



# The Changing Face of Family Care-Giving: *Age, Income and Other Factors Among Families with Adult Family Members with ID/DD*

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AAIDD 2013 Meeting, June 5, 2013



# NCI Collaborative Partnership

**NASDDDS**



Human Services  
Research Institute

**Participating  
State DD  
Agencies**

# WHAT IS NCI?

- Multi-state voluntary collaboration of state DD agencies
- Interested in measuring state IDD agency performance along several areas, including:
  - employment,
  - community inclusion,
  - choice and rights,
  - health and safety
- Launched in 1997 in 15 participating states
- Supported by participating states

# *Meeting the Needs of State Agency Administrators and Policy Makers for Data*

- Document the effect of services on the day-to-day lives of the people who receive them
- Document the experience of program participants
- Manage service delivery and improve policy and practice
- Track key performance goals and outcomes
- Assess the impact of regulatory activities on individual experience
- Respond to the demands of consumers and families for information on system responsiveness
- Assess the impact of financial actions



# National Core Indicators Design

## ***Valid***

- Measure what is intended to be measured

## ***Reliable***

- Provide consistent results over time

## ***Risk Adjusted***

- Provides multiple state comparisons



# NCI Performance Assessment



## Personal Outcomes

- Employment
- Community Participation
- Choice & Decision making
- Relationships



## Family Outcomes

- Information & Planning
- Access & Service Delivery
- Choice and Control
- Community Connections
- Satisfaction
- Outcomes



## Health, Welfare, System

- Health and Welfare
- Respect & Rights
- Medications
- Safety
- Service Coordination
- Staff Stability





## Core Indicators Drive Improvement

The **core indicators** are the foundation of the effort. The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety

**Participating states** pool their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out comparable data collection strategies, and **share results in order to understand the overall health of public developmental disabilities agencies.**



## NCI Data Used by Self-Advocates and Families

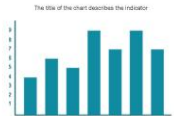
by Josh Engler

HSRI and NASDDDS staff were in the beautiful state of Washington last week to observe Lisa Weber and the rest of the WA NCI team in action. Part of the agenda included attending a DD Council focus group meeting. This meeting was made up of self-advocates, family members of children with developmental disabilities, and...

[READ MORE](#)

## Featured Core Indicators

Understanding the overall health of public developmental disabilities agencies



The title of the chart describes the indicator

Indicator Name or Description
X

**Indicator Name or Description**

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Integer a sollicitudin nisi in Massachusetts:

Suspendisse quis nunc sapien. Fusce erat elit, scelerisque a facilis a, pharetra non eros. Vivamus elit diam, pellentesque non lobortis ac, viverra ac eros. Etiam sagittis metus ac nulla sodales et sagittis magna euismod.

[Link One](#)
[Link Two](#)

**Indicator Name or Description**

*Brief description of featured indicator that encapsulates the importance of the indicator...*

MORE

## Participating NCI States

Select a participating state to view it's profile



## November - 2010 Report Released: National Core Indicators (NCI) 2008-09 Annual Summary Report

HSRI and NASDDDS are pleased to announce the release of the National Core Indicators 2008-09 Annual Summary Report. The Annual Summary Report highlights selected aggregate results from several of the NCI data sources...

[READ MORE](#)



# NCI Data Sources

- Adult Consumer Survey
- Family Survey
  - Adult Family Survey (person lives at home; 18 and older)
  - Family Guardian Survey (person lives out-of-home; 18 and older)
  - Children Family Survey (child lives at home; under 18 years old)
- Provider Survey
  - Staff Stability
- System Data
  - Mortality
  - Incidents

Selected Results 2011-2012

# Adult Family Survey

# Adult Family Survey

- Administered by mail
- Families of adults with IDD who live at home and receive at least one publicly-funded service in addition to case management
- Includes demographics, six outcome areas – Information & Planning, Access & Delivery of Supports, Choices & Control, Community Connections, Satisfaction, and Outcomes
- Combination of 5-point scale and yes/no response options, open-ended comments
- 74 questions on AFS

# Data on Support to Families

- Adult Family Survey, 2011-2012 data cycle
- 14 states –
  - AZ, CT, FL, GA, HI, LA, MD, MI, NC, NH, OK, PA, SD, and WA
- Mailed a total of 17,419 surveys
- 5,869 returned; 5,478 valid surveys
- Response rate 34%
- State response rate varied from 18% to 71%

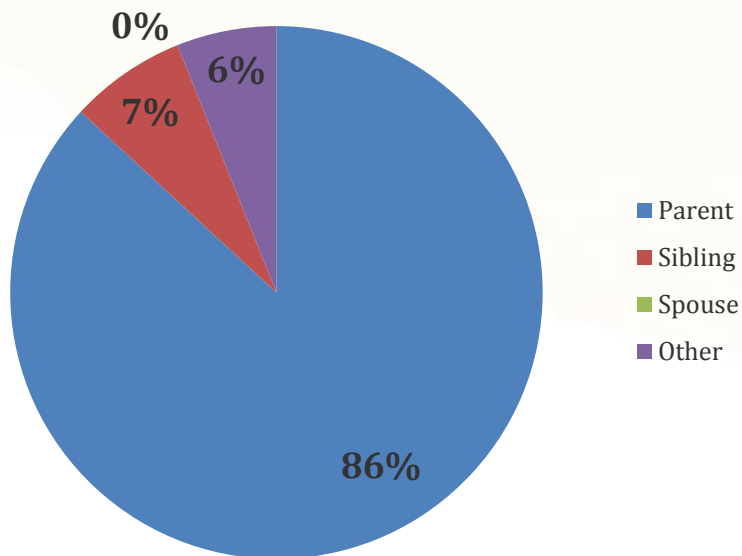
# Questions And Goals

- Identity and circumstances of family caregivers
- Care-givers' perception of the quality and adequacy of the services received by their family member
- Whether they receive enough information to plan for the future
- Satisfaction with services and information they receive

# FINDINGS

## Respondent Demographics

### Relationship



Number of people with IDD in household:

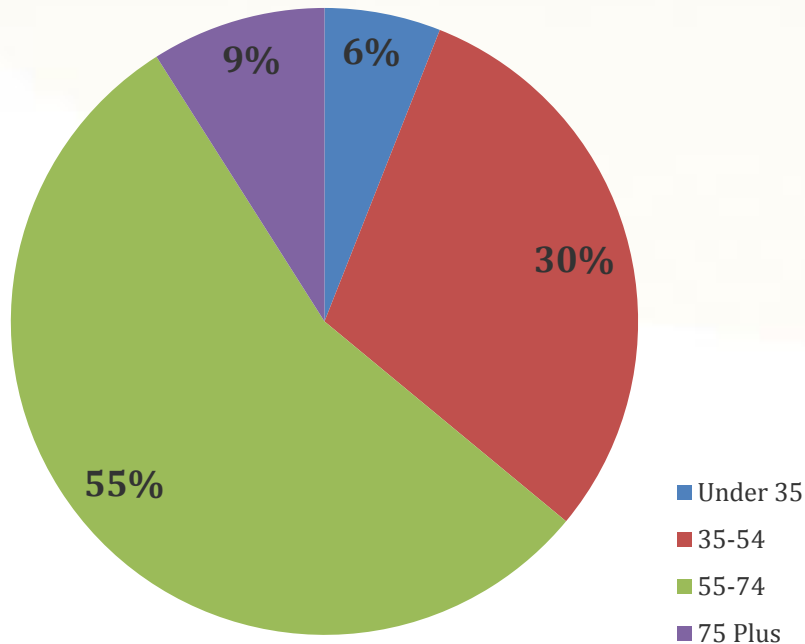
**One - 88%**

**More than one - 12%**

# FINDINGS

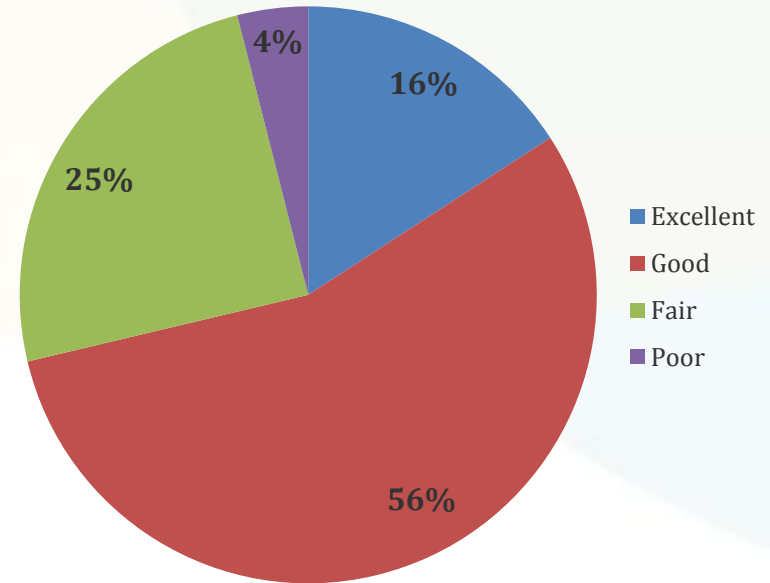
## Demographics – Age and Health

Age



➔ 64% over age 55

Health



➔ 29% in fair or poor health

# FINDINGS

## Relationship between household income and out-of-pocket expenses

		Health of respondent				Total
		Excellent	Good	Fair	Poor	
Age of respondent	Under 35	16%	55%	26%	3%	100%
	35-54	20%	57%	19%	3%	100%
	55-74	15%	58%	24%	4%	100%
	75 Plus	6%	44%	44%	6%	100%

28% of respondents 55-74 are in fair or poor health

50% of respondents 75 and over are in fair or poor health

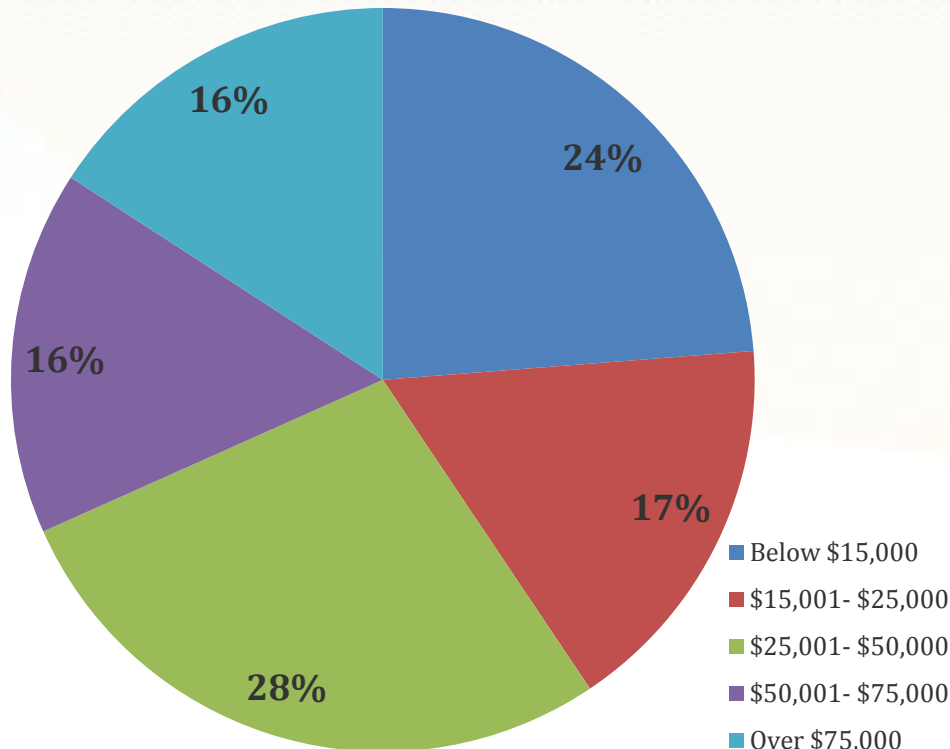


# FINDINGS

## Respondent Demographics

### Household income

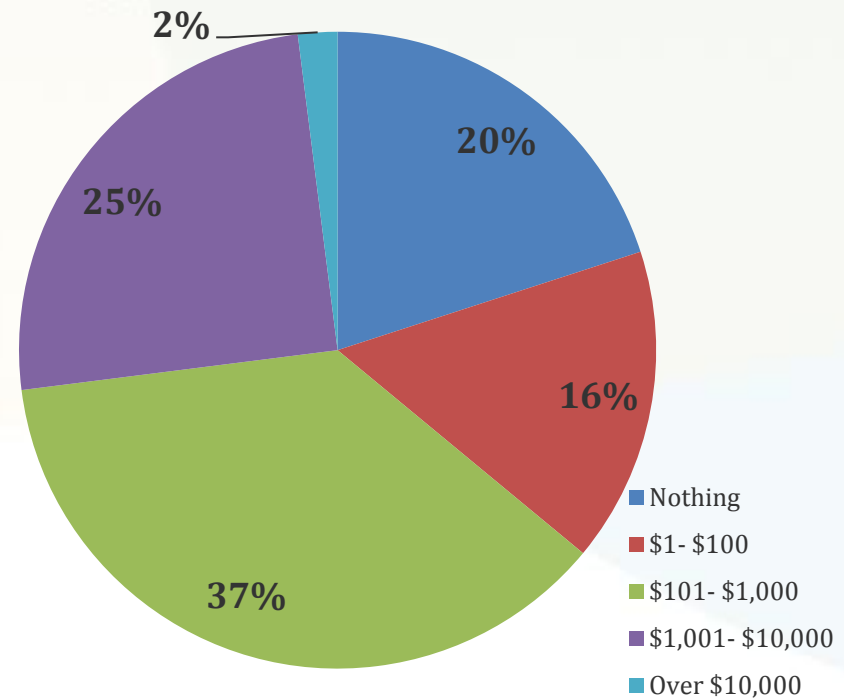
14% - missing data



41% below \$25,000

### Out-of-pocket expenses

7% - missing data



62% have out-of-pocket expenses between \$101 and \$10,000

# FINDINGS

## Relationship between household income and out-of-pocket expenses

17% - missing data

		Out of pocket money spent					Total
		Nothing	\$1-\$100	\$101-\$1,000	\$1,001-\$10,000	Over \$10,000	
Household Income	Below \$15,000	31%	22%	34%	12%	1%	100%
	\$15,001-\$25,000	24%	20%	41%	15%	1%	100%
	\$25,001-\$50,000	17%	15%	39%	27%	2%	100%
	\$50,001-\$75,000	12%	11%	39%	36%	2%	100%
	Over \$75,000	10%	12%	33%	37%	8%	100%

Higher income – higher out-of-pocket expenditures, BUT

56% of those with incomes below \$15,000 spent between \$1 and \$1,000

61% of those with incomes between \$15,001 and \$25,000 spent between \$1 and \$1,000

66% of those with incomes between \$25,001 and \$50,000 spent between \$101 and \$10,000

# FINDINGS

## Relationship between age and household income

15% - missing data

		Household Income					Total
		Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	
Age of respondent	Under 35	36%	20%	21%	14%	9%	100%
	35-54	22%	15%	29%	16%	18%	100%
	55-74	21%	17%	28%	17%	17%	100%
	75 Plus	40%	26%	24%	6%	4%	100%

66% of respondents 75 and over had household income below \$25,001

# FINDINGS

## Relationship between number of people with IDD and household income

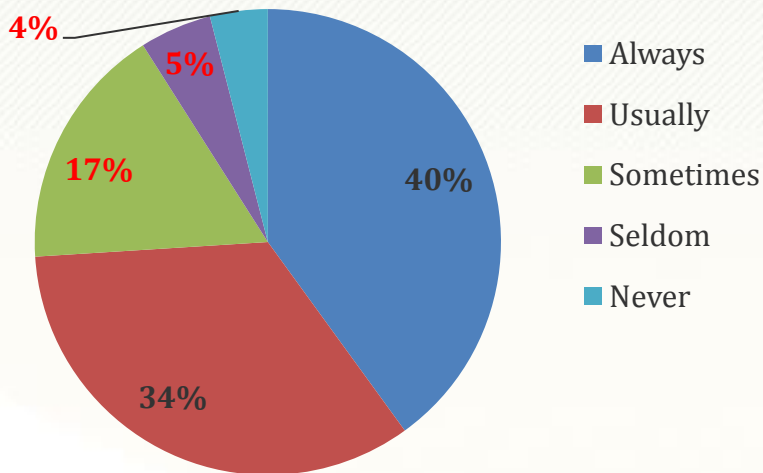
18% - missing data

		Household Income					Total
		Below \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	
Number of people with IDD in household	More than one	37%	21%	23%	13%	7%	100%
	One	22%	17%	28%	16%	17%	100%

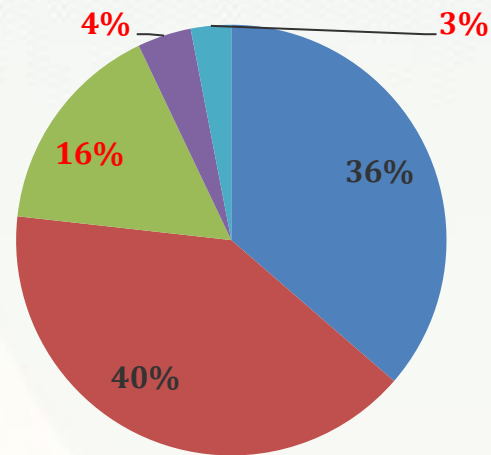
Families with more than one person with IDD more likely to have household income below \$25,001

# Quality of Services Received

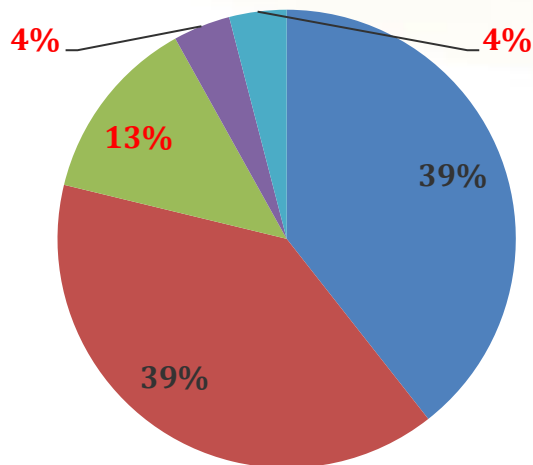
## Family gets supports needed



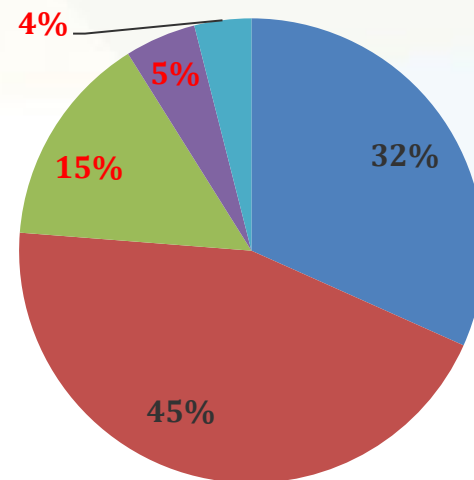
## Supports available when needed



## Services available within reasonable distance

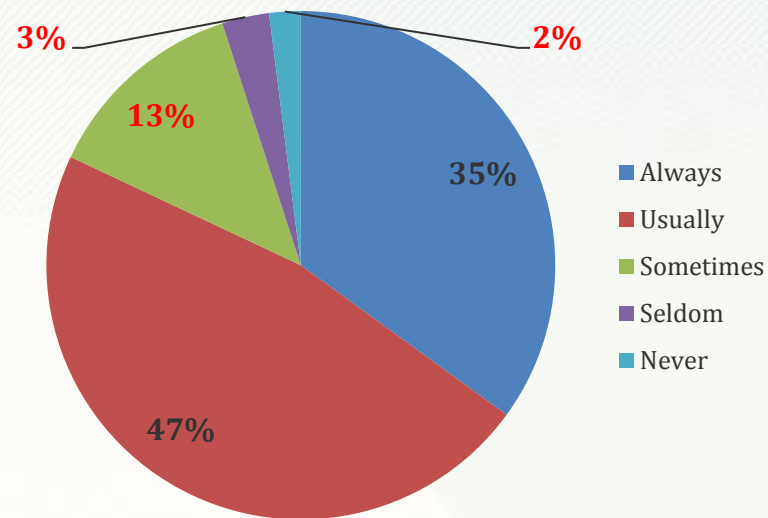


## Services change when needs change



# FINDINGS: Quality of overall services

## Overall satisfied with services and supports



- Enough supports to work/volunteer in community (yes/no)? – **64% yes**
- Supports have made a positive difference (yes/no)? – 95% yes
- Supports reduced out-of-pocket expenses (yes/no)? – **82% yes**
- Supports address goals in service plan (yes/no)? – 90% yes
- Services made a difference in keeping family member at home (yes/no)? – 87% yes
  
- Services reduced/suspended/terminated in past year (yes/no)? – **32% yes**
- If yes, negative effect (yes/no)? – **69% yes**

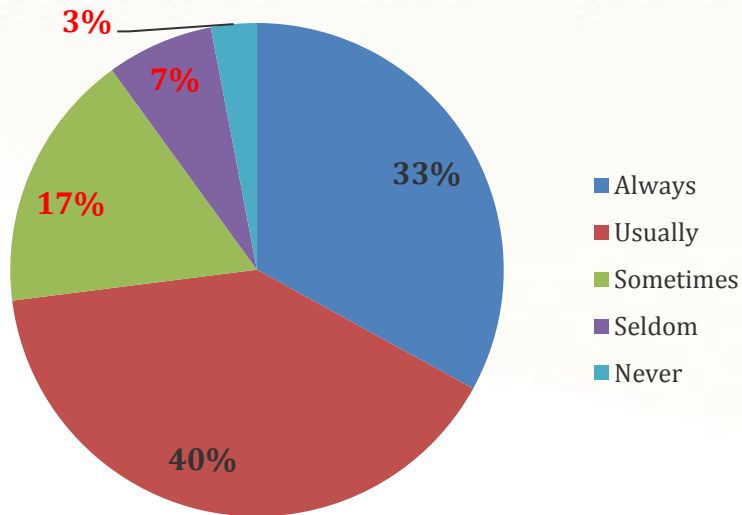
# Quality of Specific Services

- Access to health services for family member (yes/no)? - 97% yes
- Access to dental services for family member (yes/no)? – 80% yes
- Access to necessary medications for family member (yes/no)? – 97% yes
- Access to mental health services for family member (yes/no)? – 83% yes
- Access to quality respite services for your family (yes/no)? – 72% yes
- If asked for crisis/emergency services, were services provided when needed (yes/no)? – 78% yes
- Are there services needed for family member than are not currently offered (yes/no)? – 45% yes

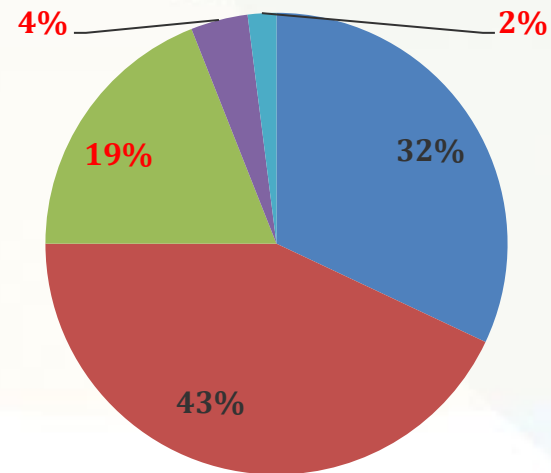
# FINDINGS

## Information and planning

### Gets enough info



### Info is easy to understand



- Plan includes things important to family (yes/no)? – 93% yes
- Plan includes all supports that family member needs (yes/no)? – 74% yes
- Discussed handling emergencies (yes/no)? – 71% yes



# CONCLUSIONS

- Many of these families are very vulnerable
  - health
  - age
  - availability of resources
- Level of satisfaction with overall services is fairly high,
- Many families experiencing reductions in services,
- Satisfaction with crisis and respite services –a critical type of services for families with a family member with ID/DD living at home – is lower
- The level of satisfaction with amount and type of information received is not very high,
- While service plans include things that are important, not all needed services are included,
- Emergency planning is concerning

# Questions



# Contacts

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