



Supporting Oregon Students Returning to School after a Traumatic Brain Injury: Feedback from Regional Leaders

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Executive summary

The Injury and Violence Prevention Program (IVPP) of the Oregon Public Health Division (PHD) conducted a round of informational interviews about current practices in Oregon to support Return to School services (RTS) for students after a traumatic brain injury (TBI). The purpose of these interviews was to learn about:

- Current practices
- Barriers and challenges
- Aspects that are going well
- Recommendations for next steps to improve the system
- Ideas for next steps to further evaluate the system

The evaluator conducted interviews with 11 regional leaders between February and March 2022. This report summarizes findings from these interviews, along with recommendations for next steps.

Key findings

Current practices

Services and practices vary greatly across regions, and across school districts within regions, and much more is known about practices supporting students with more severe TBIs than milder TBIs. For the most part, students with significant injuries are well-navigated and tracked through the system and structures are in place to provide for their needs when returning to school. For students with milder injuries who do not receive support from more formal structures inherent with an Individualized Education Plan or 504 plan, a wide variation in support activities exist within and across regional levels. Regional liaisons help lead efforts to identify youth after a TBI, connect youth to RTS services, advise and train healthcare and school professionals, and conduct a variety of initiatives to improve services. The team approach is an important aspect of facilitating these services, from the broader regional team to local teams at the district and school level.

What has been going well

Most participants praised the TBI Regional Inclusive Services Network and the leadership provided by the Center on Brain Injury Research and Training (CBIRT) and the Oregon Department of Education (ODE), a model which works well to provide centralized support and resources across the state for RTS services. Other aspects going well included the strong performance of regional and many local TBI teams, as well as legal changes that allowed Credible History interviews and directed the dissemination of a standardized student accommodations form.

Important barriers and challenges

The top three barriers included:

- Insufficient funding for regional services supporting RTS
- Under-identification of students with brain injuries
- Lack of mandate accompanying HB 4140

Additional barriers included:

- Disruptions due to the COVID pandemic
- Difficulty monitoring and tracking students in the system
- Problems due to staff turnover

Recommendations

The top recommendations for next steps based on these interviews included:

- Increase funding for regional and local RTS efforts to support the complex and time-consuming array of regionally-led activities
- Continue and expand training activities to educate and raise awareness about TBI and concussion basics, such as prevention and medical characteristics, and about providing and coordinating RTS services. Groups to target should include school staff, families, and healthcare providers
- Improve identification of youth with brain injury by primarily improving communication through notification systems between healthcare and schools or a regional TBI point person
- Advocate for legal changes to amend HB4140 to require the use of ODE's student accommodation form upon a student's return to school after a TBI
- Consider a policy to require and provide support for convening local TBI teams at the school or district level

Background

Purpose

The Injury and Violence Prevention Program (IVPP) of the Oregon Health Authority (OHA) Public Health Division (PHD) engaged an evaluator to conduct a round of informational interviews with regional and state experts about current practices in Oregon to support students returning to school after a traumatic brain injury (TBI). These experts included liaisons responsible for leading efforts regionally within the TBI Regional Inclusive Services Network along with others working at the statewide level. The purpose of these interviews was to learn about the following issues, primarily at the regional and statewide level:

- Current practices
- Barriers and challenges
- Aspects that are going well
- Recommendations for next steps to improve the system
- Ideas for next steps to further evaluate the system

This report summarizes findings from these interviews and provides information about legislative and funded initiatives to better describe the context of these Return to School (RTS) regional efforts in Oregon.

TBI vs Concussion

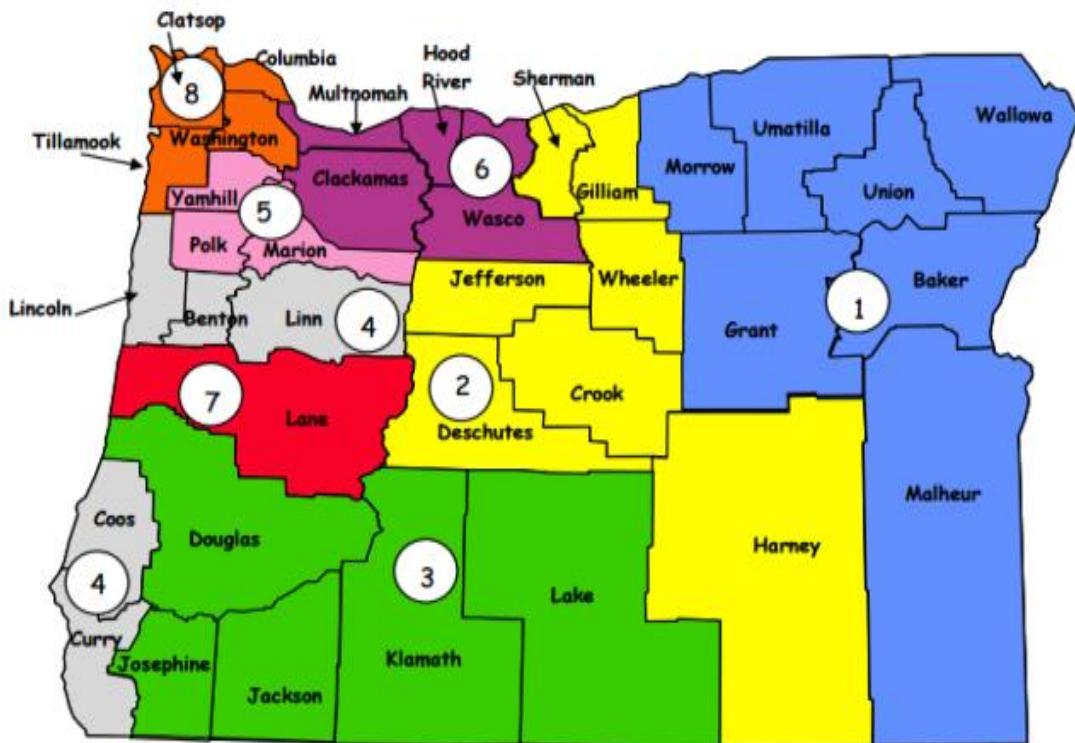
A concussion, while medically included in the broader term of TBI, is often used in practice to indicate injuries on the milder end of the mild-severe spectrum, while TBI refers to more severe. This report primarily uses the term TBI or “brain injury,” modified as necessary to indicate severity.

Overview of the TBI RTS services organized within Oregon’s TBI Regional Inclusive Services Network

For nearly 30 years, the Oregon Department of Education has provided support services for with a regionally organized network that helps to ensure students with low-incidence disabilities receive required specialized educational services¹. TBI is one of these disabilities, alongside such others as deaf and hard of hearing, deafblind, blind visually impaired, orthopedic impairment, and autism spectrum disorder. A regional liaison leads efforts in each of 9 separate regions, which are displayed in the map below (while 8 regions are defined, one is separated into two distinct regions):

¹ https://www.oregon.gov/ode/students-and-family/SpecialEducation/RegPrograms_BestPractice/Pages/Traumatic-Brain-Injury-Education-Services.aspx

Figure 1: Regions within the TBI Regional Inclusive Services Network



TBI liaisons are primarily responsible for supporting the identification, evaluation and monitoring of students experiencing more severe TBIs eligible for specialized educational services under the federal Individuals with Disabilities Education Improvement Act (IDEA²). This policy allows for a “special education designation” and the implementation of an Individual Education Plan, or IEP. As resources allow, liaisons support a variety of other activities to include services for those experiencing mild and moderate TBIs. Liaisons typically perform the following roles in their regions:

- Establish relationships with hospitals and communities to maximize early referral and smooth transitions back to school
- Be a primary contact for new TBI referrals and new inquiries
- Connect requests for assistance or information to one or more mentors in the region
- Track students and provide data for those with an IEP
- Assist the region to build TBI support capacity at all levels, including a regional and district TBI teams
- Support and train members of the regional TBI team
- Support efforts to identify youth needing RTS services after a concussion, particularly those eligible for special education services

² <https://sites.ed.gov/idea/>

Federal funding is administered via the Oregon Department of Education for liaison staffing, and for statewide consulting and resources services to help guide and support the liaisons in their work, which is provided by the Center on Brain Injury Research and Training (CBIRT).

Other Context for RTS supports in Oregon

Max's Law

With the passage of Max's Law in 2009,³ Oregon enacted legislation requiring specific concussion management policies for student athletes within Oregon school districts. Oregon's law included the following elements:

- **Recognize:** All coaches must receive annual training in recognizing the symptoms of concussion
- **Remove:** Students suspected of having a concussion must be removed from play
- **Refer:** Students suspected of sustaining a concussion must be evaluated by a properly trained medical professional
- **Return:** A student may return to play when all symptoms have resolved, at least one day has elapsed since the injury, and the student has obtained a medical release

Beyond these elements are recommendations for additional best practices:

- Train all school staff, student athletes and their parents in concussion management
- Develop a clear district-wide concussion management policy
- Return the student to full activity using an individualized graduated plan to guard against symptom exacerbation or second injury

Jenna's Law

Related legislation known as Jenna's Law,⁴ enacted in 2014, expanded requirements of concussion management for young people in non-school athletic programs, which included students at private schools

Individualized Education Plans (IEP) and eligibility for special education services

The federal Individuals with Disabilities Education Act (IDEA) mandates special education services for those found eligible because of typically severe forms of TBI, one of 12 total disabilities covered under this act in Oregon.⁵ Eligibility is stipulated by IDEA and by Oregon regulations and rules and involves formal assessment and documentation of the student's disability and need for specialized services. It results in the development of an IEP by a team of professionals convened for this purpose, which is

³ https://cbirt.org/sites/cbirt.org/files/resources/max%27s_law.pdf

⁴ https://cbirt.org/sites/cbirt.org/files/resources/jenna%27s_law.pdf

⁵ https://www.oregon.gov/ode/students-and-family/SpecialEducation/RegPrograms_BestPractice/Pages/CCSS-and-IEP-Through-Lines.aspx

reviewed annually. This plan will specify not only class-based accommodations but also individualized designed instruction and educational services. This designation for “special education” eligibility and the development of an IEP is seen as the most robust form of student support and tracking for RTS services.

504 Plan

A 504 plan is associated with the federal law Section 504 of the Rehabilitation Act of 1973 and is aligned with civil rights protection for individuals with a disability under the American with Disabilities Act.⁶ While less arduous than the eligibility process for an IEP, a primary 504 Plan criterion includes that the disability is expected to last for a minimum of 60 days. A 504 designation does not provide for specialized education but mandates that a team convene to develop a list of curriculum- or classroom-based accommodations for the student, which is then formalized in a written plan.

House Bill 4140

Developed during 2020 and enacted in August 2021, HB 4140⁷ created a requirement for ODE to develop, distribute and make available for use a form⁸ describing academic accommodations that a public education program may make for a student diagnosed with a concussion or other brain injury. While not mandating the use of the form, HB 4140 requires public education programs to make the form available to educators, staff or families when requested or when notice is received that a student has been diagnosed with a concussion or other brain injury.

Credible History allowance under Oregon Administrative Rules

Medical documentation of a TBI and its severity is necessary for establishing eligibility for the IDEA special education designation. This has often been an important barrier in cases where this formal documentation was not available. In 2019, an Oregon Administrative Rule⁹ was adapted allowing for that documentation to be established through an alternative route, the “credible history interview.” The credible history interview entails a significant history of one or more traumatic brain injuries reported by a reliable and credible source and/or corroborated by numerous reporters.

⁶ <https://www.oregon.gov/ode/students-and-family/equity/civilrights/Pages/Section504.aspx>

⁷ <https://olis.oregonlegislature.gov/liz/2020R1/Downloads/MeasureDocument/HB4140/Enrolled>

⁸ https://www.oregon.gov/ode/students-and-family/SpecialEducation/RegPrograms_BestPractice/Documents/Concussions%20TBI%20Accommodations%20Form.pdf

⁹ https://www.oregon.gov/ode/students-and-family/SpecialEducation/RegPrograms_BestPractice/Documents/tbioar.pdf

Methods

Interview development and implementation

A TBI Evaluation Workgroup consisting of staff from OHA Program Design and Evaluation Services and TBI experts designed this project and developed the interview questions; please see a full list in the Acknowledgements section, p. 2. This group developed a semi-structured protocol to guide the interviews which included questions about:

- Resources currently in place to support students returning to school after a TBI or concussion
- Important barriers and challenges in providing support
- What has been going well to support student
- Important next steps for improving the system
- Ideas about next steps for evaluation

This group identified a list of regional and state TBI leaders, including TBI liaisons within the nine Regional Inclusive Programs for Low Incidence Disabilities, along with additional experts on school TBI practices from ODE and CBIRT. The evaluator conducted interviews by phone between February and March, 2022.

Analysis

The evaluator audio-recorded the interviews and created verbatim transcripts and conducted content analysis from the transcripts using NVivo qualitative analytical software (v.12) to identify and summarize the primary themes using a general inductive approach¹⁰. Categories of comments are organized within sections from most- to least-often mentioned, to help readers understand the relative salience of different categories of comments.

¹⁰ An inductive approach uses interview data to develop general categories or themes, compared with a deductive approach which uses interview data to test a theory.

Results

The evaluator talked with a total of 11 people, including eight of the nine targeted TBI regional liaisons and three of the three additional state experts from ODE and CBIRT. This resulted in a participation rate of 11 out of 12, or 92%.

Current statewide practices supporting Return to School

Results for this section and the next will distinguish current practices and initiatives best considered at the statewide level and at the regional (liaison), district or school level. While not designed to capture the comprehensive current practices happening to support RTS for students following a brain injury or concussion, these results highlight the most salient current practices from the perspective of the participants.

The TBI Regional Inclusive Services Network

While practices across regions vary greatly, the TBI regional network itself is a statewide entity which creates a standard practice because of the centralized nature of its organization and the shared resources that support it.

With CBIRT and ODE support, this network provides a consistent forum for the training of the nine regional TBI liaisons, along with routine network meetings that provide the opportunity to network with and learn from each other. Another important standard element within regions is a regional TBI team, made up of champions and leaders across the region, which the liaisons organize and support through ongoing communication, training, and routine team meetings.

CBIRT

While CBIRT functions across various pathways conducting TBI-related research and providing technical assistance and training across the state and northwest region, it also plays a key role supporting statewide RTS practices by providing ODE-funded consultative and resource services for TBI. This involves a leadership role shared with ODE for the TBI Regional Inclusive Network, as well as advocacy and support for legislative and administrative rule changes to improve RTS services. CBIRT's role in developing and providing trainings for professionals and families and conducting outreach to improve awareness of TBI-related issues and available resources has grown in recent years. Importantly, many of these trainings, including 21 webinars presented in the last year, have been archived to improve availability and to facilitate dissemination.

ODE

ODE provides two dedicated staff positions to provide leadership and consultation for special education resources and 504 plans that support RTS practices across the state. ODE staff coordinate the TBI Regional Inclusive Network, along with CBIRT, and support legislative initiatives to improve RTS services. ODE manages federal funding to support RTS services, overseeing distribution of available funds to support network liaison staffing and the consultation and leadership role played by CBIRT.

Current regional, district and school practices supporting Return to School

An important theme identified from the participant interviews was that services and practices vary greatly across regions, and across school districts within regions, and much more is known about practices supporting students with more severe TBIs than those servicing students with milder injuries. Students with significant injuries are well-navigated and tracked through the system and structures are in place to provide for their needs when returning to school. For those with milder injuries, who fall outside of the more formal structures inherent with an IEP or 504 plan, a wide variety in support activities exist. These activities range from school- or district-based areas that successfully identify, track and provide accommodations for students, to regions with little or no centralized services to support or track progress of students with milder TBIs. The following sections highlight some of these differences, but also focus on region-based initiatives and activities happening now to support RTS across the spectrum of severity.

Getting the process started: identifying youth after a TBI or concussion

A method that several liaisons mentioned for identifying those suffering a brain injury--particularly severe cases--involved a triggered, pre-set communication from hospitals either to the liaison, regional team member, or to CBIRT about a child under care for a TBI. Oregon Health and Science University (OHSU) concussion clinics and Doernbecher Children's Hospital Pediatric Critical Care and Neurotrauma Recovery Program were examples of programs participating across several regions. This has been a labor-intensive method to establish and is not available for most youth in Oregon treated for a severe TBI.

Because of Max's Law, more structured identification and service initiation process is provided for athletes injured while participating in sports. But for those with injuries across the spectrum of severity, most liaisons mentioned reliance on families or students to communicate with school staff when there has been an injury, and for that staff to initiate the process for follow-up. This process can be hit or miss though, depending on the awareness of concussion protocols by specific staff. As one participant noted:

"So anything that is happening is voluntary, from a local school administrator's perspective. So for the school-district level, picture is very diverse. Some schools that have, for example, school nurses on site, and they have a good front-office staff who has antennas up when a parent walks in and mentions that "Hey, my child was in an accident." They probably are better equipped to quickly get the school nurse mobilized and do some post-concussion assessment, but some districts, smaller districts where there is no school nurse at all, it's really at the mercy of whoever hears the information about a child getting the head injury."

Some students have their TBI identified after time has gone by following an injury, when symptoms worsen or start to cause difficulties with school or behavior that get noticed by school staff or parents.

In general, liaisons acknowledged a lack of standardized processes at the school level for identifying students with mild brain injuries, including the connection between healthcare and schools, along with a lack of knowledge about to what extent these students are identified and connected with services.

Connecting youth to services

For more severe injuries, a school- or district-based response typically involves convening a team to review needs for evaluation and documentation for the purpose of initiating special education designation and the creation of an IEP with its specialized instructional support. Liaisons reported wide variation on their involvement and role in tracking and monitoring those under a special education designation. Some districts act independently to care for their students, while other, typically smaller or more rural districts, reach out for guidance and consultation about how to proceed, or even ask the liaison to participate on the local team.

Another path for initiating formal services may happen for less severe injuries that are eligible under a 504 plan, written by school-based staff, and which focus on accommodations needed for students to stay engaged within the general education population. Again, liaisons reported a great range in their involvement. Some provide advice and consultation routinely; others rarely get involved with these students.

Several liaisons mentioned that they rely on their regional team members to help initiate and provide support for these processes, and to reach out to the liaison as needed for support and assistance.

Connecting those with milder injuries to services

Some liaisons acknowledged very little involvement with the process for establishing or supporting services for students with milder injuries, while others spoke of providing general support or guidance to districts or school staff, such as school nurses asking about accommodations, or conducting outreach and education to help raise awareness about resources. Some stay more connected to the process with an online referral system for school staff to use when requesting help from a liaison, or a Google form used to input information when school staff start up services for a student. A couple of liaisons mentioned that athletic trainers were the ones likely to start up a process for those with milder injuries.

One area of recent activity has been to raise awareness and disseminate information about HB4140. This was noted as a promising development for standardizing an immediate response by schools to select personalized classroom-based accommodations from the comprehensive ODE list for students returning with either mild or more severe injuries. One liaison mentioned having developed their own region-specific list of accommodations that they disseminated to primary care providers and schools. This has been used to develop accommodations for returning students and has served as a tool for convening school staff and families to monitor services and modify over time as needed.

The importance of the team approach

The importance of a team model was a consistent talking point for the liaisons interviewed. The structure of a statewide network team, a regional team, and district- and school-based teams appears to function well to create the cohesive links from centralized state-level leadership and coordination to the

local school and district level where students receive RTS services. Inconsistencies across the state in the existence of teams at the school and district level reflect the current patchwork nature of the system. However, the overall tiered structure appears to support work to build a robust and responsive network for RTS.

Liaisons typically organize meetings for the regional team during the year, and team members participate in professional development opportunities. As these teams expand in number, they have an impact in more schools and districts, functioning to support and help build standing or ad hoc local district- and school-based TBI teams. As one participant noted,

“And so the 39 or so team members that I pull together every year for five meetings, they are all kinds of miscellaneous-trained folks, some speech paths, some OTs, some school nurses, some ed assistants ... And they are the ones who are my right hands. And they can assist onsite in a school district or in a school building with the logistics of a return-to-school student's needs. And I'm really banking on them helping me because I obviously cannot be everywhere.”

Local team structure and operation varies across and within regions, largely determined by district size and population density. In smaller and more rural districts, “teams” may consist of just one person and may rely more on liaison and regional team support. Larger and more metropolitan districts vary in how independently their local teams work from the regional team and liaison and vary by organization at the school or district level. One liaison reported having a team at every high school in the region, while another spoke of a regional preference to have teams set up for each district to help ensure more standard procedures districtwide. An example of a highly functioning district team is at Dalles School District.

“Dalles School District has a great TBI team. And they actually meet weekly. And if there's any concussion, and it could be mild all the way to severe, which requires hospitalization, any from the entire spectrum, those kids are talked about each week. And the parent comes, and there's school nurse there... as well as a few of their academic teachers across subject areas, school counselors, and even mental health professionals, if they're able to attend.”

Providing advice

An important role for a liaison and the regional team is to provide ad hoc advice, guidance and resource referrals for school and district staff as they navigate the complicated pathways of RTS services. Liaisons and team members provide guidance across a variety of topics, including (but not limited to):

- Supporting evaluations to determine eligibility for special education designation and 504 plans
- Providing solutions for complicated pathways of injuries that do not resolve as expected.
- Reviewing and helping with accommodation plans
- Helping schools or districts develop communication strategies with hospitals and primary care clinics
- Developing strategies to identify students returning to school after an injury
- Advising how to conduct a credible history interview to document
- Answering questions about school responsibilities and opportunities related to HB4140

- Helping school staff conduct credible history interviews for determining IEP eligibility

RTS-related initiatives happening around the state

Given the variety of ways that liaisons are working within their respective regions, the following list of initiatives mentioned by participants could help clarify current activities across the state. These initiatives were mentioned by individual liaisons, except where noted.

Raising awareness about services

Several liaisons mentioned current or recent education and outreach activities to raise awareness about the role of the liaison and regional team and about RTS resources and guidelines. These activities have targeted school staff such as superintendents, special education directors, teachers, and behavior specialists. Other targets have included primary care physicians, emergency departments and hospitals. One liaison mentioned plans for reaching out specifically to rural areas.

Starting or strengthening school- and district-based Concussion Management Teams

Another popular activity mentioned by liaisons included ongoing or future plans to build concussion management teams “in every school” or at the district level.

Other initiatives mentioned by single participants

- Using additional funding to provide “concussion coaching” supports around the region as needed for school staff asking for help implementing RTS services.
- Advocating for changes in Oregon school health curriculum, to include information about TBI and concussions.
- Engaging with partners in other states to learn about what’s happening outside of OR.
- Talking with athletic directors to set up a process of communication among school staff.
- Developing and disseminating one-page TBI “flow charts” for healthcare professionals and school nurses, to outline the recommended process for communicating about injuries and starting up RTS services.
- Developing a spreadsheet to track and monitor symptoms and services for students identified with an injury within one district.

What has been going well?

Most comments about what has been going well revolved around the structure and functioning of the TBI Regional Services Network and particularly the resources and leadership provided by CBIRT and ODE.

The TBI Regional Inclusive Services Network and CBIRT/ODE Leadership

Liaisons gave effusive praise to Melissa McCart of CBIRT and Linda Brown of ODE for their tireless advocacy and assistance, their responsiveness and ability to assist regions as needed, and their leadership in organizing and facilitating a robust network of regional liaisons providing RTS services.

Liaisons called out CBIRT for providing support and resources such as:

- Helping produce and disseminate educational material such as flyers and tip sheets for teachers and other staff
- Developing communication system between hospitals and doctors with liaisons and schools
- Developing a resource-intensive website
- Providing professional development opportunities to help keep liaisons up to date on TBI information and resources
- Creating on-demand trainings, such as archived webinars, that can be shared remotely
- Advocating for changes in legislation and administrative rules

Participants also mentioned the worth of the regional network itself, with the eclectic strengths and quality of the liaison team and the ability to network and share resources with each other.

"I think that statewide kind of liaison model has worked really, really well. That's where I get all my information. That's where I feel supported. I can contact them anytime if I need some help or have a question. That model with CBIRT has been fantastic."

"I know that if I need something, I can go to CBIRT's website, and there's so many resources for parents, there's so many resources for teachers. I don't have to feel like I'm an 'N of one' who needs to know it all. I just need to know where to go and where to direct people to. I think that's worked really well."

After this dominant theme of the TBI Regional Team and leadership strengths, a second tier of themes emerged that included important legal changes, and the strength of regional and local teams.

Legal changes that have improved service delivery

The most often-mentioned legal change that has improved service delivery was the state's recent allowance of a Credible History Interview to stand in place of more formal medical documentation to establish the history of a brain injury. Despite being a recent change, it has already helped to increase the number of students designated with a TBI special education designation by about 20-25% in the last year. Participants also mentioned the importance of HB 4140, Max's and Jenna's Laws, and the general importance of heightened risk perceptions by districts to help motivate follow-through in student identification and provision of services.

Regional and local TBI teams

The regional team model has been going well, with routine professional development and meetings led by the liaisons to provide the structure for a volunteer network of support. These team members are the "ears and eyes" at the local level, disseminating information and resources, and helping to coordinate services within schools and districts.

Local teams were also seen as a strength, with both school-based and district-based teams mentioned.

Other things mentioned as going well

Some other aspects mentioned as going well included:

- Having good communication with and reports from healthcare providers in the region
- Supportive partnership with OHSU and Doernbecher Hospital
- A supportive regional director
- Strong district leadership from superintendents and principals
- District-wide unified RTS protocols
- Working as an administrator in the role of regional liaison

What are important barriers and challenges to providing services?

Themes that dominated this discussion included lack of sufficient funding, the under-identification of youth with an injury, and the lack of a mandate accompanying HB 4140. Participants also spoke of a wide range of additional barriers and challenges, described below.

Insufficient funding for regional services supporting RTS

Most participants discussed the lack of sufficient funding as a barrier, citing that the level, about \$21,000 per region, has remained the same for at least 10 years while student populations have grown. Liaisons typically serve many roles in their regions other than supporting TBI services, and feel stretched too thin to do all they want to do to build their teams, work with local hospitals and pediatricians, improve awareness and education among district and school staff, and assist with providing and tracking services.

“Funding. For regional inclusive services, which is the avenue where we provide support and our TBI liaison, that's been flat funded for about a decade. What we've done is we keep kind of watering down our support services for kids because the funding has been so static, and at the same time our student numbers have gone up about 30%. Funding's a huge thing.”

“The regional programs ... we do have this mandate to serve this population, but it's horribly underfunded, horribly underfunded. We should be able to provide more staff with expertise in this area to support those kids.”

Finding the students: under-identification of students with brain injuries

Most participants also spoke of the difficulty identifying all students who have a TBI or concussion to start up supportive RTS services. Participants spoke of various causes for this challenge and acknowledged that this seemed most important for, though not limited to, those with mild to moderate injuries.

Lack of communication between healthcare and schools

Several participants spoke of challenges related to finding out about students with an injury because that information does not usually get reported by the hospitals or primary care providers. While progress has been made to implement a reporting mechanism with some hospital systems, communicating to the school about a brain injury typically is left to the parents. It has been challenging to set up reporting agreements for several reasons:

- Lack of time for this labor-intensive activity
- Lack of access to healthcare systems and/or lack of a healthcare champion to help reach leadership
- Challenges developing or promoting the use of standardized release of Information (ROI) process to allow direct communication from healthcare to schools
- Health provider concerns about HIPAA restricting direct reporting to school.

Under-reporting of injuries by parents and family

Parents often are overwhelmed after a child's brain injury, which can lead to denial or confusion about how to proceed. Due to lack of awareness and education, they may also not consider a TBI as a serious enough condition to report. When the cause of an injury is parental abuse, parents may be reluctant to report it.

TBI is a silent disease

That brain injuries often do not lead to easily observable symptoms was also cited as a contributing factor for under-identifying incidence of TBIs. Among teachers and other school staff, lack of awareness about common signs of a concussion can lead to a mistaken impression that a student is just not working hard enough. And students may be found eligible for special education services under a different low-incidence injury category (such as learning disability or orthopedic impairment) which could mask or be prioritized over TBI, and which likely leads to significant under-identification of those needing TBI-related special education IEPs.

"And if I'm lucky, I get a call from somebody, but most of the time I don't. Gosh, I think I took over the TBI liaison role six years ago, I have not received a single phone call from a local hospital. I got probably a dozen from Doernbecher's, I got zero from our local healthcare providers because they don't even know I'm here. So this is the biggest barrier, that I'm not getting calls from healthcare."

"The very first barrier is that I am not aware of all the students who suffered a concussion and TBI because that information doesn't readily come to me. And it's from the fact that we don't have a very consistent process, or mandated process, about reporting the kids to the schools. So that's the first barrier, that I don't even know who they are."

Lack of mandate accompanying HB 4140

While participants praised the recent passing of HB4140 as a good start in providing a standardized list of accommodations for schools to use when initializing supportive services for returning students, most

were frustrated that the law did not include a mandate to use the accommodation form or to establish local concussion management teams. Given the overwhelming nature of work as a school administrator, teacher or other staff, initiatives framed as voluntary will likely not be prioritized, acted upon, or even noticed in a consistent way.

"And then we don't have really mandated legislation...So when something is not in a mandate, when something is just best practice recommendation, it's not really being implemented. So the ODE tried to put out this accommodation form, but the only message is, 'please consider it'."

Following these three main themes mentioned by the majority of participants, several additional themes had multiple mentions, indicating the breadth of barriers and challenges for providing RTS services. Of this second tier of themes, challenges related to the pandemic, to monitoring and tracking those in the system, and staff turnover were mentioned most often.

Disruptions due to the COVID pandemic

Not surprisingly, many mentioned the pandemic as a huge barrier for RTS services over the past two years. Generally, the pandemic “put the brakes” on ongoing work, disrupting attempts to build local teams and to work with nurses and other school staff now stretched thin performing additional and sometimes overwhelming COVID-related tasks.

Difficulty monitoring and tracking students in the system

Several participants spoke of the inconsistent system for tracking and monitoring those students with a brain injury once they are identified and back at school. While those with special designation remain well-monitored, the lack of systematic communication over time makes tracking problematic for those with mild or “mild complicated” injuries who need accommodations and are staying in the general education population, including those with 504 plans. This can be particularly true for smaller districts and younger children, when students move across district lines or move out of elementary school.

"You're going to have kids that are at risk. You're going to have teachers that aren't sure who to turn to when they need support. You're going to have just that lack of follow-up, that lack of documentation that maybe impacts the child further down the line when delayed symptoms appear... And you're going to never realize that child had that injury, just those kinds of pieces get lost."

Needing to “start over” because of staff turnover

A high level of turnover among school staff or healthcare partners disrupts plans for working with stakeholders to provide RTS services or implement outreach or education to raise awareness. Interviewees mentioned specific examples such as departures of school staff participating with TBI

teams, champions in doctors' offices, site 504 coordinators, special education directors, or district administrators.

"Another challenge is staff turnover, and in education right now, the turnover rate is incredibly high. And so we'll get something established at a school and then the following year, say we get a TBI team established at the school level, the following year half of that team is gone, or the leadership is gone. And so it's a consistent process of retraining."

Coordination and communication hampered by silos

Communication can be difficult across traditionally distinct stakeholder roles and service categories, which can hamper coordination of RTS services. The type of "silos" mentioned included athletic trainers, general education teachers, healthcare professionals, 504 plan administrators, school nurses, and special education staff.

Rural areas face unique challenges

Certain aspects for providing and coordinating RTS services regionally can be particularly challenging in more rural areas of the state. Reasons mentioned included more difficult access to healthcare services, problems inherent to smaller populations and a low-incidence condition, large distances to travel for regional support services, the many competing roles played by fewer staff positions, and a general "valley-centric" focus on the more populous regions for state services.

Other barriers and challenges

Several other challenges were mentioned by participants, including issues related to:

- Setting up Credible History interviews because it was a new process
- Lack of authority for the liaison role if it is not at an administration level
- Getting through to the ODE consultant for 504 questions
- Lack of licensed or certified status for TBI specialists
- Lack of a system for tracking existence of school TBI teams
- Inadequate coverage of TBI-related information in teacher and specialist education curriculum
- Problems identifying TBI point people at the district level
- Reduced district support for staff participation with the regional TBI team
- Inconsistent protocols across districts for child identification and RTS services
- Difficulty for smaller districts to conduct and interpret results from comprehensive TBI evaluations
- Inadequate utilization of mental and emotional health support for students with brain injuries
- Variation across the state in providing services due to unequal access to TBI support resources
- Delays in navigating students through the 504 and IEP evaluation process
- Lack of pediatric neurological specialist in a region

- Lack of TBI-related awareness or knowledge among parents or staff

What are important next steps for improving the system of RTS services?

Comments about important next steps for improving RTS services were split relatively evenly over four main themes:

- Increase funding
- Continue and expand training activities
- Improve identification of youth with brain injury
- Continue to advocate for legal changes

Increase funding

While some of the feedback was about increasing funding in general, most comments included suggestions about specific areas where funding could be added to improve services. Most commonly, participants suggested adding funding for enhanced staffing, to provide more time to liaisons or others providing specialized and dedicated RTS services to support the complex and time-consuming array of regional activities. Other specific suggestions included funding to support:

- Stipends to help reimburse regional team members for their time
- RTS activities in rural areas
- A tiered services delivery system to organize resources across the spectrum of severity

“Funding for regional services for someone who can handle nothing but traumatic brain injury... who can help run the concussion teams, attend the IEPs, consult with students, observe students and consult with the teams from those observations... the outreach to families and getting the information from physicians whenever possible, and helping to facilitate those connections between the medical field, the athletic field, and the educators, that would be amazing.”

Continue and expand training activities

Comments about expanding training focused on informing and raising awareness about TBI and concussion basics, such as prevention and medical characteristics, and about providing and coordinating RTS services. The targeted groups for these activities were varied and included:

- School staff, including general education teachers, athletic trainers, school counselors, and front-line staff such as secretaries
- Parents and students
- Healthcare providers
- Early childhood care providers

Some made suggestions about alternative mechanisms for trainings, to be more customized or intensive, such as:

- Customized training for parents with a child receiving services
- Observation and coaching for teachers
- Professional development to include active feedback
- Inclusion of specialized training for TBI specialists

Improve identification of youth with brain injury

The most frequent comment about improving child identification related to building notification systems between healthcare and schools or a regional TBI point person. This would likely include the development and dissemination of release of information mechanisms so to avoid relying on parental notification. Other comments about improving identification included:

- General comments to develop communication systems within schools
- Develop online referral systems
- More accurate identification of a TBI within the eligible low-incidence disability options¹¹

Continue to advocate for legal changes

Almost all comments about legal changes related to amending HB4140 to better specify how schools should use the accommodation form, and to require that it be used by districts. Some also suggested adding a mandate for school TBI teams or a dedicated point person to add structural RTS supports at the school level. An additional suggestion was to make TBI and RTS-related training mandatory for school staff.

“We need to amend House bill 4140 and make it mandatory, because right now it is optional for districts to use the form. So making that mandatory would give it a little more umph. And we know that people respond to policy.”

Other suggestions for next steps

A few other suggestions included the following:

- Build in peer support for students dealing with a brain injury
- Create regional hubs for information and resources

¹¹ Low-incidence disabilities occur in the general population at such a low rate that it is difficult to employ specialized staff and provide a full range of educational services for these students. The eligible low-incidence disabilities include deaf or hard of hearing impairments, visual impairments, autism spectrum disorders, orthopedic impairments, deafblindness, and traumatic brain injury. (https://www.oregon.gov/ode/students-and-family/SpecialEducation/RegPrograms_BestPractice/Pages/Regional-Programs.aspx)

- Create a system for using temporary accommodations
- Collect and share data related to TBI incidence to raise awareness and support RTS services
- Develop a system for tracking students who have had a TBI
- Identify a TBI point person in every school district

What are some ideas for next steps in evaluation?

While this prompt generated less feedback than other questions, several participants thought it would be a good idea to continue learning about current RTS practices, particularly at the school or district level. Ideas included conducting surveys or interviews with staff and administrators at the school or district level:

<u>School level</u>	<u>District level</u>
<ul style="list-style-type: none"> • Principals • General education teachers • Counselors 	<ul style="list-style-type: none"> • Lead nurses • Superintendents • Special education directors

Other ideas included:

- Interviews with parents and students to better understand their needs.
- Describe RTS services at “gold standard” sites.
 - School team
 - District
 - Physician champion and improving intersection between healthcare and schools

Conclusions

As with any project, it is important to acknowledge limits and urge caution in interpreting the findings. Results from these interviews were based on a limited range of potential RTS stakeholders, which focused on a regional rather than a school- or district-level perspective. Additionally, information may have been limited because of interview lengths that ranged from 20-40 minutes or the focus on capturing the most salient information with the limited number of topics. These findings are based on self-reporting. The findings may be inaccurate due to factors such as difficulty with recall or omissions due to any perceptions that the information might be sensitive.

Summary of key findings

Current practices

Services and practices vary greatly across regions, and across school districts within regions, and much more is known about practices supporting students with more severe TBIs than milder TBIs. For the most part, students with significant injuries are well-navigated and tracked through the system and

structures are in place to provide for their needs when returning to school. For students with milder injuries who do not receive support from more formal structures inherent with an Individualized Education Plan or 504 plan, a wide variation in support activities exist within and across regional levels. Regional liaisons help lead efforts to identify youth after a TBI, connect youth to RTS services, advise and train healthcare and school professionals, and conduct a variety of initiatives to improve services. The team approach is an important aspect of facilitating these services, from the broader regional team to local teams at the district and school level.

What has been going well

Most participants praised the TBI Regional Inclusive Services Network and the leadership provided by the Center on Brain Injury Research and Training (CBIRT) and the Oregon Department of Education (ODE), a model which works well to provide centralized support and resources across the state for RTS services. Other aspects going well included the strong performance of regional and many local TBI teams, as well as legal changes that allowed Credible History interviews and directed the dissemination of a standardized student accommodations form.

Important barriers and challenges

The top three barriers included:

- Insufficient funding for regional services supporting RTS
- Under-identification of students with brain injuries
- Lack of mandate accompanying HB 4140

Additional barriers included:

- Disruptions due to the COVID pandemic
- Difficulty monitoring and tracking students in the system
- Problems due to staff turnover

Recommendations for next steps

The top recommendations for next steps based on these interviews included:

- Increase funding for regional and local RTS efforts to support the complex and time-consuming array of regionally-led activities
- Continue and expand training activities to educate and raise awareness about TBI and concussion basics, such as prevention and medical characteristics, and about providing and coordinating RTS services. Groups to target should include school staff, families, and healthcare providers
- Improve identification of youth with brain injury by primarily improving communication through notification systems between healthcare and schools or a regional TBI point person
- Advocate for legal changes to amend HB4140 to require the use of ODE's student accommodation form upon a student's return to school after a TBI
- Consider a policy to require and provide support for convening local TBI teams at the school or district level

Also to consider—Recommendations for next steps based on results¹² of a 2019 survey with athletic trainers about Max's Law:

- Continue coordination and strategic planning among the Oregon School Activities Association, Oregon Concussion Awareness and Management Program, Center on Brain Injury Research and Training, Oregon Department of Education and Oregon Health Authority to support school efforts in concussion management
- Help schools overcome barriers to train coaches, including resources to help organize reminders, overcome coach hesitancy and improve outreach to non-mainstream coaches.
- Provide resources and raise awareness among qualified healthcare providers about current concussion management best practices
- Improve provider education, an important consideration after the recent passage of Senate Bill 1547 expanding types of providers eligible to clear students for return to play and stipulating required training

¹²

https://www.oregon.gov/oha/PH/PREVENTIONWELLNESS/SAFELIVING/KEEPINGCHILDRENSAFE/Documents/le2955_maxs_law_imp_eval_final.pdf