# Person-Centered #CarePlanning – What data?

By **Danny van Leeuwen** | January 4, 2017 | Edit

Last month, in Communicate What? #CarePlanning, I declared the #CarePlanning hashtag, and told from personal experience the importance of communication in enabling participatory care. I ended with this – my perspective as the person who has the problem and the *only* person who is always there at the point of care:

> I have goals and a plan. I monitor and communicate it.  I'm the connector for my team of more than a dozen. This is **person-centered #CarePlanning**.

Our health teams struggle to communicate at transitions (between team members, when adding a new team member, between people, offices, and settings) – it's a perfect tower of Babel.

The Tower of Babel (Wikipedia – Peter Brueghel the Elder)

In its simplest form, communication is who, what and how.  Who needs to communicate? What do they need to communicate? How will they communicate?

#CarePlanning focuses on the what. What are the goals of the person on the health journey? Who's going to do stuff to get there? When? How will these goals and activities be tracked and shared across time and settings?

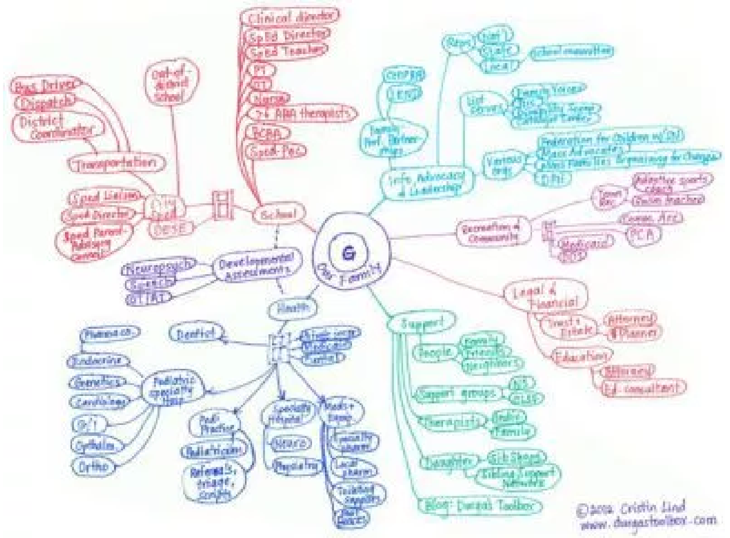
Let's engage to better understand #CarePlanning from the point-of view of the person (mostly as patient, sometimes not; usually including family and/or caregiver), rather than from the point-of-view of the doctor, the hospital, or the insurer. What does the person want to accomplish, who on their team (including the person) is going to do what? by when?

Let's also narrow our focus to #CarePlanning that can be communicated during transitions between settings rather than within settings (For example,  between home and clinician office, between hospital and rehab center, between home and work or school. Not within the home, hospital, clinic, or agency).

Next, let's look at #CarePlanning during illness rather than wellness or prevention. Edward Suchman devised an approach for studying **illness** behavior (Social Patterns of Illness and Medical Care, 1965) with five key **stages of illness** experience:

1. symptom experience
2. assumption of the sick role
3. medical care/*healthcare* contact *(my italics added)*
4. dependent patient role
5. recovery and rehabilitation.

Finally, let's be sure to include the *social determinants of health* – or as we non-academics call it, *life*.



A Care Map drawn (c) 2012 by Cristin Lind, for her child with complex needs. From her blog "Durga's Toolbox"

So, we're considering #CarePlanning from a person point-of-view, between settings, when people are sick, and including life, not just medicine.

#CarePlanning happens when we talk to and text with each other, when we write stuff down (lists and logs) and electronically in electronic records and apps. I've never met anyone who doesn't strongly advocate for and believe in #CarePlanning; it's a no-brainer.

At the same time I haven't yet seen **a universal description of what goes into a person-centered care plan.** Without that, how can we know whether we're doing it right? How can we improve? How can we achieve the best possible care, given the resources we have? How can we teach it?

What are the minimum data elements for a care plan – verbal, written, and electronic formats?

I've been working on this with @GeriLynn Baumblatt from Emmi Solutions, @BevinCroft from HSRI, @yogileana Balcu from the Society for Participatory Medicine, Todd Katzman from Boston Children's Hospital, and Juhan Sonin @JSonin, @Beth11Herlin, and Edwin Choi @rexcraft8 from Involution Studios. See Involution's fine work on their Care Plans page.

I submitted the #CarePlanning hashtag to Symplur, an organization that logs and tracks the thousands of healthcare hashtags on social media. (What does it say that there wasn't one already?)

One of the next steps is to inventory the data that the many vendors, associations, advocacy and information standards groups, and professions call care planning. Would you like to join us? Leave a comment on this post and I'll get back to you. More to come. Onward!

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**Sandra Raup** on January 5, 2017 at 10:05 am (Edit)

As you said, Danny, this is a no-brainer. As Gordy used to say when I worked in direct care (and encountered lack of patient-centered team work), "you work in a caste system." Each profession has their own language and sees power in it. Even in the hospital, doing "shared care planning" meant a bunch of different professionals creating their own care plans while talking to each other! Yikes!! Is it any wonder they don't include the patient? They can't even include each other! Sandra Raup, R.D., J.D., M.P.H.

Reply

**Jill Whan** on January 31, 2017 at 11:46 am (Edit)

Person-Centered #CarePlanning-What Data?
Jill Whan, Nursing Student

It took four semesters in a nursing program for me to fully begin to understand the concept that you have stated so simply above. #CarePlanning focuses on the what: What does the patient want to accomplish? Two years ago this may have seemed vague, but when followed up with the additional questions; what are the patient's goals, who's going to do stuff to get there, when will they do this stuff, and how will these goals be tracked and shared it all seems to make sense.

Possibly if this had been laid out so simply on day 1 of NSG 112 I would have grasped the concept and grew with it. It's truly the backbone of nursing and vital to our success as well as the patient's success. It took me quite a while to understand and left me confused and lost along the way. My goals as a nurse are to plan, monitor, and communicate. Possibly I need to look at who is going to do stuff to get me there, when, and how I can share my experiences.

Reply

**Danny van Leeuwen** on January 31, 2017 at 4:34 pm (Edit)

Jill, as nurse for 40+ years, I also marvel at the disconnect between nursing that says we're all about the patient and my experience as a patient, caregiver, and nurse. I'm delighted my message was digestible. I look forward to letting us us know about your journey.

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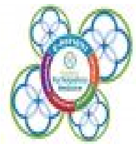

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