DISABILITY VOICES UNITED

Prepare for Your Medical Care!

Documents to prepare patients with disabilities for medical visits

Print and keep these documents in a secure place. Fill out any blank forms with relevant information. In the event of a medical emergency or even a routine visit, we encourage you to bring them with you. The information may improve your interactions with healthcare providers.

Tip Sheet for Providers to Support Patients with Intellectual and Developmental Disabilities

The SUPPORT Tip Sheet is a one-page guide to inform healthcare providers on how they can support and accommodate patients with intellectual and developmental disabilities according to their preferences. It includes specific recommendations, identified by self-advocates and family members, to support patients who use augmentative and alternative communication (AAC).

Healthcare Passport

A healthcare passport tells providers about a patient's unique preferences, needs, and ways of communication in medical situations. It also includes their medical history, allergies, and current medications.

Plain Language Durable Healthcare Power of Attorney

A Durable Healthcare Power of Attorney allows an individual to choose a supporter, called an agent, to help them understand and make decisions for situations in healthcare. The agent may help make all or only certain health care decisions according to the person's expressed wishes. The agent also helps with obtaining informed consent.

Plain Language HIPAA Authorization Form

HIPAA, the Health Insurance Portability and Accountability Act, is a law that protects private medical information. With a HIPAA Authorization Form, a person can give a supporter the right to see their private medical information and discuss their medical care without the person in attendance.

Sample Pain Chart, Picture Board, and Letter Boards

For patients who use augmentative and alternative communication (AAC), we have attached a few sample communication boards that may support communication if customized devices are unavailable. We encourage you to search for assistive visuals that meet your individualized needs.

Contact Information for Supporters

This plain language contact sheet lists up to three supporters, their relationship to the patient, and their contact information in case of emergency.

California All Facilities Letter

The California All Facilities Letter authorizes the presence of a support person during the COVID-19 pandemic for patients with physical, intellectual, and/or developmental disabilities, and patients with cognitive impairments. Most healthcare providers are informed about this update to visitor guidelines, but we recommend bringing this document with you in case any issues arise.

Supported Decision-Making Agreement

A Supported Decision-Making (SDM) Agreement identifies chosen supporters in the areas where a person may want assistance, such as in health care decision-making. Uniquely tailored to the person, the SDM Agreement can be attached to legal documents, like powers of attorney, advanced medical directives and HIPAA authorization forms.

Personal Documents

We recommend that you also include a photocopy of the front and back of all insurance cards, identification cards, and driver's licenses. In addition, include any other personal documents that are critical to your care. For instance, you may want to add a mental health advance directive or living will.

SUPPORT Patients with Intellectual and Developmental Disabilities in Emergency, Hospital, & Outpatient Care

SEEK INFORMATION

Ask about patient preferences for communication and care.* Many patients with Intellectual and Developmental Disabilities may converse using non-verbal gestures, or augmentative and alternative communication.

USE SUPPORTERS CHOSEN BY THE PATIENT**

Supporters can help obtain informed consent, discuss choices for care, and assist with the patient's decision-making. Chosen supporters may not always be present with the patient.

PRESUME COMPETENCE

Speak directly to the patient using a normal voice and plain language. Do not force eye contact—patients are still listening. Always ask patients or supporters if clarification is needed—do not make assumptions.

PROVIDE ACCOMMODATIONS

Be patient when time is needed to understand or use communication devices. Meet the patient where they are comfortable (e.g. some may sit on the floor or stay in the hallway). Provide a quiet, private environment with minimal distractions, when possible.

OBTAIN PERMISSION

Ask before making physical contact with patients—some do not like being touched. Explain what you are going to do before doing it, and check for understanding.

ROLE-PLAY WITH VISUALS

Use role-play with supporters to provide examples of treatment. Demonstrate on pictures, dolls, or the supporter.

TRAIN OTHERS

Share notes about accommodations, communication needs, and helpful strategies with the care team. Prepare new providers during shift changes. Ensure that patients and supporters understand discharge instructions.

*Patients may provide information in a health passport, one-page profile, or communication dictionary.

**Many states have issued guidance requiring health facilities to allow one support person for a patient with intellectual or developmental disabilities during the Covid-19 crisis.

This tip sheet was written by the self-advocates and family members of Disability Voices United, a California-based disability rights organization: disabilityvoicesunited.org.

DISABILITY VOICES UNITED

My Health Passport

If you are a *health care professional* who will be helping me,

PLEASE READ THIS

***before* you try to help me with my care or treatment.**

My full name is: _____

I like to be called: _____

Date of birth: ___/___/_____

My primary care physician: _____

Physician's phone number: _____

Attach your picture here!

This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

Please keep this with my other notes, and where it may be easily referenced.

My signature: _____ Date completed: ___/___/_____

You can talk to this person about my health: _____

Phone number: _____ Relationship: _____

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/ support is needed)

_____

_____

_____

_____

My brief medical history: (include other conditions (e.g. visual impairment, hearing impairment, diabetes, epilepsy) past operations, illnesses, and other medical issues)

My current medications are:

-
-
-
-
-
-

When I take my medication, I prefer to take it: (e.g. with water, with food)

I am allergic to: (list medications or foods, e.g. penicillin, peanuts)

If I am in pain, I show it by: (also note if I have a low/high pain tolerance)

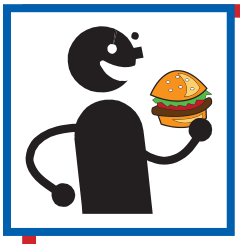
If I get upset or distressed, the best way you can help is by: (e.g. play my favorite music)

How I cope with medical procedures: (e.g. how I usually react to injections, IV's, physical examinations, x-rays, oxygen therapy—also note procedures never experienced before or in recent years)

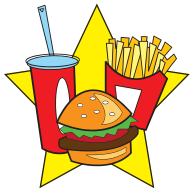
My mobility needs are: (e.g. whether I can transfer independently, devices I use, pressure relief needed)

When getting washed and dressed, you may assist me by:

When drinking, you may assist me by:



When eating, you may assist me by:

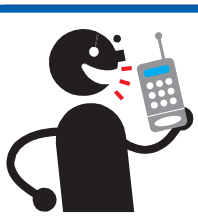


My favorite foods and drinks are:

I do not like to eat or drink the following:

I am very sensitive to: (specific sights, sounds, odors, textures/fabric, etc. that I really dislike, e.g. fluorescent lights, thunderstorms, bleach, air freshener)

Things I like to do that will help pass the time:



How to make future/follow-up appointments easier for me:

(e.g. give me the first/last appointment of the day, allow extra time for the appointment, let me visit before my appointment, give information to my caregiver, etc.)

USF UNIVERSITY OF SOUTH FLORIDA
COLLEGE OF BEHAVIORAL & COMMUNITY SCIENCES

FCIC Florida Center for Inclusive Communities

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For further information contact Dr. Elizabeth Perkins at eperkins@usf.edu.

treat me right!
www.supportforliving.org.uk

This passport was adapted with permission from the "*About Me—My Hospital Passport*" from the Treat Me Right campaign.

Durable Health Care Power of Attorney

(Plain Language Durable Power of Attorney for Health Care, adapted from the ACLU Disability Rights Program, adapted from CA Probate Code § 4701)

Help Making Medical Choices

My name is _____

My birthday is _____

My address is _____

_____

My agents

If I cannot make health choices for myself, I want someone to make choices for me. The person who will make these choices for me is called my agent.

My agents cannot be my doctor or someone who works in the hospital or a group home where I live.

My agent will only make choices for me if I cannot say what I want.

My agent's name is _____

Their phone number is: _____

Their address is _____

_____

If I need help and my agent is away or cannot help me, another person can help me. This person is a back-up agent.

Backup agent's name: _____

Their phone number is: _____

Their address is _____

_____

When my agent can help me:

- My agent can make choices for me if my doctor says that I cannot make my own choices.
- If the doctor thinks I cannot make my own choices, he or she must explain why in writing.

What my agent can do:

(Select everything you want the agent to be able to do for you.)

☐ My agent can make choices for me if I cannot make my own choices:

☐ My agent can choose what medicine I will get.

☐ My agent can see the notes doctors and nurses write about me.

☐ My agent can choose when I should stay in the hospital.

When my agent is making choices for me, my agent must do what I want. I will talk to my agent about what is important to me.

If my agent does not know what I want, he or she must make choices that will help me the most or talk to other people who love me and care about me.

I know that I have to sign this form with two people who are witnesses. My witnesses will sign on the next page.

I know that I can stop or change this agreement at any time.

My signature: _____

Today's date is: _____

THIS DOCUMENT MUST SIGNED BY TWO WITNESSES.

Certain individuals cannot serve as witnesses, as set forth in the following witness statements:

I declare under penalty of perjury under the laws of california

(1) That the individual who signed or acknowledged this Power of Attorney for Health Care is personally known to me, or that the individual's identity was proven to me by convincing evidence.

(2) That the individual signed or acknowledged this Power of Attorney for Health Care in my presence,

(3) That the individual appears to be of sound mind and under no duress, fraud, or undue influence,

(4) That I am not a person appointed as agent by this Power of Attorney for Health Care, and

(5) That I am not the individual's health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

First Witness

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

Second Witness

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

ONE OF THE PRECEDING WITNESSES ALSO MUST SIGN THE FOLLOWING DECLARATION:

I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operations of law.

Signature: _____

Date: _____

IF THE PERSON MAKING THIS POWER OF ATTORNEY IS UNABLE TO WRITE, BOTH WITNESSES MUST SIGN THE FOLLOWING DECLARATION:

_____, being unable to write, made his/her mark in our presence and requested the first of the undersigned to write his/her name, which he/she did, and we now subscribe our names as witnesses thereto.

Signature of Witness #1: _____

Signature of Witness #1: _____

IF THE PERSON MAKING THIS POWER OF ATTORNEY LIVES IN A NURSING HOME, THIS SECTION MUST BE COMPLETED BY THE PATIENT ADVOCATE OR OMBUDSMAN:

I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by Section 4675 of the Probate Code:

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

HIPAA Authorization

(Plain Language HIPAA Authorization for Disclosure of Health Information, adapted from the ACLU)

Sharing My Medical Information

My name is _____

My doctor's office
or hospital is called: _____

It is in this city: _____

My doctors and nurses write notes about me. They also write about the tests they do. These notes are called records. I want to share my medical records.

The person who can see my records is:

Name: _____

Address: _____

Phone number: _____

Email address: _____

This person can see: *(Select one)*

☐ All of my medical records.

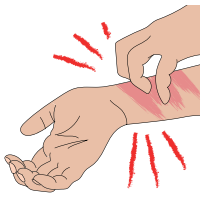
☐ Only some records. The records this person can see are:
(Write what records you want the person to see.)

_____

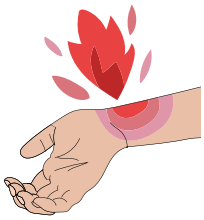
_____

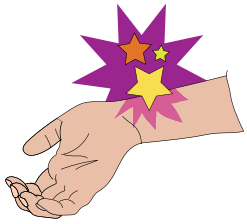
Pain Chart

Pain Level
10
9
8
7
6
5
4
3
2
1

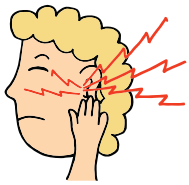

itches


hurts


burns

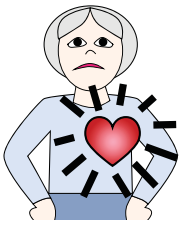

stings

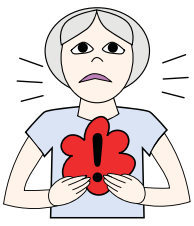

headache


ear ache


sore throat


back pain


heart pounding


upset stomach

question	afraid	sad	funny	happy	hurt	sick	mad	body	good
time/now	I/me/my	want	make	ride	have	thing	gone	together	more
late/later	here	home/place	eat/drink	work	open	get	all	same	thought/idea
early/earlier	it	can/do	go	help	close	put	in	different	on
wait	you/your	like/love	turn	play	read	wash/clean	out	up	off
yes	maybe	no	to	buy/pay	tell/say	listen	watch/see	down	stop
COVID-19	medicine	doctor/nurse	testing	headache	cough	breathe	away	hot	bathroom

TECH OWL
TECHNOLOGY FOR OUR WHOLE LIVES

800-204-7428 V
866-268-0579 TTY
TechOWL@temple.edu

Temple University
College of Education
Institute on Disabilities

Q	W	E	R	T	Y	U	I	O	P

A	S	D	F	G	H	J	K	L

Z	X	C	V	B	N	M

1	2	3	4	5	6	7	8	9	0

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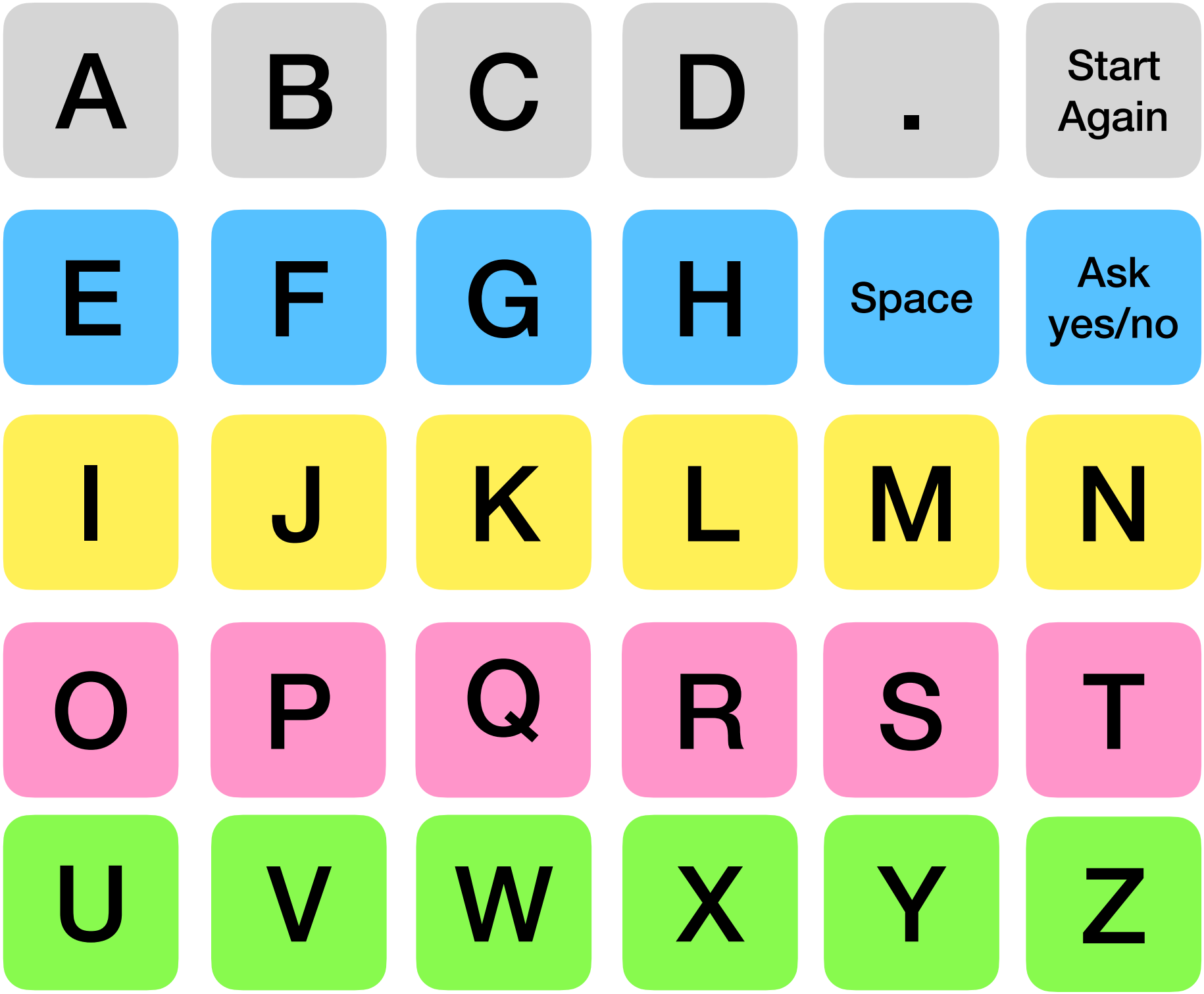
TechOWLpa.org

Temple University
College of Education
Institute on Disabilities

disabilities.temple.edu

A		B		C		D		SPACE		END OF MESSAGE		I'M HAVING TROUBLE BREATHING.							
E		F		G		H		START OVER		I DON'T KNOW		WHAT WILL HAPPEN NEXT?							
I		J		K		L		M		N		WILL I GET BETTER?							
O		P		Qu		R		S		T		WHAT ARE MY OPTIONS?							
U		V		W		X		Y		Z		I WANT TO DISCUSS MY OPTIONS.							
1	2	3	4	5	6	7	8	9	Ø	YES 	NO 	I HAVE ANOTHER QUESTION.							


A
B
C
D
.
Start Again
E
F
G
H
Space
Ask yes/no
I
J
K
L
M
N
O
P
Q
R
S
T
U
V
W
X
Y
Z

Communication Board

This communication board is to be used with individuals who do not have the ability to point and their eye use is poor.

You are setting up a system where you, the Communication Partner (CP), ask a question to organize the communication and the communicator must be able to respond with an “affirmative” or “negative”

You first list through the colors. The communicator will need to confirm “affirmative/yes” when you say the color of the intended letter.

“ gray” “blue” “yellow” “pink” “green”

Once the row is determined the CP lists from left to right the letters/message in that row. The communicator will confirm “affirmative/yes” on their desired letter/message.

Repeat this sequence until the message is complete.

Emergency Contacts

This is a list of the people that support me. If I require assistance, please contact:

Contact Information			
Supporter #1			
Name:			
Relationship:			
Home Phone:		Cellphone:	
Work Phone:		Fax No.:	
Supporter #2			
Name:			
Relationship:			
Home Phone:		Cellphone:	
Work Phone:		Fax No.:	
Supporter #3			
Name:			
Relationship:			
Home Phone:		Cellphone:	
Work Phone:		Fax No.:	

Supported Decision-Making Agreement

Adapted from the ACLU Disability Rights Program Supported Decision-Making Agreement
and edited by Disability Rights Education and Defense Fund

This paper is called a "supported decision-making agreement." A supporter is someone who helps the person with a disability. This paper says how the supporters will help the person with a disability. The person with a disability and their supporters need to understand and sign this paper for it to be used. There are different ways the person with a disability can understand this paper. The person with a disability can read this paper by themselves. Someone else can also read the paper out loud to them. The person with a disability can read the paper using a sign language interpreter. The person with a disability can use other ways to understand the paper. The way of communicating and understanding should be a way that the person with a disability needs and likes. Two witnesses or a notary must be there when everyone signs the paper.

My name is: _____

I want to have people I trust help me make decisions. The people who will help me are called supporters. I know that I can rely on my supporters to offer information and discuss options and choices with me.

I make decisions about my life, with support.

This agreement can be changed at any time. I can change it by crossing out words and writing my initials next to the changes. Or I can change it by writing new information on another piece of paper, signing that paper, and attaching it to this agreement.

I will look over this document with my supporters **every two years** to make sure it is still what I want and to make any changes if I wish. I can also end this agreement if I want to. I can end this agreement by writing that I want the agreement to end. I can also end this agreement by saying that I want to stop using this agreement.

If my supporter acts against my wishes or hurts me, I have a right to report them under the Elder Abuse and Dependent Adult Civil Protection Act.

These are my supporters:
(If you have more than three, just list the first three)

Supporter's name: _____

Supporter's name: _____

Supporter's name: _____

This is my monitor:

Monitor's name: _____

My supporters can talk to each other about me: *(Check one box:)*

☐ Only when I say it is OK

☐ Whenever they want

Meeting with my support team

I can talk to my supporters anytime I want to. But my whole team might meet together sometimes to talk about how we are doing. (Check one box:)

☐ I want my entire support team to meet _____
(Write how often your whole team will meet, like "every week" or "every two months" or "before every IPP meeting".)

☐ I do not want my support team to meet on a regular basis.

Special directions and other information

I can write any other information or special directions here. I can also write more information on a separate piece of paper and attach it to this agreement. For instance, I may communicate here through the use of a visual system or format unique to me.

_____

_____

I am signing this supported decision-making agreement because I want people to help me make choices. No one is making me sign this agreement.
I know that I can change this agreement at any time.

This supported decision-making agreement starts right now and will continue until the agreement is stopped by me or my supporters.

My printed name: _____

My address: _____

My phone number: _____

My email address: _____

Wait to sign your name until a notary or two witnesses are there to watch you sign.

My signature: _____

Today's date is: _____

My Supporter

(This page can be duplicated for as many supporters as you want to sign the agreement)

Supporter's name: _____

Their address: _____

Their phone number: _____

Their email address: _____

I want this person to help me with these choices:
(check as many boxes as you want)

Personal Care:

- ☐ Making choices about food
- ☐ Making choices about clothing
- ☐ Taking care of personal hygiene (showering, bathing)
- ☐ Remembering to take medicine

Staying Safe:

- ☐ Making safe choices around the house (for example, fire alarms, turning stove off)
- ☐ Understanding and getting help if I am being treated badly (abused)
- ☐ Making choices about alcohol and drugs

Home, Work, and Friends:

- ☐ Making choices about where I live and who I live with
- ☐ Making choices about where to work or what activities to go to
- ☐ Choosing what to do in my free time
- ☐ Finding support services, hiring and firing staff

Health Choices:

- ☐ Choosing when to go to the doctor or dentist
- ☐ Making medical choices for everyday things (for example, check-up, small injury, taking aspirin)
- ☐ Making choices about major medical care (for example, big injuries, surgery)
- ☐ Making choices about medical care in emergencies

Partners:

- ☐ Making choices about dating, sex, birth control, and pregnancy
- ☐ Making choices about marriage

Money:

- ☐ Paying the bills on time and keeping a budget
- ☐ Keeping track of my money and making sure no one steals my money
- ☐ Making big decisions about money (for example, opening a bank account, signing a lease)

Other:

(Write any other areas where you want support from this person):

- ☐ _____
- ☐ _____
- ☐ _____

My Monitor

If I want someone to help me make choices about money, I can also choose someone to make sure my supporters are being honest and using good judgment in helping me with my money. This person is called a monitor. The monitor should not be a supporter.

I do not have to write anything here if I am not asking anyone to help me with money. I do not have to write anything here if I do not want a monitor.

Monitor's name: _____

Their address: _____

Their phone number: _____

Their email address: _____

Consent of Supporter

I, _____, (name of supporter)

consent to act as _____'s (name of decider) supporter under this agreement.

I understand that my job as a supporter is to honor and express their wishes. I will not encourage the disabled person to make decisions that solely benefit myself. My support might include giving this person information in a way he/she can understand; discussing pros and cons of decisions; and helping this person communicate their choice.

I know that I may not make decisions for this person. I agree to support this person's decisions to the best of my ability, honestly, and in good faith.

I have read the areas that the decider checked and wrote above under My Supporter. I agree to support the decider in those areas.

I certify that I meet the requirements of serving as a supporter in the State of California. I would not be qualified to serve as a supporter if any of the following were true:

(1) The adult with a disability previously made, or makes, an allegation against me under the Elder Abuse and Dependent Adult Civil Protection Act.

(2) The adult with a disability has obtained, or obtains, an order of protection from abuse against me.

(3) I am the subject of a civil or criminal order prohibiting contact with the adult with the disability or I have been subject to a restraining order with respect to the adult with a disability.

(4) I have been removed as the conservator of the adult with a disability, based upon a finding that I did not act in the conservatee's best interest.

(5) I have been found criminally, civilly, or administratively liable for abuse, neglect, mistreatment, coercion, or fraud.

Signature of supporter: _____

Date: _____

Consent of Monitor

I, _____, consent

to act as a monitor for _____'s financial decisions under this agreement. I agree to review the financial records of the person with a disability when provided by the supporters at least every quarter. I agree to make reasonable efforts to ensure that the supporters under this agreement are acting honestly, in good faith, and in accordance with the choices of the person with a disability. If I suspect financial abuse, misuse of funds, bad faith, or failure to comply with the decisions of the person with a disability, I will require the supporters to explain their actions. If the supporter fails to provide this information or if I continue to have reason to believe that the supporter is abusing or failing to comply with the wishes of the person with a disability, I will promptly inform Adult Protective Services.

Signature of monitor: _____

Date: _____

Seal of notary:

My commission expires: _____

Signature of Notary or Witnesses

This document must be read in front of either a notary or two witnesses.
Witnesses may not include supporters, monitor, or the person with a disability.

Signature of Notary

State of California, County of _____,

On _____ *(date),* before me _____ *(name of person with a disability)*, personally appeared, along with _____ *(names of all signers)*, who proved to me on the basis of satisfactory evidence of identification to be the people whose names are signed on this Supported Decision-Making agreement.

The text of this agreement was communicated to the person with a disability in my presence by:

☐ Reading the full agreement aloud

☐ Otherwise communicating the agreement to the person with a disability
(describe communication used): _____

Seal of notary:

My commission expires: _____

or

Signature of Witnesses

I, _____, swear that this Supported Decision-Making Agreement was communicated in my presence to the person with a disability.

Signature: _____ Date: _____

I, _____, swear that this Supported Decision-Making Agreement was communicated in my presence to the person with a disability.

Signature: _____ Date: _____

DISABILITY VOICES UNITED

Together We Will Be Heard

We need your voice.

We are stronger together than we are alone. By supporting Disability Voices United, you send a clear message that you, too, want to improve regional centers and education — and you want major changes now for people with developmental disabilities.

To learn more about our work and opportunities to get involved, visit

DisabilityVoicesUnited.org

Disability Voices United

@DVoicesUnited

530-JOINDVU (530-564-6388)
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