

Exploring the burden of "work" in the paediatric cochlear implant assessment process

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Introduction

Burden of Treatment Theory¹ is a structural healthcare model that focuses on the work of patients and their networks. Considering the physical, emotional, social and financial factors experienced by families helps understanding of variations in healthcare utilisation and adherence in different healthcare settings.

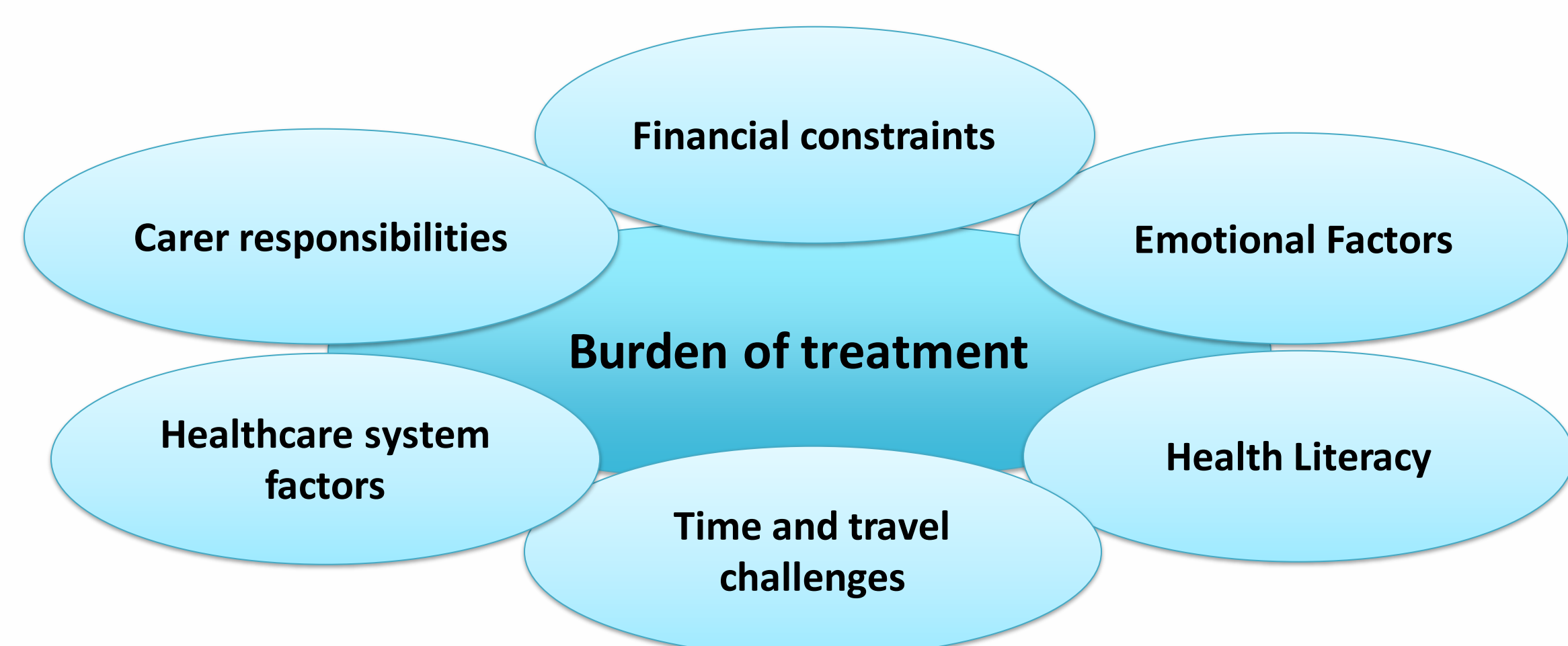


Figure 1. Factors associated with burden of treatment

Method

The themes discussed in this poster became apparent following a research project which investigated the barriers and facilitators to cochlear implants (CIs) for children². Through face-to-face, semi-structured, interviews parents described how they felt about the experience of navigating the paediatric CI assessment process.

Grounded theory analysis of clinic observations and interview data revealed the concept of "work" which families of deaf children felt they were undertaking during CI assessment.

Results

The process of finding out whether a CI is an appropriate option for a deaf child involves both practical and emotional work for parents, with the amount of work varying across different families. Use of the term "work" refers to the practical and emotional tasks associated with assessment rather than implying the child's hearing loss is a burden



Figure 2. Parental voices describing aspects of the "work" they face in the CI assessment process

Not all parents found the work excessive. However, socioeconomic factors such as lack of financial resources and low health literacy were identified as contributors to the challenges faced by families. Medical complexity of the child was another important contextual factor.

Discussion

The findings of this study are consistent with Burden of Treatment Theory¹. The theory predicts when the work becomes excessive adherence to the treatment reduces. So, in the case of CI assessment, it may take longer to reach a conclusion, for example, through non-attendance at appointments, feeling overwhelmed with information or extreme anxiety about the CI surgery.

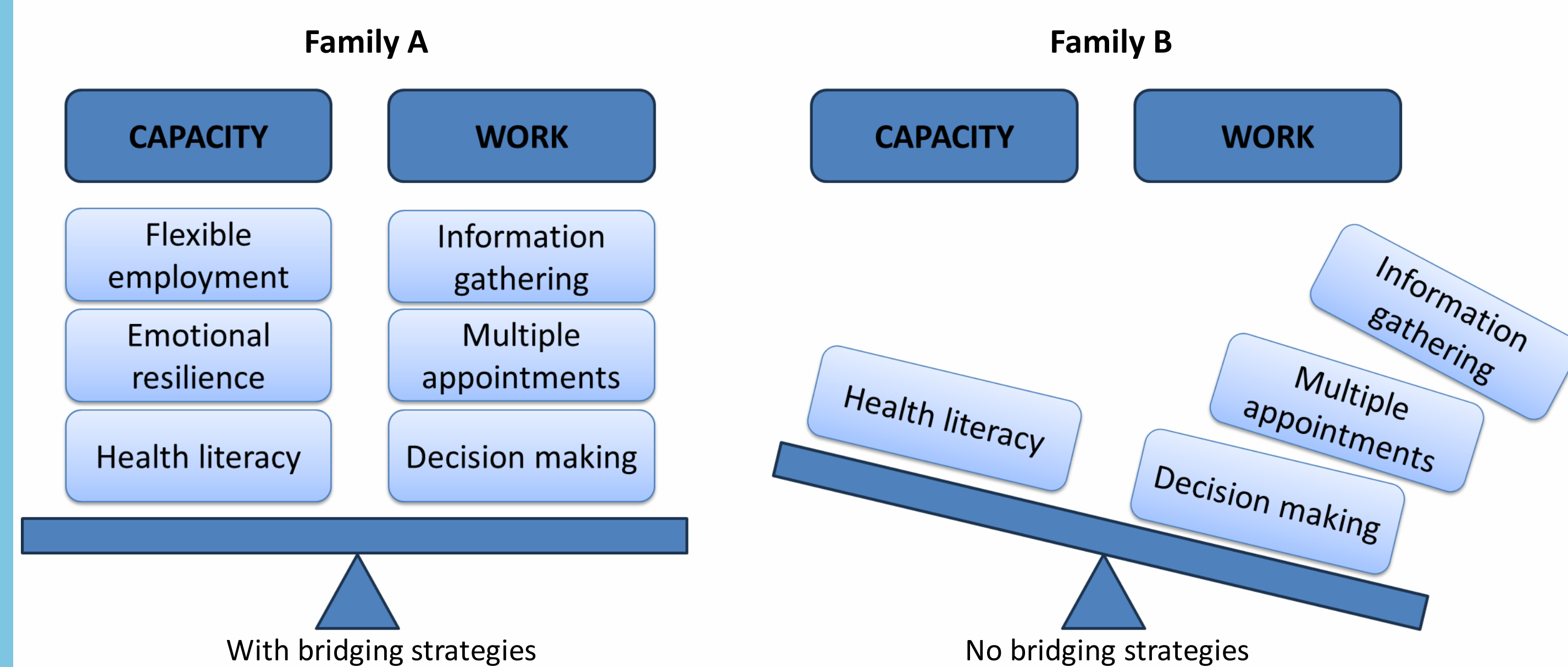


Figure 3. Shows the relationship between the work parents may be required to do as part of the assessment process and the capacity to manage the work within the context of their own lives For Family A the work and the capacity are balanced with the help of bridging strategies. For Family B the work outweighs capacity and bridging strategies are lacking or insufficient for the CI assessment process to continue in a timely manner.

Bridging strategies are used by parents and professionals to balance work with capacity. For parents this can include local support networks including extended family and friends, other families with deaf children, discussions with local professionals. Professionals look to provide information and support the family through the assessment process.

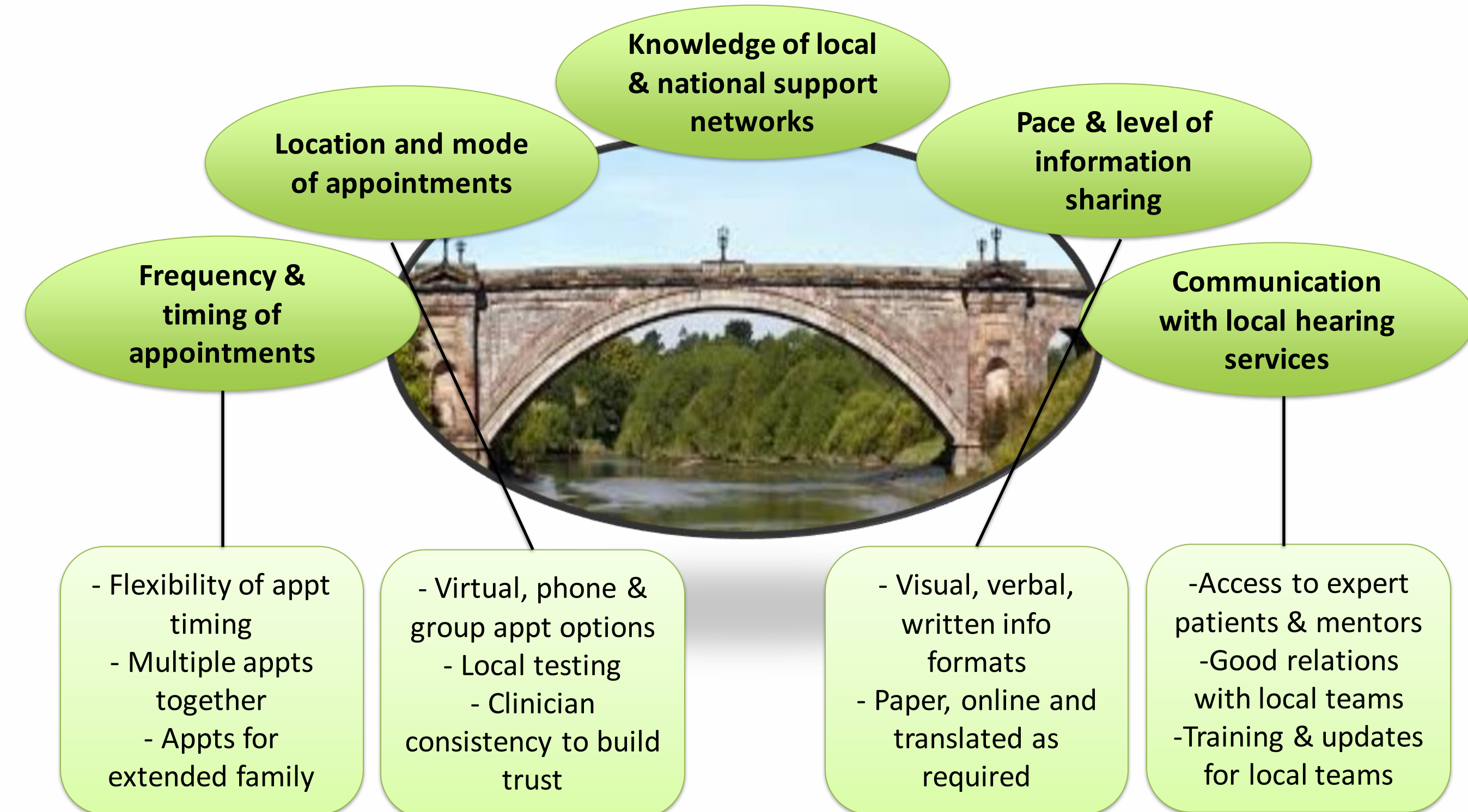


Figure 4. Examples of bridging strategies routinely employed at the Midlands Hearing Implant Programme Children's Service

Conclusion

The CI assessment process generates significant work, both practical and emotional, which varies across families². The capacity of parents to manage the work also varies significantly and can change over time. It is not always possible to predict which families will experience the greatest challenges. However, recognising the treatment related burdens of the CI assessment process and understanding the specific barriers faced by families allows healthcare services to improve access and enhance patient care. CI services should examine how they can facilitate parents bridging strategies within their local context.

References

- May, C.R., Eton, D.T., Boehmer, K. *et al.* Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Serv Res* 14, 281 (2014). <https://doi.org/10.1186/1472-6963-14-281>
- Hall, A., Ambler, M., Hanvey, K. A qualitative investigation of the assessment process to cochlear implantation for children with hearing loss. (2023) Manuscript accepted for publication by International Journal of Audiology.

