

Does Person-Centered Thinking, Planning, and Practice Get Waived in an Emergency? Absolutely Not!

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National Center on Advancing Person Centered Practices and Systems



NCAPPS

HCBS Conference
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Presentation Outline

- NCAPPS: A focus on Person Centered Planning and Practice in HCBS
- Keeping the Person at the Center in an emergency
 - Health Care Person Centered profiles
 - Pandemic Wisdom Video Shorts: insights, lessons and key themes.
- Person centered community supports – preparing for and responding to unprecedented times.



NCAPPS Goals and Priorities

NCAPPS Goal:
Promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan

Key Priorities:

- Participant and family engagement
- Racial justice, equity, and cultural and linguistic competence
- Cross-system collaboration

...transforming how we think, plan, and practice

National Center on Advancing Person- Centered Practices and Systems (NCAPPS) is for...

**States, Tribes, and
Territories**

**Systems for people with
disabilities and older adults
with long-term service and
support needs, including**

Brain injury

Intellectual and
developmental
disabilities

Aging and disability

Behavioral health

Supported by ACL, CMS



Person-centered approaches include person-centered thinking, planning, and practice



Person-centered thinking

- A foundational principle requiring consistency in language, values, and actions
- The person and their loved ones are experts in their own lives
- Equal emphasis on quality of life, well-being, and informed choice

Person-centered planning

- A methodology that involves learning about a person's preferences and interests for a desired life and the supports (paid and unpaid) to achieve it
- Directed by the person, supported by others selected by the person

Person-centered practices

- Alignment of services and systems to ensure the person has access to the full benefits of community living
- Service delivery that facilitates the achievement of the person's desired outcomes


PCP in HCBS

CMS HCBS Final Rule:

“...service planning for participants in Medicaid HCBS programs under section 1915(c) and 1915(i) of the Act must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals.”

PCP in HCBS~ encountering COVID

Limitations imposed by COVID-19 emergencies in states:

- Restrictions on in-person planning meetings
 - Disrupted routines. In some cases change in residence.
 - Shifted priorities towards health/safety (balancing what is important to the person to what is important for the person – and in the context of public health guidance). Focus on preparing for or responding to acute health concerns.
 - Staff and others unable to provide in-person supports
 - Limitations on support staff/family in health care environments
 - Concerns for staffing, family providers.
 - And the list goes on...
- 

CMS moves to support ongoing Person Centered Supports.

Examples of Approved Section 1915 (c) Waiver Appendix K Strategies to Address COVID-19

- Permit virtual evaluations, assessments, and person-centered planning meetings in lieu of face-to-face (50 states)
- Temporarily institute or expand opportunities for self-direction (7 states)
- Temporarily permit payment for services rendered by family caregivers or legally responsible relatives (if not already permitted in waiver) 39 states
- Temporarily modify person-centered plan development process and responsible individuals 40 states
- Additionally in State Plans - Telehealth: expanded coverage and access in all states

As modifications were underway, NCAPPS acted to develop supports and resources for states, providers, individuals and families.

NCAPPS COVID Response

- COVID 19 Resources – videos, toolkits, templates to support person centered planning
- NCAPPS Shorts: Wisdom in the Pandemic
 - Goal: Draw from NCAPPS network’s expertise
 - Individual, personal reflections on what person-centered thinking planning and practice means
 - What do person-centered thinking, planning, and practice look like in time of crisis?
 - How do we hold on to - and even promote – person-centered thinking, planning, and practice at this time?
 - How do we balance collective, public health with person-centered, individual well-being?
 - What lessons we can apply from person-centered thinking, planning, and practice to get through this time of pandemic?



NCAPPS Shorts: Wisdom During the pandemic

“A lot of times, people think a person-centered planning is something that we would just do if we had enough time, or if it was something that we would do if we just want to think about the future. But the reality is, is that it really helps ground us in the day-to-day problem-solving; we can make about anything that's happening in our lives. It gives us an opportunity to calm down, recognize the value of the voice and understand what that person wants. Sometimes we're making really quick decisions because of the crisis that we're in. And as we're making those quick decisions, what are we doing that's really taking away from the supported decision making or what that person's good life really is. Person-centered thinking should be something we actually fall back on during this time of crisis, to really help us navigate that, to help us understand that we do need to think about the whole, but it's all about the person's quality of life. And how are we balancing that with both health and safety, as well as ensuring that we're not making decisions that are going to have a long term impact that undoes all of the self-determination, social capital and inclusion that we fought so hard for.”

Sheli Reynolds (:38 to 1:48)

https://www.youtube.com/watch?v=RJtHmhikoZ4&list=PLYet2AiOYpYhOhuQNmS7jvCWNxof120Q_&index=6



Health Care Person-Centered Profile *What Matters to Me*



Please call me

Mr. Blake

1. What people appreciate about me

Caring son, cousin
Great cook -- famous for his meatloaf and mac and cheese
Basketball fan and former college player at UW

2. Who and what is important to me

* My Blake lost his son years ago in a car accident. He hears his son's voice and often talks to him in return. This is comforting to him and nothing to worry about.
* Listening to music (e.g. Dave Mathews Band) and watching historical movies or LA Lakers basketball are his favorite activities
* Mr Blake does not always agree with his mother. She means well, but tries to make decisions for him he does not agree with. Mr Blake prefers you respect his wishes as outlined in this Passport and his AD.
* Mr. Blake has an Advance Directive, the information card is in his wallet - His cousin Mathew Harris is his health care proxy (314-548-3329)

3. How to best support me

* Keeping pain under control helps Mr. Blake stay calm
* Mr Blake has strong thoughts about the government, especially during crisis -- he fears he is under surveillance by the FBI and CIA. Don't challenge or dismiss him as he may get upset. Reassure him of his safety and let him know you are there to help.
* Even when Mr. Blake is struggling with psychiatric symptoms, he understands much of what is being said. Always speak with him and explain what you are doing, and why.
* Mr. Blake's favorite snacks for his diabetes: almonds, yogurt, apples

This Health Care Person-Centered Profile was completed by: Me Someone else
Name and relationship:

Healthcare Person-Centered Profile

- Released by ACL and NCAPPS
- 2 pages only
 - Page 1: Captures brief/vital information on health status.
 - Page 2: Captures the Person-Centered Profile to assist medical staff in providing more person-centered care
- Profile tool and instructions available @ <https://ncapps.acl.gov/covid-19-resources.html>

NCAPPS Resources

ncapps.acl.gov/covid-19-resources.html



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COVID-19 Resources

Health Care Person-Centered Profile



Health Care Person-Centered Profile

[Instructions for Developing a Health Care Person-Centered Profile](#)

Profile Examples:



Brian



James



Josie



Mariam



Marty



Veronica



Jordan

We know that many people may have to go to the hospital to receive care for symptoms related to COVID-19. A common concern is that we, or that person we care about or care for, may have to go or receive this care alone, without the support of people they know and trust, because of risk or restrictions. NCAPPS subject matter experts have created a tool – the Health Care Person-Centered Profile – to communicate a person's wants and needs if they are hospitalized without the direct support of their caregivers, family, neighbors, or friends.

The tool has two pages. The first page can be used to capture brief and vital information about the person's health status. The second page contains the Person-Centered Profile, a one-page brief description of the things that can assist medical staff in providing more tailored and person-centered care. You can use the accompanying instructions to fill out the template for yourself, someone you love, or someone you're caring for. We have also created examples that show how the tool can be used by people with a range of different backgrounds and concerns

Resources for Person-Centered Planning during the Pandemic

The resources found here may be useful for people in various scenarios related to the COVID-19 Pandemic. Please check back frequently because we will add resources as they are available. If there is a resource that you believe would be useful to highlight here, please send a message to ncapps@hsri.org.

Person-Centered Thinking Skills in a Time of Crisis

This short video from Michael Smull describes how to apply person-centered thinking skills during the COVID-19 crisis. It includes discussion of balancing what's "important to" and "important for" a person and the use of tools such as Good Day, Bad Day, One-Page Profiles, and Learning Logs.



[Video Transcript](#)

Three Buckets and the COVID-19 Pandemic

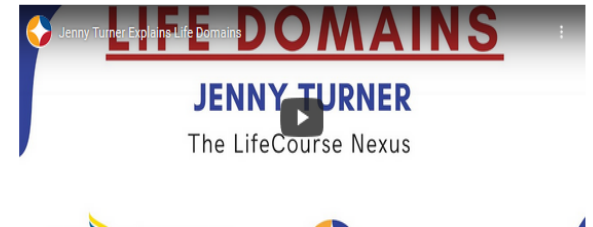
Jenny Turner from the Charting the LifeCourse Nexus at the University of Missouri Kansas City Institute for Human Development describes how to apply the concept of "3 Buckets" of supporting the needs of people and their families during the COVID-19 pandemic.



[Video Transcript](#)

Life Domains and the COVID-19 Pandemic

Jenny Turner from the Charting the LifeCourse Nexus at the University of Missouri Kansas City Institute for Human Development describes how to apply the concept of "Life Domains" to supporting the needs of people and their families during the COVID-19 pandemic.

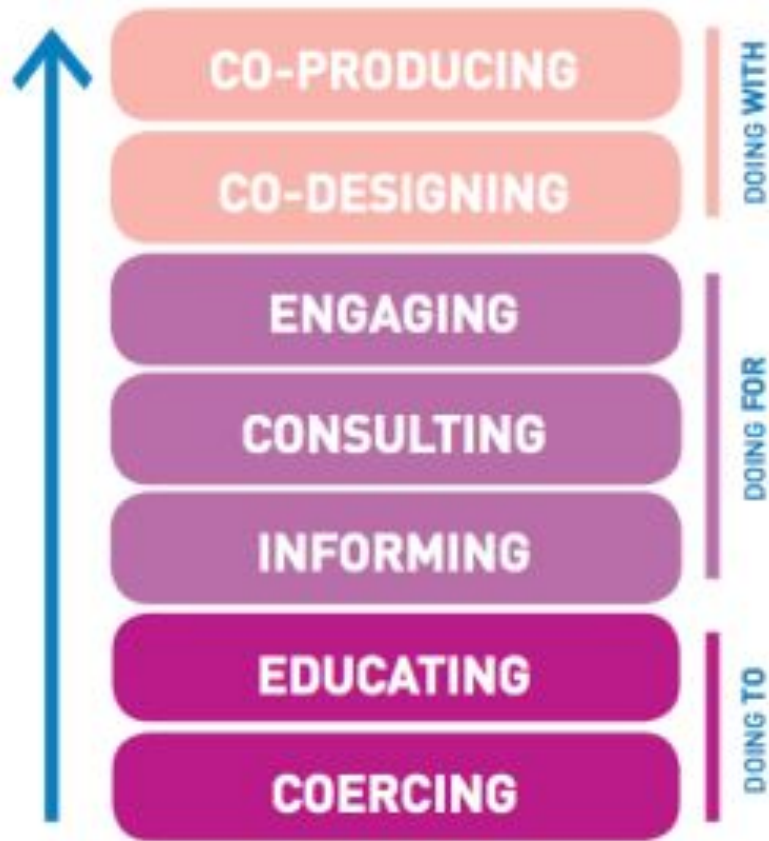


[Video Transcript](#)

Person centered community supports – preparing for and responding to unprecedented times.

- *(supporting people to continue work, volunteer*
- *More control of own services and supports has allowed for more flexibility (expanding self-direction)*
- *Support coordination: working with families to get plans amended, operating in a virtual environment)*





Source: new economics foundation

The Myth

Once a program, always a
program

(Slides 16-20 are adapted from The Collaborative for Citizen Directed Supports-New Jersey's 'Control Your Day-A Conversation About Alternatives to Congregate Day Services' as developed by Cherry Oakley, Patty Kowalchuck, Christina Rappisi and Marian Frattarola-Saulino 2020)



The Facts

Person Centered Planning ensures you make the best decisions for you, and you can change your mind and your plan

The Home and Community Based Final Rule emphasized the importance of Person Centered Planning

Providers of Home and Community Based Services must honor your preferences and your plan

Part of the planning process can be asking yourself:

- 'What is best for me at this time?
- Could my life look different during and after COVID-19?

Program Centered Services

+

A place

Opportunities

'Supervision'

Predictability

Structure

Other benefits

^

A place

Opportunities

'Supervision'

Predictability

Structure

Other limits



Person Centered Practices

- Supports not just supervision that are completely tailored to the person who is purchasing them
- The opportunity for a person, and their support circle, to think and plan a meaningful routine where a person can truly belong and contribute
- Flexibility that's based on the needs and preferences of the person, not the facility
- Many places to develop new skill sets and interests and meet new people and possibly form friendships
- Predictability
- Structure



Days without Walls

Sample Calendar of Self-Directed Life

Monday 9-3	Tuesday 9-3	Wednesday 9-3	Thursday 9-3	Friday 9-3	Saturday 9-3	Sunday 9-3
9-11 am Explore a local park: fish, birdwatch	9-10 am Food shopping list, meal planning	9-12 pm Breakfast & Video Games	9-11 am House cleaning	9-12 pm Volunteer @ animal shelter	9-12 pm Breakfast with Girlfriend	9-11 am YMCA for swim lessons
11-1 pm Grab lunch at local café	10-1 pm Food shop & Meal Prep	12-1 pm Lunch	11-1 pm Lunch & Judge Judy	12-2 pm Lunch with Mom	12-2 pm Mall Stroll	11-1 pm Massage
1-3 pm Museum with SDE	1-3 pm Research and plan next week's schedule	1-3 pm Chill & Read book	1-3 pm Laundry	2-3 pm Pickup and drop off shelter donations	2-3 pm Arcade with friends	1-3 pm Chair yoga & meditate
Explore!	Plan!	Chillin'!	Help @ Home!	Help Out!	Fun!	Self-Care!

Maintaining Person Centered Planning and Practice

~ A Rights Perspective

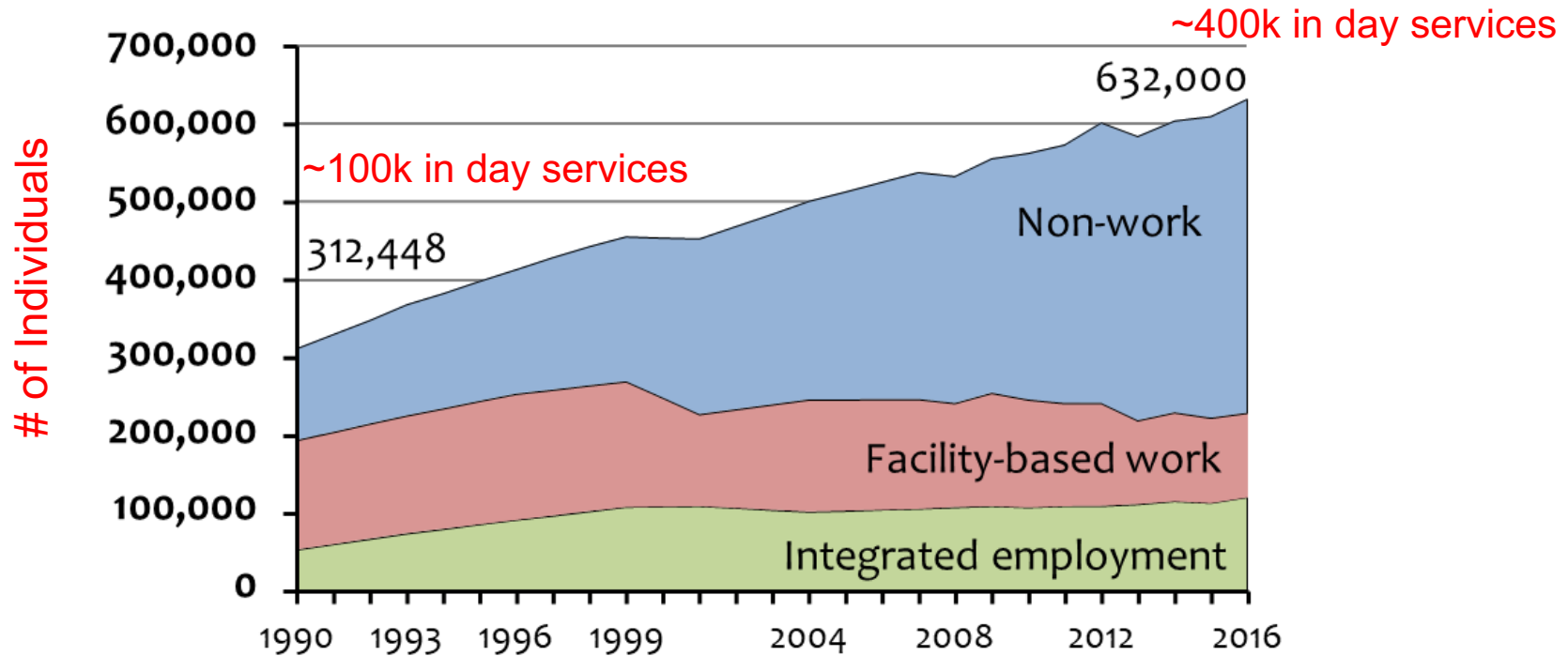
Possible Rights Violations Related to COVID-19

- Limitations on movement.
- Inability to make personal decisions.
- **Restricted access to community (people, places, things).**
- Restricted ability to work.
- Rules or requirements different from other people in similar situations.
- Discharge from a provider for failing to comply with a restriction.
- Blanket bans on individual rights.

Person-Centered Planning Modifications

- The following must be documented in the plan:
 - Identify a specific and individualized assessed need
 - Positive interventions and supports used prior to modification
 - Less intrusive methods tried
 - Describe the condition that is directly proportionate to the specified need
 - Regular collection and review of data to review effectiveness
 - Established time limits for periodic review to determine if modification is still needed
 - Informed consent of the individual
 - Assure interventions and supports will cause no harm

Use of Day Services Has Grown Dramatically



StateData.info

Source: ICI National Survey of State IDD Agencies

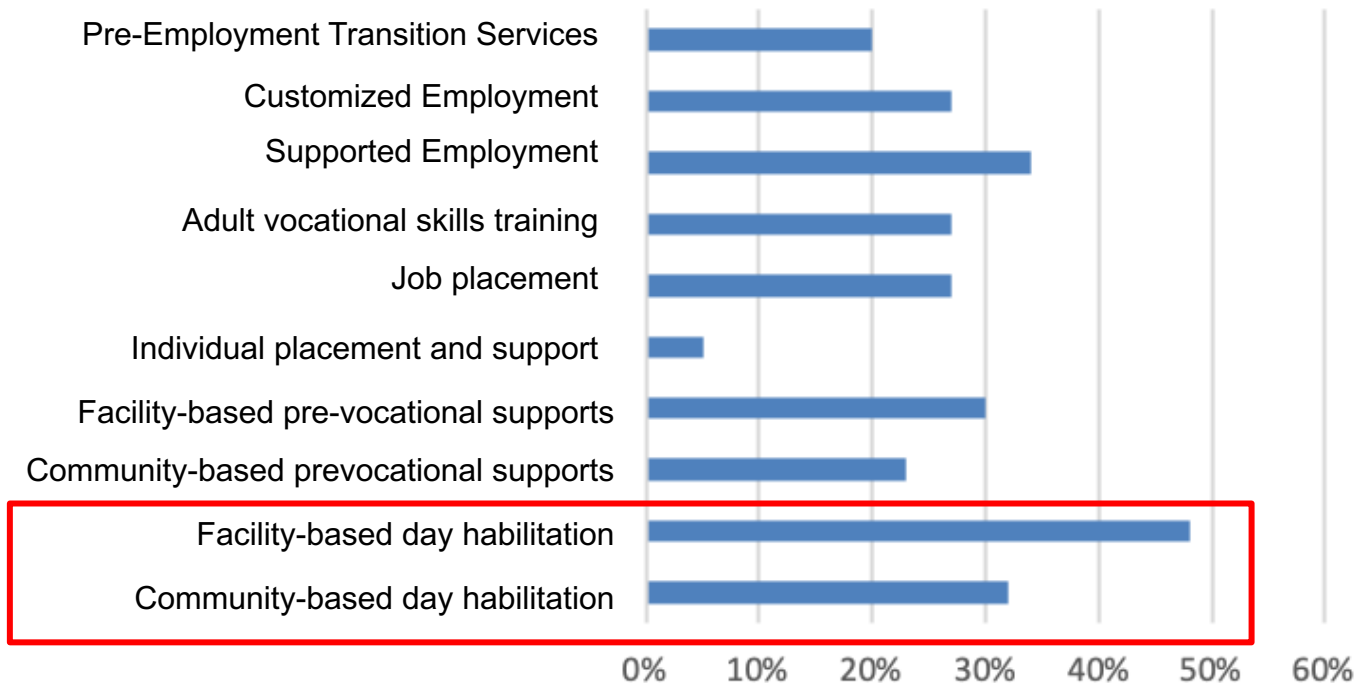
ThinkWork!

COVID-19 May Shut Many Disability Services Programs for Good

- ANCOR surveyed 191 organizations nationwide.
- 77% have shut down or discontinued programs.
- 16% do not plan to reopen their programs.
- Employment and day services most affected.
- Causes: ↑ costs (PPE, testing); ↓ revenue.
- <https://www.disabilityscoop.com/2020/08/24/covid-19-may-shut-many-disability-programs-for-good/28795/> (August 2020)

COVID-19 Has Hit Day Services Providers Especially Hard

% of Providers No Longer Providing Services



Association of People Supporting Employment First. (2020). *Impact of COVID-19 on disability employment services and outcomes*. <https://apse.org/covid-19-impact-survey/>

Can Without Walls Day Services be
part of the solution?



Reducing Costs by Closing Brick-and-Mortar Locations

- MRCI serves more than 2,000 individuals across Minnesota with employment and day services.
- Plans to sell buildings or not renew leases on rentals.
- Reductions in expenses for:
 - Maintenance
 - Heating/cooling
 - Insurance, etc.
- Reduced use of transportation getting individuals to and from these facilities.
- Long-term move to “day services without walls.”

Adaptation and Innovation Benefit Providers and People

Benefits to Providers: Lower Costs, More Sustainable Business Models	Benefits to People: Improved Choice and Community Integration
Reduced brick-and-mortar costs	Greater independence through remote supports
Selling private pay services on a national scale to grow revenue	Enhanced choice: virtual or in-person
Using volunteers to diversify workforce and lower labor costs	Enhanced choice: pathways for personal growth and the pursuit of individual interests
	Enhanced integration: virtual communities
	Enhanced integration: in-community day supports

Reminder: Day services are *services not places*.

Final NCAPPS Short: Wisdom During the pandemic

Eric Washington (1:49 – whole video)

<https://www.youtube.com/watch?v=Z7AV2o4eLfs&list=PLYet2AiOYpYbOhuQNmS7jvCWNxoF120Q&index=12>

Hello, my name is Eric Washington, and I'm a part of the NCAPPS family.

I reside in Kansas City, Missouri. Well, I'm involved with three organizations that mean a lot to me: Community Services lead, which helps remedy homelessness in Eastern Jackson County, the Adult Brain Injury program, as well as the Brain Injury Association of Missouri, and they help advocate for persons with brain injuries. I know right now, people are scared. People are worried people are, you know, unemployed, but if we all stick together, things will get better. Right now we're dealing with the coronavirus pandemic or COVID-19 pandemic. That can be remedied by vaccines, social distancing, washing your hands, just being safe in general, until doctors come up with a way to actually lower the risk for people. But we're also dealing with the epidemic and that's social and cultural inequalities and injustices that takes effort that takes time that takes having conversations that people don't want to have. So, I challenge everyone to be a part of the solution instead of a part of the problem. So, I'm gonna leave you guys with this stuff. I looked up something with the Health Foundation and they have four principles of person-centered care. But the main thing that I found they said that person-centered care is affording people dignity, compassion, and respect. So if you're culturally uncomfortable to have certain conversations, can you truly be person-centered? Okay, I want to thank you guys and I want everyone to be safe.

Thank You.

For more in for upcoming webinars at
ncapps.acl.gov

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