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Service Provision for Children and Young People with Acquired Brain Injury; Practice Recommendations.

Abstract:

Background: Providing appropriate rehabilitation services for Acquired Brain Injury (ABI) in childhood presents a number of challenges for caregivers, health and education professionals and the young person as they develop. **Primary Objective:** To record the challenges and possible creative solutions generated by an international group of professionals to address the needs of children with ABI. **Review of Information:** Recommendations were generated from children's special interest group meetings of the International Brain Injury Association (Turin Italy, 2001, Stockholm Sweden, 2003, Melbourne Australia, 2005, Lisbon Portugal, 2008) and through meetings of the International Paediatric Brain Injury Society (IPBIS), formed in 2009. Delegates participating in the workshops were representative of nations from around the world and included The Netherlands, New Zealand, Australia, UK, Finland, Germany, South Africa, USA, Canada, Sweden, Brazil and Italy. **Outcomes:** The information presented is based on a retrospective review of those meetings and the summaries of the topics considered.

Service Provision for Children and Young People with Acquired Brain Injury; Practice Recommendations

Background: While the various challenges and recommendations about medical care, family burden, financial supports and community reintegration after acquired brain injury (ABI) have been well documented in the adult literature, considerably less information has been available regarding children. However, the challenges children, youth and their families face after sustaining an ABI have been the subject of discussion across the international community for over 15 years. A small group of professionals and family members began to record the challenges and possible creative solutions as they met at a number of international conferences. As the group grew and an international paediatric society formed, these challenges and possible solutions have developed into several themes with recommendations. The basis for the recommendations that follow result from the children's special interest group meetings of the International Brain Injury Association's World Congress (IBIA) (Turin Italy, 2001, Stockholm Sweden, 2003, Melbourne Australia, 2005, Lisbon Portugal, 2008) and through meetings of the International Paediatric Brain Injury Society (IPBIS), formed in 2009. These included an interactive workshop organised by IPBIS at the 23rd Annual Meeting of the European Academy of Childhood Disability in Rome, Italy, in June 2011, meetings of the IPBIS in Edinburgh Scotland in 2012 and San Francisco in 2014. Delegates participating in the workshops were representative of nations from around the world and included the Netherlands, New Zealand, Australia, UK, Finland, Germany, South Africa, USA, Canada, Sweden, Brazil and Italy. The following information is based on a retrospective review of those meetings and the summaries of the topics considered.

Definition of Acquired Brain Injury: While definitions may vary, the definition used in this article is: any type of injury to the brain after birth or the immediate neo-natal period. An ABI

can be caused by oxygen deprivation, accident, stroke, substance abuse, infection or a blow to the head. The resultant brain damage can result in varying levels of emotional, cognitive and physical impairments that may be temporary or permanent. Deficits may vary from mild to severe.

Existing Recommendations and Guidelines:

There have been efforts to provide suggestions, consensus papers, and recommendations for the care of children and adolescents with brain injury on a regional and national basis.

Guidelines that require a vigorous literature review, consensus by expert panels, and multiple iterations prior to publication are less available for this population.

Review of a selection of those papers published shows that many focus on the acute phase of care in children and adolescents with traumatic, rather than acquired brain injury [1]. The National Institute for Health and Clinical Excellence in the UK [2] discuss the need for rapid assessment following traumatic injury, the use of computed tomography and information provision at discharge. The recognition of long term follow-up and return to school are included in a number of local provisions in Sweden, [1] with the Swedish Pediatric Neurology Society currently seeking to develop their own national standards. Guidelines for the management of severe TBI, which are primarily aimed at the acute phase of hospital care, were produced in the USA by the Brain Trauma Foundation [3]. The Centre for Disease Control and Prevention (USA) is currently developing a set of guidelines for the care of youth with mild TBI (mTBI). The Ontario Neurotrauma Foundation in Canada [4] developed guidelines for the management of paediatric concussion, which provide information for healthcare professionals, families and educators. These guidelines provide comprehensive and practical advice on how to treat children based on the best available evidence and expert consensus from North America.

Current problem:

The majority of existing publications describe medical aspects of care, but fail to consider the needs of the child and family post discharge from acute to rehabilitation settings and at later key developmental transitions. The withdrawal of clinical input, and the realisation that the family must now go-it-alone, often creates a sense of abandonment and anxiety among families.

In the case of children, the impairments associated with ABI are variable, but in many cases require life-long assistance. Currently, service provision for paediatric populations with ABI can be haphazard and dependant on the location of the child, visibility of the injury and ability of the parents to advocate for the child. Further, even when an adequate plan has been implemented in one developmental time period, there may be a lack of service provision when the child transitions between developmental stages (i.e. pre-school to school, or school into the workforce). For interventions to be maximally effective, their implementation requires seamless support across developmental transition points. A universal model that contains the same basic requirements for service provision is necessary to ensure that seamless care for children and families exists.

IPBIS Recommendations for Service Provision for Paediatric Acquired Brain Injury:

IPBIS is committed to suggesting first steps in developing an international service provision model. These recommendations differ from existing recommendations and guidelines which have been created on a regional or national basis. Our recommendations come from a broad perspective, and draw on multiple countries' existing recommendations in addition to a wealth of clinical and academic experience. The recommendations discuss the concept of ABI in contrast to other bodies which focus on TBI. Those guidelines which discuss treatment following TBI or mild TBI specifically exclude children who receive their injury

through non-traumatic means. As there is such variety in severity of injury, illness and residual challenges, this paper does not focus with specificity on any particular severity of injury or the multiple potential remaining issues, but rather focuses on broader issues related to the entire spectrum of brain injury and associated needs.

In order to form a basis for future discussions about the needs of children and young people with ABI, and to make recommendations that can lead to a service provision model, the summaries of the panel discussions from the international delegates and their varying perspectives were reviewed. There was a striking level of consensus in terms of the main issues that were consistently highlighted in the different meetings and time points (2001-2014). These perspectives were analysed for themes and resulted in identification of the following areas of primary concern: medical and rehabilitation, family and education, and cognitive and behavioural (for learning and socialisation). These areas of concern and possible recommendations for an international audience to consider were reviewed through the IPBIS Board. The following is a consensus from that group regarding the major themes and recommendations for service provision that will serve children and their families more consistently across our nations. The recommendations provide guidance on care of the child and family, beginning at transition from hospital care to rehabilitation, and continuing to ongoing care in the community and education settings. Our recommendations highlight the need to support the family in a holistic manner, and which acknowledges that ABI is a chronic condition that impacts all family members. These recommendations need to be adapted for each country according to diversity and specific policies, but can stand as a basis for creating a baseline of support.

The recommendations of the IPBIS are strategically set out as a single list employing a multidisciplinary perspective; particularly as consistency, sharing of information and liaison across disciplines were key factors agreed upon by all participants. The following list

includes recommendations for specific action and recommendations for which further research or agreement would be necessary.

IPBIS RECOMMENDATIONS:

1. Increase education regarding ABI for medical practitioners.

Medical practitioners are front line providers of care for children with ABI. Moreover, recommendations made by these individuals when the child is discharged will have an impact on interventions offered within the educational setting [5]. However, research suggests that medical professionals lack knowledge regarding the needs of children following ABI [6]. Given the importance of the role of medical professionals in acute and post injury care in terms of making appropriate referrals and recommendations for rehabilitation to other professionals, there is a need to increase education for medical practitioners. Education should focus on raising awareness regarding the ongoing and often late onset of difficulties resulting from ABI, and should include reference to cognitive and behavioural sequelae, which can be overlooked in comparison with those difficulties affecting motor function.

Action: Provide already developed materials to medical and allied health colleges; present clinical research at medical conferences; publish in medical journals. Emphasise that in addition to physical deficits, there may be ongoing and late onset difficulties that are not recognised in acute care settings. Difficulties may include deficits in cognition, interruption to developmental progress, behavioural issues and associated educational challenges.

2. Increase collaboration between health and education services.

Transition from an acute (hospital/rehabilitation unit) to post-acute (educational units) setting is often a time when service provision may be lost. In a large scale study which followed the hospital discharge of over 24,000 children, it was found that the majority of children with

functional limitations were not given referrals to potentially beneficial services [7]. While this large scale research was conducted some years ago, more recent research confirms this disruption in service provision continues [8, 9]. In a recent study by Glang et al (2008) it was reported that written/verbal communication between the hospital and school was one of the major factors in provision of formal special education services, [5] and that without this communication the child was less likely to receive services. Greater collaboration is required between service providers to ensure best co-ordination of services and to create a seamless pathway of care for young people with ABI that extends across developmental transition points [10].

Action: Provide on websites models of collaboration that exist in some countries for others to adapt; assure agency policy provides for communication with other community agencies who will work with the child and family; make a personal commitment to communicate with other professionals who work with the child and family.

3. Commit to use of dedicated ‘case managers’.

Families often feel overwhelmed with the medical and legal issues which can accompany their child’s brain injury [11, 12]. This creates enormous strain for the family and can lead to mental ill health [13, 14]. A dedicated individual or team of individuals who could act as an intermediary would make this process/experience much easier. Many countries manage communication through case managers; while others have different allied health personnel take on this role (we have used the term case manager to refer to both systems). Timely communication is crucial to ensuring continuity of appropriate service provision. Therefore, there is a need for dedicated case managers to be employed to support young people with ABI and their families across environments and through developmental stages. A case manager is an individual who is responsible for the co-ordination and facilitation of

rehabilitative input which meets the unique needs of the young person with ABI. In the acute phase the case manager would coordinate the provision of medical care whilst ensuring the needs of the patient are met [15]. In the post-acute phase this individual would manage the transitions between hospital to rehabilitation centre and home.

Action: Increase recognition that case managers are an essential member of the rehabilitation team.

4. Recognise the long-term outcomes of ABI.

Savage, et al. (2005) have suggested that the rehabilitation needs of children are often overlooked, and recognition of the long-term consequences are not always considered in management of children with ABI [16]. This is somewhat surprising given that it is generally acknowledged that the total impact of ABI may not fully manifest until some years following insult [17-19]. There is increasing evidence that deficits persist into adulthood, including social [20], behavioural [21], cognitive [22], academic and psychosocial outcomes, even following what might be considered a relatively mild ABI [23, 24]. There needs to be greater recognition of the potential for ABI to have a long term impact on the child's life.

Interventions and management strategies need to have this long term view as their focus [25].

A long-term perspective may be achieved by an increased sharing of information between health and educational professionals, family and the young person across the their life span.

Action: Require a long-term outcome statement on all intervention plans. Ensure that professionals are aware that the rehabilitation of the young person may require interventions which extend into adulthood.

5. Recognise the developmental stage of the child.

Physical, emotional and cognitive development occurs rapidly during childhood [26], with identifiable periods of rapid brain development [18]. It is not surprising therefore that the rehabilitation needs for children who have ABI are not static, but rather require updating as the child matures [27]. However, rehabilitation plans and intervention strategies are often developed to meet the acute needs of the child, and are not updated to meet longer-term needs. For example, Slomine et al. (2006) reported that in a group of children with moderate to severe TBI, 31% had unmet or unrecognised health care needs 12 months following injury. Cognitive rehabilitation input were most commonly reported as being unmet or unrecognised [28]. It is important to ensure that rehabilitation plans are updated regularly, and particular attention needs to be paid to key educational and social transition points, e.g. preschool → school → high school → work environment, so that interventions do not become redundant or ineffective.

Action: Use internationally focused health websites to provide current information about the impact of developmental issues on ABI.

6. Require rehabilitation and educational professionals working with children who have ABI to demonstrate a good understanding of deficits associated with these injuries.

Recognition of deficits for children with ABI is complex for a number of reasons. Firstly, children are in a process of development, and deficits may not manifest for some years post insult as the child fails to keep pace with their peers or do not develop an expected new skill [18, 29, 30]. Secondly, assessment tools used to measure deficits may not be sufficiently sensitive to detect the child's deficits [22]. For those working in hospitals, rehabilitation centres or schools with young people who have ABI, it is crucial that they: 1) apply formal and informal assessment that can adequately demonstrate the child's strengths and weaknesses, and that assessments are sufficiently sensitive to detect cognitive consequences

of ABI; 2) understand how deficits may manifest in assessment, i.e. an overall classification of ‘average’ (which spans a wide range within a normal distribution curve) does not indicate that a child with ABI has no deficits [22] or does not require intervention, and understand that deficits may emerge over time; 3) employ a number of evidence based – informed treatment techniques that are based on the developmental strengths of the child; 4) pass on adequate assessment and treatment information when transitioning the child to the next environment [31].

Action: Require proof of training about ABI for individuals who treat or teach children with ABI. This could be achieved by means of accredited online training courses that could be taken as part of a process of continual professional development, and hold data on individual course completion.

7. Require appropriate recording of progress in professional documentation

The healthcare needs of paediatric survivors of brain injury are likely to change as damaged regions of the brain grow and mature. However, following discharge from hospital there is a marked reduction in contact with clinical services [32, 33]. In order to meet the changing needs of children it is important to monitor and review their progress. ‘Road to Health’ charts used in some countries to track progress throughout childhood, and to detail medical histories, should be used more widely to ensure that all professionals (e.g. health, education etc.) are aware of the child’s relevant history. These should be updated by specialist nurses or parents operating a ‘red flag’ system (problems to watch for) for young people with ABI. In the acute phase of care this document would provide an overview of medical care and procedures undertaken in hospital. In the post-acute phase, care received by community services and educational interventions would be recorded to provide an indication of the child’s improvement.

Action: Use notebooks (paper/electronic) with families and professionals to maintain adequate documentation of services. Electronic medical records should be used where possible. Employ mandatory triggers for referral and assessment to ensure appropriate pathways of care.

8. Provide assessments and interventions that are family-centred.

Families are the foundation for the rehabilitation of their children following ABI. However, there is consistent evidence that suggests that healthcare professionals focus on the medical aspects of recovery, rather than taking a holistic, family-centred approach to care [33, 34]. At times healthcare professionals have been accused of failing to listen to the needs [35] and views of family [36]. Further, support for the family is often not available even when required [37]. However, research demonstrates that children with ABI treated with the family's active participation present with improved cognitive and motor outcomes after 1 year of intervention when compared to children treated exclusively by professionals [27]. Gan, DePompei and Lash (2012) suggest that family resilience is strong in many families, and that supporting these families to be accepted as team members who advocate well for their children is essential [38]. They recommend that families be routinely included in assessment and intervention planning for their child. They also suggest that families are experts who can help determine the direction of community reintegration [39]. In the long-term rehabilitation process, families should be instructed how to include activities in the child's daily life that will contribute to rehabilitation.

In addition to including the family (and child if possible in planning), a second approach that is important is ensuring that parents and families have appropriate information and guidance to support good decision making. Research shows that the provision of written information to carers in the early stages following injury is greatly valued and results in the reduction of

anxiety [40, 41]. However, information giving is not a trivial exercise, as parents may feel overwhelmed in the acute phase of care and be unable to process highly technical information [35]. It is therefore important to note that any information provided to families should be phrased in an easy to read format that is accessible by all [32, 42]. Assistance with transition to the community is necessary in order to avoid inadequate service provision following the acute phase [43] that can leave families feeling isolated and abandoned. Periodic contact with a healthcare professional may benefit some families and alleviate the burden of care [44, 45].

Action: Acknowledge that families are the experts on their child, and include them in the decision-making and long-term rehabilitation processes; instructing them on how to include activities in the child and family's daily life that will contribute to rehabilitation. Ensure that families are provided with appropriate written information to aid them in their decision-making.

9. Provide a timeline to assist parents monitor progress of their child.

Following injury, parents are forced to assume a number of different roles in addition to that of care giver [46]. They often become advocates for their child's care and must deal with the intricacies of the healthcare system [11]. As recommended in point 3, a dedicated case manager should be appointed to the child to assist families navigate the health system. In addition, to avoid confusion and facilitate timely access to appropriate services, a single information and 'timeline' document should be provided for parents and professionals from all disciplines with the following information: i) details regarding upcoming interventions; ii) details regarding what circumstance/outcomes should 'trigger' interventions; iii) provide time lines for scheduled services; and iv) provide contact information ('who to ask'). During the acute phase this 'timeline' document would help carers become accustomed to the services and professionals involved in their child's care, and provide an unambiguous plan to inform

service providers of ongoing care. In the post-acute phase this document could augment the role of case managers [15] and help provide continuity of care where case managers were not available. In the longer term, a ‘timeline’ would provide a historical record of care provision and highlight follow-up points in future care.

Action: Develop a policy that requires use of the timeline to be shared with family and other professionals. Connect with social service /mental health service providers, and ensure their involvement in the system.

10. Provide families with guidance regarding social and behavioural issues.

Families often feel a return to normality when their child leaves hospital, and may be unprepared to cope with post-injury changes in behaviour. Poorer social and behavioural functioning are common following moderate to severe TBI, and can mean that children are aggressive, impulsive, easily distracted and less attentive [47, 48]. These traits can result in the child being excluded from peer networks and becoming socially isolated [49]. Families may have to cope with a child who has disengaged from school, whilst also facing increased economic burden due to their caring role [50]. Social issues are often an unexpected outcome, and greater information/guidelines are required for parents, families and professionals regarding social concerns that may become problematic. These concerns may include sexuality, abuse, substance abuse and economic social challenges. In the acute phase social problems may be less of a worry for families, but early intervention through information giving may prepare them for the future [33]. It is important that when problems arise that families are directed to evidence based programmes and interventions to assist with management of social and behavioural issues.

Action: Use evidence-informed websites and pamphlets early with families to inform them of possible social and behavioural issues that can emerge.

11. Provide appropriate educational accommodations for students with ABI.

Because the spectrum of injury and resultant academic challenges can vary for each child, the use of educational placements and resources can also vary from simple in-class supports to specialised classroom placements. The complex nature of ABI means that specialised educational resources are often required to meet the changing needs of many children [51].

Representatives from all countries indicated that adequate placement for students with ABI is challenging. Various countries' laws and policies about students with special needs are challenging for students with ABI as they do not fit adequately into categories of disability for learning and social development that are designed for other types of special needs.

Additionally, those students with milder injuries who need supports within the regular classroom for lesser amounts of time are often not identified, or are not provided with necessary strategies for classroom success. Teacher training largely ignores ABI, and teachers appear to be ill informed on the condition [9, 52]. These problems are exacerbated by a lack of identification of children with TBI for educational support [51]. If these children are to have a successful school experience, greater efforts must be made by the education sector to meet their needs [53]. If children with ABI are not attending special schools, then where appropriate, trained facilitators should be made available in mainstream schools. Early efforts in return to school should include assessment of the child's needs based on their strengths and weaknesses [54]. An individualised plan of support should be implemented, potentially updated over many years following a process of periodic assessment [55].

Action: Advocate internationally for specialised plans of educational support within the country's legal structure. Plan to work with each child for the entirety of their education within the spectrum of injury.

12. Increase education of teaching professionals about ABI characteristics and learning abilities.

Educational professionals have a major role in the rehabilitation of children with ABI. However, research demonstrates children with ABI are often returned to the classroom without specialist help [56], placing the burden for rehabilitation on teachers who are often not educated in the needs of children with ABI [9]. This is a major problem as children with ABI often have significant educational issues (behavioural, cognitive, communicative, physical, social) [8, 21] which may complicate planning for their educational needs [52]. The teacher is often the professional who provides the greatest number of rehabilitation hours for young people with ABI, and it is important that appropriate support and education is provided to them. This support for teachers can be achieved by ensuring that the curriculum for teacher training includes sufficient focus on the needs of children and young people with ABI [57], and ensuring that teaching professionals are aware of ongoing and the often late onset of difficulties resulting from ABI [52].

Action: Place training modules on websites and provide means for teachers to access them. Include acute care or rehabilitation staff in early transitioning and ongoing care where possible.

13. Provide a comprehensive approach within the school environment.

A child with ABI will often require a range of different services within the school environment including speech pathology, teachers aid and occupational therapy. Often these services work in isolation, which may lead to a lack of integration and focus for the rehabilitation team [58]. Further, members of the rehabilitation team may find it difficult to attend meetings due to conflicting demands [58]. To ensure a comprehensive approach within the school environment, involvement from all team members is required [59]. Involvement of team members can be facilitated via an environment that is supportive of collaborative practice, and where there is shared decision making [60]. Further, it is essential that all

professionals have basic information and skills to work with children with ABI. For example, information documents must be provided for teacher aides and peers who are the primary social and educational supports, but who may not receive adequate guidance about how to assist the young person [54].

Action: Provide technology that allows for team conferencing or provide time each week for team planning. Create age appropriate materials for peers, and adapt existing educational materials for educators, depending on international context.

14. Engage in greater ‘international collaboration’.

There are few large scale trials of interventions in brain injury research [61]. Thus, while many potentially useful interventions are created, their effectiveness is rarely determined. This may be due to a lack of resources, small local populations or a unique cultural environment. International collaboration is required to share research and compile information regarding assessments and treatments that are successful with the ABI population. IPBIS supports a web site where results of research can be posted and information shared. In the short-term this site could be used as a gateway to bring together researchers and clinicians. In the longer-term, collaborations begun online could translate into small scale proof of concept ideas, and later large scale trials. Collaborations could also be instrumental in raising the profile of paediatric brain injury with funding bodies to facilitate such work.

Action: Create better networks for improved cooperation through the use of established organisations such as IPBIS and IBIA. Create opportunities at international conferences and through dedicated websites to work together. Encourage the development of national and international databases to increase research and understanding for all forms of ABI.

Special considerations:

15. Concussion.

Concussion, also known as mild Traumatic Brain Injury (mTBI), is one of the most frequently occurring injury types during childhood [26, 62]. Its symptoms include fatigue, dizziness, irritability, sleep problems and sensitivity to loud noises or bright lights[63].

Because the injury often has no visible signs, “mild” may be associated with insignificant. As such, children are often returned to school and home with no formal rehabilitation plan, and with the belief that they will spontaneously recover [64]. However, there is increasing evidence that some children will experience a complicated recovery from concussion, and others will have psychosocial deficits that are detectable into adulthood [21, 23, 65-67].

However, the majority of the literature regarding the management of mTBI has focused on return to play guidelines, rather than overall management of this injury, and there is a general lack of understanding about this injury among the general public [68-71]. To enhance recovery and to highlight the problems associated with these injuries, school boards need to develop policies for identification and Return to Learn/Return to Play guidelines for concussion (Halstead, McAvoy et al 2013). Further, ongoing monitoring is recommended to ensure that any persisting difficulties can be identified and addressed early to ensure a positive recovery [72].

Action: Advocate for post-injury monitoring of children with concussion. Development of rehabilitation and academic plans tailored to the child’s individual needs, that include rest and a graduated return to pre-injury activity, including return to school/learning is essential.

16. ABI in the third world.

The recognition and treatment of ABI/TBI in children in the developing world appears to be a function of both the accessibility to services as well as the value placed on the economic viability of long-term rehabilitation. The primary health care model dominates with secondary and tertiary services being centralised in the larger cities [73]. With the medical model being the approach of choice, the quality of care is crucially focused on acute and sub-acute stages. In a 2008 study of the high burden of injuries in South Africa, interpersonal violence and injuries stemming from rapid urbanisation and ongoing socio-economic disparities, together with road traffic injuries, were found to be two to seven times the global rate, and the leading causes of injury [73, 74]. Underpinning this is the lack of reliable health statistics, with the reality that for each death recorded there are several survivors with permanent disabling sequelae. Acquired brain injuries due to trauma such as falls, accidents, fires, violence and abuse are managed in the initial stages through community centres and triaged to secondary and tertiary hospitals if assessed as necessary [74]. After discharge from hospital, the responsibility of rehabilitation falls largely on the family [27].

Action: Engage policy makers in third world countries to recognise/prioritise funding for ABI services; develop low cost interventions to assist families who care for children with ABI; encourage research collaborations to address the unique social and economic environments children with ABI face in the third world.

Conclusions:

The themes identified, issues outlined and recommendations and actions provided in this paper result from a consensus of opinions from children's special interest group meetings that have taken place over a 12-year period. The identified needs and recommendations are based solely on their suggestions.

Their consensus is that ABI is a common source of academic, social and behavioural problems during childhood. And there is increasing evidence that these problems may continue into adulthood. However, there remains a lack of understanding and consensus among health professionals regarding how to optimise positive outcomes for children with ABI. Much of the existing and historical misunderstanding that surrounds ABI comes from insufficient information sharing between professionals, a lack of appropriate training for those working with these children and young people, and a lack of a pathway of care designed to ensure that appropriate rehabilitative, educational and social support are provided beyond the acute period, across developmental transition points and into adulthood. This discussion paper is intended to highlight the need and provide a framework for an international model of service provision for children and young people with acquired brain injury. It is a precursor to further recommendations, currently being developed by IPBIS, that will be based on this paper plus additional delegate suggestions from the first international paediatric conference held in Liverpool, UK in September 2015.

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