

## Priority Research Questions—Caregivers in Oakland

1. What would an integrated, coordinated system for management of chronic conditions that also meets development and family needs look like?
2. How do we design a system to pay for healthcare across the lifetime of children with chronic conditions?
3. How can we better support young people who experience social isolation or hurtful social encounters because of their condition?
4. Who will advocate for my child when I'm no longer around?
5. How to ensure continuity of information between providers: how can we make sure specialists know what's going on and are on the same page? what can be done to better support families with specialists from different institutions?
6. How can you connect with the healthcare system when you don't know it? How to find information?
7. What support can be provided to my child's mental health especially when she doesn't feel comfortable talking about her condition with others?
8. What can be done to better prepare/ manage the transition for young people from pediatric to adult care?
9. How can you support young people to be individuals when they don't always have capability or have fluctuating capabilities? How can parents be supported to support their child when they no longer have medical authority, but the young person has many chronic illness needs and still needs support?