

## When Working for Becomes Working with: Coproducing Improvements in Care Together with Patients and Families

Sarah Myers MPH, RN  
Cincinnati Children's Hospital  
Nursing Grand Rounds

November 9, 2016



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Thinking about your own care, removing yourself from your roles as a professional or parent...

- *Have you been asked to provide a clinician or clinicians with ideas for improving the care that they provide to all patient?*
- *Have you been involved in creating or implementing solutions to an identified issue?*



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## Learning Objectives

- **Describe** one example of how care centers in a large Learning Network have gotten started coproducing improvements in clinical care with patients and parents
- **Identify** one potential goal related to coproduction with patients in the clinical setting



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### By the end of this talk:

- You will know what I mean when I say co-production
- You will be able to share at least one example of how centers in another collaborative quality improvement network got started with coproduction at the local level
- You will have ideas for setting 90-day goals related to coproduction at your center



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### Think big!

Discuss with one person at your table...

*What would you like to say about partnership and working together with parents/families in your care setting that you can't say today?*

*What is the biggest barrier to getting there?*



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FOR HEALTH SYSTEMS EXCELLENCE



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THE JAMES M. ANDERSON CENTER FOR HEALTH SYSTEMS EXCELLENCE

Vision

- To be the catalyst for improving child health

Mission

Serve as trusted and effective partners to:

- Achieve unprecedented outcomes, experience, safety and affordability at Cincinnati Children's
- Help Cincinnati's kids to be the healthiest in the nation
- Create new knowledge and accelerate its application into practice and policy
- Cultivate learning health systems
- Develop leaders for health system transformation



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IMPROVE CARE NOW



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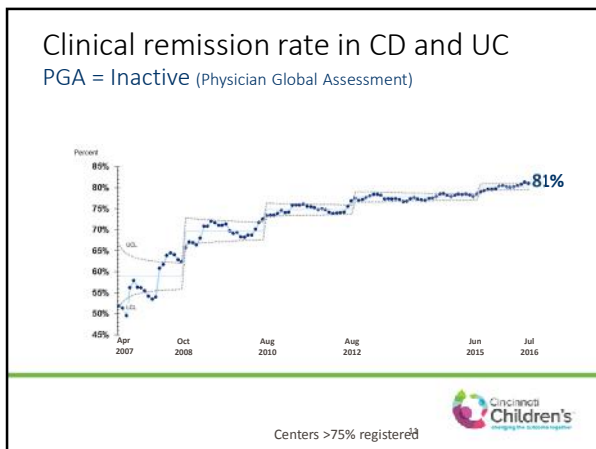
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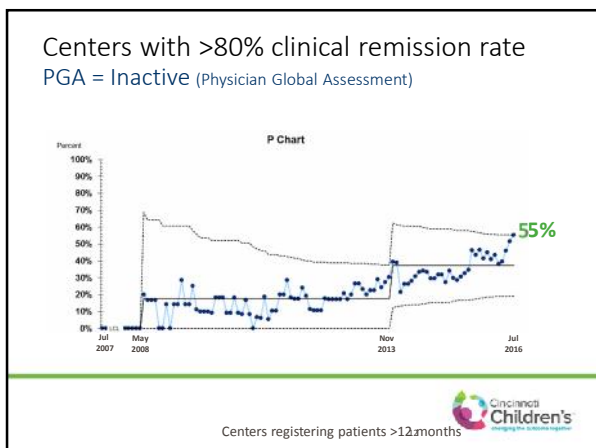
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They all have a story.  
AND they all have knowledge,  
ideas, and talents that will help  
improve care.

Cincinnati Children's  
changing the science together

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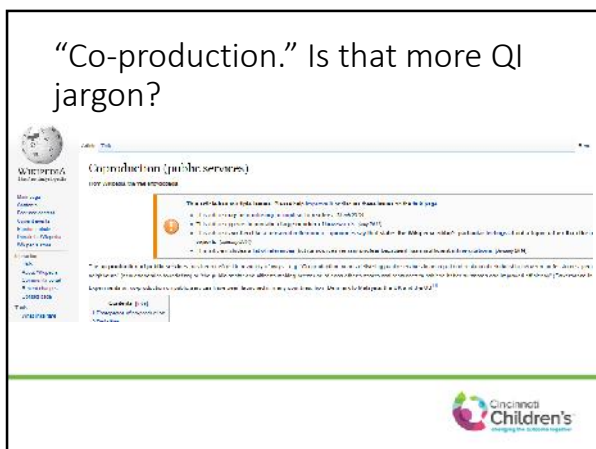
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### “Co-production.” Is that more QI jargon?



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### Maintaining community aesthetics and health



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Working to improve schools together



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Other Examples?



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It's really pretty simple:

- It's producing things—in this case improvements in care and outcomes—together.

Co-production is patients, families, clinicians, and researchers collaborating as equal and reciprocal contributors to produce **information** (e.g., clinical data, patient reported outcomes), **knowledge** (informal insights and formal research), and **know-how** (expertise) to improve healthcare and health outcomes.



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Co-production is a way of thinking and way of doing – it's a culture change

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There is no single way to embed co-productive practices – it takes creativity & tailoring approaches to your site

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The idea must be embraced as a priority by service providers and service users.

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Communication – honest about expectations


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Trust -- leads to changes in well-defined roles for patients and professionals

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Relationships & Reciprocity – “You need me” becomes “We need each other”

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Clinician = Care Giver

Patient = Care Receiver

Everyone = Care Improver

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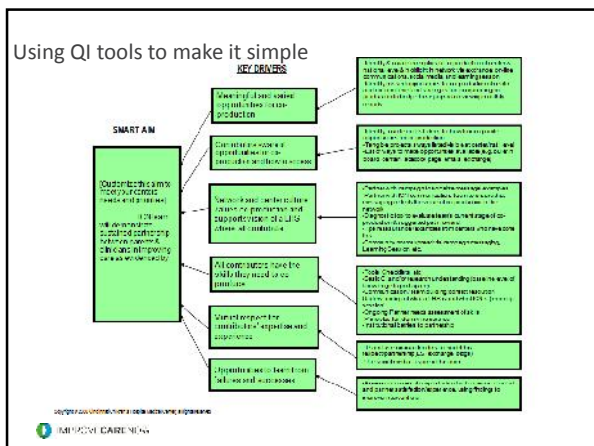
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## Key Drivers of Co-production

- Meaningful and varied opportunities
- Awareness of opportunities and how to participate
- Culture values coproduction
- Contributors have skills they need
- Mutual respect for expertise and experience
- Opportunities to learn from success and failures

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## Nursing is the Perfect fit for Coproduction!

- You are often the ones who have most contact with family
- You take part in human-to-human discussions
- Many inpatient and clinic settings provide opportunity know kids over time

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Coproduction at the network level



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**People + Structure + Trust =**  
Engagement and coproduction that we previously thought impossible!



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**People:** Driven by Generosity, Experience, and Collaboration



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### Parent Working Group: Professional Experience

**PROFESSIONAL EXPERIENCE WORD CLOUD:**  
 Mechanical engineer, Sales rep, Managed care medical director, Camp director, Meeting and events coordinator, Physician, Statistician, Business development manager, Electrical engineer, Information systems consultant, IT project manager, Nurse, VP of new technology, Childbirth educator, Product manager, Realtor, Respiratory therapist, Clinical researcher, Writer and editor, Foundation director, Director of sales, OPERATIONS SPECIALIST, Hedge fund manager, Healthcare consultant, Media consultant.

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### Why I participate

- I hate being sick.
- I trust my doctors.
- I want to help my doctor help me.
- I want answers to difficult clinical questions based on facts, not hunches.
- I want to help make pediatric health care participatory.
- I don't want other young people with IBD to feel as if their care is beyond their control.

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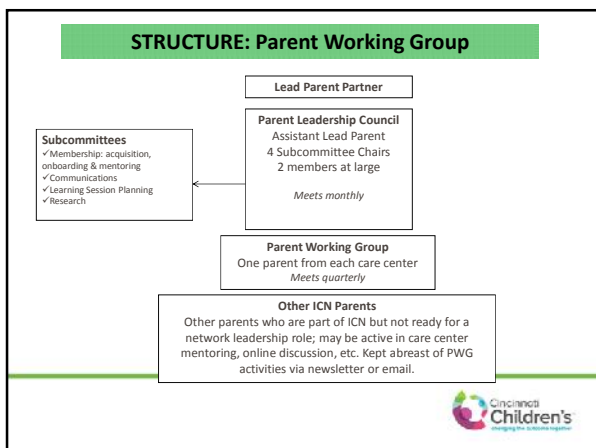
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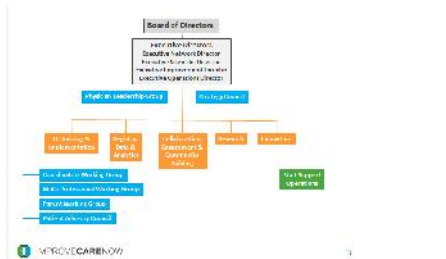
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Patients and Parents as Part of Network leadership




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Trust

- Families need to *trust* that they are seen as full partners
- We need to *trust* that we are still needed
- We need to be able to give and take feedback and be honest if one side is pushing too far too fast
- Get to know each other as people in order to establish this *trust*, just as one would any *co-worker*




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Parent Working Group | Profile

**Tania Moon**

**Title |** Parent Rep  
**ICM Center |** Nationwide Children's Hospital  
**Child's Age, Diagnosis |** 10, Crohn's Disease (diagnosed at age 5)  
**Profession |** Family Rep, Stay at home mom  
**Volunteer Activities |** Nationwide Children's Hospital Volunteer, ICM Foundation, CCMC, Case-Steps, Case-Steps, CCM Board Member, Central Ohio School Volunteers, Impoverished by Gels volunteer  
**IBD Journey |** Our 3 year IBD journey has been a roller coaster ride. This disease has taught us to become advocates for everyone impacted by these diseases. We realize the impact it has on the entire family, as a mom, we can't quite grasp places with my son and take away his Crohn's Disease. My goal is to help as many families as I can because I still remember the day of diagnosis like it was yesterday.  
**Tell us one thing no one knows about you |** When I was in grade school, I won the GSS Essay!




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A Week of Learning from Patient Partners!

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**IMPROVECARENOW**

**Remstart Patient Rebate Program Helpful Hints**

1. Request a copy of your enrollment form from GI department
2. Make a copy of your enrollment form for your records and mail or fax a copy to:  
Remstart:  
14001 Weslon Parkway  
Suite 103, Cary, NC 27513  
Phone: (800) 222-3771  
Fax: (877) 234-3348  
www.remstart.com
3. One week after mailing/faxing your enrollment form, call Remstart at (888) 222-3771 to confirm they received your application.

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ICN Exchange: Enhancing Knowledge Sharing

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### Sharing tacit knowledge



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### QI Cheat Sheet for ImproveCareNow Parent Partners

Version 3.0  
April 2015

**Our basic Model for improvement:**

1. What do we want to accomplish? (our aim)
2. How will we know if a change is an improvement? (our measure)
3. What changes can we make that will lead to improvement? (our changes)

**About AIMS:**

- In Improvement efforts, we focus on what we can control, set our goals, and use indicators for what we can improve on projects that will help them reach their target goals.
- **Keep it SMART:** Specific, measurable, achievable, realistic, time-bound  
 Not too broad, not too narrow, patient-focused, and we plan to do this. Instead of a goal of 100 patients we will have one set during by June 30, 2015.
- Develop your aim as a team so all are aligned around what you are trying to accomplish.

**About Changes:**



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### Co-production at the individual CARE center level



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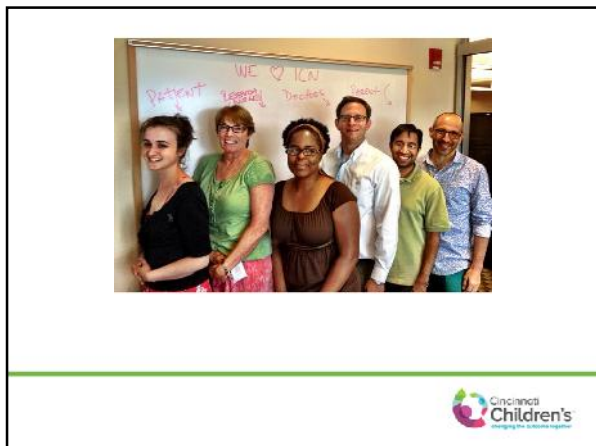
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### Levine Children's Hospital: Guidance for the IBD Journey

Levine Children's Hospital Educational Videos

<p>Social Work</p>	<p>IBD and Surgery</p>
<p>IBD and the Ili</p>	<p>Camp Victory Junction</p>

Cincinnati Children's logo in the bottom right corner.

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### Riley Children's Hospital: Easing the Financial Burden

**Buzzy: A small tool to help in a big way**

The Buzzy is a small, handheld device that is used to numb the skin before a procedure. It is made of plastic and has a small motor that vibrates. The Buzzy is used to numb the skin before a procedure. It is made of plastic and has a small motor that vibrates. The Buzzy is used to numb the skin before a procedure. It is made of plastic and has a small motor that vibrates.

Cincinnati Children's logo in the bottom right corner.

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# Northwest Pediatric GI: Raising Awareness & Building Bridges

Page 2 ImproveCareNow

## Who me? Get Involved?

By Jennifer Erickson

We name Jennifer Erickson and I am a parent of an IBD patient, and the Patient Advisory Board for NWPGI and Improve Care Now. I chose to become a familiar face in the community and clinic, a comforting voice as we discover new ways to best support our families, and a bridge for increased communication between our patients and physicians.

There is an established support group for adults through the CCTA, known as the Northwest [www.improvecarenow.com](http://www.improvecarenow.com) that meets up at CHSU on a monthly basis. We hope to add to the good they do through our own group, NWCL, geared for kids with Crohn's and Colitis. Our kids and us parents are bound by a common diagnosis and similar struggles. Compassion and humor can ease a great deal in healing the spirit. Our

Please LIKE our  
Facebook page at  
<https://www.facebook.com/NWCColitis>



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# Nationwide: Leveraging Professional Experience

## Twitter Engagement

Let's help Twitter to help all the children in need with their health care. We can do this by sharing our experiences and knowledge with others who are facing similar challenges. We can do this by being a part of the conversation and helping to support each other through our struggles.

How can we leverage our professional experience to help children in need? We can do this by sharing our knowledge and expertise with others who are facing similar challenges. We can do this by being a part of the conversation and helping to support each other through our struggles.

- Share your professional experience with others who are facing similar challenges.
- Be a part of the conversation and helping to support each other through our struggles.
- Share your knowledge and expertise with others who are facing similar challenges.
- Be a part of the conversation and helping to support each other through our struggles.
- Share your knowledge and expertise with others who are facing similar challenges.
- Be a part of the conversation and helping to support each other through our struggles.



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### Our PFAC Litmus Test



- Large scale impact?
- Inspire Support?
- Fit in QI?

- Burden to the team?
- Will we help?



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### Lessons learned from an ICN care team parent partner

- What goes on behind the scenes; gave me a greater appreciation for all my care team does for me
- How to tell my story to frame it in a way that will help others
- Lots of great ideas but a lack of man power/time to implement them- made me want to jump in head first and start helping in whatever way I can



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“But they must have a lot of resources. We are so busy.”



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### Coproduction is **not** a Change to Test

- Coproduction is not a new QI intervention. It's a way of doing work that helps you move further, faster, and in ways that are more meaningful to families.
- Coproduction does not equal more work in the long run but you have to put thought into working in this way
- When it becomes part of the way you do QI, it helps get projects done



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### Common “fears”

- It will take more time that we don't have
- We will air our “dirty laundry”
- Parents will want to focus on their own child's care
- My ideas won't be needed or heard anymore



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### Key Drivers of Co-production

- Meaningful and varied opportunities
- Awareness of opportunities and how to participate
- Culture values coproduction
- Contributors have skills they need
- Mutual respect for expertise and experience
- Opportunities to learn from success and failures
- What's missing?



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## Changes to Test: Getting Started

- Talk as an improvement team about what coproduction **means to you** and your improvement work. Talk about your concerns and fears.
- Identify a **champion** who “gets” what parents and partners bring to the table...someone who will make this way of thinking prominent in all conversations
- Think about a **few parents** that might have good input into a small-scale project—start small, start this week (start with a list of 4-5 parents who are likely to want to contribute)




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## Feeling ready to start?

- Invite a parent to attend your next QI meeting
- Invite a parent to review an educational tool that you haven't updated in a while
- Ask a newer parent for feedback on the new diagnosis process and one thing they would improve




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## Bottom line: Just starting talking and connecting as people.

What are the 3 things you like most about your visit to our clinic?
If you could change 2 things about the care you receive for your IBD what would they be?
What do we wish the clinic team knew about your life with IBD before every visit with you?
What are the top 3 challenges you face in your day-to-day life with IBD?
How might we as your care team better support you in dealing with these challenges when you are at home between clinic visits?




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Working Together to  
ImproveCareNow



IMPROVECARENOW

Co-Production Change Package  
Version 2.1: Catalyzing Community Input  
May 5, 2015



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Examples of 90-Day Goals: Small to ambitious

- Mercy: "Host advocacy event- education/resource fair for IBD patients and families."
- Greenville: "Identify and engage 2-3 volunteers demonstrating commitment as parent leaders."
- Iowa: "Identify at least 5 parents who are willing to provide support to new diagnosis patients."



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Think big!

Discuss with one person at your table...

*What would you like to say about local partnership with parents/families at your care center that you can't say today?*

*What is the biggest barrier to getting there?*



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Questions?

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