

Client Empowerment: Engaged Care through Connected Records

Karis Grounds
2-1-1 San Diego

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All In: Data for Community Health

children's optimal health

Client Empowerment: Engaged Care through Connected Records

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San Diego 211 Community Information Exchange Summit

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**NATIONAL
NEIGHBORHOOD
INDICATORS
PARTNERSHIP**

CONTEXT: The BIG Vision

Build a Community Data Ecosystem for Children



- **Health care systems:** struggle to coordinate care and engage patients and care givers
- **Education systems:** struggle to coordinate services for students and engage parents/families
- Understanding child well-being involves health, school systems, social supports, equity issues
- How do we leverage advancements in technology and communications to create an integrated data ecosystem?

Community Data Ecosystem for Children: Multiple cross-sector collaborative projects

- Early Childhood Results Count!
 - Early identification of children with developmental delay, linkage to appropriate care
 - Closed loop referral system
 - Medical providers, Early Childhood providers, 211 UWATX, Aunt Bertha
 - STATUS: Addressing MOA and consent issues, data gov, planning for pilot
- **STORY App**
 - Parent/patient-centric integrated system for children with medical complexity
 - Value based health care
 - STATUS: Being deployed, identifying superusers
- Community School Model for a Campus-Coordinated Health System
 - Health equity challenges impact school success
 - Wrap around family services, school health, mental health, FQHC Clinics
 - STATUS: Concept submitted for review



Community
Information
Exchange

Participant Portal

Community Information Exchange Core Components



Network Partners

Collective approach with standard Participation Agreement, Business Associates Agreement and participant consent with shared partner governance, ongoing engagement, and support.



Shared Language (SDoH)

Setting a Framework of shared measures and outcomes through 14 Social Determinants of Health Assessments and a Risk Rating Scale: Crisis, Critical, Vulnerable, Stable, Safe Thriving



Bidirectional Closed Loop Referrals

Updated resource database of community, health, and social service providers. Ability to accept/return referrals and to provide outcomes and program enrollment.



Technology Platform and Data Integration

Technology software that integrates with other platforms to populate an individual record and shapes the care plan. Partners access the system. System features include care team communication feeds, status change alerts, data source auto-history and predictive analytics.



Community Care Planning

Longitudinal record with a unified community care plan that promotes cross-sector collaboration and a holistic approach.



Client Record Sample

Client Profile

- Demographic and important information about the client

Domains

- Examples like Housing, Food & Nutrition,
- Categorization of Needs (SDOH) & Risk Level
- Shared Assessments and Values across agencies

Care Team

- Case Managers working with client across agencies
- Contact Information

Referrals & Program Enrollment

- Agencies or programs client is referred
- Connection to Services

Alerts

- Notification of emergency services & jail
- Ability to notify Care Team Members of changes

Feed

- Ability to communicate with Care Team members (twitter-like feed)

The shared client record integrates data from multiple partners into a user-friendly display:

Individual and demographic Information

Individual Information

Client Name: John Doe

Email: J.Doe1942@email.com

Last 4 of SSN or PIN: 6789

Mobile: (858) 465-1234

Birthdate: 04/12/1942

Birth Month/Year: 04/1942

Address Information

Home Street: 1200 DEPOT RD APT 2

Home City: SAN DIEGO

Home State/Province: CA

Address Line 2:

Home Zip/Postal Code: 91910

Home Country: United States

Demographics

Primary Language: English

Age: 72

Gender Identity: Man

Race: Bi-Racial/ Multi-Racial

Ethnicity: Hispanic

Marital Status: Widower

Income & Benefits

Employment Status: Disabled

Monthly Income Amount: \$ 970.00

Sources of Income: Supplier Income, Social Security (SSI)

Net Cash Benefits: N/A

Highest Level of School Completed: Associates Degree

Monthly Income Amount: \$ 970.00

Percent of AHA: 30% or less

Percent of PPL: 43.03 %

CalFresh Renewal Date:

Notifications of significant events, such as when a client is transported by ambulance or booked in jail

Privacy Records (1)

PRIVACY	PRIVACY TYPE	PRIVACY METHOD	CREATED BY
P-253599	Authorization	E-mail	John Doe II

Client Data Sources (3)

SOURCE RECORD	SERVICE	SOURCE ID
CDG-990000	PATH San Diego	ServicePoint
CDG-990001	Alpha Project	ServicePoint
CDG-990002	Outreach Center	ServicePoint

Alerts (1)

ALERT NAME	TOTAL # OF RECURRING	LAST INCIDENT
EMS	2	2/15/2018 2:02 AM

Domains (6+)

DOMAIN	RISK	ACTIONS	REFERRALS
Health Management	Vulnerable	2	3
Transportation	Critical	1	2
Housing	Critical	1	2
Nutrition	Critical	2	5

Care Teams (3)

CARE RECORD	CARE MANAGER	AGENCY	DATE ASSIGNED
CT-00000044	Thomas Laccetti	Jewish Family Services	10/05/2018
CT-00000045	Jeri Hernandez	SCRC (Southern Calif...	10/03/2018
CT-00000047	Arcia Munoz	Access to Independence	10/03/2018

Program Enrollments(3)

ENROLLMENT RECORD	SERVICE	STATUS	ENROLLMENT DATE
PE-00008199	PATH Connections	Active	8/07/2018
PE-00008197	Outreach Team	Active	8/30/2018
PE-00008194	Enrollment Center	Closed	7/24/2018

Referrals to programs

Information on the client's care team

Current and prior program participation

Measures of client well-being across different domains

People and Process

Why build the STORY App?



Physicians: Hospitals,
Specialty Clinics



Durable Medical Equipment



Home Health Nursing



PT/OT/Speech Therapists

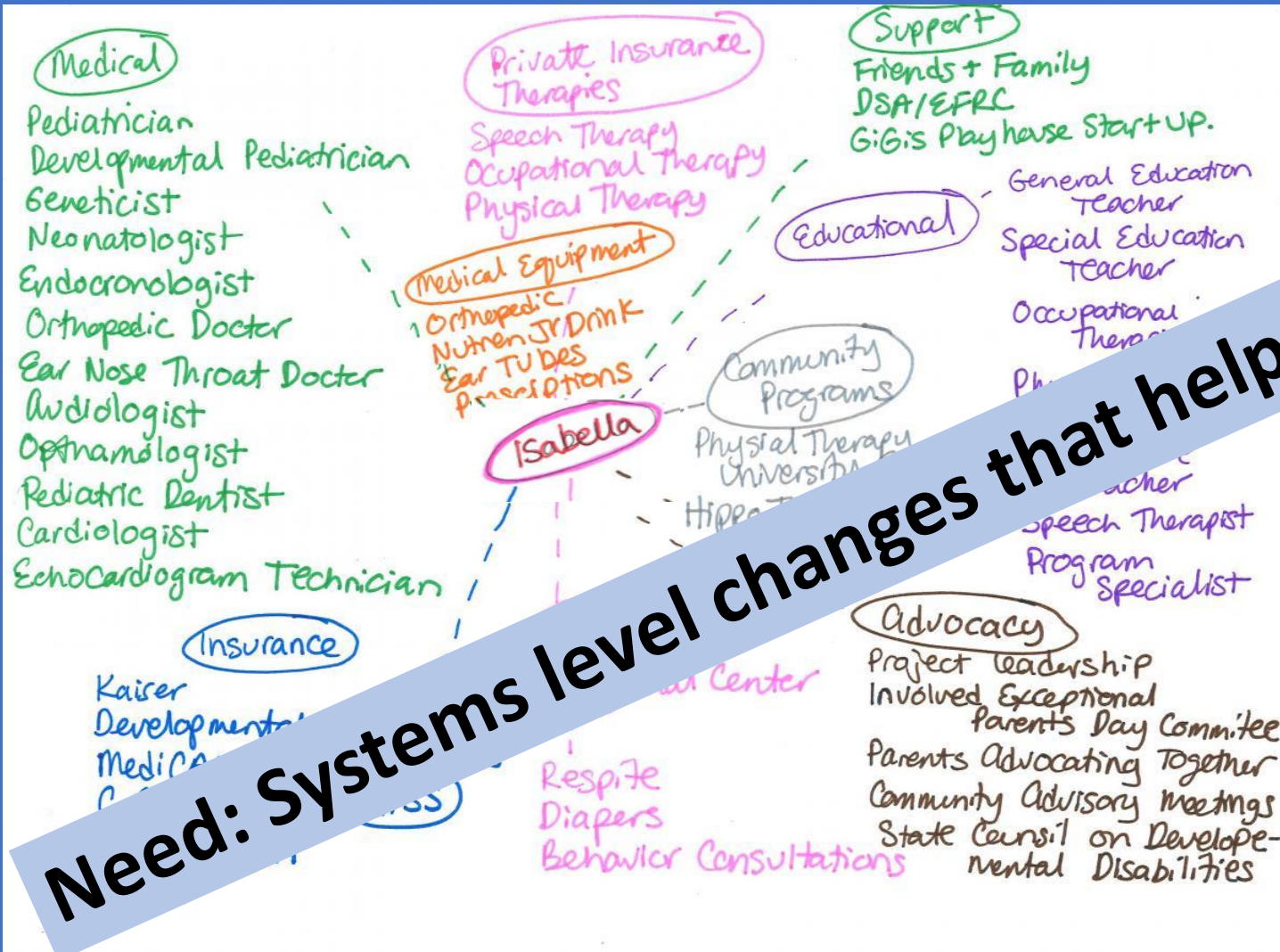


Insurance Providers



School Nurses

Why include the patient perspective?



Parent Identifies

11 Systems

(not just hospitals and clinics)

44 Providers/Programs

How did you build the STORY App?

Theresa Neil

STRATEGY + DESIGN



Knowing Users vs Speaking to Users

Theresa Neil

You probably do know your users, so work that relationship during the UX (re)design process. Here's 3 good times to talk:



Research



Concept Validation



User Testing

Discovery → Strategy → Design



Theresa Neil
STRATEGY + DESIGN



Prototype → Test → Revise → Pilot/Deploy

What were key successes/challenges?

Successes



- Desktop
- Mobile
- DPT
 - DME, Nurse, OT/PT
- Shared Care Plan
- Child's Story
- Data Core
- Utilization Data
 - Value based care

Challenges

- Bureaucratic complexity
 - Needing national approvals
 - Multiple committees
 - Inertia
- Multiple Tech Systems
 - Hospital EMR
 - Clinic EMR(s)
 - Home Nursing
 - Durable Medical, PT/OT
- Business negotiations, trust
 - Small, facile developer
 - University data backbone
 - Research Medical School



People and Processes

Importance of Participant Portal

- Person-Centered Model
- Community-owned data (ability to consent and revoke)
- Tracking who is helping me (Referrals, Programs, Care Teams)
- Empowerment (access and collection)



Collective Development

Feedback from Community Partners (on behalf of clients/patients)

- System wide Person-Centered
- Helpful for uploading/storing documents
- Ability to choose to create profile and consent
- Information requested vs. needed

Feedback from Participants

- User interface-easy to use, looks good, intuitive
- Support themselves or others within network
- Update own information
- Too much information (asks for too much)
- Track services they have access
 - Examples of testing sites: Library, Mental Health & Addiction Services, Senior (Grandparents Raising Grandchildren)

Chief Compliant:

- How much is too much?
- Expectations different in clinical vs. social services
- User Interface/Utilization

Success:

- True Client Empowerment and Access to Information
- Shared Communication
- Limited Patient Portal for social services vs. EHR/medical



Technical and Legal Development

What is the STORY App?

- It is ***NOT*** an Electronic Medical/Health Record, HIE, CIE
- STORY is a **platform independent solution**
 - **Entities continue to use their existing record systems**
 - Creates a 'Curated STORY' of the person
 - Collating essential details from across key persons involved in care
 - STORY view is tailored to user needs (MD, Nurse, Therapist, Parent)
 - Best practice guidance via physician order sets, care plans
 - Parent controls consent, who has access
 - Holistic time-series view of the patient's health
 - Aggregates utilization data across patient, provider, site, etc.
 - Essential for developing value-based health care

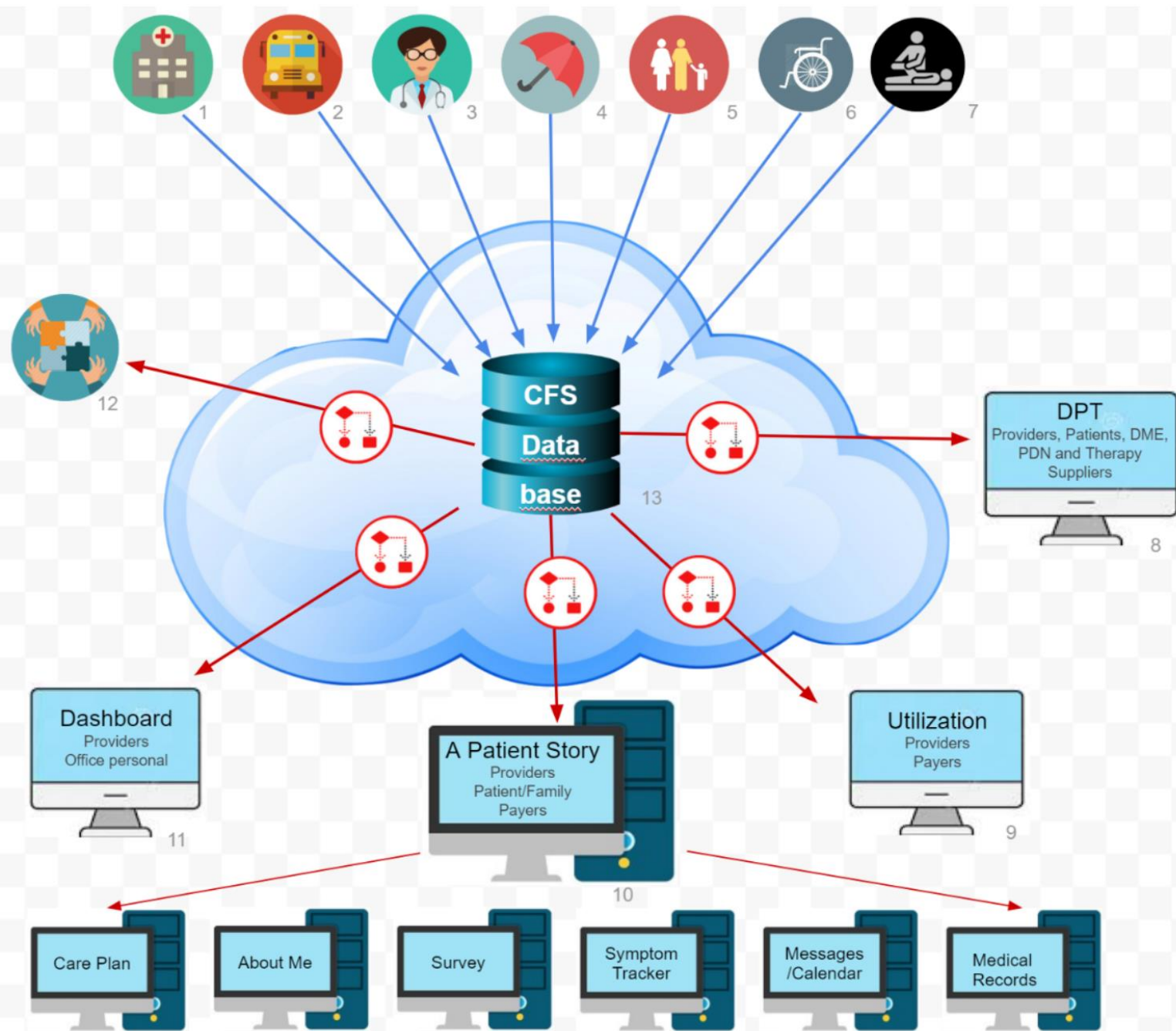
Technical Development and Data Governance

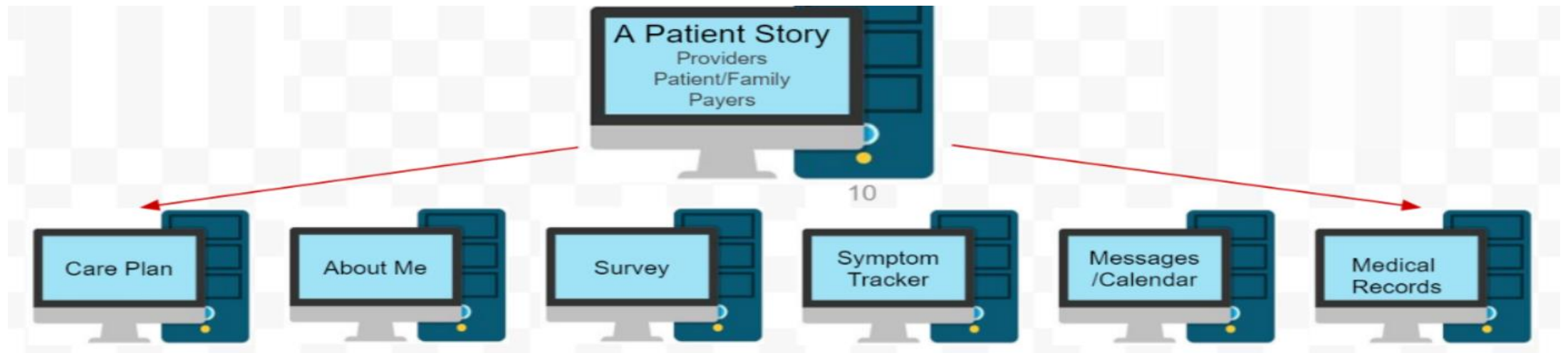



- Innovative, facile developer
 - Intellectual Property protection
 - Patenting
- Based on Fast Health Interoperability Resource (FHIR)
- Application Programming Interfaces (APIs)
- Ascension/Seton (national health system)
 - Required multiple reviews/approvals from local to national
 - Hospital and Clinic EMRs are different
- Trusted 3rd party for back end (Dell Medical School)
 - BAAs, DUAs
- Data Governance issues TBD



The University of Texas at Austin
Dell Medical School





**Story** Patient Story

Blake Johnson

About Me

Medical

Care Plan


DME

PDN

Therapy

School

Medical Timelines




Blake Johnson


DOB: Oct 16, 2004
Languages: N/A


Provider Summary: Blake is a 12yr old boy who is a former 26-week premie who was born with congenital heart disease, and congenital brain malformation with agenesis of the corpus callosum. He had an ASD and VSD -repaired in infancy in Houston which followed a complicated course that led to hospitalization in Houston his entire first year of life. Presently - he has cerebral palsy, blindness and epilepsy. He is G-tube dependent for his nutrition and has unexplained gastroparesis - related to acute illness or anesthesia. He has sleep maintenance problems that has not responded to multiple


Collapse


Care Team

 Dr Barbara Taylor
General Practice

 Dr Rahel Berhane
Pediatric Medicine

 Dr Adam Rosenbloom
Internal Medicine

 Dr Greg House
General Practice

 Dr James J Walker
Interventional Pain ...

- 26-week premie
- Congenital heart disease
- Congenital brain malformation
- Cerebral Palsy
- Blindness
- Epilepsy
- G-tube dependent



About Me

Medical

Care Plan

DME

PDN

Therapy

School

Medical Timelines



Blake Johnson

DOB: Oct 16, 2004

— Collapse

Care Team



Dr Barbara Taylor

General Practice



About Me

MY STORY

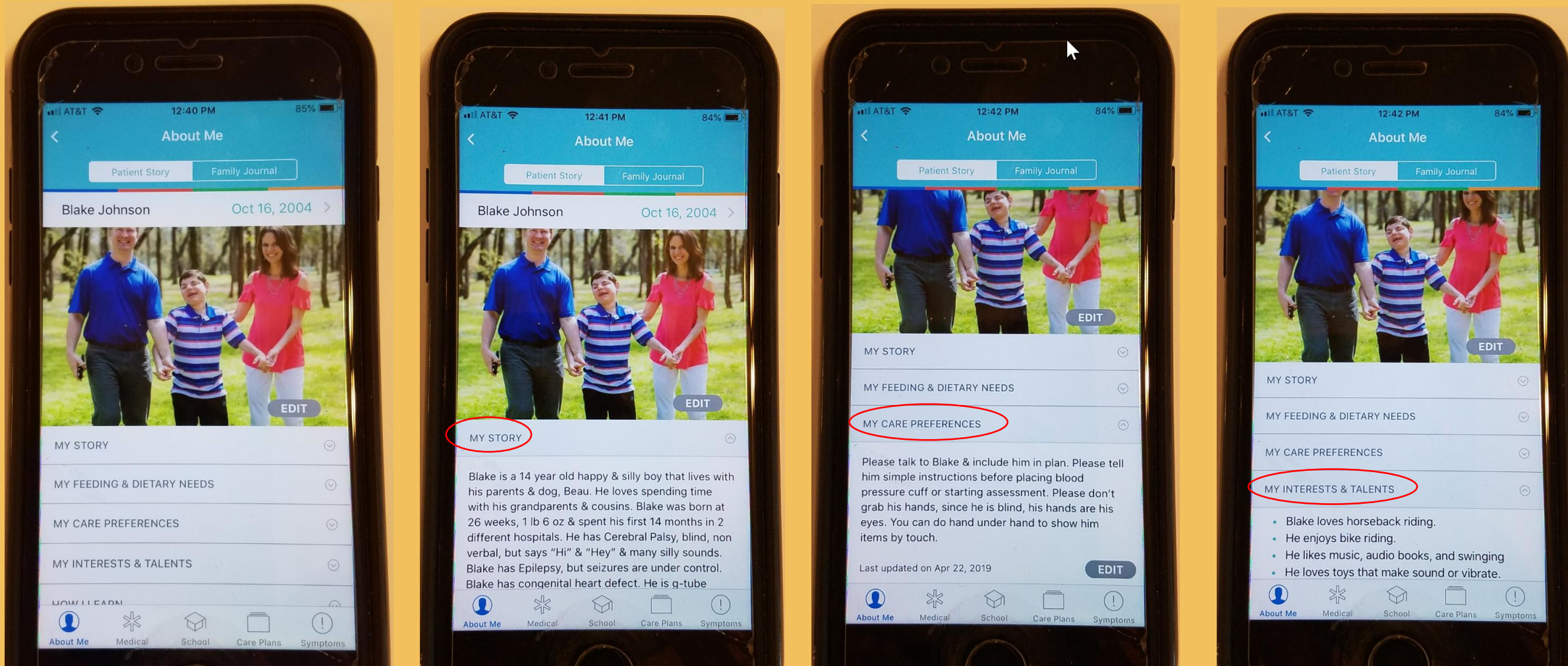
Blake is a 14 year old happy & silly boy that lives with his grandparents & cousins. Blake was born at 26 weeks in hospitals. He has Cerebral Palsy, blind, non verbal, Epilepsy, but seizures are under control. Blake has recently had bilateral hip surgery for dislocation. He

MY INTERESTS & TALENTS

- Blake loves horseback riding.
- He enjoys bike riding.
- He likes music, audio books, and swinging
- He loves toys that make sound or vibrate.

Last updated on Apr 22, 2019

- Please talk to Blake & include him in plan.
- Please don't grab his hands, since he is blind, his hands are his eyes. You can do hand under hand to show him items by touch.
- Please tell him simple instructions before placing blood pressure cuff or starting assessment.
- Blake says Hi/Hey, uses happy/unhappy sounds; He is learning 3D symbols for Go, Stop, Like
- He pushes or throws items for refusal.
- He bites hands when excited or frustrated. We use chewelry or toys for re-direction.



- This is REALLY Great for kids with multiple disabilities! I carry a notebook to all appointments that's hard to keep up to date. Doing this on my phone would be so much easier.
- I have providers in different cities/health systems. I want to include all providers to keep them all informed.
- I'd like to be able to print pages from my phone. Forms in medical offices don't have enough space to write all hospitalizations, meds, etc. I could print the page and they would have it.
- Ability to add video clips is great. Then the psychiatrist/psychologist can see the behaviors I describe.

Technical and Legal Development

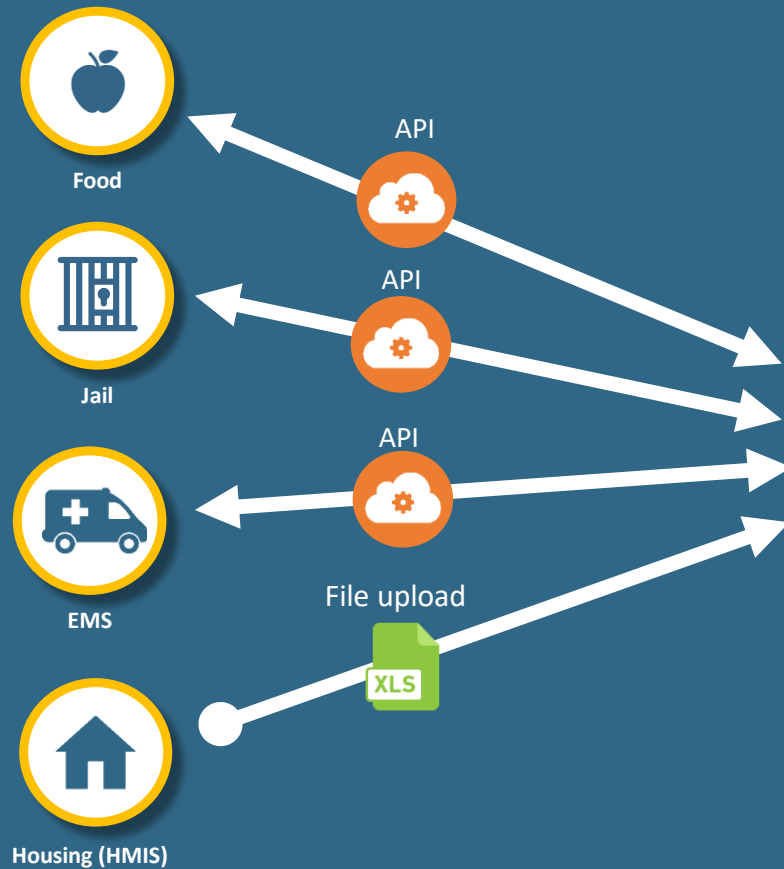
Technology/Building Portal

Goal: Access, empowerment and participant involved with their care

- View into the CIE with ability to set-up account on their own
- Aggregates both social and medical information
- Holistic view of access to services, resources and people
- Interface pulls select data from full community portals
- Provide insights from their perspective



Technology Platform



MDM

Master Data Management

- Detects and merges duplicate records
- Ensures the accuracy, completeness, and consistency of multiple domains of enterprise data



ETL

Extract Transform Load

1. Reads data from a database
2. Converts the data for the new database
3. Loads into the new database



Alerts



Single Sign on



Community
Information
Exchange



Resource
Database
and
Bi-directional
Referrals

Resource Database

Hub for social and health sites and providers

24/7
SAN DIEGO

← Search our menu ⓘ

Reset Search

Food

Emergency Food

Commodity Supplemental Food Program

Food Pantries

Food Vouchers

Sack Lunches/Dinners

Specialty Food Providers

Food Collection and Storage

Food Outlets

Food Production

Meals

enter search keywords

enter location

Search

Target Populations ⓘ

Print this list

358 results

1 2 3 ... 36 >

Senior Food Box
Bayside Community Center
(858) 278-0771
5882 LINDA VISTA RD
SAN DIEGO, CA 92111
Monthly box of food for seniors ages 60 years and older who meet income and residency requirements.
Eligibility

Senior Food Program, Carlsbad Community Center
Jacobs and Cushman San Diego Food Bank
(866) 350-3663
3368 EUREKA PL
CARLSBAD, CA 92008
Provides food and nutrition education to eligible low-income seniors 60 years or older once a month. USDA food is given to registered participants on a monthly basis at a local distribution center. 30 pound boxes usually contain reduced-fat milk, L...
Eligibility

Senior Food Program, Oceanside Senior Center
Jacobs and Cushman San Diego Food Bank
(866) 350-3663
455 COUNTRY CLUB LN
OCEANSIDE, CA 92054
Provides food and nutrition education to eligible low-income seniors 60 years or older once a month. USDA food is given to registered participants on a monthly basis at a local distribution center. 30 pound boxes usually contain reduced-fat milk, L...
Eligibility

Emergency Food Assistance Program (EFAP), St Agnes Church
Jacobs and Cushman San Diego Food Bank
(866) 350-3663
1145 EVERGREEN ST
SAN DIEGO, CA 92106
The Emergency Food Assistance Program (EFAP) distributes USDA food each month. Eligible participants who do not exceed low income guidelines may be eligible to receive EFAP once a month. Food items vary from month to month. A typical EF...
Eligibility

Emergency Food Assistance Program (EFAP), Metro Good Neighbor Center, Meade
Jacobs and Cushman San Diego Food Bank
(866) 350-3663
3295 MEADE AVE
SAN DIEGO, CA 92116
The Emergency Food Assistance Program (EFAP) distributes USDA food each month. Eligible participants who do not exceed low income guidelines may be eligible to receive EFAP once a month. Food items vary from month to month. A typical EF...
Eligibility

Emergency Food Assistance Program (EFAP), MAAC Project Villa Lakeshore Apartment
Jacobs and Cushman San Diego Food Bank
(866) 350-3663
12506 LAKESHORE DR
LAKESIDE, CA 92040
The Emergency Food Assistance Program (EFAP) distributes USDA food each month. Eligible participants who do not exceed low income guidelines may be eligible to receive EFAP once a month. Food items vary from month to month. A typical EF...
Eligibility

Emergency Food Assistance Program (EFAP), Greater Victory Baptist Church
Jacobs and Cushman San Diego Food Bank
(866) 350-3663
1045 S 29TH ST
SAN DIEGO, CA 92113
The Emergency Food Assistance Program (EFAP) distributes USDA food each month. Eligible participants who do not exceed low income guidelines may be eligible to receive EFAP once a month. Food items vary from month to month. A typical EF...
Eligibility

Map Satellite

Search

Map data ©2018 Google, INEGI Terms of Use Report a map error

- Shared taxonomy language for referrals (AIRS)
- Dedicated resource staff
- Regular updates made to resources
- Standards to listings and requirements
- Inclusion/Exclusion Criteria
- Linked to health conditions
- Tracks resource availability and unmet needs



Participant Portal



Sadie Blue

MY PROFILE

MY PLAN

GET CONNECTED

MY FAVORITES

PRINT

My Profile & Settings

Edit

Adding information now can save you time later when you are getting help from 2-1-1 and other providers.

About Me:

First Name

Sadie

Last Name

Blue

Birthdate

01-01-1969

Phone

(770) 402-5191

Email

sadieblue@gmail.com

Last 4 digits of Social Security Number

1234

My Summary:

Things people should know when I am asking them for help:

I have two kids, and we've been struggling for a couple years. I'm looking for any kind of help, food, shelter, and maybe getting a job.

Challenges I have experienced when accessing resources:

It's hard getting around town. My car was impounded and I couldn't afford to get it back.

Resources or support that I am already using:

I have SNAP

Pulls relevant information from Community Portal to Patient Portal

- Only specifically identified fields
- Reformatted language to be personal and relevant

My Profile & Settings

- Who you are?
- Demographics and Contact Information

My Summary

- Ability share thing about myself
- Things I need help or support with
- Challenges



My Plan

Care Team

- Case Managers who I am working with


Referrals & Program Enrollment

- Agencies or programs client is referred
- Connection to Services

Eligibility


- Programs I may be eligible for





Sadie Blue

MY PROFILE **MY PLAN** GET CONNECTED MY FAVORITES

PRINT 

Care Teams: connect to the people you are working with

CASE MANAGER NAME	AGENCY	CASE MANAGER PHO...	CASE MANAGER EMAIL	DETAILS	EMAIL
Jeri Hernandez (Demo)	Southern Caregiver Resource Center (SCRC)	(858) 392-6823	jher Hernandez@scrc.org	Details	eMail
United Way User	United Way of San Diego County	(858) 492-2000	pweleay@unitedwaysd.com	Details	eMail

Eligibilities: see services you may be eligible for

SERVICE
Food Distribution

Program Enrollments: track the resources you are currently using

SERVICE	AGENCY	STATUS	ENTRY DATE	DETAILS
Housing Navigation	2-1-1 San Diego	Active	Jan 15, 2019	Details
EFSP New Move In Rental Assistance, Unions United	United Way of San Diego County	Active	Dec 11, 2018	Details

Referrals: see all the resources you have been referred to

SERVICE NAME	AGENCY	REFERRAL DATE	REFERRAL STATUS	DETAILS
VI-SPDAT and Housing Navigation Services	Townpeople	Jan 10, 2019	Active	Details
Housing Navigation	2-1-1 San Diego	Jan 10, 2019	Completed	Details
EFSP New Move In Rental Assistance, Unions United	United Way of San Diego County	Jan 15, 2019	Pending Client Action	Details
Food Distribution	Somali Bantu Association of America	Jan 21, 2019	Pending	Details
Housing Inspection Program, Housing & Economic Development	City of National City	Jan 21, 2019	Expired Consent	Details

My Favorites

*Use media features that are familiar to participant
"Facebook like or favorite"

Resources I like:

- Ability to Favorite programs
- Learn more about eligibility
- Empowerment



Sadie Blue

MY PROFILE

MY PLAN

GET CONNECTED

MY FAVORITES

Career Horizons for Young Women

[Just In Time for Foster Youth](#)

Supports youth who are pursuing a GED high school diploma and those who are pursuing vocations: police work, cosmetology, welding, graphic design, plumbing, and teaching. Also provides needs such as transportation, in addition to career exploration and networking opportunities with individuals within the community. *Career Horizons for Youth Eligibility*

(760) 505-6647

4560 ALVARADO CANYON RD STE 2G
SAN DIEGO, CA 92120

[Remove from Favorites](#)

Senior Nutrition, Brawley Senior Center

[Catholic Charities](#)

Provides lunch to seniors in a congregate meal setting. Transportation to the congregate meal site is also available in El Centro, Brawley, Calexico, and Salton City. *Eligibility*

(760) 353-2748

575 J ST
BRAWLEY, CA 92227

[Remove from Favorites](#)

National School Lunch Program

[United States Department of Agriculture](#)

The National School Lunch Program (NSLP) is a federally assisted meal program operating in public, nonprofit, and private schools and residential child care institutions. It provides nutritionally balanced, low-cost or no-cost lunches to children each school day. *Eligibility*

(800) 952-5609

[Remove from Favorites](#)

Use, Outcomes, Next Steps

Use, Outcomes, Next Steps

Front End Implementation

Use and Outcomes

- Desktop is deployed
 - Clinicians can use
 - Cost savings from Durable Medical Equipment
- Mobile version moving from pilot testing to full deployment
 - Positive responses from pilot parents

Next Steps

- 10 Superusers targeted among parents, buddy system
- Assess what will make mobile use 'sticky', tool for daily use

Use, Outcomes, Next Steps

Back End: Data Core/Dell Medical School

Use and Outcomes

- Cloud Forest Data Environment fully functioning
- Data mirrored in Dell Medical School Data Core

Next Steps

- Enhance data flows into DMS Data Core
- Add EMR Aggregators, extends EHR systems that can be included
- Address Data Governance for research, community learning

Use, Outcomes, Next Steps

Insights: Utilization and Care Transformation

Use and Outcomes

- Seeking to give parent/caretaker equivalent status with medical team
 - Payer data is incorporated
 - Utilization analyzed by patient, provider, site, clinic, procedure
-
- **Next Steps**
 - Improving turnaround time in accurate payer data (current 2 month delay)
 - Cost analysis
 - Value-based care

Use, Outcome and Next Steps

State of Participant Portal

Use and Outcomes:

- Still in demo site, testing with more participants before launch
 - Homeless/Housing Instability is crucial
- Meaningful Launch-ensure buy-in

Next Steps:

- Data Analytics on Utilization (consents and data sharing)
- Evaluation on Client Empowerment and impact on care by using app

Thank You!



Podcast link

<https://www.allindata.org/resources/podcast-designing-a-family-centered-care-plan-for-children-with-special-needs-in-austin-tx/>



Dr. Susan Millea (Left) and Dr. Rahel Berhane (Right)

Thank you!

Karis Grounds
Vice President of Health and Community Impact
kgrounds@211sandiego.org

