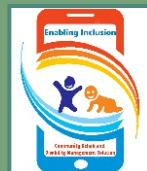




Family Centered Services Manual for Service Providers

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Enabling Inclusion through
Early Intervention (EI) Programme



AMAR SEVA SANGAM



Amar Seva Sangam (ASSA) is a premier organisation in the field of disability management focusing on rural areas, located in Ayikudy Village in Tenkasi District of Tamil Nadu. Our approach is to establish a centralised resource center to act as a catalyst for change in the development of children and adults who are differently abled and intellectually challenged. We do this by involving the village community in the process. This mission of ASSA is to establish a Valley for the Disabled, whereby persons with physical / intellectual challenges live in a pro-active society where equality prevails irrespective of physical, intellectual or other challenges with the rest of the society. It is a futuristic vision whereby Amar Seva Sangam plays the role of an enabling agent to provide persons with physical / intellectual challenges "equality of status, equality in opportunities and equality in access".

Amar Seva Sangam (ASSA) was established by Mr. Ramakrishnan, in the International year of the Disabled to cater to disability management focusing on rural areas.

S. Ramakrishnan, Founder President



S. Ramakrishnan, while in his 4th year engineering, injured his spine while attending the last round of Naval officers' selection test and became a quadriplegic. He established ASSA in 1981, the year for the Disabled and named it after his Doctor and mentor Air Marshal Dr. Amarjit Singh Chahal of Defence hospital. **Padma Shree awardee** S.Ramakrishnan is the President of ASSA.

S. Sankara Raman, Secretary



S. Sankara Raman, a Chartered Accountant and a wheel chair user, affected by muscular dystrophy joined ASSA in 1992. He is the Secretary of ASSA. Along with Mr. Ramakrishnan, they have built a **Valley for the Differently Abled** in a 30 acre land

at Ayikudy, as a Rehabilitation and Development Centre and developing models for self-help initiatives by integrating individuals with disabilities within society for improved living conditions.

In 2020, he established Amar Seva Global, a social enterprise focused on spreading Amar Seva's Enabling Inclusion program globally.



What is Development Delay ?

Skills such as taking a first step, smiling for the first time, and waving “bye-bye” are called developmental milestones. Children reach milestones in how they play, learn, speak, behave, and move (for example, crawling and walking). Children develop at their own pace. However, when developmental milestones are not met by a certain expected age, it is called “developmental delay”. Early stimulation and intervention can help children reach these milestones.

What is Development Disability?

Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, social or behavioral areas. These conditions begin during a child's developmental period, may impact day-to-day functioning, and can last throughout a person's lifetime. According to the WHO, “If children with developmental delays are not provided with appropriate early intervention, their difficulties can lead to lifetime consequences, increased poverty and profound exclusion”.

What is Early Intervention?

Interventions promoting child development should address physical, social, emotional, language, and cognitive areas of development. Services targeting these domains of development are termed, “Early Intervention therapy” and can encompass physical therapy, occupational therapy, speech-language therapy and special education. Early Intervention has a significant impact for children who have delayed development in physical, cognitive, emotional, sensory, behavioural, social and communication domains of development. With quality early intervention services, children can reach their potential, live a meaningful life and integrate into their communities.

Enabling Inclusion Programme

Amar Seva Sangam's Enabling Inclusion programme uses community rehabilitation workers to provide early intervention services to children in their own homes or in community centres by connecting these community workers with rehabilitation specialists (physiotherapists, occupational therapists, speech therapists/trainers and special educators) through the use of the award winning Enabling Inclusion (EI) app. The program has proven to improve outcomes for children with disabilities and their family members and has allowed many children to reach their potential.





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The Family and Coping with the Demands of Raising Child with Disability

Families of Children with Disability carry a huge burden:

- Understanding the child's conditions and needs.
- Time spent for everyday child's care.
- Time spent for therapy and hospital visits.
- Financial burden for therapeutic and medical care.
- Care of siblings and other family members.
- Expectation of extended family members from the child.
- Stigma posed by the society
- And there are many more.

Uniqueness of the families:

- Each family is different; each family's beliefs, needs and coping mechanism are different.
- Each member of the family face different level of stress and it is interlinked.
- The family's emotion and wellbeing directly affects/ have impact on the child's intervention.
- Family is with the child all the time; it is constant in the child's life.
- Family knows the child best, what works, how the child performs, her likes and dislikes etc. they are the expert in knowing the child.
- Family knows their situation, environment best

As a professional and service provider, we know about the condition and the possible therapeutic intervention.

Family knows the particular child, their environment, their needs and priorities.

Families are equal and important member of the team that facilitates the services.



Family: The recipients of services:

Intervention for children can be facilitated only through the parents/caregivers. Child is the part of the family and the family has full responsibility in bringing up the child. Parents/families are the main pillar in training the children the children. For effective intervention family's needs and coping mechanism should be considered.

What are Family Centered Services?

Family Centered Services is an approach that acknowledges the importance of the family as a recipient of services, ensuring the participation of all its members in the planning of actions and revealing a new model of service, offering the opportunity for the family itself to define its own problems.

It is a set of values, attitudes and approaches to service for children with special needs and their families.

Elements of Family-Centered Care (FCC) as proposed by the Institute for Family-Centered Care (2005)

- Recognizing the family as a constant in the child's life;
- Facilitating parent-professional collaboration at all levels of intervention
- Honoring the racial, ethnic, cultural, and socio-economic diversity of families;
- Recognizing family strengths and individuality and respecting different methods of coping;
- Sharing complete and unbiased information with families on a continuous basis;
- Encouraging and facilitating family-to-family support and networking;
- Responding to child and family developmental needs as part of health care practices;
- Adopting policies and practices that provide families with emotional and financial support;
- Designing health care that is flexible, culturally competent, and responsive to family needs.



How to be Family-Centred?

- ✓ Acknowledge the strengths of the family and respect its individuality and manner of caring.
- ✓ Family's priorities in addressing the child's care.
- ✓ Encourage family members to identify their needs and goals and possible ways of achieving those goals and meeting those needs.

While goal setting, ask the families about their priorities
While planning the intervention consider their time, economical status, educational status, human and economic resources etc.

- ✓ Acknowledge Family's concerns and limitations in addressing the child's needs.
- ✓ Share information on therapeutic services and other related services, general information on the relevance of therapeutic services, source for further reference etc.
- ✓ Involving other family members and extended family members; give examples of possible ways of involving them.
- ✓ Therapy visits should be planned in consultation with family by finding out the best date, time, place.
- ✓ Encourage parents to ask questions and take time to address these questions.

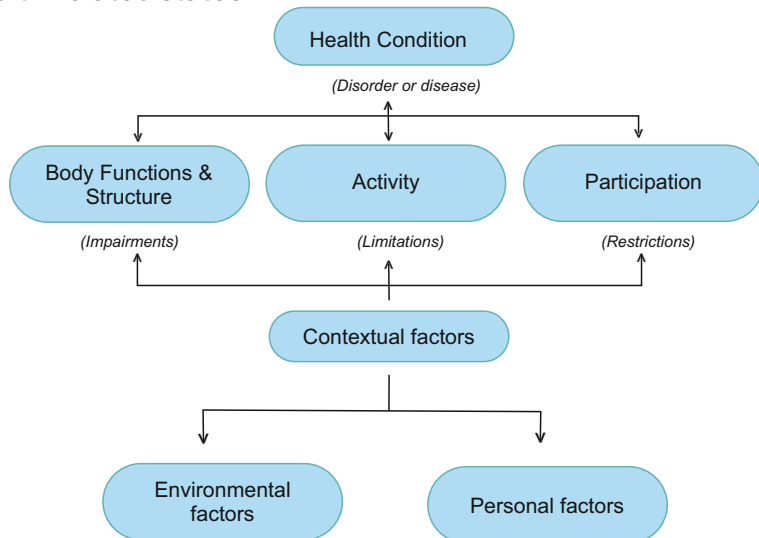


International Classification of Functioning, Disability and Health (ICF)

People who suffer from the same health conditions **do not** necessarily have the same amount of limitations in function and participating in social life.

For example, consider two persons have same type of cardiac disease. But their functional and participatory level may not be at same level. There are other factors that have direct impact on the level of functioning than the disease itself. Any health care system that addresses the disease in isolation may not directly give the same expected result.

Understanding this fact, WHO (World Health Organization) has introduced a framework interlinking the various factors involved in functional outcome of a person when he/she has a health condition – International Classification of Functioning, Disability and Health (ICF). It provides a unified and standard language and a framework for the description of health and health-related states.





Scope of ICF

ICF provides a description of situations with regards to human functioning and its restrictions and serves as a framework to organize this information. It structures the information in a meaningful, interrelated and easily accessible way.

ICF organizes information in two parts.

Part 1: Deal with Functioning and Disability

Part 2: Covers Contextual Factors.

Each part has two components.

Components of **Functioning and Disability** are divided in:

(1) **Body component** including Body functions and Anatomical structures. A problem in body function or structure is noted as an **Impairments**;

(2) **'Activity' and 'Participation'** components

Activity is defined as the execution of a task or action by an individual

Participation is defined by involvement in a meaningful life situation.

Component of **Contextual factors** is an independent and integral component of the classification and is divided into:

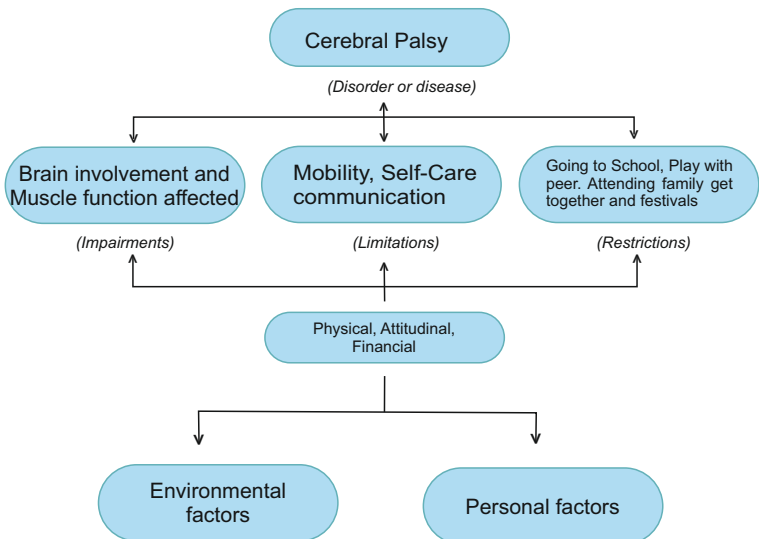
(1) **'environmental factors'** (physical, attitudinal, social) and, (2) **'personal factors'**

'Environmental factors' have an impact on all components of functioning and disability and can act as barriers or facilitators.



The conceptualization provided in the ICF makes it impossible to understand disability without consideration and description of the environmental factors. The language used in this framework is neutral, placing the emphasis on participation rather than condition or disease.

Application of ICF in Childhood Disability



There will be limited outcome in **Activities** and age-appropriate **Participation** of persons with Cerebral Palsy when we work on person's impairment level like minimizing the tone, correction of posture, facilitation of developmental milestones etc.

If our goals are towards promoting participation, all other relevant factors will be addressed from impairment to contextual factors.



ICF and F-words

The CanChild Centre for Childhood Disability Research, Canada have introduced - “F” words in the ICF framework for childhood disabilities. The “F” represents the child's “favorite words”.

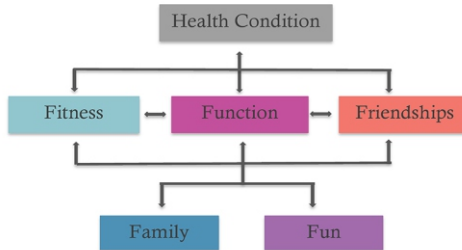
The purpose of the F-words in ICF framework

- To shift attitude towards holistic strengths-based approach.
- To promote physical activity and rehabilitation-based intervention.

**“The ‘F-words’ in Childhood Disability:
I swear this is how we should think!”**

Help us spread awareness on these 6 F-words!
Function – Family – Fitness – Fun – Friends – Future

The F-words in Childhood Disability¹ are based on research and build on the World Health Organization’s (2001) International Classification of Functioning, Disability and Health (ICF) Framework². These 6 F-words are important to ALL children’s development and remind us to focus on what children CAN do.



**FOR MORE
INFORMATION
PLEASE VISIT:**

<http://canchild.ca/en/research-in-practice/f-words-in-childhood-disability>



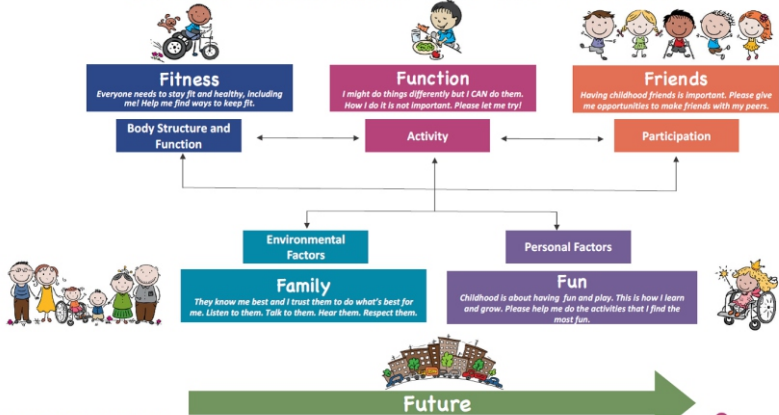
References:

- ¹Rosenbaum, P., & Gorter, J.W. (2012). The ‘F-words’ in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, 38(4), 457 – 463.
- ²World Health Organization. (2001). *The International Classification of Functioning, Disability and Health (ICF)*. World Health Organization, Geneva, Switzerland.

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The ICF Framework¹ and the 'F-Words'²



¹ World Health Organization. (2001) International Classification of Functioning, Disability and Health (ICF)
² Rosenbaum, P. & Gorter, J.W. (2012). The 'F-words' in childhood disability: I hear this is how we should think! Child Care Health Dev. 38.
 *Photos shared with permission from World CP Day.

For more information visit the F-words Knowledge Hub:
www.canchild.ca/f-words



CEREBRAL PALSY

My Favourite Words

FUNCTION

I might do things differently but I CAN do them. How I do it is not important. Please let me try!



FAMILY

They know me best and I trust them to do what's best for me. Listen to them. Talk to them. Hear them. Respect them.



FITNESS

Everyone needs to stay fit and healthy, including me. Help me find ways to keep fit.



FRIENDS

Having childhood friends is important. Please give me opportunities to make friends with my peers.



FUN

Childhood is about fun and play. This is how I learn and grow. Please help me do the activities that I find the most fun.



FUTURE

I will grow up one day, so please find ways for me to develop independence and be included in my community.



Based on Rosenbaum, P. & Gorter, J.W. (2012). The 'F-words' in childhood disability: I hear this is how we should think! Child Care, Health and Development, 38:4. Visit fcpa.ca and www.canchild.ca for more information on our work in childhood disability for more resources.

World Cerebral Palsy Day
 #WorldCPDay worldcpday.org





Understanding the Rights Perspective:

Consider we are invited for a meeting on the second floor of a building in our town. Our presence in this meeting is essential for our future endeavours. When we reach the building, we realize that there are no steps to go to the second floor and only a rope is hung. Only few people that can climb up could get to the second floor.

What would be our reaction?

Wouldn't we ask for a reasonable way of reaching the venue? We believe that it is our rights to ask for a reasonable way and it can be demanded.

Finally, we find steps to get to the venue. Most of the people reached the place. Few Persons with physical disability still could not get through the steps and they are demanding for a lift.

What would be our reaction?

Do we all consider this request is genuine?

Similarly, we should understand the right perspective for children and people with disabilities. We need to modify their environment and make the world more functional for them so that they can reach their potential.

The ICF, F-words and Goal settings

The ICF framework gives a holistic approach for functioning and participation while F-words for childhood disability brings these ideas into the child's life; here we work on what the child would be doing in her life (Function and Participation) rather than what the child cannot do and working on improving these individual skills. (Limitation in body structure and function)

When we work with the families and setting goals for the child, we introduce the F-words to the families and let the family members to think through these ideas for their child.

We use the COPM for **participatory goal setting**. So family is involved all the way from selecting the goals to working on



these goals. The step 1 A would be mostly the goals for function, step 1 B and 1 C would be the goals for friends and Fun. The goals for fitness would align with participatory goals.

Participatory Goals chosen by parents and using the EI App Case Study 1

Name: Kavin.

Age: 3½ years

Sex: Male.

Diagnosis: Autism.

Family: Kavin lives with his mother in maternal grant parent house and his cousins' family live nearby. His father is working in Indonesia and visits him once in 6 months.

Kavin will attend Kinder Garden School regularly from June 2020. The preparatory skills necessary to attend KG school are identified by the parent.

With the guidance of F-words – family set the following goals for Kavin:

Parents Goals facilitated through COPM and F-words:

Goal 1: To eat tiffin items by himself with minimal verbal prompting by teachers.

Goal 2: To express his needs to use toilet, pain and discomfort verbally to the teacher.

Goal 3: To use water taps only for need.

Goal 4: To play games like ball throw, riding cycles in turn and hide and seek with

ICF and F-words Components

Goals 1,2,3 fall under the **FUNCTION** (*activity*) aspect of F-words. Goal 4 falls under the **FRIENDS** (*participation*) and **FAMILY** (*environment*) aspect of F-words.

His grandmother and elder cousin will be facilitating the goal 4. His grandfather will take him to water theme park at weekends (positive reinforce) to condition him to use water taps only when needed. In this way, the **FAMILY** (*environment*) is involved and supporting the child. He loves playing in water, so going to water theme park is **FUN** (*personal factors*) and that is taken as a reinforcer.



El App Goal Components

The GOALS identified are **Self-care aspect, socialization aspect of special education and speech component of the El App.**

Classification	Problem	Goals	Activities
Special education (personal)	Unable to take food with fingers	To eat with fingers	To take food with fingers
Special education (personal)	Unable to indicate verbally for	To indicate verbally for	Indicate verbally for toileting
Speech (Personal)	Does not communicate his/her intention	Attempting to communicate his/her intention	Teach appropriate simple word for each need like food, toy, play, sleep etc. Encourage child to tell these words appropriate situation.
Special education (behavioral)	Constantly engaged in activities that gives pleasure	Engage in pleasure activities only on allotted time	To condition for using the pleasure only on given time



Case Study 2

Name: Udayakumar

Age: 6 years

Sex: Male

Diagnosis: Hearing Impairment

Parent identifies their priorities for Udayakumar. They wish for him to participate in class activities by understanding the common commands and expressing his needs by words.

With the guidance of F-words – family set the following goals for Udayakumar:

Parents Goals facilitated through COPM and F-words:

Goal 1: To participate in class by understanding common commands in school (to identify 20 commands in the school setting with the teachers)

Goal 2: To express his needs using words in school (identify words to be trained)

Goal 3: To greet his teacher using words and to tell his name when he is asked.

F-words Components

Goal 1, participating in class activities, falls under the **FRIENDS** component of the F-words. (Age-appropriate activities with his friends). Goals 2 and 3, expressing verbally, fall under the **FUNCTION** component of the F-words.



EI App Goal Components

The GOALS identified are **speech** and **special education** of the **EI App**.

Classification	Problem	Goals	Activities
Speech-Labeling through speech	Unable to say objects in school	To label through speech.	Using real objects, flash cards and lips reading.
Speech-Sound identification and production	Unable to identify and produce "aa", "oo", "ee", "mm" sounds.	To identify and produce "aa", "oo", "ee", "mm" sounds and appropriate.	Teach "aa", "oo", "ee", "mm" sounds in isolation, initial, middle and end

Other Components:

Environment	Request teachers to get Udayakumar's attention and give instruction slowly so that he can follow the instructions. Initially simple gestures along with oral instructions can be used and gradually it can be increased. When he speaks with sound, reinforce with the word.
	Other students to get Udayakumar's attention and talk to him.



Case Study3

Name: Karthik Raja

Age: 7 years

Sex: Male.

Diagnosis: Down's syndrome

Family: Karthik's family members are his parents, one younger sister and Grandparents.

With the guidance of F-words – family set the following goals for Karthick:

Parents Goal's facilitated through COPM and F-words:

Goal 1: Karthik will be attending his class at least 2 periods each day.

Goal 2: Karthik will play hide and seek and duck goose games with his friends for 15 minutes

Goal 3: Karthik express his basic needs by words in school whenever required.

Goal 4: Karthik express his needs (toys, actions and other materials – 25) by single words.

F-words Component

Goal 1 falls under FRIENDS component of F words; Goal 2 falls under FRIENDS, FUN and FITNESS, Goal 3 and 4 fall under FUNCTION component of F-words.

He likes to be with children, so play with other children is taken as goal which is FUN for him and promotes his FITNESS.



El App goal components:

The goals identified are **special education** and **speech component of the El App**.

Classification	Problem	Goals	Activities
Special education (social)	Unable to play with other children	To play with two children cooperatively	Passing the ball
Special education (social)	Unable to wait for his turn	To wait for his turn in the classroom, playground, dining room	Other play activities
Special education (social)	Unable to differentiate stranger from familiar people	To respond appropriately to words along with gesture	Identify his/her family member
Special education (social)	Unable to respond appropriately to words and gestures	To follow simple commands without gesture	Look at the persons (such as come, up, go, bye-bye,
Special Education (social)	Unable to follow simple commands	To follow simple commands without gesture	Create a situation
Special Education (personal)	Unable to indicate verbally for toileting	To indicate verbally for toileting	Indicate verbally for toileting
Environment	Teachers should be guided suitably to engage the child in the class with other children during the selected 2 periods. Positive reinforcement can be used to strengthen and maintain the behavior. (to stay in his class)		
Family	Father can be involved in facilitating the play with the peers.		



Case Study 4

Name: Subba

Age: 3½ years old

Sex: Female

Diagnosis: Cerebral Palsy-Spastic Diplegia- GMFCS Level III

Family: Subba's family members are his parents, one older brother and grandparents.

Home environment: Lives a small 1 level house with irregular grounds around home.

With the guidance of F-words – family set the following goals for Karthick:

Parents Goal's identified through COPM and F words:

Goal 1: Subba walk indoors for function and short distances outdoors with support for socialization with neighbourhood friends.

Goal 2: Subba will participate at mealtimes and eat dosa with hands sitting on floor with her family

Goal 3: Subba will express her needs using short sentences

F-words Component

Goal 1 falls under FITNESS, FUNCTION AND FRIENDS component of F-words; Goal 2 falls under FUNCTION and FAMILY, Goal 3 falls under FUNCTION component of F-words.

She likes to be with children, so walking outdoors to be with other children is taken as goal which is FUN for him and promotes his FITNESS and FUNCTION. Expressing her needs falls under the FUNCTION component of the F words; participating in meals with family falls under the FAMILY component of the F words.



El App Goal Components

The goals identified are **physiotherapy, special education and speech components of the EIAPP.**

There is also environmental adaptations needed and use of walking aids.

Classification	Problem	Goals	Activities
Physiotherapy	Unable to walk with a walking aid	To walk with a walking aid within the home for	Provide a walker
Physiotherapy	Unable to sit independently without arm support	To sit with 1 arm support- to allow hand use for eating	Sitting with straight back and reaching up (unilateral or bilateral)
Special education	Unable to eat by self with fingers	To eat by self when food is mixed and given	Provide physical assistance or verbal guidance as needed
Speech	Unable to use simple sentences	To use simple sentences	Teach to express needs through modelling

Other Components:

Environment	Subba will be prescribed her own walker, adaptations to be made to home and area surrounding her will be levelled. Subba will sit on floor with back in corner or against a wall while eating
Personal	Family members will support Subba's use of her walker, will encourage her to sit with them at mealtimes to feed



Case Study 5

Name: Sivaana

Age: 2 years old

Sex: Female

Diagnosis: Cerebral Palsy-Spastic Quadriplegia- GMFCS Level IV, Cortical Visual Impairment (CVI)

Family: Sivaana 's family members are his mother and grandmother. She is an only child.

Home environment: She lives a small home with little resources.

With the guidance of F-words – family set the following goals for Karthick:

Parents Goal's facilitated through COPM and F words

Goal 1: Sivaana will look and reach for a small bright object in her hands for play

Goal 2: Sivaana will hold her head to look at parents face for short periods in a supported sitting position

Goal 3: Sivaana will roll for floor mobility

F-words Component

Goal 1 falls under FITNESS (vision) and FUNCTION component of F-words; Goal 2 falls under FUNCTION and FAMILY, and Goal 3 falls under FUNCTION component of F-words.



El App goal components:

The goals identified are **physiotherapy** and **special education components of the El app.**

Classification	Problem	Goals	Activities
Physiotherapy	Unable to reach for an object with 1 hand	To reach for an object in midline	Use bright object in midline Guide arm
Physiotherapy	Unable to sit without support Unable to hold head up in midline	To sit with support To lift head up in midline in supported sitting	To provide adaptive supported sitting, stabilize pelvis and trunk Encourage head lifting in supported sitting with bright toys or sound toys
Physiotherapy	Unable to roll supine to prone, prone to supine	To roll supine <-> prone	Guide arms, legs, trunk for rolling Use motivating object
Special education Low vision	Unable to fixate or follow an object	To fixate a bright object	Move a bright object in front of child's eyes
Special education Low vision	Unable to follow a moving ball	To follow a moving ball	Move a rattle ball in front of eyes slowly



References:

1. http://www.scielo.br/scielo.php?script=sci_arttext&pid=S010407072012000100022&lng=en&nrm=iso&tlng=en
2. <http://rssandbox.iescagilly.be/international-classification-of-functioning-disability-and-health.html>
3. <https://www.canchild.ca/en/resources/256-f-words-awareness-poster>
4. [_CP My Favourite Words Poster \(New Design\) World CP Day](#)

Other Resources:

[ICF Resources | CanChild](#)

[F-Words in Childhood Disability | CanChild](#)

[F-Words Tools](#)

[F-Words Goal Sheet \(canchild.ca\)](#)



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<https://earlyintervention.amarseva.org/>



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