

## **Hello!**

\*Si usted prefiere completar esta encuesta en español, por favor, sepa que hay una edición en español disponible.

The Hand in Hand Team is sharing this survey as a quality improvement project to investigate home health nursing needs and home health care nursing access. We are very grateful to you for your generous and thoughtful time to complete this 20 minute survey.

Please fill out this form once per child – if you have multiple children for whom this form applies, please fill out a separate form per child.

### **Demographics**

Age of child: \_\_\_ years or \_\_\_\_\_months

Gender of child:

Male or  Female

Nutrition technologies (please select all that apply)

- Feeds by mouth
- NG tube (tube in nose)
- G tube/GJ tube (tube in stomach)

Respiratory technologies (please select all that apply)

- Room Air
  - Nasal cannula oxygen
  - BiPAP
  - CPAP
  - Tracheostomy without ventilator
  - Tracheostomy with ventilator
- (If on ventilator only part of day, choose both)*

Zip code of residence: \_\_\_\_\_

Primary Language Spoke at Home:

- English
- Spanish
- Other: \_\_\_\_\_

Type of current insurance (select all that apply):

- Private insurance company
- Waivers
- Medicaid insurance company
- Other: \_\_\_\_\_

Number of other children in home: \_\_\_\_ children

Number of adults in the home: \_\_\_\_ adults

Marital status:

- Single
- Separated
- Divorced
- Cohabiting
- Married
- Other

Custody arrangement:

- Does not apply; one family unit
- Sole Maternal Physical Custody
- Sole Paternal Physical Custody
- Joint custody (if so, describe days of month with each parental figure):

---

---

---

---

---

For each adult in the home, please complete employment table below:

Unemployed	Employed within the home	Employed outside the home
Adult 1 <input type="checkbox"/> Yes <input type="checkbox"/> No	____ hours per week	____ hours per week
Adult 2 <input type="checkbox"/> Yes <input type="checkbox"/> No	____ hours per week	____ hours per week

## Home Care Hours

How many hours per week do the adults in your home provide hands-on “nursing-type” care for your child?

\_\_\_\_ hours

Approximately how many hours per week do the adults in your home not work outside of the home in order to provide this hands-on "nursing-type" care for your child?

\_\_\_\_ hours

How many hours per week do the adults in your home receive waiver fund coverage (if any)?

\_\_\_\_ hours

If your child does not currently have home health services and you believe your child does not have home health care needs, please designate that here:

\_\_\_\_ *Does not apply (This then ends survey if you feel “does not apply”)*

Please complete this table to show how many hours per WEEK is your child approved for in-home nursing as compared to how many hours per WEEK your child actually receives:

Nursing type	Approved for (hours)	Actually receives
Full nursing care day hours	___ RN	___ RN
	___ LPN	___ LPN
	___ MA	___ MA
Full nursing care night hours	___ RN	___ RN
	___ LPN	___ LPN
	___ MA	___ MA
Respite hours	___ RN	___ RN
	___ LPN	___ LPN
	___ MA	___ MA
School nursing coverage hours	___ RN	___ RN
	___ LPN	___ LPN
	___ MA	___ MA

**If** more than one adult has custody, please list home health hours approved and received for each custodial parent:

Parent 1: \_\_\_ nursing hours approved for that home; \_\_\_ hours received in that home

Parent 2: \_\_\_ nursing hours approved for that home; \_\_\_ hours received in that home

If there is a difference in the number of nursing hours allowed versus the number of nursing hours received, is that difference because:

- I don't perceive a need for that many hours for my child
- I don't want to have that many nursing hours for my child
- I perceive a need and I want to utilize more nursing hours but I am not able to access nursing coverage

## Home Nurse Search

How many different staff members care for your child:

Home health company nurses: \_\_\_\_ nurses per month

Private duty nurses: \_\_\_\_ nurses per month

Have your nursing hours ever been fully staffed for the allowed number of nursing hours?

Yes

No

If Yes, what year was it when you were fully staffed? \_\_\_\_\_

What zip code did you live in when fully staffed with nurses? \_\_\_\_\_

For how many months were you fully staffed with nurses? \_\_\_\_\_

If you have searched for nursing coverage, please share how long have you been looking nursing coverage?

\_\_\_\_ months

If you have searched for nursing coverage, please share how many total hours you have invested (in the past 12 months) in this search for nursing coverage? Please include hours you have invested writing letters; gathering medical records; making phone calls; etc, etc.

\_\_\_\_ hours

In this past month alone, how many hours have you spent managing insurance paperwork/phone calls regarding nursing needs for your child: \_\_\_\_ hours

Types of searches (check all that apply)

Phone calls

On-line

Flyers

Newspaper

Word-of-mouth

Other: \_\_\_\_\_

## Care Settings

Where does your child receive care during the week (mark all that apply day or night):

Setting	Day	Night
Own Home		
Relative's Home		
Babysitter's Home		
Day Care		
Respite Center		
Skilled care facility		
Rehabilitation Center		
School		
Other: _____		

If your child has multiple care settings, is the number of care settings based on:

- Because I believe each of these care settings is important for my child's development/wellness
- Because I have to piece together care settings to get adequate nursing coverage

### Delay to Discharge

In your child's lifetime, has your child's hospital discharge ever been delayed due to not having nursing coverage outside of hospital setting?  Yes or  No

If Yes;

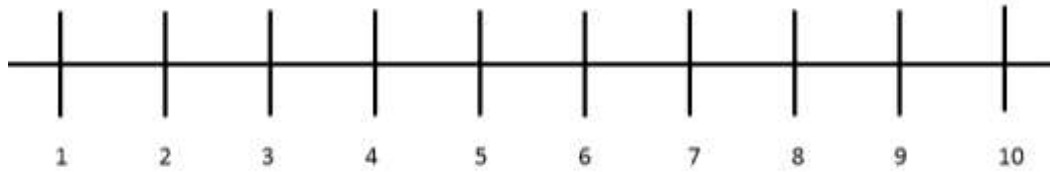
Number of times discharge has been delayed after hospitalization due to lack of nursing coverage:  
\_\_\_\_\_ hospital discharges

Estimated average number of days of delay per delay: \_\_\_\_\_ days per hospital discharge

**Psychosocial Impact:**

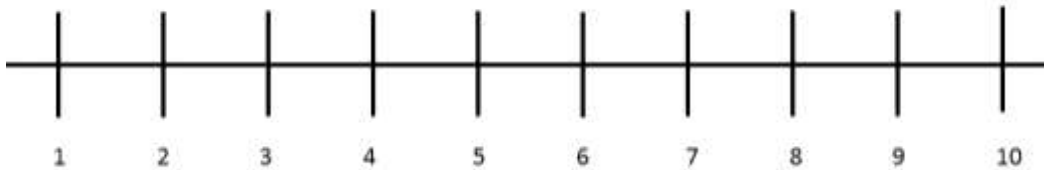
(Use scale 1-10 here with 1 being mild stress and 10 being severe stress)

In this past month alone, how would you rank your personal overall stress level regarding home health

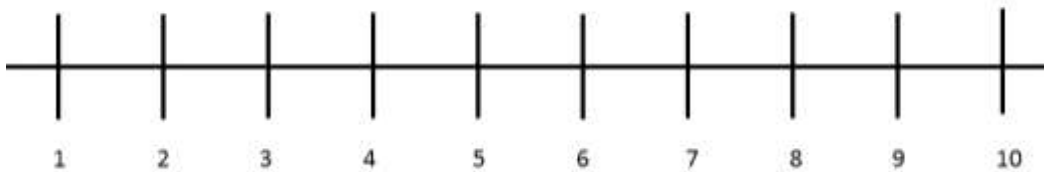


nurse access

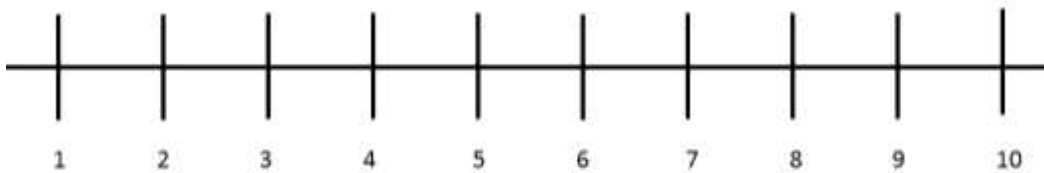
In this past month alone, how would you rank your stress level regarding ability to focus on parenting your other children based on home health nurse access?



In this past month alone, how would you rank your stress level regarding adult couple unity (togetherness in relationship whether dating or marriage) based on home health nurse access?



In this past month alone, how would you rank your stress level regarding your own work/employment ability based on home health nurse access?



**Thank you**

Thank you, sincerely, for your time and thoughtfulness in completing this survey!