

Communication Profiles of Young Children with Fetal Alcohol Spectrum Disorder (FASD): A South African Perspective



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Introduction



- South Africa has the highest prevalence of FASD world wide
- Estimated at 14/1000 (UNICEF, 2008)
- 68.0 – 89.2 per 1000 children in Cape province (Peadon, Fremantle, Bower & Elliott, 2008)
- **SA: 65.2 – 74.2 per 1000 (2005, Gr 1 learners in WC)**
- Highest ever reported in the world
- Countries also suspected of high prevalence but no data yet is Italy, Russia and Finland
- This is true for countries among where prevalence figures are known.



Introduction



- FASD is the leading cause of preventable mental disability in the United States.
- Statistics: 1 % of live births in USA (Burd & Christensen, 2009)
- Despite high prevalence, critical lack of appropriate services in SA



Introduction



- **Dept of Health (2001): Acknowledged a lack of appropriate identification & management of most genetic & congenital disorders in SA.**
- **Young children with FASD have an established risk for communication delay from birth (Rossetti, 2001)**
- **Established risk = need for appropriate EI services.**



Research need



- A need for research regarding the **COMMUNICATION ABILITIES** of young children with FASD was thus identified
- This need formed the platform for conducting this research project in the South African context



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Etiology:



Fetal pathophysiology:



- Unimpeded bidirectional alcohol transference between mother & fetus
- Fetus depends on maternal hepatic detoxification
- Why? Because the activity of alcohol dehydrogenasis in the fetal liver is less than 10 % of that in the adult liver

Etiology:



- Amniotic fluid = alcohol reservoir = prolonged fetal exposure
- Thus leading to: Alteration of fetal development on a cellular level, affecting DNS, fetal growth & causing chronic fetal hypoxia
- Alcohol intake = pervasive effects on developing fetus!

(Dittmer & Lentz, 2004)



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Cascading impact of environmental influences

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graph TD; A[Difficulty understanding communication needs/neglect/abuse] --> B[Disrupts normal social interaction]; B --> C[Consequent negative impact on attachment]; C --> D[Cascading negative impact on language development];
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Difficulty understanding communication needs/neglect/abuse

Disrupts normal social interaction

Consequent negative impact on attachment

Cascading negative impact on language development

Environmental influences



- The caregiving context of the infant & young child is another **contributing factor** to symptom severity.
- Multiple substance abuse impacts the care-giving relationship
- **Optimal energy spent on addiction** not caring for the infant



Environmental influences



- Risk & protective factors present in each young child's life
- Risk factors can contribute to maladaptive parenting & being placed in foster care
- Ecological model comes into play
- There is a strong interplay present between aspects relating to nature & nurture, where interaction takes place between the characteristics of the child with FASD & the environment in which the child is raised



Environmental influences



- **Main characteristics present in caregiving contexts:**

**Health
concerns**

**Safety
concerns**

**Relational
problems**

**Chaotic
lifestyle**

Diagnostic criteria of FASD:

(Carmichael Olson, Jirikowic & Astley, 2007)



Diagnostic terminology	Diagnostic characteristics	Description
1. fetal Alcohol Syndrome (FAS)	<ul style="list-style-type: none">•Prenatal &/or postnatal growth deficiency•CNS impairment•Cluster of cranio-facial dysmorphology•Confirmed prenatal alcohol exposure.	<ul style="list-style-type: none">•Height or weight less than the 10th percentile for GA at birth or later in life•Structural, functional or neurologic brain impairment•Small palpebral fissures (eye slits), thin upper lip, smooth philtrum•Reliable evidence of maternal alcohol consumption*

Diagnostic criteria (cont'd)



- (* If evidence not obtained, it is not deemed necessary if the cluster of facial features is fully present)

Diagnostic terminology

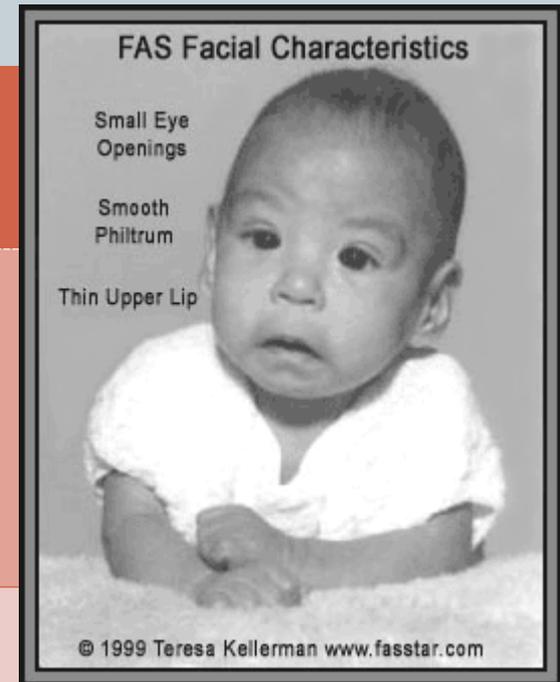
Diagnostic characteristics

2. Partial fetal Alcohol Syndrome (PFAS)

- Growth deficiency
- Cluster of cranio-facial dysmorphology
- CNS impairment

3. Alcohol-Related Neurodevelopmental Disorder (ARND)

- CNS impairment
- Confirmed prenatal alcohol exposure



Role of Early Interventionists: Identification & Assessment



- **What is the aim of comprehensive Early Childhood Assessment?**

Determining each child's profile of strengths & weaknesses

Determining protective & risk factors in family environment

Identification & assessment



- Abkarian (1992) & Rossetti (2001): Early identification & diagnosis are possible as result of recognizable physical appearance which is more pronounced during infancy.
- But, PROBLEM with early id: Later manifestation of deficits or impairments in the cognitive & other developmental domains, can thus lead to inconclusive diagnosis early on.



Identification & assessment



- What helps with id & assessment?
- Knowledge of symptoms in different systems (hand-out available from presenter)
- Tables provide a comprehensive description of most documented possible symptoms in young children with FASD
- The Early Interventionist should thus be aware that children with FASD display a **BEHAVIOURAL PHENOTYPE = biological disorder**



Identification & Assessment



- **Behavioral phenotype (Steinhausen et al., 2003) consists of characteristic patterns of deficits in:**

Motor development

Cognitive development

Linguistic development

Social development

Identification & assessment



- To facilitate ***early*** identification & ***appropriate*** assessment a comprehensive communication profile of the peculiar speech & language deficits of these children would be helpful.
- A literature overview will be provided regarding current knowledge, then the assessment framework & procedures used in the study will be presented and then the communication profiles obtained in this study will be discussed.

Literature overview: Communication profile



- Divided in two periods: infancy & early childhood (see table in hand-out)
- Communication impairment encompass: auditory impairments, feeding difficulties & all aspects of language & communication
- Very limited description of receptive language (most probably because closely related to level of cognitive impairment so does not receive sufficient attention as separate entity)
- **Communication impairment already manifest in infancy**



Literature overview: Communication profile



INFANCY

- Areas most affected in this period of development:

Oral-motor development

Feeding

Expressive language

EARLY CHILDHOOD

- Areas most affected in this period of development:

Expressive language

Pragmatics

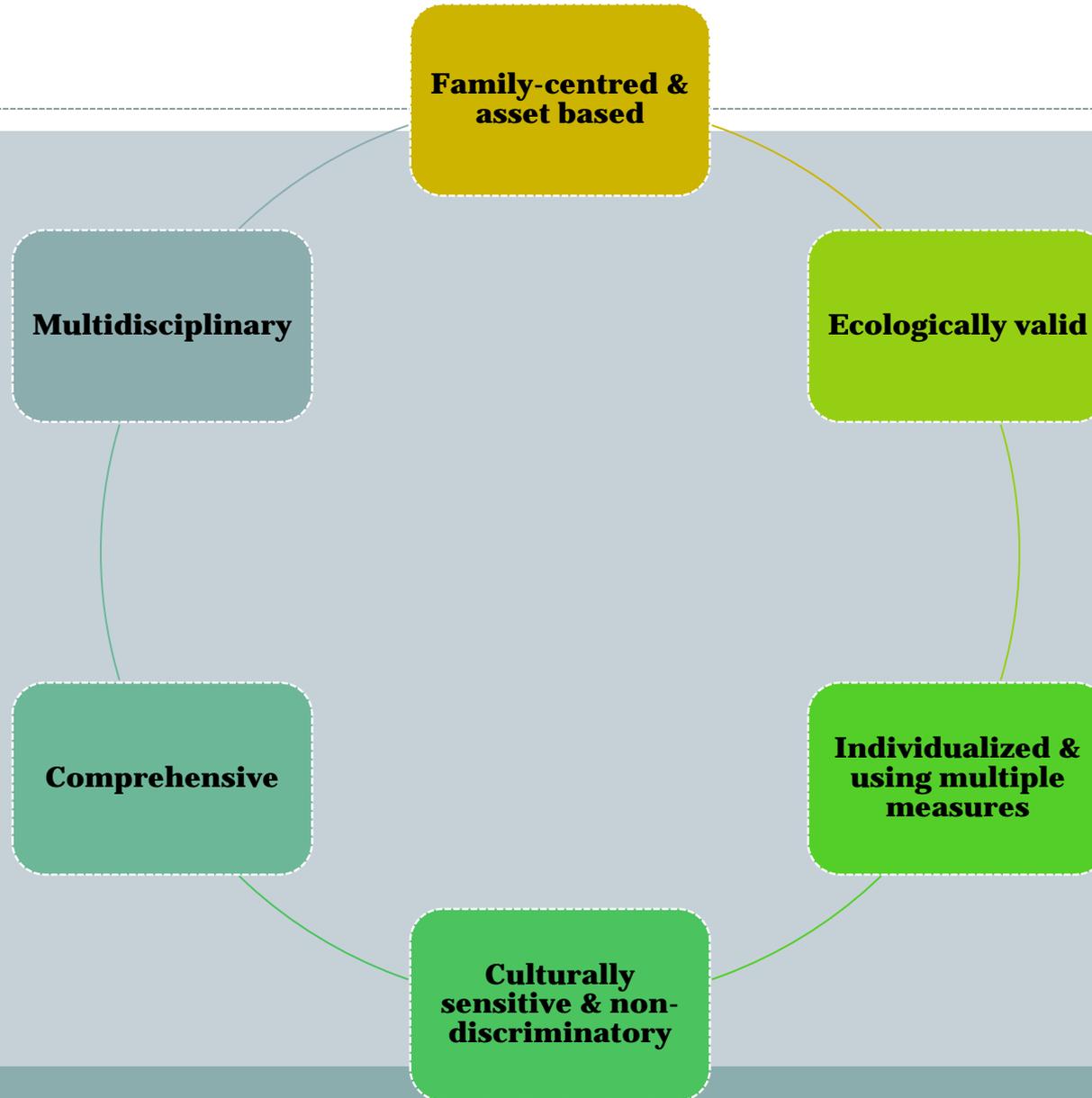
Literature overview: Communication profile



- **High incidence of otitis media** with effusion creating a risk for SNHL = this can also be seen as contributing factor to manifestation of expressive and receptive language impairment
- **Positive characteristics: socially engaging, interested in others, very talkative & overtly affectionate.**
- Prognostic outcome: Children reach academic ceiling during adolescence.
- Life-long persistent problems: memory, learning, attention, judgment & pragmatics



Applied principles of assessment

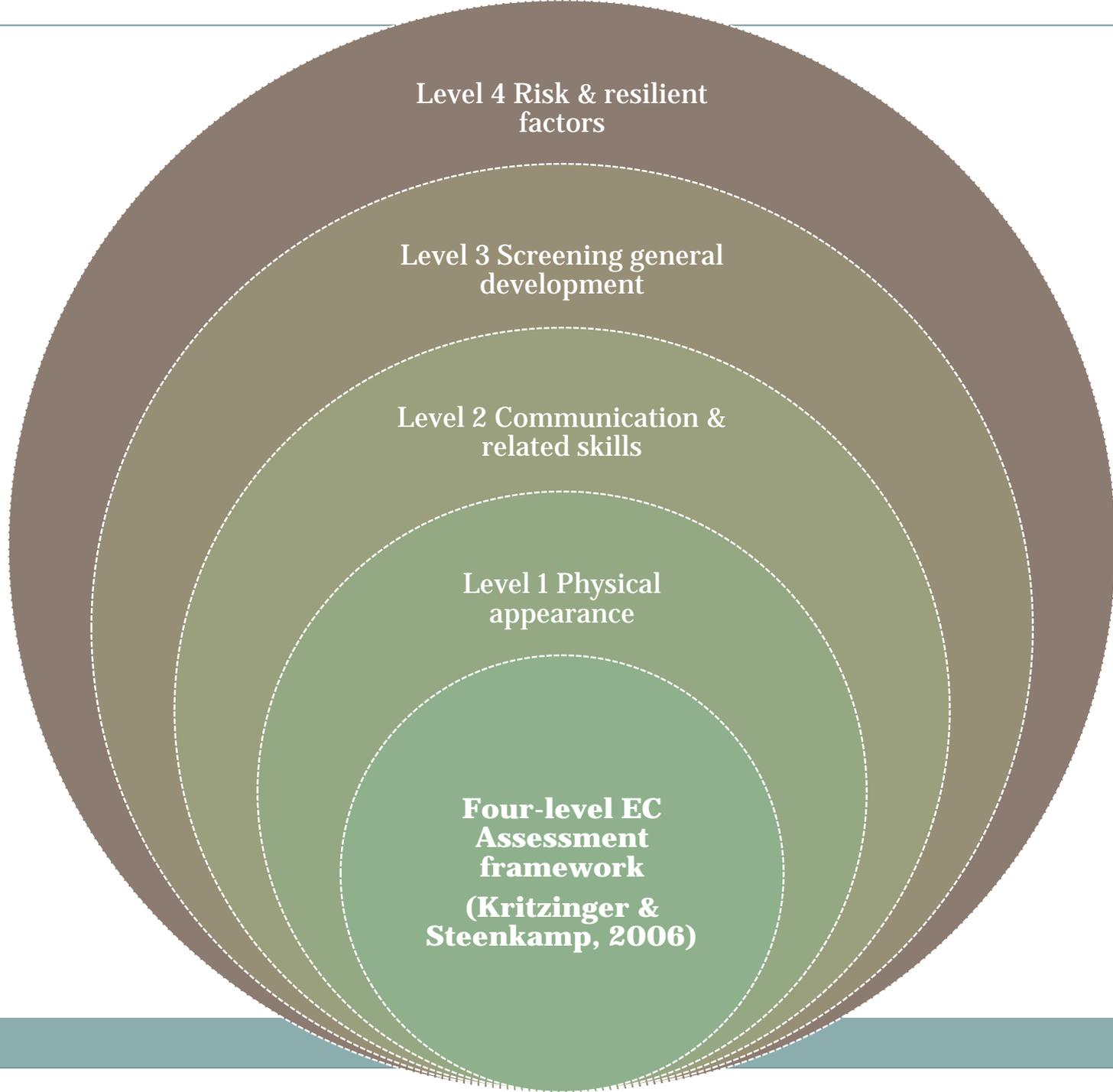


Four-level EC assessment framework (Kritzinger & Steenkamp, 2006)



- A framework with a descriptive developmental orientation, considering transactional nature of development was used in the study
- Previously & currently used at CHRIB
- **Integrative assessment approach may aid you to deliver more valid and appropriate assessment services to this population.**





Results of the study



CASE HISTORIES OF THE PARTICIPANTS:

- Participants' biological families present with **typical problems associated with alcohol abuse**.
- All participants had a confirmed diagnosis of FASD, indicating that early diagnosis occurred despite reports by Viljoen (1999) that children were mostly identified at school entry level in South Africa.
- All participants were living in **foster care**, one was adopted, one in process of adoption



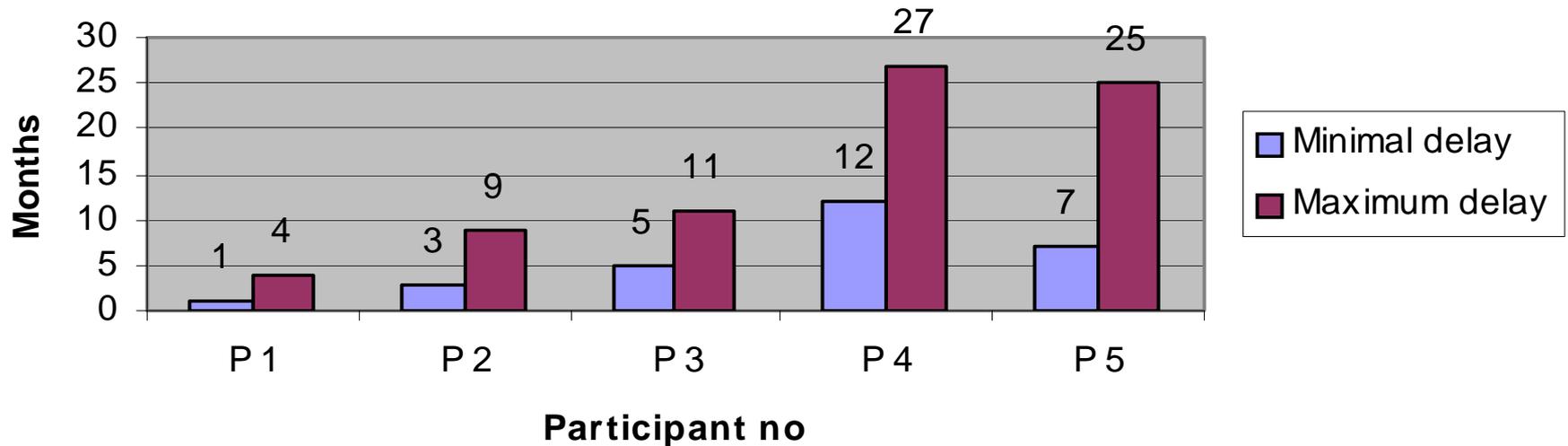
Results of the study



DEVELOPMENTAL TRENDS:

- All developmental profiles were combined to identify possible developmental trends.
- Key: Minimal delay = 1-6 months in comparison with chronological age
Maximum delay = more than 6 months in comparison with chronological age

Developmental Trend



Results of the Study



- **Delays & impairments present in the participants became more pronounced with an increase in chronological age.**
- Trend corresponds with findings of Henry et al (2007) indicating that secondary disabilities associated with FASD often become more disabling as the individual ages.
- In this study there was an increase in the greatest delays and a decrease in the minimal delays, indicating that the severity of the delays was increasing.



Communication Profile: Infancy – 58 months



Infancy

- Expressive language (phonetic inventory, babbling, cooing)
- Oral-motor difficulties (difficulties with feeding)
- Regulatory difficulties

+ - 18 months

- Expressive language (vocab)
- Pragmatics (social use)
- Oral-motor difficulties
- Listening skills (paying attention to speech)
- Receptive language (understanding)
- Emergent literacy (interest in books & drawing)
- Cognition

Communication Profile: Infancy – 58 months



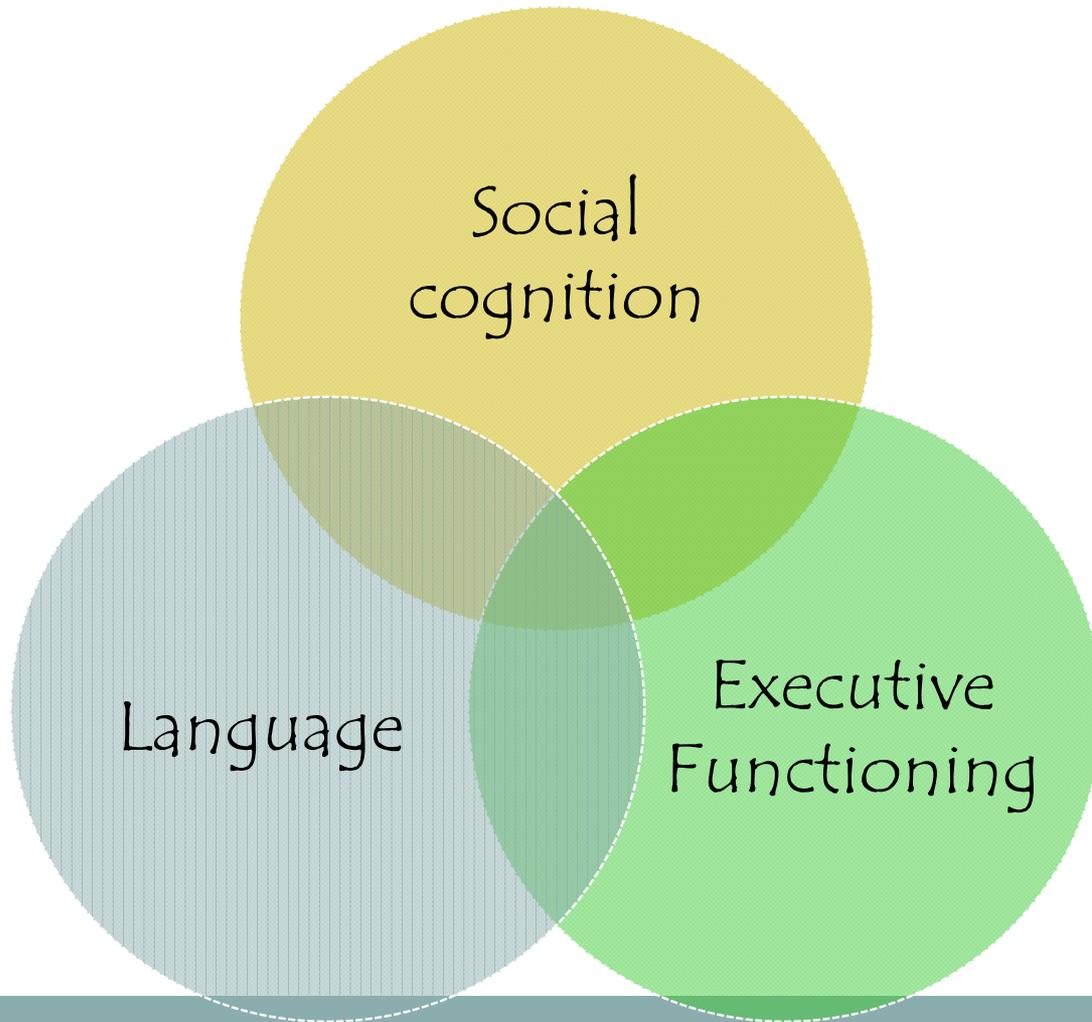
35 months

- **Additional:**
- **Personal-social skills (interaction)**
- **Play**
- **Resolving:**
- **Oral-motor difficulties**

51 & 58 months

- **Increase in severity of range of communication difficulties**

Putting it together: 3 similar areas of impairment



Putting it together



- Young children with **FASD** present with **complex histories, cultural perspectives and clinical profiles** (Rogers-Adkinson & Stuart, 2007).
- Dynamic, interactive assessment in an interdisciplinary team is thus crucial
- Knowledge regarding the **triad of impairments** described by Coggins et al. (2007) could serve as a guideline for the Early Interventionist when assessing a young child with FASD.



Putting it together



- **Timely ECI is important**, because **developmental plasticity is still present to facilitate developmental gains** & to minimize the effect of the communication and general developmental impairments that are present (Batshaw & Conlon, 1997).
- It is also clear from the results of the collective case studies that **prenatal alcohol exposure has an impact on core developmental processes** such as the neuro-physiological growth of the brain and nervous system, psychological development regarding personality formation and social cognition and communication (Henry et al., 2007).



Putting it together



- Due to the effect of FASD on the core developmental processes a **wide array of developmental domains are affected in infants and young children affected with FASD.**
- The results of the **study also confirmed severe communication impairments as the area of key deficit.**



Putting it together



- Furthermore, to confirm the evidence of language impairments in infants and young children with FASD, voxel-based morphometry data showed anomalies in the **temporo-parietal cortices in the left hemisphere, which are the areas critical for language processing** (Kodituwakku et al., 2006).
- Speech-language therapy is therefore most important for children with FASD, as language functioning is a predictor of school success (Rossetti, 2001).



Putting it together



- Thus **language impairments will impact on the areas of academic, behavioural and social interactive competence** in young children with FASD.
- A comprehensive Early Intervention service delivery plan is thus required to address the needs of young children with FASD and their families.





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