

This is a Vinaigrette report looking into some of the issues surrounding the supply of paediatric equipment in the Halton area.

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Background, I am a paediatric occupational therapist in the community for Halton Borough Council who is passionate and dedicated in delivering a professional service to my service users.

The motivation for this research derives from the frustration of being unable to resolve a particular intervention from the 24/01/2022 to the 06/06/2022. Creating commensurate anxiety and stress for the family.

The Aim is to identify some of the issues surrounding the delay in provision of disabled paediatric equipment in the Halton area and the impact on families.

The Research Strategy and Methodology included Journals, Literature reviews, books reports, policies and legislation Acts, Wiley Online Library, Occupational Therapy International, CINAHL, Science direct, BMJ Journals on line, Google Scholar, RCOT British Journal of Occupational Therapy, Australian Journal of Occupational Therapy, American Journal of Occupational Therapy, The Cochrane Library, and the EBSCO research platform. Further research into relevant legislation and policies again led to again forming a platform for the production of a process chart identifying the systems and processes that service providers use.

Key words used;

Paediatric, Equipment, Provision, Early intervention. Acts, Legislation, and reports.

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Poster.

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Background to Halton Borough Council's Pediatric Occupational Therapy service

At Halton Borough Council (HBC), the Disabled Children's Occupational Therapy (OT) service supports disabled children to live safely and independently in their own homes. The service can assist children or young persons to use essential facilities in their sleeping, bathroom, living room and play areas. . In my professional opinion, EARLY INTERVENTION IS THE KEY to achieve an appropriate and acceptable outcome. Early Intervention has been identified as a priority for global research in developmental disabilities (Collins et al. 2017.) Disability is defined as an individual who has a physical or mental impairment, which has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities (The Equality Act 2010).

My role

My role as a community OT is that, after referral, I make contact and complete an initial assessment in their home environment. I engage and build a relationship of rapport and trust of the service user and parents within the first meeting. I then assess and identify a service user's needs through holistic data gathering, and prescribe appropriate interventions of equipment or adaptations using an eclectic and pragmatic approach that will meet the their present and long term needs, within the policies and resources available to me. A relaxed and friendly service provider is perceived as having a greater insight into daily family life, and therefore a greater capacity to provide services to meet family needs (K. Thompson 2006).

The importance of early intervention

Early intervention is important if a child is to progress and develop, increase independence, enhance their wellbeing and experience and have the same opportunities as any other child. This is echoed in a report by Christine Craik (BJOT 2015). Early intervention is the key to achieve an appropriate and acceptable outcome. Trine Roald also agrees that "Early intervention is not only possible but also Crucial". (Trine Roald Oslo CP convention 2018).

However this can only be measured over time and the effectiveness of the intervention prescribed. This is echoed by a Professor Feinstein who wrote 'We know that if you deliver high-quality services to people who need them, the right features of quality, delivered at the right time they can be transformative in most circumstances, the question is not whether it works; the question is when it works and how to make it work more'. (House of Commons , 2017-1).

Family's expectations and their perception of a prescribed intervention after an initial assessment and time scale of when supplied can be very different in reality due to processes and supply. Most families anticipate once you have identified a possible solution to the child's issue it will arrive in a couple of weeks. It is very important to be transparent during any conversations you have with the family and not enhance their expectations of time scales of provision of equipment or adaptations. This can lead to anxiety, stress, frustration and often anger. When necessary equipment is not provided in an acceptable time a child's development can decline, as may their health and that of those who care for them (E, Bennet .2010 Counting the costs 2010).

The practical and emotional support from service providers is extremely important. A professional who shows genuine interest of a child and the concerns of the family are highly valued by the family, (K. M. Thompson 1998).

Case study example

An example of delayed intervention in my case load who will be known as child A, who has Cerebral Palsy (CP),Global developmental delay, is dependent for all transfers, is doubly incontinent and needs personal care. The parent also had a disability. After prescribing the appropriate intervention, it took approximately six months to supply and install. During this time, the child's condition may lead to deterioration due to an ill-fitting piece of equipment, possible risk of injury and increased tension, anxiety and distress to the parents who then exerted their frustration at me, as I am their main contact throughout the process.

It was this particular service user's case which led me to research some of the issues surrounding the time scales in providing specialised equipment for disabled children/young persons within the Halton area.

(1)

Searching for information

This proved difficult frustrating and disappointing and here starts my journey.

Initial thoughts were to research HBC policies and procedures for providing and funding equipment for service users on our web site under Local Offers. The site is informative, however, it does not disclose a policy for the provision of equipment, or provide reasons for possible delay in provision or service process. It does quote part 111 s17 of the Children's Act which primarily at present, under the Children's Act 1989 states that the legal obligation to provide equipment for disabled children lays at the door of the local authority.

After contact with an Occupational Therapist in a research café forum and after networking only minimal information of possible areas was identified.

Comparing different borough councils

After contacting adjoining boroughs of Halton, Warrington and St Helens the following information was provided:

St Helens (SHBC): After contacting a member of the occupational therapist team to discuss the process used for the provision of paediatric equipment in their community discussions failed to provide the necessary information I had hoped for due to them experiencing staffing difficulties. Contact with a previous employed paediatric OT from SHBC, informed me that their system was similar to HBC apart from there was no panel to approve a request, it was approved by a manager then straight onto procurement to purchase. This method could improve efficiency and process.

Warrington: After contacting Warrington borough council (WBC) community social care paediatric occupational therapist (OT) to discuss their process used for the provision of paediatric equipment led me to believe that the process used by WBC was in fact very similar to that of Halton's process. However, WBC retains a large core stock of paediatric equipment. Having this core stock enables supply of an early intervention and prompt service to the service user.

Searching journal articles

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Turning to the University of Salford for consent to access research journals, literature reviews and books for information in my chosen subject took some time to achieve due to policies and procedures for external researchers to obtain. Gaining approval, I also researched journals, literature reviews, books and reports on external web sites for information. Repetitive searching of endless journals, literature reviews and reports, to my disappointment could not find any relevant specific information relating to my question of the issues surrounding the provision of specialised paediatric equipment.

(2)

Searching relevant legislation and policies

Investigation of Gov.UK led to a report in 2017 commissioned by the House of Commons states “In addition to the impact on child and adult outcomes, proponents of early intervention frequently note its ability to save costs in the long-run, by avoiding expensive statutory interventions and lost productivity”.

In 2016, the Early Intervention Foundation estimated that the national cost of ‘late intervention’ (the acute, statutory and essential benefits and services that are required when children and young people experience significant difficulties in life that might have been prevented) was £16.6bn’ .69 (House of Commons Science and Technology Committee Evidence-based early years intervention Eleventh Report of Session 2017–1)

Perusal of The **Care Act 2014** in the hope that I would glean some data from this huge Act, lead to the ownership of the local Authority’s responsibility to provide equipment. It states that local authorities have new functions. Although the Act is crucial to person-centred care and services none apply to children under the age of 18, they only apply when a child transitions into adulthood.

The Children and Family Act, 2014 .The Act has been amended over the years. It has ten areas, which are wide ranging, and cover what is expected of local authorities, who must provide services for families. This includes children and young people that are vulnerable or require additional needs, disabled children and those supported in an educational setting. However, it appears to focus on children and young people in education. It does not highlight the provision of equipment in the home for children or young persons with disabilities.

However, under schedule 2 ‘4. 1 states that every local authority shall take reasonable steps, through the provision of services under part 111 of this Act, to prevent children within their area suffering ill treatment or neglect. Not providing equipment within a timely manner may be perceived, as neglect in the eyes of the receiver could it not it there are long delays in providing an intervention prescribed by the service users occupational therapist.’ (Gov. uk)

The Children’s Act 1989. Section 17 (1) States, ‘It shall be the general duty of every local authority the provision of services for children in need, their families and others.

(a) To safeguard and promote the welfare of children within their area who are in need; (b) so far as is consistent with that duty, to promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children’s needs.

S.17 (10) s.17 (10) states that a child shall be taken to be in need if:

(a) The child is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services by a local authority under Part III of the Children Act 1989; (b) The child’s health or development is likely to be significantly impaired, or further impaired, without the provision of such services; or (c) The child is disabled.’

The Chronically Sick and Disabled Persons Act (CSDPA) 1970 places a specific duty on local authorities to provide the support which a disabled child is assessed as needing when it comes within the scope of the CSDPA. This will include arrangements for the provision of assistance for an eligible disabled child for adaptations to their home, or the provision of any additional facilities designed to secure greater safety, comfort or convenience. This also includes the provision of equipment. The child’s Occupational Therapist (OT) on behalf of Children’s Services usually undertakes such assessments.

There is no age distinction under the CSDPA so it applies equally to adults and children. However, in 2020, the historical experience of the Act is telling. The Act contained no definition of need, and there was no legal recourse against local authorities for disabled people who did not receive services. A national standard of local authority disability services and a statutory duty to provide them are needed. The Act did not require that the number of people with knowledge of disability issues should be increased on local authority committees. (Taylor and Francis Online, Disability and Society Vol 35,2020 Issue 5).

The National Service Framework 2004 (NSF) also relates to Disabled Children and devotes one of its themes to 'Equipment and Adaptations' subsequently this also sets a number of standards;

'Disabled children and young people should have the equipment and housing they need for their health, well-being, development and social inclusion; and for their families' health and well-being;

Disabled children and young people should have access to the equipment they need in all the settings in which they find themselves.

Local Authorities, ensure that policies, procedures and practices are reviewed on a regular basis, to remove barriers, improve access and to ensure disabled children and their families are not disadvantaged.'

Department for Health Change for Child Every Child Matters 2004. DH Publication.

After researching other Acts information was of a similar nature. None actually stated that it is a legal requirement to provide equipment. I then came across Michael Mandelstam's guidelines report (2016), which highlights areas of the Care Act 2014 for minor adaptations and equipment. He says to understand the effect on equipment it is necessary to consider what the Care Act states and how it relates to other legislation, including health and education. It is also essential to remember that Social Services, Education and Health are totally separate and individual when it comes to funding as they operate under different policies (see appendix). In the report he also states that S.17 of the Children's Act may be comprehensive. Its duty is broad, but relatively weak, as enforcing equipment under this section for an individual child would be difficult, because the duty is a general one toward children in need in their area, not toward an individual child. (Copyright March 2018 London Borough Occupational Therapy Management Group (LBOTMG)

In 2014 a report for the British Healthcare Trades Association (BHTA) summarises that:

More than one in twenty children (5.7%) in the UK is disabled in some way. (Office for National Statistics (2012).

- Specialist equipment, including wheelchairs, seats, communication aids, beds and postural support systems, plays a vital role in protecting the health of disabled children and those who care for them.
- At present, this equipment is under-provided by the bodies which have a statutory obligation to ensure that the needs of disabled children are met.
- This failure to provide equipment is worsening existing conditions and leading to complications which necessitate additional medical intervention.
- This costs dearly in terms of avoidable pain and suffering, as well as creating a substantial medical bill for surgery, hospital admissions, therapeutic interventions and physiotherapy.
- The vast majority of medical care is around £1.6 billion, while just £0.2 billion was spent on equipment. . (Office for National Statistics (ONS)(2012).

It would cost £0.5 billion each year to provide every disabled child with all the equipment they need. This entails more than a doubling of present day spending. (Office for National Statistics (ONS) 2012. Produced by the Centre of economics and business research (CEBR) and are based on independent research. However, the BHTA in May 2020 states" that the report does not necessarily reflect their views, how confusing why have the report commissioned? All of the above Acts outline the obligation on local authorities including social services to provide care and services for disabled children, including the provision of equipment for disabled children.

According to a report conducted by Newlife Charity in 2012, systems of provision and who funds them via official routes are fragmented and confusing for professionals when prescribing specialised equipment to meet a child's needs. The reasoning is that if no funding is assigned and need is never catalogued, subsequent budgets are set too low to make proper provision, leading to a year on year spiral of failure.(Newlife Charity, From the front line 2012).

Regarding Newlife's comment over a need not being catalogued, this is contradicting as, in Halton, a child's need is always recorded on our observations and when requesting via panel for specialised equipment the assessors clinical reason for provision is always stated within the form.

They also suggest that disabled children's needs are not being met as applications for the charity to provide families with equipment has risen over the last few years and that children are effectively rendered invisible. (Newlife Charity, from the front line 2012).

Further research into reports, journals and Acts of legislation identifies the importance of early intervention and whom the responsibility falls upon to provide equipment and adaptations for the disabled, however, none give or indicate an acceptable time scale of when an intervention of equipment or adaptation should be installed or completed by.

Change of direction – producing process charts.

It was at this point of my research I was introduced to a fellow professional and researcher at the University of Liverpool, Amanda Bennet. After some lengthy discussions she suggested that, for my research question, I should look into what systems and process I use as a service provider and how the stages I undertake from assessment to provision of an intervention may impact the delays encountered, using a process chart. It was at this point I started to compile a process chart from start to finish of an assessment, identifying the factors that could delay or prohibit provision of equipment. Surprisingly it highlighted areas not previously taken into account this started to unravel the research question. Process charts can help a service to set quantifiable objectives, identify deliverables and schedule tasks. It is a systematic guide to observe where and what stage the flow of provision takes place. (NHS England and NHS Service Improvement and Redesign Tools 2022).

The construction of a process chart mirrored the assessment stages it identified issues not previously taken into account e.g. from referral to provision can take approximately nineteen stages including time scales.

Stage (1) Referral received. Stage (2) Initial assessment team load referral. Stage (3) Referral triaged by duty OT and allocated, time two days. Stage (4) placed on OT new referral waiting list, depending on length of list can take up to two weeks before contact. Stage (5) Contacting and arranging assessment can take up to two-three weeks depending on availability of the parent and child, holistic assessment completed, I would prescribe a specific piece of equipment. Stage (6) I would contact two representatives of supplier's to complete further assessments of the equipment its appropriateness and that it meets the child's needs, this can take a further two-three weeks to arrange. Stage (7) Await quotes from suppliers, decision made. Stage (8) I then have to produce a special request form containing clinical reasoning why the equipment is required, one day. Stage (9) Forward request to panel, can take one-two weeks depending when panel sits. Stage (9) Decision made, If approved forwarded to procurement. Stage (10) Decision, procurement assess supplier to confirm they are on the SBS system, if not this could take up-to 14 weeks if not to register, order goes on wait list. Stage (11) SBS forward purchase order to supplier, supplier takes on average eight to twelve weeks for delivery into stores, however, it can take longer if parts are not available. Stage (12) Stage (13) Stores receive equipment administration takes place for asset number, can take two-three days depending how busy they are. Stage (14) Stores contact OT that the order and then arrange delivery to service user, one to two weeks depending on their circumstances. Stage (15) I then contact service user to assess appropriateness of equipment and adjust if required, a further one week usually. (Process chart provided in appendix).

Appendix:

Conclusion.

The research undertaken has reinstated my curiosity and to question why and where can the answers be found to issues surrounding the delay in providing paediatric equipment. The importance and impact of delaying early intervention highlighted in the poster as a metaphor of child A in the boat and the time taken to provide a particular piece of equipment. After long periods of researching journals, Acts, legislation and reports for factual information and not being completely satisfied with all the results, my question of the issues surrounding the supply of equipment in the Halton area. Initially funding was the assumed issue, however, local authorities have struggled with funding cuts since 2010 which affect all arrears of service. This issue would require more in-depth research into funding of who decides the amount of funding, as paediatric equipment is extremely expensive, what budget is responsible and how it is processed and allocated. Funding may be a considerable part of the issue but not in totality. Other factors are the external and internal process and system issues. My research has highlighted that nothing is as simple as it seems as there are barriers not obvious or considered when providing an early intervention such as policies, processes and systems. Internal system, process and policy issues are areas that we as a Local Authority can look to improve. However, external processes may continue to delay provision. In addition at Halton we provide a very good service to its service users with the resources available. In my opinion the ever-changing circumstances of Acts, legislation, government funding allocation and global provision of materials will continue to create barriers beyond the control of service providers and front line workers.

However, I am cautiously optimistic of the outcome of this report, if these issues are resolved. HBC in my opinion would provide the quality service of early intervention our service users deserve.

Recommendations for Halton, as a result of this research are:

Review how the process of service provision could be streamlined.

Compile a policy for the supply of all equipment for disabled children encompassing acceptable time scales in all areas of provision.

Purchase a core stock to reduce early intervention time after initial assessment.

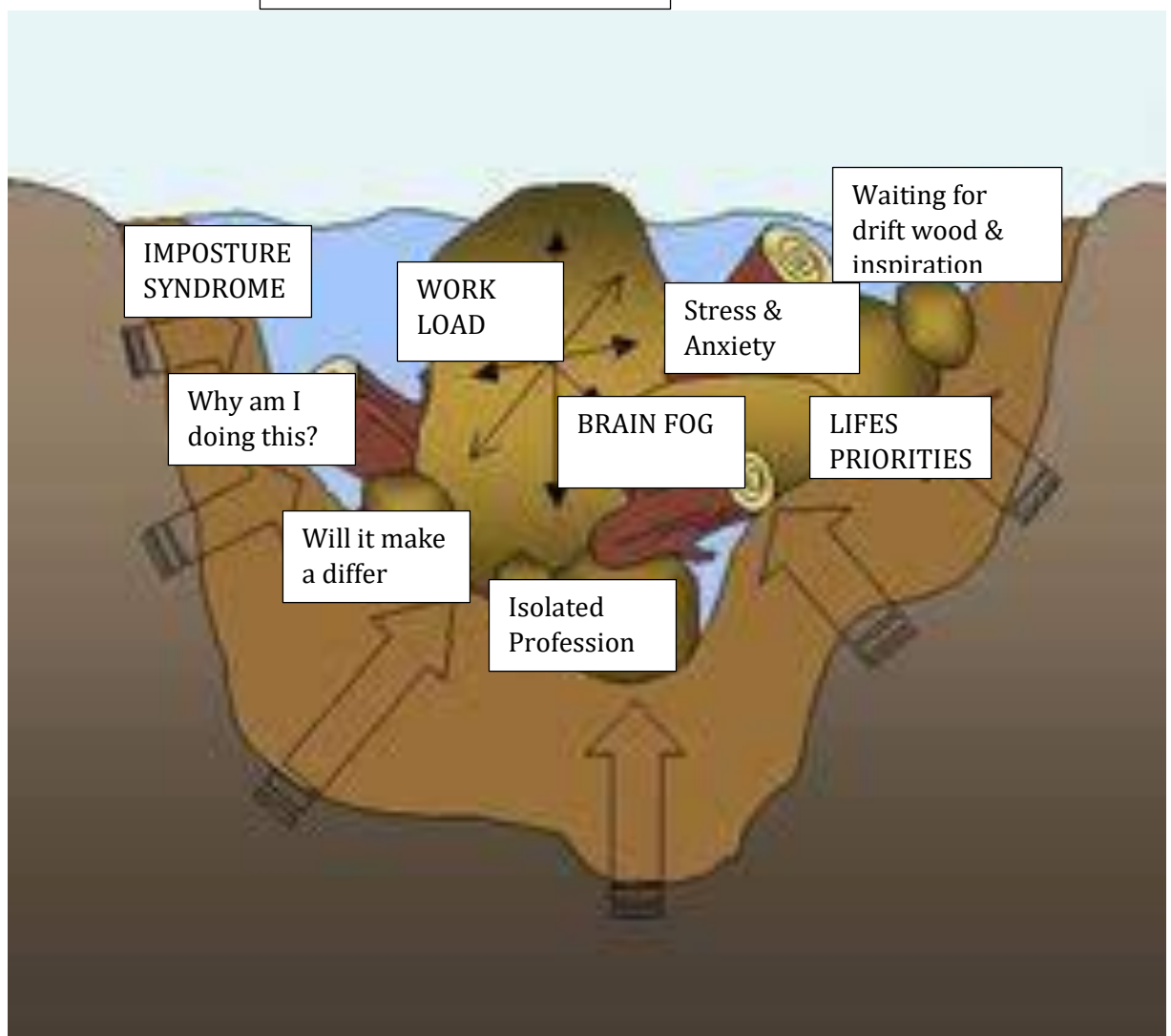
Provide a **Substantial Increase** in the children's budget that reflects the purchase cost of specialised bespoke equipment.



The KAWA Model of Occupation used as a metaphor for my research journey.

Kawa model is a model that uses the metaphor of a river with different contextual elements to represent human life. The key features of Kawa model include water, river sidewall and bottom, rocks, driftwood, and space between obstructions. Water represents a client's life flow or life energy. River sidewall and bottom reflects a client's physical and social contexts which are inseparable with the water flow. Rocks represent the problems or difficult situations that hinder smooth water flow and they are usually difficult to remove. Driftwood represents a client's personal attributes and resources to enable a person to move forward.

BOLDERS AND LOGS
REPRESENTS OBSTICLES IN
THE JOURNEY.



(8) References:

- Collins,P.Y., Pringle,B.,Alexander,C.,Darmstadt,G,L., Heyman,J.,Huebner,G.,Kulesic,V.,Polk,C.,Sherr,L.,Shih,A.,Sretenov,D.,&Zindel,M.(2017).*Global services and support for children with developmental delays and disabilities: Bridging research and policy gaps*. PLoS Med, 14(9), e1002393.
- Kirsty .M. Thompson (2006) .*Early intervention services in daily family life: mothers' perceptions of 'ideal' versus 'actual' service provision*. <https://onlinelibrary.wiley.com/doi/abs/10.1002/oti.76>
- Disabled Children and Young People and those with Complex Health Needs.40494/Disabled Child - National Service Framework for Children, Young People and Maternity Services DH Publications Orderline.
- Department for Education and Skills *Every Child Matters* The Stationery Office September 2003 www.dfes.gov.uk/everychildmatters.
- Bennet, E. Counting the costs 2010.*The Financial reality for families with disabled children*. [Contact.org.uk/wp-content/uploads/2021/03/counting the costs 2010.pdf](http://Contact.org.uk/wp-content/uploads/2021/03/counting-the-costs-2010.pdf).
- Mandelstam, Michael. *Legal Framework for Equipment Provision Guidelines*.2016.London Borough Occupational Therapy Management Group.
- Newlife Charity From the front line (2012)<https://newlifecharity.co.uk/press-statement/from-the-front-line-disabled-childrens-needs-are-invisible/>
- Title: National Framework for Children and Young People's Continuing Care Author: SCLGCP/CMHI/IDC/14100 Document Purpose: Guidance Publication date: January 2016
- Chronically Sick and Disabled Persons Act 1970 (England and Wales) Legislation.Gov.uk/ukpga/1970/44/contents.
- NHS England and NHS *Improvement* . Project management – an overview .Online library of Quality, Service Improvement and Redesign tools Quality, Service Improvement and Redesign Tools: Project management: an overview <https://www.england.nhs.uk › uploads › 2022/02>
- Christine, Craik (2015). British Journal of Occupational Therapists, 2015. Vol.78 (10) 519-592.
- Trine Roald Oslo CP convention 2018) <https://blog.madeformovement.com/early-intervention-is-crucial?hsLang=en>.
- House of Commons Science and Technology Committee Evidence-based early years intervention, Eleventh Report of Session 2017–19 .*Report, together with formal minutes relating to the report Ordered by the House of Commons to be printed 30 October 2018*. Published on 14 November 2018 by authority of the House of Commons.
- The Children's Act 1989 /www.legislation.gov.uk/ukpga/1989/41/contents.
- The National Service Framework 2004.www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services.
- The Children's and Family Act 2014. www.legislation.gov.uk/ukpga/2014/6/contents/enacted.