Early Intervention System for Aruba National Action Plan

(Children 0 - 4 Years)

Report from the Stakeholder Summit June 7 - 11, 2021

Aruba,
Department for Children and Youth
Social Crisis Plan

Michael B. Abel, Ph.D. Associate Director

Kelly Hantak, Ed.D. Sr. Research Associate

Hepsi Swarna Sr. Research Assistant







Introduction

Early intervention is defined as the services and supports offered to infants and toddlers with developmental delays or disabilities¹. This report is a summary of proceedings from a Stakeholder Summit, held in Aruba, June 7 – 11, 2021 to explore the feasibility of establishing an early intervention system in the country. The system will focus on children from birth to four-years-old. During the 5-day summit, key national stakeholders formed the Plataforma Intervencion Trempan Aruba (PITA) (translated to Early Intervention Platform Aruba for children with a special need) and agreed to meet quarterly. The Summit also resulted in a 3-year National Action Plan, contained in this report.

The National Action Plan includes 20 objectives related to four functional areas: assessment, intervention, resources, and regulation. The stakeholders crafted sixteen long-term goals (to be completed in three years), twelve short-term goals (to be completed in 2021), and over 30 related activities. PITA developed the following

Statement of Purpose:

The Plataforma Intervencion Trempan Aruba seeks to ensure that all children in Aruba, including those with disabilities, will be healthy, accepted by society, included in the community, and experience well-being.

The Statement of Purpose is informed by the Inclusion @ Work Framework for Building a Disability-Inclusive Organization established by the Employer Assistance and Resource Network (EARN) on Disability Inclusion² that follows a continuum of awareness, acceptance, respect, and inclusion (integrated into society).

This report also provides additional information to inform the development of an early intervention system in Aruba, including:

- Historical and Current Context of Early Intervention in Aruba
- A detailed account of the proceedings of the Stakeholder Summit
- A list of the participants and their organizations
- Methodology and results of a cognitive mapping activity used during the Summit
- Detailed presentation of the National Action Plan with objectives, goals, and activities

¹ Centers for Disease Control and Prevention. (December 9, 2019). *What is "early intervention"?* https://www.cdc.gov/ncbddd/actearly/parents/states.html

² Cornell University. (2021). *Inclusion* @ work overview. https://askearn.org/training-center/inclusionwork-trainings-webinars/



Historical and Current Context of Early Intervention in Aruba

In 2006, the *Convention on the Rights of the Child* (1989)³ expanded its work to address the needs of children and adults with disabilities under the *United Nations Convention on the Rights of People with Disabilities* (CRPD). The CRPD recognized persons with disabilities, including young children, with rights to receive an education, access information, and appropriate health care within the same environment as individuals without disabilities.⁴ To date, 164 countries, including Aruba,⁵ have signed the CPRD international agreement that includes a commitment to invest in early intervention programs protecting "the rights and well-being of children with disabilities." In 2007, the Kingdom of Netherlands (of which Aruba is a constituent country) signed the CRPD with confirmation of their pledge occurring in 2016.⁷

There is little information available regarding children with disabilities in Aruba.⁸ The 2010 Central Bureau of Statistics Aruba (2020) reported 25,644 children birth to 17 years of age lived on the island of Aruba. Of these, 5,084 were three years old or younger. The 2010 census data show 45.8% of children from birth to three years of age attended an educational program or play garden, which reflected a 37.5% increase from the 2000 report.⁹ The Bureau reported that less than 1% (21 of 6,507) were identified with a disability.¹⁰ Stakeholders believe this statistic is much higher because many children with disabilities are not identified.

In a 2019 report to the United Nations' Committee on the Rights of the Child,¹¹ Kock addressed families with a child with a disability and the challenges they experienced, such as difficulty in locating a medical doctor with a specialization or formal training dedicated to children with exceptionalities. Without this training, they may fail to

³ United Nations Human Rights Office of the High Commissioner. (1989). *Convention on the rights of the child.* https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

⁴ United Nations enable. (2007). Frequently asked questions regarding the Convention on the Rights of Persons with Disabilities. https://www.un.org/esa/socdev/enable/convinfofag.htm

⁵ United Nations Department of Economic and Social Affairs Disability. (2021). *Convention on the Rights of Persons with Disabilities (CRPD)*. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

⁶ Wertlieb, D. (2018). Inclusive early childhood development: Ensuring the rights and well-being of infants and toddlers with disabilities and their families. Zero to Three, 38(4), 22-30.

⁷ United Nations Treaty Collection. Chapter IV: Human rights. https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en#EndDec

⁸ United Nations Children's Fund (UNICEF). (2021). Aruba. https://data.unicef.org/country/abw/

⁹ Central Bureau of Statistics. (2020). Profile of Aruba's children. https://census2020.aw/wp-content/uploads/2020/09/Profile-of-Arubas-children.pdf

¹⁰ Central Bureau of Statistics. (2020). *The prevalence of disability in Aruba.* https://census2020.aw/wp-content/uploads/2020/09/The-prevalence-of-disability-in-Aruba.pdf

¹¹ Kock, C. J. (2019). List of issues prior to reporting (LOIPR) from non-governmental organizations (NGO's) of Aruba to the United Nations' committee on the rights of the child. https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/NLD/INT_CRC_NGO_NLD_35896_E.pdf



recognize the child has a disability or make a misdiagnosis. Early childhood educators could also benefit from specialized training in working with children with disabilities. In doing so, the educators can address each child's needs within the educational setting. Kock also suggested the cost of quality child care programs created a hardship for families and child care regulations in Aruba were deficient.

Currently, the educational system in Aruba consists of a kindergarten program for children to attend from four to six years of age. Upon completion of their kindergarten experience, children attend a primary education program within seven school boards located on the island until they become 12 years old. For children who may need additional assistance in their kindergarten or primary education settings, their parents can choose to enroll them in a special education program. Upon completion of their primary education, students usually attend a secondary program followed by vocational training or attending a program in higher education.¹²

An array of government programs and non-government organizations (NGOs) in Aruba support children with mild to severe developmental disabilities as well as children identified as deaf or hearing impaired. The educational system in Aruba does not identify or serve young children with a suspected or confirmed diagnosis of autism spectrum disorder (ASD) as compared to a child diagnosed with a hearing impairment, visual impairment, or a learning disability. While the public programs and NGOs provide many services, Aruba lacks a system to ensure that the services are comprehensive and accessible for all children. Most of the services are provided through the following organizations represented on PITA.

¹² Visit Aruba. (2021). Education. https://www.visitaruba.com/about-aruba/general-aruba-facts/education/

¹³ Departamento di Ensenabsa Aruba. (2021). *Primary Education*. https://www.ea.aw/pages/english/primary-education/



Brighter Future Aruba Center for Autism provides applied behavior analysis services to children from two to 12 years of age and have received a diagnosis of autism. Programs offered include individualized ABA therapy as well as small groups focusing on the development of appropriate behaviors, communication, and social skills. Therapists also help children increase their cognitive, self-help, and play skills.¹⁴

Fundacion pa Esnan cu Problema di Oido (FEPO) addresses the academic, physical, and social-emotional needs of individuals who experience deafness or hard of hearing. This includes a person with a cochlear implant. Services and programs include assistance with hearing aids, cochlear implants, and speech therapy services.¹⁵

Wit Gele Kruis Aruba, an independent healthcare foundation, provides a variety of healthcare services for individuals throughout the community. The White Yellow Cross implements home healthcare programs as well as nutritional services. For young children, medical personnel provide maternal care to pregnant mothers and then follow up with pediatric care until 18 months or the child is assigned to a general practitioner. Within the first week of life, the infant participates in a neonatal hearing screening. Young children begin dental and nutritional checks starting between 20 to 24 months. Children can receive consultative services starting between 30 to 36 months of age. 16

Fundacion Pa Nos Muchanan shares information regarding child developmental milestones for children from birth to 12 years for families and educators. FPNM advocates on behalf of young children as they work with governmental and NGO agencies.¹⁷ Child care providers can seek resources and professional development training from FPNM.¹⁸

Fundacion Autismo Aruba provides services to individuals of various ages and diagnosed on with an autism spectrum disorder. The organization also advocates on behalf of and along with individuals with autism, their family, and caregivers.¹⁹

Stichting Casa Cuna Progreso provides temporary shelter for children from birth to eight years who may experience an abusive home environment. Professionals also provide services to parents or foster parents.²⁰

¹⁴ Brighter Future Aruba. (2021). About brighter future Aruba. http://brighterfuturearuba.com/about.html

¹⁵ Org.aw Community Guide Aruba. (n.d.). *Fundacion pa esnan cu problema di oido*. http://www.org.aw/index.php?id=org_profile&do=fepo

¹⁶ Stichting voor Volkshygiene Wilt Gele Kruis Aruba. (2021). *Parent, child and maternity care*. https://www.witgelekruisaruba.org/en/Parent-child-and-maternity-care

¹⁷ Org.aw Community Guide Aruba. (n.d.). *Fundacion pa nos muchanan.* http://www.org.aw/index.php?id=org_profile&do=fpnm

¹⁸ Visit Aruba. (2021). *Pundacion pa nos muchanan*. https://www.visitaruba.com/fundacion-pa-nos-muchanan/

¹⁹ Org.aw Community Guide Aruba. (n.d.). *Fundacion autismo aruba*. http://www.org.aw/index.php?id=org_profile&do=autismoaruba

²⁰ Org.aw. (n.d.). *Stichting casa cuna progreso.* http://www.org.aw/index.php?id=org profile&do=casacuna



Stichting voor Verstandelijk Gehandicapten Aruba provides care and guidance to individuals with intellectual limitations. The foundation also offers support to the individual's family members.²¹

Tienda di Educacion shares positive guidance strategies for parents of children from birth to 18 years. Strategies include positive problem-solving techniques for parents to implement at home. The agency provides the services to parents at no cost, does not keep a wait list, and receives referrals from parents or educators.

Centro Hoben y Famia provides services and programs for families to help children increase their social-emotional skills. Parents learn positive guidance strategies with their child while children learn appropriate social-emotional skills. The center developed as a result of the Social Crisis Council in 2018.²²

Directie Volksgezondheid Aruba (DVG)/Jeugdgezondheidszorg (JGZ) maintains the physical and mental well-being of children across the island of Aruba. Per national regulations, any child counted in the Census data for Aruba receives access to a doctor, which can include those employed by the White Yellow Cross.²³

Bureau Multidisciplinair Centrum (MDC) implements a multidisciplinary approach by professionals who support students enrolled in primary and secondary education as well as their parents and educators. Professionals work with children three to 18 years of age and are diagnosed with learning challenges, including behavioral and psychological support. As part of the government of Aruba, the department includes an Expertise Center and Teacher Care. The agency also offers individual or group therapy programs to help children as well as consultative and professional development for educators and administrators.²⁴

Bida y Famia provides an economic system supporting individuals who need assistance in order to ensure their well-being. The Department of Social Affairs holds a mandate for this department to provide individuals access to appropriate welfare, legal, and social services.²⁵

Fundacion Salud Mental Aruba (Respaldo) was developed through an agreement between the governments of Aruba and the Netherlands and the General Health Insurance. Professionals at Respaldo implement services for individuals with mental health needs for children and adults living in Aruba. With two locations on the island, individuals can receive psychiatric services as well as participate in therapy sessions.²⁶

²¹ Org.aw Community Guide Aruba. (n.d.). *Stichting voor verstandelijk gehandicapten aruba.* http://www.org.aw/index.php?id=org_profile&do=svga

²² Social Crisis Plan. (2020). *Hoben y famia*. https://www.scparuba.com/centro-pa-hoben-y-famia/

²³ Org.aw Community Guide Aruba. (n.d.). *Directie volksgezondheid afdeling jeugdgezondheidszorg*. http://www.org.aw/index.php?id=org_profile&do=jgz

²⁴ MDC. (2021). Office multisciplinary center. http://www.mdc.aw/index.html#extContent2-23

²⁵ Org.aw Community Guide Aruba. (n.d.). Seccion 'bida y famia' – Directie sociale zaken.

²⁶ Respaldo. (n.d.). Over respaldo. http://fsma-respaldo.com/over.php



Social Psychiatrische Dienst (SPD) also addresses the mental health needs of children and adults in Aruba. Funding through the Social Crisis Council allows team members to implement an integrated approach to providing psychiatric services to those in need.²⁷

Fundacion Arubano di esnan Visualmente Incapacita (FAVI) assists children and adults with visual and/or sensory impairments acquire the skills needed to become engaging community members. FAVI provides rehabilitation therapy and will provide transportation to their clients. The primary goals for individuals receiving services through FAVI is for them to "enjoy life" and become engaged members of their community.²⁸

Social Crisis Plan

In response to recent reports of child abuse increasing in Aruba, in 2018 the government introduced the SCP. As part of the projects within SCP there was a call for a revision of the Daycare Law and establishes the "Four Sector Protection Law" to increase collaboration in the areas of social issues, education, legal outcomes, and public health.²⁹ As a result, the council of ministers approved the creation of the Department of Children & Youth. The department plans to address the lack of early intervention services, particularly to identify young children with developmental delays and/or disabilities who may need services.

Through an intersectoral approach, the SCP Plan outlined various components required to support children and families from birth through adolescence.³⁰ Topics addressed in the plan were selected to ensure children's safety included economic development, laws of protection, and strong support systems for families through programs implemented by different agencies.³¹

²⁷ SPD/Sociaal Psychatrische Dienst. (2021). About. https://www.facebook.com/SPD297/?ref=page_internal

²⁸ Org.aw Community Guide Aruba. (n.d.). *Fundacion arubano di esnan visualmente incapacita*. http://www.org.aw/index.php?id=org_profile&do=favi

²⁹ Bureau Voorlichting. (2021). *Social crisis plan serves to improve many aspects of the social area.* https://www.government.aw/news_47033/item/social-crisis-plan-serves-to-improve-many-aspects-of-the-social-area_55604.html

³⁰ Department of Social Affairs. (n.d.) *Social crisis plan*. https://translate.google.com/translate?hl=en&sl=es&u=https://www.das.aw/sociaal-crisis-plan/&prev=search&pto=aue

³¹ Department of Social Affairs. (2020). Social crisis plan (SCP) intersectoral approach.



Stakeholder Summit

Policy members of the Ministry of Social Affairs and Labour along with coordinators from the Departamento pa Mucha y Hoben (DMH) identified potential stakeholders, comprised of medical, therapeutic, and educational professionals to attend a Stakeholders Summit from June 8-11, 2021 in Oranjestad, Aruba. Thirty-two individuals from 15 organizations or government agencies participated in the Summit. Table 1 lists the participants.



Table 1. Participants

Name	Organization	Organization (English)
Minister Glenbert Croes	Ministry of Social Affairs and Labour	Ministry of Social Affairs and Labor
Ms. Sue-Ann Ras	Policy Advisor of Ministry of Social	Policy Advisor of Department of Social
	Affairs and Labour	Affairs and Labor
Mrs. Glenda Hernandez	Director Social Crisis Plan	Director Social Crisis Plan
	Aruba/Process Manager of Social	Aruba/Process Manager of Social
	Crisis Plan Aruba	Crisis Plan Aruba
Mrs. Alysha Boekhoudt	Bida y Famia	Life and Family
Mrs. Juritza de Cuba	Bida y Famia	Life and Family
Mrs. Sharisa Hererra	Bida y Famia	Life and Family
Mrs. Uleike Tromp	Brighter Future Aruba Center for Autism	Brighter Future Aruba Center for Autism
Mrs. RosAnna van Dijk	Bureau Multidisciplinair Centrum	Multidisciplinary Center
Mrs. Rashell Gibbs	Centro Hoben y Famia	Youth and Family Center
Mrs. Yvonne Bermudes	Centro Hoben y Famia	Youth and Family Center
Ms. Anouk Eman	Departamento pa Mucha y Hoben	Department of Children and Youth
Mrs. Surella Croeze	Departamento pa Mucha y Hoben	Department of Children and Youth
Mrs. Swinda Dumfries	Directie Volksgezondheid Aruba/Jeugdgezondheidszorg	Department of Public Health Aruba
Mrs. Joan van Heyningen	Directie Volksgezondheid Aruba/Jeugdgezondheidszorg	Department of Public Health Aruba
Dr. Luis Cortes	Directie Volksgezondheid Aruba/Jeugdgezondheidszorg	Department of Public Health Aruba
Mr. Cesar Palma	Directie Volksgezondheid Aruba/Jeugdgezondheidszorg	Department of Public Health Aruba
Dr. Janice Essers-Hooft	Directie Volksgezondheid Aruba/Jeugdgezondheidszorg	Department of Public Health Aruba
Mrs. Meredith Faarup-Lacle	Fundacion Arubano di esnan	Aruban Foundation of the Visually
	Visualmente Incapacita	Incapacitated
Mrs. Sary Wernet	Fundacion Arubano di esnan	Aruban Foundation of the Visually
	Visualmente Incapacita	Incapacitated
Mrs. Annemarie Navas	Fundacion Arubano di esnan	Aruban Foundation of the Visually
	Visualmente Incapacita	Incapacitated
Mrs. Carolina Span	Fundacion Autismo Aruba	Aruba Autism Foundation
Mrs. Kristel von Nes	Fundacion pa Esnan cu Problema di Oido	Foundation for Those with a Hearing Problem
Mrs. Stella Monstsanto	Fundacion pa Esnan cu Problema di Oido	Foundation for Those with a Hearing Problem
Mrs. Natasha Glikes	Fundacion Pa Nos Muchanan	Foundation for Our Children
Mrs. Janelle Artsen	Fundacion Pa Nos Muchanan	Foundation for Our Children
Mrs. Felishah Ponson	Fundacion Pa Nos Muchanan	Foundation for Our Children
Mrs. Rochelin de Cuba	Fundacion Salud Mental Aruba (Respaldo)	Fundacion Salud Mental Aruba (Respaldo)
Mrs. Juliette Koolman	Social Psychiatrische Dienst	Social Psychiatrists
Mrs. Mildred Croes-Caster	Social Psychiatrische Dienst	Social Psychiatrists
Mrs. Renate van Dongen	Stichting Casa Cuna Progreso	The Children's Home Casa Cuna
Mrs. Gisella Polo	Stichting Casa Curia Frogreso Stichting voor Verstandelijk	Foundation for the Mentally Disabled
IVII 3. CISCIIA FUIU	Gehandicapten Aruba	I duridation for the ineritally Disabled
Mrs. Rhomyko Winklaar	Tienda di Educacion	The Education Shop
Mrs. Linda Croes	Wit Gele Kruis Aruba	White Yellow Cross
Mrs. Maryla Solognier	Wit Gele Kruis Aruba	White Yellow Cross
S. mar, a Sologinoi	3010 111010 / 11000	1 011011 01000



Stakeholders received a daily agenda, participated in small and large group discussions, and completed an evaluation survey daily. To ensure a safe environment and address language preferences, each participant was encouraged to expressively communicate in Papiamento or English. If a stakeholder chose to speak in Papiamento, then another stakeholder fluent in both languages interpreted the comments and questions with the facilitators.

The Summit was facilitated by Drs. Michael Abel and Kelly Hantak with the Institute for Human Development at the University of Missouri-Kansas City, in the United States. On the first day of the summit, Dr. Abel started by sharing information about systemic thinking. Dr. Hantak reviewed information pertaining to the elements of an early intervention system through a global perspective. Ms. Anouk Eman shared draft survey results, in which staff members met with childcare directors and educators to identify potential developmental concerns they observed in young children from birth to four years of age attending educational programs. After sharing the data, Dr. Abel implemented an activity, using the "Jigsaw Method," as stakeholders separated into three small groups to review the data and respond to the following questions.

- What is the nature of children and families in Aruba?
- What is the nature of childcare centers in Aruba?
- How is child safety ensured in Aruba?

Dr. Hantak wrapped up the session by asking stakeholders to reflect on stories of children with intellectual or developmental disabilities.

The next morning, Dr. Hantak facilitated a large group discussion where stakeholders shared their stories as part of the reflection assignment from the previous day. Dr. Abel then led the group through an activity that used "Fuzzy Cognitive Mapping" (FCM), a qualitative research technique, to help stakeholders develop ideas and barriers in establishing an early intervention system. Additional details regarding the data collection and results are in the following section. As the stakeholders experienced difficulty with identifying the age group in which children would participate in an early intervention system, Dr. Hantak assigned the topic as the daily reflection assignment.

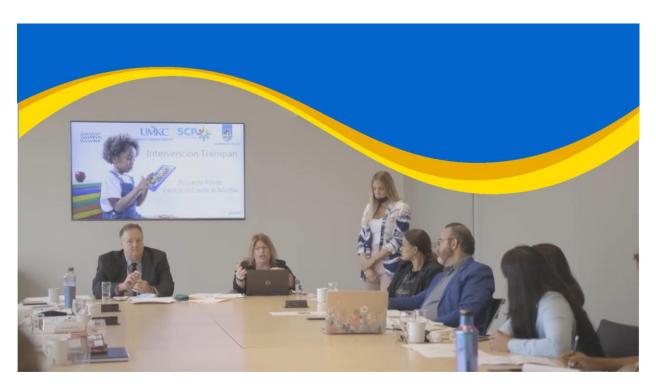
On Wednesday, Dr. Hantak facilitated the game, *That's Me!* Dr. Hantak shared a statement and asked stakeholders to stand and say, "That's me." if it pertained to them. She then asked stakeholders to share their thoughts from the reflection assignment. As a result, the stakeholders reached a consensus for an early intervention system to apply to children from birth to four years of age. Dr. Abel shared the results from the FCM session with the stakeholders for the remaining time. Dr. Hantak closed the session by asking the stakeholders to reflect on the data results and prepare any questions or comments for the following morning.

Thursday morning started with Dr. Hantak facilitating the large group discussion, in which stakeholders asked questions and shared comments about the data results presented by Dr. Abel. Stakeholders arranged themselves into several small groups to



develop a strategic plan outlining their suggestions for objectives, goals, and action steps. A representative from each group shared their ideas with the large group. Dr. Abel collected their worksheets and closed the session with final comments.

On the final day, stakeholders reviewed a draft of the National Action Plan and suggested revisions. They created a name for their group and stated they wanted to meet quarterly. Ms. Sue-Ann Ras provided closing remarks to conclude the summit.







Cognitive Mapping

Fuzzy Cognitive Mapping, or "idea mapping" is designed to gain insight into the conceptual and causal relationships participants perceive between facilitators and barriers related to the ultimate vision for this initiative that all children in Aruba will be screened and diagnosed for developmental disabilities and receive appropriate services (Kosko, 1986). The mapping facilitates "sense-making" by helping stakeholders communicate about strategies and decisions (Jetter & Schweinfort, 2011). Through the mapping session, the participants were able to gather the viewpoints of multiple stakeholders and to develop a better understanding of patterns between specific variables (Gray, Chan, Clark, & Jordan, 2012; Jetter & Schweinfort, 2011). This methodology is highly participatory and fosters social learning between participants (Jetter & Schweinfort, 2011). UMKC-IHD has experience using this methodology with a range of audiences, from families of children with special needs, to adults with intellectual disabilities, to public health professionals to educators and researchers.

The mapping session was held on Tuesday, June 8, with a strong and diverse representation of stakeholders. UMKC-IHD researchers began by describing the destination for the map (All children in Aruba are screened and diagnosed for developmental disabilities and receive appropriate services). Next, participants were asked to list "facilitators;" up to five factors that would make it easier to achieve the vision. Then participants were asked to list "barriers;" up to five factors that would make it more difficult to achieve the vision. Finally, participant drew directional arrows between the numerous factors (including the vision statement, for which all variables related) and assigned a weighting value (e.g. weak, moderate, or strong) for each connection. UMKC-IHD researched led a discussion of the ideas presented on the maps to deepen understanding of participants' experiences, stories, and recommendations. During the discussion participants shared ideas on how systems and organizations could better support an early intervention system in Aruba.

Mapping Process/Coding: A total of 18 maps were developed by the stakeholders. We used 8 broad concepts to code the maps. Four of these concepts are "facilitators" meaning that they increase the likelihood of all children in Aruba getting screened and diagnosed for developmental disabilities and receive appropriate services. Four of these concepts were "barriers" which means that they decrease the likelihood of children in Aruba getting screened and diagnosed for developmental disabilities and receive appropriate services. Codes and definitions were developed from examining the maps as shown in Table 2.



Table 2. Cognitive Mapping Codebook

Codes	Definition
Facilitators	
Assessment	The act of screening and/or evaluating a young child to determine the need for intervention services and supports.
Intervention	Direct services to young children and their families. Includes children with a diagnosed intellectual or developmental disability by pediatric health professional or therapists and children who are determined to have a developmental delay. Professionals provide support to parents and/or caregivers of young children with a disability. Intervention may involve multidisciplinary service provision depending on the needs of the child. Services may be delivered in specialized settings or occur in the child's natural environment.
Resources	Information provided to parents and/or caregivers of a young child with a disability, direct service personnel, stakeholders in the early intervention system, government agencies, and the public. Information may be related to referral for assessments, identification of developmental delay, sources of financial assistance, funding for the early intervention system, modern technology, augmentative and alternative communication, database systems, parent and community awareness, knowledge for parents and professionals, parent and professional training, and how different professionals can work together collaboratively.
Regulation	Includes legislation (e.g., the SCP), monitoring regulations, registration, governmental and/or organizational policies, professional codes, licensing, professional certification, licensure, measures of fidelity to best practices
Barriers	
Negative Cultural Perception of Disabilities	Stigmatizing individuals with a disability; cultural taboo; lack of transparency
Lack of Information	Lack of knowledge; inadequate data; unregistered programs; undocumented children; lack of certification and/or licensure;
Inadequate Public Policy	Need for increased monitoring, program evaluation, constructive feedback, measurement instruments; funding limitations of payment for programs and interventionists; lack of funds available to meet the needs of each child with a disability; lack of collaboration among organizations; need to address poverty
Lack of Capacity	Waiting lists; limited number of professionals to optimally support the early intervention system; inability to screen all children (personnel and access); lack of a quality infrastructure; lack of access to specialized programs (ex. transportation); limited networking opportunities



Central Variables: Most Impactful Facilitators to Success in Screening &

Diagnosis. The facilitator concepts were ordered by their centrality. The contribution of a variable in a cognitive map can be understood by calculating its centrality, which shows how connected the variable is to other variables and what the cumulative strength/weights of these connections. In the Idea Mapping technique, a variable can be more "central" although it has fewer connections if the connections carry larger weights or are stronger (Kosko, 1986). Essentially, "the centrality of the variable is not only a frequency of expression but also how important that variable is given to the whole structure of the cognitive map." (Özesmi, U. & Özesmi, S.L., 2004). The central facilitators identified for this session are shown in Figure 1.

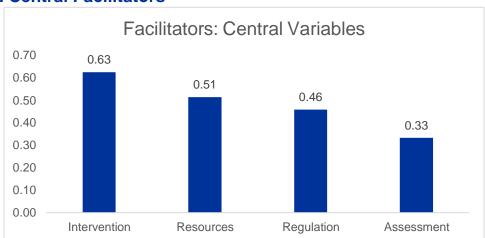


Figure 1. Central Facilitators

The barrier concepts were also ordered by their centrality. The central barriers for this session are shown in Figure 2.

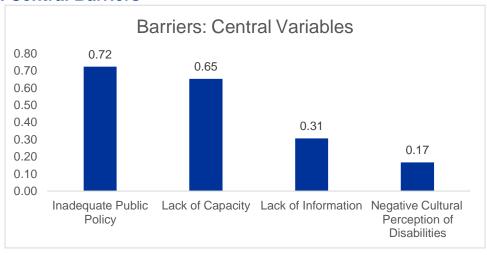


Figure 2. Central Barriers

Additional Variable Types. In addition to the central variable, we calculated the number of receiver, transmitter, and ordinary concepts. Receiver concepts are those



that are most strongly affected by other system concepts but have no effect on other concepts. Success was the primary receiver concept by design because the goal of this exercise was to discover what concepts are most important to facilitating and limiting the success of screening and diagnosis for developmental disabilities and receiving appropriate services. There was one transmitter concept (lack of information), which is the concept that has a strong impact on other concepts but is not impacted by other concepts. There were seven ordinary concepts which are concepts that play both a transmitting and receiving function within the maps – those concepts that influence and are influenced by other concepts. Figure 3 shows the strength of impact among the various variables.

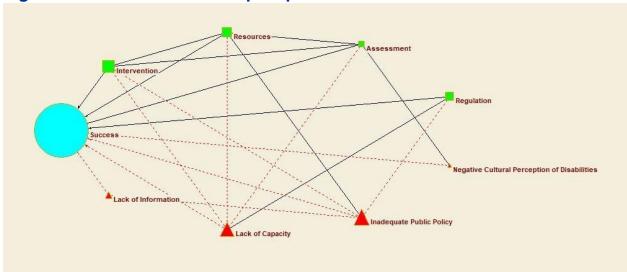


Figure 3: Variable Relationship Map

National Plan

Results of the idea mapping session were presented to the stakeholders on Wednesday, June 9 and used to develop 20 outcomes, to be completed in three years, for the early intervention system. Table 3 shows the Outcomes, grouped by the four central facilitators identified in the mapping session. Also included in this table are the four central barriers and presented as "Current Situation" and the Vision for the project which is reflected in the Statement of Purpose for the Plataforma Intervencion Trempan Aruba (Early Intervention Aruba).



Table 3. Outcomes

Current	Outcomes /3 years)	Vision
Situation Negative cultural	(3 years) Intervention	All children in
perception of disabilities.	Parents give permission for and actively participate in the interventions for their children.	Aruba are screened and
Lack of information available about children with disabilities Inadequate public policy to	There are an adequate number of professionals to provide needed services for each child.	diagnosed for developmental disabilities and receive appropriate
	 A comprehensive referral system supports connecting families to the right professionals and organizations for services. 	
	An Individualized Family Service Plan (IFSP) is prepared for all children with identified disabilities.	services.
	Funding is available so that all children with identified disabilities receive needed services.	* see Plataforma Intervencion
support an early	Resources	Trempan Aruba
intervention system	 There is general public awareness about children with disabilities, the need for early intervention, and the services available. 	Statement of Purpose
Lack of capacity in professionals,	 Services are coordinated across the early intervention system and for each family 	
organizations, and	 All families are financially able to access early intervention services. 	
infrastructure to support an early	 A robust data system tracks of children with disabilities and the early intervention services provided to them. 	
intervention system	 Families access the early intervention system through a central referral point (e.g., the hospitals). 	
	Regulation	
	 There are an adequate number of specialized mental health professionals to provide needed services for each child. 	16
	Professional guidelines and standards of practices are established.	
	 Licensing regulations for all daycares are established, including rules for children with disabilities. 	3
	 Specialized programs provide intensive services as needed. 	
	 Every individual with a physical disability can gain access to public buildings across Aruba. 	
	Assessment	
	 Valid and reliable screening and assessment tools are used in the child's primary language (e.g., Papiamento, English, etc.) 	
	 All children in Aruba are screened for disabilities at least once each year. 	
	 Children with identified disabilities are assessed for disabilities at least once each year. 	
	 Assessors are properly trained to conduct screening and assessments. 	
	 Families are aware of the need for their child to participate in screening and assessments to identify developmental delays or disabilities. 	



As the stakeholders processed the objectives within the four facilitator groups, some additional practical themes emerged related to operationalizing a system. The five themes are capacity, funding, collaboration, awareness, and information sharing. Conversations related to these themes were highly detailed and nuanced. Summary of the discussion is described below.

Capacity

Stakeholders recognized that in order to assess and serve all children in Aruba, additional professionals were needed for assessment; communication with parents, daycare owners, and teachers, and to collect information about each child's trajectory of development.

Funding

Stakeholders also noted that additional funding was needed to support an emerging system. Financial resources are needed to assist families for necessary medical and therapeutic treatments not covered through medical insurance. The therapists who provide services to young children with disabilities through their private practice reported when they provided services for free so children could receive necessary treatment. Although this action helps families, it can decrease the therapist's total annual income.

Collaboration

In order to prevent the likelihood of a young child with disabilities receiving duplicated services by multiple professionals, the stakeholders identified collaboration and sharing information as an important outcome. Duplicated services occur when a family takes their child to more than one agency or program for the same type of services, such as speech-language pathology or psychological services. Through collaborative communication, professionals from various specialties can work together to develop the best treatment for the child with a disability. As such, the family may not feel the need for the child to spend time with the multiple professionals for duplicated services.

Awareness

Community members and parents should become aware of the importance for all children between birth to four years of age participating in a developmental screening on an Annual basis. Through a comprehensive referral system, parents would become aware of where they can locate qualified professionals to assess their child. Through early intervention service coordination, parents provide consent before the professionals conduct an assessment or share information with other professionals, such as their child's doctor, teacher, or another therapist. A robust database could allow government departments to become aware of how many young children in Aruba receive a diagnosis related to a disability or exhibit a developmental delay through the assessment process.

Information Sharing

Stakeholders acknowledged the need for a system to share information among organizations. There was also discussion that parents would be the owners of the information about their children and consent to share must be ensured. Creating a safe portal was suggested. Sharing information among registered providers and the need for data sharing agreements among hospitals and schools was also proposed.



Long-term Goals

The researchers defined long-term goals as goals to be completed in three years. The stakeholders developed one long-term goal for each outcome by the Central Facilitators identified in the mapping activity. The following long-term goals (to be completed in three years) were created by the stakeholders:

	Long-Term Goals	
1.	Foster collaboration among key stakeholders and organizations	
2.	Identify a centralized access point for information and referral	
3.	Identify a single agency for case management (e.g., DMH)	
4.	Establish support groups for families and direct service providers in each district by disability type	
5.	Infuse additional personnel resources into the early intervention system that includes assessors, nurses (4), and fully funded positions within the Department of Children and Youth	
6.	Establish multi-disciplinary teams of service providers (e.g., behavioral specialists, speech therapists, social workers) for home-based interventions	
7.	Create a curriculum module (train-the-trainer) on young children with disabilities that could be delivered at Educacion Profesional Intermedio (EPI College)	
8.	Identify and approve developmental checklists and/or screening tools to be used in the early intervention system	
9.	Translate assessments in four languages	
10.	Develop a central database for the early intervention system	
11.	Establish national standards, guidelines, and protocols for best professional practice, including screening (including newborns in the hospital) and diagnosis	
12.	Require daycare licensing	
13.	Legislate a national disability act	
14.	Adapt the national health insurance laws to cover more services	
15.	Ensure there are inclusive schools in each school district with early intervention programs	
16.	Implement a program for an early detection bus (mobile unit during awareness month)	

A thorough review of national standards, guidelines, protocols, and best practices is needed for professionals within their specific disciplines. This includes continuous education through modules in the school curriculum to train the trainers for those working with young children with a disability. The modules provide opportunities for professionals to increase their knowledge and improve their practice regarding various topics within their field, including assessments.

The Department of Children and Youth needs to be fully funded by the government. Another long-term goal included a call for the expansion of health insurance to ensure families of every child with a disability can receive the appropriate number of services



and materials needed for them to succeed at home and/or daycare. By expanding the national health insurance system, more children with a disability could receive early intervention services as well as allow therapists to receive payment for all services delivered to the child.

In addressing collaboration and sharing information, assurance of early intervention programs on a national level became a long-term goal. It appeared a need to identify inclusive schools within each district exists. If a district does not contain an inclusive school, then a feasibility study may need to occur in order determine how many schools should emerge. To help families. By establishing inclusive programs, professionals can implement a multi-disciplinary approach where they communicate and share information regarding the services and treatment each child with a disability receives from birth to four years of age.

The creation of a centralized center where families can receive information and referrals to appropriate professionals can raise awareness and provide support for children with disabilities and their family members. The creation of a database containing information on children from birth to four years of age can help determine the types of services a child with a disability may need as well as establish trends. An analysis of trends may determine the type of marketing campaign or topics related to early intervention services as well as particular disabilities as a means of raising awareness to the public and families. An "early detection bus" can raise awareness to all families living in Aruba as well as provide space for young children to participate in developmental assessments.

Short-term Goals and Activities

Stakeholders identified the following short-term goals and associated activities (to be completed by December 31, 2021) as steps toward reaching the long-term goals:

Short-term Goals	Activities
Develop a sustainable early intervention system within the Aruban government	 Establish MOUs between NGOs and the government Create accessibility policies for public buildings Examine privacy laws Continue to develop a government department to oversee daycares Begin developing safety guidelines and policies for daycares Begin creating education and development programs for daycares



Short-term Goals	Activities
Hold regular meetings of Plataforma Intervencion Trempan Aruba (PITA) to implement the National Early Intervention Plan	Convene quarterly PITA meetings
Expand capacity by adding personnel to the early intervention system	 Add a service coordinator position Create a new staff position for the information and referral system Add a remedial educationalist at WGK to help with early detection Planning to add: doctors (4), nurses (4), social workers (4), and psychologists (2)
Develop a national awareness campaign regarding to early intervention	 Launch an "Early Intervention Week" in October 2021 Involve stakeholders (e.g., FAA, WGK, JGZ, FAVI, FEPO, Respaldo, SVGA) Involve professionals (e.g., OB/GYNs, midwives, primary care physicians, maternity ward hospital staff) Workshops for parents, professionals, and educators Webinar Social media blasts Expo on early intervention Develop a mass media plan for information, including social media, dissemination Introduced during pregnancy (OBGYN's, midwifes, primary care physicians, maternity wards) Align the awareness campaign to the SCP Coordinate with DMH (Department of Children and Youth) Secure funding to support the campaign
Conduct a detailed environmental scan of the early intervention services	 Inventory current projects and professionals that support early intervention Inventory materials and assessment tools Document norms, protocols, and guidelines being used for screening and diagnosis



Short-term Goals	Activities
	 Examine regulations regarding early intervention and accessibility laws Identify NGOs that could be involved Analyze how professionals can best support the system to optimize child outcomes
Establish a national database for early intervention and children with disabilities	 Convene a meeting in September with all stakeholders Presentation following a Train the Trainer format on working with young children with disabilities by Uleike Tromp from Brighter Future Aruba Center for Autism Meet with a computer engineer for database development Establish a system for regular periodic data collection
Establish a workgroup to develop national standards, guidelines, and protocols for best professional practice	Examine screening and diagnostic tools to determine protocols for their appropriate use
Establish a collaboration with early intervention specialists	Invite behavioral specialistsInvite specialist from all stakeholder organizations
Train professionals in the use of screening and assessment tools and/or identifying developmental delays or disabilities	 Train and certify professionals in the use of the DAYC-2 Train mental health specialists Train nurses Train daycare workers in what to look for to make referrals (two times per year; collaborate with behavioral specialists)
Create an online resource (social network) with information about screening and assessment tools	 Develop a website to disseminate information Determine appropriate screening and assessment tools for evaluation purposes
Develop a fundraising plan that includes approaching foundations for donations	 Explore potential funders Including brainstorming with NGO partners (e.g., FEPO, FAVI, SVGA, and FAA) Solicit donations



A common theme among the short-term goals focused on the need for government approval or support for hiring new personnel. This included a firm commitment from the members of the government as well as establishing formal Memoranda of Understanding between non-governmental organizations the government agencies. Stakeholders advocated for public accessibility protocols through a Disability Act across all districts in Aruba. The government could also require daycare licensing with safety guidelines to ensure all children attending daycares spend their day in a healthy and safe environment.

Stakeholders decided to continue to meet quarterly to discuss programs and events developed for families of young children with disabilities. Early intervention educators and therapists could separately hold monthly meetings to receive information pertaining to the team and/or early intervention system. Professionals can also utilize the meeting time to ask questions regarding specific activities and strategies that can provide assistance to a young child and a family they serve. An electronic database could track each child's medical and/or therapy services. An "early intervention week" sponsored by organizations providing services to young children with disabilities could raise awareness of families, professionals, and the public.

Activities were proposed and aligned to the short-term goals. They were specific and often identified responsible parties and time frames to be completed by the end of 2021. Some activities addressed more than one short-term goal. Stakeholders estimated the need to add four additional doctors, four nurses, four social workers, and two psychologists to operationalize the early intervention system. For collaborative and coordinated services, additional assessors would be needed such as specialized teachers and pediatric therapists. Many professionals throughout Aruba will need specialized continuing education workshops and/or webinars to increase their knowledge on assorted topics related to pediatric disabilities, national standards and protocols, and best practices related to their field of service.

Funding an early intervention system will need to be addressed. This could take the form of government assistance for families of young children with disabilities. Stakeholders identified gaps in the health insurance system for children of undocumented families. Working with foundations and community organizations could lead to the funding of services or programs for young children with disabilities. These conversations could raise awareness regarding the needs for the children and families as well as those of professionals implementing early intervention services. Communication through social media and marketing campaigns were suggested as a means for increasing public awareness.

Stakeholders suggested establishing a department to regulate daycares, which could create policies and provide guidance to daycare employees regarding children with disabilities. Daycare owners and teachers could increase their knowledge about developmental milestones and developmental disabilities through a two-year education program and continuing education opportunities. The SCP currently recommends



additional training for daycare owners and teachers about referral of children with possible developmental concerns to medical personnel for diagnosis and early intervention services.

Conclusion

The National Action Plan is ambitious and will require a sustained effort by the PITA member organizations. While the process during the Summit was informed by the initial SCP report and the cognitive mapping activity, additional information is needed to ensure that the implementation of the National Plan is data-driven. A detailed environmental scan that clearly documents norms, protocols, guidelines, regulations, and laws related to early intervention is essential for supporting the Plan's implementation. The scan should also examine the interagency relationships that exist and are needed to shift the system along the continuum from cooperation to coordination to collaboration.³² Infrastructure is needed to scaffold the system which includes creating an integrated database; expanding capacity by adding personnel and training them to perform functions effectively; and increasing public awareness through a comprehensive information dissemination system.

The implementation of the SCP, the Stakeholder Summit, and the establishment of PITA are significant steps toward establishing an early intervention system in Aruba. It is evident that many of the elements that are needed for the system are in place and through collaboration, stakeholders will be able to make advancements in early intervention through child assessments, expanding services, creating additional resources, and instituting regulations. The level of cooperation demonstrated at the Summit was remarkable and bodes well for successful outcomes. We believe there is sufficient will to address the negative cultural perceptions of children with disabilities and to build a public policy infrastructure to increase capacity and disseminate information. Striving toward a vision that "all children in Aruba are screened and diagnosed for developmental disabilities and receive appropriate services" is realistic and possible within the 3-year time frame outlined in this report.

-

³² Goldman, H., & Intriligator, B. (1990). Factors That Enhance Collaboration among Education, Health and Social Service Agencies.



Published July 2021

© Copyright (2020) by The Curators of the University of Missouri, a public corporation.

Authors: Michael B. Abel, Ph.D., abelm@umkc.edu

Kelly Hantak, Ed.D., hantakk@umkc.edu

Hepsi Swarna, Sr. Research Assistant, hsbgr@umkc.edu

This project is supported by the government of Aruba, Department for Child and Youth, Social Crisis Plan (DMH & SCP). Points of view or opinions do not, therefore, necessarily represent official positions of the Aruban government, UMKC, or any other partnering entities.

This report is published by:

UMKC Institute for Human Development University of Missouri-Kansas City ihd.umkc.edu · 816-235-1770

Suggested citation:

Abel, M., Hantak, K., & Swarna, H. (2021). Early Intervention System for Aruba: National Action Plan. Kansas City, MO: Institute for Human Development, University of Missouri-Kansas City.

This report is available in alternate formats upon request. UMKC does not discriminate based on of race, color, ethnic or national origin, sex, sexual orientation, gender identity, religion, age, ancestry, disability, military status, veteran status, in admissions, educational programs or activities and employment. The University complies with all federal and state laws and University of Missouri System policy regarding nondiscrimination and affirmative action, including Title IX of the Education Amendments of 1972, Section 504 of the rehabilitation Act of 1973, Title VII of the Civil Rights Act of 1964 and the state of Missouri Human Rights Act Chapter 213 RSMO.

Electronic versions of this report are available at ihd.umkc.edu

Graphics courtesy of Microsoft Word.

Photographs courtesy of Department of Children and Youth and PITA Facebook page.



Acknowledgements

We wish to acknowledge the investment and support provided by the Office of Social Affairs and Labour, including the following individuals.

- Mr. Glenbert Croes, Minister of Social Affairs and Labour
- Ms. Sue-Ann Ras, Policy Advisor for the Ministery of Social Affairs and Labour
- Ms. Anouk Eman, Medewerker Kinderopvang, Department of Children and Youth
- Mrs. Carolina Thiel-Span, President of Fundacion Autismo Aruba

During this project, we relied on numerous stakeholders to help gather and disseminate information. We would like to offer thanks to all those organizations and their representatives who offered assistance and support.

The authors are most grateful for the opportunity to be involved in this ambitious and meaningful project. We are honored to participate in this work to improve the lives of children with disabilities and their families in Aruba.



