



Family-centred early intervention: Supporting a Call to Action

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Contributors to this presentation

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- **Marlene Bagatto, PhD, AuD**
- **Andrew Johnson, PhD**

Henderson, R., Johnson, A., & Moodie, S.T. (2014). A conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing. *American Journal of Audiology*, 23(4), 437-448. doi: 10.1044/2014_AJA-14-0029

Henderson, R., Johnson, A., & Moodie, S.T. (2016). Revised conceptual framework of parent-to-parent support for parents of children who are D/deaf or Hard of Hearing: A modified Delphi study. *American Journal of Audiology*, 25, 110-126. doi: 10.1044/2016_AJA-15-0059

Bagatto, M.P. & Moodie, S.T. (2016). The ICF-CY in EHDI programs. *Seminars in Hearing*, 37(3), 257-271. doi:10.1055/s-0036-1584406

Acknowledgements

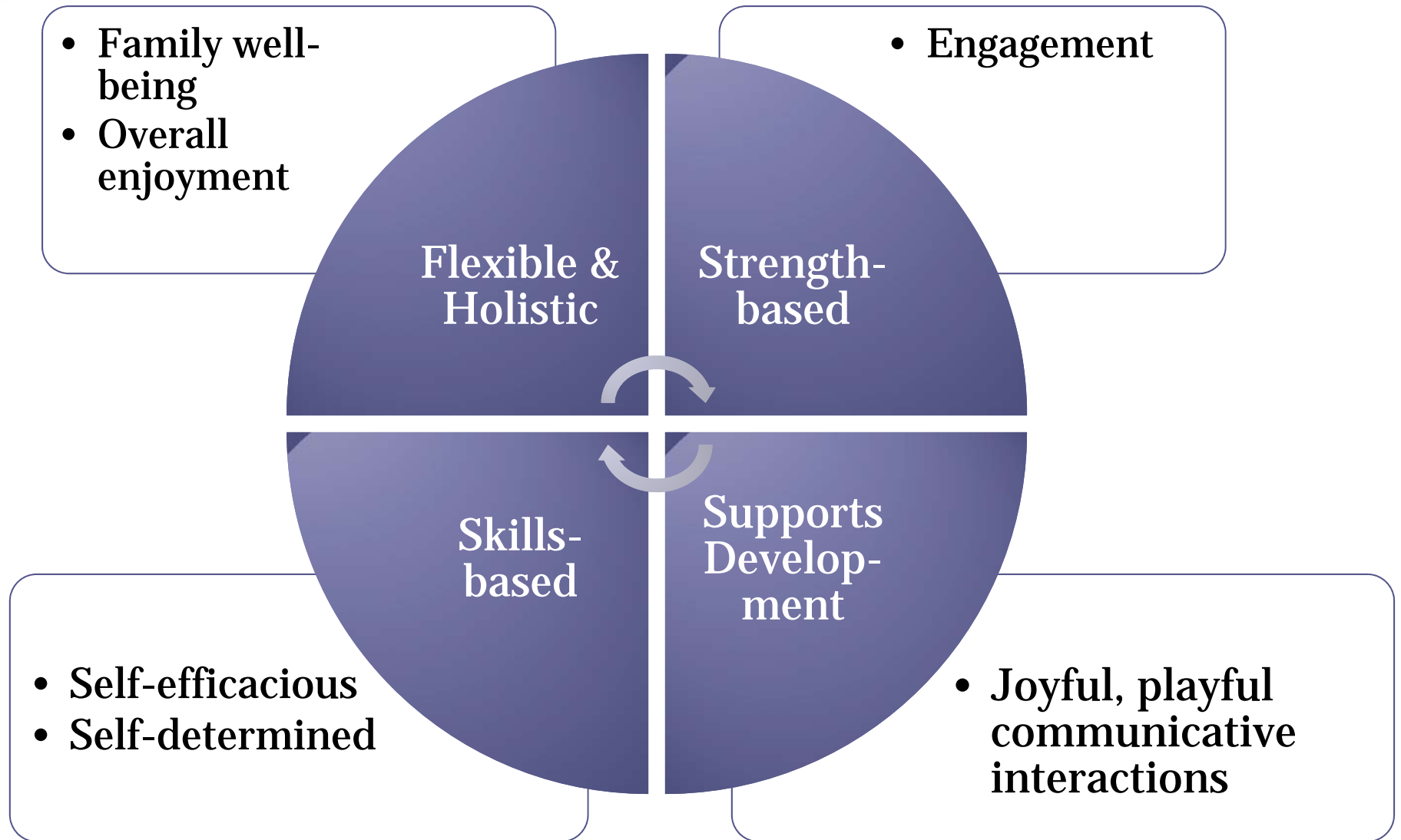


- **MRIS, Early Researcher Award to Sheila Moodie**
- **MCYS, Infant Hearing Program**
- **Researchers, parents, and advocates who continue to contribute to FCEI literature**
- **Professionals and parents who participated in the Henderson et al., eDelphi study**



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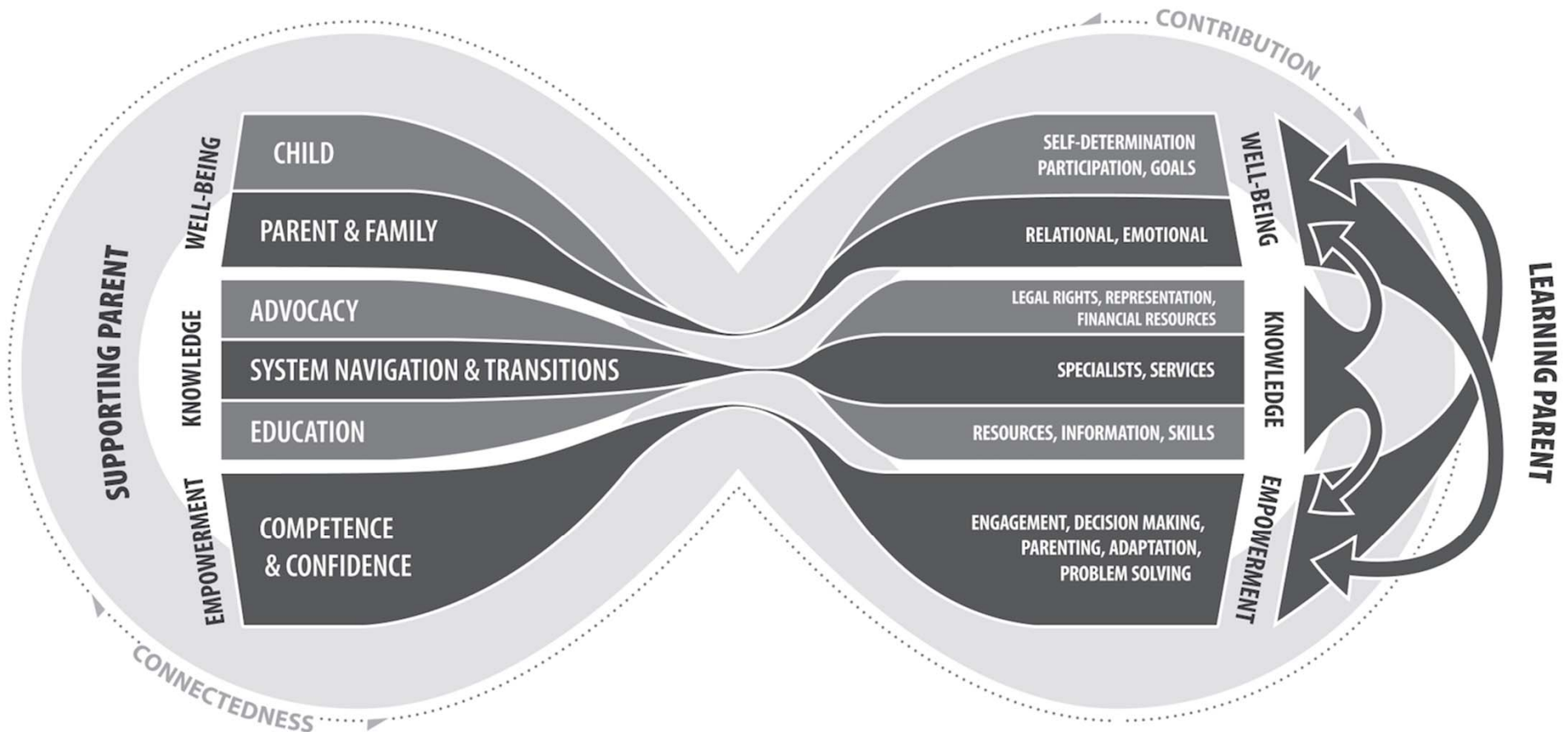


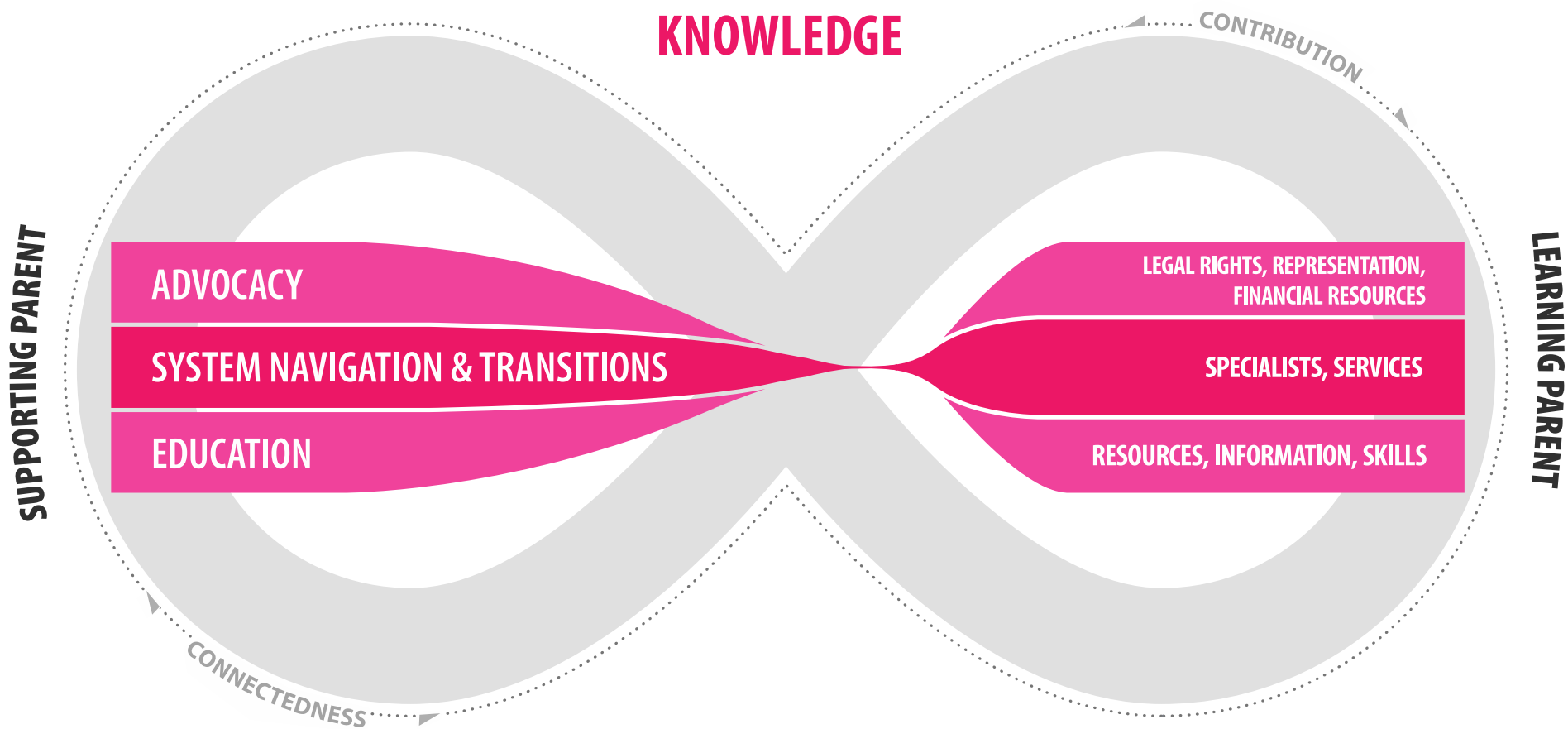
“Parents are the more important partners They have more at stake and have the greatest impact upon their children, particularly the younger ones, and their informed participation can be crucial.”

Mark Ross



Parent-to-Parent Support for Parents of Children who are Deaf / Hard of Hearing: Revised Conceptual Framework (2016)





HearOn

Parent Video Intervention to Increase Hearing Aid Use in Infants with Hearing Loss

Two key factors that contribute to success in spoken language for children with hearing loss include early amplification and higher than average parent participation in treatment (Moeller, 2000). Unfortunately, studies have shown 50% of parents failing to keep hearing aids on their infants for more than 4 hours a day (McCreery et al. 2015, Moeller 2010).

An intervention plan was developed, guided by input from both experienced Audiologists and Speech-Language Pathologists. A framework for behaviour change, The Behaviour Change Wheel (Pekala et al., 2011), helped to better describe the areas in which to target and to identify potential behaviour change techniques. With stakeholder input, 12 videos were developed for parents of children newly diagnosed as part of an Early Hearing Detection and Intervention program. The videos are designed to be delivered weekly beginning at ABR confirmation/diagnosis of permanent hearing loss.



David Sindrey, MCISc LSLS Cert. AVT & Sheila Moodie PhD

Western University, Faculty of Health Sciences,
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Western University, National Centre for Audiology,
Family-Centred Early Intervention Laboratory



1 Your Child's Hearing

Theme

Explains the pathway of hearing in easy to understand language with clear visuals.

Explains the ABR and how test results relate to hearing loss.



Key Ideas

Hearing is a pathway that parents can understand. Audiologists have tools to assess that pathway. The ABR is a reliable test, even though the child is asleep. How ABR works and how test results relate to hearing loss.

Rationale

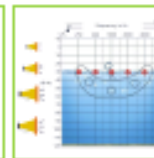
Parents may have misconceptions about hearing loss. Parents may distrust ABR diagnosis.

2 The First Audiogram

Theme

Explains the HI audiogram and degree of loss.

Gives degree-specific hearing loss simulation with and without hearing aids.



Key Ideas

The HI audiogram is a tool to see how a child's threshold compares to typical hearing.

Residual hearing can be useful for amplifying speech.

Rationale

Parents may have trouble understanding degree of loss. Parents may overestimate or underestimate impact of loss.

3 From Hear On

Theme

Explains the advantage of early detection and amplification.

Stresses family involvement and extended family support.



Key Ideas

Early identification is a valuable opportunity for maximizing language growth by kindergarten.

Amplification and family involvement is key to success.

Rationale

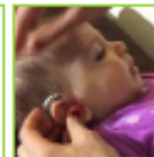
Parents may undervalue language exposure for infants. Parents may have adopted a "wait and see" approach.

4 New Hearing

Theme

Basic orientation to hearing aids.

First mention of goal to have listening technology on and working "all waking hours".



Key Ideas

Although children sometimes respond to sound without hearing aids, softer sounds and softer speech is missed, which has an effect on language development. Maintaining hearing aids is a simple and attainable goal.

Rationale

Parents may be intimidated by the technology. Parents may not recognize the need for hearing aids.

5 How Technology Helps

Theme

Introduction of the SPL-o-graph.

Using the SPL-o-graph to demonstrate benefit from hearing aids. Degree-specific hearing loss simulation.



Key Ideas

Although children sometimes respond to sound without hearing aids, softer sounds and softer speech is missed, which has an effect on language development. Maintaining hearing aids is a simple and attainable goal.

Rationale

Parents may be intimidated by the technology. Parents may not recognize the need for hearing aids.

6 Eyes Open Ears On

Theme

Hearing well means hearing more words, and more words means better language growth.

Both Parent talk & hearing aids are key to spoken lang. success.



Key Ideas

Parents vary in the amount of talk they do with child. Talkative parents have talkative kids with higher language abilities. Not wearing the hearing aids full time can impact language growth.

Rationale

Parents may not recognize the need for increased language input. Parents may not recognize the need for hearing aids.



Parent Video Intervention to Increase Hearing Aid Use in Infants with Hearing Loss

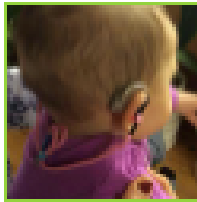
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Keep On Keeping On #1

Theme

Importance of setting a goal to keep hearing aids on and working all waking hours.

Degree-specific hearing loss/sound simulations.



Key Ideas

Keeping the hearing aids on can be difficult at times but problem solving with professionals & other parents can work. Keep hearing aids on longer up to sleep time and on again right after.

Rationale

Parents may not realize hearing aids are off child's ears for so long around sleep times. Parents need realistic first goals.

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The Importance of an Early Start

Theme

The value of language input in the first year and how the quality and quantity of that input affects language development later. How hearing aids must be worn in order to access.



Key Ideas

Babies begin learning from listening before birth. There are important connections related to language all through the first year built upon listening to the language of the home. Babies with hearing loss need hearing aids to access input.

Rationale

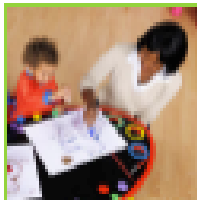
Parents may not realize importance of language in infancy. Parents may not realize impact of not hearing in first year.

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Keep On Keeping On #2

Theme

Practical tips on how to keep hearing aids on and working with emphasis on weather and outings for babies birth to age 1.



Key Ideas

Some situations can be more challenging. There are strategies other parents have found useful for overcoming these obstacles. Other people who care for the child during the day are responsible for keeping hearing aids on.

Rationale

Parents may not hold alternate caregivers responsible for hearing aid use. Parents need strategies weather & outings.

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Datalogging

Theme

How the audiologist can help with datalogging information from the hearing aids. Measurement of "time off" can help parents to set short term goals and measure progress.



Key Ideas

When information from hearing aid datalogging is shared by the audiologist it can be a useful tool for parents, measuring progress towards "all waking hours" of device(s) use for the child. Degree-specific hearing loss/sound simulation review.

Rationale

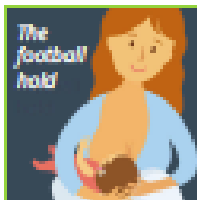
Parents may not be aware of how much time the child is actually wearing amplification. Datalogging is a tool/not app.

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Keep On Keeping On #3

Theme

Practical tips on how to keep hearing aids on and working with emphasis on weather and common activities for babies birth to age 1.



The football hold

Key Ideas

Some activities can be more challenging. There are strategies other parents have found useful for overcoming these obstacles. The child's state (fussy, tired, teething, etc.) can be a great obstacle. Strategies and reassurance given.

Rationale

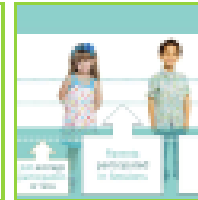
Parents may be helped by knowing that other parents face the same challenges. Successful strategies may be unknown.

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The Magic Ingredient is You

Theme

Information about 2 key factors predicting success (percentage or better language ability by kindergarten): early consistent amplification & above average parent participation.

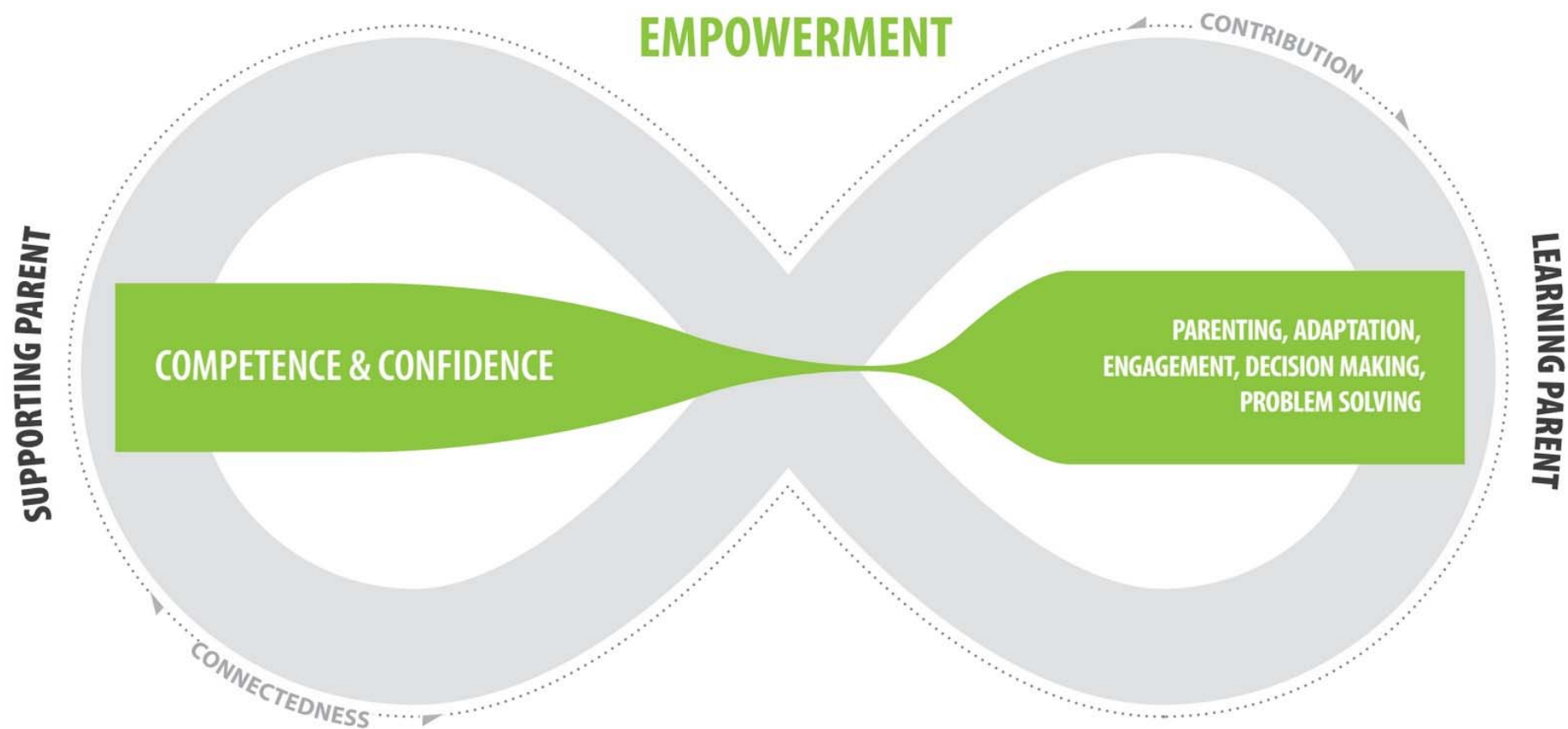


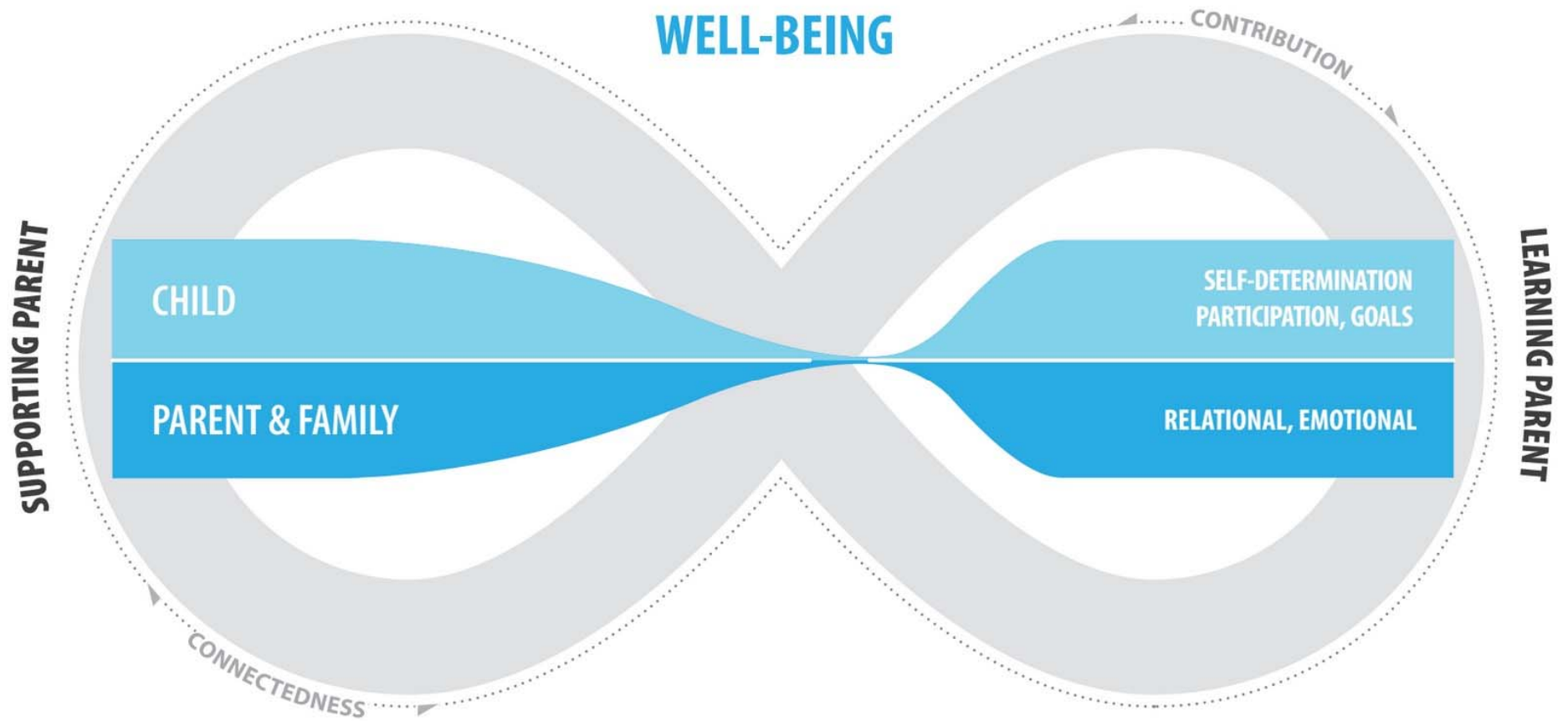
Key Ideas


Results of a study by Mueller et al. (2006) are shared showing that parents VERY involved in their child's treatment helped them to achieve normal language ability by age 5. Hours between treatment sessions should be language rich.

Rationale

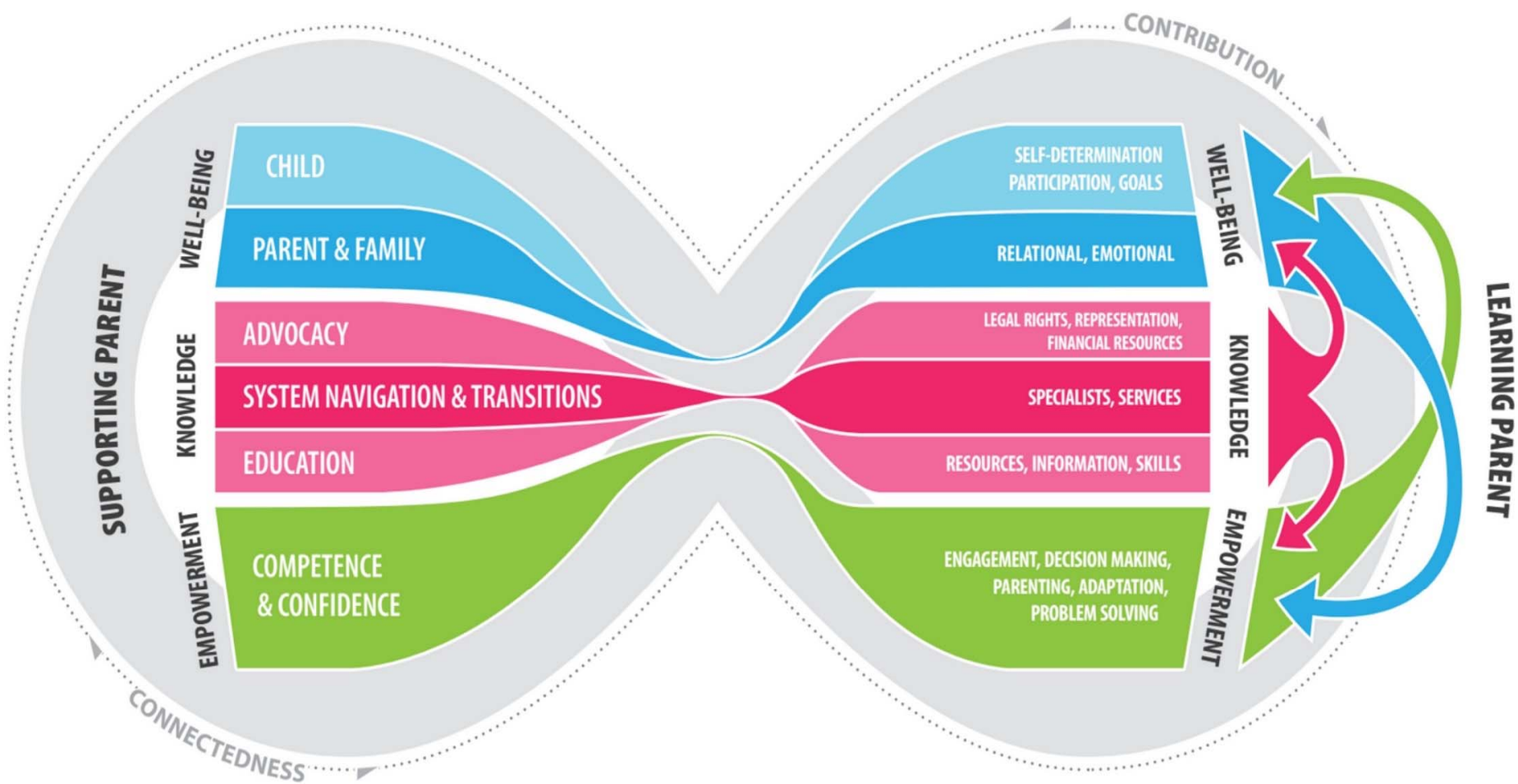
Parents may feel specialist interaction is the answer to their child's language needs & not their use strategies themselves.



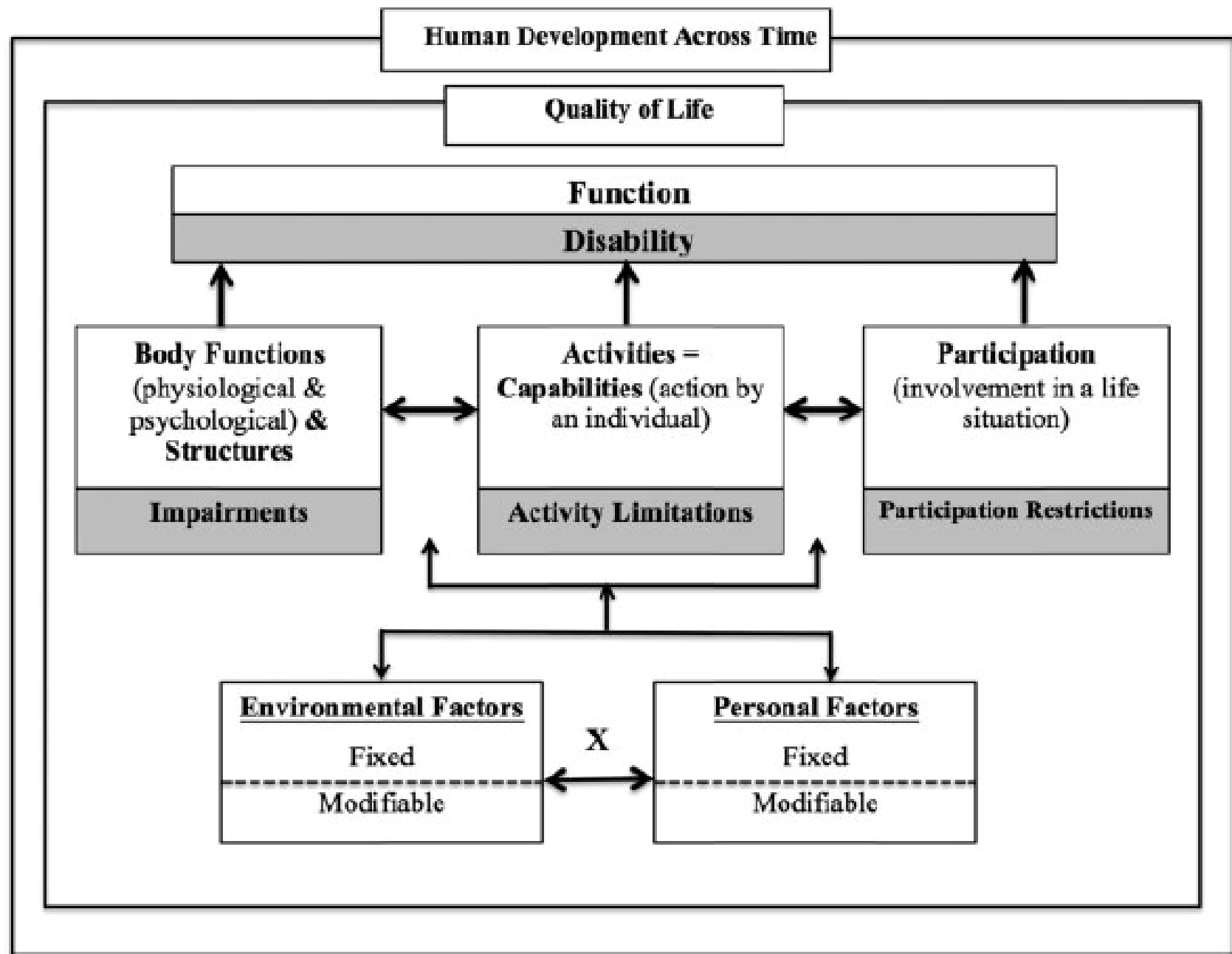




“This exercise has me thinking so much about moments in my life of being supported and supporting other families.... So at the end of the day, there is a component of parent-to-parent support that I believe cannot be written about, researched, labeled, frameworked, or defined. It just is. Maybe it's the listening part, the laughter, the tears, the humor and the wine that just got me through to the next thing, the next day, etc. in this thing we are calling a 'framework' it just is.”





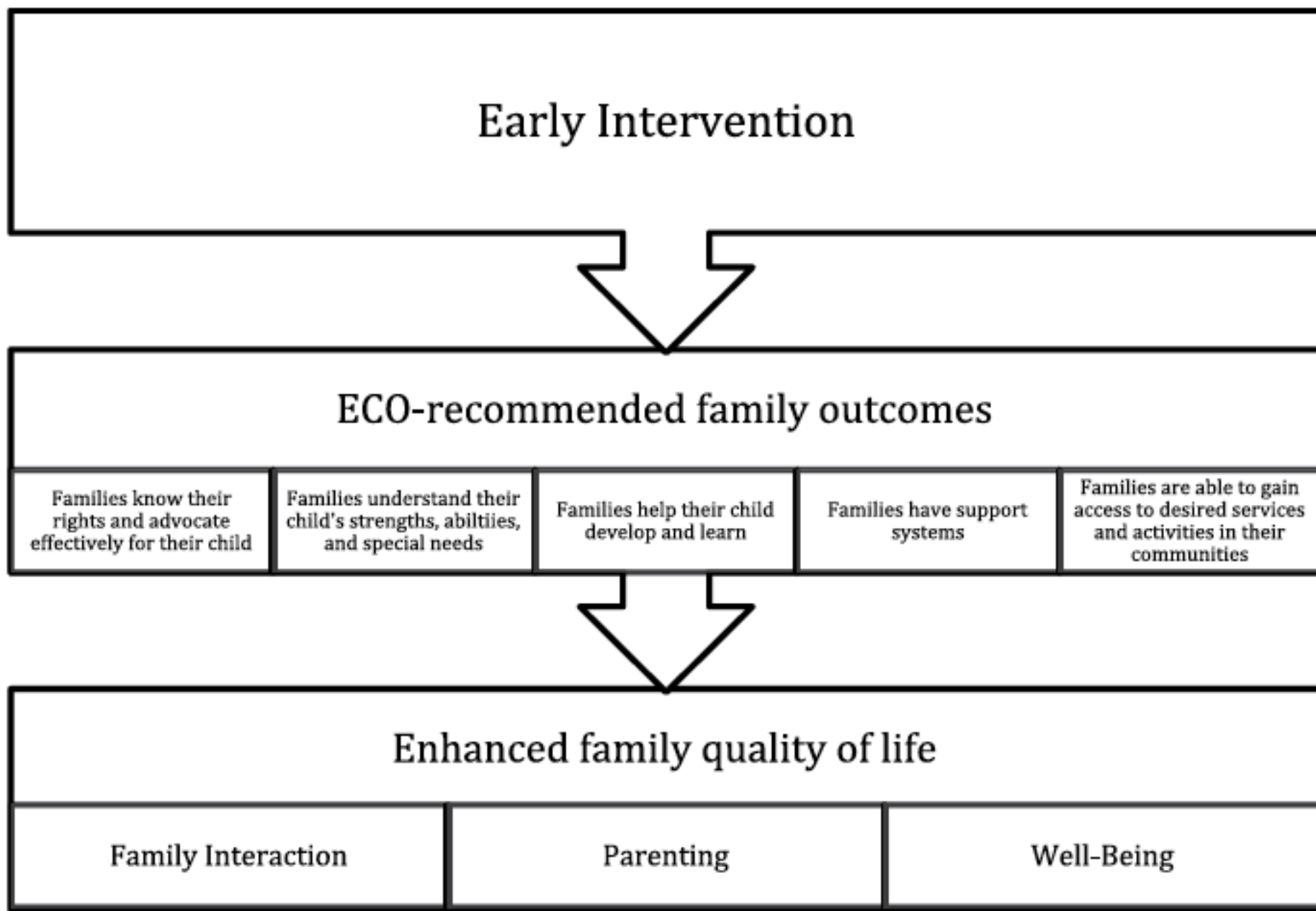


Bagatto & Moodie, 2016

Everyday life situations of children ages birth to 6 months



Adolfsson, Bjorck-Akesson, & Lim, 2013



Bagatto & Moodie, 2016; Wainer, Hepburn, & McMahon Griffith, 2017

Explaining the disability paradox

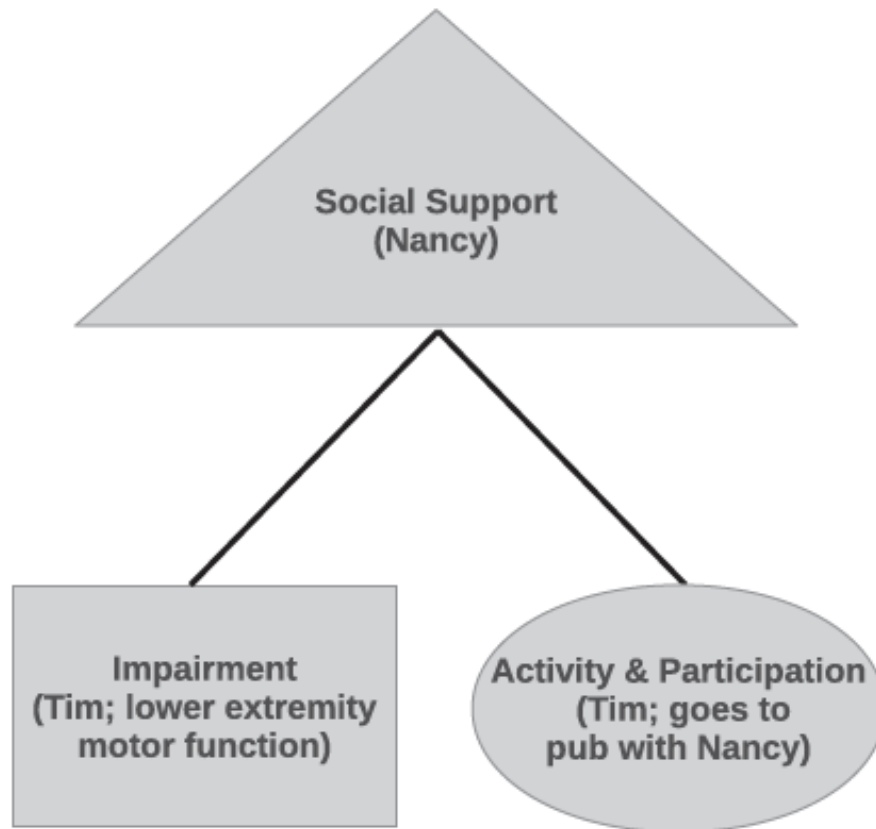


Figure 1 Conditional independence graph. The figure shows an example of a conditional independence graph. Due to the support of Nancy, Tim - who operates in a wheelchair - is not limited in his participation in common activities (e.g. going to a pub).

Fellinghauer *et al. BMC Public Health* 2012, **12**:655
<http://www.biomedcentral.com/1471-2458/12/655>

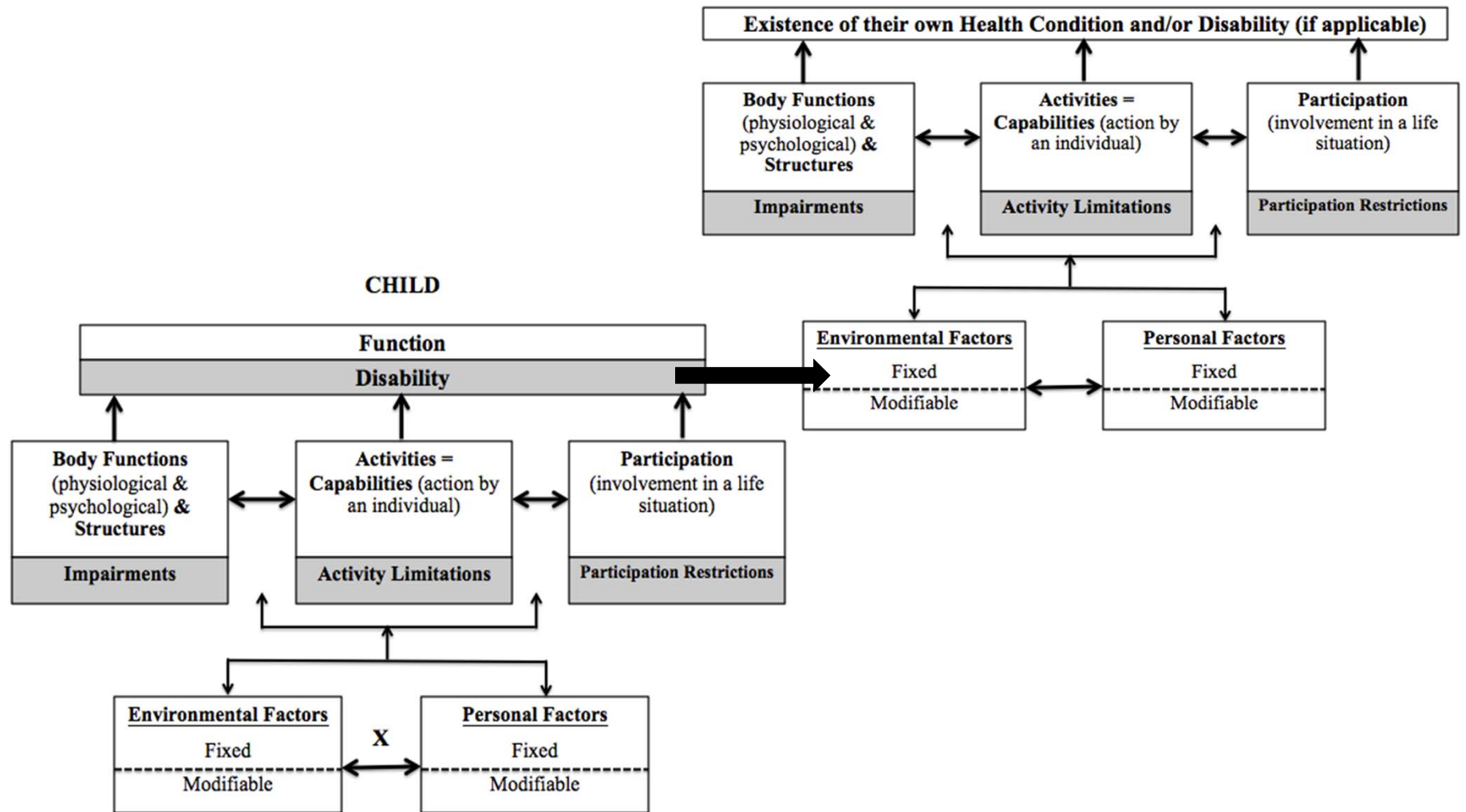
Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement

(Moeller et al., 2013, p. 435)

Principle 4: Family Social & Emotional Support Service providers

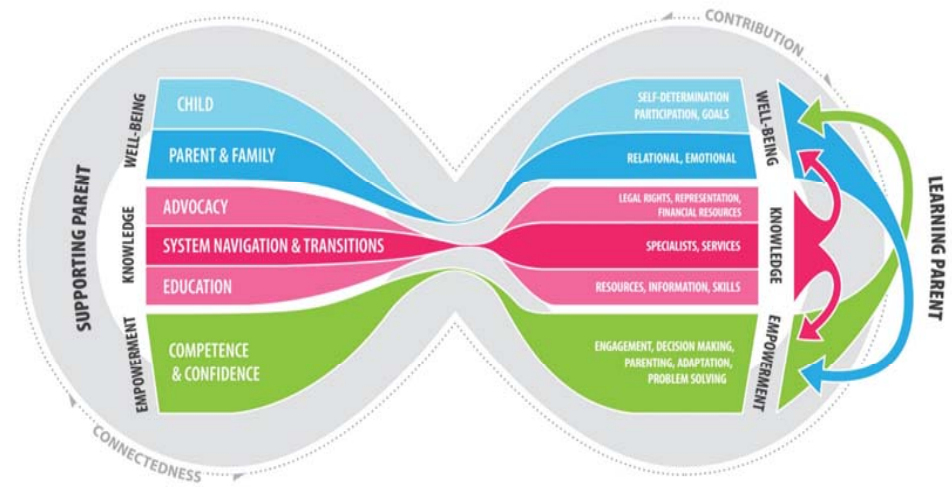
Families are connected to support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their D/HH children.

PARENT(S) FUNCTIONING and THIRD PARTY DISABILITY



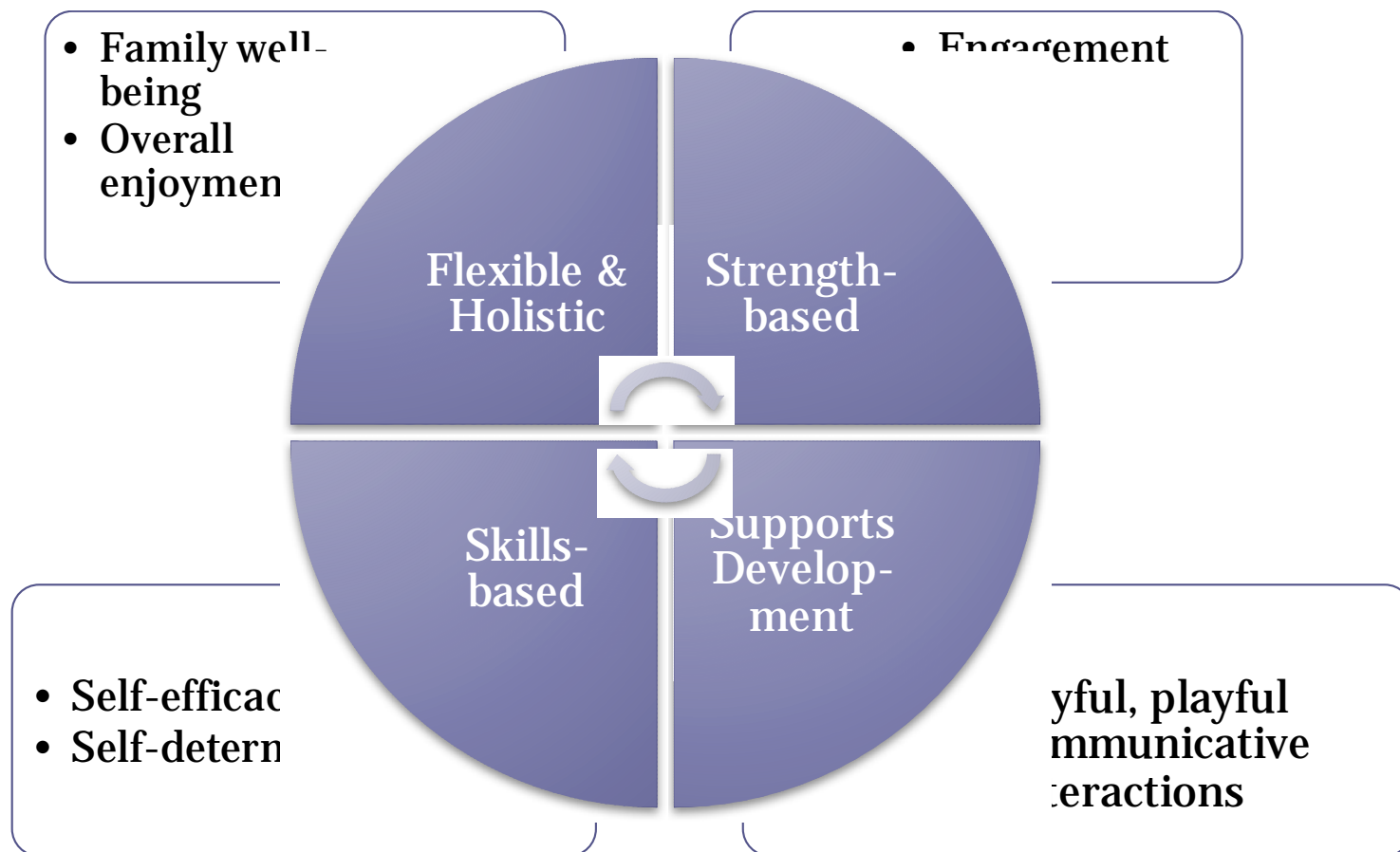
Bagatto & Moodie, 2016. Adapted from Hickson & Scarinci, 2007

Promoting a common understanding



- can help decision-makers understand context and content better, and facilitate interventions
- 20/21 respondents agreed with significant certainty that the conceptual framework has the ability to serve as a model for parent-to-parent support for parents of children who are D/HH.

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Thank you

For further
information or
discussion - or if you
are a potential MSc or
PhD student:



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