



SPINA BIFIDA
ASSOCIATION

Improving Lifespan Outcomes in Spina Bifida The Role of SBA in Clinical Care, Research, and Systems Change

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President & CEO

To build a better and brighter future for all those impacted by Spina Bifida

Why This Matters

People with Spina Bifida Are Living Longer.

Our Systems Have Not Kept Pace.

More adults
living with SB
than ever
before.

Persistent
variation in care
and outcomes

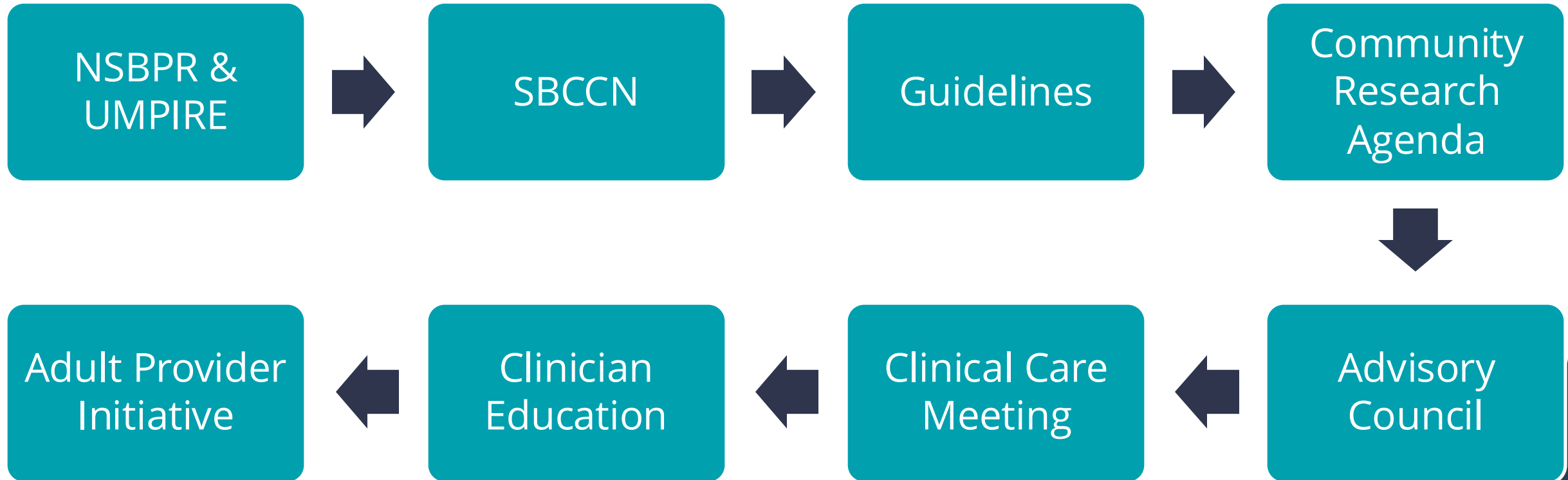
Growing
workforce and
access
challenges

Increasing need
for lifespan-
focused
systems

The next era of Spina Bifida care requires coordinated national infrastructure.

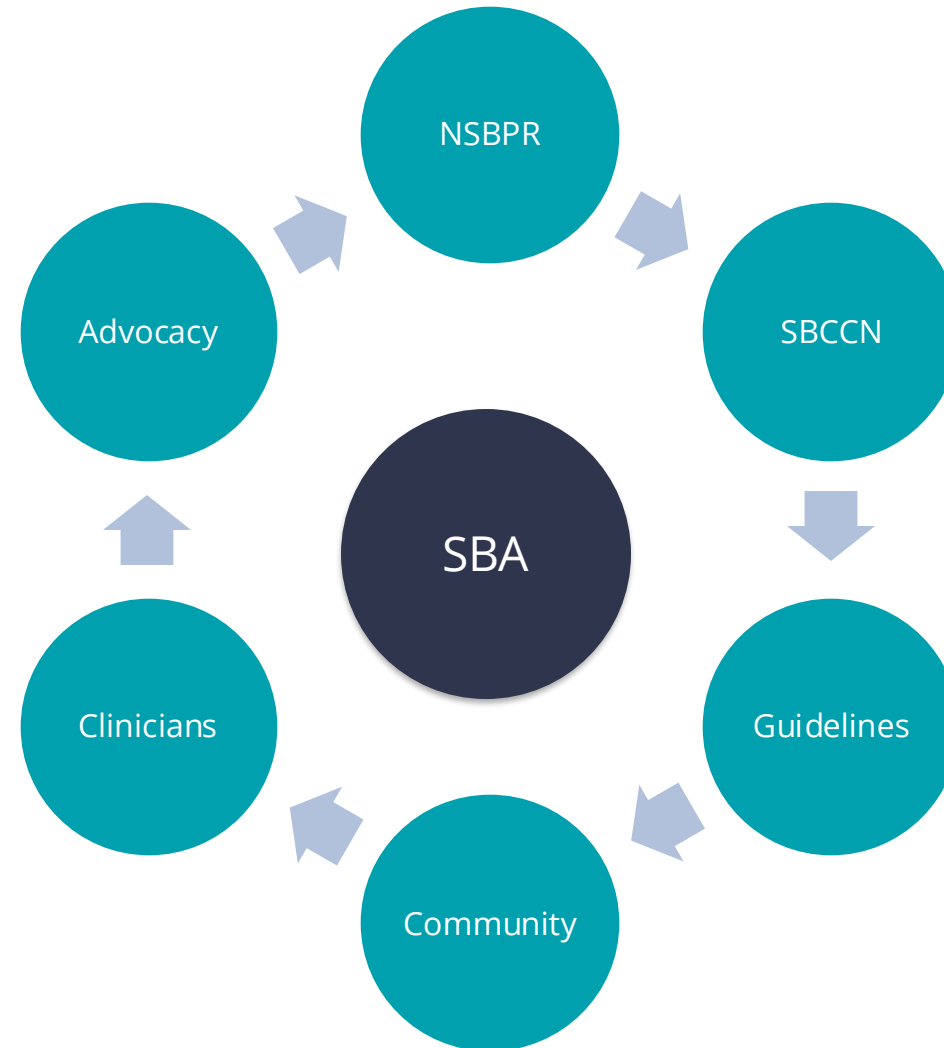
SBA's Evolution

From Community Support Organization → National Field Leader

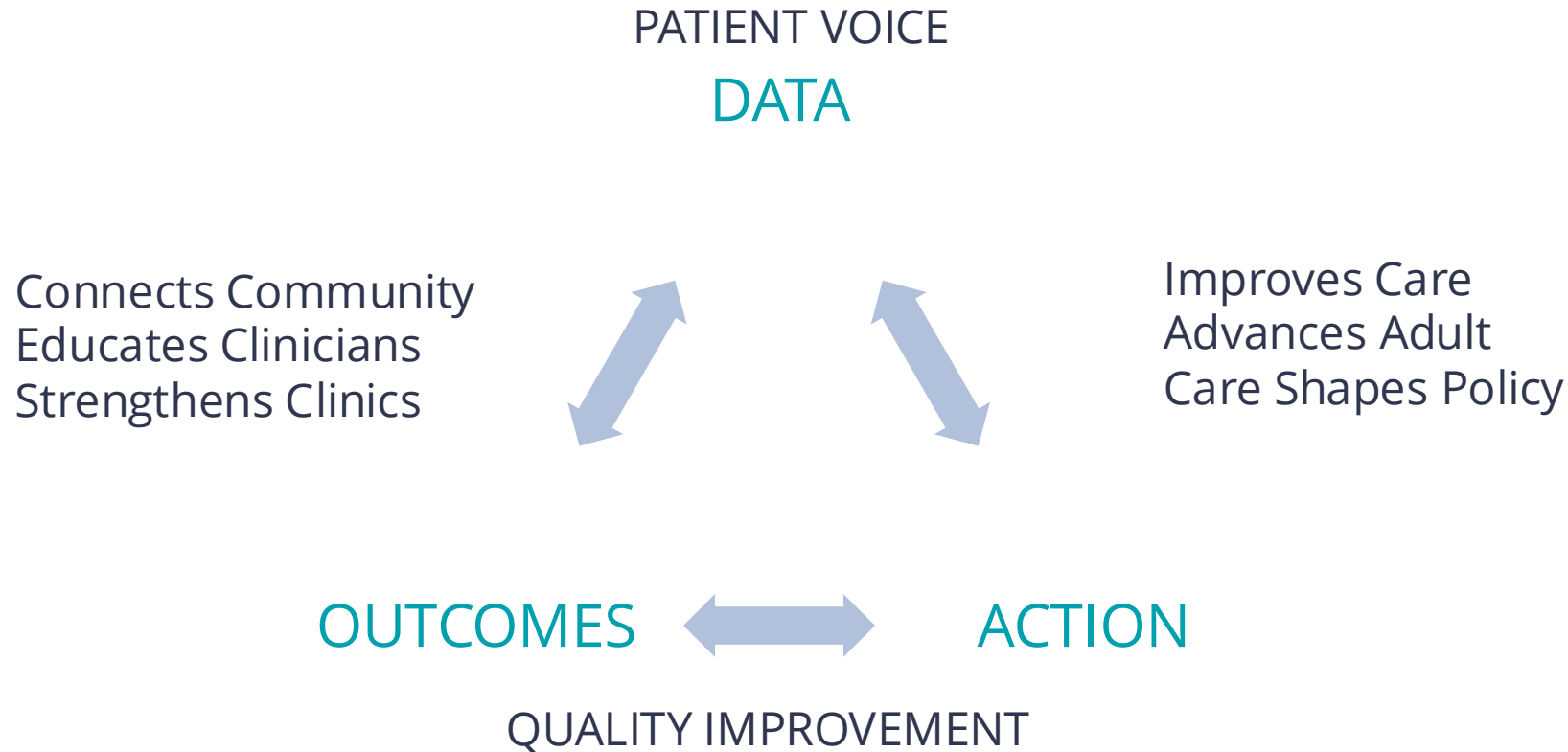


The SBA Care Improvement Flywheel

Registry → Practice → Policy → Funding → Better Outcomes



National Spina Bifida Patient Registry (NSBPR)



SBCCN transforms the NSBPR from a registry into a national improvement engine.

What SBA Is Building

National Infrastructure for Lifespan Care

Clinical

- CCM
- Guidelines
- Clinic Collaboration

Research

- NSBPR
- UMPIRE
- Community Research Agenda

Community

- AAC
- Parent AC
- Self-Management Resources

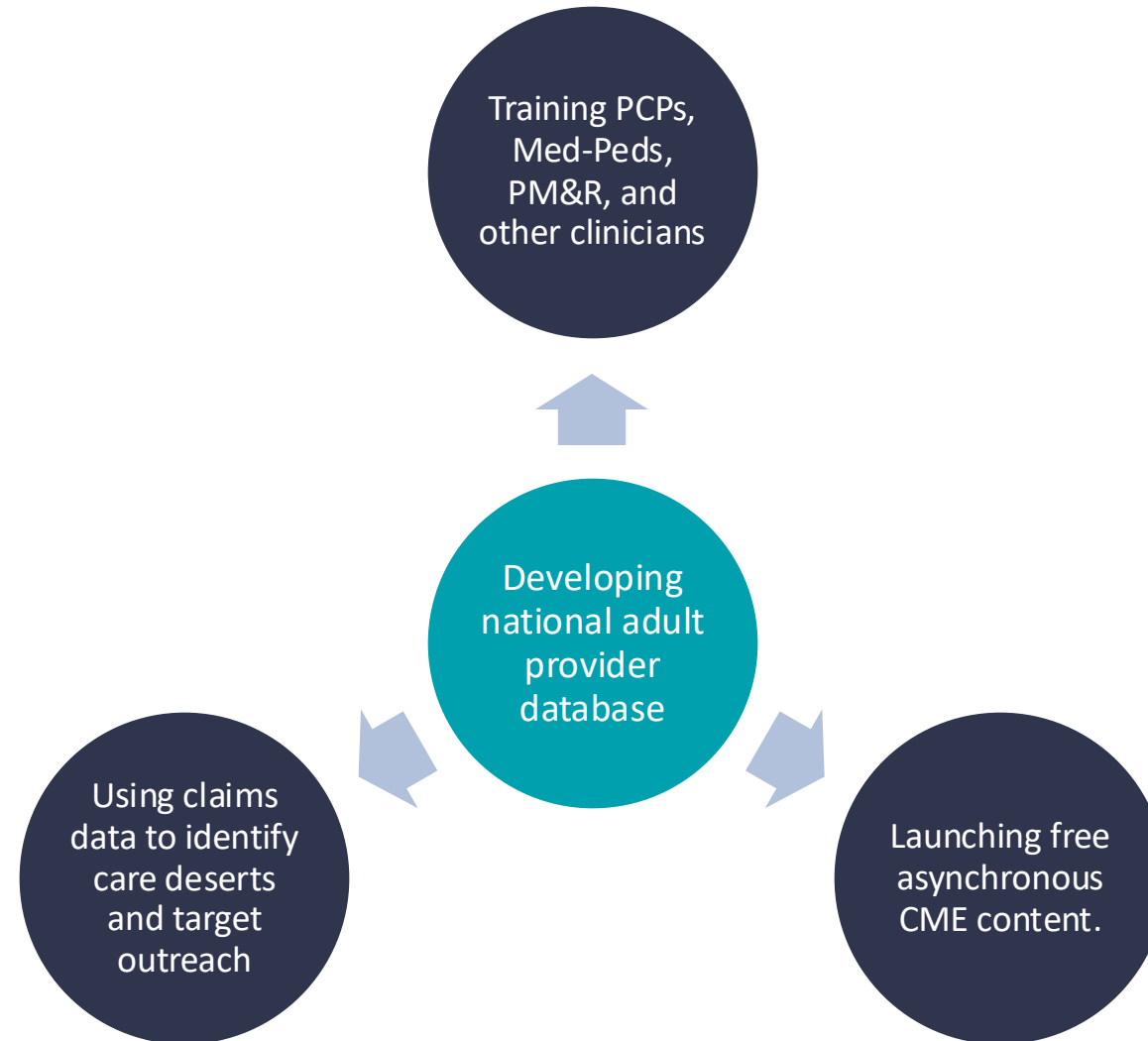
Workforce

- Adult Clinician Education
- Provider Database
- Transition Support

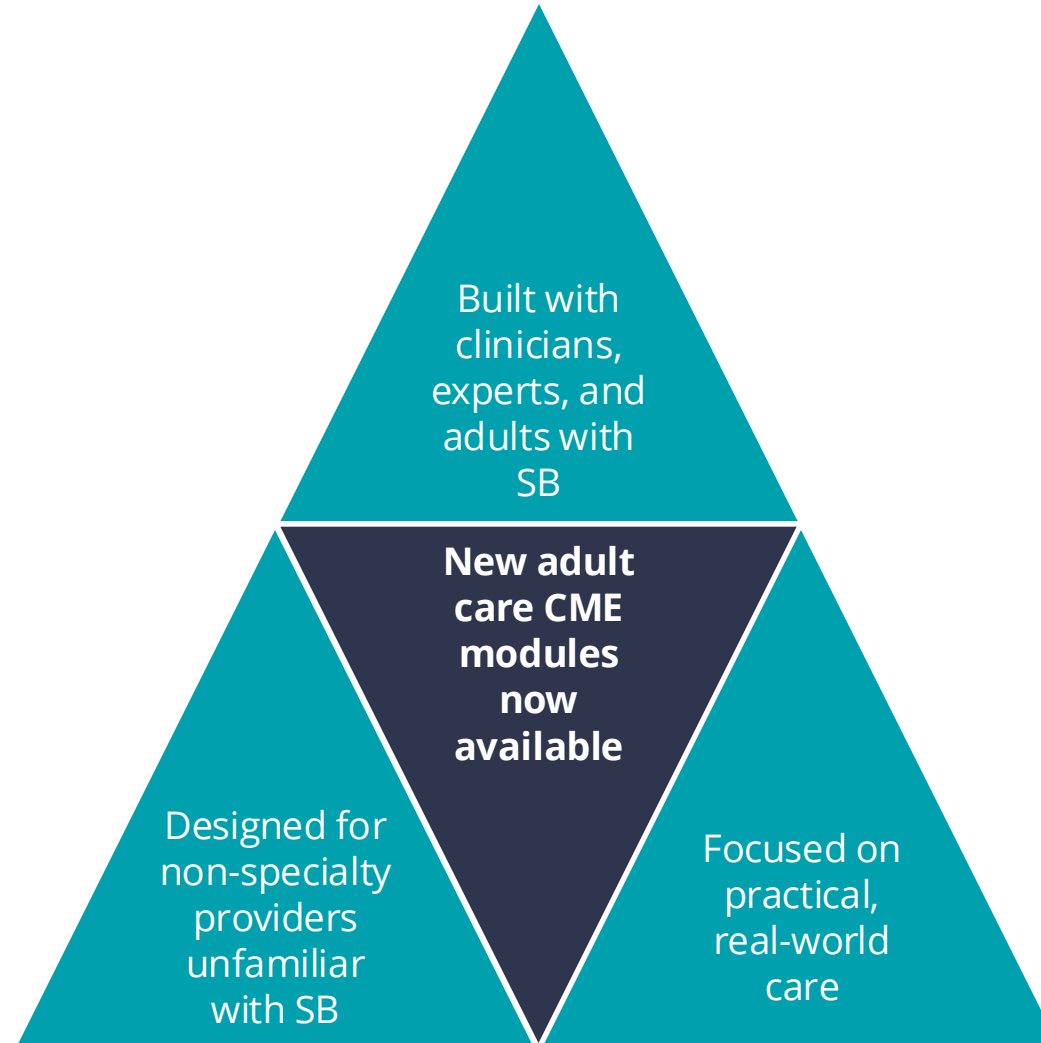
Why SBA Matters to the NSBPR



Adult Care Expansion



Clinical Education and CME



Research and Outcomes Work



The Biggest Gaps We Still Face

Adult Access

Transition
Fragmentation

Workforce
Shortages

Mental Health

Skin Integrity

Bowel/Bladder
Management

Data Gaps
Beyond
Pediatrics

**SBA cannot solve these alone.
Progress requires clinical partnership.**

Where We're Going Next

**Over
the
next
10-20
years**

- Lifespan Outcomes
- Adult Systems of Care
- Better Implementation Science
- Practice Transformation
- Expanded Data Structure
- National Clinician Collaboration
- Stronger Policy Protection

Call to Partnership—We need YOU at the Table



Participate in NSBPR

Share Best Practices

Engage in Clinical Education

Contribute to Implementation Work

Support Advocacy

Better Outcomes Require More Than Excellent Individual Clinics

Connected

- They require a connected national system.



Together

- SBA is committed to building that system together.



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