# Saudi National Disability Registry

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On behalf of the Saudi Disability Registry Group KACST and MoSA

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# Saudi Arabia – Key Facts



### Saudi Arabia

Area 2,149,690 sq. km

Natural resources

Petroleum, natural gas, iron, gold & copper

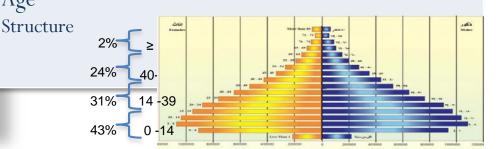
### Population (Million)

country comparison to the world: 47 Life Expectancy: 74.58 years Population Growth: 2.7% / Year

### 28.79 million

Urban population: 82.3% Expatriates: 5.5m

Age



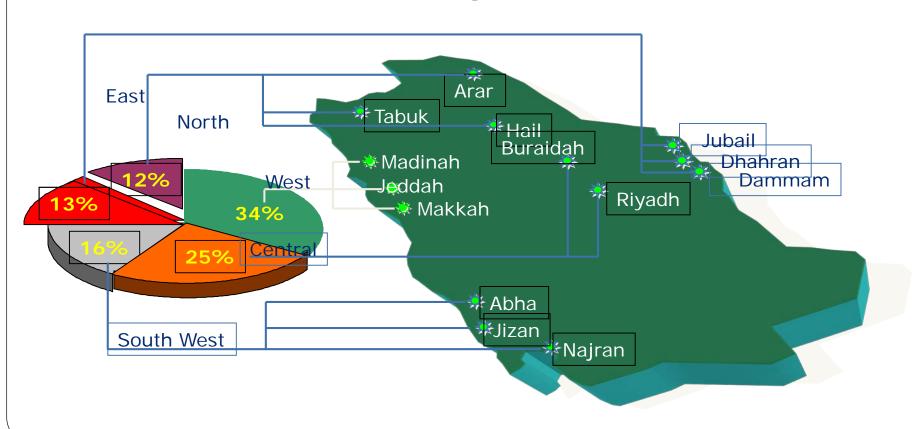
# Saudi Arabia - Demography



- 4 13 Provinces
- **\*** 150 Cities
- More than 2000 villages
- Vast distances between cities

Saudi Arabia has an homogeneous population in that the people share common linguistic, religious and cultural values

### Saudi Arabia - Regional Distribution of Population



### **Economic Overview**

# Saudi Arabia - Key Facts

Saudi Arabia				
GDP Current Prices (Billion US\$) Country comparison to the world: 21	US\$ \$883.7			
GDP per Capita Country comparison to the world: 45	US\$ 30,500			
GDP Growth %	5.97%			
GDP - composition, by sector of origin	Agriculture: 2% Industry: 65% Services: 33%			
Budget Budget Surplus +13.1% Country comparison to the world: 7	Revenues: \$326.5 billion Expenditures: \$234.8 billion			
Inflation	4.91%			
Total expenditure on health as % of GDP	5.6%			
Exports Imports	\$388.4 billion (90% Oil) \$141.8 billion			

# Status Of Disability Data In KSA

- No single source of national data for disability in KSA
- No formal data collection approach for the country
- Very Limited publications have addressed prevalence of disability in KSA
- In 2007, MOH commissioned the national world health survey as part of the WHO international campaign.
- Despite its limitation of being non disability specific survey, The WHS presented the first opportunity to get an estimate figures on the prevalence of disability in KSA

### WHS Questionnaire Structure & Analysis

- Total of 8 self reported questions on Mobility, Self Care, Pain and Discomfort, Cognition, interpersonal activities, vision, sleep and energy affect.
- Questions are on 5 points LIKERT scale (ranging from Non to Extreme), asking the patients how they felt about each of the above domains in the past 30 days.
- A subject was considered disabled if he/she has answered any of the questions with "Severe", or "Extreme"

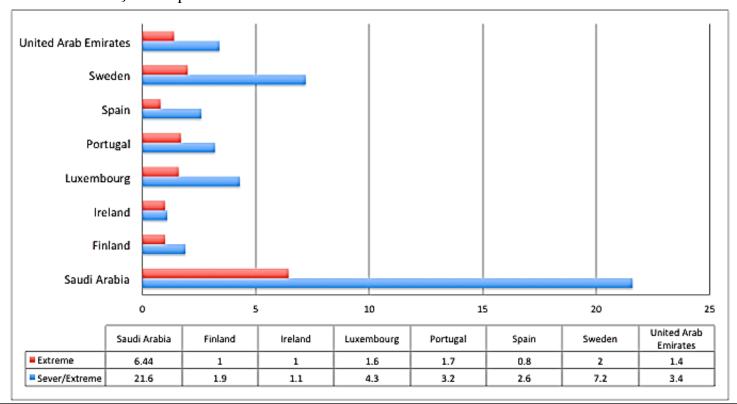
### WHS items involved in assessing

Self-reported assessment scale:

oen reporte	1. None 2. Mild 3. Moderate 4. Severe 5.				
	Extreme/Cannot Do				
Mobility					
Q2002	Overall in the last 30 days, how much difficulty did you have with moving around?				
Q2003	In the last 30 days, how much difficulty did you have in vigorous activities, such as running 3 km (or equivalent) or cycling?				
Self Care					
Q2004	Overall in the last 30 days, how much difficulty did you have with selfcare, such as washing or dressing yourself?				
Q2005	In the last 30 days, how much difficulty did you have in taking care of and maintaining your general appearance (e.g. grooming, looking neat and tidy etc.)				
Pain and Dis	scomfort				
Q2007 Q2008	Overall in the last 30 days, how much of bodily aches or pains did you have? In the last 30 days, how much bodily discomfort did you have?				
Cognition					
Q2010	Overall in the last 30 days, how much difficulty did you have with				
	concentrating or remembering things?				
Q2011	In the last 30 days, how much difficulty did you have in learning a new task (for example, learning how to get to a new place, learning a new game, learning a new recipe etc.)?				
Interperson	al Activities				
Q2012 Q2013	Overall in the last 30 days, how much difficulty did you have with personal relationship or participation in the community?  In the last 30 days, how much difficulty did you have in dealing with conflicts				
	and tensions with others?				
Vision					
*Q2021,22	Do you wear glasses or contact lenses?				
Q2023	In the last 30 days, how much difficulty did you have in seeing and recognizing a person you know across the road (i.e. from a distance of about 20 meters)?				
Q2024	In the last 30 days, how much difficulty did you have in seeing and recognizing an object at arm's length or in reading?				
Sleep and Energy					
Q2016	Overall in the last 30 days, how much of a problem did you have with sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning?				
Q2017	In the last 30 days, how much of a problem did you have due to not feeling rested and refreshed during the day (e.g. feeling tired, not having energy)?				
Affect					
Q2018	Overall in the last 30 days, how much of a problem did you have with feeling sad, low or depressed?				
Q2019	Overall in the last 30 days, how much of a problem did you have with				

# Prevalence of Disability IN KSA is Considerably higher than that of other high income countries

Prevalence of Subjects reported Extreme or Severe/Extreme Difficulties in one or more domains



# In KSA, the Patterns of Disability Severity level Differs Between Males and Females

	Men (n=2852; Weighted n=6,810,881.8) or % (SE)	Women (n=2947; Weighted n=7,086,101.6) % (SE)
Severe/Extreme Disability	16.21(0.86)	26.78 (1.07)
Extreme Disability	5.08(0.49)	7.76 (0.58)

Source: Ministry of Health, Saudi Arabia 2007 WHS Survey

# Prevalence of Extreme Disability is higher among older age groups.

	N	Weighted N	No	Yes
Age				
≤19 Years	326	758,352	96.96(1.20)	3.04(1.20)
20-29 Years	1708	4,079,240.8	96.03(0.57)	3.97(0.57)
30-39 Years	1491	3,635,929.4	96.56(0.65)	3.44(0.65)
40-49 Years	1048	2,505,355.4	96.72(0.61)	3.28(0.61)
50-59 Years	582	1,422,294.3	91.19(1.32)	8.81(1.32)
60-69 Years	343	814,935.6	85.86(2.15)	14.14(2.15)
>70 Years	301	680,869.8	61.39(3.11)	38.61(3.11)

Source: Ministry of Health, Saudi Arabia,  $2007\,\mathrm{WHS}$  Survey

At older Age Women have Twice the Prevalence of Extreme Disability Compared to Men in the Same Age Group

	N	Weighted N	No	Yes
Male				
≤19 Years	168	377,797.4	96.29(2.04)	3.71(2.04)
20-29 Years	797	1,893,415.6	97.91(0.62)	2.09(0.62)
30-39 Years	647	1,595,906.4	98.55(0.61)	1.45(0.61)
40-49 Years	580	1,363722.1	97.61(0.71)	2.39(0.71)
50-59 Years	304	726,991.9	94.02(1.47)	5.98(1.47)
60-69 Years	184	451,930.7	90.47(2.58)	9.53(2.58)
>70 Years	172	401,111.6	62.64(4.35)	37.36(4.35)
Female				
≤19 Years	158	380,554.6	97.62(1.27)	2.38(1.27)
20-29 Years	911	2,185,825.2	94.41(0.93)	5.59(0.93)
30-39 Years	844	2,040,023	95.01(0.96)	4.99(0.96)
40-49 Years	468	1,141,633.3	95.65(1.04)	4.35(1.04)
50-59 Years	278	695,302.4	88.24(2.22)	11.76(2.22)
60-69 Years	159	363,004.9	80.12(3.61)	19.88(3.61)
>70 Years	129	279,764.3	59.60(4.83)	40.40(4.83)

# **Disability Population**

		N=5799 (Weighted N=13,896,983.4), % (SE)			
	None	Mild	Moderate	Severe	Extreme
• Mobility					
Moving Around	78.17 (0.68)	11.99(0.52)	6.19 (0.38)	3.15 (0.29)	0.50 (0.10)
Vigorous Activities	63.58(0.92)	15.23 (0.60)	9.01(0.48)	8.25 (0.45)	3.92(0.29)
• Self care					
Self care	91.41(0.43)	5.21 (0.35)	2.04(0.20)	1.02(0.15)	0.32(0.08)
Appearance	91.60 (0.43)	4.71(0.33)	2.49(0.23)	0.87(0.13)	0.33(0.08)
• Pain and Discomfort					
Bodily Pain	67.03(0.84)	19.68(0.64)	8.26(0.44)	4.76(0.36)	0.27(0.08)
Bodily Discomfort	68.00(0.84)	19.14(0.64)	8.58(0.46)	3.74(0.32)	0.54(0.12)
<ul> <li>Cognition</li> </ul>					
Memory	75.44(0.75)	15.72(0.60)	6.25(0.38)	2.37(0.23)	0.21(0.08)
Learning	76.60(0.75)	14.06(0.58)	5.36(0.37)	3.03(0.28)	0.95(0.15)

Source: Ministry of Health, Saudi Arabia

# Implication Of Disability In KSA

- 2012 Survey report of Central Department of Statistics and Information, Saudi Arabia: 143,000 people above the age of 15 who are out of labor due to disability.
- MoSA Registered beneficiary for the financial support is approximately 400,000 person with disability.

### Social Services in Saudi Arabia





Ministry of Social Affairs



### Ministry of Labor

Kingdom of Saudi Arabia



المؤسسة العامة للتأمينات الاجتماعية General Organization for Social Insurance حَقِّ لَكُمْ

# Social Service Programs address

- The unemployed
- Persons with disabilities
- Widows and widowers
- Females with no living family members to support them
- Orphans
- Families of those serving custodial sentences
- Victims of natural disasters
- Disability resulting form occupational hazards

# Saudi Arabia Healthcare

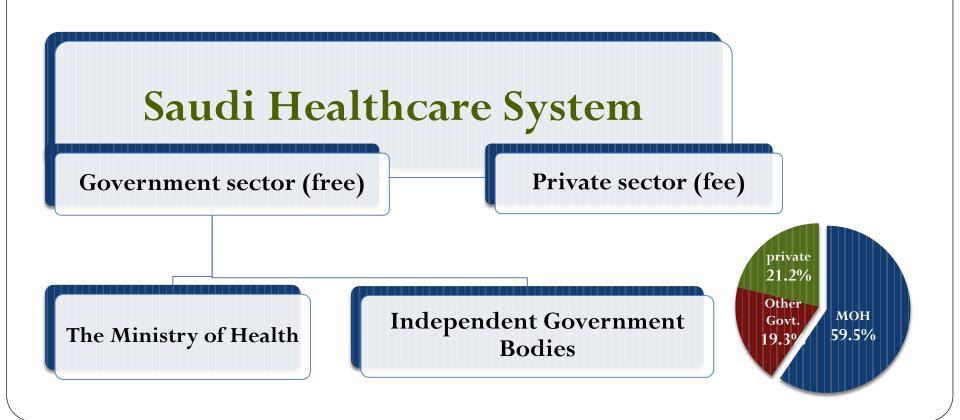
### **Healthcare**

# Saudi Arabia – Key Facts

Healthcare & Social Development Budget 2013: USD 23.1 b. (+26%)

Total expenditure on health as % of GDP	5.0%
Total expenditure on health per Capita	\$ 1,150
Physicians Density Physicians (All Sectors): 66,014	0.94 physicians/1,000 population
Nursing	129,792
Hospital Bed Density	2.2 beds/1,000 population
Obesity - adult prevalence rate  Country comparison to the world:19	35%
Diabetes – adult prevalence rate	20%
Chronic Kidney Disease Prevalence	9.3%

### Saudi Arabia – Healthcare Segments



### Healthcare

### Saudi Arabia - Governmental Sector

- Referral hospitals (e.g. King Faisal Specialist Hospital and Research Center)
- Ministry of higher education hospitals (teaching hospitals)
- Royal commission for Jubail and Yanbu health services
- Security Forces Medical Services
- Army Forces Medical Services
- National guard health affairs
- ARAMCO hospitals













# Challenges

- limited preexisting epidemiological data
- Wide geographic area
- Large Number of independent stakeholder
- Wide variability of connectivity of stakeholder
- Unclear ownership of the Disability Registry

### SAUDI NATIONAL DISABILITY REGISTRY



# Objective

To create a database in the form of a national registry, that would

- Provide vital information to the organizations catering to persons with disabilities
- Aid in the provision of necessary services for this population
- Allow information on persons with disabilities to be registered or to add information about persons with disabilities

# The Role of the National Registry

**National** 

Registry For

People With

Disability

No Centralized Data Hub

 No National standards for Disab l classification

 No Coordination between benefits provider • Reliable data for better planning and equitable benefits distribution.

Employ national standards for disability classification

• Platform for coordination between various stakeholders.

### Approach for Developing National Registry for People with Disability

### The road map for developing the national registry

### Feasibility Study

### Call for Proposal

### Implementation & Deployment

Monitoring & Improvement

- Initial Assessment
- Selection of measurement tools
- Develop Technical measurement.
- Develop request for proposal.

- Call for proposal
- Review of technical and financial offers.
- Selection of vendors and awarding the project

- Development of the national registry
- Initial pilot and assessment.
- Role out of the final deployment of the national Registry.

- Continuous monitoring.
- Improve current registry according to feedback and trends

### **Action Plan**

- Creation of the team and drafting of the action plan
- Engagement of Stake holders
- Planning for collection of data and information
  - Questionnaire
  - Pilot testing
  - Final questionnaire
  - Standardization and Training

### Action Plan (cont...)

- Preparation of the organizational structure of the administrative and technical
  - Examination and study of different managerial and technical structures, local and international
  - Identification of detailed components for specific models of the administrative and technical structure for national records for disability
  - Benefit from consultation services, national, regional and international

### Action Plan (cont...)

- Establishment of equipment and facilities
  - Identification of technical requirements
  - Establishment of equipment and facilities
    - Data center
    - Main Office
- Training for staff
  - Questionnaire/data gathering
  - Technical
  - Administrative

# Data Source for the Registry

- Interview
  - Questionnaire designed for the registry
  - Integration of the Washington Group Extended Set of Questions (WG ES-F)
- Online input of data

# Overview of Questionnaire

- Demographic data
- Modified Washington Group Extended Set on Functioning (WG ES-F)/ ICF Based Disability Component
- Clinical/ Medical Background
  - Current diseases (ICD-10 Classification)
  - Current Medication
  - Exercise
  - Smoking
  - Alcohol Intake
  - Substance abuse
  - Reproductive function

# Overview of Questionnaire (Cont...)

- Disability Related Component
  - Financial Support
  - Other Types of Support
  - Respondent's Perception of Current Support He/She Receives
- Interview details
  - Who conducted the interview
  - Date
  - Respondent
    - Person with disability himself/herself
    - Guardian/other representative
    - Both

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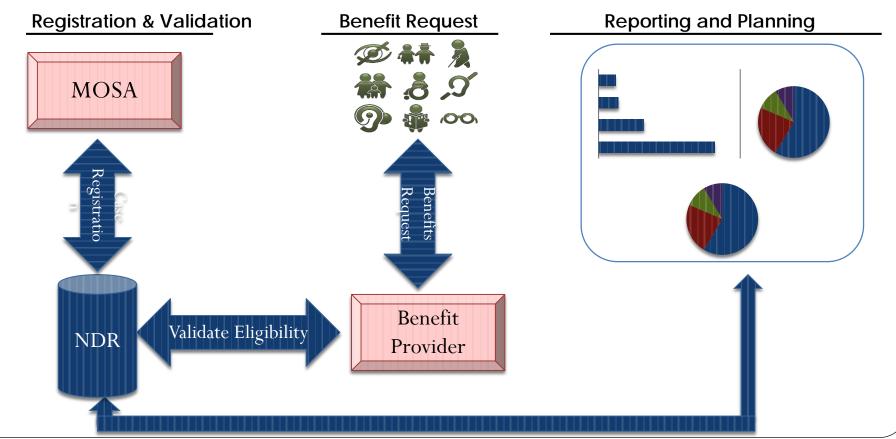
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# Progress To date

Activities/Milestones	Status
Situation and Stakeholders analysis	Completed
Review of Available disability measure tools	Completed
Translation and Validation of ICF to Arabic	Completed
Develop Data collection and Analysis Protocol	Completed
Develop Human Resources Plan	Completed
Develop budget estimate	Completed
Develop Request for Proposal	Completed

# National Registry Process



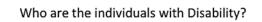
# Impact of The Registry

**Stake Holder Beneficiaries MOSA** Persons with Disability **Nationa** MOE MOH Registry MOI Decision Makers Others

### <u>Implications</u>

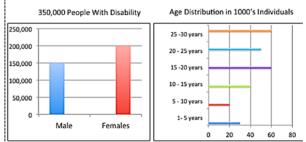
- Universal Access to services
- Ease of access to benefits
- Awareness of the following: legislation, rights of persons with disabilities, and current programs for persons with disabilities
- Reliable data for planning
- Internationally-comparable data
- Platform for information dissemination
- Accurate reflection for the resources utilization

### Some of The Key Analytics of the Registry

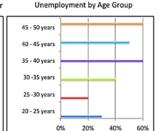


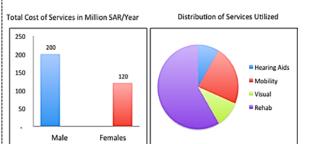
Employment and Income of Individuals with Disability

### Disability Services Utilization and Cost

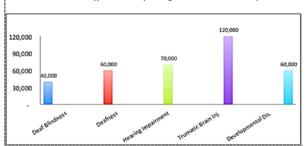




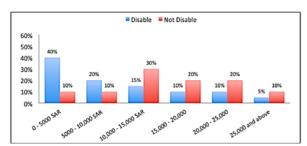




Distribution of Type of Disability Among Individuals with Disability



Distribution of Income Among Working Disabled and Not Disabled individuals



Total cost (in 1000') Allocation by the Type of Disability

