



An Inventorization of the Facilities for Persons With Disabilities in Aruba

drs. Caroll J. Kock

A little bit about me...



drs. Caroll J. Kock Freelance Researuch Policy Consultant



Personal

- 57 years
- Single, 1 daughter
- Hobbies: cooking, free cell



Academics

- Maastricht University
- Masters Public Health Administration
- Mid late '80s



Work Experience

- Dept. of Public Health: 10+ years
- Dept. of Social Affairs: 10+ years:
 - Research and policy, persons with disabilities



Achievements as freelancer

- Since 2016: Several research projects
- 2020-21: for PAHO rel. persons with disabilities
 - Community Based Rehabilitation
 - Impact of COVID on persons with disabilities

This Morning...

- Present the findings
 - You can see what other organizations have said
- Is part of the study at hand
- Your feedback is of utmost importance:
 - Do you recognize your expressed opinion?
 - Do you want to add to it?
- Feel free to interrupt me!

A Couple of Real-Life Cases of Persons With Disabilities in Aruba

This Is David*



* Some names have been changed

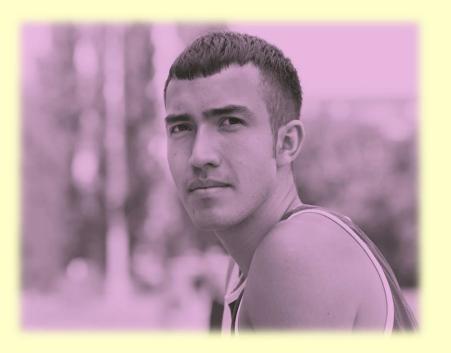
- Man, now in her late 50's
- Motor-cycle accident in 1985 → left him paralyzed from his chest down
- Spent 16 years in Holland for rehabilitation; was functioning, even playing rugby as a sport
- Car accident 1997 \rightarrow left him even more paralyzed
- In 2000 back in Aruba, got married, divorced 2007; married again in 2018, divorced again in 2022.
- Since 2002 as IT programmer working for the government
- Adapted car; adapted workplace; adapted house
- Daily challenges: prep warm meal, clean, do laundry →
 "alpha hulp"

Know the case of Margarita

- Woman in her mid-50s, severely visually impaired caused by hereditary illness
- Married for over 30 years, abused by husband, now separated (don't want divorce) and living on her own
- Never worked before, no income, receives small amount from husband → cannot receive 'bijstand'
- Has good cooking skills, doing household chores and looking after the elderly, but cannot hold a steady job
- Has psychiatric problems, emotionally unstable, suffers from anxiety, under treatment
- Poor social and communication skills, low intellectual ability, very low self esteem,



And Finally, Michael



- Young man, in his early 20's
- No visible disability, slight intellectual disability (congenital)
- Very sociable, loves to work, but cannot hold a job for very long
- Finds it hard to get negative feedback →
 becomes difficult to handle, gets fired!
- Used to get disability pension, must start the process all over again

Disability or Handicap?

- The Convention on the Rights of Persons with Disabilities
 - ✓ Does <u>not</u> use medical model
 - ✓ Uses **social model**, giving a human rights definition
- Article 1 of the Convention:

"Persons with disabilities **include** those who have longterm physical, mental, intellectual or sensory impairments which *in interaction with various barriers* may hinder their full and effective participation in society on an equal basis with others."

Same disability ...



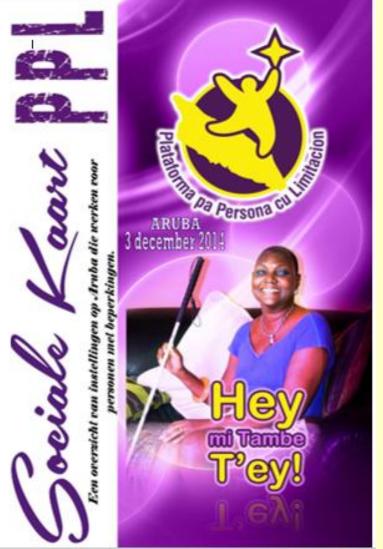


handicapped r

not handicapped

Relevance of This Study

Why This Study?



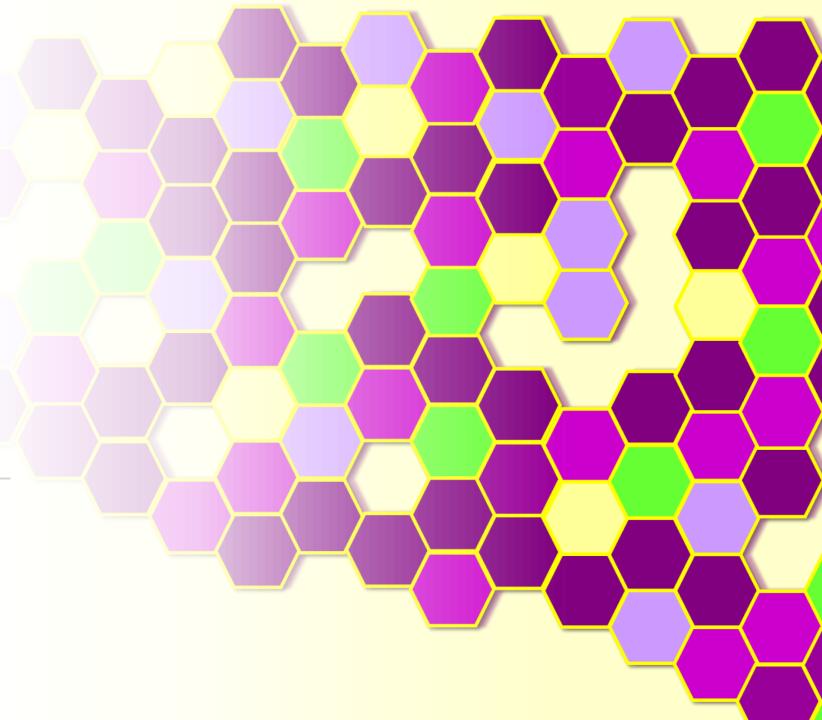
- In 2015: PPL produces its Social Map
- <u>Needed</u>:
 - Systematic inventorization of services for persons with disabilities on macro level
 - With the goal to identify the gaps and challenges in the provision of service
 - Screening by the Economisch Bureau Amsterdam: Screening (2022)

Areas of Focus

- A) Labor
- **B) Socializing**
- **C) Mobility & Accessibility**
- D) Health & Rehabilitation (incl. freedom from abuse)
- **E) Education**



Based on Censuses & Other Research



How many persons with disabilities? (CBS 2010, 2020)

	<u>2010</u>	<u>2020</u>
Abs.	6,955	5,591
% of pop.	6.9%	5.2%



CBS: Census 2020 was possibly influenced by the pandemic in two ways:

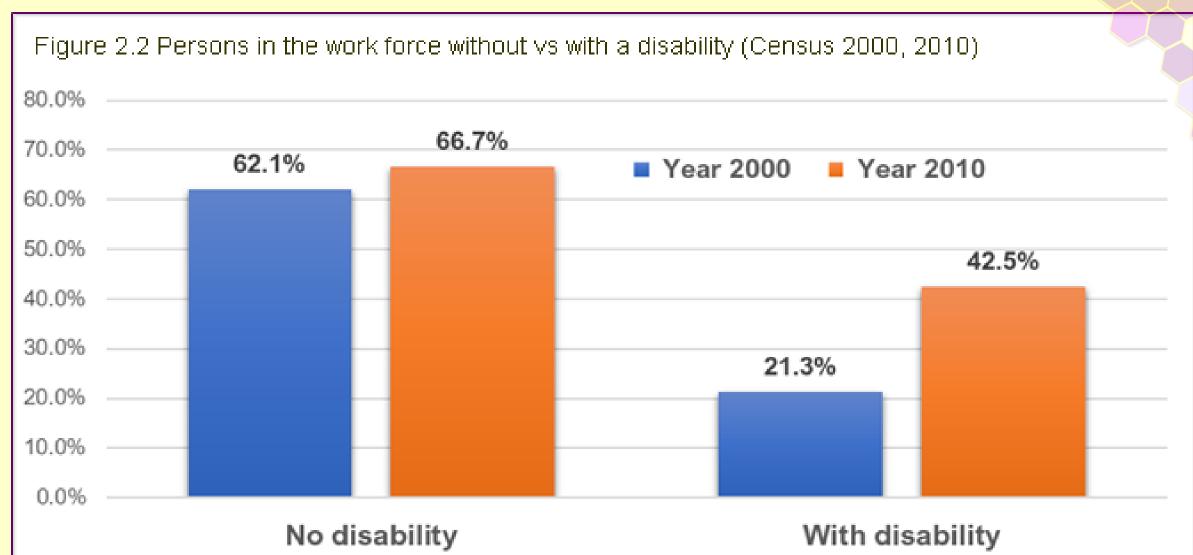
- a) since it was online, a "proxy" responded, possibly overlooking answers by persons with disabilities;
- b) people viewed own health and disabilities from another perspective, compared to those affected by COVID-19, downplaying their own disabilities.

Type of disabilities, 2010 vs 2020

Figure 2.1 Type of disability Census 2010 vs. Census 2020.

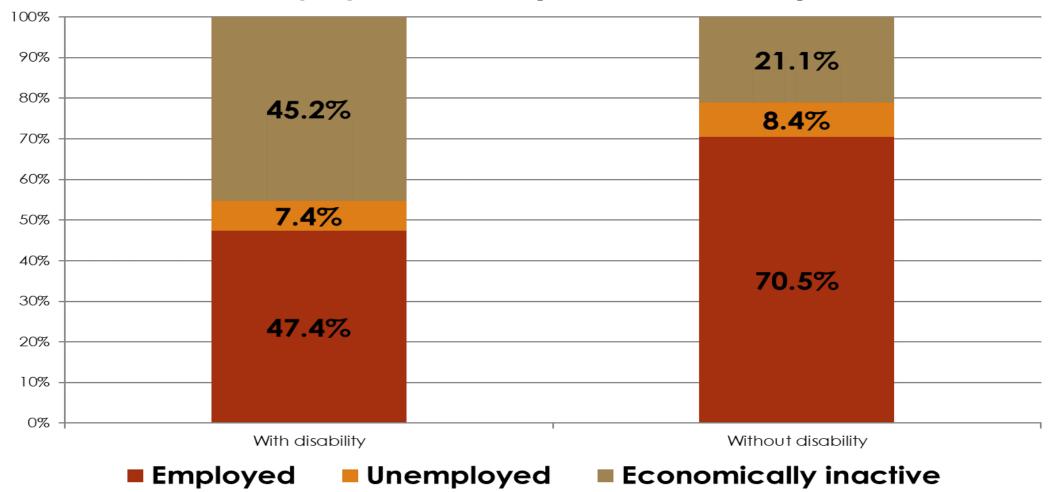


Persons with disabilities are better integrated in the workforce (Censo 2000, 2010)



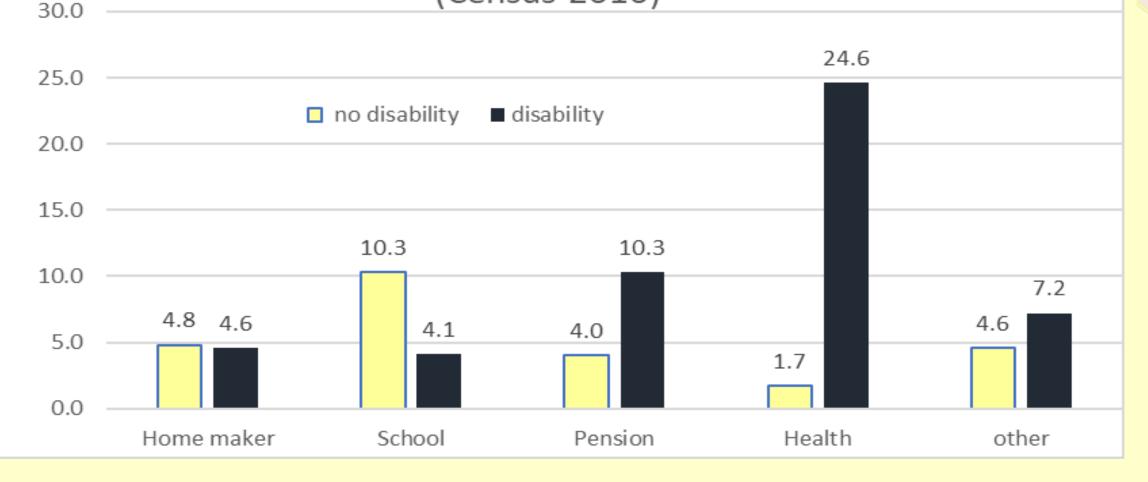
Persons with disabilities are more economically inactive

Persons (16-59 yrs) with and without disability by employment status (Census 2010, CBS)



Health issues are a real challenge for persons with disabilities to work

Reasons for not working, with and without disability (Census 2010)

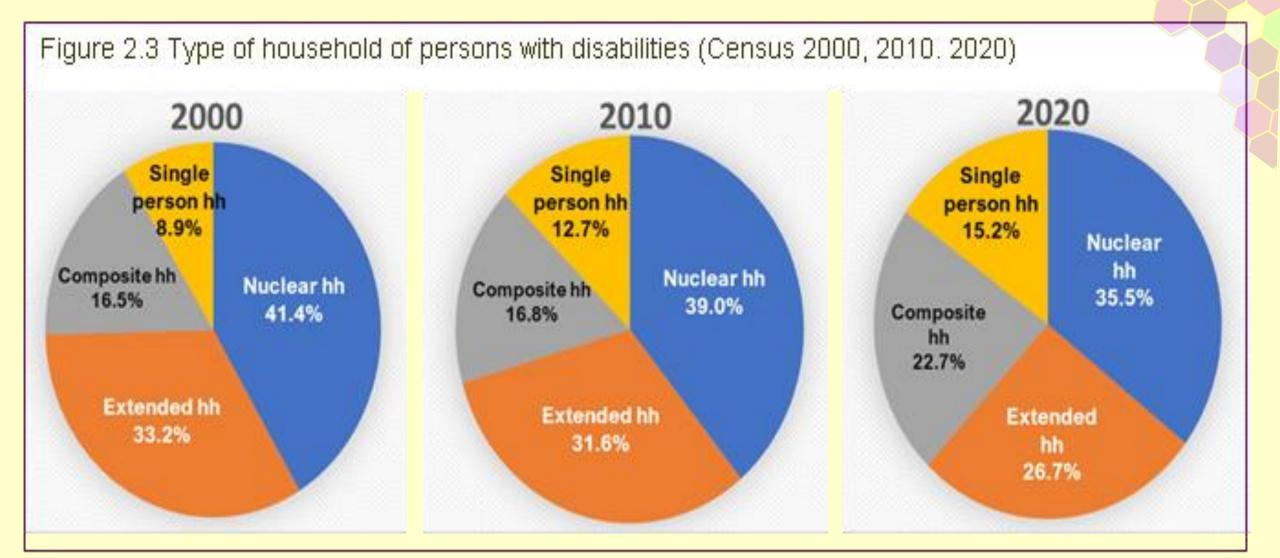


Persons With Disabilities and Socializing

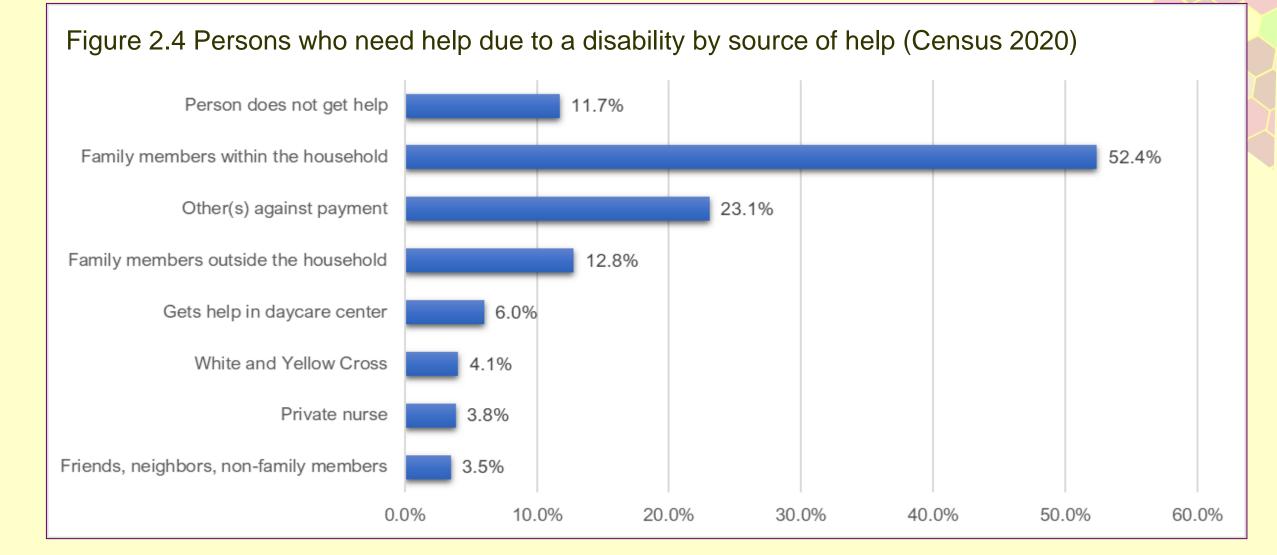
Welfare Survey (DAS 2009):

- How important are the following items for being integrated and included into social life?
 - <u>17 items:</u>
 - Able to operate a computer
 - o Able to speak Papiamento, English, Dutch, Spanish
 - Having a driver's license
 - Having friends
 - $\circ~$ Having one's own family and children
 - Not having a chronic disease or disability
 - Engage in voluntary work
 - Having the Dutch nationality
 - Having a higher education

Persons with disabilities are living increasingly on their own or with people that are not family (Censo 2000, 2010, 2020)

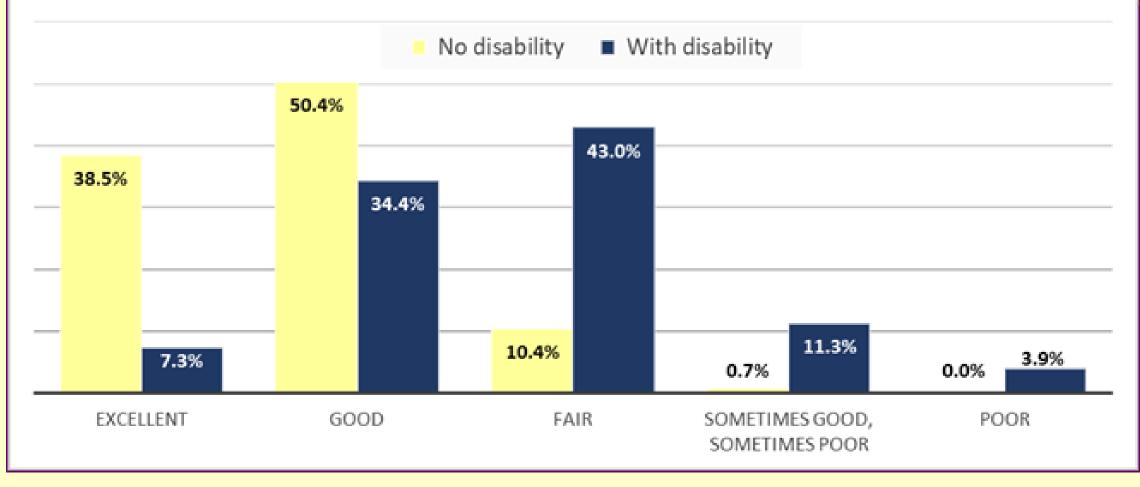


Persons with disabilities needing help from care givers (Censo 2020)



Persons with disabilities have worse health compared to persons without disabilities (Censo 2010)

Figure 2.6 Perceived health of persons with and without a disability (Census 2010)



Persons with disabilities are less able to afford assistive devices (Censo 2010)

Average household, no person with disability

> Average income: AWG. 4.597

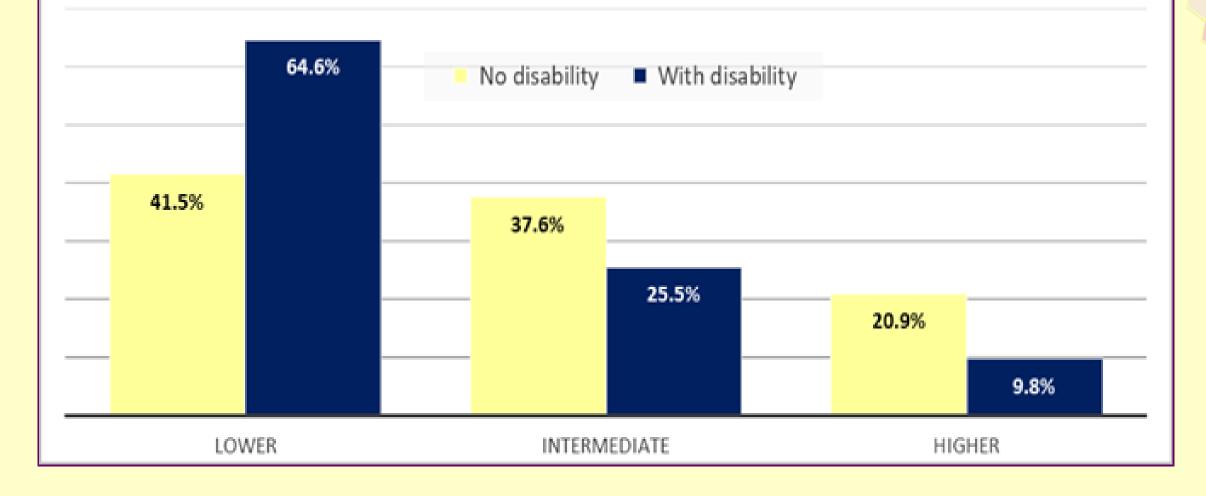
Average household, person with disability



Average income: AWG. 3.496

Persons with disabilities have a lower level of education (Censo 2010)

Figure 2.7 Level of education of persons with and without a disability (Census 2010)



Study Objectives

Main objective

Conduct an inventorization of the services in the provision of disability care in Aruba, with the goal to identify gaps and to look at potential collaborations to maximize the use of available (non-financial)

resources.

Definition of person with disabilities (for this study)

A person of any age having a long-term visual, hearing, motor, intellectual, or psychiatric impairment caused at birth (congenital) or by injury, old age, or an illness.

Research Subjects (1 of 4)

Organizations offering services to persons with disabilities

Current members of PPL (in alphabetical order)

Fundacion Arubano di esnan Visualmente Incapacita (FAVI)

Fundacion Arubano pa e Invalidonan (FUNARI)

Fundacion Autismo Aruba (FAA)

Fundacion Biba Bou Guia (FBBG)

Fundacion Pa Esnan cu Deficiencia Auditivo Aruba (FEDAA)

Fundacion pa Esnan cu Problema di Oido y Habla (FEPOH)

Fundacion Siña Mi Paso pa Paso (FSPP)

Mickey's Foundation

Ouderenvereniging Sonrisa

Stichting Ambiente Feliz/Cas Briyante (SAF)

Stichting Ambiente Nobo (SAN)

Stichting Eliezer

Stichting Trampolin pa Trabou (TpT)

Stichting voor Verstandelijk Gehandicapten Aruba (SVGA)

Research Subjects (2 of 4)

Organizations offering services to persons with disabilities

Non-governmental organizations not members of PPL (in alphabetical order)

Bright Minds
Brighter Future (Academy)
Cas Marie
CVA Aruba
FARVa
Fund. Diabetico Aruba (FDA)
Fundacion Iglesia Alianza Nobo
Fundacion Muchila Creativo
Fundacion Wiel Parandiando
Hoofs of Hope
Paralympic Committee
Special Olympics
St. Hunto (=SPD+FMAA)
Stichting Arubaanse Bejaardenthuizen Aruba
We Welcome Wheelchairs
White Yellow Cross (WGK)

Research Subjects (3 of 4)

Organizations offering services to persons with disabilities

Government Departments (in alphabetical order)

Dept. Education (DEA)

Dept. Labor & Research (DAO)

Dept. Labor Advancement (DPL)

Dept. Public Health (DVG)

Dept. Public Works (DOW)

Dept. Social Affairs (DAS)

Dept. Youth Health (JGZ)

Research Subjects (4 of 4)

Organizations offering services to persons with disabilities

Schools and Education (in alphabetical orde	er)	
Caiquetioschool		
Educacion Profesional Basico (EPB)		
Emmaschool		
Multidisciplicair Centrum (MDC)		
Scol pa Ofishi (SPO St. Cruz)		
Scol Paso pa Futuro		
Scol Dununman	Health care (in alphabetical order)
Scol Dornasol		
	Renabilitation	Department dr. H.O. Hospital
	Executive Boo	dy AZV (UO AZV)
	FSMA/Respal	do

Study Areas & Questions

A) Labor

- **B) Socializing**
- C) Mobility & Accessibility
- **D) Health & Rehabilitation**
 - (incl. freedom from abuse)
- **E) Education**
- F) Other facilities

For each area:

- What facilities do you offer?
- What personnel do you have?
- What could you share with
- others and on what basis?



- Needs of your organization?
 Solutions?
- Challenges for Aruba?
 Solutions?

Executive level

- G) Use of UN Sustainable Development Goals
- H) Convention on the Rights of Persons With Disabilities

UN's 2030 Agenda for Sustainable Development

- Adopted by the United Nations in 2015
- Ambitious plan of action of the international community:
 - ✓ peaceful and prosperous world
 - ✓ where dignity of an individual person
 - ✓ equality among all
- Involve 17 goals conjointly integrated
- 5 Pillars:

- People
- Planet
- Prosperity
- Peace
- Partnership

UN's SDGs



Convention on the Rights of Persons with Disabilities

- Equality, non-discrimination, equal access to justice (art. 1-7, 12, 13)
- Awareness raising (art. 8)
- Personal mobility, accessibility (art. 9, 20)
- Right to life, integrity, dignity, privacy, freedom to make choices (art. 10, 17-19, 21, 22)
- Security, freedom from abuse (art. 11, 14-16)
- Family, getting married, having children (art. 23)
- Education (art. 24)
- Health; rehabilitation and habilitation (art. 25, 26)
- Work, income, standard of living (art. 27, 28)
- Socializing: participation in society (art. 29, 30)
- Preconditions, statistics & data, monitoring, implementation (art. 31-50)

Limitations

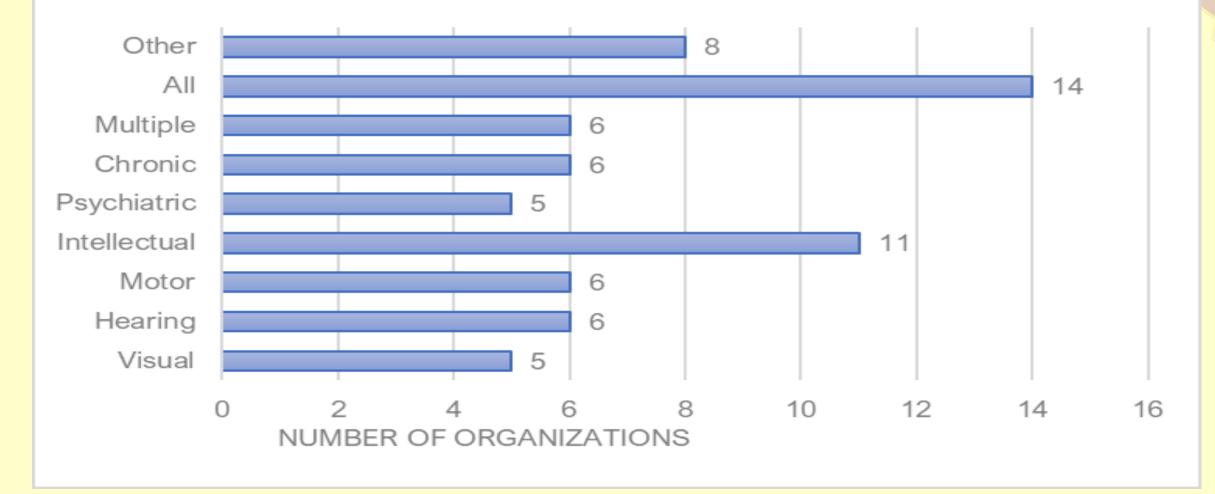
- Interview persons with disabilities
 - Needs assessment among persons with disabilities done in 2012 by Department of Social Affairs (November 2012)
- Interview care takers
 - ✓ Recommended on a later date (!)



	Invited	Responded
PPL Members	14	13
NGOs (no PPL Member)	16	10
GOs, education, health	16	15
Total	46	38

Organizations per target group

Figure 4.1 Number of organizations per target group



By the way... ... why the honeycomb?



What Can We Learn From the Bees

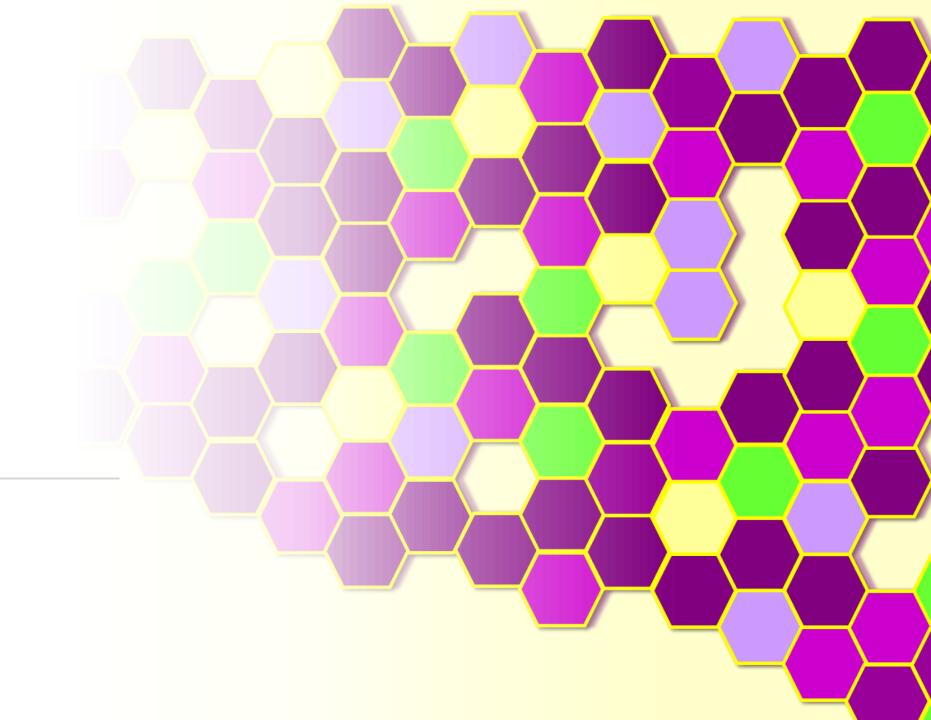
- Achieve thriving colony through good communication and hard work
- Worker bees do not hesitate to share information about the best plants using a "waggle dance" to give precise directions
- How to economize: hexagonal cells require the least total length of wall, economizing labor and wax

Sources: https://blog.numitea.com/4-lessons-from-honey-bees; https://nautil.us/why-nature-prefers-hexagons-235863

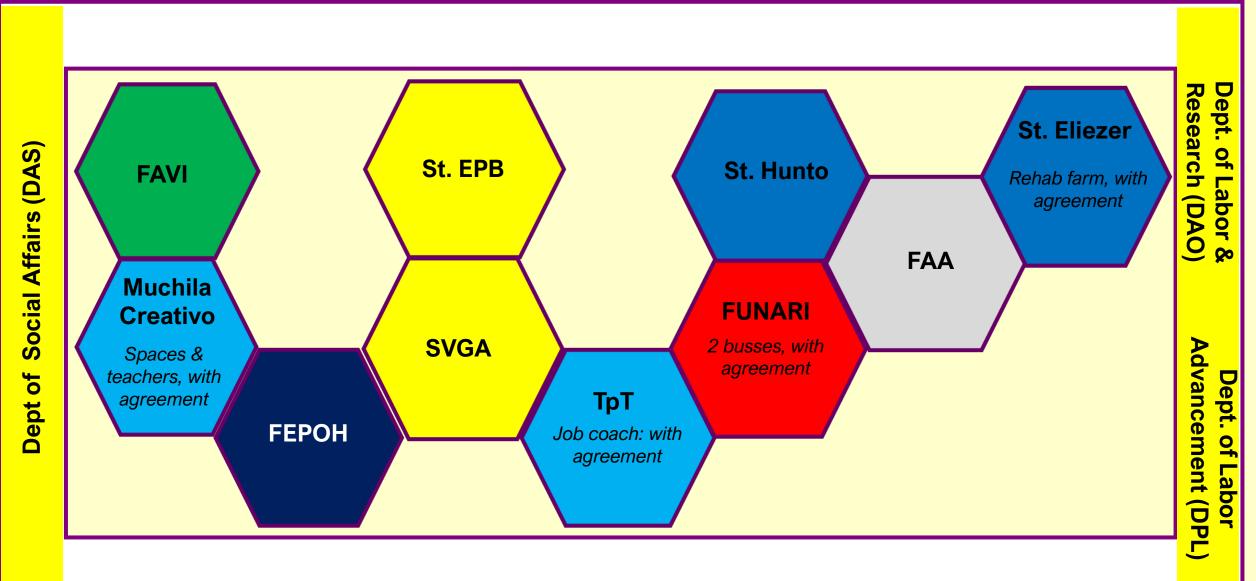
Color codes

Visual Hearing Motor Intellectual Psychiatric Chronic disease Multiple disability All disabilities ther

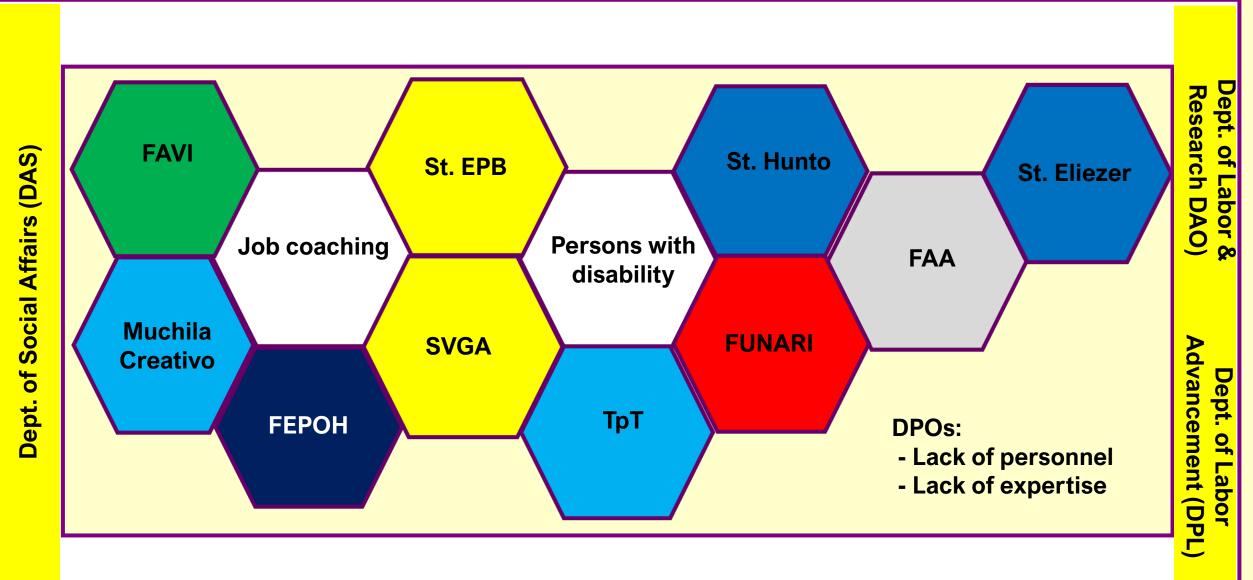
A) Labor



Services in A) Labor



Gaps in A) Labor



A) Labor (1 of 4)

System (legal, departments, education, etc.)

- ✓ PWDs on Disability Allowance (GUNS):
 - No guarantees if work doesn't work \rightarrow create guarantees
 - Working on therapy basis: not insured at SVb \rightarrow insurance?
 - Costs to work do not make it worth it \rightarrow create incentives of PWDs
- ✓ Legal
 - Lack of laws to protect rights of PWDs \rightarrow create laws
- ✓ PWDs with working abilities
 - How many PWDs with wish/ability to work → support DPOs to do survey
 - How many job coaches to guide these PWDs
- ✓ Lack of more secondary education for children with intellectual disabilities
 - Establish secondary education
 - Better use of digital student tracking system

A) Labor (2 of 4)

Job coaching

- How many PWDs with wish/ability to work \rightarrow support DPOs to do survey
- ✓ Clients need more hands-on assistance → create clear pathways towards a job; guide clients based on (intellectual) abilities
- ✓ Lack of enough job coaches \rightarrow job coaches specialized in PWDs in DPL

Community

- ✓ Lack of knowledge, belief that PWDs are not capable to work, PWDs already labelled → awareness programs to change perception of community
- \checkmark Over-protective culture \rightarrow support parents/care takers of PWDs

A) Labor (3 of 4)

Job market, employers

- ✓ Lack of diversity of jobs \rightarrow create more diversity
- ✓ Employers lack knowledge, trust, time, willingness, and resourcefulness
 → programs to educate employers about the worth of persons with disabilities; more support to those who employ PWDs; create funds to do adaptations, invest in assistive devices
- ✓ Employers must be stimulated or required to hire PWDs → laws and regulations to stimulate (e.g. tax benefits) or require (e.g. quotas)

Mobility, accessibility, infrastructure, transport

- ✓ Adequate transport is lacking or too expensive → Better transport arrangements: car pooling, volunteers, Arubus arrangements
- ✓ Lack of good infrastructure → Adjust infrastructure to include more PWDs on the job market

A) Labor (4 of 4)

DPOs

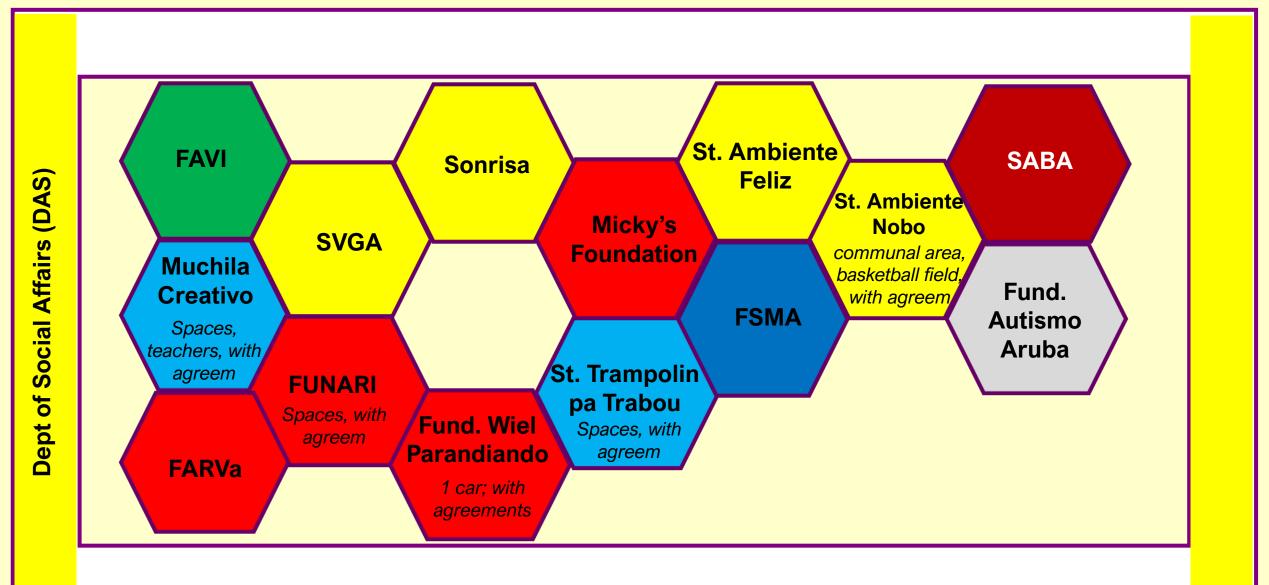
 \checkmark Lack of personnel and expertise \rightarrow Support DPOs to hire personnel

Persons with disabilities

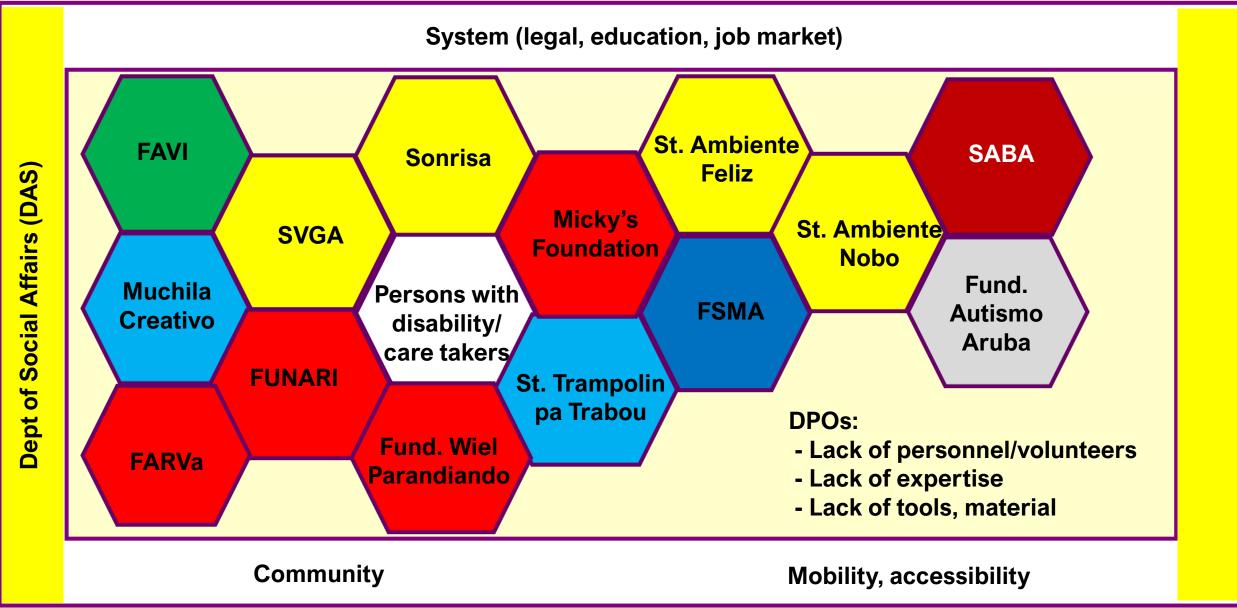
- ✓ Many clients do not have enough work experience or skills → preparation course to train clients to gain needed skills
- ✓ Some PWDs lack of interest to work → Educate clients and parents/family about ability to work and positive effect on their quality of life
- ✓ Not all have job potential

B) Socializing

Services in B) Socializing



Gaps in B) Socializing



B) Socializing (1 of 3)

System (legal, education, job market)

- ✓ Reach PWDs most vulnerable \rightarrow registration system
- ✓ Lack of laws to protect rights of PWDs → create laws
- ✓ PWDs having no jobs (see under A)
- ✓ Lack of financial means for quality of life
- $\checkmark~$ AZV covers limited number of therapy sessions $\rightarrow~$
- ✓ Lack of enough and adequate facilities → do research on the need of facilities to invest more targeted

Community

- \checkmark Society do not understand or accept PWDs \rightarrow more awareness programs
- ✓ Lot of taboo around psychiatric disability

B) Socializing (2 of 3)

Persons with disabilities and care takers

- ✓ Persons with disabilities
 - Many are in isolation
 - Lack of confidence in themselves
 - Fear to be accepted by community
 - Not all can deal with triggers in social settings
- ✓ Care takers
 - Weak network → Create a system with case managers to support parents at birth or adults when they become disabled
 - Do not accept PWD in their family
 - Are themselves older and in need of help → Do a needs assessment among care takers

B) Socializing (3 of 3)

Mobility, accessibility, infrastructure, transport

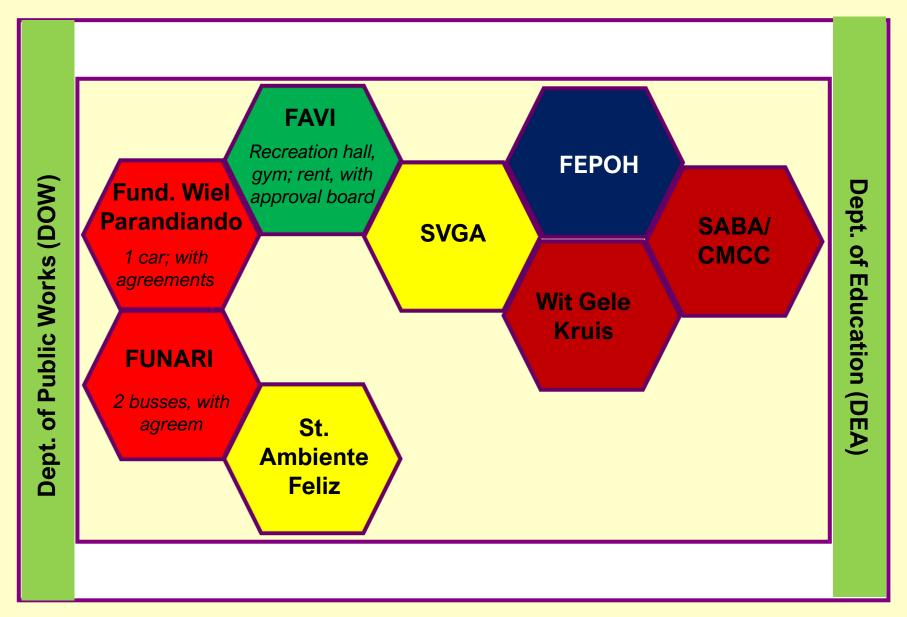
- \checkmark Wheelchair transport too expensive \rightarrow better arrangements.
- ✓ Inaccessible stores, restaurants, sport facilities, etc. → macro investments in infrastructure; better building laws

DPOs

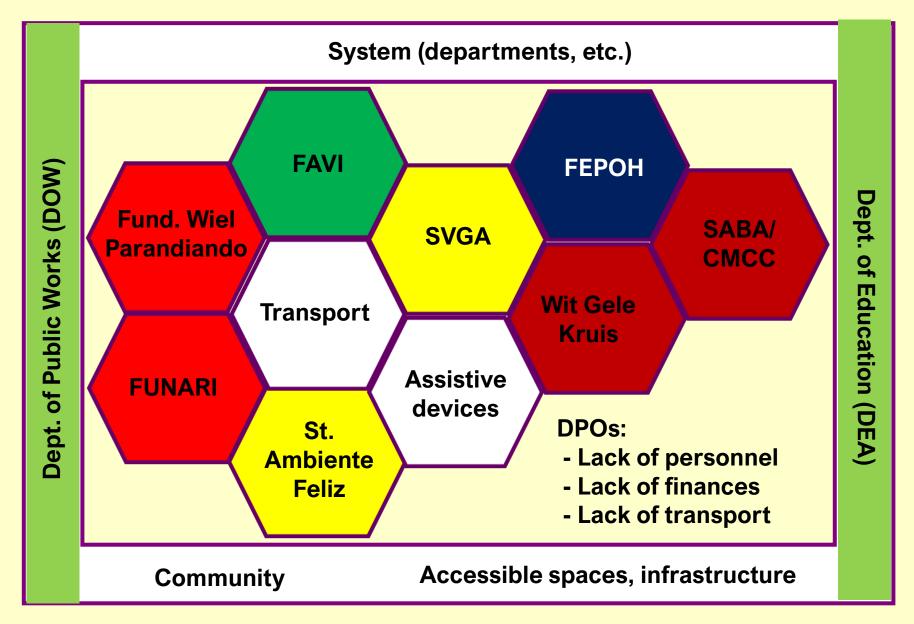
- ✓ More paid personnel & volunteers to expand services → recruit volunteers among welfare recipients
- ✓ Services for socializing are limited → Organize more neighborhood events, to get clients out of isolation
- ✓ Lack of financial means to organize more activities
- ✓ Lack of wheelchair transport

C) Mobility & Accessibility

Services in C) Mobility & Accessibility



Gaps in C) Mobility & Accessibility



C) Mobility & Accessibility (1 of 2)

System (departments)

- \checkmark Lack of laws to protect rights of PWDs \rightarrow create laws
- ✓ Lack of cooperation between departments and NGOs → More cooperation

Accessibility, infrastructure

- ✓ Inadequate infrastructure in general, no laws → Draft laws and regulations to ensure accessibility of buildings, walkways, toilets, etc.; install advisory committee
- ✓ Inaccessible stores, restaurants, sport facilities, etc. → macro investments in infrastructure; government & commerce must see this as a priority

Transport

- ✓ Wheelchair transport too expensive \rightarrow car pooling, volunteers
- \checkmark Arubus busses not adequate \rightarrow arrangements with Arubus

C) Mobility & Accessibility (2 of 2)

Assistive devices

- ✓ No braille in restaurants
- ✓ ATMs not accessible for persons with visual impairments → ATMs voice guided

DPO

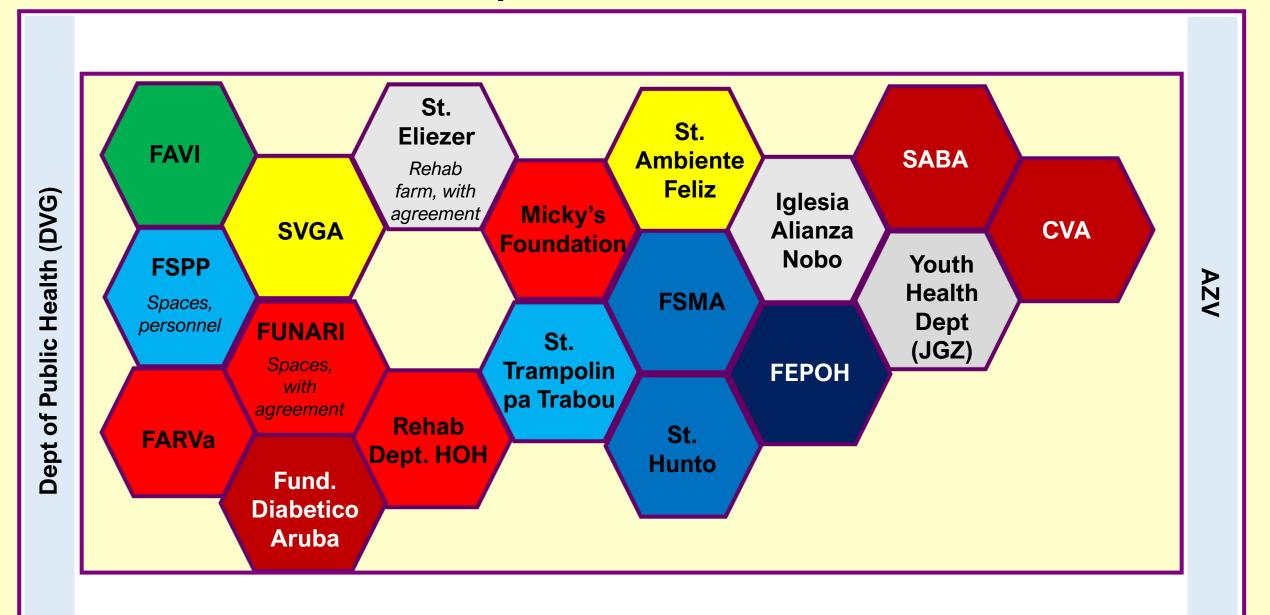
- ✓ Mobile teachers to home school children
- ✓ Lack of finances
- ✓ Lack of transport for clients

Community

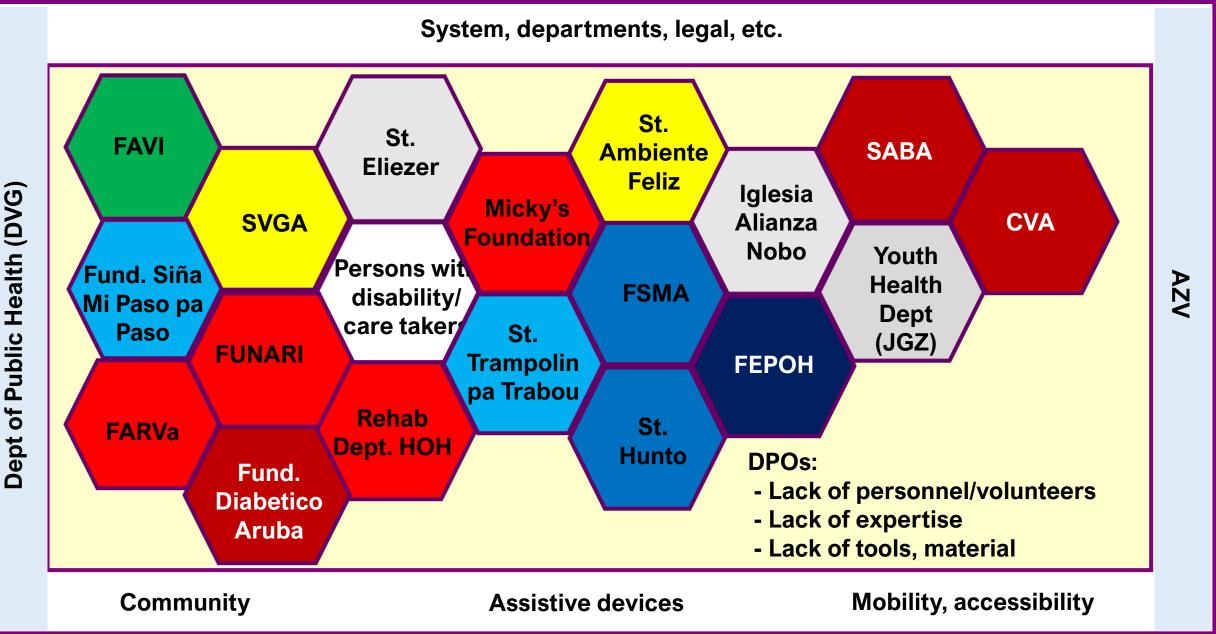
- ✓ Society do not accept that PWDs also have abilities, disability is a taboo
 → more awareness programs
- ✓ SETAR personnel do not know how to support clients with disabilities → training to SETAR personnel
- ✓ Websites (banks, WEB, ELMAR, etc.) that are better accessible

D) Health & Rehabilitation

Services in D) Health & Rehabilitation



Gaps in D) Health & Rehabilitation



D) Health & Rehabilitation (1 of 4)

System (health, legal, departments)

- ✓ Long waiting lists at several organizations, St. Hunto
- \checkmark Lack of good communications between organizations \rightarrow
- ✓ Lack of working efficiently for the benefit of the client
- ✓ Lack of continuity when there is a change in government → Put into effect the plans already written
- ✓ Lack of early detection \rightarrow re-introduce early detection program
- ✓ No Rehabilitation Center in Aruba → A collaboration between AZV, government and HOH to set up a care system for child rehabilitation by highly qualified therapist; DVG develops a strategic plan for rehabilitation for the island
- ✓ AZV's coverage is very restrictive on the service
- ✓ AZV covers health care costs, not care costs → Create a long-term care law instead of subsidy

D) Health & Rehabilitation (2 of 4)

Persons with disabilities & care takers

- ✓ Lack of good cooperation with families, government depts, employers, etc → better cooperation
- Parents of children with hearing disability need to learn how to communicate with their child
- ✓ Deaf clients more sensitive to become victims of abuse, addiction, become drop-outs
 → social worker to help stand up for themselves
- ✓ No financial aid to support parents of children with disabilities
- Cases of negligence were observe w/ parents who do not know how to care for their child
- Clients with intellectual disability are not labeled as psychiatric, while the problematic behavior is still present
- Need to learn to recognize the signs of abuse and how to report it, also in case of doubt
- \checkmark With mental health issues, s.t also at home
- ✓ Many PWDs cannot afford to pay for care at home

D) Health & Rehabilitation (3 of 4)

DPOs

- ✓ <u>Personnel</u>:
 - Lack of staff at JGZ \rightarrow Get more personnel
 - More paid professionals \rightarrow request government subsidy again
 - More GP support officers
 - Need of social worker to help clients
 - Lack of specialized child rehabilitation specialist, so misdiagnose or no diagnose
 - Because of understaffing, no attention for mental health issues
 - Need doctor or nurse to administer medication
 - Lack of in-house physical therapist, together with other NGOs
 - Offer speech therapy to all children with hearing disability

D) Health & Rehabilitation (4 of 4)

- ✓ <u>Financial</u>
 - Lack of financial means, no government subsidy
- ✓ <u>Material, tools</u>
 - EZRA-software \rightarrow reinstall EZRA software
 - Better equipment

Assistive devices

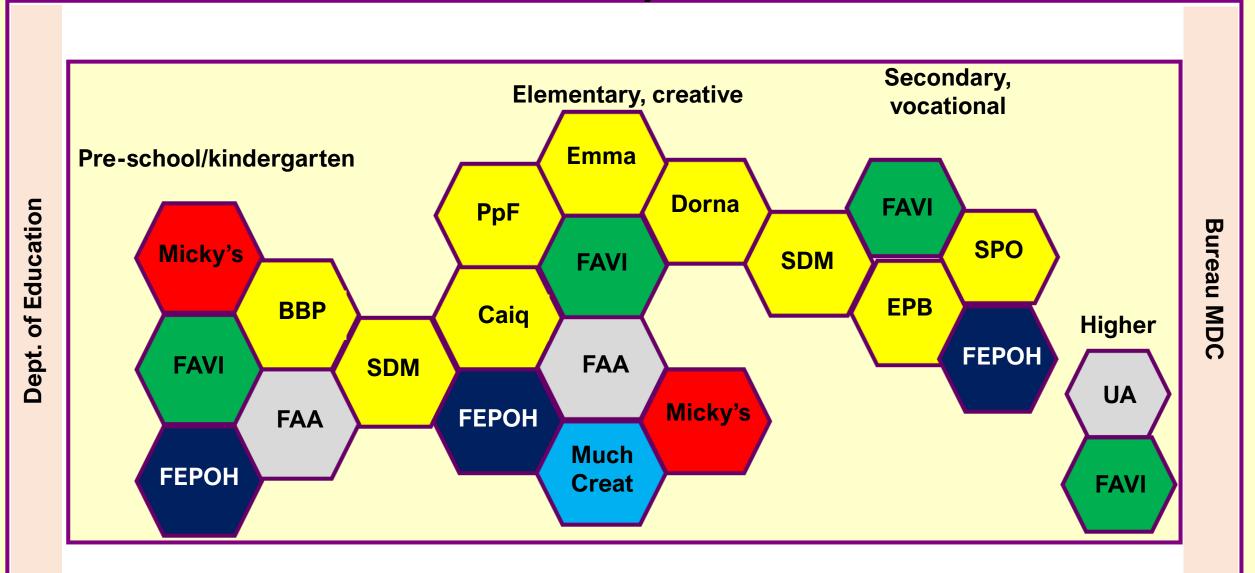
- ✓ No assistive devices available or they are not affordable
- It takes sometimes too long for patients to get their wheelchairs and/or beds

Community

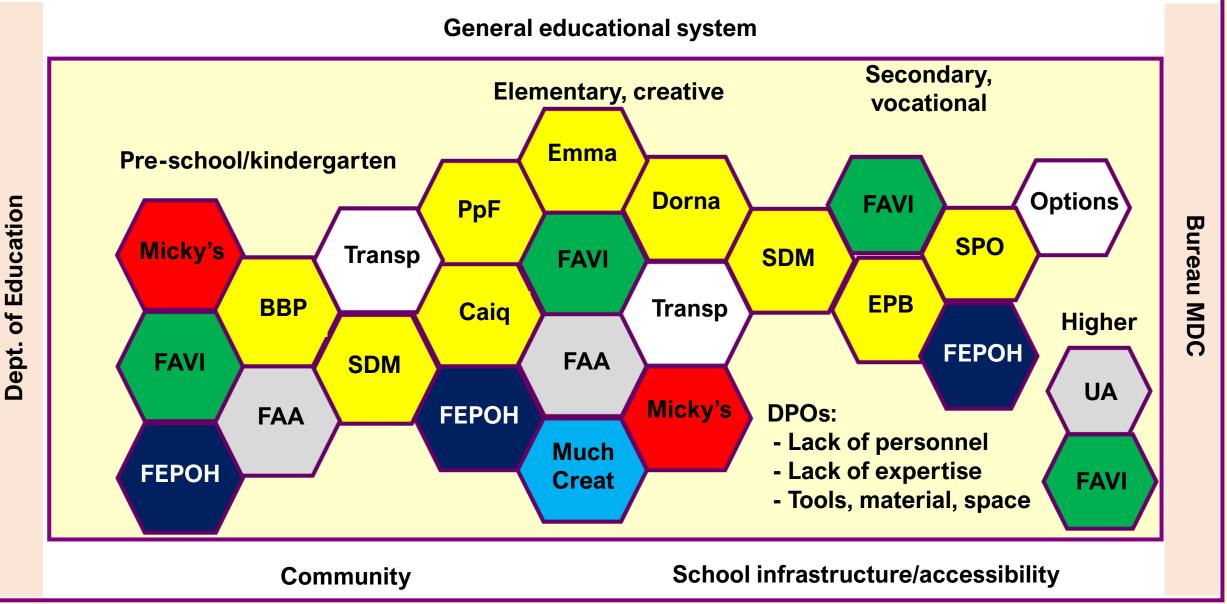
- ✓ No acceptance of clients by family, community in general, employers → Better acceptance of rehabilitated addicts
- \checkmark Talking about abuse is a taboo in the community

E) Education

Services in E) Education



Gaps in E) Education



E) Education (1 of 3)

General educational system

- ✓ Lack of investments in schools for children with disabilities
- ✓ One-size-fits-all type of education system
- ✓ No appropriate schools for many children with disabilities
- ✓ Not enough options available for secondary or vocational education
- ✓ Children with CI, normal intelligence, but with language delay, cannot go to regular school, follow classes with children with intellectual disabilities
- There is a lack of an organization taking care of this group; sometimes families are overwhelmed with all needs of the client
- ✓ Waiting lists in several schools
- ✓ Closing of MdC's Observation Center: no optimal early intervention
- ✓ Lack of timely placements in special education

E) Education (2 of 3)

DPOs: Personnel

- ✓ Lack of psychologists, social workers, health professionals in schools →
 Fill the vacancies at MDC according to the approved formation plan
- Lack of the necessary experts in education, like remedial teachers, social workers, and school assistants.
- Lack of knowledge and expertise to evaluate individual possibilities to have optimal indication and placement at the appropriate school
- ✓ Funds to send teachers abroad to update themselves and to keep expertise and competence on a high level
- ✓ Not enough knowledge about autism among teachers → Provide educators with workshops on autism more regularly

E) Education (3 of 3)

DPOs: Material, tools, space

- ✓ Funds to purchase material to modify books for blind children
- ✓ Lack of material in Papiamento
- ✓ Difficulty getting ergonomic chairs and tables, custom keyboards, larger screens, electronic devices to accommodate the educational needs → Investments in necessary school material and tools to provide quality education

Accessibility, infrastructure

- ✓ Accessibility of many schools is lacking Inaccessible stores, restaurants, sport facilities, etc. → macro investments in infrastructure
- ✓ Better transportation for students in a wheelchair to reach school every day

Community

- Wrong idea that a child with a disability can do little or nothing because of his/her disability
- Business owners and community in general should give our students a chance to show their potential

F) Other Facilities

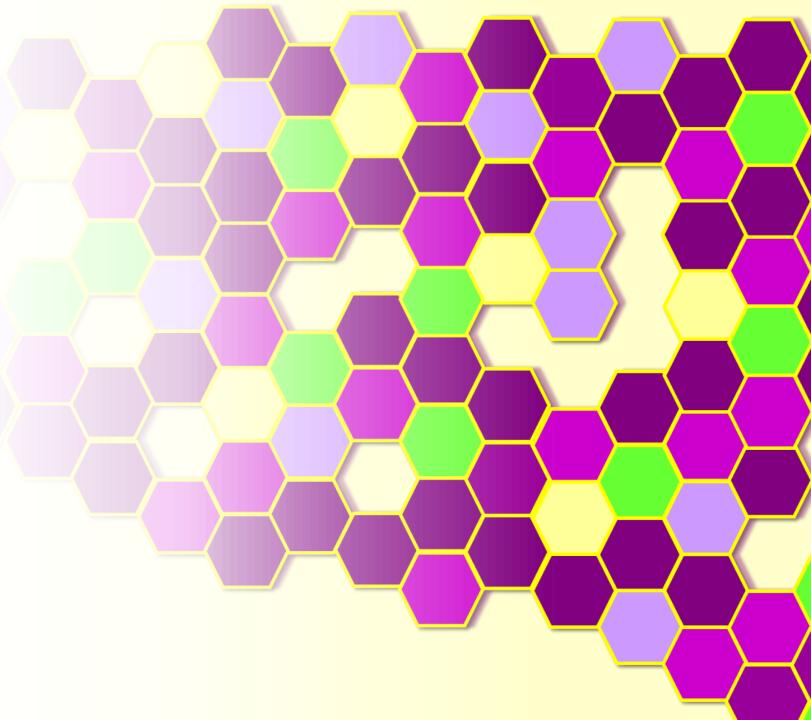
Services in F) Other services

- Residential services
 - ✓ Fund. Biba Bou Guia
 - o 25 houses; 29 clients
 - ✓ SVGA:
 - Cas Sjabururi: 12 adults (18+ yrs)
 - Cas Blenchi: 6 children (6-24 yrs)
- Religious services: Iglesia Alianza Nobo
 - ✓ Bible based therapy for substance addiction

Recommendations

- Need for more residential services: waiting lists
- Residential facility for children suffering with psychiatric disorders
- Subsidy for IAN

G) UN Sustainable Development Goals (SDGs)



SDGs most worked on

Figure 11.1 Number of organizations per SDG

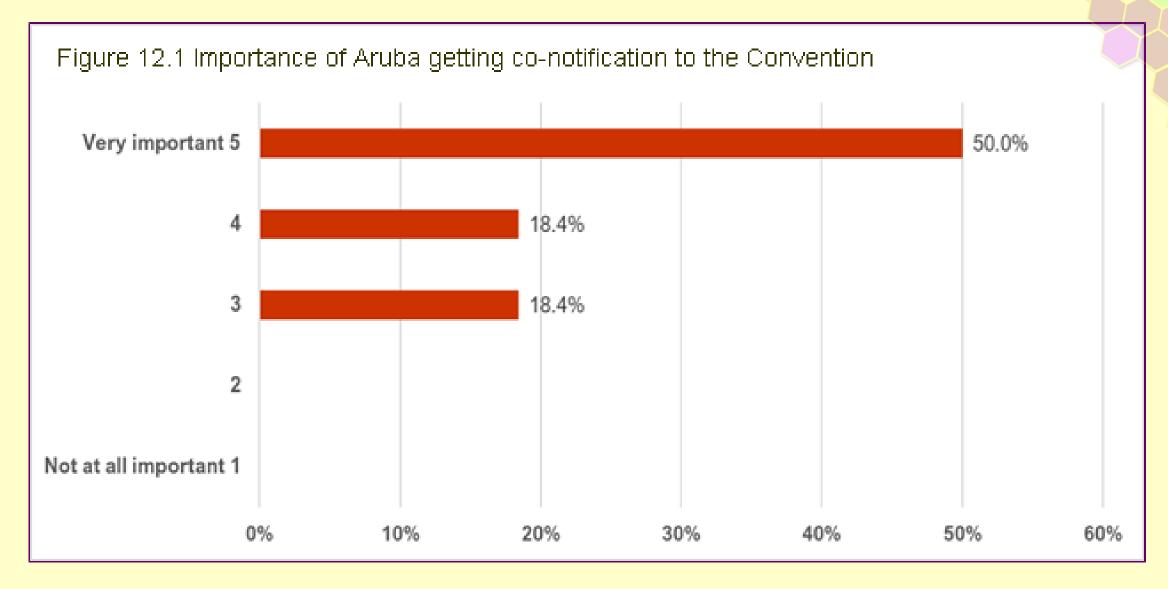
SDG#12: Responsible consumption З. SDG#2: Zero hunger 5 SDG#1: No poverty 5 SDG#5: Gender equality 8 SDG#8: Decent work 13 SDG#10: Reduced inequalities 14SDG#17: Partnerships 15 SDG#4: Quality education 15 SDG#3: Good health & Well-being 22 We have not been working on these as yet 8 5 10 15 25 20 0

Recommendations

- Adopting the SDGs on an organizational level
- More awareness on responsible consumption
- More attention for gender equality

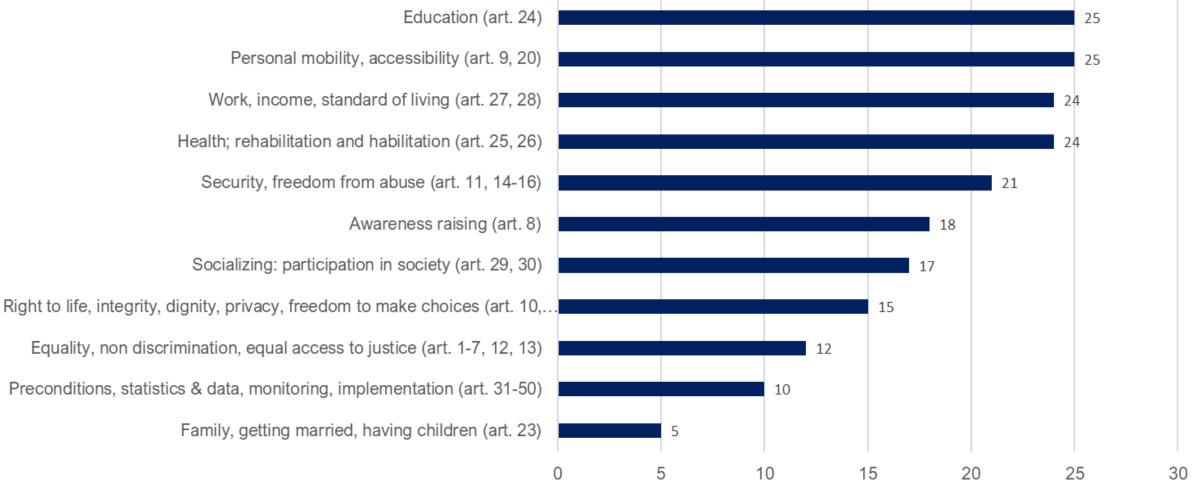
H) The Convention on the Rights of Persons with Disabilities

How important?



Topics Aruba needs to improve

Figure 12.2 Topics in the Convention participating organizations found Aruba still needs to improve in (descending order)



Recommendation

- Urge Parliament to make Aruba part of the CRPD
- •

