, Centre for Health Services Management, University of Technology Sydney, Sydney, New South Wales; **5** Faculty of Medicine, School of Women's and Children's Health, University of New South Wales, Sydney, New South Wales; **6** Community Child Health, Sydney Children's Hospital, Randwick, Sydney, New South Wales, Australia.

Correspondence to Laurel Mimmo at c/o Clinical Governance Unit, Level 0 South, Sydney Children's Hospital, High Street, Randwick, NSW, Australia 2031. E-mail: laurel.mimmo@health.nsw.gov.au

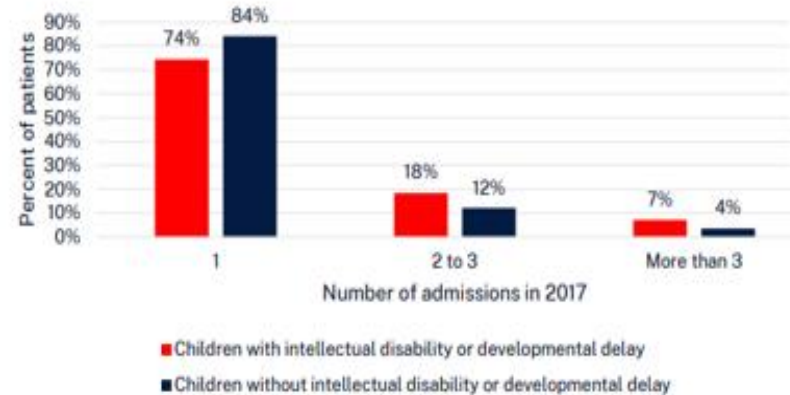
This original article is commented by Tenenbaum on page 279 of this issue.

Retrospective chart review – random sample of SCHN admits >23 hours in 2017.

### Prevalence and health utilisation



### Number of admissions for children with and without intellectual disability in 2017 of >23hrs to SCHN



### Admissions with reported clinical incidents\*



\*p-value: 0.06

For children with intellectual disability: 21.5 hours greater median length of stay ( $p=0.001$ ); \$3098.42 greater median cost of admission ( $p=0.001$ ); overrepresented in IIMS ( $p=0.06$ ).

# Patient Safety Issues for children and young people with intellectual disability

Received: 29 November 2021 | Accepted: 14 April 2022  
<https://orcid.org/0000-0002-0962-443X>  
 DOI: 10.1111/dmch.12202



## ORIGINAL ARTICLE

### Reported clinical incidents of children with intellectual disability: A qualitative analysis

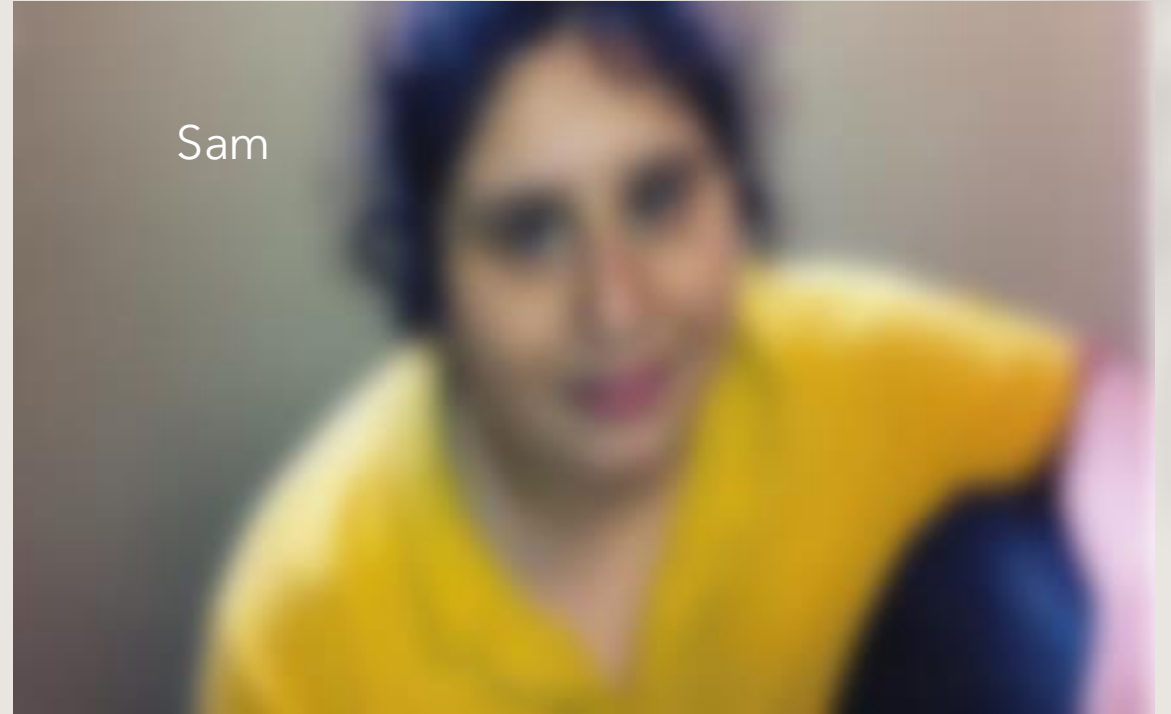
Natalie Ong<sup>1,2</sup> | Laurel Mimmo<sup>3,4</sup> | Diana Barnett<sup>2</sup> | Janet Long<sup>5</sup> | Janelle Weise<sup>6</sup> | Merrilyn Walton<sup>1</sup>



Categories (derived from the open-ended text of IMS reports)	Total number of incident reports for children with intellectual disability (n=440), <sup>a</sup> n (%)	Total number of incident reports for children without intellectual disability (n=167), <sup>a</sup> n (%)	$\chi^2$	p
Medication-intravenous fluid issues	19 (43.18)	60 (35.97)	0.782	0.376
Communication failure	7 (15.91)	19 (11.38)	0.662	0.415
Equipment issues	7 (15.91)	28 (16.76)	0.0185	0.891
Care issue identified by parent	6 (13.63)	8 (4.79)	4.398	0.035
Delayed, wrong, missed, diagnosis or treatment	6 (13.63)	31 (18.56)	0.584	0.444
Deterioration of state not picked up in timely way	3 (6.81)	5 (2.99)	1.396	0.237
Documentation	3 (6.81)	13 (7.78)	0.046	0.829
Forms labels and wrong patient information	3 (6.81)	12 (7.18)	0.0071	0.932
Process issue	2 (4.54)	13 (7.78)	0.553	0.456
Blood products	1 (2.27)	11 (6.58)	1.208	0.271
Fall or injury	1 (2.27)	5 (2.99)	0.006	0.797
Total safety events	58 (31.81 >1 incident)	205 (22.7 >1 incident)		



Reflections on the past



Sam

# Service Gap

- **No Road Map**
- **Not many services skilled- reasonable adjustments**



• Photos provided by Unsplash

- **Shift from Reductionism**
- **Self-organizing systems**
- **Resilient medical organisations capable of complex problem solving**

OPINION ARTICLE

## **Continuing Professional Development through the lens of complexity science: Becoming agents of change in the healthcare system**

Natalie Ong<sup>1</sup>, Janet Long<sup>2,4</sup>, James Woodruff<sup>3,5</sup>

<sup>1</sup>Children's Hospital at Westmead Clinical School

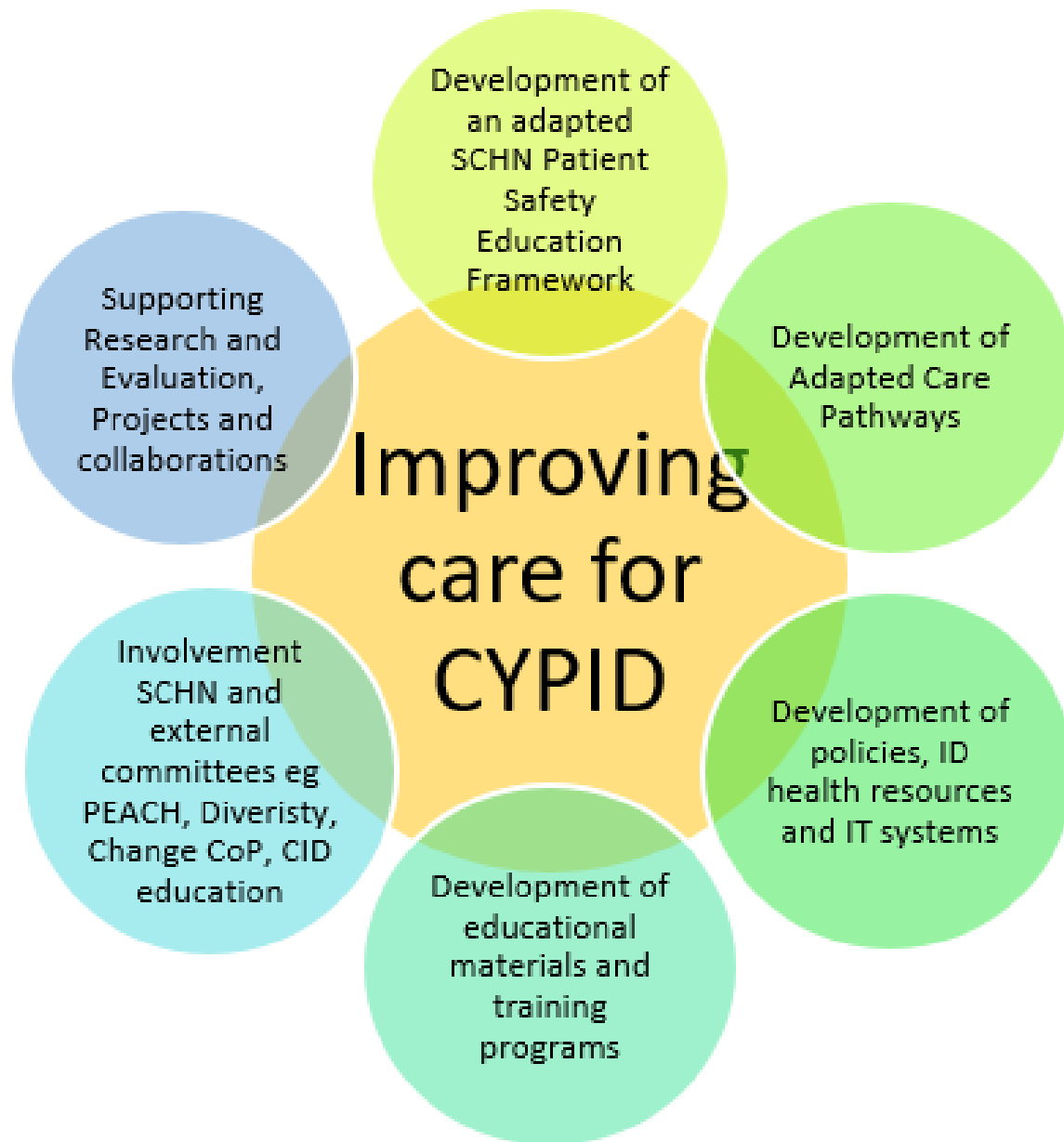
<sup>2</sup>Australian Institute of Health Innovation

<sup>3</sup>Australian Institute of Health Innovation

<sup>4</sup>Pritzker School of Medicine

<sup>5</sup>Pritzker School of Medicine





# Putting into action

## Adaptive Care Pathways

- Quiet Pathway
- Difficult to Vaccinate Pathway

## Training and Education

- Motivated for Change

## Identification in electronic systems

- All About Me tile



# Adaptive Care Pathways

Quiet Pathway  
Difficult to Vaccinate Pathway

## Adaptive Care Pathways

- Quiet Pathway
- Difficult to Vaccinate Pathway

## Training and Education

- Motivated for Change

## Identification in electronic systems

- All About Me tile

A photograph of a hospital entrance. In the foreground, a man in a blue surgical cap and gown is talking to a woman in a brown coat. A young boy in a blue jacket is holding the hand of a man in a black vest and cap. The background shows a modern building with large windows and a sign that says "Children's Hospital".

# The Perioperative Quiet Pathway

Department of Anaesthesia

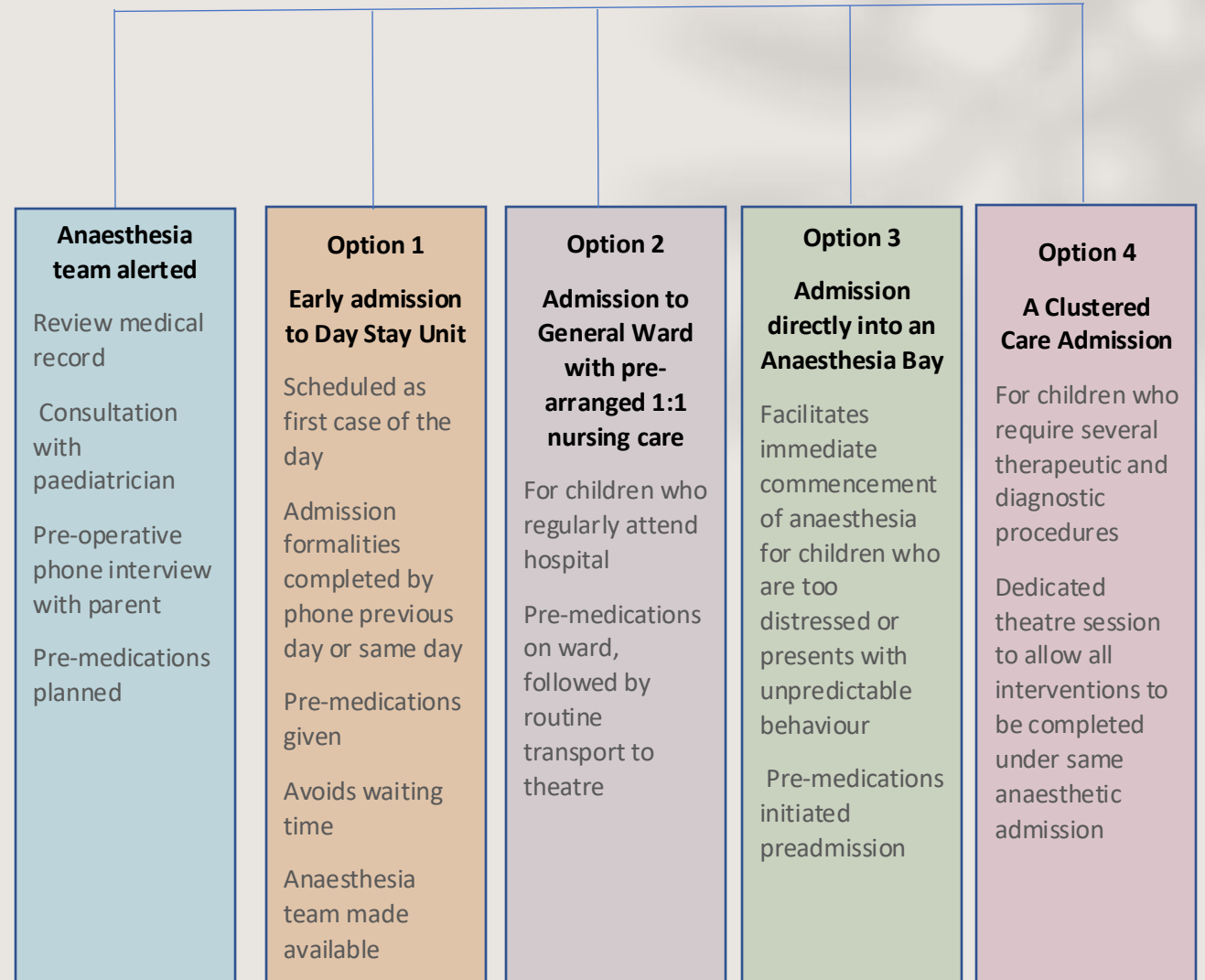
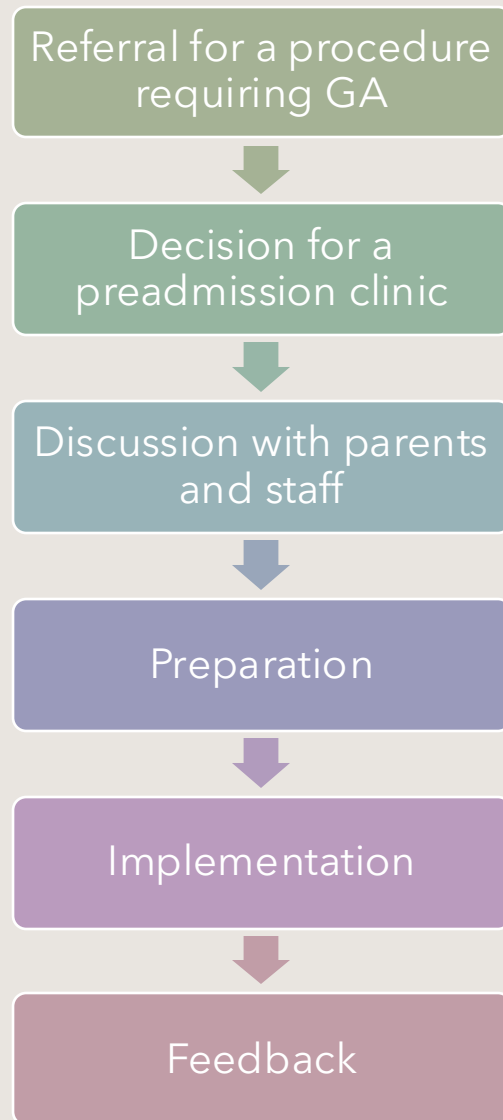
Middleton Ward

Patient Flow

General Medicine

Facilitated by CDU

# Perioperative Quiet Pathway







# The Quiet Pathway experience and support for families

## Support provided during admission

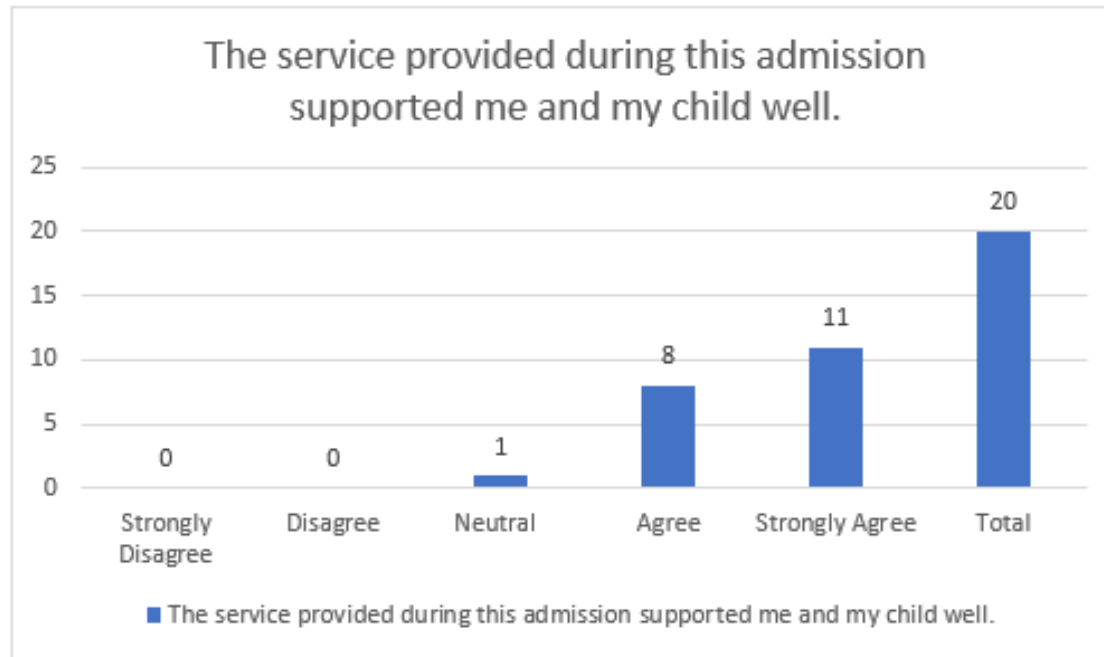


Figure 2 Support provided during admission

Research Feature

JOURNAL OF PERIOPERATIVE PRACTICE

**fpp**  
The Association for Perioperative Practice

Journal of Perioperative Practice  
1-11  
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Sage

### Perioperative pathways for children with neurodevelopmental conditions and behaviours that challenge: An evaluation of parent experiences for service improvement

Natalie Ong<sup>1,2</sup>, Hema Ahuja<sup>2</sup>, Jonathan de Lima<sup>3</sup>, Gail Tomsic<sup>2</sup>, Pankaj Garg<sup>4,5</sup>, Natalie Silove<sup>2</sup>, Bobbi Henao Urrego<sup>6</sup> and Andrew Weatherall<sup>1,7</sup>

**Abstract**  
Previous research shows that children and young people with neurodevelopmental conditions experience greater challenges accessing care in hospitals and having their health needs met. **Aim:** To elicit experiences of parents of children with neurodevelopmental conditions using a new perioperative pathway. **Method:** Parents of children accessing an adapted perioperative clinical pathway in a tertiary children's hospital between July 2019 and December 2020 were invited to participate. A mixed method study was conducted comprising a short survey questionnaire followed by telephonic interviews. **Results:** From 67 postal surveys sent out, 20 were completed. Six out of 20 parents participated in phone interviews and one parent submitted written prose. Parents were positive about their experiences. Six themes emerged: *Negative past experiences* (highlighting the need for adapted perioperative pathways); *Reasonable adjustments* (improving child and parent's hospital journey); *Facilitating communication, convenience and collaboration*; *Parent's satisfaction and relief*; *Barriers to overcome* and *Areas in need of improvement* were discussed. **Conclusion:** Parents of children with neurodevelopmental conditions report great satisfaction and relief from their experiences of a more efficient, streamlined and stress-free way for their child to have tests or procedures done. Parents report improved communication, convenience and collaboration with staff resulted in timely, safe and high-quality care.

**Keywords**  
Adapted care pathway / Quality and safety / Qualitative research / Neurodevelopmental conditions / Autism spectrum disorder / Developmental disability

Provenance and Peer review: Unsolicited contribution; Peer reviewed; Accepted for publication 22 April 2024.



# = Themes and Quotes

Negative past experiences highlight the critical need for adapted perioperative pathways

Reasonable adjustments improve the child and parent's hospital journey

Things that helped: communication, convenience, and collaboration

Parent's satisfaction and relief for a more positive experience

*“On the day itself, it would not have been possible to have received better medical treatment or care or to have had a better outcome. Everything went as planned without any complications and that is due entirely to the hospital staff. I simply cannot commend them highly enough we are very grateful that they removed so much of the stress from the whole experience.” Participant 2 (p8)*

# So what happened to Sam?

Quiet Pathway Video



## PREPARATION

"By failing to prepare you are preparing to fail."  
Benjamin Franklin

DIYDESPAIR.COM

## The development and evaluation of a vaccination pathway for children with intellectual and developmental disability and needle fear

Natalie Ong<sup>1,2</sup> | Deidre Brogan<sup>3,4</sup> | Abbie Lucien<sup>5</sup> | Shayna Wolman<sup>6</sup> |  
Denise Campbell<sup>7</sup> | Lucy Deng<sup>3,4</sup> | Archana Koirala<sup>3,4</sup> | Pankaj Garg<sup>8</sup> | Ketaki Sharma<sup>3,4</sup>

Susceptible vaccine  
preventable diseases

Often have significant  
needle phobia

Video: COVID 19  
Vaccination Quiet Pathway



# The development and evaluation of a vaccination pathway for children with intellectual and developmental disability and needle fear

## Adaptive Care Pathways

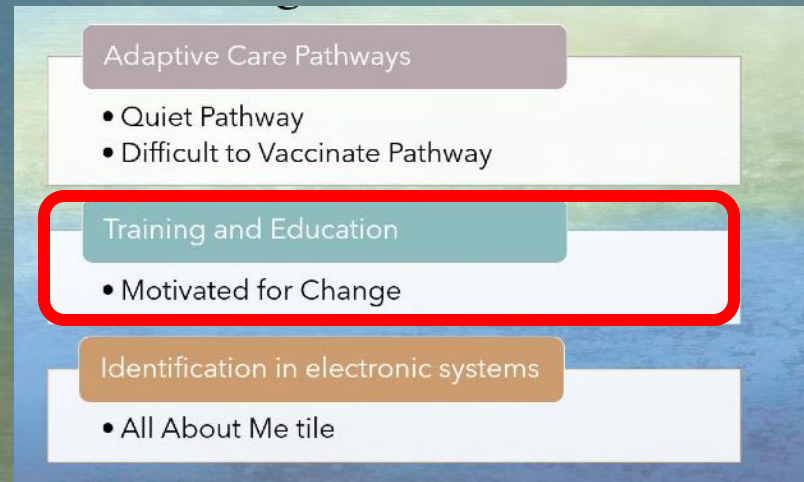
- Quiet Pathway
- Difficult to Vaccinate Pathway

- Co-design and Process Mapping
- Local Champions and Stakeholders
  - Improve quality and safety
  - Ownership and Advocacy

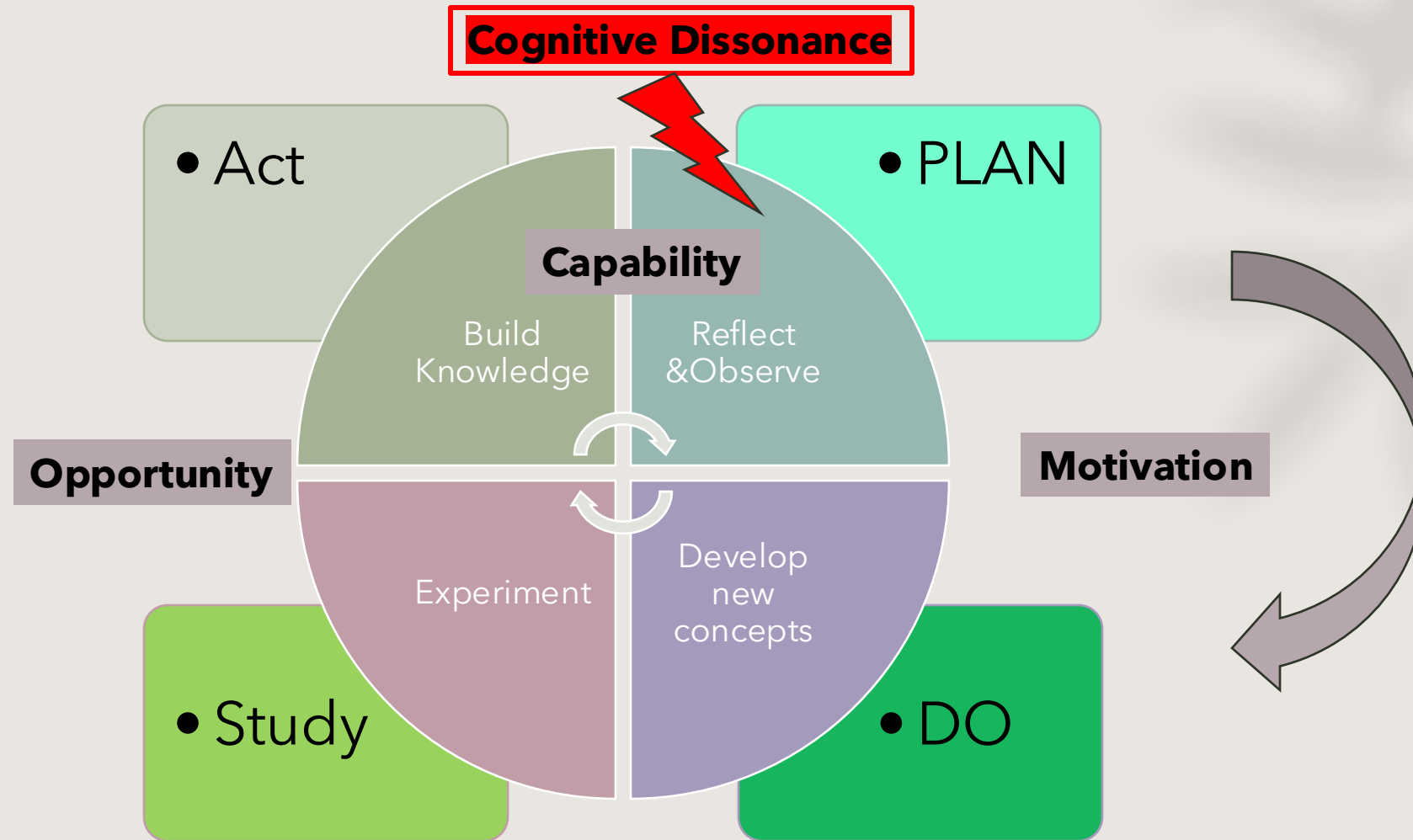


# Training and Education

Motivated for Change Program

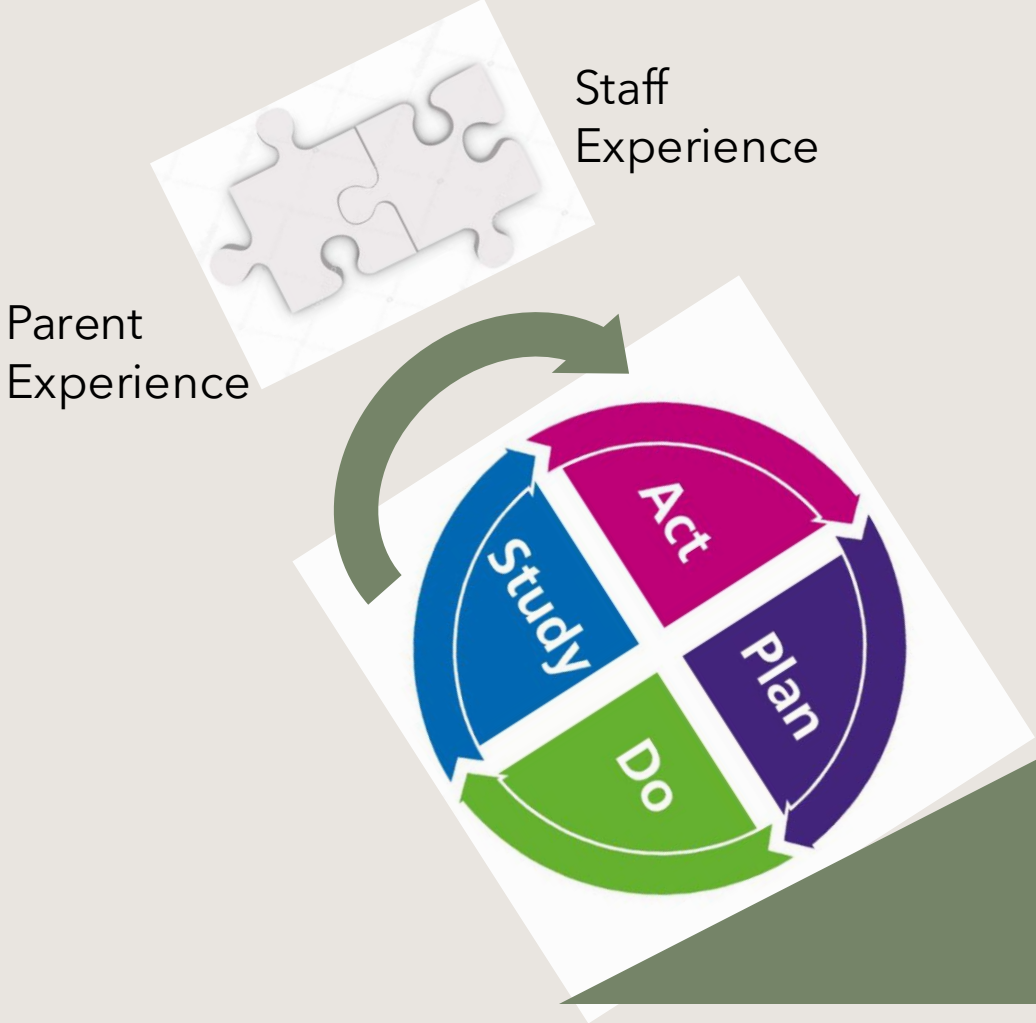


# Motivated for Change Program - Pedagogical Framework



Ong, N., Gee, B. L., Long, J. C., Zieba, J., Tomsic, G., Garg, P., Lapointe, C., Silove, N., & Eapen, V. (2023). Patient safety and quality care for children with intellectual disability: An action research study. *Journal of Intellectual Disabilities*, 27(4), 885-911. <https://doi.org/10.1177/17446295221104619>

# Action Research/ Co- production



Time Period

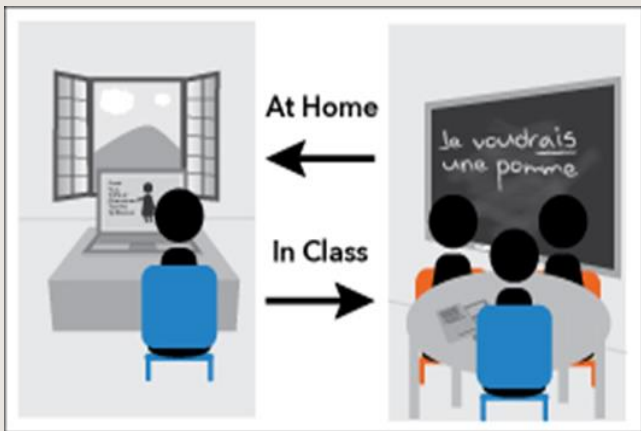


# MOTIVATED FOR CHANGE: Session Structure



## GROUP MOTIVATIONAL INTERVIEW

Engaging and Evoking → Focus and Planning



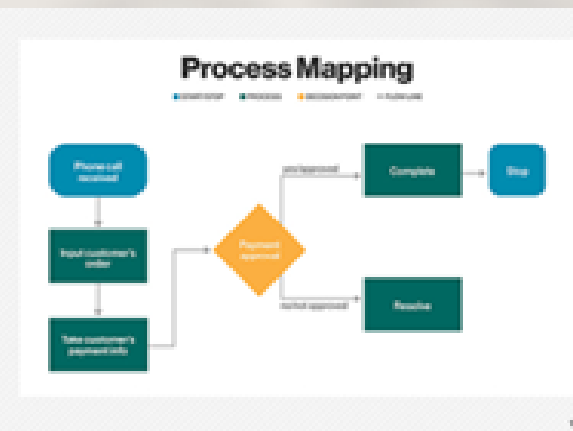
FLIPPED CLASSROOM



GROUP FACILITATION



SIMULATION



PROCESS MAPPING

# Program Evaluation

Improvements in care, adjustments and patient experience

Journal of Intellectual Disabilities

Restricted access | Research article | First published online June 3, 2022

Patient safety and quality care for children with intellectual disability: An action research study

[Natalie Ong](#), [Brendan Loo Gee](#), and [Valsamma Eapen](#) [View all authors and affiliations](#)

[Volume 27, Issue 4](#) | <https://doi.org/10.1177/17446295221104619>



Sleep Unit

Engagement  
Codesign

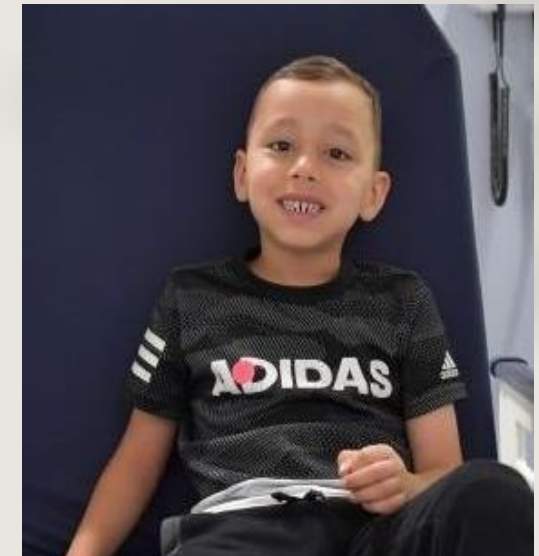


Kids Research

Codesign  
Co-production



Medical Imaging



Emergency

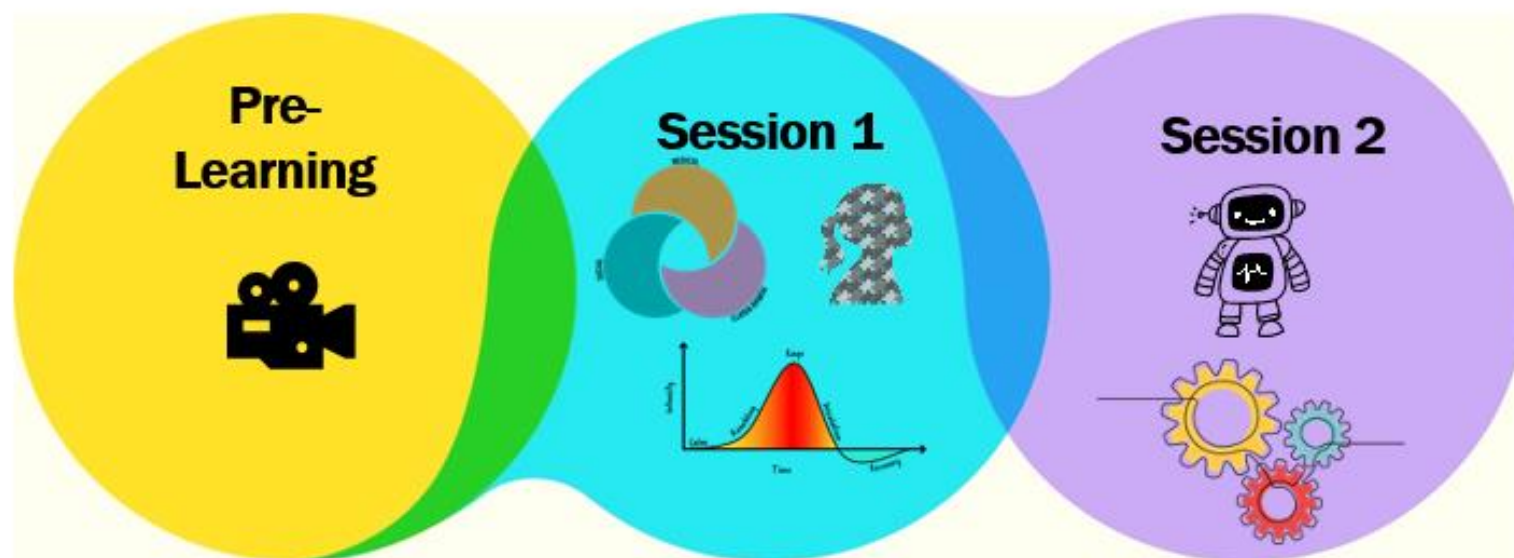
Parent and Staff  
Coproducton



# Motivated for Change ED Journey

Staff and parent  
Survey  
Interviews  
Observations

**EMPOWER AND  
MOTIVATE ED STAFF TO  
BETTER CARE FOR  
CHILDREN WITH  
INTELLECTUAL  
DISABILITY**



**P R A C T I C E**



Leadership meeting February 2023

Project Role Out: March - June



# Significant differences in knowledge, skills and experience in the pre and post intervention scores

	Knowledge	Skills and Experience
Working with people with intellectual disability	Z: -3.40; p<0.001	Z: -3.44; p<0.001
Working with people with intellectual disability and behaviours that challenge	Z: -2.63; p=0.008	Z: -3.09; p=0.002
Working with people with communication difficulties	Z: -3.66; p<0.001	Z: -2.78; p<0.001
Working with strategies to support communication differences	Z: -4.25; p<0.001	Z: -3.49; p<0.001
Working with triggers and causes of behaviours that challenge	Z: -3.46; p<0.001	Z: -3.54; p<0.001
Working with strategies to manage behaviours that challenge	Z: -3.52; p<0.001	Z: -2.65; p= 0.008

# Staff Feedback

## Post intervention



### Success in communication strategies

*The 'one voice' was a good strategy re procedures that I haven't utilised previously.*

*Amazing...even things like, you know, I used One voice. It worked really well.*



### Using reasonable adjustments

*Provide quiet room if available. Get distraction toy/book. Contact child life therapist. Talk to parents about individual needs. Diff - Busy/ no single rooms*

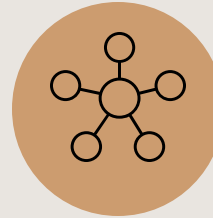
### Improved documentation

*Every time I see it [system alert], and I see that they put history of autism*



### Behaviour curve informs response

*Understanding the body language so like kind of knowing where they are on their on their escalation curve. So what are the signs that they're calm and rumbling ....*

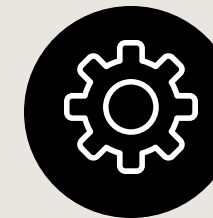


**Aware of impact of procedure on child** ...*we decided like it was a chaotic day, very busy. But we identified that this was a patient who would really benefit from taking the time to make sure that we did this properly because we didn't want to, you know, make it a bad experience for him...[knowing he would return]*



### Integrate into staff orientation

*...possibly like integrating it into the orientation programme of the hospital 'cause. I feel like it's such a great programme that it shouldn't just be ED who's learning about it.*



### Becoming a local champion

*....how to best look after this patient. So everything that I've heard after motivated for change has been implemented, has been positive and that's why I'm so glad to be a part of its implementation as well in our ED.*

# Parent Experiences

Interviews

10x increase in use of reasonable adjustments



## Parents report noticing change

*...we have had reasonable, you know, numbers of interactions in the hospital, so it's very interesting from my perspective to see how things have changed.*



## Use of communication tool

*So she introduced me to this passport profile thing or something that you guys have there, which I thought was brilliant.*



## Improved communication

*I wasn't left wondering why we were sitting there, you know, [un]like my previous experience..*



## More positive experiences

*So from my perspective, we've gone from like, say a two out of 10 up to a 10 out of 10.....*



## Child Engagement

*that's another thing that I really noticed was different. the people were looking at [child]and talking to him...*



## Technical glitches

*Where we need all that information to pop up is not popping up*



35



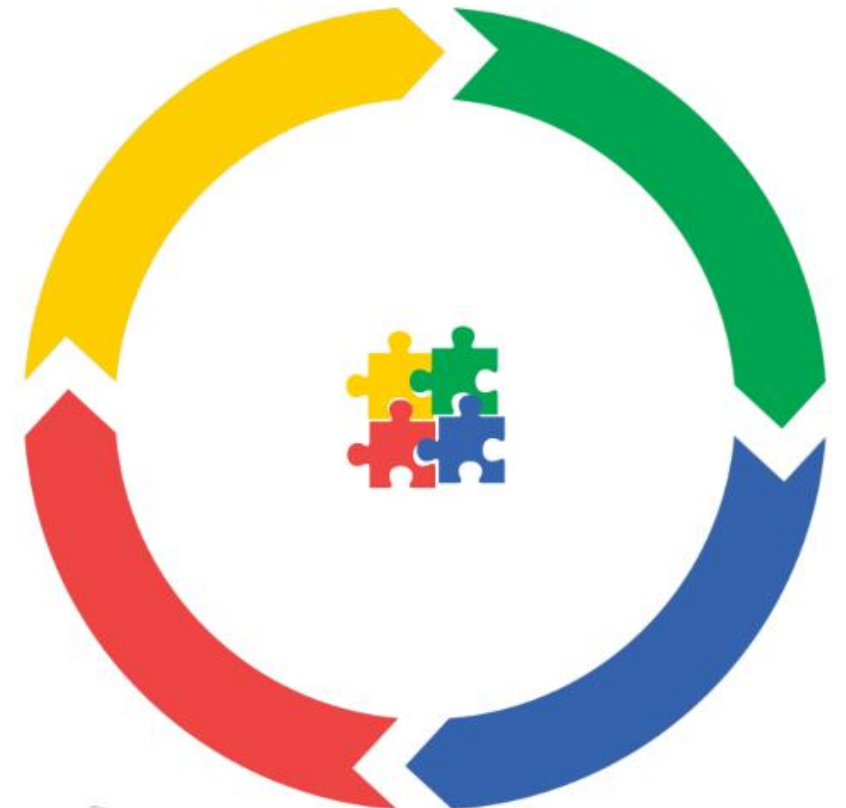
i9 presentation to Joe Smith



“From code  
blacks and  
restraint to  
calm  
cooperation”



# Embedded in ED nursing and medical CPD programs










# Self-Developed Resources

## Top questions to ask

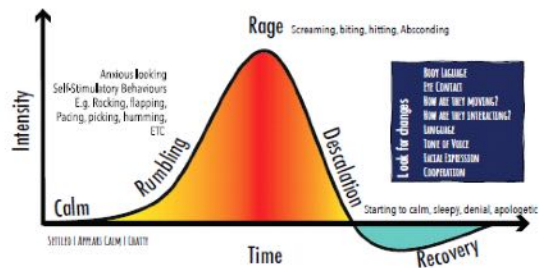
WHEN IDENTIFYING A CHILD WITH NEURODEVELOPMENTAL DISABILITY ASK THESE IMPORTANT QUESTIONS

-  How can we make this visit a success for you and your child?
-  How does your child best communicate?
-  What are your child's likes and dislikes?
-  What does it look like when your child is unsettled & what strategies work to calm them?
-  How can we adjust the environment to make it more comfortable for your child?



## The Escalation Curve

IDENTIFY WHERE ON THE ESCALATION CURVE THE CHILD IS & MAKE SOME REASONABLE ADJUSTMENTS



## One Voice Communication Technique

- ONE VOICE SHOULD BE HEARD DURING THE PROCEDURE | NEED PARENTAL INVOLVEMENT | EDUCATE PATIENT ABOUT PROCEDURE | VALIDATE CHILD WITH WORDS | OFFER MOST COMFORTABLE POSITION | INDIVIDUALISE GAME PLAN | CHOOSE APPROPRIATE DISTRACTIONS | ELIMINATE PEOPLE NOT ACTIVELY INVOLVED

## Reasonable Adjustments

PROVIDING BEST CARE FOR CHILDREN WITH NEURODEVELOPMENTAL DISABILITY IN CWH ED

-  **P** PARENTS & CARERS AS PARTNERS  
Ask carers about their child's specific needs. Partner with them as they know their child best
-  **R** READINESS: PLAN & PREP  
Find out the child's specific needs to help plan and prep for care and health encounter(s)
-  **A** ADAPTATIONS OF PROCESS & SYSTEMS  
Give specific feedback on how ED can continually improve to care for children with neurodevelopmental disability(s)
-  **C** COMMUNICATION OPTIMISATION  
Use developmentally appropriate communication methods e.g. social stories, show tell do, visuals, simple phrases, ONE voice etc.
-  **T** TEAMWORK  
Work together as as a team (Child Life Therapist, nurse, doctor, allied health etc.)
-  **I** IDENTIFY TRIGGERS & DEESCALATION STRATEGIES  
Ask early what are potential triggers and calming strategies specifically for this child. Where are they on the escalation curve?
-  **C** CARE COORDINATION & HANDOVER  
Handover and document reasonable adjustments that have worked or not worked well!
-  **E** ENVIRONMENT MODIFICATION  
Optimise child's surrounding environment to keep them calm and engaged



## STORY BASED GUIDES: Step-by-step story guides for common procedures in ED

Today in ED...

-  I'm going to see a... nurse and doctor 
-  I'm going to have an... X-ray or ultrasound 
-  I'm going to have a... blood test and cannula 
-  I'm going to have... happy gas (nitrous air) 
-  I'm going to have... a CT scan 
-  I'm going to see the... dentist 



Guideline No: 2016-9006 v3  
Guideline: Non-restrictive Practices for Paediatric Inpatients with Co-morbid Intellectual Disability and/or Autism Spectrum Disorder



## NON-RESTRICTIVE PRACTICES FOR PAEDIATRIC INPATIENTS WITH CO-MORBID INTELLECTUAL DISABILITY AND/OR AUTISM SPECTRUM DISORDER

PRACTICE GUIDELINE \*

Guideline No: 2019-121 v2  
Guideline: Pharmacological Strategies for Children with Developmental Disability During Investigations/ Procedures



## PHARMACOLOGICAL STRATEGIES FOR CHILDREN WITH DEVELOPMENTAL DISABILITY DURING INVESTIGATIONS/ PROCEDURES

PRACTICE GUIDELINE \*

# Motivated for Change: Providing Best Care for Children with Intellectual Disabilities in ED

The Sydney Children's Hospitals Network

Finalist: Excellence in the Provision of Mental Health Services Award



## Related links

Meet the other finalists for the Excellence in the Provision of Mental Health Services Award.

[Aboriginal Mental Health Transfer of Care](#) →

[Safe Ways of Working in Wyong Mental Health Inpatient Unit](#) →

[Therapeutic Dragon Taming: Using a Role-Playing Game for Mental Health Recovery](#) →

## Training and Education

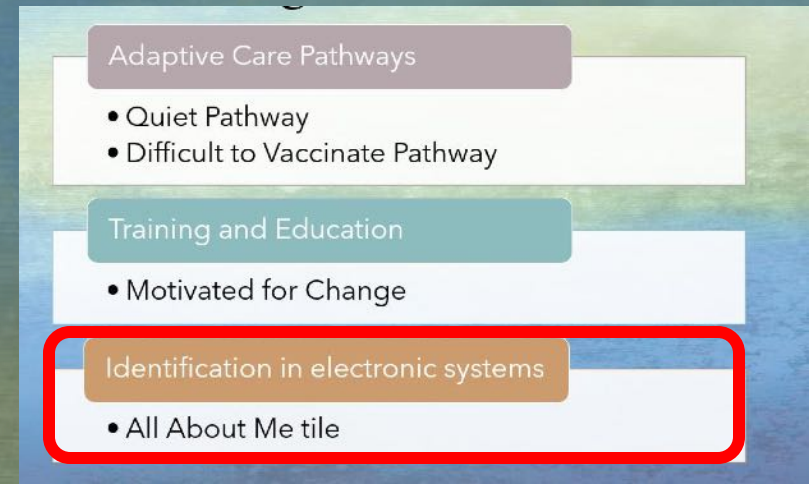
- Motivated for Change

- Behaviour Change Psychology/ Adult Learning Theory/ Quality Improvement strategies
- Emergence Local Champions
- Team capacity to adapt/ solve complex issues
- Sustainability



# Identification in Electronic Systems

All About Me tile



# All About Me

Adapted from ADHC - Child centered information for teachers

## Things to consider

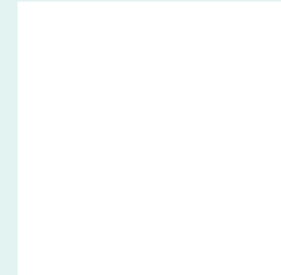
- What helps your child feel reassured and settled?
- Are there any specific behavioural signs or language that indicate feelings or needs?
- How can staff encourage communication and engage your child in activities or procedures?
- Are there any situations that may cause distress to your child?
- What are their “must haves” items or comforters?
- Are there any routines or rituals that staff should be aware?
- What are their favourite books, games, toys etc?



the children's hospital at Westmead

The Children's Hospital at Westmead is part of Sydney Children's Hospitals Network

**My name is:**  
**Name here**

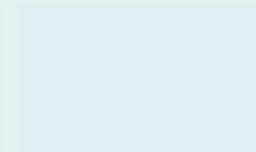
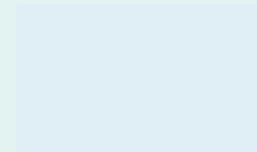


**THESE THINGS ARE THE IMPORTANT THINGS TO KNOW ABOUT ME**

**1**

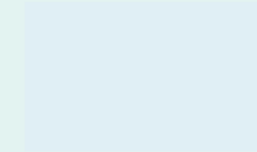
**2**

**3**



**4**

**5**



# Personal Plan/ Hospital Passport

Information about me		
Date of birth		
Medicare number		
Address		
Phone number		
Main contact people Name and phone number	Main carer: _____	Who to contact in emergency: _____
	Key worker: _____	GP: _____
	Person responsible: _____	Other therapists: _____
Religion and cultural requests	<input type="checkbox"/> Aboriginal <input type="checkbox"/> Torres Strait Islander	
	Religion: _____	
	Ethnicity: _____	
	Language: _____	
Allergies		
Current medications	Please include name, dose and frequency of use:	
Current medical conditions	<input type="checkbox"/> Epilepsy	<input type="checkbox"/> Diabetes
	<input type="checkbox"/> Gastrointestinal disorder	<input type="checkbox"/> Breathing problems
	<input type="checkbox"/> Other: _____	<input type="checkbox"/> Heart condition
Current treatment plan	Please include any medical treatment plans:	
Blood group (if known)	<input type="checkbox"/> A positive	<input type="checkbox"/> B positive
	<input type="checkbox"/> A negative	<input type="checkbox"/> B negative
	<input type="checkbox"/> AB positive	<input type="checkbox"/> O positive
	<input type="checkbox"/> AB negative	<input type="checkbox"/> O negative
		<input type="checkbox"/> Unsure
Consent for medical procedures	<input type="checkbox"/> Understand most concepts and am able to consent	
	<input type="checkbox"/> Understand most concepts but am not able to consent	
	<input type="checkbox"/> Need parents/carers to consent on my behalf	
	Name of person consenting on my behalf: _____	

## This is my Health Passport

*Capturing important information about me and my health care needs.*

If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me. It needs to be available to staff and a copy should be put in my notes.

My name is:

Nursing and medical staff please look at my passport before you do any interventions with me.

I am NDIS registered:

Date completed:  Completed by:

This document belongs to me. Please return it to me or my carer.

Central Manchester University Hospitals NHS Foundation Trust

Royal Manchester Children's Hospital

**Reasonable Adjustments Required**  
**Person Centred Assessment of Child's Individual Specific Needs**

(To be placed on the front of Child's notes/care plan)

Patient's Name ..... Hospital No ..... Clinician .....

Patient with Autism  Learning Disability  Medical Complexity

Communication Flag requested on  PAS  Bedman  Other

Reasonable Adjustments Completed: Yes  No  PCA Enclosed: Yes/No

Translator/Interpreter required Yes/No Requested Yes/No/ N/A

Date to be Admitted/Seen .....

Ward/Area .....

Actions Required .....

Room required due to individual sensory needs

**Important points to be Aware of on Admission or Appointment :**

**Red High Priority /Dislikes**

.....

.....

.....

**Amber Medium priority**

.....

.....

.....

**Green Likes/Interests**

.....

.....

.....

**Assessment Completed Via:**

Telephone  Ward/Department  Other

Parent  School/Nursery/Senco  Learning Disability Nurse

Signed ..... Name .....

Professional Status ..... Date Completed .....

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## ORIGINAL ARTICLE

# To flag or not to flag: Identification of children and young people with learning disabilities in English hospitals

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## Abstract

**Background:** Children and young people with learning disabilities experience poor health outcomes and lengthier hospital admissions than those without learning disabilities. No consistently applied, systematic approach exists across the NHS to identify and record this population. This paper describes practices in English hospitals to identify children and young people with learning disabilities.

**Method:** Interviews: 65 NHS staff. Questionnaire: 2,261 NHS staff. Conducted across 24 NHS hospitals in England.

**Results:** No standardized approach exists to identify children or young people with a learning disability or for this information to be consistently recorded, communicated to relevant parties within a hospital, Trust or across NHS services. Staff reported a reliance on parents to inform them about their child's needs but concerns about "flagging" patients might be a significant barrier.

**Discussion:** Without an integrated systematic way across the NHS to identify children with learning disabilities, their individual needs will not be identified.

## KEYWORDS

children, hospitals, identification, learning disabilities, UK

Many publications citing the importance of a flagging system

Need for reasonable adjustments


Accepted: 26 August 2017

DOI: 10.1111/jar.14065

## ORIGINAL ARTICLE

WILEY Journal of Clinical Nursing

## Hospital passports, patient safety and person-centred care: A review of documents currently used for people with intellectual disabilities in the UK

Ruth Northway PhD, MSc, RN, Professor<sup>1</sup>  | Stacey Rees MSc, BSc, RN, RCBC PhD student<sup>1</sup>  | Michelle Davies BSc, RN, Health Liaison Nurse<sup>2</sup> | Sharon Williams BSc, RN, Service Improvement Lead - Learning Disabilities<sup>3</sup>



# Getting it online Recruit allies



- Digitizing
- Clinical Systems Governance: “too many alerts”
- PEACH project focus groups lobby
- Embedded in November 2023 >260 completed (80% met min standards) various depts



***“ I know when staff have read the TOP 5 and when they haven’t”***

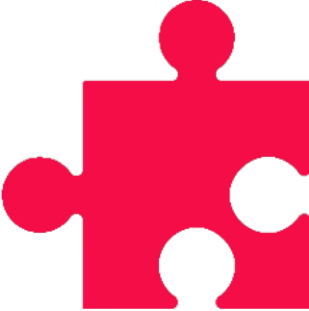


# SYSTEM ALERTS and DOCUMENTATION

- ED View
- BTF Observation Chart
- Management Plans
- Results
- Orders + Add
- ED Quick Orders
- Order Status & Results
- Medication List + Add
- Medication & Fluid Monitoring
- MAR
- MAR Summary
- Medications Request
- ContinuousDoc
- Documentation + Add
- Interactive View and I&O
- Visit List & Demographics
- Allergies + Add
- Clinical Notes
- Clinical Trials
- Form Browser
- Growth Charts
- Histories
- Imaged Documents
- Immunisation History
- Problems, Alerts and Diagnoses
- Summary Visits
- Task List
- Coding Summary
- Flowsheet

ED Summary | ED Assessment | ED Discharge | Summary Visits | ED CHW Quick Orders

### All About Me: Top 5



#### Top 5 Tips for Support

Tips charted 07/11/2023 14:22

1. I dont like loud noises
2. I like deep pressure hugs - it settles me
3. When im unsettled I pace, scream and display aggressive behaviours
4. Music helps settles and calms me
5. I communicate with pictures, gestures and communication device

#### Current Documentation

[Top 5 Tips for Support](#) (07/11/2023 14:22)

#### Add New Documentation

Chart New [Top 5 Tips for Support](#)  
Import PDFs to [All About Me: Hospital Passport](#)  
*For importing, in Clinical Notes, select the Import button and the "All About Me: Hospital Passport" Note type*

#### Links

[All About Me - Hospital Passport](#)  
[All About Me - Family Factsheet](#)  
[All About Me - Staff Factsheet](#)

**Allergies (1)** | **Microbiology (0)** | **New Order Entry**

**Alerts (2)** | **Medical Imaging (0)** | **Documents (20)**

Click links to view Management Plans

- Clinical Alerts
  - High Risk of Falls (AL00131)
  - Risk of pressure area (AL00002)
- Non-Clinical Alerts
  - There are no Patient or Social or Admin alerts entered for this patient.

**Diagnoses and Problems (1)**

- Diagnoses (This Visit / Selected Visit)

Diagnosis	Date	Confirmation	Classification
Dental disorder	07/11/2023	Confirmed	ED Medical

Chronic Problems (Across Visits)

**Intake and Output** | **Measurements and Weights (2)** | **Growth Charts**

**Document Launcher**

Select Level1... | Select Level2... | Select Level3...

Please choose an option for each of the menus to display the available documents.

**Lines, Tubes, Drains and Wounds (0)**

**Continuous Infusions (0)**

**Notes/Reminders (0)**

Tracking Board

To Be Seen SCH | PreArrival SCH | xHr Pt List / Clinical Reviews SCH | xHr Pt List SCH | Providers SCH | Reactivate D/C SCH | Pandemic SCH | Disaster SCH  
 All Patients Medical CHW | EDSSU CHW | x Pt List / Clinical Reviews CHW | Providers CHW | To Be Seen CHW | Discharge/Reas

WR:2 Total: 21 Avg LOS: 6.08 | Filter: FT + KCC CHW | Patient: STRATTON, Cooper

Bed	Name	T	R	TBS	LOS	Age/IA	Alerts	Presenting Probl/Pwa	MoC	Dx	BTF	To Do	Done/Comple	PLAN	Medical Imaging	RAT Result	RAT Date
KCC_05	SHAH, Vivan	4		1	1:24	4 yea		Medical assessm									
KCC_01	ORLO, Isma	4		1	2:16	7 yea		Respiratory - cou						Resp RV[]			
FT Wait R	HAN, Samira Jean	4		1	2:25	5 yea		Injury - fracture s						Rpt resp RV 1330[]			
FT Wait R	ALIC, Philip	4		1	2:33	13 ye		Injury - fracture s									
KCC_18	ANEJA, Anush	4		1	2:35	8 yea		Pain, abdominal						CIN[x] declined analgesia			
KCC_17	ZULUETA, Sadie Galu	4		1	2:49	4 mo		Rash, non-specif						TOF[@] Constipation FS[x]			
KCC_16	YAGAR, Talha	4		1	2:54	10 ye		Pain, abdominal						ECCG[x] LMX[]			
KCC_15	ITO, Isis Marley	4		3	3:04	7 mo		Vomiting and dia						TOF[@]			
KCC_03	YKUDI, Kenneth	4		1	3:13	14 ye		Injury - fracture s									
KCC_14	MALAW, Ranna Idris	4		2	3:25	14 mi		Fever						TOF[x]			
KCC_09	REGUID, Hudson Acc	4		1	3:40	6 yea		Pain, abdominal						LMX[]			
KCC_02	ATEL, Krish bhavik	4		1	4:05	11 ye		Injury - fracture s		1 Closed f				Plaster[@]			
KCC_13	ASSANAN, Ibrahim	4		1	4:13	3 yea		FEVER		1 Viral illn				EDSSU for TOF & monitoring			
FT_06	STRATTON, Cooper	4		1	4:30	9 yea		1: DENTAL DISOI		1 Dental d				*NEM* OT 1500 - no consent			
KCC_12	NAND, Rohan Micha	4		1	5:03	9 mo		Fever									
KCC_10	ATF, Mustafa Yousef	4		1	5:03	5 yea		1: ABDOMINAL P		1 Abdomin				Cap IVF 1700			
KCC_07	MARRIS, Leora Lynette	4		1	5:03	3 yea		Fever		1 Fever				DC		Negative*	07/11/2023
KCC_11	SHAH, Divyansh	4		1	5:05	6 yea		VOMITING AND		1 Hypogly		U					
KCC_04	PAREKH, Yash	4		1	16:12	17 mi		FEBRILE CONVI		1 URTI - Ir				Cap IVF once awake[] IVABx CXR[x]		Negative*	07/11/2023
KCC_08	ROBERTSHAW, Sebas	4		1	16:24	3 mo		RESPIRATORY		1 URTI - Ir				Failing TOF?		Negative*	06/11/2023
KCC_06	KARPA, Kiyah Ali	4		1	22:16	3 yea		1: GASTROENTE		1 Gastroe				GenMed making paperwork		Negative*	06/11/2023

## Identification in electronic systems

- All About Me tile

- System alert
- Provide information
  - Transferable
  - Updated



What does the future hold?

# Next Steps: Translation & Scaling

Translation to other LHD/ adult settings

Greater reach: Blended learning and Train the trainer

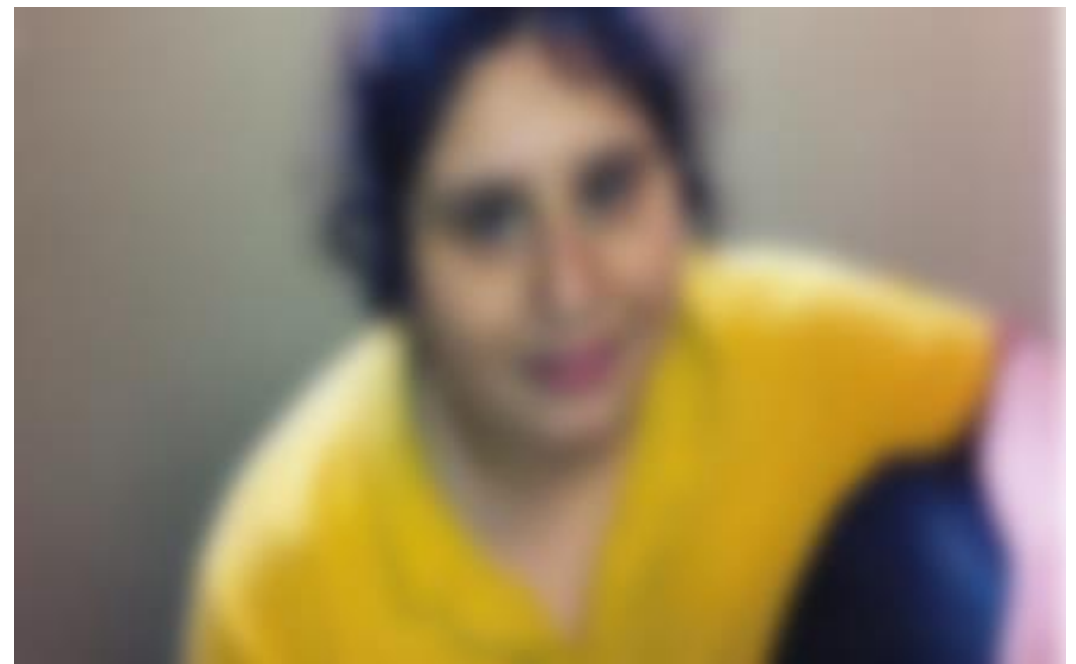
Future Research : Outcomes/ Sustainability/ Diffusion/ Translation

Permanence allows broader service provision



Envisioning the  
future

Sam needs to go to hospital



NSW GOVERNMENT The Sydney children's Hospitals Network

Donate Emergency

Factsheets Find a service Visiting and staying Clinical hub Kids health hub About

Home > Child Development, The Children's Hospital At Westmead

## Child Development Unit, The Children's Hospital at Westmead

### Patient and family resources

It is important to have a local doctor or general practitioner (GP) to support you with the day to day needs of your child and with whom you feel comfortable, and who listens to you and your family.

Make sure you continue to see your child's Pediatrician every 6 to 12 months for ongoing review of your child's development and specialist management.

### Hospital passport

The hospital passport is a way of providing health staff with person-centered information about the child or young person with intellectual disability, Autism or developmental disability, to assist them to access a health care appointment or admission.

This information will help staff to adjust care plans or use reasonable adjustments to engage your child in the health encounter and prepare for their arrival.

### Story resources

Use this resource to help orientate your child when they are coming to an appointment with us.

[Hospital passport](#)

[My personal profile - information sheet for families](#)

[My personal profile - information sheet for professionals](#)

[TOP 5 All About Me - information sheet](#) →

[Visiting the hospital](#)

# Call to Action

- Reach out
  - Like learn more or collaborate
  - Access to our resources
  - Future: CoP



## Acknowledgements

### Children's Hospital at Westmead

Department of Anaesthesia (Perioperative Services)  
Paediatric Emergency  
Specialist Immunisation Team  
Day Stay Ward Staff  
Department of Dentistry  
Department of Medical Imaging/ Kids Research  
Department of General Medicine/ Sleep Unit  
Critical Care Directorate/ ICU  
Executive Office, SCHN

### Parent Advisory Group

Patient Safety for Children and Young People with Intellectual Disability

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Australian Institute of Health Innovation, Sydney Medical School,  
University of Sydney, Australian Commission for Quality and Safety  
in Healthcare  
IDEAL (Intellectual Disability Education, Academic and Liaison -  
Working and Advisory Groups)



# Thank you

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