



Supporting Choice and Control

Michael Smull

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CMS (in the new final rule) expects that both choice and control are present

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At its core the rule asks us to support people in making informed choices about:



1. Who provides the services and supports
2. Where the person lives
3. Who they live with
4. What they do with their time
5. What they do with their resources

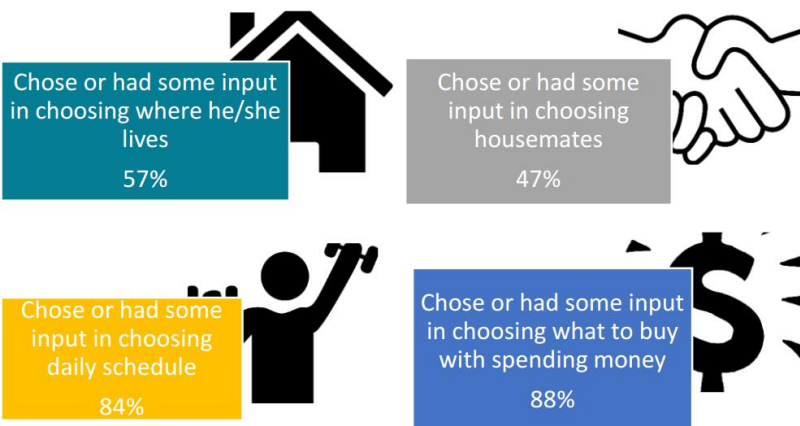
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What does NCI tell us?



Choice, Decision-making and control

Adjusted variables



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How are we responding to the 11% who don't like where they live?



Satisfaction:

Percentage of respondents who report that...

They like where they live -- 89%

They like where they work in a paid community job -- 92%

Services are helping them to live a good life -- 91%

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We all need choice to



- Have purpose and meaning, to be fulfilled
- Develop and maintain relationships
- Live in supportive environments that reflect our culture
- Manage our day to day lives

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Control



- Choice without control is a road to depression (or aggression). Without control, choice is just a list of preferences.

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The Challenge Of Choice



It seems simple –

- Everyone has preferences, likes and dislikes, things they want to be present or absent

So just

- Ask people what they want

Then

- Help them get it

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But...



- Questions about how you want to live require exploration and reflection. If you have never been asked they are hard to answer
- You may need to try new things to determine what you want
- If you communicate differently, we need to listen differently
- Past trauma impacts expressed choices
- What you want may present a risk we should not support

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And...



- Informed choice assumes
 - You know what you want
 - You know what is possible
 - What is possible includes what is desirable
 - You know about any “trade-offs” (e.g. getting this precludes having that)

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The Quality Of Choice Versus The Quantity



- Quantity doesn't matter if none are desirable
 - Taking a vegetarian to a butcher shop
- Where what someone wants doesn't exist we may be able to develop it
 - But developing new services takes time

Too many choices can be overwhelming



- “...As the number of choices grows..., the negatives escalate until we become overloaded. At this point, choice no longer liberates but debilitates.”
 - The Paradox of Choice, Barry Schwartz (pg2)

Culture and choice architecture



- We see (and process) choice thru the lens of our culture
 - Those that support choice are challenged to understand and honor culture while mediating any conflicts that arise
- How choice is presented influences the choices that are made

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Where The Person Has Others That Make Decisions



- Remember everyone wants to have control over what matters to them
- We are to use “substituted judgement” and “supported decision making”
 - We are to ask what would the person want and honor their wishes while accounting for issues of health and safety

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Choice has Boundaries for Everyone

- Imposed by society
 - Laws
 - Expectations/values
- My values
 - What is and is not OK for me and those I trust
- Tradeoffs - One choice creates boundaries on other choices
 - My relationships
 - The work I do
 - Where I live
- Resource Driven
 - Financial – how much time or money I have available
- Risk involved

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Practices



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Ralph and the seatbelt



- Sometimes what is expressed as choice is actually an effort to solve a problem

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The power of “bad” choices



- We learn by making choices and experiencing the consequences – good and bad
- We plan our future choices based on our past experiences
- To learn, we have to be able to make “bad” choices as well as good

But

- The outcome should be learning – not trauma or harm

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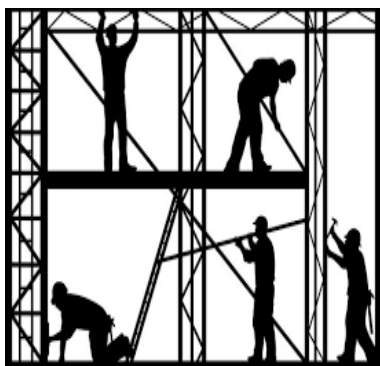
We need a frame for thinking about choice



- Frames are both windows on the world and lenses that bring the world into focus
- Frames are also tools for action and every tool has its strengths and limitations

Bolman and Deal
Reframing Organizations

The Core Concept of Person Centered Thinking



“Important To”
“Important For”
&
“The Balance Between”
Provide the framework
to help us look and act
in a different way

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It begins with learning how people want to live their life: What's Important **TO**

What is important **to** a person includes what results in feeling satisfied, content, comforted, fulfilled, and happy.

- Relationships (People to be with)
- Status and control (valued role)
- Rituals & routines (cultural and personal)
- Rhythm or pace of life
- Things to do and places to go (something to look forward to)
- Things to have



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Within that context, Important **FOR** is addressed



What others see as necessary to help the person

- Be valued (social rules, laws)
- Be a contributing member of their community (citizenship)

Issues of health

- Prevention of illness
- Treatment of illness/medical conditions
- Promotion of wellness (diet, exercise, sobriety)

Issues of safety

- Environment
- Well being (physical and emotional)
- Free from fear (threats, abuse)



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Good person centered planning that is well implemented eliminates many behavioral risks and diminishes risk, especially when linked with positive interventions

But

Those who plan and train must avoid the trap of “either/or” that is: **happy or safe.**

A Good person centered plan assures
BOTH/AND



Important To and For Are Connected

- ‘Important to’ and ‘important for’ influence each other
- No one does anything that is ‘important for’ them (willingly) unless a piece of it is ‘important to’ them

Balance is dynamic (changing) and always involves tradeoffs:

- Among the things that are ‘important to’;
- Between important ‘to’ and ‘for’

Always begin with what we know and ask if we really understand



- Every time we consider choice and risk we should start with

- Important to and important for

Plus

- What else we need to learn

But do we recognize what we really need to learn?

Sometimes it is simple Shelia and the chirpy people



Sometimes it is our assumptions



- Ronald and going for a walk

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And often it is more than one thing



- John having choice and control
 - Locks and keys
 - Menus, food, “legal” cheats
 - Matching staff

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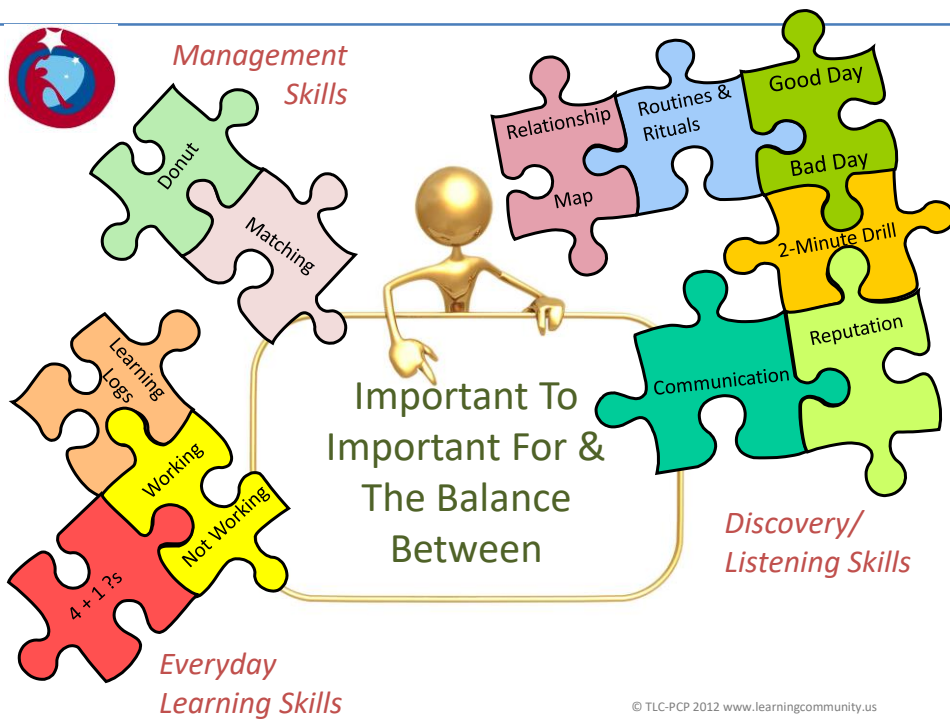
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We need tools that support the framework

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Descriptions of who the person is and how to support are critical and work for humans

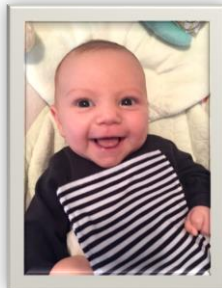
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Zachary (3 months)

What is Important to me

- Be held upright like a big boy
 - Playing with people
- Cooing, smiling, and giggling with others
- Hitting the guys on my playmat and kicking my feet
- Looking out the window, or going outside
 - Tummy time
- Singing songs like head shoulders knees and toes
 - Listening to music
- Baby massage for relaxation
 - Playing with my feet
- Being with my Mommy and Daddy



What others like about me

- Great big smile
- Cute laugh
- I give the best hugs
 - Big talker
 - Always happy
 - Cutie Pie
- Mover and a Shaker

How to support/comfort me

- When I am tired I like to chill with my nuk and be held
 - If I get fussy you can rub your hands across the front part of my hair
- Hold me upright and walk around a little, you may pat my back lightly or rub my back
 - Sing to me, or play music, its relaxing
- Always talk to me- I enjoy having a conversation with you
 - Talk with me and play when you change my diaper
- I will rub my eyes and yawn when I am tired. Sometime my eyes will look red. You can help me nap by holding me and have me use my nuk
- If I am napping and I wake up to early and fuss, please help me by giving me my nuk and rubbing my tummy lightly or running your fingers around the front of my hair. If I still don't go back to sleep, you may need to hold me and rock me.
 - I need a little time to get up from my nap. I may use my nuk.
- I do pace feeding with a bottle. Burp me and hold me upright after you give me a bottle

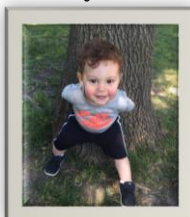




What's important to me

- Going outside and playing at the park
- Being with people I know, trust, and love
- Exploring and seeing what is going on
 - Being a part of the action
- Playing with cars, trains, and buses
- Reading books, playing blocks and puzzles
- Going for a walk or stroller ride
- Playing with my family and friends

Zachary toddler



What others like about me

Always Happy
Great smile
Contagious laugh
Explorer- always on the move
Loveable Cuddle bug
Loves interacting with others
Wild One

How to support me with sleep

- I nap with my nuk and my blanket as my cover. If I need help going to sleep, please rub my back. Say "shhhh." I may want to hold your hand and rub your fingers.
- If I wake up to early from a nap (after only one hour) give me my nuk and rub my back to help me go back to sleep. I will lay on my cot for a while before I get up.
 - I named my nuk - by making a clicking sound.

How to support me with Eating

- My Mommy and Daddy send me organic milk.
- I love to eat, but sometimes I am particular about what I want to eat and I will tell you.
- My favorite food is strawberries. If my friends have them and I don't, I may grunt.
 - I eat fast. My Mommy and Daddy tell me to eat "one at a time."
 - Remind me to use my words or signs (for more please)
- Give me my main dish first, then my veggies (which I sometimes don't eat) and my fruit last. I need encouragement to eat my veggies. Sometimes I will eat them with a fork.
 - I am learning to use a fork and spoon. I like using them to eat.

Other ways to support me

- Tell me to put my bottom down when standing in places that are not safe.
 - Remind me to take turns and share; and to slow down when running.
- If there is a sub teacher- I may be shy and cling to my teacher for a little bit.
- I don't always like my hands dirty, like from art projects. Help me clean them off.

What's important to my Mommy and Daddy

- To have great communication with the teachers who look after me
- To check in with his teachers at drop off (tell about morning) and pick up (hear about his day)
- To be kept involved of any changes in my routines
- To know Zachary is loved and cared for

IT'S ALL ABOUT ME
ELIZABETH KATES

What we love about Elizabeth!
(see pages 4-5 for more info)

- She's a determined self-advocate – ask her about her rally speeches
- A gutsy gal
- Talk about organized!
- A true blue friend
- She lights up a room!
- She's a Fashionista

A Few Things That Are Important TO Me...
(Please see pages 6-10 for more information)

- My independence
- A thriving social life
- Being organized and prepared
- School – Graduation in May 2011!
- Taking good care of myself
- Routines
- Planning for the future – including a job, an apartment, and a boyfriend
- Everything Michael Jackson
- Diet Coke
- Singing at church
- Fun with friends & family
- Writing in my journals
- Avoiding conflict
- Fashion
- Close relationships with Family & Friends

...And A Few Things That Are Important FOR Me:
(Please see pages 11-13 for more information)

- CPap machine, plenty of sleep (may include naps)
- Seizure medications
- Healthy diet and exercise
- Writing in my journals
- Conflict free environments & relationships
- Avoiding a "fireball"

Here's How You Can Support Me:
(Please see pages 12-14 for more information)

- Help me with time, money, cooking, shopping & some cleaning
- Help me find a job and job training
- Assist me to fix my hair & pick out cute outfits
- Help me make healthy food choices and to exercise
- Understand if I'm upset, I'm probably tired.
- Talk to me nicely & quietly. No bad words.
- When people around me are angry or there is conflict, help me get away
- Help me understand what's going on, what to expect





~ Sara's One Page Description ~

What People Like and Admire about Sara (Pg 5)

- She has a passion and zest for life
- Friendly and fun
- Positive energy in wanting to advocate for others
- Likes to help and is protective of others
- Very independent
- Knows what she wants to do and is resourceful



What is Important to Sara (Pg. 6-8)

- Being respected and people not breaking their promises
- Being social, joking and doing things with friends
- Making a difference for people
- Being able to smoke without being bugged
- People not messing with her things

Supports Sara Needs to be Happy, Healthy and Safe (Pg. 10-15)

- One person to provide clear directions and expectations
- Give her choices to keep her from getting bored. Always have a "plan B" in case things don't work out
- To be supported unconditionally so she can gain trust in you to help when she moves
- Must have people be consistent with her and talk with her when she get upset or starts self-diagnosing herself
- Have consistent respite for Sara and others to relax and recharge
- ASK Sara to do something, rather than tell her.
 - Always follow through with a promise or give an explanation of what is going on and when you can keep the promise if something comes up
- Always check in with others that support Sara to be sure you have the full story and can be consistent with the support she needs.

Sara's Picture Of A Life (Pg. 20-

- Live in a Host Home where she can have her own living space and be able to smoke outside
 - Have an active community that has good public transportation and advocacy opportunities
- Have a GED class that can lead to paid work for her
- Have mental health services to support Sara and her new provider

Tammy's Description

Tammy's One Page Description

What People Like and Admire about Tammy (Pg 6)

- Is always smiling
- Totally accepts people
- WONDERFUL personality
- Stylish
- Accepting and forgiving
- Resilient
- Great sense of humor
- Friendly and social



What is Important to Tammy (Pg. 7-8)

- Being a part of things
- Having eye contact with everyone
- Looking stylish and having her hair and nails done
- Being comfortable and not having her tubes underneath her
- No roughness in personal care

Supports Tammy Needs to be Happy, Healthy and Safe (Pg. 10-14)

- Always have her head elevated
 - To be suctioned frequently (5-6 times per shift). Gurgling noises means she needs to be suctioned
- To have people be kind, sensitive, loving and have a gentle touch
- Be gentle with brushing her hair (she doesn't like it, but wants it to always look nice)
- Always make sure her clothes match and make sure it's not sweat clothes
- Tammy needs to be repositioned every two hours
- Always follow through with a promise or give an explanation of what is going on and when you can keep the promise if something comes up
- Be sure to have Tammy use her body to keep flexible

Tammy's Picture Of A Life (Pg. 19-21)

- Live in a big wheelchair accessible home with extra wide doors, close to her family
- Have a fun and social housemate
 - Have a beautician she can go to regularly
 - Have a social medical day program close to home
- Have specialized medical services and medical equipment (including backup generator)







Great Things About Andrew:

- A loyal friend
- An incredibly hard worker
- A committed distance runner and athlete
- A good son & brother
- Persistent – will work for the things he wants
- An overcomer
- Sensitive to the feelings of others
- A role model
- A train expert
- Creative photographer
- A very careful driver



ALL ABOUT ANDREW

What matters to Andrew.

- My truck
- My independence & freedom
- Our dogs, Miss Finon & Sam
- Music of all kinds – I really like classic rock
- Distance running & competition
- Spending time with friends at Starbucks & Chick-Fil-A
- My faith in God
- Celebrations with friends, family & food
- My zero-turn mower
- Wearing baseball caps, UF or Cross Country clothing
- \$5 in my pocket






What it takes...

- Help me understand what you want me to do. You might have to slow me.
- Give me plenty of space and time before asking me to "shift gears" (transition)
- Don't push me or lecture me ("sticks on my head")
- Help me manage my medications and diet
- Help me manage my spending \$\$ and still having some to save.
- Allow me to try new things but don't let me get hurt.
- Supervise my work from time to time to make sure I'm doing the job correctly.
- Use a silly sense of humor with me. It works a lot better than demanding.

Our friend & colleague: Sophia

What's Important To Sophia During Her Recovery...

- Avoiding "scary hospital hair" always! Keep hair untangled and unmattd.
- Being included in aspects of her care and plans for her recovery
- Having time to think about things; not having to make a commitment immediately
- Planning things out after having the time to consider her decisions.
- Being dressed colorfully and comfortably – even if it's a hospital gown!
- Looking good – not in a vain kind of way, but in a stylish, lady-like way.
- Not being bored – she wants things to do and to think about.
- Having her privacy and modesty protected even in the midst of necessary medical procedures.



How You Can Support Sophia During Her Recovery:

- Before you leave the room, make sure she has her "Security System" within reach:
 - IN HER LAP:
 - her cell phone
 - the call light
 - the hospital phone
 - the TV Remote
 - ON THE TABLE TRAY:
 - *Hair brush
 - *Hair clips
- Remember she is an expert in supporting other people. She knows a lot and when she doesn't know the answer she knows people who do. Ask for her suggestions about her own care.
- Ask her directly when you have a question. Listen.
- Make sure she has time and assistance to look her best every day.
- Inform her about what you are doing and why. Let her tell you how she'd like it done.
- A sense of humor is always appreciated. Enjoy Sophia's

What We Love About Sophia!

She is quick to laugh; she helps us see the fun side of life! She wears really cool jewelry and artful, stylish clothing.

She's a gracious southern lady who can be gracefully direct and straightforward.

She's an amazingly creative problem-solver.

Her priorities are clear: Dan, Cathy, Rick & Sue, and The Grand-Boys.

She's a very talented trainer and has much expertise in supporting people.

Sophia will crack you up!

She is generous and kind.

She is a Scrabble Shark. Don't let her sweet face fool you!

Sophia's glass is always half-full.

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SDA – Michael Smull

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~ Ruth's One Page Description (at home) ~

What People Like and Admire about Ruth

- Such a "grandmother"
- A true lady
- Has the gift of gab ~ can hold a conversation with anyone!
- Always dressed so nice ~ everything always matches, right down to socks and earrings
- Very liberal thinker for her age



What is Important to Ruth

- Living with granddaughter and grandson-in-law
- Being warm and feeling safe with caregivers
- Having "a little pour" before bed (rum and tea)
- Being a part of whatever is going on at home ~ being in the middle of it!
- Sweets during the day!

Supports Ruth Needs to be Happy, Healthy and Safe

- Needs people to ask frequently if she is warm enough and help her put on sweater/sweatshirt if she is not (she'll be cold when you're not)
- Must have assistance with her medications ~ knows them by color but you need to dole them out and keep track of times
- Needs assistance with bathing and dressing ~ will tell you what clothes she wants to wear for the day/event
- When bathing, no water on face ~ she will wash with cloth
- Must talk with daughter 2-3 times a week on the phone ~ will need you to dial for her
- Must see her doctor right away if she has cough, fever or is "off balance" ~ indications of systemic infection that will grow quickly!

People Who Support her Best

- Like to chit chat
- Are timely and stay busy
- Polite and mannerly
- Have a witty and dry sense of humor
- Can be reassuring and help Ruth feel safe

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Nora

What is Important to Nora

- To do what she wants to do when she wants to do it
- Time with her family –
 - Hanging out with Anne and Sarah, seeing her great grandchildren
 - Eating out and shopping with Bev and Carla
 - Daily phone calls from Jeff, visits from Jeff
- Being a "lady"
 - Looking good – hair done, nice outfit
 - Being addressed as Mrs. G until she gives permission to call her Nora
- Not getting help she feels she doesn't need or doesn't want
 - Dressing, undressing
 - Using the bathroom
 - Bathing
- Hates tub or shower baths – always "washes around"
- Having people to chat with
- Going shopping
- Having everything in its place
 - Only being in tidy, clean environments
 - Picking up (or trying to pick up) any specks of dirt or lint
- Feeling useful, a part of things
 - Having a "job" to do when dinner is being set up and helping to clean up after
- Going out for a walk and to sit on sunny, nice days
- Going for a ride most any day when feeling well



What others like about Nora

- Funny
- Fiercely independent
- Loving
- Her sweetness

How to support Nora

- If you are new, remember to call her Mrs. G until she tells you to call her Nora.
- Always ask if you can help her with something even if you know that she needs help
- If you are helping Nora do something where she doesn't want the help she will tell you to go away. Stop, back off for a minute then gently try to help again – while you tell her you are just there to help
- When she won't get up, won't get dressed, hits out, seems unusually disoriented, etc. she may have a urinary track infection and/or be dehydrated –
 - o Let Beverly or Carla know
 - o Give her sometime to getup, drink, etc. but keep encouraging her to be up and especially to drink
 - o When she feels bad she is less steady – she wants less help but needs more – so you need to make sure she gets the help while apologizing for having to be there when she doesn't want you to be
- For things Nora wants to do – help her get ready early (that is a life long pattern) but not too early. She gets confused about time and will want to get ready hours (or even a day) in advance.





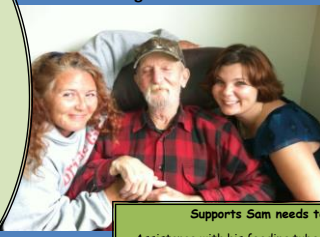
~ Sam's One Page Profile ~

Important to Sam

- At least weekly calls from each of his 3 kids (Tina, Dixie, and Bobby).
- Getting to see people he likes every day
- Feeding the hummingbirds at the complex (the water for the food MUST come from Spring Creek)
- His friends, Bill and Vince
- Staying busy

What People Like and Admire about Sam

- He always wants to help others before he takes care of himself
- He tells great, funny stories...some are pretty raunchy...get used to it.
- He can fix ANYTHING and will always offer to assist
- He is a jokester. Sam loves "Pierre and Boudreaux" jokes and must know 100's of them.
- He loves his family and friends and always has time for them



Supports Sam needs to be Happy, Healthy and Safe

- Assistance with his feeding tube (he will tell you how much to fill it by showing you with his thumb and forefinger).
- Someone to assist him with shopping (if he's too tired to cross the street)
- Support with taking the morphine through the feeding tube. He doesn't want enough so that he is sleepy, but, he needs enough to cut the pain. He'll show you how much he wants.
- Someone must assist in filling the hummingbird feeders. He is distressed if they are empty
- Rides to his medical appointments. It helps if you can check with the discharge desk for any special instructions. Sam doesn't hear well and gets frustrated.
- Help him remember to rest throughout the day, which may include limiting visits or length of visits. He falls when he is exhausted, but will choose company over safety.

Sam LOVES:

Budweiser (his daughter has figured out how to make beer slushies (recipe on freezer door)...help him have a teaspoon or so every once in a while. He will spit it out if his throat is sore, but, he loves the taste

Person Centered Planning results:


1. Sam Being listened To: Sam moved to his own apartment, without constant caregiver presence. Friends and family provide transportation and other assistance.
2. Less than 2 hours of support per day (with the exceptions of days when he has a chemo treatment and may need a friend or family member to sleep over)
3. Focus on his desires and what he is interested in doing (fishing, talking, telling jokes, feeding hummingbirds)



Sam rang the bell at the cancer center on the day of his last chemo treatment. He is joined here in front of the bell by two family members. Sam died peacefully at home later this day. Ginny (pictured in blue) was listening to him tell a story when he passed.







Max Neill
While I have months to live

How will decisions be made: who will be involved

I should be involved and have final say in all decisions
I want Lorraine involved without question

What is important to me...

- Good food!
- Spending quality time with my family and people that matter to me.
- My Masters Graduation
- My work
- My blogging
- Feeling on top of my pain
- Adam and Giulia's Wedding
- Charlotte, Michael, Isaac and Jake
- All the grandchildren
- Richard & Louise (and family)

How to support me and those I love...

- Be straight and honest with me about my condition.
- Don't worry about saying the wrong thing, feel free to talk to me. Understand this is hard on my family and they have had less time to think about this than me.

What must happen

- I must have a good stock of pain medication

What must not happen

- My pain relief must not be disrupted for any reason!



Michael as TLC Board Chair



What other Board member's like or admire

- His vision
- Being a beacon
- An original thinker
- Gives a clear message
- Has a clear and unwavering purpose
- Explains complex things with an economy of language

Best Support

- I am a good leader but not a good manager – support my strengths
- There are always more things to do than there is time.
 - Action plans, with clarity about who does what by when, are needed
 - I appreciate being reminded about what is helpful and necessary.
 - Remember I am best at working on future concerns, but will help with what is needed now
- When you want feedback, ask
- I lose the balance between work and life, gentle reminders are helpful

Important to me

- Helping others to grow
- To be part of an organization that works on changing the system.

Where -

- We work in partnership
- I am part of the problem solving and testing the solutions
- We learn how to do quality at scale
- We share the learning and help our efforts spread

- To focus on the future, to work on "what is next"
- That TLC-PCP grows and prospers, now and after I am no longer directly contributing -
 - The longevity and integrity of the work
 - Creation of a true learning community

For more information
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