

United Parents
Parents & Caregivers for Wellness

PARENT AND CAREGIVER ENGAGEMENT TOOLKIT



United Parents

United Parents provides resources to empower, strengthen and support parents who have children with mental health, emotional, and behavioral disorders.



Parents & Caregivers for Wellness

A collaborative project to strengthen the voice of parents and caregivers and improve services and supports for families.

Amplifying Our Voices Together

PC4W as a Catalyst for Child, Family, and Community Well-Being: Engaging Parents and Caregivers with Lived Expertise

United Parents recognizes that Parents & Caregivers 4 Wellness (PC4W) is a powerful catalyst for change. In the six years since PC4W was formed, there has been considerable progress across the continuum of involvement. This has resulted in significant capacity building towards “parent voice and choice,” particularly regarding the decisions that affect their children and families.

What is “parent voice and choice”? Until now, this concept was largely referred to as “parent/youth driven.” The concept of voice and choice began to lay a foundation for parents and caregivers, young people, tribal partners, and others to be supported in choosing the types of treatment, interventions, and supports provided (with increasing youth/young adult self-determination based on age and development). **Parent voice and choice is much more than that!**

Over the years, United Parents’ engagement of parents and caregivers has been developmental, having progressed along a continuum. To initiate relationships, United Parents started at the beginning, but as PC4W grew, engagement rapidly progressed to higher levels of parent/caregiver involvement on the continuum. Any stage of engagement in participation can be entered at any time with intentionality.

Engagement and amplification of parent voice by United Parents is based on the “Spectrum of Public Participation” developed by the **International Association for Public Participation**¹ (IAP2)—an international professional organization that works to advance the practice of public participation globally.

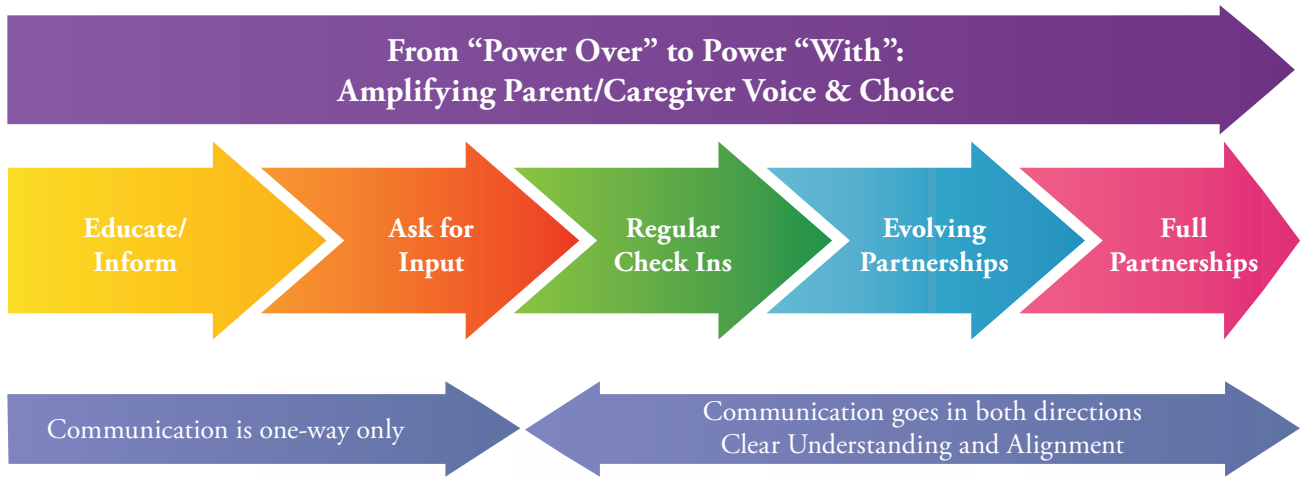
The version adapted from this model by UP (depicted below), is called, “Parent/Caregiver Co-Powering Continuum of Engagement”. It details what it takes to move from “power over” to “power with”. Essentially this means parents and caregivers are increasingly recognized as full, capable partners and over time take on increasing responsibility for implementing their own voice and choice.

“Thank you for helping us realize we as parents and caregivers’ matter. I was able to come together with others and understand we can make a difference in building a better future for our children and families.”

- Evelyn Cortez

¹<https://www.iap2.org/page/pillars>

Parent/Caregiver Co-Powering Continuum of Engagement



	Educate/ Inform	Ask for Input	Regular Check Ins	Evolving Partnerships	Full Partnerships
Goal of PC Engagement	We let parents & caregivers know about what is happening, availability of services, pending legislation, etc.	We ask parents & caregivers for their input, opinions, needs and what is working, what is not working.	We work with P/Cs consistently to make sure we understood their concerns and are acting on them appropriately.	We look to your for solutions, and stick with the exchange until you confirm your preferences are reflected.	You are at the table. You make the final decisions.
What We Tell Parents & Caregivers	We are a reliable source of accurate information.	We want to hear your needs and concerns, and may provide more information related to them.	We work with you to help make sure your concerns are reflected in services, programs and policy.	You know what you want and need, and have good ideas about what it takes to address your needs.	We will work to make sure your decisions are implemented.

Stages of Parent/Caregiver Co-Powering

1. Educate/Inform

The goal of an educating/informing process is based on the belief that service providers and decision makers know things that parents/caregivers do not know. When we merely educate or inform parents and caregivers, they are largely passive recipients of information, although they may use the information they receive at a later time (e.g., “just in time parenting”). *When it is effective*, the information shared with parents/caregivers is as objective, accurate, and up-to-date as possible. *The process of educating/informing can be ineffective*, or even harmful, when staff or decision-makers are not fully transparent and withhold important or essential information. Staff or decision makers may do this, at times, because they themselves do not know, or when the information they provide is biased or outdated.

For example, making a referral for concrete supports in times of need, such as emergency food, can make a parent/caregiver feel they are getting the “run-around” (or that goods and services are withheld) when the pantry says, “we ran out last week,” but the parent was told they have availability. It can undermine the credibility and motives of the person providing the information in the first place.

2. Request Input

A step closer to engagement is requesting input from parents and caregivers on what they need, and how their needs can best be met. Parents and caregivers contribute their viewpoints, opinions, or preferences, and then those in control of policy or resources use this information to make their own decisions. *This and the previous step are both examples of one-way communication—giving something to parents/caregivers (information) or taking from parents/caregivers (their opinions). There is no feedback or reciprocity.*

Merely asking for input, but not taking it into consideration, or when important stakeholder groups are not asked in the first place (such as youth or BIPOC² communities), can create challenges. As a result, parents and caregivers sometimes feel as though a large amount of their time has been taken (often without compensation), and that nothing really happens. Parents and caregivers can feel manipulated, or as though service providers or decision-makers are merely “checking a box” by asking for input, but then proceed to do “what they want,” or what they “had been planning all along,” regardless of input from parents/caregivers.

²Black Indigenous People of Color

3. Check-in Regularly

When we check in regularly, we are beginning to build in reciprocity: two-way communication. Those requesting input summarize what they heard to see if they understood correctly. The conversation with parents and caregivers evolves to solutions about the input given. In this way, parents and caregivers are actively involved in a decision-making process organized by those gathering their feedback. *When this works well, parents and caregivers are involved in meaningful roles* (e.g., by training them to be facilitators or giving them some degree of leadership authority, such as chairing a committee). *Regular check-ins alone can become problematic*, however, when leaders and organizers do not provide the training, education, encouragement, or other forms of support that parents and caregivers may need to participate fully or competently. Sometimes the opportunities provided for parent and caregiver involvement feel inauthentic.

For example, engagement opportunities feel inauthentic when leaders are “forced” by policymakers to involve the public in a decision-making process, and then they merely go through the motions for the purpose of compliance, or when leaders unilaterally overrule participant decisions they disagree with. This is an example of exercising “power over”.

4. Evolving Partnership

The hallmark of an authentic partnership is when parents and caregivers are actively involved in each aspect of the decision including the development of alternatives and the identification of the preferred solution. There is a true collaborative process, where leaders and public officials work in partnership with parents and caregivers to identify problems and develop solutions. When it works in the way it is supposed to, *genuine collaborative processes and partnerships give both leaders and participants equal status*, even though those who hold the power share some degree of control (“power with”), or decision-making authority with participants.

5. Full Partnership

Full partnership can be a co-powering process in which the final decision-making is in the hands of parents and caregivers. In a co-powering process, leaders and public officials may partially or entirely turn over control, management, or decision-making authority to parent and caregiver participants.

UP/PC4W is working towards this kind of full partnership where parents and caregivers are trusted with decision-making authority.

Strategies for Building Ongoing Parent and Community Engagement

According to Casey Family Programs, authentic voice and choice³ are achieved when birth parents, relative caregivers, foster parents, and youth in care or alumni of care “provide ongoing and meaningful input and leadership that the system then utilizes for continuous improvement.” The feedback and expertise provided by parents and caregivers comes from their own knowledge of their needs and their personal experience in receiving services and navigating through complex service systems. This feedback/input, or “voice and choice” should be used to develop service plans; improve existing programs and services; figure out what new supports and services are necessary as parents/caregivers needs evolve; and identify how to achieve the best possible wellness outcomes for their families, while advancing system change.

The process of moving to “power with” from “power over” to amplify parent voice and choice starts with some basic considerations:

- 1. Deep understanding of context and meaning** for parents as well as provider organizations. At times, despite good intentions on the part of many, harm has been done to families by systems and approaches that did not consider their needs and preferences; served as “gatekeepers” to needed services; and/or broke trust by not following through.
- 2. Willingness and capability to adopt an adaptive mindset.** Authentic, sustainable engagement is uncharted territory for many. It requires us to realize we cannot do what we have done in the past to achieve different results; rather we must be willing to step out of silos, known best practices, and positional authority to bridge person-to-person relationships.
- 3. Becoming an Equity Ally.** Nicole Asong Nfonoyim-Hara, the Director of the Diversity Programs at the Mayo Clinic, defines the act of allyship as “when a person of privilege works in solidarity and partnership with a marginalized group of people to help take down the systems that challenge that group’s basic rights, equal access, and ability to thrive in our society”.⁴

An example might be when a decision-maker ignores or speaks over a parent or caregiver, explaining the topic from their perspective as if their thoughts are more important than those of the parent or caregiver. An ally would step in to stop the exclusion from happening and invite the parent or caregiver to finish speaking. To be an ally is to be an advocate, and one who addresses harm and makes change to prevent further harm from occurring.

³<https://www.casey.org/constituent-voice-choice/>

⁴<https://www.edi.nih.gov/blog/communities/what-allyship>

Parent/Caregiver Engagement for Co-Powering Criteria

Recommended Strategies

Engagement starts from the very beginning. Be mindful of everything you do; do it well and with measured intention. Start by utilizing a team approach. That way team members feel supported, and parents/caregivers have continuity when there is staff turnover.

VISION

Have a clear vision on how to engage parents/caregivers by.

- Using their preferred language
- Going to the places they and their children frequent

LEAD WITH WELLNESS

Using a strengths-based, trauma-informed wellness approach could mean

- Drafting a list of questions to ask parents to get them engaged and ask if they would like to be more involved in their child's well-being
- Eliminating judgment and do not ask WHY questions but more HOW questions

STAFF CAPABILITIES

Ensure the staff have the ability to connect with the parents and caregivers. To the greatest extent possible, all staff should

- Be a parent or caregiver themselves (shared perspectives and credibility)
- Speak the first and/or preferred language of the parent or caregiver
- Understand the parent's culture from an "inside/out" perspective:
 - Staff knows how to navigate and bridge cultures
 - Staff understands how their own culture(s) impacts their life choices
 - Staff approaches parent/caregiver with cultural humility
- Be empathic and sympathetic to the parent/caregiver's needs/asks
 - Staff understands and respects that the parent/caregiver knows what they need
 - Staff always approaches parents and caregivers with empathy, genuineness, and respect—never with a checklist, or sense of "doing a job"

RELATIONSHIP MATTERS

- Make a positive connection with parents:
 - Focus on strengths, while also not dismissing the challenges of the family
 - Focus on power "with," not power "over"

Implementation and Sustainment of Parent Participation and Voice

Recommended Plan

Once parents and caregivers show initial interest, it is vital to foster and sustain participation at increasing levels of influence, given parent's time and interest.

- 1. Team Approach** First and foremost, have a dedicated team or committee that oversees parent engagement/involvement.
- 2. Meet on Their "Turf"** To sustain parent participation and voice, meet parents and caregivers where they are, in the language they prefer in a trusted environment. Be consistent with the meeting location, time, and expectation.
- 3. Hospitality/Welcoming Environment** Allow parents time to engage with one another and "break bread" by providing food/meals with items they are familiar with consuming.
- 4. Foster Parent/Child Positive Interaction** Provide childcare allowing the parents to feel close to their children but giving them a separate space to open up and freely discuss their needs/strengths. Including the children in on the conversation but in their own space. Encourage the children to talk to their parents openly and to share their own struggles and strengths.
- 5. Mutual Assessment** Ask parents their opinion on their child's needs. Let them know that their voice matters and is important in influencing positive change.
- 6. Catalyze Community Connections and Influence** Provide the parents/caregivers opportunities for community engagement and involvement in their child's wellbeing. Conduct mock council meetings to prepare parents/caregivers for a potential opportunity to apply this skill in a real setting. Schedule opportunities for parents to attend local city council meetings. Introduce parents/caregivers to key decision makers in their community.
- 7. Shared Knowledge = Power** Provide training for the parents/caregivers to instill more confidence including their role as a parent and their rights as parents in disciplining their children; culturally effective parenting; technology use and how to effectively use and communicate using technology; understanding the systems and removing stigma associated with system involvement.
- 8. Be Real** Transparency throughout the whole process is key in maintaining parent trust; letting them know the objectives, goals, the process, and their role throughout. Reiterate the importance of their role in the process.

Building Ongoing Parent and Community Engagement

On the Ground Insights

United Parents (UP) has drawn additional lessons learned that are applicable to the field from a time when they were scheduling and hosting discussion sessions. They discovered what worked and what didn't work when engaging community. There were hard, but good lessons along the way that led to a deeper understanding of the best strategy for working with a particular community, as well as other communities.

These insights are shared here in hopes they will spark and inspire your work in engaging families/caregivers and sustaining their participation over time. *Most importantly, support the parent's/caregiver's mental/physical health and well-being as well as those of their children.*

Engagement Process/Approach:

- 1. Refrain from “Alphabet Soup” and words that hold stigma.** Do not use unfamiliar jargon or words that remove engagement including “mental health” or “special needs”. Use words like “wellness”.
- 2. There are many “right” answers.** Be open to more holistic styles for wellness.
- 3. Listen to the parents/caregivers and put what they say into action.** Parent/caregiver time is important and they should never feel that their time is being wasted and their voices are falling on deaf ears.
- 4. Guard privacy so parents/caregivers choose when and how to share.** Provide space for sharing their fears and concerns- not in a group setting. Families are struggling and might feel either ashamed or embarrassed to discuss their deficits/needs in a group setting.
- 5. Remember it is a family affair!** Make sure that all family members are involved and there is support for each of the family members including fathers, mothers, grandparents, siblings, etc.

How to Structure Engagement:

- 1. Timing is Important.** Consider parent/caregiver work schedules when scheduling events. Host on weekday evenings close to dinner time and offer WARM and culturally appropriate meals. Weekends also work, but Sunday afternoons may work best because some families like to attend church.
- 2. No one likes the “run around”.** Provide a “one stop shop” that is hosted at the same time and same location at least weekly.
- 3. Basic needs come first and meeting them builds trust.** Families need basic necessities and are more likely to attend and engage if food, clothing, or medical attention is provided.
- 4. Make the message accessible.** Use a variety of written communication methods, such as flyers, signs, door hangers, newsletters, letters, postcards, monthly calendars of events, Web sites, social media, text messaging, and e-mail messages. Keep in mind that some families are not able to read or write so having outreach workers and other parents/caregivers attending local events to verbally discuss parent involvement.
- 5. Create On-Ramps.** Provide a variety of volunteer opportunities that could lead to long-term job opportunities.
 - Parent/Caregivers:**
 - Encourage parents to serve as ambassadors for their community.
 - Invite parent volunteers to lead exercise groups, cooking meals for meetings and invite their children and other family members.
 - Community Partners:**

Invite community partners who provide health services for children AND parents to talk about their services, mission, partners, and ways they can collaborate with the families.

Implementation of Parent Voice and Choice Checklist

This toolkit lays out how to effectively engage with parents after they express initial interest. The Recommended Plan on page 8 provides guidance for steps to be taken while pages 9-10 dive deeper, providing insights from United Parents’ work on the ground.

The checklist below is provided as a tool that follows the **Recommended Plan**.

	We Are Already Doing This	We Have Plans To Do This	We Need To Make A Plan To Do This
Team Approach			
Meet on Their “Turf”			
Creating a Welcoming Environment			
Foster Parent/Child Positive Interactions			
Mutual Assessment			
Catalyze Community Connections and Influence			
Shared Knowledge = Power			
Be Real			

