




**Advocating for
Optimal
Outcomes and
Supports**

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**A little
personal
background**


Who am I and what drives
me to be an advocate?

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- ❖ Earned a Master of Divinity
- ❖ Knight of Columbus; serving my parish and community at large
- ❖ Bowling Green Swim Club Masters swimmer
- ❖ Special Olympics Assistant Coach
- ❖ Employee at Nineteen Services
- ❖ Creator of Be **BRAVE** | Be **BOLD** advocacy movement

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Workplace
discrimination
because of being
misinformed



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Defining the term Advocacy

"The action of advocating, pleading for, or supporting a cause or proposal"

-Merriam-Webster Dictionary

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But so...?

Advocacy must be put into **ACTION!**

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Step 1:

ACCEPT that I have a disability and EMBRACE IT!

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Living with a rare Developmental Disability

❖Until I was 34 years old, I believed I had Cerebral Palsy because at 18 months old the following were evident

- Delay in speech and inability to form certain words
- A weaker left arm
- I also started presenting gran mal seizures at 13 years old

❖After extensive testing at Cleveland Clinic, I learned that I really have Congenital Bilateral Perisylvian Syndrome!

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Living with a rare Developmental Disability

- ❖**Congenital** - During the stages of development prior to birth
- ❖**Bilateral** - Affects both hemispheres of the brain
- ❖**Perisylvian** - Dealing with the deep grooves and folds in the brain
- ❖**Syndrome** - (in the context of humans) - A chronic lifelong condition

Because of the symptoms, someone with CBPS had often been misdiagnosed with having Cerebral Palsy

Some Developmental Disabilities have only been recently "discovered" and little is known, despite ongoing research; CBPS which was not discovered until the early 1990's

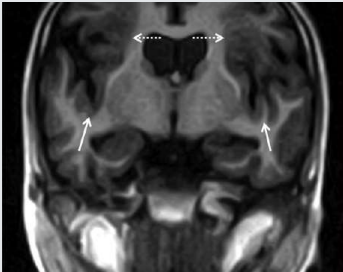
9



Step 2:
EDUCATE others!

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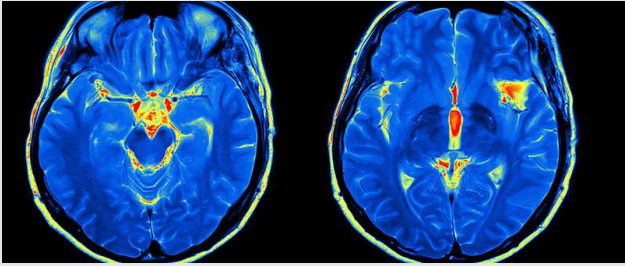
A brain affected by CBPS



©Chatur C, Balani A. Congenital bilateral perisylvian syndrome. Neurol India 2018;66:1847-9

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MRI of a brain during a seizure



https://medicinehealth.leeds.ac.uk/images/iStock_614832326

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Things to keep in mind along with seizure protocol

DON'T

- > Rush the post-ictal period
- > Badger
- > Assume activity has stopped

DO

- > Allow the post-ictal period to occur
- > Phrase yes and no questions calmly
- > Be prepared for possibly another

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Why am I able to share my story?

Intervention... I received intervention as soon as my parents were made aware that I was afflicted!

- >Occupational therapy
- >Speech therapy
- >Family intervention
- >Neighbor boy's intervention
- >Traditional classroom education setting instead of Special Education setting

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Step 3:

FIGHT for CHANGE!



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❖ People are not defined by their disability

➢ Description of diagnoses must stop – NO MORE “MR”

❖ Behaviors may not be an “issue to fix”

➢ People no longer have their authentic personality

❖ Showing compassion should never demean

➢ “Hey, give me a high five buddy!”???

❖ People with DD’s are not tasks to be done

➢ Not a Medicaid number, DODD Number, or documentation checklist



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Advocacy

Within the Team Process



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Things to consider as a Provider while in Team Meetings

THINK ABOUT THE IMPORTANT TO'S

What does the individual REALLY want? Not abstract ideas, but concrete wants.


THINK ABOUT THE IMPORTANT FOR'S

Why should the desire for an Outcome or Service happen? Happiness? Productivity? Self-worth?

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Remembering who all is part of the Team

- ❖ **THE INDIVIDUAL!**
- ❖ Service and Support Administrator/QIDP
- ❖ Guardian/Advocate
- ❖ Parent
- ❖ Providing Agencies
 - Day Program
 - Medical/Behavioral
 - ICF/Congregate DSP
 - HPC/Independent Provider/NMT



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What does Team need to do?

- ❖ Do not wait until a scheduled Team meeting or annual Team ISP evaluation!
- ❖ Speak up so the quality of life can be improved by revising the ISP mid-span.



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The 'Why' Behind It All

OISP Outcomes
Service Documentation
Compliance



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Overview of the Compliance Tool

- The 004 Compliance tool is for Agency providers (note Licensed homes)
- Over the last couple of years DODD split out a compliance tool for CB Accreditation
- There is a separate tool for ICF's and Independent providers
- The compliance tool is typically reviewed and updated every 6 mths – in April and November
- The purpose for this is to keep the tool as up to date with rule changes and compliance trends
- All DODD Reviewers are certified thru the Office of Compliance to conduct reviews

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Types of Reviews

- There are two types of reviews that can be conducted for agency (and independent) providers, they are:
 - Regular Reviews
 - Typically happen every 3 years around the time of the providers certification timeframe
 - Special Reviews
 - Can happen unannounced at any time.
 - The purpose of these reviews is typically from a series of non-compliance, complaints, MUIs – generally the local CB is involved in some capacity with these

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Layout of the Compliance Tool

1. Service Planning
2. Medication Administration
3. Behavior Support
4. Personal Funds
5. Service Delivery & Documentation
6. MUI/II
7. Personnel
8. Transportation
9. Physical Environment
10. Remote Support



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Section 5 - Service Delivery & Documentation

- Documentation (sheet) requirements
- All basic service requirements are housed here (start/stop times/frequencies/type of service, etc.)
- MAR requirements
- Goal/Outcome/Services doc
- Following the ISP
- Waiver Nursing
- ADS and Voc Hab specific requirements
 - For community rate
 - Employment reports (annually)
 - Virtual
- NMT documentation

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Outcomes, Services & The OISP 'Crosswalk'

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Required Elements for Documentation Sheets

Does service delivery documentation include the following elements?

- Date of service,
- Individual's name,
- Individual's Medicaid number,
- Provider name,
- Provider number,
- Signature or initials of person delivering the service,
- Place of service, and
- Group size?
- Type of service
- Units
- Scope
- Start/stop times

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Outcome Example

Outcome: What does the person want to accomplish and why?
 I will actively participate in planning activities so that he can be able to go back to his community.

Details to Know:
 I am very social and enjoy having opportunities to go out into the community in order to go shopping and be with other people.

Experiences: In order to accomplish the outcome, what experiences does the person need to have?

What needs to happen	How it should happen	Who is responsible	When/How often
I will pick which activities he would like to participate in while he is participating in day program.	Staff will present options of activities that he can choose from that he participates in day program.	Mr. [Redacted]	Minimum 1x/ month Monthly
I will choose activities to participate in that are of interest to him.	Staff will communicate with his house staff in order to give the activities that he would like to do.	Mr. [Redacted]	Minimum 1x/ month Monthly
I will assist with planning his yearly vacation.	Staff will communicate with his house staff in order to share activities that he would like to do and budgeting for shopping, lodging and meals in preparation for the vacation.	Mr. [Redacted]	Minimum 1x/ month until vacation is completed Monthly

Outcome/Experiences Review:
 What will progress look like/How will we know it is happening?
 Provider will note progress and report to SSA at a minimum of 1x/ year.
 Provider will note progress and report to SSA at a minimum of 1x/ year.

Important and Relevant History:

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Outcome Documentation

Individual Name: John Smith, Span Date: 1/1/2024-12/31/2024, Provider: #1 Provider, Inc.

Outcome # 1

Details to know:
 John will actively participate in planning activities so that he can be able to go back to his community.
 John is very social and enjoys having opportunities to go out into the community in order to go shopping and be with other people.

Experience #	What needs to happen	How it should happen	When/How often
#1	John will pick which activities he would like to participate in while he is participating in day program.	Staff will present options of which activities are available for him that he can participate in day program.	Minimum 1x/month Monthly
#2	John will choose activities to participate in that are of interest to him.	John will communicate with his house staff in order to give the activities that he would like to do.	Minimum 1x/month Monthly
#3	John will assist with planning his yearly vacation.	John will communicate with his house staff in order to share activities that he would like to do and budgeting for shopping, lodging and meals in preparation for the vacation.	Minimum 1x/month until vacation is completed Monthly

Month/Year	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	

Date	Outcome/ Experience #	What happened? What was learned? What worked well/did not work well? What did the person like/dislike?	Initial

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Services & Supports Example

Services and Supports
Paid Supports:

Who is Responsible	Assessment Area	Service Name	Scope of Service: What support looks like:	How often/ How Much?	Begin Date/End Date:	Funding Source:
Community Living	Homemaker Personal Care	Staff will assist with planning vacations and trips for his 21 year old son.		Other - span 1-6x's per span	September 15, 2023 - September 14, 2024	HCBS - Individual Options Waiver
Community Living	Homemaker Personal Care (HPC) Transportation	Staff will be transported by his staff to events and appointments.		Monthly 200 miles	September 15, 2023 - September 14, 2024	HCBS - Individual Options Waiver
Community Living	Homemaker Personal Care	Staff will assist him in ways to sale his car work online and in person.		Other - Per span 1-6x's per span	September 15, 2023 - September 14, 2024	HCBS - Individual Options Waiver

Does this person meet criteria for any add-on?

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Service & Support Documentation

Hennepin Adult Residential Care (HARC) - SERVICE DELIVERY DOCUMENTATION FORM - County Authority

INDIVIDUAL'S NAME: Jan-Dan PROVIDER NAME: ELIZABETH, INC.
 PLACE OF SERVICE DELIVERY: 11000000000000000000 PROVIDER ID NUMBER: 00000000000000000000
 INDIVIDUAL'S MEDICAL & CLINICAL SERVICE MONTH: January 2024 ISP Open VISA 10/1/2024

Time	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31		
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Sample Key (ISP Follow-up service delivered) F = Full service T = Not Delivered

Sample HPC Documentation, September 2023

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When services are provided that are not in the ISP

Provider feels they are acting in the best interest of the individual

Provider is wanting to give the individual more opportunities

Provider feels the individual deserves more

Provider doesn't see negative impact

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How to Avoid Compliance Issues

Train staff on the ISP:

- Specific details regarding health & welfare, risk factors, important to & for


When services deviate from the ISP and pose a risk to the individual:

- Generally, an incident report would be generated

Speak up:

- Initiate conversation with the SSA for a team meeting and possible ISP revision

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THANKS FOR JOINING US TODAY!

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