# Seattle Autism Center

## Background
## and Portal Concept

**October 22nd, 2018**

*Note: "Seattle Autism Center" serving as a placeholder name; naming study TBD*

# Vision Statement

## SEATTLE AUTISM CENTER (SAC)

**Unique Strengths & Capabilities**

SAC

**All Disciplines**

**All Lifespan**

**All Community**

**All of WWAMI**

**Nat'l Network**

Seattle Children's® HOSPITAL · RESEARCH · FOUNDATION

UW Medicine

UNIVERSITY of WASHINGTON
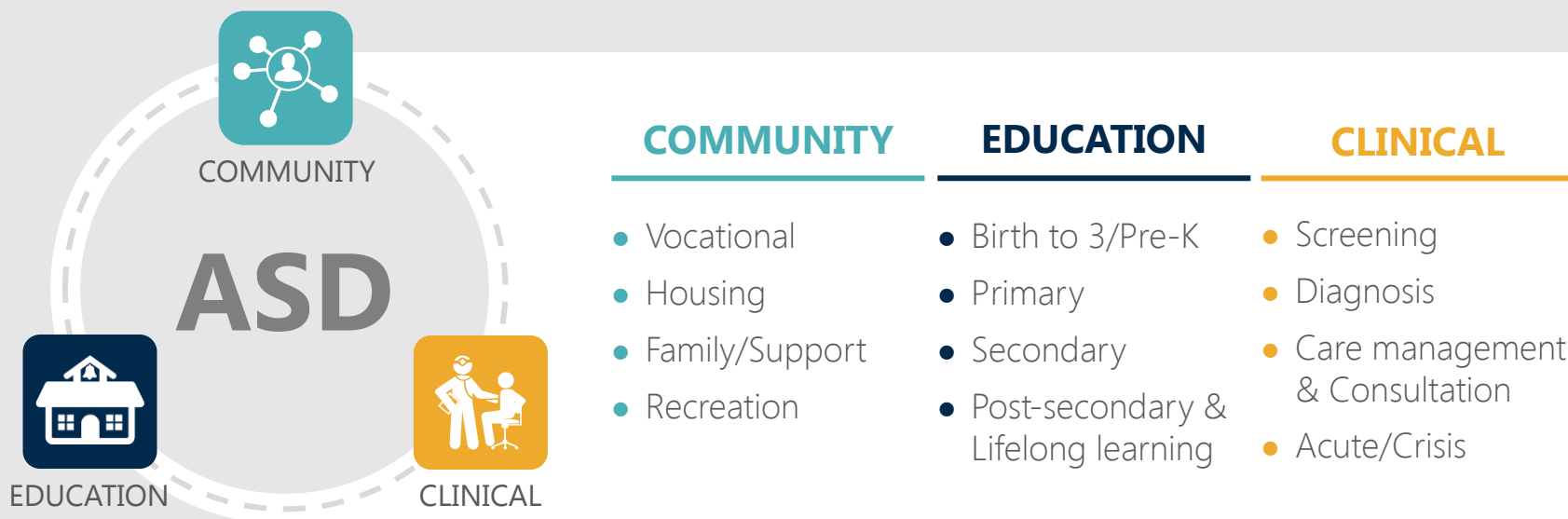
That all individuals and families impacted by ASD and related disorders / conditions across the lifespan will have access to individualized, state of the art services and support when they need it, how they need it and where they need it in order to build on strengths and improve quality of life.

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# Dimensions of Autism Spectrum Disorder (ASD)

## INDIVIDUALIZED NEEDS BY SEVERITY, AGE & GEOGRAPHY

COMMUNITY

**ASD**

EDUCATION

CLINICAL

### COMMUNITY
- Vocational
- Housing
- Family/Support
- Recreation

### EDUCATION
- Birth to 3/Pre-K
- Primary
- Secondary
- Post-secondary & Lifelong learning

### CLINICAL
- Screening
- Diagnosis
- Care management & Consultation
- Acute/Crisis

Critical Success Factors

**RESEARCH**

**POLICY**

**TRAINING & WORKFORCE DEVELOPMENT**

**TECHNOLOGY**

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# Prioritization of the Portal Design

Initially focusing on the design and rollout of the portal provides immediate value to constituents impacted by ASD while building consensus internally.

**Initial design efforts should be prioritized on**

*The SAC Portal*

**Rationale:**

**Sets a Strong Foundation for Future SAC Design**

Will lead design team to consensus by working through content and will help identify strengths and gaps in current offerings for future design

**Addresses a Meaningful Need**

Will provide an immediate, material improvement to the support individuals and families receive navigating the ASD landscape today

**Provides a Tangible Display of SAC's Value**

Will be a visible illustration of the SAC's current value and future aspirations:
- Demonstrating externally to the community how the institutions are coming together
- Signaling internally across institutions our bold vision

# Overview of the Portal Concept

The portal serves to simplify the constituent experience by collating and linking SAC intellectual property to provide a singular, expert-supported resource.

**Resource Portal** with personalized information / dashboards for:
- Individuals w/ ASD & their families
- Professionals
- Employers
- Other constituents

**Educational Information, Navigation, Resources**

**Client Support Dashboard**

**Registry Linkage, Research Participation Information & Social Networking**

**Share the Future Vision of the SAC**

Online Portal with Phone Support

PATIENT + 24/7

# Overview of the Portal Concept

The portal serves to simplify the constituent experience by collating and linking SAC intellectual property to provide a singular, expert-supported resource.

## Educational Information, Navigation, Resources

- *Provide multimedia educational content and holistic navigation resources*
- *Based on individual's location / age / severity, provide actionable information e.g.:*
  - *Pre-screening guidance*
  - *Diagnostic support*
  - *Guidance on building out local care team post-diagnosis*
  - *Information on ongoing interventions and educational, communal & vocational resources*

## Client Support Dashboard

- *Access to patient / client portal (including links to existing portals e.g. SCH, UWM)*
- *Additional clinical support info / navigation resources (e.g. full treatment / med mgmt. history)*
- *Relevant personal information on education, training and consultation for constituents*

## Registry Linkage, Research Participation Information & Social Networking

- *Share relevant study information & promote enrollment*
- *Provide opt-in social networking (subtype, community members, other constituents)*

## Share the Future Vision of the SAC

- *Provide SAC's perspective on:*
  - *What is the magnitude of the ASD problem? What does success look like?*
  - *How is SAC uniquely positioned to achieve this?*
  - *What does SAC need to achieve this?*

# Orienting SAC Portal Subject Matter

ASD-related subject matter needs to be organized in a manner relevant to its constituents.

| Subject Matter |
| :---: |
| Screening |
| Diagnosis |
| Intervention |
| Med Mgmt. |
| Adult Care |
| Crisis Mgmt. |
| Research |
| Education |
| Rec & Community |
| Professional Training |
| Vocational |
| Housing |
| Advocacy |

As subject matter is built out, orient content around relevant constituent journeys*:

**High-level categorizations:** **&** **Specific constituent pathways**

I'm concerned that my child / patient / student has autism

- *How to get screening / diagnosis*
- *What to do while you wait*

My child / patient / student has autism

- *What to do in the 1st 100 days post-diagnosis*
- *Building out your care team*

I'm in need of crisis support

- *Support information (crisis support hotline)*
- *Next steps post-crisis*

*Based on complexity of topic, different permutations of pathways may be needed based on severity, age and geography and constituent type*

# SAC Portal Subject Matter Scope

The scope of the ASD subject matter provides the building blocks for portal content design and should be comprehensive.

| Subject Matter |
|:---:|
| Screening |
| Diagnosis |
| Intervention |
| Med Mgmt. |
| Adult Care |
| Crisis Mgmt. |
| Research |
| Education |
| Rec & Community |
| Professional Training |
| Vocational |
| Housing |
| Advocacy |

## Subtopics For Each Subject Matter Area…

- General Info
- FAQs
- Suggested best practice or protocol(s)
- Available tools (e.g. multimedia)
- Other educational content
- Local resources
- National resources

## …with content varying by constituent

- Individuals with ASD
- Parents / families
- Social workers
- Medical providers / licensed mental health providers
- BCBAs / RBTs
- Educators
- Vocational counselors
- Employers
- Law enforcement / EMS

*Note: List of subtopics will vary by constituent*

# Overview of Portal Uses and Access

How constituents engage with the portal will vary based on several factors including location and formal interactions with the SAC.

| Portal Use Case Phases (contingent on funding) 1 2 3 — Constituent | Educational Info, Nav & Resources | Share Future Vision of SAC | Support | Client Support Dashboard | Registry, Research & Social |
|---|---|---|---|---|---|
| Active / Former Patient / Student | ● (personalized if in WWAMI region) | ● | ● | ● | ● (targeted study & enrollment info, social network opt-in) |
| Active / Former Study Participant | ● (personalized if in WWAMI region) | ● | ◉ Research support, limited clinical | ◉ (limited data) | ● |
| Ind. w/ ASD; Lives in WA | ● | ● | ◉ Partial support (e.g. general info and crisis) | ◉ (if data in system) | ● (targeted study & enrollment info, social network opt-in) |
| Ind. w/ ASD; Lives in WWAMI | ● | ● | ◉ Partial support (e.g. general info and crisis) | ◉ (if data in system) | ● (targeted study & enrollment info, social network opt-in) |
| Ind. w/ ASD; Lives in USA | ◉ (no personalized information) | ● | ○ | ◉ (if data in system) | ◉ (general study & enrollment info) |
| Ind. w/ ASD; Lives out of USA | ◉ (no personalized information) | ● | ○ | ◉ (if data in system) | ◉ (general study info) |
| Professionals, employers, teachers, etc. | ◉ (personalized resources for WWAMI) | ● | ◉ Partial support (e.g. general info and crisis) | ◉ (non-clinical personalized dashboard for WWAMI) | ◉ (social networking / collaboration support) |

**Key:** ●=Full Access ◉=Partial Access / Limited Functionality ○=No Access

# Guiding Principles for SAC Portal Design

National examples emphasize the importance of the user experience, data integration and promoting action in portal design.

**It's not just having the right content, it's presenting it the right way.** Subject matter should be oriented in the manner most meaningful for constituents. Content should be presented seamlessly while keeping each organization's function clear and distinct.

**There's value in information integration.** Whether it's generalized subject matter or personal record data, having a one-stop-shop is important for constituents.
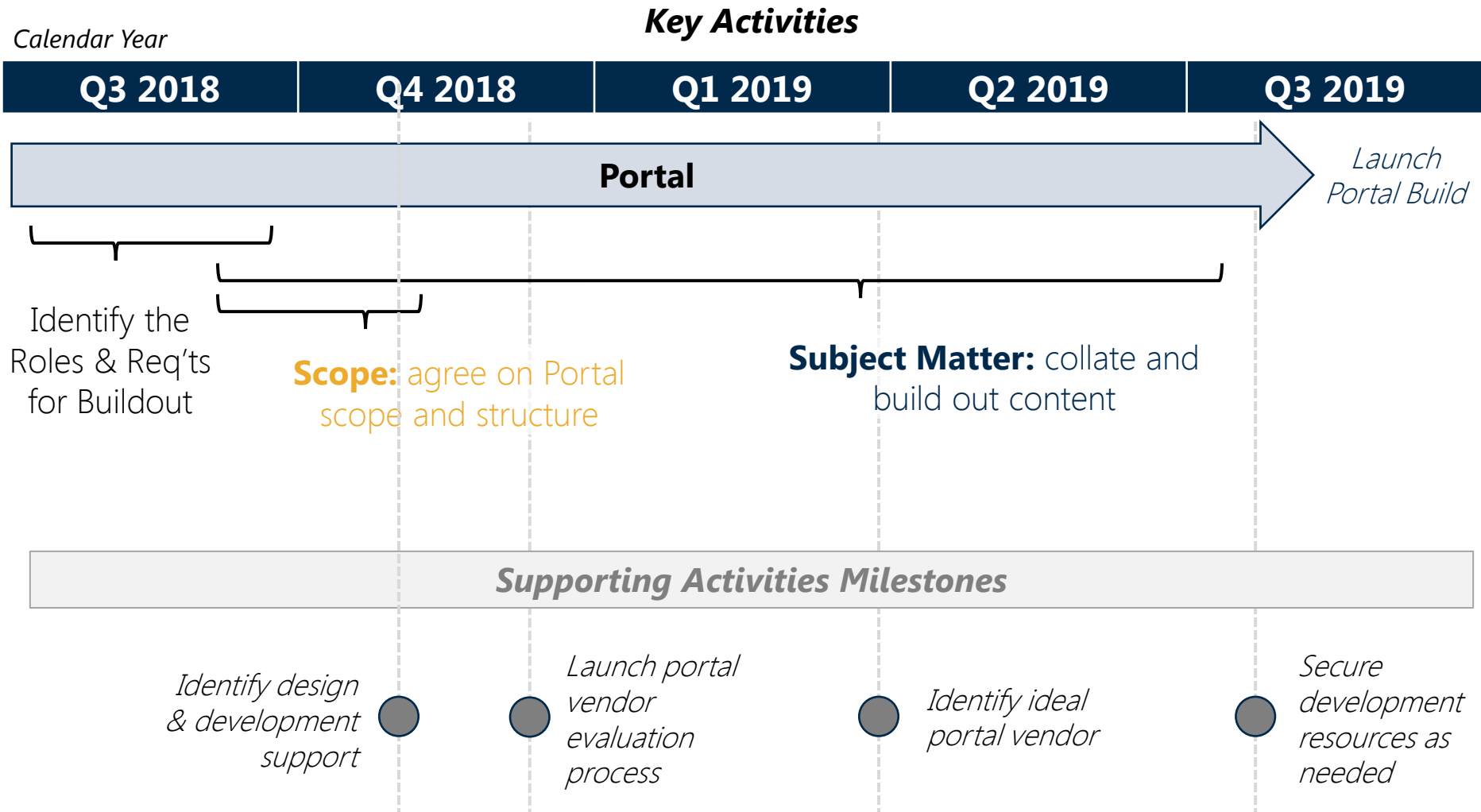
**Virtual content should motivate real world action.** From scheduling an appointment to connecting with a peer for assistance, the portal should be a platform that elicits action from constituents.

# Appendix: Additional Portal Details

# High Level Timeline for Portal Design

Scope definition and subject matter buildout are required over the next 6-9 months to develop the portal concept into reality.

## Key Activities

Calendar Year

| Q3 2018 | Q4 2018 | Q1 2019 | Q2 2019 | Q3 2019 |
|---------|---------|---------|---------|---------|

**Portal** → *Launch Portal Build*

Identify the Roles & Req'ts for Buildout

**Scope:** agree on Portal scope and structure

**Subject Matter:** collate and build out content

### Supporting Activities Milestones

*Identify design & development support*

*Launch portal vendor evaluation process*

*Identify ideal portal vendor*

*Secure development resources as needed*

# Catalyst and Transform Strategy Summary

**Catalyst Strategy**
STARTUP PHASE

**Transform Strategy**
SUBSEQUENT PHASES

Convene a WA service delivery network to deliver the best care today and accelerate the development of better care for tomorrow

Expand and extend models throughout WWAMI and beyond, driving national and global impacts

## SUMMARY GOALS

Lay the foundation for a coordinated autism program that will:

- Implement short and long-term improvements in care and access, **including building an improved navigation/portal to simplify constituent experience**

- Accelerate research efforts

- Enable local communities to better serve

- Engage key stakeholders in policy and advocacy efforts

Build upon Catalyst Phase success to:

- Develop systems of care that address gaps in WWAMI and beyond

- Define sustainable and effective best practices that can be implemented regionally, nationally and globally

- Drive research that helps us understand the etiology of autism and supports development of future therapies
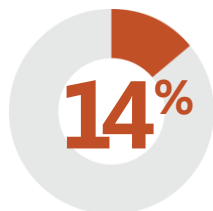
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# What is the Magnitude of the Problem Today?

**1,100 KIDS IN WA**

**50K NATIONALLY**

ANNUAL "AGE OUT" OF PEDIATRIC/ YOUNG ADULT SUPPORT SYSTEMS

**14%** PAID EMPLOYMENT RATE FOR ADULTS W/ASD

*People with ASD die* **16** YEARS YOUNGER THAN **GENERAL POPULATION**

**50%** OF INDIVIDUALS WITH ASD **have a clinical co-morbidity**

MEDICATION MANAGEMENT LEADS TO **7.5x** IN SPEND PER YEAR COMPARED TO PEERS

Autistic Individuals Utilize Emergency Departments **4x** MORE THAN PEERS

and on average spend **2.3x** MORE THAN PEERS

**~35th** OUT OF **50** IN BCBAs PER POPULATION

Several Counties have **ZERO** BCBAs **0**

WA State BCBAs Medicaid Reimbursement **55%** OF THE NATIONAL AVERAGE

**38TH** OUT OF **50** IN SPECIAL EDUCATION FUNDING PER PUPIL

**46TH** OUT OF **48** IN DROPOUT RATE FOR STUDENTS WITH DISABILITIES

**$165M Funding Gap** FOR SPECIAL EDUCATION IN WA LAST YEAR

**PRIMARY CARE COMMUNITY**

*high variability of screening*

**no training for how to handle abnormal screens**

**DIAGNOSTIC BACKLOG**

**8** MONTHS

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