

Exploring Disability Data Registry: progress report Aruba

Data Registers Workgroup

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Aruba

Overview

1. Rationale
2. Workgroup Data Registers
3. Main activities Aruba
 1. Literature review – disability data registries
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1. Rationale

- During the 13th WG meeting several representatives expressed the need for the WG to look into the use of data registers in the compilation of disability statistics.
- The workgroup would be asked to develop a proposed work plan for presentation at the next WG meeting.
- The meeting participants would then decide if this was a feasible objective for the WG to take on and provide recommendations on how the work group should proceed.

2. Workgroup Data Registers

- Workgroup members:
 - Aruba
 - Central Bureau of Statistics (CBS)
 - contact: Mr. Patrick Suykerbuyk; Psuykerbuyk@cbs.aw
 - Saudi Arabia
 - Saudi National Disability Registry (SNDR)
 - Contact: Mr. Sultan A Al-Mubarak; smubark@kacst.edu.sa
 - Peru
 - National Statistical and Informatic Institute (INEI)
 - Contact: Mrs. Genara Rivera Araujo; Genara.Rivera@inei.gob.pe

2. Workgroup

- Work by workgroup members:
 - No specific action plan was elaborated within workgroup
 - Workgroup decided that each member would explore the feasibility and/or opportunities within his/her country
 - Exploration steps within country:
 - Inventory of stakeholders
 - Inventory of disability data sources (both existing as potential)
 - Raise support base for a (national) disability data registry
 - Inquiry of technical and financial needs
 - Recommendations
 - Progress made by Saudi Arabia: see separate presentation by Mr Sultan A Al-Mubarak
 - Progress made by Aruba: this report

3. Main activities Aruba

December 2013:

CBS Aruba expressed interest in participating in work group on data registers

January 2014 – April 2014:

Literature review on (national) disability data registers, especially in Europe & Caribbean region

Mei 2014 – September 2014:

Inventory and meetings with local stakeholders

3.1 Literature review

- Several publications and websites were consulted regarding (continuous) disability registers.
- Among others, following key publications and/or organizations were selected for this progress report:
 - A. *The Training Manual of Disability Statistics – WHO 2008*
 - B. *World Report on Disability – WHO 2011*
 - C. *European disability statistical data compilation*
 - D. *European Disability Strategy 2010-2020*
 - E. *European Key organizations*
 - F. *Example of the use of a National Disability Registry – Taiwan*
 - G. *Caribbean key organization: ECLAC*

3.1.A The Training Manual of Disability Statistics -1

A. The Training Manual of Disability Statistics (WHO)

- includes a discussion of the Strengths and Weaknesses of the different data collection methods.
- summarizes the salient advantages and disadvantages of census, sample surveys, and administrative data collections (both one-time and continuous) as approaches to the collection of disability data.

TRAINING MANUAL on DISABILITY STATISTICS

World Health Organization /
United Nations Economic and Social Commission for
Asia and the Pacific

2008

REF: <http://www.inclusive-education.org/system/files/publications-documents/WHO%20ESCAP%20Training%20Manual%20Disability%20Statistics.pdf>

3.1.A The Training Manual of Disability Statistics -1

Box 3.6: Disability Data Collection Methods Practiced in Selected Countries

Country	Method of Data Collection
Cambodia	Social Economic Surveys and Population Census
Fiji Islands	Census of Population and Household Income and Expenditure Survey
Hong Kong, China	Survey on Persons with Disabilities and Chronic Diseases
India	Census, National Sample Survey Organization, Survey and Voluntary Registry
Indonesia	National Socio-Economic Surveys
Islamic Republic of Iran	Census
Mongolia	Limited registry in capital city (voluntary, impairment-based registry)
Philippines	Population and Housing Censuses
Thailand	Disability Surveys, Bureau of Empowerment for Persons with Disabilities National Registry and Censuses

Table 3.1: Population Censuses: Advantages and Disadvantages ²

Advantages	Disadvantages
Data can be tabulated for small, local areas.	Questions limited to basic socio-economic and demographic characteristics, restricting the scope of disability questions.
Prevalence rates can be calculated for small geographical areas because data are also gathered for the population at risk.	Data collection is infrequent – usually every 10 years. The time between data collection and data dissemination can be considerable.
Detailed descriptive cross-tabulations are not subject to sampling errors.	In some censuses, populations in institutions with disabilities may not be included.
If disability questions remain comparable, they can be useful analysis of disability rates across time.	Subject to high non-response rates and under-enumeration because of the complexity and sensitivity of the question.
Identified set of persons with disabilities is usually large, allowing more detailed cross-tabulations and analyses.	It is costly and time-consuming to identify a relative small population of persons with disabilities by asking questions of the entire population.
Can provide a useful sampling frame for research on persons with disabilities who are otherwise difficult to find.	May be too costly to train enumerators in the specific guidelines required for disability questions.

Table 3.2: Sample Surveys: Advantages and Disadvantages

Advantages	Disadvantages
Flexibility in the depth and range of topics covered.	Limited sample size for small geographic area resulting to higher sampling errors, thus, limited ability to analyse prevalence rate for local areas.
Special probes can be used to ensure that persons with disabilities are identified.	Persons with disabilities account for less than 20 percent of any population, so unless the survey is very large, the sample size of persons with disabilities will be small
If sampling frame and survey infrastructure in place, relatively easy to initiate.	Coverage poor for institutionalised persons, the homeless, refugees or nomadic populations.
If comparable with census and other surveys, can be used for detecting change over time.	Time-series analysis of ad hoc surveys is uncertain.
Because of limited coverage and smaller sample, there is greater control over the conditions of observation and interviewing.	Detailed surveys require close supervision of fieldwork and special disability training for field supervisors and interviewers.
Capacity to locate persons with disabilities can be increased with design modifications (e.g. co-coordinating probability sample selection with the census, using registered population lists, stratifying the sampling stage, or increasing the sampling fraction).	
Greater opportunity for field work supervision, specialised field training, question pre-testing.	

Table 3.3: One-time Registration Data Collection: Advantages and Disadvantages

Advantages	Disadvantages
Easy to initiate.	Extent of coverage and the degree of representation are unknown and sampling error cannot be estimated.
Does not require a large, on-going staff.	Population at risk is unknown, so prevalence and incidence rates of disability cannot be calculated.
Can provide a large number of cases for complex data analysis where extensive cross-tabulations and disaggregation are required.	Double counting is a problem, given many classes of informants and multiple registration lists of registered persons with disabilities.
May be used to assist governmental and private agencies (e.g. social security and social welfare offices and medical and educational organizations) locating persons with disabilities in need of services.	Findings can be easily or validly extrapolated to a larger population of persons with disabilities.
May be used to prepare sampling frame for research on populations with specific disabilities.	

Table 3.4: Continuous Registration Data Collection: Advantages and Disadvantages

Advantages	Disadvantages
Tabulations can be prepared for small geographical areas.	Reporting based on when disability was diagnosed rather than onset.
Detailed dis-aggregation is not subject to sampling error.	Population at risk must be determined independently from census data or from population estimates or projections.
Can provide numerator data for incidence and prevalence rates.	Registration systems are inflexible to changes to content and procedure.
Both short and long-term series are easier to compile and more reliable because of institutional continuity in the collection process.	Organization and administration require well-trained statistical personnel.
Data collection can be closely linked to the provision of special services.	Data collection and compilation over time is complex.
Provides a sampling frame for in-depth research on populations with specific disabilities.	Multiple registration, and double counting, is difficult to detect.

WHO, 2008

3.1.A The Training Manual of Disability Statistics - 2

- A comparative summary of the strengths and weaknesses of these four principal data collection methods for estimating and describing disability is given in **Table 3.5**.
- Like mortality and fertility, ***disability is a phenomenon that is neither uniformly nor normally distributed*** across the total population.
- ***Disability reporting has many of the same problems as in the reporting of mortality***, such as the reliance on non-expert description of medical events, difficulty recalling the time of an illness or disability, and problems determining the most eligible and knowledgeable respondents.
- The ***12 criteria for evaluating the data sources*** shown in the table below are particularly relevant to the collection of data about disability.

Table 3.5: Data Collection Methods for Disability Statistics: Comparative Summary

Criterion	Population Census	Sample Surveys	One-time Registration	Continuous Registration
Ability to capture detailed disability characteristics	Weak	Weak to moderate	Moderate to strong	Moderate to strong
Ability to capture topical detail (richness and diversity of non-disability characteristics)	Moderate	Strong	Moderate	Weak
Accuracy and coverage	Moderate	Strong	Weak to moderate	Weak to moderate
Absence of sampling error	Strong	Weak	Weak	Weak
Timeliness of data	Weak	Moderate to strong	Strong	Moderate
Geographical detail	Strong	Weak	Strong	Strong
Ability to obtain information on the population at risk	Strong	Strong	Weak	Weak
Ease of organization in a developing country	Moderate	Strong	Strong	Weak
Number of cases available for the analysis of selected disabilities	Moderate to strong	Weak to moderate	Moderate	Strong
Ability to estimate prevalence rates	Strong	Strong	Weak	Weak to moderate
Can identify persons requiring special services	Weak	Weak	Strong	Strong
Usefulness for community-based project planning for persons with disabilities	Weak to moderate	Weak	Moderate to strong	Moderate to strong

3.1.B World Report on Disability

“Recommendation 8: improve disability data collection”

- ***Internationally***, methodologies for collecting data on people with disabilities need to be developed, tested cross-culturally, and applied consistently. Data need to be standardized and internationally comparable to benchmark and monitor progress on disability policies and on the implementation of the CRPD nationally and internationally.
- ***Nationally***, disability should be included in data collection. Uniform definitions of disability, based on the ICF, can allow for internationally comparable data. As a first step, national population census data can be collected in line with recommendations from the United Nations Washington Group on Disability and the United Nations Statistical Commission. A cost-effective and efficient approach is to include disability questions – or a disability module – in existing sample surveys. Data also need to be disaggregated by population features to uncover patterns, trends and information about subgroups of persons with disabilities.
- ***Dedicated disability surveys*** can also gain more comprehensive information on disability characteristics, such as prevalence, health conditions associated with disability, use of and need for services, quality of life, opportunities, and rehabilitation needs.

3.1.C EU - Disability statistical data compilation

STUDY OF COMPILATION OF DISABILITY STATISTICAL DATA FROM THE ADMINISTRATIVE REGISTERS OF THE MEMBER STATES

**STUDY FINANCED BY DG EMPLOYMENT, SOCIAL AFFAIRS
AND EQUAL OPPORTUNITIES
(CONTRACT No VC/2006/0229 – EUR 363,268.42)**

**APPLICA & CESEP & EUROPEAN CENTRE
FINAL REPORT**

NOVEMBER 2007

REF: <http://ec.europa.eu/social/BlobServlet?docId=3007&langId=en>

3.1.C EU - Disability statistical data compilation

THE MAIN SOURCES OF DATA:

- ***Social insurance funds and related Ministries*** in order to collect data on people receiving disability benefits. These data generally cover people who have established eligibility for benefit through their employment record.
- ***Social protection Ministries*** in order to identify people receiving income maintenance assistance linked to having a disability. This generally concerns those who have not established eligibility for benefit through their employment record.
- ***Work pension funds and related Ministries*** in order to identify people receiving pensions or benefits linked to accidents at work and occupational diseases.
- ***Ministries of Education, the European Agency for Development in Special Needs Education as well as EURYDICE*** in order to collect data on the number of pupils with specific educational needs in special schools and in the general education system.

3.1.C EU - Disability statistical data compilation

- **Other Ministries or bodies** charged with administering other relevant benefits (which are likely to differ between countries).
- ***National Statistical Offices.***
- ***The Eurostat Labour Market Policy Database (LMP)*** in order to collect data on the number of disabled people employed in sheltered workshops and those hired on the regular labor market thanks to specific state subsidies paid to the employers.
- ***The High Level Group on Disability*** also provided some help in filling the major gaps (and/or identifying the national sources in question).
- ***Several other studies*** also helped, in particular the work carried out by the Brunel University for the European Commission, which analyzed the definitions of disability used by Member States for the reporting of administrative data, but also the Comparative Tables on Social Protection in the European Union, produced by MISSOC (the Mutual Information System on Social Protection) in January 2006.

3.1.D European Disability Strategy 2010-2020

- The ***European Disability Strategy 2010-2020*** is the EU framework for implementing the UN Convention (*). Disability statistics should monitor the situation of disabled people with reference to the Europe 2020 targets and the areas for action included in the Strategy

(*) *The United Nations Convention on the rights of persons with disabilities states that “persons with disabilities include those who have long-term 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”. Disability statistics provides data on the number of disabled persons as well as on their involvement in the society, through data related to living conditions, social inclusion, labor market, health, or education.*

3.1.D European Disability Strategy 2010-2020

- The following surveys provide **data corresponding to different aspects of the European Disability Strategy**:
 - **The EU Statistics on Income and Living Conditions (SILC)** instrument collects annually data on long-standing activity limitation due to health problems and provides information on income, social inclusion and living conditions (from 2004 onwards)
 - **The European Health Interview Survey (EHIS)** collects every 5 years data on the level of functioning and activity limitations in the population and provides other information on health status, health determinants and health care use
 - **The European Health and Social Integration Survey (EHSIS)** collected data in 2012/2013 on the barriers to participation in different life areas for people having a health problem or a basic activity difficulty
 - **The Labour Force Survey (LFS)** collected in 2002 and 2011 data on the situation of disabled people on the labour market within specific ad-hoc modules.
 - **The European System of Integrated Social Protection Statistics (ESSPROS)** has also some data dedicated to disabled people, in particular disability benefits and disability pensions.

3.1.E Key European Organizations

- EUROSTAT/Disabilities
 - (<http://epp.eurostat.ec.europa.eu/portal/page/portal/health/disability/>)
- The Academic Network of European Disability experts (ANED)
 - (<http://www.disability-europe.net/dotcom>)
 - was created by the European Commission in December 2007.
 - established and maintains a pan-European academic network in the disability field to support policy development in collaboration with the Commission's Disability Unit.
 - Its philosophy and aims support the objectives of European disability policy towards the goal of full participation and equal opportunities for all disabled people.
 - develops and maintains comparative data and indicators relevant to the EU2020 Strategy and selected thematic areas.
 - develops new indicator methodologies for monitoring disability rights, and publish statistical Indicators of Disability Equality in Europe (IDEE).

3.1.F National Disability Registry Taiwan

Research in Developmental Disabilities 34 (2013) 3766–3772

Contents lists available at [ScienceDirect](#)



Research in Developmental Disabilities

Trends in the prevalence of childhood disability:
Analysis of data from the national disability registry of
Taiwan, 2000–2011

Der-Chung Lai^{a,b}, Yen-Cheng Tseng^c, How-Ran Guo^{d,e,*}

3.1.F National Disability Registry Taiwan

- Childhood disability is not uncommon, but data at the national level are limited, especially those on the changes in the prevalence over time.
- On the basis of the **Disabled Welfare Act**, Taiwan began to certify disabled residents and provide various services in 1980.
- ***All the cases receiving services are registered***, and the registry provides a rare opportunity for studying childhood disability at the national level.
- Using the data from 2000 to 2011, the authors calculated the ***age-specific prevalence of all disability combined and assessed the changes over time.***

3.1.G ECLAC – Caribbean efforts

- **ECLAC**: Economic Commission for Latin America and the Caribbean
- Some recent publications:
 - Availability, collection and use of data on disability on the Caribbean subregion (ECLAC, January 2011);
 - A further study on disability in the Caribbean: rights, commitment, Statistical analysis, and monitoring (ECLAC, December 2009);
 - Disability in the Caribbean. A study of four countries: a socio-demographic analysis of the disabled (ECLAC, June 2008).

Table 2
Main instruments for collecting disability statistics

	<i>Administrative Registers</i>	<i>Population Censuses</i>	<i>Sample Surveys</i>	<i>Other sources</i>
Aruba		✓	✓	
Bahamas		✓		
Barbados		✓		
Belize		✓		
Bermuda		✓	✓	✓
British Virgin Islands		✓		
Cayman Islands	✓	✓		
Dominica		✓		
Grenada		✓		
Guyana	✓	✓	✓	✓
Jamaica		✓		
Montserrat		✓		
Netherland Antilles		✓		
Saint Lucia		✓		
Trinidad and Tobago		✓		

Table 4
Main categories of data available by sex and year (s) for which data is available

<i>Country</i>	<i>Categories of disability</i>	<i>Age</i>	<i>Rural/urban residence</i>	<i>Level of Education</i>	<i>Employment Status</i>	<i>Type of employment</i>	<i>Income Categories</i>	<i>Origin/ cause of disability</i>	<i>Age at which the disability occurred</i>
Aruba	1981, 1991, 2000	1981,1991, 2000	No	2000	2000	2000	2000	2000	Not available
Bahamas	2000	2000	2000	2000	2000	2000	2000	Not available	Not available
Belize	1991, 2000		1991,2000					Not available	Not available
Bermuda	1991, 2000	1991, 2000		1991, 2000	1991, 2000	1991, 2000	1991, 2000	Not available	Not available
British Virgin Islands	2001	2001	No	2001	2001	No	No	2001	No
Cayman Islands	No	1999	No	No	No	No	No	No	No
Grenada	2001	2001	No	2001	2001	2001	2001	2001	2001
Guyana	2002	2002	2002	2002	2002	2002	NCD ⁶ Register	2002	NCD Register
Jamaica	2001	2001	No	2001	2001	2001	No	No	No
Montserrat	2001	2001	No	2001	2001	2001	2001	2001	2001
Saint Lucia	2001	2001	2001	2001	2001	2001	2001	2001	2001
Netherland Antilles	2001	2001	Not Applicable	2001	2001	2001	2001	2001	Not Available
Trinidad and Tobago	2000	2000	2000	2000	2000	2000	2000	Not available	Not available

Note: In all cases, the data above was available from the census and years stated above correspond to the census years

⁶ National Commission on Disability

Table 2: Commitments to Persons with Disabilities in Jamaica's Vision 2030^{xiii}

National Strategy	Priority Sector Strategy for Years 1-3	Key Actions for Years 1-3	Responsible Agencies
Create an enabling environment for persons with disabilities	Increase access to public goods and services for persons with disabilities Promote respect and dignified treatment for persons with disabilities	Strengthen the capacity of the Jamaica Council for Persons with Disabilities	Ministry of Labour and Social Security and Jamaica Council for Persons with Disabilities
		Create a registry of persons with disabilities	Jamaica Council for Persons with Disabilities
		Build partnerships with businesses and other groups to empower persons with disabilities	Ministry of Labour and Social Security and Jamaica Council for Persons with Disabilities
		Provide training regarding appropriate interaction with persons with disabilities to all public service personnel	Ministry of Labour and Social Security, Jamaica Council for Persons with Disabilities and Training Institutions
		Promote public awareness of the rights of persons with disabilities	Ministry of Labour and Social Security, Jamaica Council for Persons with Disabilities and Media
	Promote respect and dignified treatment for persons with disabilities	Increase access to public buildings for persons with disabilities	Ministry of Transportation and Works and Parish Councils

3.1.G ECLAC – Caribbean efforts

Main Observations in Caribbean subregion

- limited use of administrative registers or records as a source of disability data;
- the census was the main source of disability data in the majority of the countries;
- only Guyana indicated the use of those systems for generating data on persons with disabilities;
- challenges with the use of the administrative registers and records may stem from the lack of financial and human resources to maintain such systems;

3.2 Progress in Aruba

- A. Inventory disability data sources
- B. Local stakeholders
- C. Political momentum
- D. Ongoing activities and perspectives

3.2.A Inventory Disability data sources

- Sources at CBS (i.e., census and survey data):
 - Census data: Census 2010 used WG questions
 - Labor Force Survey (2006): no use of WG questions
 - Household Income and Expenditure Study (2006): included WG questions
 - WHO/STEPS Aruba 2006: no use of WG questions
- Sources at *Section of Persons with a Limitation (SPL), Ministry of Social Affairs (routine data)*:
 - Records of all persons with a disability who benefit financial assistance from the Aruban government
 - (survey is ongoing to collect comprehensive data of all recorded persons with a limitation)
- Sources at NGO's and Foundations involved in field of persons with a disability
- Sources scattered among different social and welfare stakeholders

3.2.B Main Local Stakeholders

- CBS
- Section of Persons with a Limitation (SPL), Department of Social Affairs, Ministry of Social Affairs, Youth and Labor
- Platform for Persons with a Limitation (PPL), umbrella committee representing 16 Foundations/NGO's in the field of Persons with a disability
- Community-Based Rehabilitation team of Aruba
- White Yellow Cross
- CEDE Aruba (i.e., a development and co-financing organization that supports the development and financing of programs and projects in the field of welfare.)
- Department of Public Health

3.2.C Political Momentum

The Aruban Minister of Social Affairs, Youth and Labor:

- declared recently to prioritize the inventory of persons with a disability
- Wants to increase number of shelters for disabled persons
- Ultimate goal is to improve participation rate in society
- Wants to give persons with a disability more chances on the labor market. **For instance, his cabinet plans exploring the possibility that disabled persons can keep their payment and that the employer tops it up to at least the minimum wage.**

3.2.D Ongoing activities and perspectives

- A pilot is ongoing to evaluate a **registration system** for all NGOs/foundations which are subsidized by the Ministry of Social Affairs, Youth and Labor. CBS and SPL are examining whether or not and how this registration system could play a prominent role in the development of a disability register on Aruba.
- A consultation meeting with all stakeholders will be held this autumn to agree on several aspects, such as:
 - **juridical** (e.g., who will be the owner of the data, who will have access),
 - **technical-logistic** (i.e., where will the data be stored, how will the data be transferred to the central platform),
 - **financial** (e.g., which partner will finance the start of the project as well as maintenance of IT-infrastructure),
 - **content-based** (e.g., which data will be registered besides WG questions data, periodic or instant data transfer).

3.2.D Ongoing activities and perspectives

- CBS included in the long form of the ongoing ***Economic Census 2014*** questions regarding disability related aspects (including WG short- form questions) as part of survey-based data collection.

This data will be linked with other data. This data will give more insights, e.g.:

- on the number (and type) of disabled persons working in a non-governmental establishment or foundation,
- the type of specific accommodations
- The main reasons why disabled people are not recruited by an establishment or foundation

3.2.D Ongoing activities and perspectives

- Other survey-based initiatives including WG-questions are taken into consideration for 2015 (depending on financing):
 - Household Income and Expenditure Study (CBS)
 - Aruban Health Survey (Dept of Public Health)
- Furthermore, participation to the multi-country study of the Model Disability Survey will be examined.

4. Discussion and General Recommendations

Additional to:

- the recommendations made in the World report on disability (WHO, 2011) to improve disability data collection (3.1.B);
- the strengths and weaknesses of four principal data collection methods, including the 12 criteria for evaluating data sources (WHO, 2008; 3.1.A);

we should not neglect the ***confidentiality of respondent data (WHO, 2008)***:

- E.g., registry respondents should always be made aware of confidentiality assurance policies as part of questionnaire introductions so that fear of disclosure of personal information does not affect results.

4. Discussion and General Recommendations

Methodological issues experienced on the field (also summarized by *(*)*)

- Statistics from a variety of different sources of administrative data are likely to be based on a variety of different definitions and classification systems.
- Moreover, definitions and criteria for disability can also vary according to policy objectives, legislation and administrative standards.
- Inside the same country, different definitions can be used by different Ministries according to their needs.
- The Ministry of Employment, for example, might use a different definition from the one used by the Ministry providing assistance to people who are in need of care

() <http://ec.europa.eu/social/BlobServlet?docId=3007&langId=en>*

4. Discussion and General Recommendations

Therefore,

1. the WG members should discuss what type of data should be at least collected in the data registry (e.g., short-form, long-form WG-data). For instance, the table shell distributed by WG coordination for annual report could be a minimal data in-/output.
2. the WG members should discuss whether or not it would be more appropriate and feasible to develop an user-friendly software/application or spreadsheet that can be used to introduce/record directly all the necessary data in the correct form (i.e., using the correct –uniform – definitions and classifications) or that can transform uploaded data files into the right form and produce the necessary national and international tables. Such tools are already available for cancer and mortality statistics, as well as automated economic analysis (ADEPT; World bank; <http://econ.worldbank.org/WBSITE/EXTERNAL/EXTDEC/EXTRESEARCH/EXTPROGRAMS/EXTADEPT/0,,menuPK:7108381~pagePK:64168176~piPK:64168140~theSitePK:7108360,00.html>); and many software applications developed by WHO, for instance.

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