



# **Oregon Integrated Care for Kids**

## **Parent, Youth and Young Adult Advisory Group (PYYAG):**

### **Summary of Input Collected in 2020 and 2021**

#### **Table of Contents**

Background about the PYYAG .....	4
Parent, Youth, and Young Adult Advisory Group.....	4
Recruitment of the Parent, Youth, and Young Adult Advisory Group .....	4
Eligibility Criterion.....	4
Compensation .....	5
PYYAG Members .....	5
Activities Conducted to Date .....	6
Key Learnings from PYYAG on Needs, Opportunities and Barriers to Integration of Care for Health Complex Children.....	6
Opportunities- When it Works and Why .....	7
Services where they live and with trusted people.....	7
Wraparound services .....	7
Inpatient services for behavioral supports that allow for connection to families.....	7
Providers Who Care About and Create a Full Picture of the Family .....	8
Barriers.....	8
Care coordination is put on the family .....	9
Primary Care Homes Play a Critical Role, But Not the Only One for Children Who Have Complex Medical Needs, Behavioral Health Needs, and Are in School.....	9
Competing demands in getting services and barriers to fidelity of services .....	10
Lack of Communication and Coordination .....	12
Burden of paperwork and forms.....	12
Lack of coordination between health and schools .....	12
Insurance coverage .....	13
Child-specific care coordination that doesn't take into account the family unit and competing demands within the family .....	13

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Medicalized models of care coordination.....	13
The COVID-19 Pandemic .....	14
Suggestions from the Group Members .....	15
Case Management .....	15
Centralized Information and Centralized Supports Across Different Providers .....	16
Address Gaps in Access To, Capacity of, and Coverage of Key Services .....	16
Specific Feedback to OHA Informed by the PYYAG .....	17
Advisory Council of Parents, Youth and Young Adults .....	17
Focus on the Family as a Unit: Create Policies, Structure, Processes and Payment Models that Will Ensure a Family Focus .....	17
Strong primary care homes are necessary, but not sufficient to meet the coordination needs of children with medical complexity and behavioral health needs. ....	18
Gaps in Access, Services, and Coverage.....	18
Behavioral Health.....	19
Inpatient Behavioral Health .....	19
Wraparound or Comprehensive Care Supports.....	20
Dental Care .....	20
Paperwork and Eligibility Criterion .....	20
Community Engagement and Coordination with Schools .....	21
Adolescents Transitioning to Young Adults .....	21
Conclusions .....	21
Appendix .....	22
<b>Appendix A:</b> Detailed summary and descriptive information about PYYAG Members. ....	22
Betty Thunderflower .....	22
Cordelia Johnson.....	22
Rose Texas.....	22
Hailey Lynn.....	22
Roland Cheshire and Brooke Gaines.....	22
Bre Reid .....	23
<b>Appendix B:</b> PYYAG Care Maps.....	24
Betty Thunderflower .....	24
Cordelia Johnson.....	26

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Rose Texas.....	29
Hailey Lynn.....	30
Roland Cheshire .....	31
Bre Reid.....	32
<b>Appendix C: Summary of Findings Presented to OHA.....</b>	<b>33</b>



## Background about the PYYAG

The Integrated Care for Kids (InCK) Model is a child-centered local service delivery and state payment model that aims to reduce expenditures and improve the quality of care for children under 21 years of age covered by Medicaid through: 1) Prevention, 2) Early identification, and 3) Treatment of behavioral and physical health needs. The Oregon Pediatric Improvement Partnership (OPIP) served as the lead organization for the InCK Model, working in close partnership with the state's Medicaid agency, the Oregon Health Authority (OHA). OPIP's vision is to create a meaningful, long-term collaboration of stakeholders invested in child health care quality, with the common purpose of improving the health of the children and youth of Oregon. A key component of OPIP's vision was to ensure that the voices of children and their parents drive and inform the improvement efforts needed. OPIP and community partners worked together during the pre-implementation period to try and develop a model that was designed to ensure systematic integration of child services and targeted integration of care coordination and case management for families that experience medical and social complexity so that families receive an integrated experience of care.

### Parent, Youth, and Young Adult Advisory Group

A core component of OPIP's mission and vision is to ensure that improvement efforts are consumer centered and consumer informed. The purpose of the Parent Youth and Young Adult Group (PYYAG) was to ensure that the persons with lived experience that would be engaged and impacted by InCK were co-collaborators in the operational development of the model and that they reviewed each component of the model for validity, practicality, and meaningfulness. The role of each advisory group member was to describe their current care experiences, share what was working and identify opportunities for improvement. They were also asked to provide input and insight on all components of the InCK Model to ensure that it was parent-and-youth-centered and met the needs of children and youth in the community.

### Recruitment of the Parent, Youth, and Young Adult Advisory Group

Recruitment for the PYYAG was completed through a snowball approach that involved outreach by the InCK Partnership Council members and local community partners. The InCK Partnership Council was comprised of key local core child service representatives with an integral role in service delivery, care coordination, and case management for that community's children. The purpose of the Partnership Council was to convene regularly and provide input on the formulation, priorities, and implementation of the InCK model and implementation. Partners were asked to share a flyer detailing the eligibility, expectations, and compensation for each potential PYYAG member.

### Eligibility Criterion

Criteria for membership included whether the child, youth or young adult would meet the Oregon proposed criteria for Service Integration Level 2 or Service Integration Level 3 based on

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experiences and needs that aligned with the data driven, system-level needs assessment that was proposed in the Oregon InCK Model. The criterion included that the child, youth, or young adult was publicly insured, resided in the InCK model region, and met medical and social complexity factors aligned with Oregon’s risk model such as: child welfare involvement, out of home placements or parental social complexity factors such as incarceration, substance abuse disorder, mental health, and other factors.

### Compensation

The advisory group members were paid for their expertise in their lived experiences. The payment was deliverable based and tied to completion of specific activities. Members were paid \$100 per hour of time attending and actively participating in meetings, \$75 for reviewing materials and \$200 for completing a care map.

### PYYAG Members

In total, there were six members, two residing in Central Oregon and four residing in Marion and Polk Counties. OPIP had planned on continuing recruitment and engagement in the fall of 2021, but based on Centers for Medicaid and Medicare Innovation (CMMI) clarifications and discussions, we paused those communications. Each member was given the choice to select their own pseudonym and their child’s pseudonym(s) for this report. **Appendix A** provides a more detailed summary and descriptive information about each member.

Table 1. Demographics of PYYAG members.

Group Member	Family Role	County	Race	Child Age Groups	Medical Complexity	Social Complexity
Betty Thunder-flower	Mother	Deschutes	White	Adolescent (14-18)	Low	High
Cordelia Johnson	Mother	Deschutes	White	Elementary (6-13)	High	Low
Brooke Gaines	Mother	Marion	White	Adolescent (14-18)	High	Low
Roland Cheshire	Young Adult					
Hailey Lynn	Mother	Marion	White	Preschool (birth-5) Adolescent (14-18)	Low	High
Bre Reid	Mother	Polk	White	Preschool (birth-5) Elementary (6-13) Adolescent (14-18)	Low	High
Rose Texas	Mother	Polk	White	Preschool (birth-5) Elementary (6-13)	Low	High



## Activities Conducted to Date

The activities listed below were conducted with the PYYAG members. Some planned activities were stopped due to CMMI clarifications that impacted the Oregon InCK Model and for which we needed clarity on before engaging the PYYAG in detailed input on our proposed needs assessment and service integration plans.

All PYYAG members:

- Participated in a 1-on-1 introduction and feedback call with an InCK OPIP staff person or Kiara Yoder, the Community Engagement Liaison for Marion and Polk.
- Completed a care map of their current care experiences.
- Participated in a discussion with InCK OPIP staff or Kiara Yoder about their care map and the plans to share and distill their care map with the InCK team.
- Participated in 1-on-1 feedback calls with an InCK OPIP staff person or Kiara Yoder to share what was learned from Partnership Council in response to the care map, to provide the member an opportunity to share about additional successes and barriers that occurred since the care map was first created, and for the InCK OPIP team to describe how the feedback obtained from them was used as part of the model design discussions and within the work streams being conducted with PacificSource Community Solutions (PCS) and Oregon Health Authority (OHA).
- Participated in a group meeting on 10/26/21 (or individual meeting if they were unable to attend the group meeting) to share about: the Oregon decision to not apply to continue the InCK model starting in 2022 and the implications for the PYYAG advisory group, a distilled summary of the learnings that will be shared with OHA and PCS to inform their ongoing efforts, and OPIP's hopes for sustaining momentum and seeking funding to continue the work.

## Key Learnings from PYYAG on Needs, Opportunities and Barriers to Integration of Care for Health Complex Children

**Appendix B** provides each PYYAG care map that was shared with the Partnership Council. We have used pseudonyms to protect the privacy of the group members. Within each care map, one can see the various services, sectors, and supports that the family is or has been involved with and the amount of care coordination burden that is put on the family or young adult. We also had follow-up discussions in order to clarify, expand, and update the care maps as well as to discuss findings and potential recommendations as a group. The following is a distillation of learnings from the discussions with the PYYAG members to be considered by OPIP, OHA, PCS, and CMMI in order to examine and include the parent, youth and young adult perspective about opportunities for and barriers to service integration.

## Opportunities- When it Works and Why

### Services where they live and with trusted people

Many services and programs provided much needed supports for families in the PYYAG. The most trusted and important services tended to be convenient in location, comprehensive in their support, and available either at any time or at convenient times such as during or after the school day. Betty noted the Independent Living Program has been instrumental in preparing her niece to live on her own by providing her with car parts for her car, helping with college applications, helping obtaining a driver's license, clothes, school supplies, and accessing medical care. Cordelia's daughter has a personal support worker that has been extremely valuable in helping with school, chores, personal hygiene for four hours a day, every day. Cordelia has also found help at the Youth Villages Program and the Stabilization Center run by the Bend police. Both offer short-term mental health support 24/7. Both Bre (a parent) and Roland (a young adult) expressed the importance of teachers in their lives and how important they are. Rose's daughter has benefited from school counselors. She appreciated when the school warned her of a change in the school counselor. Rose has also found support from her daughter's therapist who recently moved closer to her home, reducing the family's travel time.

### Wraparound services

Wraparound services have been very helpful for parents in Central Oregon. Betty had several of her children participate in programs with Wraparound services including volunteer work, help with school, and child run meetings with support providers. She notes that Wraparound can be a great program if the child is willing to do it. Cordelia received care coordination through wraparound services. The multidisciplinary team, including the pediatrician, behavioral specialist, counselor, educators, and Intellectual and Developmental Disability (IDD) professionals, come together to take on paperwork and referrals for her child.

### Inpatient services for behavioral supports that allow for connection to families

Inpatient services have been hugely useful and supportive to PYYAG members when they allow connection to families and support after checking out. Cordelia noted that a local faith-based residential childcare foster care facility, was an important part of her community. It is a community formed by several homes in one area that is managed and run 24-hours a day by house parents. Children are assigned to different houses/families, but everyone in the community has meals together.

Oxford House was a huge help to Hailey as she was adjusting to the world after being incarcerated. She lived there with her daughter and son. She has yearly reunions with the other women that were in the facility with her. They have all supported each other in staying clean and supporting their kids. Hailey credits Grandma's House, a home for pregnant and parenting young mothers and their children in Bend, with saving her life. They took her in when she was pregnant and homeless. They walked her through the emancipation process and taught her

about cooking, parenting, housing, and bills. She is still in contact with the director of Grandma's House.

## Providers Who Care About and Create a Full Picture of the Family

Families benefit when providers have a full picture of a family's life and can share or receive information from other providers. They noted the power of one agency and one entity that knew about the full needs of their children and the full sets of services. It should be noted, this was the goal and purpose of leveraging the existing child health complexity data so that the existing story and past experiences of the families could be leveraged. When a provider knows the full story of the family, they feel like the providers care about them, and it reduces the time that the family spends re-telling their story. Betty cited the citizen's review board for foster kids at DHS as being a big part of helping parents with the process. The review board is made up of volunteers who go through the case and make sure every provider involved is informed and doing their jobs. Cordelia found her experience with the multidisciplinary team at Oregon Health and Science University Doernbecher Child Development and Rehabilitation Center helpful. A group of care providers including doctors and behavioral specialists come together to discuss care for her child.

## Barriers

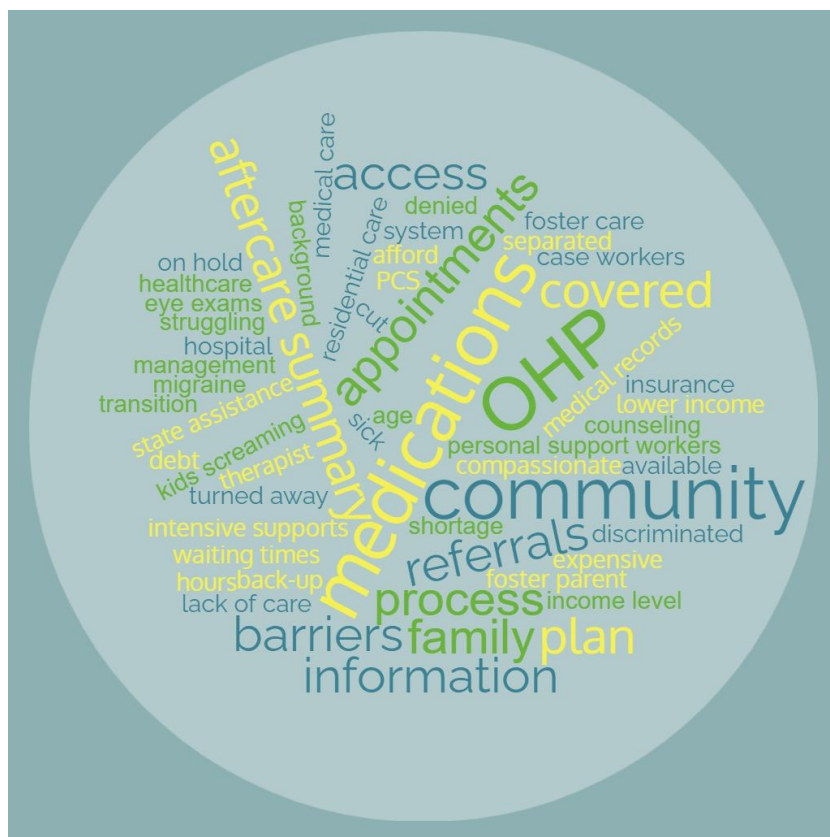


Figure 1. Word cloud of responses from group members to the question, "What barriers do you wish could be removed?"

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### Care coordination is put on the family

Care coordination falls on the families to work through the various systems with little to no support for navigating the complicated process of receiving care. Brooke and her young adult son, Roland, had a care coordinator through their CCO in the past who was very helpful. Whenever there were questions about insurance and the various therapies, the family only had to make one call to receive answers and get connected to services. At about the same time as the family lost their care coordinator, each of the five children in the family were unexpectedly transitioned from the same pediatrician that all five kids were seeing to a different family practice provider for each child.

Timely medication management has been a challenge over the years due to transitions in medication management providers and providers not agreeing with each other during those transitions. At the time of the call with Roland's family, they were dealing with the unexpected Primary Care Provider transition and the work to coordinate medication was falling on the family. The clinic would not take the family's calls about medication, so the family called the pharmacy, who would call the provider, who did not know the family (due to the sudden forced change in primary care). Roland is transitioning to adulthood and is beginning to manage his own care without parental support. It would be extremely valuable for Roland to have a care coordinator to assist him.

Hailey has also faced issues with the switch in Coordinated Care Organizations (CCOs). The dentist the family was seeing closed due to COVID-19 and the family was unable to find a dental provider that was within their community and accepting new Medicaid-covered patients, despite calling many dental offices. They currently drive over an hour to see a dentist. Prior to the change in CCO, the family would call the CCO to receive assistance in transferring providers.

### Primary Care Homes Play a Critical Role, But Not the Only One for Children Who Have Complex Medical Needs, Behavioral Health Needs, and Are in School

For many, Primary Care is not seen as the primary home or central node for communication given the level and number of services received. Brooke and her young adult son, Roland, as mentioned previously, have had great difficulty since early 2020 when they were suddenly no longer able to see the pediatrician they had been seeing for many years. It is clear that it would not be practical to rely on their primary care clinic as a central node for communication of other services. While Rose takes her child to regular checkups at the pediatrician's office, her daughter fears going to the doctor due to past experiences. The behavioral health provider is not co-located with the primary care home, nor is the therapist. As seen in Appendix B, Bre did not originally include her primary care provider in her care map at all. She has her children immunized at the local school-based health center instead of their primary care home as the school-based health center is much more accessible for the family.



## Competing demands in getting services and barriers to fidelity of services

### *Transportation*

Many families have limited resources and must travel to access care. During the weekdays, Cordelia's family can access their primary care home, which is close to their home. If the family needs care on the weekends, however, they must drive 30 minutes away. Her kids also have visitations with their birth families 2-3 times per week, which require transportation. Often, the closest specialist is over an hour away. Two of Bre's children were referred to specialists located more than an hour away by car. While Bre's family does have a car, depending on her husband's work schedule, she may or may not have access to it. The family often uses the city bus, non-emergency medical transportation, or their extended family to get to appointments. Hailey rode the city bus for a year after her license was revoked for unpaid tickets. While covered by a previous CCO, Hailey received occasional monthly bus passes to access care. She was able to get her license back only after filing for bankruptcy. She notes not having a license is a huge barrier to getting to doctor appointments as well as getting to a job, which provides money to pay for housing.

### *Access*

There are often issues with accessing appropriate and high-quality care. Cordelia has limited access to behavioral health counselors that can provide services to her daughter with IDD. Their current counselor does not have a lot of experience and Cordelia often feels like she must teach her. Cordelia is required to stay with the Deschutes County Behavioral health in order to access their psychiatrist. She recognizes this may not be the best match for counseling, but they have to stay at this facility to access the psychiatrist.

### *Availability*

Many families have a hard time finding available appointments, receiving support, or getting call backs when they have a question. When care coordination falls on the families and there is an issue with availability, this creates more work for the families experiencing medical and social complexity. For example, Hailey struggled to get a dental appointment for her children after their dentist closed. When she would call dental offices, she would not receive a call back and had a difficult time finding anywhere in her area that had available appointments. Ultimately, she was able to find a dental provider located an hour away. Rose has had issues with the long processing times for referrals. She had received a referral for medication management that took 2 months to call her and another month to get an appointment. In the intervening months, her child's medical needs were not being addressed. Hailey and other members have been on hold with Oregon Health Plan and Pacific Source for hours. On some occasions when this happens, Hailey has given up and chose to receive care at a hospital. Betty also noted long wait times at appointments. She has had to wait as long as 2 hours, which is difficult with a sick and upset child.

### *Culturally and linguistically appropriate services*

Culturally and linguistically appropriate care is important so that families feel comfortable, supported, and heard. Several families have noted the supports that their church has given them. Cordelia, Bre, and Rose have received social support from their respective churches and Hailey has received meals from local churches. Cordelia thinks her local faith-based residential childcare foster care facility is the best model she has ever seen. It is a community-based organization that includes several homes and is managed and run 24-hours a day by house parents. While the care facility's model was ideal, it was well outside of Cordelia community and the family had to travel to visit their child. When Cordelia's child had to leave her community to receive residential care, it separated her family. Hailey expressed a wish that OHP was more understanding about the importance of teeth and the effects that having damaged or crooked teeth can have on self-esteem. As she is struggling to pay for school supplies, her insurance will not cover a full root canal. Hailey has also felt discriminated against by medical offices because she is on state assistance. She believes she has been turned away because she uses the Oregon Health Plan and only recently found that there is an avenue to report discrimination. Two parents, Cordelia and Bre, spoke to the importance of in-person (as opposed to online) care and schooling.

Cordelia has a daughter who experiences severe mental health episodes. They have gone to the E.R. multiple times which has been very traumatic for the child and family. It has also been very costly for the family and the system. During one episode, Cordelia called the crisis line and was not able to receive the supports she needed. The crisis line operator was focusing on what support Cordelia had instead of making suggestions for supporting her daughter through this crisis. This was distressing and unhelpful to Cordelia during a time of crisis.

One limitation of our PYYAG is that all the members identified as white and spoke English as their first language. Future investigation into integrated care should include group members who speak other languages and come from a wide variety of cultural and ethnic backgrounds.

### *Care competes with other responsibilities*

Often parents' work schedules can make it difficult to arrange care for their children. Cordelia has a 45-minute commute and works the same hours that the care facilities are open. She has tried to make appointments for both kids on the same day, but there are barriers with availability. Brooke and her husband work full time and it is difficult to find appointments for their five children, particularly since the kids were all switched to different primary care providers. Hailey also works full time and has trouble accessing available appointments. It has been so difficult that she has given up on finding an appointment that would fit her schedule.

Hailey gave birth to her son while incarcerated. There is only one location in Oregon in which the newborn is permitted to stay with the mom while mom is incarcerated; at every other facility, the baby is taken away from the mother immediately. Hailey's son was taken

from her immediately after she gave birth to him. She was released from prison when her son was six months old.

#### Lack of Communication and Coordination

Many families noted their frustration in needing to tell their story and information about their needs repeatedly. There is little communication between services which results in a greater burden being placed on families. Betty notes that she would like to see more communication between DHS and outside therapy. Roland and Brooke have experienced issues with obtaining medications. They have been moved to several different medication managers and the prescribers have disagreed on the medications that Roland should be on. This has caused delays in receiving medications on time. The families do not feel like they have a voice in the transition to a new doctor or in the medication that is prescribed.

Betty's foster daughter was paired with a new caseworker when she turned 18. The case worker has canceled several meetings and they have not met in person yet. Emails are not returned. As her foster mom and legal guardian, Betty has limited capabilities. COPA cannot give Betty after-care summaries. The case worker has not been recording information or sharing it with others. A DHS worker came for a random check and they did not know anything about Betty's foster daughter or what they needed to check on. This resulted in additional meetings and additional days where the kids had to miss school. Betty asked why DHS can take kids out of school all day and received the answer: "That is how things are done."

#### Burden of paperwork and forms

Families often express frustration over the amount of paperwork for every entity that they need to utilize. Cordelia has to fill out 50-70 page intake forms. She suggests a central database for basic information about their family.

#### Lack of coordination between health and schools

Families expressed a desire for more communication and coordination between school and health care. Within Betty's foster daughter's high school, there are counselors for each grade, but the family wishes that therapy outside of school could communicate more readily with counselors in school. Rose and Hailey both expressed a desire for greater coordination between school and healthcare. Rose has had to take on work of organizing teachers and school officials to obtain an Individualized Education Plan for her child. Cordelia has experienced issues with receiving a dyslexia diagnosis for her youngest daughter. Medical will not give the diagnosis and refers Cordelia to the school. The school can not cover the cost for diagnosis. Cordelia is saving up money for high quality dyslexia testing. She has also tried to set up tutoring, but has not been able to coordinate that service. Cordelia also notes that the school could do more to support students with dyslexia and other learning disabilities by changing the curriculum to better suit their needs. It should be noted that, while all parents wanted more communication with the schools, not all parents wanted to work within the



school's system. Bre wanted accommodations for her children in school, however she did not want the label of "IEP" applied to her children as her eldest child, who does have an IEP, had faced physical and verbal bullying from other children due to his IEP status. All systems should be mindful of the social consequences that can come with labeling a child.

#### Insurance coverage

Some group members have had trouble getting their trusted services covered by insurance. Two of Hailey's children were referred to a mental health practitioner by their primary care provider, however insurance has not approved the visits. Her kids like this mental health practitioner; it took a lot of trust building for Hailey's nephew, Jordan, to open up to this mental health provider and Hailey is unwilling to jeopardize the gains they've made with this provider by switching to another provider. The practitioner is working to get the visits covered.

Many group members expressed a desire for more of their needs to be covered by their medical plans. Hailey would like to see housing for kids that is covered by the Oregon Health Plan and not related to drug use. She also suggested a program for adolescents and young adults to receive orthodontic and optometric care. Her family has faced bullying as a result of homelessness and their lack of access to orthodontia.

#### Child-specific care coordination that doesn't take into account the family unit and competing demands within the family

No family we spoke with only talked about healthcare for their child with the most needs. The majority of our group members (4/6) included their entire family at the center of their care map. During conversations, all the families shared their experiences with multiple children with multiple needs. While they may be able to get care for some children, the parents or other kids may have different issues or are covered by different plans. For example, Betty's family goes to two different primary care homes. Brooke's five children were all going to the same pediatrician when they received five letters indicating that each child was being switched to a different provider. In addition to the scheduling challenges this sudden change provoked, it also put the family in a situation of having to tell and re-tell their family's story multiple times. Hailey noted that her own health issues can get in the way of her child's care. She has bad migraines and has been unable to find an affordable solution. She has been prescribed a \$1500 medication that is not covered by her insurance.

#### Medicalized models of care coordination

Medicalized models of care coordination may be convenient for medical organizations, but they may not always be the best form of care coordination for families. The Care maps repeatedly showed the multiple medical, behavioral school-based supports that all contribute to health. Complex health management, across all the various types of providers and care systems is needed. At one time, Brooke's family was going to 30 different therapy appointments per month between 3 children. They made the executive decision for the health

of their family and social life to stop going to as many therapies. Prior to this change, Brooke's children said they felt that their parents were trying to fix them instead of helping them. Her family has been happier after they have transitioned away from an overwhelming amount therapy appointments. To aid this transition, Brooke attended a training about supporting people with fetal alcohol syndrome with a focus on accommodation over therapy. She has also experienced disagreements between school expectations and the medicalized model for her son, Roland. When he was diagnosed with fetal alcohol syndrome, their doctors told them not to hold expectations for Roland's future. The school pushed back on this idea with a strengths-based model that ultimately benefited Roland by incorporating him into a typical classroom and holding high hopes for his abilities.

Peer-based models may be more accessible, convenient, and comfortable for families. Hailey noted that at different points in her life, various support groups and community organizations have been crucial to her success as a parent. Hailey stated that one such organization quite literally saved her life. It got her off the street when she was underage, pregnant, and homeless and taught her life skills so that she was able to care for her infant. Primary care did not come up as a support for Hailey until the last few years (her oldest child is 15 years old). Until then, all supports that Hailey mentioned were peer-based and/or community organizations.

Social networking and other shared platforms have been important for families to connect with their peers and stay updated. Betty's foster daughter found huge support in "Text Teen 2 Teen," a text support service offered 24/7 which will answer any questions or talk about anything. Betty is part of several useful Facebook groups including groups for parents, moms, and foster parents. Bre has both found and provided childcare and transportation through Facebook groups for Polk County parents.

### The COVID-19 Pandemic

We have had the advantage of following many families through their care coordination journeys during the COVID-19 pandemic. They have shared the ways that their care has changed for the better in some cases (telehealth; increased benefits) and for the worse (lack of access to social supports; difficulty getting in-person appointments). Hailey shared that they received an increase in SNAP benefits due to COVID. SNAP has also allowed online shopping, which has made Hailey's life much easier.

Cordelia and Rose shared that spiritual health has been very important for her family and COVID has had a significant negative impact on the support they have been able to receive from their church communities. Rose's daughter loves going to church and Sunday school and has been impacted by the lack of in-person contact with trusted adults and peers at church.

Hailey has faced issues with getting dental care for her kids. Their dentist closed because of COVID and they struggled to find another dentist that was accepting new patients. They were able to find a dentist that accepted them; however, the dentist is located an hour



away, which is a burden. Bre's oldest child was seeing a behavioral health provider prior to COVID, but this stopped when the pandemic hit the region.

Online school has been a struggle for some children. Bre's children attend three different schools; all of the schools have different schedules and the schedules have changed several times. Some of her children's teachers adjusted to teaching online better than other teachers and this has been a challenge as well. Rose noted that her daughter is a social butterfly and has been impacted by the lack of social interaction with kids her own age and with the supportive adults at school. Cordelia notes that her daughter's Personal Support Worker has been very helpful in managing the change to online school. The Personal Support Worker has been able to help during school now that it is virtual. Their family has also had trouble accessing in-person care for their daughter with IDD. Deschutes Behavioral Health has virtual and in-person care, but the in-person appointments are more limited.

## Suggestions from the Group Members

### Case Management

The majority of group members confirmed that having a case manager would drastically improve their ability to manage the different services their children, or they themselves, need. Cordelia and Roland have both received case management and found it to be extremely useful, albeit temporary. In group discussions, members agreed that they would benefit from a case manager to oversee all the services that their child received including primary care, medication management, and education. Case management should also include shared platforms or sharing of information ACROSS various providers (e.g. the purpose of the health complexity data) so that the case manager has full picture of the child and child's needs. Multiple members have benefited from this type of information sharing. It is crucial that all providers are aware of the various supports and barriers that a family is experiencing. This type of group meeting has never been easier with the rise of tele-healthcare and online education during the COVID-19 pandemic. At a minimum, Hailey

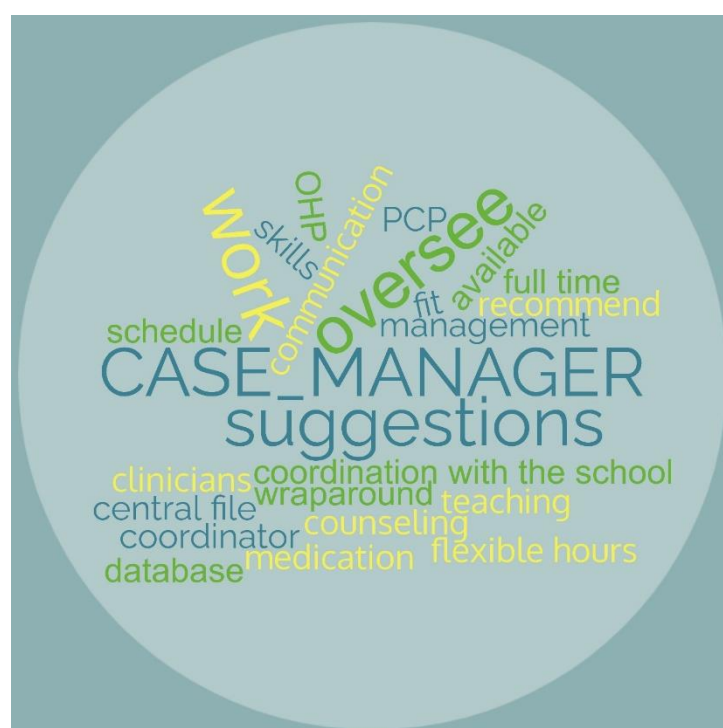


Figure 2. Word cloud of responses from group members to the question, "What do you wish existed that would help in managing, coordinating, and balancing the different services and supports your child(ren) receive and need?"

suggested a file accessible online that includes all the services a family has accessed through the Oregon Health Plan. Group members were less concerned about privacy if the purpose was clearly communicated to them before releasing any information. It should be noted, however that while some group members experienced worries about Department of Human Services removing their children from their household and facing discrimination due to their socio-economic status, none of the members shared that they faced worries about immigration issues, personal medical issues, or experiencing discrimination due to race, ethnicity, religion, gender, or sexuality. Any future efforts should include individuals experiences these worries. Hailey also suggested that greater support in the transition off the Oregon Health Plan when a family no longer qualifies would benefit both families and providers.

### Centralized Information and Centralized Supports Across Different Providers

Given the success of shared platforms and the barriers of excessive paperwork, lack of communication, and lack of availability, one of the suggestions that group members collectively agreed upon was a centralized online hub for information for all types of services. They recommended an easy-to-access online database where parents and young adults could search for doctors and services in their area and view the provider availability, accepted insurances



Figure 3. Word cloud in response to the question, "What do you wish existed that would help support you in getting your child/children the right care (or set of services), at the right time, at the right place?"

affordable prescription services, and oral health and dental care services. Group members wanted a targeted focus on **community engagement and coordination with schools** for children with medical and behavioral needs for which the system doesn't coordinate well. As was noted early the report, parents noted that if there was a priority area of focus to start with

and what approaches the providers have toward care. If a particular provider does not have availability or take the family's insurance, the database could recommend alternative options for providers that have similar approaches to care. Both Betty and Rose have had experiences where a friend or acquaintance let them know about a program, service, or specialist they had not known about. Roland recommends a mobile application for easier access. He also suggested the inclusion of emergency services on the database.

### Address Gaps in Access To, Capacity of, and Coverage of Key Services

Specific services that were noted by multiple members include: behavioral health, inpatient behavioral health,





for care coordination efforts, it would be having an experienced case manager help coordinate with the schools.

## Specific Feedback to OHA Informed by the PYYAG

In October 2021, the OPIP team summarized and distilled the recommendations that we would make to OHA, on their behalf, that take into account the stories and experiences of the members and the potential levers and opportunities that exist within existing and new CCO requirements. The recommendations were then modified and improved based on the October group meeting and are summarized in **Appendix C** which are the overview slides that were presented to each regions' Partnership Council.

## Advisory Council of Parents, Youth and Young Adults

Consider a Community Advisory Council (CAC) specific to children and youth given they are the largest age demographic covered by PCS as a CCO. This would allow PCS to hear directly from families about their needs and opportunities and would emphasize the importance of taking care of our youngest members of society from an early age. It's clear from the information we gathered from the conversation with the PYYAG that families have an important and unique voice. Their experiences accessing specialty care and behavioral health are unique to the care of children and youth. Including their voice in policy creation and changes would be invaluable.

Consider requiring CCOs to have a CAC specific to children and youth given they are the largest age demographic covered by PCS as a CCO, so that you can hear directly from families about their need and opportunities. The children and youth CAC could also include youth and young adults who are consumers. Families shared that they often feel like they do not have a voice in the care of their children including what procedures gets covered, where their services are located, and which providers their children are paired with. As was demonstrated by the information gathered from our conversations with the PYYAG, listening to family's experiences and implementing their suggestions would go a long way to providing integrated care in a way that is patient informed and addresses the needs of the families.

## Focus on the Family as a Unit: Create Policies, Structure, Processes and Payment Models that Will Ensure a Family Focus

Consider models that support a family unit of analysis and family-based care coordination for health complex children. As was clear from the experiences shared by the PYYAG, the families do not think of their children with health complexity as separate from their other children, themselves, other adults in the family, or the family unit. Considering the entire family in care coordination has the potential to save time and resources for the families as well as CCOs.

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Strong primary care homes are necessary, but not sufficient to meet the coordination needs of children with medical complexity and behavioral health needs.

Overall, the interviews with the families with health complex children sounded like interviews that happened before CCOs were established. OPIP's front line experience has been that while CCOs have positively impacted access to care and a focus on prevention, children with health complexity have largely not seen any positive impacts on their coordination of care. The programs that may exist in the CCO that are meant to support access to care and prevention, were not really offered to the parent or focused on their care management needs.

Care coordination cannot live solely at or rely solely upon the Patient-Centered Primary Care Home (PCPCH). The PCPCH is not the central node nor place of support for some medically and socially complex families. Many families in our group did not indicate their primary care home as an important part of their care coordination. It is important to meet families where they spend the most time and feel the most comfortable. For some families in our group, their child's school was an important central location where they received many services. For others, they received care from accessible programs, like the Independent Living Program or transitional facilities, such as the Oxford House.

While investments in and priorities around the role of PCPCHs are imperative, there needs to be a focus within the metrics and requirements for children who are medically complex and who have socially complex families for whom the PCPCH is not the centralized node. Some families did not include their PCPCH at all in their discussion about the care that they receive, while others experienced issues when their children were moved to different PCPCHs without family input. These investments must include a focus on hospital discharge coordination, specialty services as well as community and peer-to-peer supports with an explicit requirement and focus on children.

Investments in community and peer-to-peer supports are a critical and essential component of the model and cannot be dependent on access to primary care. Families shared that peer-based supports were instrumental in receiving care and life skills for adolescents. The peer supports mentioned by parents often included elements of in-home supports or technology-based, just-in-time supports like a texting line or a Facebook group. The availability of peer-based supports along with the comfort families feel when communicating with people who understand them are critical to their success and utility.

### Gaps in Access, Services, and Coverage

Consider barriers to access based on location and availability of culturally and linguistically appropriate care. The majority of our PYYAG members lived in rural or suburban areas that often have limited access to their best-matched care. Transportation issues can result in missed school or difficulty finding an appointment outside of work hours. Not all families have reliable transportation. It is particularly difficult for families living in rural areas to find appropriate

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specialists for their child. Lastly, nearly all noted barriers to accessing behavioral health supports.

For children with complex chronic conditions, the additive barriers that exist in obtaining care in the Portland metro region also need to be considered. Families in rural regions are often referred to specialists in Portland which can be hours away and require full days off work or school. This makes it difficult for the families to plan and schedule their visits around school and work responsibilities.

While all our members spoke English, in order understand a family's values, providers must be able to communicate complicated concepts with them. Similarly, all our members identified as white. It would benefit OHA to include culturally and linguistically diverse families in future endeavors meant to create and ensure complex care coordination for children covered by Medicaid/CHIP.

### Behavioral Health

Coordination of and facilitation of specialty and behavioral health services would be a high priority topic of centralized supports. Many families that were part of the PYYAG received essential care from specialty and behavioral health services. They also had issues receiving that care due to distance, access, and availability. Prioritizing specialty and behavioral health care would allow for children to receive more support and care in the areas that families deem essential as well as give the children the supports they need to maintain and improve their health. Addressing the gap in availability of behavioral health services should be a priority service for all members. For one family, they stopped going to behavioral health when COVID-19 mandates limited the number of non-essential services offered. Another family had trouble finding a behavioral health provider that was experienced and knowledgeable about their daughter's intellectual or developmental disability. They also experience issues with the crisis line operator not understanding the needs of their family during a moment of crisis. During this situation, they decided that the emergency room was their only option to access care even though it had been traumatizing for the family and child in the past. Increased access and availability to behavioral health services is an important part of helping families access best matched care.

### Inpatient Behavioral Health

Of the PYYAG that needed urgent mental health supports, their experiences with urgent mental health care that required emergency room care was traumatic and difficult. Exploration of creative models that can support families when their child has urgent mental health needs and easy, trauma informed pathways to these services when parents are experiencing these episodic breaks is critical. This was particularly true for members that resided in rural regions with no easy in-patient access they knew about, aside from the emergency room.

### Wraparound or Comprehensive Care Supports

Care coordination for some families takes a long time – firstly, to build trust with the families and secondly, to assist doing the ongoing care coordination that families require. Consider a pathway within the CCO’s care coordination department for socially and medically complex families who need care coordination services for much longer than three months. Several families in our group faced struggles when their care coordination with the previous CCO ended, especially when they were faced with a transition such as their child becoming a young adult responsible for their own care. Families often found it difficult to adapt when the services that they were paired with closed or changed.

Develop centralized supports and consumer facing connections that have relevant information and context about the family that helps avoid forcing the family to tell and retell their story and which provides easy access to barrier busting. Multiple PYYAG members would benefit from more centralized support. It would reduce extensive paperwork that the families are required to fill out during intake with new providers. This would also address the issues families have with medication management and providers not having the proper context when families attempt to access medication or have questions.

### Dental Care

Families also expressed a desire for their insurance providers to understand their values when it comes to the importance of dental and orthodontic care. Several members noted significant barriers to access of dental services where they live and provider reluctance to provide the services covered by OHA.

### Paperwork and Eligibility Criterion

Health complexity data and ongoing sharing with CCOs is a way to help parents avoid having to retell their story. The next step would then be USING the data to meet the needs and desires that the parents noted – of having one person (or agency) USE that information to provide better case management services. Families noted the value of a person (case manager) not in one system, but that can obtain information from the various system and provide coordination and integration of care – such as the CCO. One tool that the entity can use to complement the information in the health complexity is to have the parent or young adult to complete a care map at the beginning so that they can note their strengths and pain points around coordination and integration can be considered. An important component of this conversation would then be to understand if the family has experienced issues with continuity of care when children are switched to different primary care providers or different medication managers. The reason we note this is because lack of continuity or shifts result in increased issues with transportation, obtaining convenient appointments, and receiving medication in a timely fashion. Parents have also expressed annoyances and frustration when having to fill out forms that are as long as 70 pages. Having a connected system would alleviate the burden currently placed on families to repeat their story and maintain continuity of care.

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Specific services identified over the course of the InCK efforts which streamlined eligibility could include WIC/SNAP, Preschool Promise and other early learning programs that require an income eligibility criterion, and automated coverage of a specific “package” of behavioral and specialty services based on medical and social complexity indicators.

### Community Engagement and Coordination with Schools

There was a strong consensus in the PYYAG that better communication and coordination between schools and medical providers would benefit the health of their children and reduce the coordination burden that families carry. In some communities, the workflow and communication between medical practices and local schools is thought out and established, making this process much simpler. In one community there is a school-based health center, which allows for ease of access for the family as well as direct communication between school and medical staff. In the communities where such workflows or centers do not exist, the onus falls on the family to communicate between the two entities effectively and accurately.

### Adolescents Transitioning to Young Adults

For adolescents who have medical and social complexity, the transition of care from parent to youth can be a difficult one. The young adult participant in the PYYAG is learning, both from his parents as well as his special education classes at school, what is needed to take care of himself once he is 18. This adolescent has extra resources at his disposal, as he qualifies for Developmental Disabilities services as well as a Personal Support Worker. Despite these additional resources, if this young adult did not have his family to support him, at this point in his life he would not be able to keep track of appointments and follow through with the plan of care after appointments. A care coordinator would help enormously with this process.

### Conclusions

The OPIP team is grateful for the time and input received from each member of the PYYAG. The PYYAG provided an essential perspective on the key components of the InCK model by including the voices of persons with lived experience that the model was designed to impact. Through conversations about families’ current and past care experiences, they were able to provide invaluable insight into the current experiences of those enrolled in Medicaid/CHIP and the significant gaps in coordinated, integrated, and family-centered care that is meant for them to receive. The PYYAG members expressed sadness that the InCK effort was ending given the improvements needed and given the unique opportunity they were provided to inform and guide the effort.

## Appendix

### Appendix A: Detailed summary and descriptive information about PYYAG Members.

#### Betty Thunderflower

This family is from Deschutes County and includes two parents, a foster daughter, and two biological daughters. Their 18-year-old foster daughter, Molly, is their niece and experiences medical and social complexity. She is in speech therapy and sees a sleep specialist. She received WRAP services for depression, anxiety, and social anxiety.

#### Cordelia Johnson

This family is from Klamath in Deschutes County and includes one parent and two adopted daughters. Cordelia is a special educator and works in early childhood education. Both daughters have special needs. The youngest, Tina, is 9 years old, receives in-home supports, has asthma, chronic illnesses, and has gone to the emergency room for mental health multiple times. The older daughter, Emmie, is 12 years old and experiences anxiety and an intellectual delay. She sees a speech-language pathologist and an occupational therapist. Her youngest daughter experiences dyslexia, but her dyslexia is unidentified in the system. Cordelia has chosen to keep her girls connected to their birth families as much as is safe and is possible.

#### Rose Texas

This family lives in a large town in Polk County and includes two parents, an 8-year-old daughter, Lucy, and a 2-year-old son. Rose works for a peer child and family services organization and is a support for parents who are involved with child welfare. Lucy experiences attention deficit hyperactivity disorder (ADHD). She sees a nurse practitioner for medication management and sees therapist on a regular basis.

#### Hailey Lynn

This family lives in a small town in rural Marion County and includes one parent, one 15-year-old daughter, Mavis Lynn, one 15-year-old nephew, Jordan Cade, and one 5-year-old son, Able Cade. Hailey works for a community-based child and family services organization. She helps parents navigate through self-sufficiency systems. Hailey was a teen mom and has been involved in many systems herself along with her children. Mavis and Jordan are both receiving mental health care and are in weekly 1:1 counseling. Mavis had an IEP for many years, though currently is on a 504 plan. Able received speech therapy and behavioral support services from Willamette ESD and will continue to receive behavioral supports when he transitions to kindergarten.

#### Roland Cheshire and Brooke Gaines

This family lives in urban Marion County and is a blended family. The PYYAG participant is a 17-year-old male, Roland, however, his stepmom, Brooke, also contributed to the conversations to give familial context. Roland lives with his dad and stepmom, two stepbrothers



(ages 20 and 17) and two sisters (ages 13 and 12). Of the five children, two have IEPs (including the participant) and one has a 504. Roland has fetal alcohol syndrome, major depressive disorder, and suicidal ideations. At school, he is in a special education classroom for part of the day and is in general education for part of the day. He has a case manager and sees a speech pathologist at school. He has been involved with many different medical specialists in the past, but at the current time is not in need of as much medical care.

#### Bre Reid

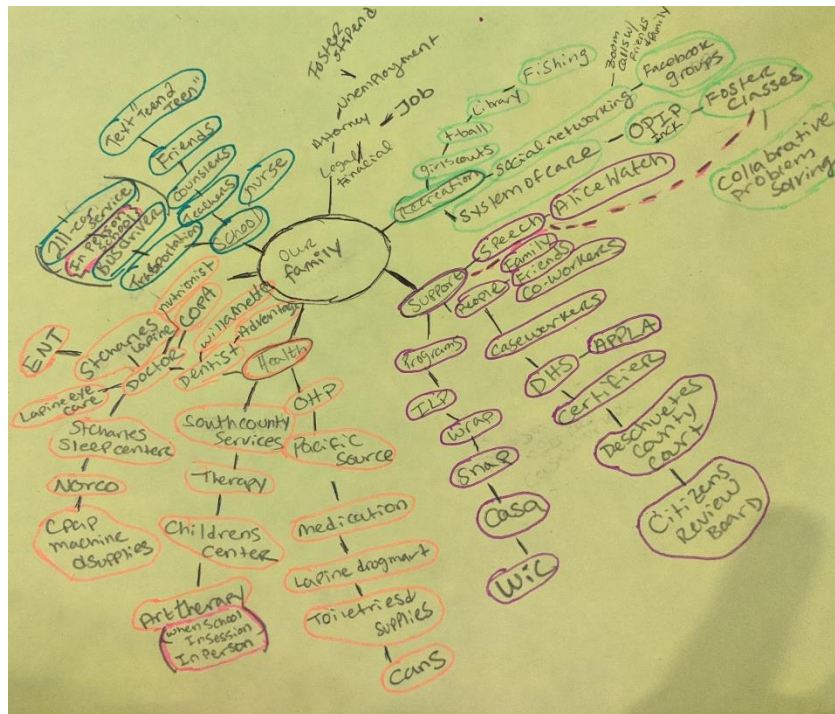
This family lives in a small town in Polk County and includes two parents and seven children, ranging in age from infant to 15 years old. The 15-year-old, Tyler, receives speech therapy services through the school and, prior to COVID, saw a behavioral health specialist at a private clinic. Both the 4-and-6-year-old see a pulmonologist and a different provider for asthma.



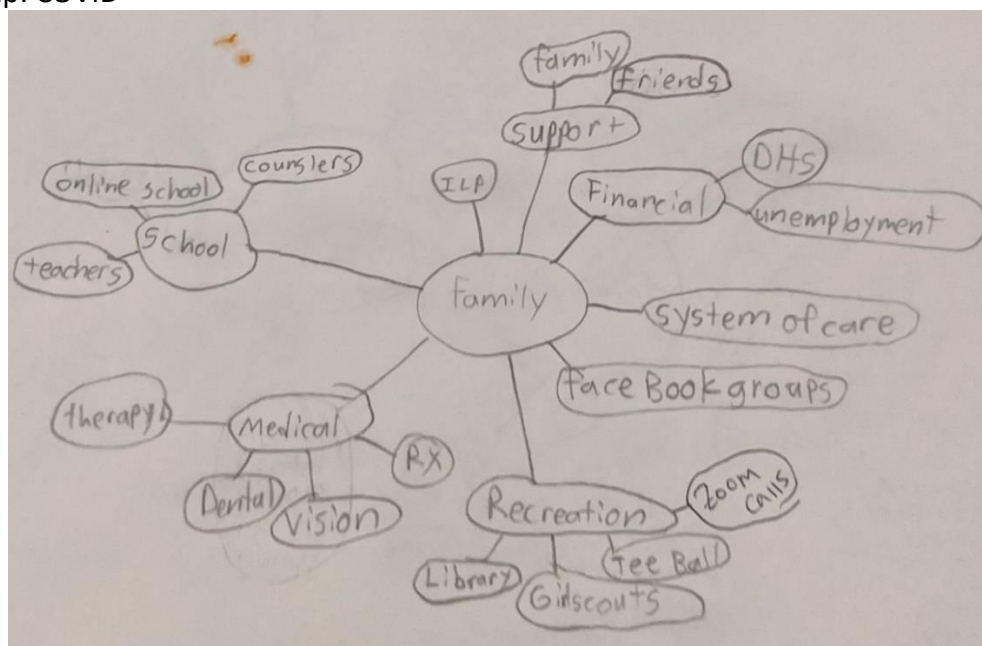
## Appendix B: PYYAG Care Maps

Betty Thunderflower

### Care Map: Pre-COVID

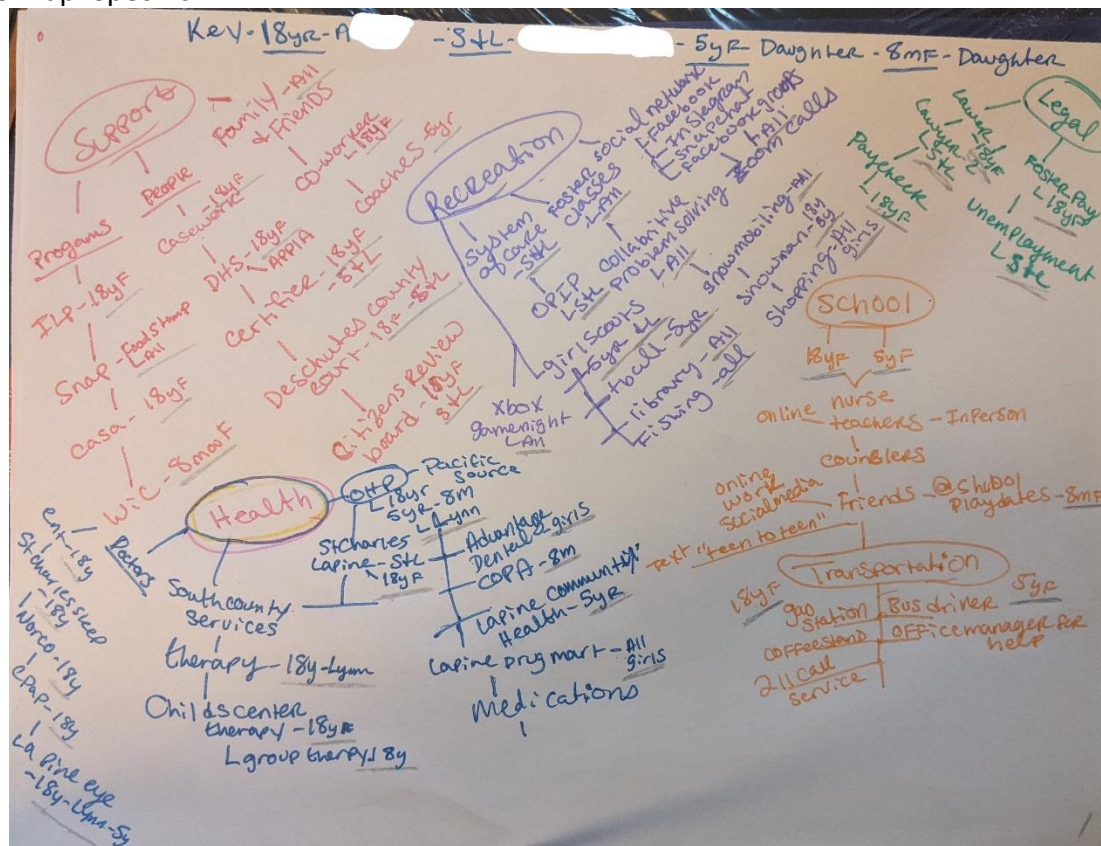


### Care Map: COVID



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Government.

Cordelia Johnson

## Care Map:

### Our Family and Supports Systems-One drop at a Time!

**2011-2012- Single Mom working mom-**  
 Has 2 girls come into her life:  
 A 3 year old and one year old  
 through the foster system  
 In Klamath County



**Jesus**  
 "Therefore everyone who hears these words of mine and puts them into practice is like a wise man who built his house on the rock."  
 is the Camerons

**CITIZEN REVIEW BOARD**

**THE WHO OF THE IEP TEAM**  
 SCHOOL REPRESENTATIVE  
 GENERALIST TEACHER  
 SPECIALIST TEACHER  
 SCHOOL NURSE  
 SCHOOL SOCIAL WORKER  
 SCHOOL COUNSELOR  
 SCHOOL ADMINISTRATOR  
 THE STUDENT  
 PARENTS OF THE STUDENT

**Child Care**

**SWIM LESSONS**  
 FOR ALL SWIMMERS

**Oregon Health Plan (OHP) Quick Start Guide**

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## Care Map:

### Our Family and Supports Systems-One drop at a Time!



2014-2015 foster care dropped  
as adoption completed  
transition to school age for  
older daughter/ younger  
daughter mental health in  
Klamath County



2018-2021 Single mom gets married  
\*Family moves to Deschute Co  
\*Household now includes mother-in-law and husband/father figure  
\*Mom still works and now has 45 minute commute  
\*Older daughter diagnosed with ID medical and education- supports added  
\*Increase in mental health with younger daughter- now in residential



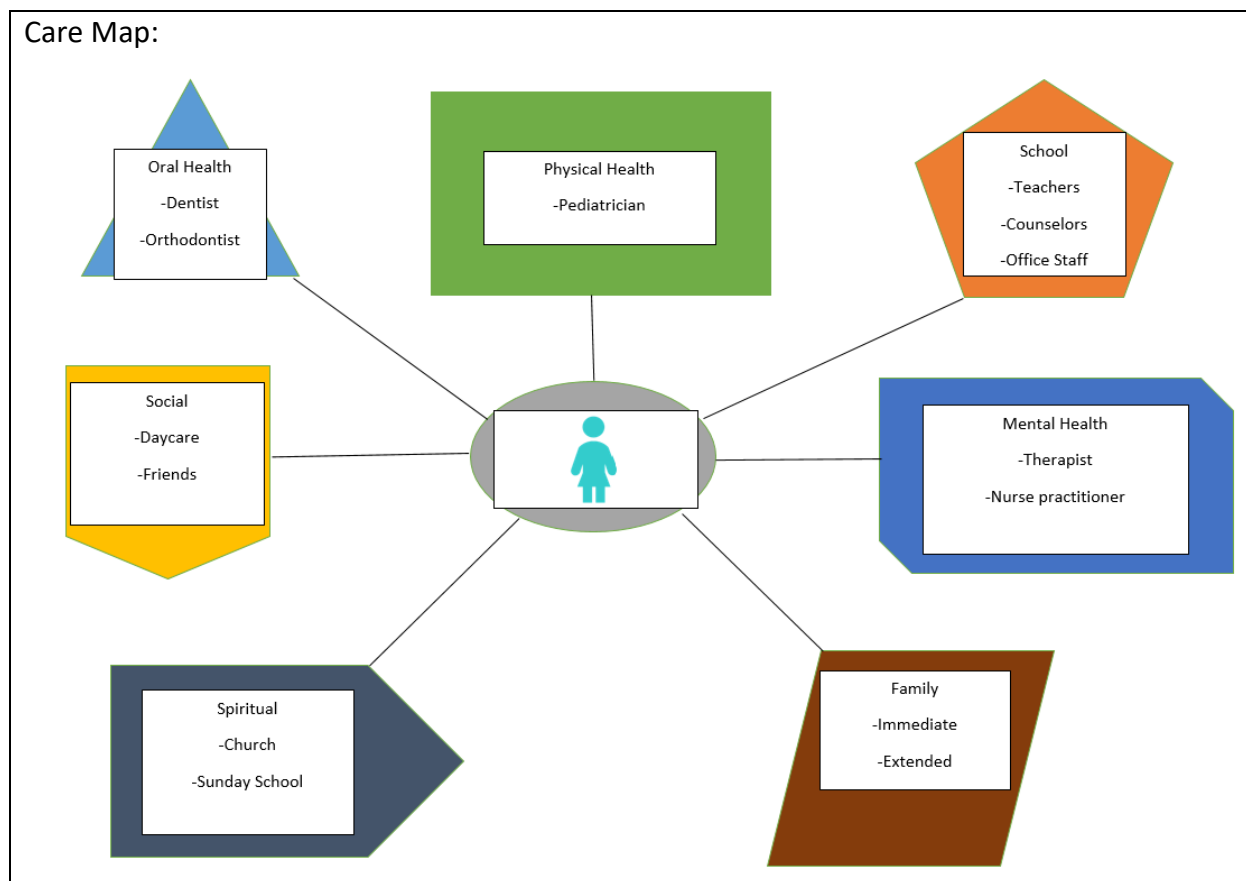


Care Map:



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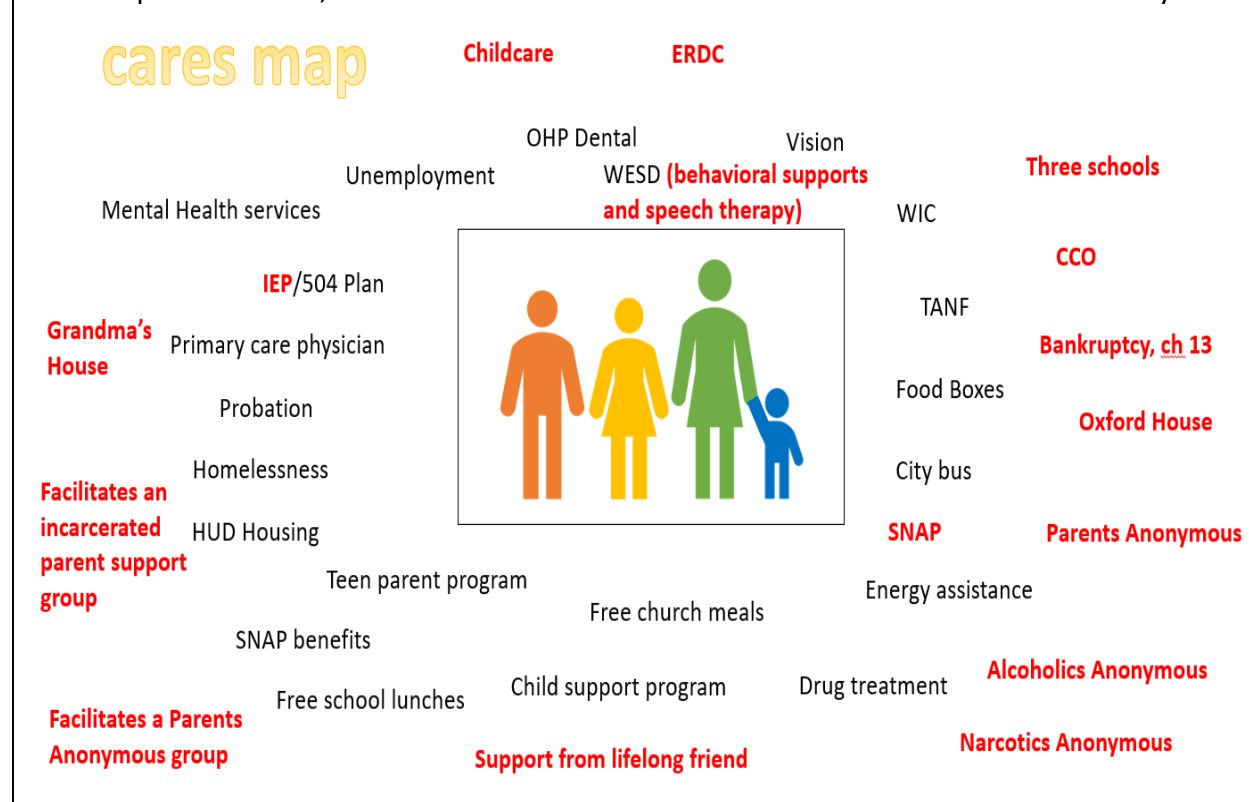
### Care Map:



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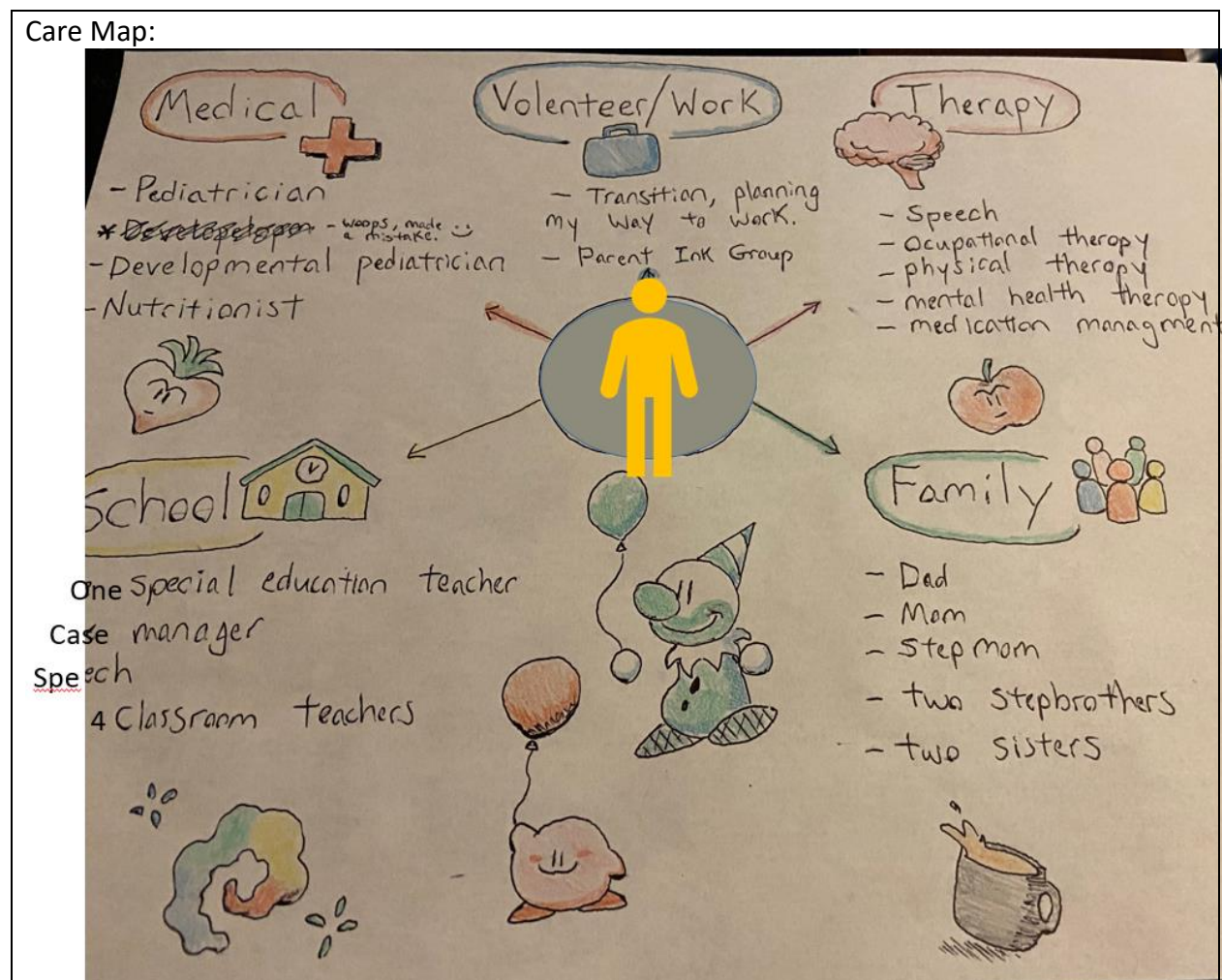
Hailey Lynn

Care Map: Please note, the additions in red were added after a conversation with Hailey



Roland Cheshire

# Care Map:

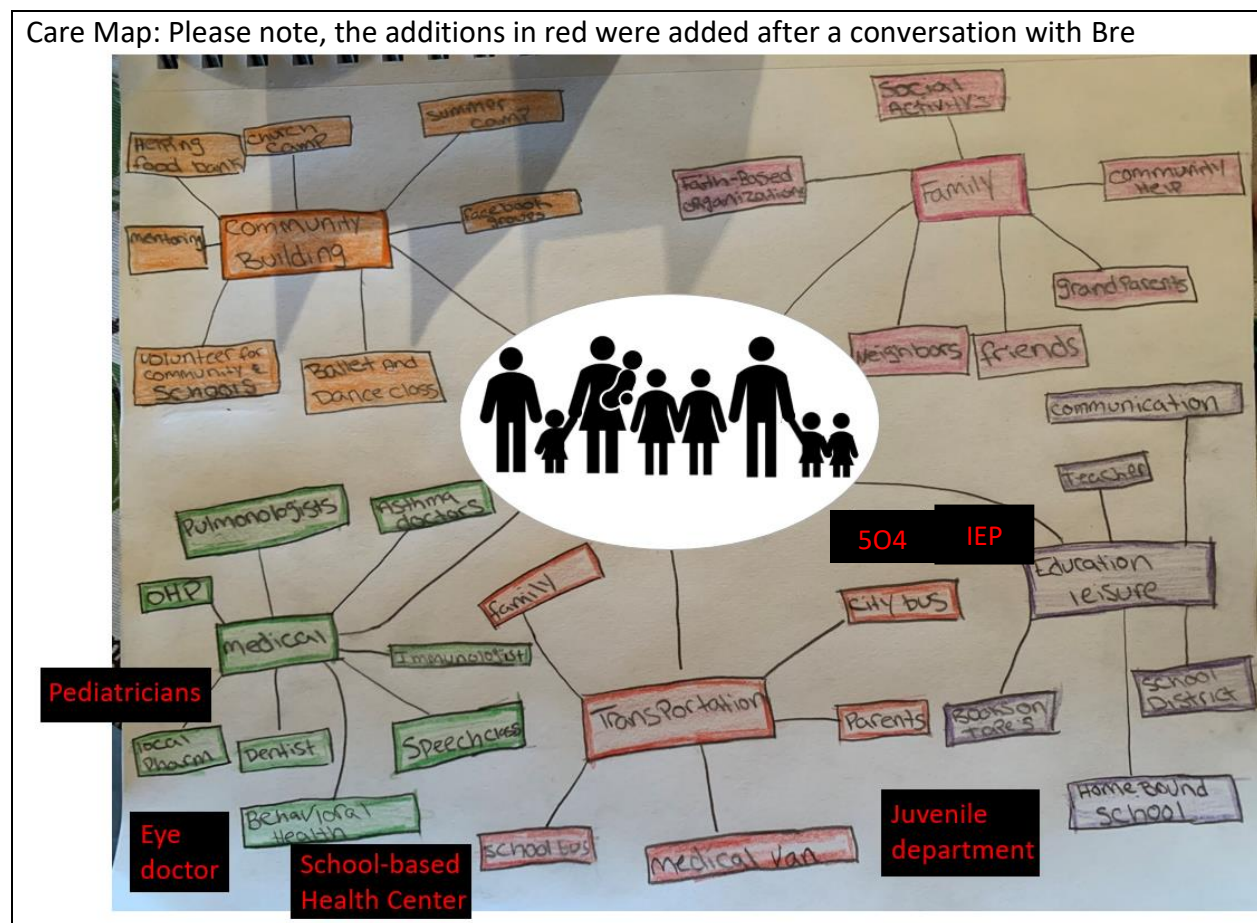


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Bre Reid

Care Map: Please note, the additions in red were added after a conversation with Bre



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## Appendix C: Summary of Findings Presented to OHA



### **Oregon's Integrated Care for Kids (InCK) Parent, Youth, and Young Adult Advisory Group: High-Level Summary of Learnings and Hopes from the Parent, Youth and Young Adult Advisory Group**



## **Opportunities We Had to Learn from the PYYAG in 2021**

### **1) Care maps each member developed**

- Who they put in their care map and who they didn't
- Services members wished were on the care map
- Given the goal of InCK was to better integrate care and take the burden off parents, youths and young adults to coordinate care, OPIP considered how much the care maps reflected whether that was happening already or not

### **2) Individual follow-up meetings**

### **3) October 2021 group meeting- Across regions**

- **Pre-reading including word clouds from the meeting.**

2

## Best Match Care is Person & Family Centered, Strength-Based

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- Each of the PYYAG members have individual and family characteristics that impact their ability to access and manage care.
  - Health care is one part of their life, not the central part.
- Many families have multiple children with multiple needs; importance of taking into account and understanding the family unit when participating in care planning
- Behavioral health supports are critical; all experienced some level of barrier
- Connection to community and addressing social connections & supports is critical to health

### ***Punchline:***

- Care plans that are centered around a specific kind of provider or a specific medical or health condition miss other factors that impact the family
- Burden to connect all pieces falls upon families
- Accessible and covered behavioral health services are a priority

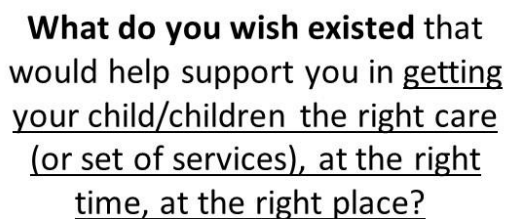
3

## Learnings relative to **policies, structure, processes and opportunities** within OHA overall and for CCOs like **PacificSource Community Solutions**:

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- Value of an **advisory council of parents, youth and young adults** that can share specific issues relative to children with medical complexity and behavioral health needs.
  - Advise their care coordination programs, centralized supports, efforts focused on children
- Policies, metrics, and care coordination models should focus on ways to view the **family as a unit** – parent(s) and child(ren) - and support the whole group overall.
  - Focus on the strengths of the family, then ask about their needs and obtain context.
  - Consider using care maps to understand context and balancing act.
  - Peer to peer models that are in places you trust and go to in the community.
- Strong **primary care homes are necessary, but not sufficient to meet the coordination needs** of children with medical complexity and behavioral health needs.
- Consider ways that **paperwork and eligibility criterion** can be streamlined. Easier and faster ways to ensure coverage of services for children with medical and behavioral health needs.

4



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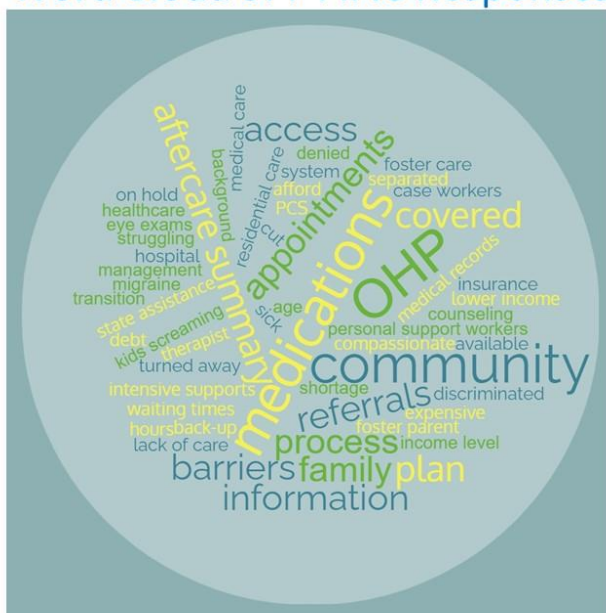
## Visioning Question #2 – If You Could Improve Your Experiences

**What do you wish existed that would help in managing, coordinating, and balancing the different services and supports your child(ren) receive and need?**



## Visioning Question #3

What **barriers** do you wish could be removed?



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