

ENTITLEMENT TO ELIGIBILITY: THE FUNDING CLIFF

National
Association
of Private
Special
Education
Centers

ENTITLEMENT VS. ELIGIBILITY

The Cliff

Entitlement

a right to benefits specified especially by law or contract

IEP

504

Eligibility

fitness or suitability to be chosen, selected, or allowed to do something



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THE CLIFF

A PARENT'S PERSPECTIVE

So
What
Is
Next
?



THE CLIFF

A PARENT'S PERSPECTIVE

- **I am the parent of a 28-year-old son with autism and I cannot die**
- Our children are entitled to an education until they are 21
- When my son graduated from school, there was no appropriate program for him
- I had to quit my job to supplement the services he needed
- In 2006 a group of parents concerned about the future of our children got together. We wanted answers to our common questions:
 - ***What will happen when they leave school?***
 - ***What does the future hold for them?***
 - ***What will happen when we die?***

THE CLIFF

A PARENT'S PERSPECTIVE

- That small group of parents and dedicated professionals pooled their resources, time, energy, and money
- Five years later, a program called Itineris began
- Today, my son and many more like him have meaningful days
- I finally was able to return to work
- Because of Itineris, my son has marketable job skills, he loves to work and he wants to work

THE CLIFF

A PARENT'S PERSPECTIVE



THE CLIFF

A PARENT'S PERSPECTIVE

- We have been searching for a job for four years
- My son has been able to obtain only one job interview
- We have not been able to break the barrier of Neurodiversity in the workplace
- The fact is, we are getting older and we will die. I do not know what will happen to Andrew when I die.

POSITIVE OUTCOME ATTAINMENT

“We want Ian to have a life that is more okay than not okay from his point of view most of the time.”

Ferguson & Ferguson, 2000
The Promise of Adulthood
Parents of Ian



Positive Outcomes are a Function Of:

+ + +

What do you think?

Positive Outcomes are a Function Of:



+



+



+



- High Quality Education
- Therapeutic Supports

Setting the Trajectory

- Home & Community Interventions
- Customized Supports

Securing the Outcome

The Stakes are High

We are Seeking to Change & Enhance the Quality of Life Trajectory



Concerns Driving Placement Into NAPSEC Programs

Lost Opportunities
Set Backs & Crisis
Suffering & Turmoil in School
Adversarial School Relationships



Program Models

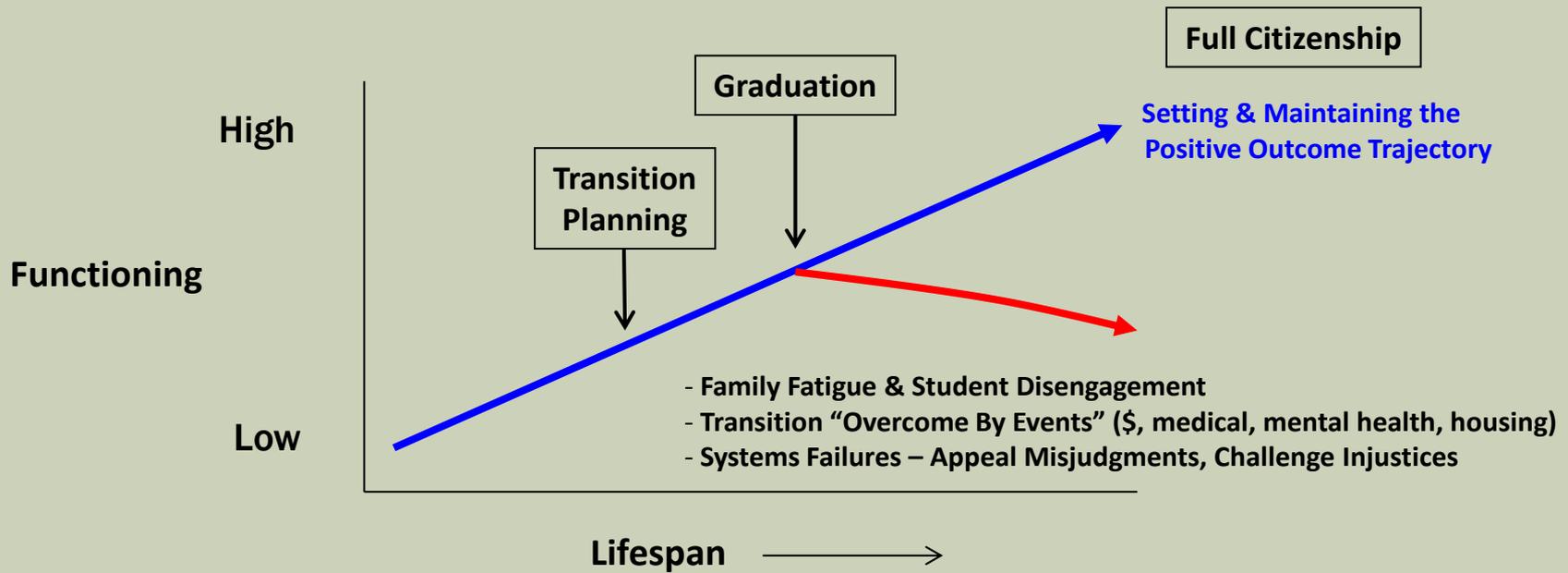
Clinical-Therapeutic Component
Smaller - Flexible
Sub-Specialty Focus
Continuity - Intensity
Person & Family-Centered

High Stakes – High Reward Work



- ✓ Students cannot afford to lose time and developmental opportunities, suffer without agency, and/or decompensate secondary to ineffective or inappropriate services.
- ✓ We need to minimize the risks of developing maladaptive behaviors that will limit opportunities in the short- and long-term.
- ✓ Students cannot afford to lose the hard-won gains achieved and the promise of a bright future once school is over.

Transition & Outcome Attainment



Start early to compensate for and/or counterbalance problems down the road!

“BEST CHANCE FOR A BRIGHT FUTURE”



- ✓ Early **advocacy training** to impact school programming & external resources/supports
- ✓ Enhance quantity & quality of **multidisciplinary outreach** into the home and community settings
- ✓ **Expand work & life experiences** for students at all functioning levels
- ✓ **External network development** as a first tier priority
- ✓ Favor **person-centered initiatives**
- ✓ Focus more on the **social determinants of health & wellness**

HUSSMAN CENTER FOR ADULTS WITH AUTISM

- Purpose
 - provide cutting-edge programming
 - training and resources
- Model
 - meaningful activities for autistic adults
 - learning experiences for students
- Estimated numbers 2008 – 2018
 - 300 autistic adults
 - 2000 students

THE HUSSMAN CENTER: A FEW SNAPSHOTS



KEY POINTS

- Multifaceted experiences and perspectives
 - self-advocate
 - founding member of Itineris
 - worked at Division of Rehabilitation Services
 - Certified Rehabilitation Counselor; at HCAA
 - Towson University in various capacities since 2010
- well-intentioned policies often result in constriction of options
- innovative programs are “stranded” without funding streams
- families are totally confused, despite best efforts at information provision
- family, individual, and practitioner readiness to navigate adult system is totally uneven

CHALLENGES

Challenges in developing and sustaining programs for adults on the autism spectrum and with related disabilities

Independence360

■ Tsunami

- In response to the critical and unmet needs for adults over 21, Independence360 was opened in 2014. In 4 years, enrollment has increased from 20 to 107. Two sites have been filled. In the next 10 years, 500,000 adults on the autism spectrum nationally will require programs.



CHALLENGES

■ Moral Imperative

- In spite of no public funding to initiate an adult program and inadequate funding to sustain, Independence360 was opened.
- Over \$600,000 was fundraised as start-up costs purchasing equipment, computer technology, furniture and renovating facilities.
- Additional \$200,000 was raised to purchase vans to meet requirements for community integration and transporting adults from home in certain geographic catchment areas.



CHALLENGES

- **Increasing Billing, Paperwork, and Regulations**
 - This year, funding for Adult Habilitation Programs shifted from state DDD funding to Medicaid. Billing changed from a daily rate to billing every 15 minutes. This required purchasing an expensive software program, additional hours for staff to prepare billing, and hiring an additional staff member to coordinate billing.



CHALLENGES

- **Inadequate and Inequitable Medicaid Funding, Glitches in System, Lack of Parent Support**
 - Rates received for individual adults are subjective based on parents' ability to communicate, not on adult needs
 - Unrealistic rate to secure adequate, qualified staff and specialists
 - Glitches often occur in eligibility, lack of supports to resolve, i.e., Social Security is stopped, resulting in loss of Medicaid.
 - Parents are not provided with information regarding availability of programs.

CHALLENGES

- **Vocation/Employment Program**
 - Inadequate funding
 - Funding for employment provides inadequate hours for assessment, placement, and ongoing job supports
 - Lack of accessibility and transportation to jobs in home communities

CHALLENGES

- **Unrealistic Regulations pose obstacles and threats - not in best interest of individual adults**
 - Requirement to be out in the community the majority of the time is not in the best interest of certain adults due to emotional, behavioral, and physical issues.
 - Workforce Innovation Opportunity Act (WIOA) doesn't allow for adults to receive funding if employed by social enterprises run by disabled organizations. Certain adults with disabilities lose jobs in community due to lack of required supports. Social enterprises run by organizations for the disabled provide these adults with the supports required to succeed as well as community integration.

CHALLENGES

- Medicaid Funding in Jeopardy
 - Proposals to change Medicaid funding restricted for disabled adults to state block grants. This will jeopardize minimal funding.

THE CLIFF: FUNDRAISE OR PERISH

Itineris

- The average client funding yields \$24,000
- Client costs average \$30,000
- Costs as a student may have been \$80,000 per year
- The client is the same person

THE CLIFF: FUNDRAISE OR PERISH

- **Money up front**
 - In order to be able to open up an agency, there must be 6 months worth of advanced client billing in the bank.
 - Paid 6 months in arrears.
- **Funding is never established**
 - Can change as quickly as every 90 days.
 - Individuals and agencies
- **Documentation**
 - As early as a child's 9th grade year.
 - Bank statement, IEP, diagnosis is reviewed by a third party.
- **Barriers**
 - People with less documented need
 - People whose parents have not been educated on the transition process
- **Staffing to support documentation**
 - Itineris operates at no higher than a 4:1 ratio, with the majority of people being in a 2:1.
 - Beyond direct service, three other levels of personnel for EACH client
 - Review documentation for accuracy to avoid audits and accusations of Medicaid Fraud

THE CLIFF: FUNDRAISE OR PERISH

- Itineris' gap for the FY19 year will be half a million dollars.
- Resources for filling this gap are fundraising events, such as an auction, annual giving and applying for grants
- The generosity of friends and families to donate as they are able.
- DORS, Pre-Ets
- After hours classes, private pay clients, and consultation
- Itineris-in-a-Box

WORKFORCE DEVELOPMENT INITIATIVES

- KKI Neurodiversity Initiative
- Partnership with Itineris
- HR Autism at Work program
- Workforce Awareness Training
- Modified HR practices
- Project SEARCH internships
- Agency partnerships: DORS; The Arc, etc.
- Educating Area Businesses (workshop & Symposium)
- Accessibility & Technology



EMPLOYMENT: WHAT WORKS?

- Takes a village, commitment from all levels of the organization & resources
- Workforce awareness training
- Inclusive Culture
- Work readiness, internships and apprenticeships
- Supported employment
- Agency Partnerships
- Vocational training that meets the needs of today's employers; skills development

ADULTS WITH ASD: THE SCALE OF THIS ISSUE...

- In 2009 a census completed in the state of California documented that approximately 70% of individuals diagnosed with ASD were less than 14-years old.
- Current estimates suggest that approximately **50,000** individuals with autism age out of the educational system each year.

THE CURRENT STATE OF SERVICES FOR ADULTS WITH AUTISM

The potential of individuals with autism to become employed and engaged adults is limited more by the failure of the systems charged with supporting them than by the challenges associated with having autism.

Organization for Autism Research (2009)

BARRIERS TO COMMUNITY INCLUSION FOR ADULTS WITH ASD

- Presence of maladaptive behavior/adaptive skill deficits
- Little Legislative Support
- No established field of expertise among adult service practitioners
- Lack of qualified staff
- Limited transportation options
- Little coordination between educational, behavioral, mental health, vocational rehabilitation, and Developmental Disabilities agencies/systems
- A lack of awareness/understanding on behalf of community stakeholders that adults with ASD have the potential to be employed if given the opportunity with effective supports

FUNDRAISING CHALLENGES

- In many cases donors interested in giving towards the development of innovative programs to provide direct service to adults with ASD have a loved one on the spectrum.
 - This can be complex as donors are not able to gain any benefit (i.e., goods/services for their loved one with ASD) from their donation
 - This may result in those donors giving in other areas related to ASD that are perceived to have a larger impact (i.e., neuroscience, prevention, cause, etc.)
 - Could there be a change to tax laws to allow for a donor to give in support of an organization that is helping many with ASD even if it also benefits a member of their family?

RUTGERS CENTER FOR ADULT AUTISM SERVICES

Service

The RCAAS Community Inclusion Center provides a model of what adults with ASD can accomplish if given the resources and opportunity for employment and community-based recreation. 100% of program participants are competitively employed in a wide variety of jobs at Rutgers University.



Training

The Rutgers Graduate School of Applied and Professional Psychology provides the nation's highest quality graduate education and training, developing outstanding practitioners to serve the needs of adults with ASD. The RCAAS is an active training site for students at all levels and across a variety of professional disciplines.

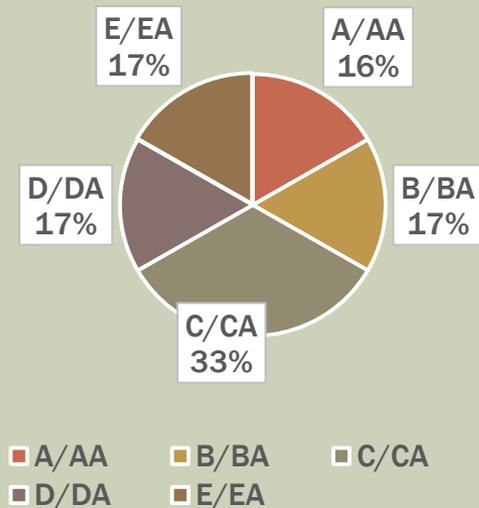
Research

A senior team of prominent researchers, including the world's first Endowed Chair in Adult Autism, has been assembled to identify and disseminate the practices that are most effective for ensuring the best outcomes for adults on the spectrum across the areas of employment, transportation, socialization, recreation, and independent living.

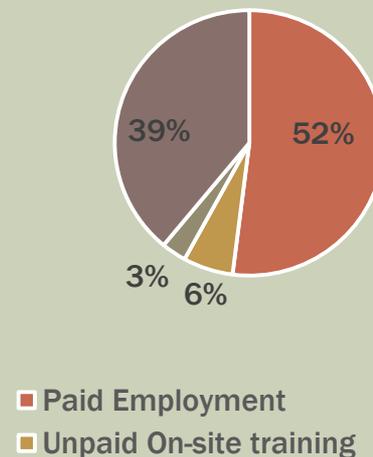


RUTGERS CENTER FOR ADULT AUTISM SERVICES

Diversity of RCAAS
Participants by NJDDD
Budget Tier



RCAAS Aggregate Program Hours



RCAAS Participants Spend **97%** of
Program Hours in the
Community!

WHAT DOES AN “INSTITUTION” LOOK LIKE?



HOW GOVERNMENT REGULATION STIFLES INNOVATION

■ Fundraising Challenges

- Could there be a change to tax law to allow for a donor to give in support of an organization that is helping many with ASD even if it also benefits a member of their family?

■ Regulations related to residential options that limit the number of adults with developmental disabilities that can reside under one roof.

- Well intentioned with the purpose of shifting emphasis from “Institutional” settings
- Can result in limited choice and lower quality services for individuals requiring significant supports
- Has been argued that telling individuals that they don’t have the choice of who they live with is discriminatory.

RECOMMENDATIONS

- Flexible policies that allow for innovative models and options while simultaneously protecting self-advocate concerns
- Robust and consistent training of transition teams and key transition professionals at the high school level to serve as “front line” advocates for youth and their families
- Community education so that the dream of integration is not hollow

RECOMMENDATIONS

- Regulations should be “adult-centered” not adhering to politically correct policies.
- The amount of time the adults are integrated into the community should be based on their readiness and individual needs—not an unrealistic percentage.
- Rates adults receive should be based on objective evaluations and diagnosis, not subjective family interviews.
- WIOA should fund social enterprises run by organizations for disabled when this is the best employment option to meet adults’ individual needs.
- Medicaid billing should be less cumbersome and relevant to adult programs and should not be based on a medical model, billing every 15 minutes.

RECOMMENDATIONS

- **Additional public funding should be provided in the following areas:**
 - **Facilitate transportation to employment**
 - **Provide training to high school staff on services that will be available when the disabled student turns 21**
 - **Provide training and support for employers to facilitate hiring disabled adults**
 - **Start-up funds need to be provided to initiate adult programs and fund vans**

APPENDIX

GLOSSARY OF ACRONYMS

- 504 - Plan from Vocational Rehabilitation Act of 1973
- ASD - Autism Spectrum Disorder
- CMS - Centers for Medicare and Medicaid Services
- DDA - Developmental Disabilities Administration
- DOE - Department of Education
- IEP - Individualized Education Program
- MA - Medicaid
- SSI - Supplemental Security Income
- SSDI - Social Security Disability Income

The Positive Outcome Equation – Implications for Professional Practice

$$O = f(K, S, O, R)$$

The **Positive Outcome Equation** presented in this PowerPoint highlights the critical developmental gains (Knowledge & Skills) and external supports outside of school (Opportunities & Resources) that must be addressed over time to achieve a positive outcome.

In short, for children and youth Outcomes are a Function Of:

KNOWLEDGE + SKILLS + OPPORTUNITIES + RESOURCES

The argument that this model presents is as follows:

If any one of the four variables that make up this equation is missing or compromised, the *individual's ability to reach their true potential is diminished and/or lost.*

What are the implications of this model on professional practice, program design, and policy development?

- ✓ Students, family members, clinicians, counselors, policy makers, and educators need to find ways to impact the real world outside of the school environment if personally meaningful supports and valuable outcomes are to be obtained. If schools and related service practitioners operate in isolation optimal results will not be achieved (this is true for the entire professional and non-professional support system). This insight in turn should influence how schools are designed, how all stakeholders work together, and how resources are disseminated.
- ✓ External opportunities and resources need to be secured, customized interventions need to be developed, and follow along supports need to be in place.
- ✓ In the end we need to design personalized, high-value interventions, supports, and services that can **“impact over time and across settings!”**

Student Complexity & Systems Challenges

Highly Personal & Individualized Process

Developmental & Experiential Variables Weigh Heavily

Student Challenges	Parent Concerns
<p>Self-knowledge, world Knowledge & dependency on others</p> <p>Lifelong inexperience in gaining control of significant parts of their life</p> <p>Evolving & incomplete developmental gains</p>	<p>Will services of value be available and will they address priority needs?</p> <p>Will the new providers and professionals be capable and trustworthy?</p> <p>How do I build a support team for when my child is out of school?</p>

THERE ARE NUMEROUS RESEARCH- BASED TREATMENTS FOR CHILDREN WITH AUTISM (14)

NATIONAL AUTISM
CENTER (2015)

Research Findings for Children, Adolescents, and Young Adults (Under 22 Years)

Established Interventions for Individuals Under Age 22

In the following pages, we provide a detailed definition and description for each of the 14 Established Interventions identified for this population in Phase 2 of the National Standards Project.

You may already be familiar with some of these options. Many volumes have been published on each of these interventions; we encourage you to learn more about those that might be most useful to you.

The following interventions have been identified as falling into the Established level of evidence:

- ❶ Behavioral Interventions
- ❷ Cognitive Behavioral Intervention Package
- ❸ Comprehensive Behavioral Treatment for Young Children
- ❹ Language Training (Production)
- ❺ Modeling
- ❻ Natural Teaching Strategies
- ❼ Parent Training
- ❽ Peer Training Package
- ❾ Pivotal Response Training
- ❿ Schedules
- ⓫ Scripting
- ⓬ Self-management
- ⓭ Social Skills Package
- ⓮ Story-based Intervention

THERE ARE NUMEROUS ADDITIONAL TREATMENTS FOR CHILDREN WITH AUTISM THAT ARE EMERGING AS A RESULT OF ONGOING RESEARCH (18)

NATIONAL AUTISM
CENTER (2015)

Emerging Interventions for Individuals Under Age 22

Emerging Interventions are those for which one or more studies suggest they may produce favorable outcomes. However, before we can be fully confident that the interventions are effective, additional high quality studies are needed that consistently show these interventions to be effective for individuals with ASD. Based on the available evidence, we are not yet in a position to rule out the possibility that Emerging Interventions are, in fact, not effective.

A large number of studies fall into the Emerging level of evidence. We believe scientists should find fertile ground for further research in these areas.

The following interventions have been identified as falling into the Emerging level of evidence:

- Augmentative and Alternative Communication Devices
- Developmental Relationship-based Treatment
- Exercise
- Exposure Package
- Functional Communication Training
- Imitation-based Intervention
- Initiation Training
- Language Training (Production & Understanding)
- Massage Therapy
- Multi-component Package
- Music Therapy
- Picture Exchange Communication System
- Reductive Package
- Sign Instruction
- Social Communication Intervention
- Structured Teaching
- Technology-based Intervention
- Theory of Mind Training

**THERE ARE
NUMEROUS
TREATMENTS FOR
CHILDREN WITH
AUTISM THAT
HAVE BEEN
DEMONSTRATED
TO BE
INEFFECTIVE (13)**

**NATIONAL AUTISM
CENTER (2015)**

Unestablished Interventions for Individuals Under Age 22

Unestablished Interventions are those for which there is little or no evidence in the scientific literature that allows us to draw firm conclusions about their effectiveness with individuals with ASD. There is no reason to assume these interventions are effective. Further, there is no way to rule out the possibility these interventions are ineffective or harmful.

The following interventions have been identified as falling into the Unestablished level of evidence:

- Animal-assisted Therapy
- Auditory Integration Training
- Concept Mapping
- DIR/Floor Time
- Facilitated Communication
- Gluten-free/Casein-free diet
- Movement-based Intervention
- SENSE Theatre Intervention
- Sensory Intervention Package
- Shock Therapy
- Social Behavioral Learning Strategy
- Social Cognition Intervention
- Social Thinking Intervention

There are likely many more interventions that fall into this category for which no research has been conducted or, if studies have been published, the accepted process for publishing scientific work was not followed. There are a growing number of interventions that have not yet been investigated scientifically. These would all be Unestablished Interventions. Further, any interventions for which studies were published exclusively in non-peer-reviewed journals would be Unestablished Interventions.

THERE IS ONLY ONE ESTABLISHED INTERVENTION FOR ADULTS WITH ASD...

NATIONAL AUTISM
CENTER (2015)

Research Findings for Adults (22+ Years)

Established Interventions for Adults

The only intervention to be identified as Established for individuals ages 22 years and older is Behavioral Interventions. The Behavioral Intervention category consists of applied behavior analytic interventions to increase adaptive behaviors and decrease challenging behaviors. Examples of specific strategies identified in the 17 articles supporting Behavioral Interventions are provided in the table on the following page.

Emerging Interventions for Adults

Emerging Interventions are those for which one or more studies suggest they may produce favorable outcomes. However, before we can be fully confident that the interventions are effective, additional high quality studies are needed that consistently show these interventions to be effective for individuals with ASD. Based on the available evidence, we are not yet in a position to rule out the possibility that Emerging Interventions are, in fact, not effective.

The following intervention has been identified as falling into the Emerging level of evidence:

- Vocational Training Package

Unestablished Interventions for Adults

Unestablished Interventions are those for which there is little or no evidence in the scientific literature that allows us to draw firm conclusions about their effectiveness with individuals with ASD. There is no reason to assume these interventions are effective. Further, there is no way to rule out the possibility these interventions are ineffective or harmful.

The following interventions have been identified as falling into the Unestablished level of evidence:

- Cognitive Behavioral Intervention Package
- Modeling
- Music Therapy
- Sensory Integration Package

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