CB-NSG Sharing best practice

Working document

22nd November 2021

Introduction

At the CBNSG in May 2021, members agreed to develop a CB-NSG document summarising examples of best practice and research when working with children, young people and adults with learning disabilities whose behaviours challenge. The purpose of the document is to keep members informed of best practice and research, which could be used to influence and develop practice in their own area. The document is also intended to connect members who are involved in or developing related areas of practice and will be shared with CB-NSG members, and available on the CBF website.

This working document is for CB-NSG members to contribute to and update as and when appropriate.

If you would like to contribute any examples of best practice / research to this working document please follow this form link.

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PBS toolkit to support children/young people with learning disabilities/autism to access support for hospital procedures

Name	Joann Kiernan
Organisation	Alder Hay / Edge Hill University
Contact email	kiernanj@edgehill.ac.uk
Brief description of best practice example / research project	We are currently involved in the development of a PBS toolkit to support C/YP with an LD/ASC to access support for their hospital procedures. This is a research project funded by the Burdett Trust to look at reducing restrictive practice. Researched based at Alder Hey, Royal Manchester Children's and Edge Hill University
Is your example for children, young people, adults, families?	Children/young people, parents/families
Who has benefited from the good practice?	We will have a 'toolkit' designed for and with C/YP, families and health professionals that they can utilise to support preparation for their visit to a hospital
What outcomes have been achieved (individual or organisational)?	This will be ready for pilot Spring 2022
Top three key findings / learning points from the example or research	Co-production of research methods Co-production of toolkit Collaboration re adoption/ review of toolkit
Any challenges / issues encountered and how they were overcome	COVID has significantly slowed progress of study
Key recommendations on how this practice could be rolled out locally and nationally	Dissemination across all paediatric trusts Publications Via CBF, key parent/carer and YP forums. Via NHSE/I networks LD/ASC acute liaison networks e.g. A2A, paediatric networks Pre reg professional education

Links to further information or resource	The project is ongoing

Investigating why current mental health practice does not always meet the needs of children admitted to inpatient CAMHS

Name	Simon Nielson
Organisation	Edge Hill University
Contact email	simonnielson@gmail.com
Brief description of best practice example / research project	This research shows that current mental health practice does not always meet the needs of children admitted to inpatient CAMHS and that there is more work to be done to understand why this is the case. The findings from this study provide important insight into children's experiences of being physically restrained within inpatient CAMHS. From what children have described, a Child-Centred Model of Experiencing Physical Restraint has been developed and presented as an appropriate model to adopt in understanding behaviour that challenges in contemporary children's mental health services. The feelings of children during the earlier stages of a potential physical restraint incident are that some of the de-escalatory efforts by staff teams are a waste of time. Children felt not listened to, patronised and unsupported, with some of the actions of the staff when a situation was developing being perceived as inflammatory. It is imperative that staff teams who work with children are experienced and knowledgeable enough to be able to de-escalate situations and work towards a reduction of physical interventions, such as physical restraint, in healthcare. The children in this study consistently made reference to how being physically restrained had made the situation feel 'worse' for them. Children perceived the experience of being physically restrained as traumatic and confusing. Therefore, there is a potential for an experience of physical restraint to become an adverse childhood experience. Without a detailed understanding of the nuanced approaches of trauma-informed care, the results for the child of being physically restrained in hospital can make their situation feel worse. When a child is admitted to mental health services, and is subsequently exposed to a traumatic experience, such as being physically restrained, a potentially damaging and traumatic cycle is perpetuated. It is proposed that this would interrupt the delivery of child-centred care, would fail to meet the needs of the child, reduce the level of trust between the child and staff teams and would disrupt the therapeutic environment. Children described situations after they had experienced being physically restrained which they perceived to be negative, unsupportive, confusing and stressful. Children gave detailed examples where they felt that staff teams were not caring towards them, did not demonstrate a positive attitude or were not open-minded.

	The children who participated in this research identified that their perspective of a physical restraint incident differs from what is taught to health professionals by using an adult-focused model. Current models used to underpin training may not adequately address the experiences of children. On this basis, it is reasonable to propose that staff teams working in CAMHS require a specific child-based model to help them to meet the needs of children by appreciating the experience of being physically restrained from the perspective of children. This model, derived from the voiced of the children who participated in this research, is the outcome of this PhD. Adoption of this evidence-based model on a national scale has the potential to make a difference to the experiences of any child or young person who faces the prospect of being physically restrained in healthcare and other services (education, youth justice etc.)
Is your example for children, young people, adults, families?	Children/young people, adults, parents/families
Who has benefited from the good practice?	This model will have the potential to be embedded within inpatient CAMHS but also any service where physical restraint of children and young people may occur as a response to behaviour that challenges or where children are in distress. The model also has the potential to benefit children up to the age of 18 within healthcare services. Embedding the model in contemporary practice will also benefit staff teams as the likelihood is that restrictive interventions, such as physical restraint, will be reduced.
What outcomes have been achieved (individual or organisational)?	As the model has been derived from a PhD which is due to be submitted in December 2021, no outcomes have been achieved as yet other than the emergence of new knowledge. Children's experience of being physically restrained is different to adults but the implementation of adult-based management strategies leave the children confused and frustrated, with opportunities to de-escalate potentially missed as is the principle of more in-depth, child-centred ongoing post-incident support.
Top three key findings / learning points from the example or research	Using an adult-based model to manage children's behaviour which is perceived as challenging in healthcare creates missed opportunities to provide person-centred care. Opportunities for early interventions, such as de-escalation, are often missed. Children do not appear to return to baseline following an incident as early as is suggested using an adult-based model; children are often left trying to make sense of what has happened without the necessary child-centred support.
Any challenges / issues encountered and how they were overcome	Accessing this group of vulnerable children has been extremely challenging but my perseverance working closely with gatekeepers and families and keeping within the ethical principles of the study has been worth it as it has facilitated an opportunity to 'listen to the voices of children' and keep their voices at the heart of the research.
Key recommendations on how this practice	Once the outcome of this PhD research is signed off, this model could be embedded as best practice in healthcare education. Adopting a child-centred model in the training of behaviour management as a standardised approach to training in CAMHS

could be rolled out locally and nationally	would demonstrate a more child-centred approach from services. A situation which may result in the use of physical restraint can be broken down into three distinct stages. An incident is re-framed and focussed on the child experiencing distress, rather than the focus being on the management of assault, aggression, anger or unwanted challenging behaviour. Existing staff teams could be re-trained through CPD using the newly-derived child-centred model to increase awareness, knowledge and understanding of what children experience when they are physically restrained by health professionals.
Links to further information or resource	Work embargoed until after final viva.

‘Getting it Right’ project 2019-2022

Name	Mary Spence
Organisation	The CBF
Contact email	mary@thecbf.org.uk
Brief description of best practice example / research project	‘Getting it Right’ is a 3-year project (2019-2022) funded by the National Lottery Community fund building on previous CBF work in Cumbria. This project aims to listen to family carers and learn about services they value and those that could be improved across the UK. The aim is that by the end of the project there are: a. More families of children with severe learning disabilities whose behaviours challenge feeling empowered and supported to improve the quality of life of their relative and reduce levels of challenging behaviour and b. More people in official and influential positions introducing evidence-based approaches in their areas and knowing where they can find support This project can be divided into three strands (this write-up will focus on the strategic local input strand): - Strategic local input, which involves working with three local authority areas to provide support, guidance, resources and to deliver out PBS workshops with the goal of leaving them with a strategic plan for the future and the ability to provide families with a better support network. The first local area was West Sussex. - Strategic national work - Sharing information and best practice
Is your example for children, young people, adults, families?	The project impacts children, young people and adults with learning disabilities and their families as well as local professionals working in health, social care and education. In West Sussex the project focused on children and young people up to 25.
Who has benefited from the good practice?	Over the 3 years, the project is working with 3 local areas. In year 1 we worked with West Sussex and in year 2 we are currently working with the Black Country. The focus in West Sussex was on children and young people 0-25, their families and local services and support.
What outcomes have been achieved (individual or organisational)?	Outcomes achieved in West Sussex: From independent evaluation: ‘Project partners worked together effectively to deliver nearly all elements of the plan, learning at every stage and adapting continuously to the restrictions and extraordinary pressures of the pandemic.’

	Local stakeholders were very positive about the benefits for families engaged by the project – through the parent-carer forums, the Behaviour Chats and the Stakeholder Event. Positive outcome for families - improved awareness and understanding of challenging behaviours associated with learning disabilities.
Top three key findings / learning points from the example or research	In West Sussex: Professionals – it is important to ensure the right people are involved at the right time Families – during the project there was a higher percentage of engagement from families with CYP with Autism diagnoses than with severe learning disabilities. It is important to consider how best to make sure this group is engaged in future projects. Process - It can take a few months to get the necessary engagement from professionals and families before key activities can begin so factoring in lead in time for engagement is essential.
Any challenges / issues encountered and how they were overcome	In West Sussex: Challenges caused by the pandemic including moving to working virtually and additional pressures on time of the project steering group and families. This meant there was limited time and capacity to support the concluding stage of the project, co-producing an action plan and a report to inform commissioning. Is one year long enough for a local area strategic change project of this ambition?
Key recommendations on how this practice could be rolled out locally and nationally	In West Sussex: It would be beneficial to build up a cumulative picture of family-carers' experiences and 'what good looks like' across each of the three local areas in the project and Cumbria (pilot area) to influence improvements in commissioning, policy and practice more widely.
Links to further information or resource	Getting It Right - Challenging Behaviour Foundation Including independent evaluation of year 1 of the project in West Sussex. Presentation delivered by the project lead and independent evaluator (CB-NSG May 21): CB-NSG meeting May 2021 - Challenging Behaviour Foundation

NHSE Advocacy Project 2021

Name	Coral Histed / Connie Mottram
Organisation	The CBF
Contact email	Connie.mottram@thecbf.org.uk
Brief description of best practice example / research project	At the end of August, the CBF, NDTi, Bringing Us Together and self-advocacy organisations were commissioned by NHSE to investigate advocacy services offered to children, young people and adults with learning disabilities in inpatient units, as well as family carers' experiences of this advocacy and the advocacy role they also provide. The CBF's remit focuses on family carers' experiences of acting as advocates for their relatives in inpatient settings, as well as the advocacy provided to their relatives.
Is your example for children, young people, adults, families?	Adults and their family carers.
Who has benefited from the good practice?	TBD – this review of advocacy is intended to better understand and advocacy services for children, young people and adults in inpatient settings.
What outcomes have been achieved (individual or organisational)?	We are mid-way through the project. As such, our outcomes have not yet been achieved. The project has involved conducting a questionnaire, focus group and desktop research.
Top three key findings / learning points from the example or research	TBD
Any challenges / issues encountered and how they were overcome	The difficulty in finding details of organisations that support family carers advocating for their relatives who are in inpatient facilities.
Key recommendations on how this practice could be rolled out locally and nationally	N/A
Links to further information or resource	We hope to share our final report at the end of the year.

‘MELD’ 2021

Name	Gemma Grant / Imarni Hill
Organisation	The CBF
Contact email	Imarni.hill@thecbf.org.uk
Brief description of best practice example / research project	The University of Warwick are leading a research study on the Mapping and Evaluating Services for Children with Learning Disabilities and Behaviours that Challenge (MELD). This project aims to find out how community-based services are structured, and what difference they make to the lives of children and their families.
Is your example for children, young people, adults, families?	Children, young people and their families
Who has benefited from the good practice?	The project is still underway, however the mapped services for children with learning disabilities and challenging behaviours will provide family carers and commissioners with a greater understanding of the services in their area and how they are structured.
What outcomes have been achieved (individual or organisational)?	For Stage 1 of the project, the research team have been mapping services in England which support children with learning disabilities and behaviours that challenge. They have also been working with the CBF and a family carer advisory group to understand the best way to measure how these services could improve the lives of children and their families. Stage 2 of the project, which aims to understand how effective these services are, is due to commence in the next few months, The project is ongoing.
Top three key findings / learning points from the example or research	TBD
Any challenges / issues encountered and how they were overcome	TBD
Key recommendations on how this practice could be rolled out locally and nationally	N/A - national research study
Links to further information or resource	For more information, you can visit the MELD study website here.

Supporting PBS implementation

Name	Karen Roche-Galvin
Organisation	GCC PBS Service
Contact email	Karen.roche-galvin@gloucestershire.gov.uk
Brief description of best practice example / research project	We provide PBS implementation support to all clients, staff and families we work with. This includes instruction, demonstration, rehearsal, feedback and repeat as necessary. Research indicates that this maximises the likelihood of PBS plans being implemented appropriately.
Is your example for children, young people, adults, families?	Adults, parents and families
Who has benefited from the good practice?	Adults with learning disabilities, acquired brain injury, dementia and/or Autism.
What outcomes have been achieved (individual or organisational)?	Greater fidelity to PBS plans leading to improvements in quality of life and reductions in behaviours described as challenging.
Top three key findings / learning points from the example or research	People/staff tend not to have the skills to change their own approach, without implementation support and active feedback as described above. The support led to a greater maintenance of PBS plans. The support reduced the likelihood of re-referrals to the service.
Any challenges / issues encountered and how they were overcome	Staff turnover means not all staff access the implementation support sessions - we try to provide practice leadership sessions for senior staff so that they can provide the implementation support once we have withdrawn. It is difficult to convince providers the necessity of this.
Key recommendations on how this practice could be rolled out locally and nationally	Ensure PBS practitioners are qualified. Ensure providers create practice leaders to lead on this type of work. Provide adequate training in the model suggested.
Links to further information or resource	N/A