**I. Welcome** – Consent to be audio recorded and sign in. Provide parking passes

**II. Dianna completes her introduction** and introduces Laura Fennimore RN, DNP as the recorder (Director of Clinical Programs, Medicaid, Special Needs Plans and Children’s Insurance Plan, UPMC Health Plan - in Pittsburgh PA). Reiterates group’s purpose and describes focus group format (fluid, open group discussion, can ask each other questions, disagree, etc – facilitator will move things along to assure we get what we are seeking).

**III. Ground rules**

* Confidential – “what happens in Vegas, stays in Vegas”. Transcript will be de-identified and while quotes from the meeting will be used, no names will be attached “
* OK to “pass”. Only share that with which you are comfortable.
* Differences of opinion are great and appreciated. This helps us learn more about the range of experience and ideas parents may have. There is no “right answer”.
* Watch “air time” so everyone has a turn. Some people jump right in and others take a few minutes to talk. We want to hear from everyone.
* There may be times that I have to change the subject of offer a new question to make sure we get the input we need. This could be frustrating, so please bear with me. There will be a chance at the end to share things that are important to you that we did not have a chance to discuss.
* There may be some questions we don’t get to, and there may be some new topics to discuss if something interesting comes up as we talk.
* Results will be anonymous, put together in group form, so no one will know who said what. This information will help us to be sure the people who are designing a pilot project using CDA’s hear about what is important to you.
* Other ground rules you want to add? Any questions?

**IV. Round Robin Participant Introductions**: Tell us about your children and family? What does your child enjoy doing? What is his/her personality like?

**V. Challenges**  . Now we would like to discuss your top 1 or 2 frustrations that you may have with “health care”, particularly as it relates to caring for your children. (what works/doesn’t work)

 Prompts if needed:

* Are there barriers that may be preventing you from better managing you or your family’s health?
* Access to providers / care
* Out-of-pocket costs
* Coordination between various doctors
* Access to durable medical equipment
* Things you wanted and thought insurance would cover but did not
* Rules that don’t make sense.

Would any of these have improved your child’s health? Avoided illness/hospitalization? Improve child/family quality of life? Probably cost less?

**VI. Consumer Directed Accounts.** A Consumer Directed Account is an account that would have some money available to you to spend on things not usually covered by your insurance or unavailable through other Medicaid programs. For example, housecleaning/washing machine, Boost nutrition (e.g., items or services). This would be part of a plan of care (probably annually) that you create with your provider/case manager or care coordinator.

* What are your initial reactions to hearing about this concept?
* Is this something you would be interested in?
* What is positive about it?
* What do you think would be the biggest challenge to using this program?
* What challenges do you think could be a part of this program.

We are especially interested in getting your feedback about what would be most beneficial to have in a program like this.

* What would be/would (item, service) have been most useful to you?

Potential Prompts/Examples:

|  |  |
| --- | --- |
| Nursing/respite care | ‘Non-medical’ items that would help my child |
| Family member to provide care to child | Companion services |
| Home/vehicle accessibility | Adapting appliances/equipment (e.g, bicycle) |
| Transportation | Gym membership |
| Illness prevention | Other therapy |

* Would you want to purchase these directly?
* Pros/cons for having an annual ‘account’. Would you use this program is you had to pay for goods and services first, but would be reimbursed later?

**VII. Care Plans/Planning** – things that you would purchase through a CDA would be based upon goals in a care plan that a care coordinator would help you prepare.

* What do you think about this?
* Where should the care coordinator be? Pros/cons in your PCP’s office?
* How should planning happen? (Meetings, phone, frequency, etc) what would work/not work?
* Other thoughts about this?

**VIII. Final** comments and questions from participants. Go around the room and give each person a chance to say one or two last things.

**IX. Any questions**, comments from Laura Fennimore

**X. Next steps** (report prep and send to families for feedback;.

**XI. Thank you’s** – distribute gift cards, ask if participants would agree to be acknowledged as contributor and sign a form indicating this.