Hello!

*Si usted prefiere completar esta encuesta en español, por favor, sepá 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
- Cohabitating
- 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:

<table>
<thead>
<tr>
<th>Unemployed</th>
<th>Employed within the home</th>
<th>Employed outside the home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>__ hours per week</td>
<td>___ hours per week</td>
</tr>
<tr>
<td>Adult 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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:

<table>
<thead>
<tr>
<th>Nursing type</th>
<th>Approved for (hours)</th>
<th>Actually receives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full nursing care day hours</td>
<td>___ RN</td>
<td>___ RN</td>
</tr>
<tr>
<td></td>
<td>___ LPN</td>
<td>___ LPN</td>
</tr>
<tr>
<td></td>
<td>___ MA</td>
<td>___ MA</td>
</tr>
<tr>
<td>Full nursing care night hours</td>
<td>___ RN</td>
<td>___ RN</td>
</tr>
<tr>
<td></td>
<td>___ LPN</td>
<td>___ LPN</td>
</tr>
<tr>
<td></td>
<td>___ MA</td>
<td>___ MA</td>
</tr>
<tr>
<td>Respite hours</td>
<td>___ RN</td>
<td>___ RN</td>
</tr>
<tr>
<td></td>
<td>___ LPN</td>
<td>___ LPN</td>
</tr>
<tr>
<td></td>
<td>___ MA</td>
<td>___ MA</td>
</tr>
<tr>
<td>School nursing coverage hours</td>
<td>___ RN</td>
<td>___ RN</td>
</tr>
<tr>
<td></td>
<td>___ LPN</td>
<td>___ LPN</td>
</tr>
<tr>
<td></td>
<td>___ MA</td>
<td>___ MA</td>
</tr>
</tbody>
</table>

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):

<table>
<thead>
<tr>
<th>Setting</th>
<th>Day</th>
<th>Night</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative’s Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Babysitter’s Home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respite Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skilled care facility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehabilitation Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: _________________</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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!