



HEALTH INFORMATION AND DATA SHARING  
**Issue Brief**

## Equitable and Effective Data Sharing to Support Healthy Transitions for Youth During Reentry

### Introduction

Youth in the juvenile justice system experience elevated rates of physical and behavioral health conditions resulting from incarceration and other structural drivers of poor health. As youth of color and particularly Black youth are incarcerated at vastly disproportionate rates, these burdens on health and wellbeing drive racial health disparities. Negative health conditions experienced by youth who are incarcerated endure after incarceration. Especially in the period immediately following release, youth experience markedly high rates of overdose and suicidal behaviors. The pre-release period, during which youth are preparing to reenter their communities, as well as the post-release reentry period are thus critical intervention points when youth would benefit from robust, coordinated support to address a host of health and health-related social needs.

Recent policy innovations are attempting to expand access to such support by making Medicaid and CHIP coverage available for reentry services designed to promote healthy transitions. These policy innovations include new Medicaid and CHIP requirements that will mandate the provision of certain pre- and post-release services to eligible incarcerated youth. In order to provide the services required by the Medicaid and CHIP reforms, states will need to ensure that relevant partners, such as Medicaid agencies, correctional facilities, and community providers, can share data across systems. Such data exchange is necessary to activate health plan coverage and to facilitate timely, appropriate, and person-centered care. But numerous challenges may impede this data sharing, including the complexity of the legal frameworks involved and the privacy concerns that arise when highly sensitive information is shared.

This resource is intended to assist states implementing the youth-focused Medicaid and CHIP reforms in navigating these data sharing challenges. It identifies the important role of data sharing in reentry services and highlights the different roadblocks that those engaged in data sharing may encounter. It then identifies legal, ethical, and practical considerations for designing equitable data sharing systems that center the voices of impacted youth and protect against further entanglement of punitive systems in health and social care. While this resource focuses on the Medicaid and CHIP reforms, many of the considerations identified are relevant to other policy initiatives to support healthy transitions for incarcerated individuals, including Medicaid section 1115 reentry waivers (experimental changes to state Medicaid programs allowing coverage of pre-release services with HHS approval).



## Background

Youth<sup>1</sup> in the juvenile justice system are at an increased risk of experiencing a host of physical and behavioral health conditions that impede their ability to live healthy, thriving lives.<sup>2</sup> Research indicates that approximately two-thirds of youth involved with the juvenile justice system have at least one substance-related problem,<sup>3</sup> and, compared to their non-incarcerated peers, they are significantly more likely to have mental health disorders<sup>4</sup> and to experience suicidal ideations and behaviors.<sup>5</sup> Rates of adverse childhood experiences (ACE) are also disproportionately high among youth who are incarcerated, a vast majority of whom have experienced at least one ACE.<sup>6</sup> Incarceration, a recognized social determinant of poor health,<sup>7</sup> can exacerbate these adverse health outcomes through health-harming conditions such as overcrowding, lack of access to health care, chronic and acute stressors of imprisonment, and traumatizing practices like solitary confinement.<sup>8</sup> The negative health effects of incarceration endure after release; incarceration during adolescence and early adulthood is associated with worse health outcomes later in life, even when controlling for other social determinants of health.<sup>9</sup>

Mass incarceration in the U.S. is deeply inequitable. Youth of color are disproportionately incarcerated,<sup>10</sup> and Black youth in particular are almost five times as likely as their white peers to be held in juvenile facilities.<sup>11</sup> Youth in the child welfare system<sup>12</sup> and youth living in poverty<sup>13</sup> are also overrepresented in the juvenile justice system. The system's burdens on health and wellbeing thus drive disparities, contributing to poor health outcomes among communities of color and particularly Black communities, while compounding health risks associated with intersecting structural drivers of health inequity.

Given the adverse health outcomes and racial disparities associated with juvenile justice system involvement, youth returning to their communities after incarceration would clearly benefit from holistic support and timely access to services to meet health and social needs. But research shows that youth face barriers to health-promoting interventions, such as lack of access to health care coverage, during reentry.<sup>14</sup> Additionally, lack of case management and coordination across health and social services can overburden families, forcing them to navigate complex eligibility criteria, differing insurance requirements, numerous appointments, and fragmented services on their own.<sup>15</sup> The resulting gaps in services pose serious risks to health, particularly for individuals with behavioral health conditions, as the risk of drug overdoses and suicidal behaviors is markedly elevated immediately following release.<sup>16</sup> And for young people in formative developmental stages, lapses in supportive services may pose unique harms to health.<sup>17</sup>

Historically, laws and policies governing Medicaid and other public benefits have contributed to these barriers, hindering access to coordinated, continuous, and affordable services for youth during reentry. For example, a Medicaid provision known as the inmate exclusion policy<sup>18</sup> generally prohibits the use of federal Medicaid funds to pay for health care received by incarcerated individuals with a limited exception for in-patient health care received in a medical institution.<sup>19</sup> Further, the eligibility criteria for the Children's Health Insurance Program (CHIP) exclude "inmates of a public institution" from coverage.<sup>20</sup>

As a result of these provisions, youth in the juvenile justice system have historically been unable to access Medicaid or CHIP coverage for most health care received during incarceration. This has hindered healthy transitions during reentry for several reasons. First, individuals may lack access to coverage after release due to delays in reinstatement of health plan coverage.<sup>21</sup> Medicaid coverage during reentry is linked to increased use of health care services as well as to decreased risk of social determinants of poor health like reincarceration, particularly for individuals experiencing financial insecurity.<sup>22</sup> Thus, policies that limit Medicaid coverage for individuals reentering deny them what can be an important component of healthy transitions. Second, the inability to start providing services, including screening, case management, and discharge planning, while individuals are incarcerated hinders efforts to link individuals to appropriate community services during reentry.<sup>23</sup> The pre-release period can be a crucial intervention point for supporting youth<sup>24</sup> and a missed opportunity when Medicaid and CHIP coverage only become available post-release.



## Medicaid and CHIP Reforms to Support Youth Who Are Incarcerated

In recent years, the federal government has advanced reforms to address some of these impediments to healthy transitions.<sup>25</sup> The Consolidated Appropriations Act, 2023 (CAA, 2023) is a key source of such reforms.<sup>26</sup> Signed into law on December 29, 2022, the CAA, 2023 lifts the Medicaid inmate exclusion policy and the CHIP eligibility exclusion of “inmates of a public institution” under specific circumstances.<sup>27</sup> This change makes federal Medicaid and CHIP funding available to pay for certain services for youth in the pre-release and reentry periods.<sup>28</sup> On July 23, 2024, the Centers for Medicare & Medicaid Services (CMS) issued a guidance letter to state health officials, “Provision of Medicaid and CHIP Services to Incarcerated Youth.”<sup>29</sup> The letter clarifies how states can comply with the Medicaid and CHIP reforms implemented by the CAA, 2023, all of which go into effect on January 1, 2025.<sup>30</sup>

As detailed in the letter, section 5121 of the CAA, 2023 requires that certain Medicaid-funded pre- and post-release services be provided to eligible juveniles, including screening and diagnostic services and targeted case management (TCM) services.<sup>31</sup> TCM encompasses a range of services designed to assist eligible juveniles in accessing the support needed to address health and health-related social needs. These include comprehensive assessment and periodic reassessment of need for medical, educational, social, or other services; development and periodic revision of a person-centered care plan; referral and related activities to connect individuals to needed services in accordance with care plans; and monitoring and follow-up activities conducted as frequently as necessary and including at least one annual monitoring.<sup>32</sup> States with separate CHIP plans are subject to similar requirements for eligible juveniles covered by CHIP.<sup>33</sup>

For the purpose of the new Medicaid required services, an “eligible juvenile” is an individual under 21 or a former foster care youth under 26 determined eligible for Medicaid immediately before or during incarceration.<sup>34</sup> For CHIP required services, an “eligible juvenile” includes incarcerated youth under the age of 19 in CHIP who are otherwise eligible for services under the new requirements.<sup>35</sup> Section 5121 limits the required services under both Medicaid and CHIP to youth who are post-adjudication, meaning that they are incarcerated following disposition of their charges.<sup>36</sup> In contrast, section 5122 gives states the option of providing Medicaid and CHIP services for eligible juveniles who are incarcerated while awaiting disposition of their charges.<sup>37</sup> A state that selects this option must provide the full suite of Medicaid and CHIP services that would otherwise be available under the state plan (as opposed to only screening, diagnostic, and TCM services).<sup>38</sup>

### Medicaid Section 1115 Reentry Waivers

Medicaid section 1115 reentry waivers provide opportunities for states to improve health care access and strengthen linkages to services during reentry. Under section 1115 of the Social Security Act, 42 U.S.C. § 1315, the Secretary of the U.S. Department of Health and Human Services may waive certain mandatory Medicaid provisions at states’ request, allowing states to test new approaches to their Medicaid programs that would not normally be permitted under federal requirements.<sup>39</sup> In 2023 guidance, CMS encouraged states to apply for section 1115 waivers to provide coverage for Medicaid services to soon-to-be-released incarcerated individuals.<sup>40</sup> As of October 2024, section 1115 reentry waiver proposals have been approved in eleven states and are pending in fourteen states and D.C.<sup>41</sup> While section 1115 reentry waivers differ from the Medicaid and CHIP reforms in certain respects—mainly, that the waivers are optional and provide states more flexibility to determine the scope of coverage—the policy changes share many objectives and implementation components, as well as needs and challenges related to cross-sector data sharing.



## Benefits of Data Sharing

Data exchange is vital for ensuring that youth who are incarcerated receive Medicaid/CHIP pre-release services and for successfully linking youth to appropriate services in their communities. In a 2023 Report to Congress, a stakeholder group convened to identify promising practices for health care transitions during reentry emphasized how data sharing can improve health care transitions for returning community members.<sup>42</sup> For example, sharing data like expected release dates between correctional agencies, carceral facilities, Medicaid/CHIP agencies, and/or Managed Care Organizations (MCO) may be necessary to facilitate reinstatement of health plan coverage.<sup>43</sup> Specifically with respect to required services under section 5121, this data exchange would involve communication of expected release dates with Medicaid/CHIP agencies or other entities to reinstate coverage as needed by the start of the pre-release period.

Additionally, as highlighted in the Report to Congress, sharing information on health care provided to individuals during incarceration is crucial for ensuring that community providers are equipped to deliver informed, appropriate, and timely care.<sup>44</sup> Community providers, for instance, may need to know information such as an individual's diagnoses, treatment plan, and current medications to address physical and behavioral health needs. Data exchange also facilitates successful linkages connecting reentering individuals to appropriate health and social services. In fact, a study of one county's efforts to promote healthy transitions during reentry found that the most critical barrier to successful linkages was the lack of data sharing between carceral and community systems.<sup>45</sup>

These data exchanges to support appropriate care and facilitate linkages will play an important role in the provision of services required under section 5121. For example, case managers providing TCM services will likely require access to information on a youth's health and social needs to develop a care plan. And that information will need to be shared with community providers to implement the care plan and to conduct follow-up activities. Without this kind of data sharing, youth and their families would shoulder the burdens of navigating complex care systems on their own and of reporting diagnoses, medications, and other data necessary for health and social care that often requires timely, accurate, and comprehensive information. These are challenging tasks for anyone and are only made more difficult by the fragmented and siloed nature of pre- and post-release services, as well as competing needs and stressors experienced during reentry.

Another benefit of sharing data across correctional and community systems is that it lessens the burden on individuals to share sensitive information over and over again. Requiring youth to tell their stories repeatedly due to lack of information sharing across providers can be traumatizing and dehumanizing, particularly for those with histories of trauma.<sup>46</sup> As a vast majority of youth in the juvenile justice system have experienced at least one ACE—not to mention the trauma of juvenile justice system involvement itself—lessening the burden on youth to tell their stories can promote trauma-informed care. Furthermore, doing so may alleviate barriers to care for youth who might otherwise forego services altogether in light of this burden.

## Data Sharing Challenges

### Complex Legal Frameworks

Agencies and other entities attempting to share data across correctional and community systems to promote healthy transitions during reentry face several barriers. For one, agencies have found navigating legal frameworks governing data use and privacy to be challenging, particularly in the context of cross-sector collaborations.<sup>47</sup> Because partners involved in care coordination often operate in distinct sectors (e.g., health care, corrections, homeless services, education, food security, etc.), they are likely subject to differing legal standards for data sharing and privacy. Accordingly, a complex patchwork of laws and regulations may govern a data exchange, making compliance challenging. Differing interpretations of legal frameworks can lead to drawn-out negotiations over data use agreements, thus delaying data sharing projects.<sup>48</sup> And for risk averse parties who prioritize limiting liability—or for those who simply lack the capacity and expertise to navigate these legal frameworks—foregoing any data exchange may appear to be the simplest option.



## Limited Interoperability

Another barrier to sharing the data of youth in the juvenile justice system is the absence of data systems designed to share information with cross-sector partners. Historically, correctional and community systems have operated in siloes, collecting and using data for their own purposes. To strengthen care continuity and improve access to informed and appropriate services, these systems need to be interoperable, meaning that they have the capability to exchange data with each other.<sup>49</sup> Currently, interoperability is impeded by systems' limited technological capacity to share information.<sup>50</sup> Interoperability additionally requires that information be recorded in a format conducive to sharing, which may not be the case, particularly given that cross-sector partners may use differing terms and taxonomies to record data.<sup>51</sup> Finally, data quality issues may pose barriers to interoperability; incomplete or inaccurate data entries can preclude matching of individuals' data across systems.<sup>52</sup>

## Highly Sensitive Data and Potential Misuses


Agencies implementing the Medicaid and CHIP reforms also face the challenge of sharing data while protecting privacy and ensuring responsible, ethical data stewardship that empowers youth and prevents harm. Youth in the juvenile justice system have unique privacy concerns. Given that a majority of youth who are incarcerated experience behavioral health problems, their health information may include types of data that are highly sensitive, such as substance use disorder (SUD) data and mental health records. Data related to HIV and other STIs that are disproportionately prevalent among incarcerated youth,<sup>53</sup> as well as information on an individual's history of incarceration, are similarly sensitive. Even well-intentioned disclosures of such data may result in harm, like stigmatization of and discrimination against youth.<sup>54</sup> Additionally, misuses of sensitive data like SUD information and HIV-related data can lead to further criminalization,<sup>55</sup> exacerbating risk for communities already subject to disproportionate arrests and juvenile-justice system involvement, such as youth of color and youth with disabilities.<sup>56</sup>

## Privacy Concerns and the Need for Trust in Seeking Health Care

Protecting the confidentiality of youth health information lays the foundation for trusting relationships with providers, thereby promoting access to well-informed and higher quality care. Research shows that concerns about confidentiality are a primary reason why young people forego seeking health care.<sup>57</sup> When youth believe that the confidentiality of their health information will be protected, they report greater willingness to disclose such information to their health care providers.<sup>58</sup> Building trust may be particularly important in the juvenile justice context, as concerns that personal data will be misused and low levels of trust in institutions that collect personal data, including law enforcement, are most common among individuals with lower levels of household income and education, as well as among communities of color,<sup>59</sup> all of whom are overrepresented in the juvenile justice system.<sup>60</sup> These valid concerns are grounded in the reality that such institutions may use data to surveil and subjugate targeted groups.<sup>61</sup> Further, well-deserved medical mistrust within Black communities stemming from legacies of harm and contemporary mistreatment in the medical field may heighten privacy concerns.<sup>62</sup> Systems for sharing data must therefore build trust through meaningful privacy protections to rectify harm and promote access to person-centered, affirming care.

## Inequitable Power Distributions

Systems for data sharing are often designed in ways that fail to empower the individuals whose data is shared, instead vesting control in the governmental agencies and other organizations that hold the data.<sup>63</sup> These data systems can reinforce structural racism and other drivers of health inequities by, for example, using data to penalize communities of color subject to oversurveillance.<sup>64</sup> Likewise, technological innovation facilitating data collection can operate to exacerbate inequitable distributions of power through oversurveillance, exploitation, and exclusion of certain communities from the benefits of technological advancements.<sup>65</sup> Agencies implementing the Medicaid and CHIP reforms must promote community involvement and ensure that the voices of youth, and particularly youth of color, guide development and implementation, building power among impacted communities and avoiding inequitable data sharing practices that reinforce and further injustice.



## Considerations for Effective and Equitable Data Sharing

In short, data sharing across correctional and community systems is complex and laden with risk, but failure to share data entails risk as well given the vital role data plays in effective pre- and post-release services to support youth during a particularly unsafe period. Thus, data sharing partners must not shy away from the admittedly hard work of navigating these challenges. Rather, partners must work towards effective and equitable cross-sector data sharing, recognizing the value of disclosure *and* the imperative of safeguarding privacy. This work necessitates community-driven, empowering data sharing that protects against further entanglement of punitive systems in health and social care.

What follows are considerations drawn from prior data sharing initiatives to support health during reentry and other cross-sector data collaborations to address health and social needs. These considerations and best practices are intended to guide agencies and other partners implementing the Medicaid and CHIP reforms in their use of data to promote and protect the health of youth.

### Strong Partnerships

Building collaborative relationships among partners will lay the groundwork for successful data sharing in the implementation of the Medicaid and CHIP reforms.<sup>66</sup> In this context, partners who share data with each other may include state Medicaid agencies, MCOs, community health and social services providers, correctional agencies, and correctional facilities, among others. Data sharing relies on trust as well as ongoing coordination, so it is important for these partners to communicate extensively with each other.<sup>67</sup> Other key relationships include those with partners who do not necessarily disclose or receive data but whose experience and buy-in are critical to developing equitable and effective data sharing initiatives, such as community-based organizations and youth and families with lived experience.<sup>68</sup> Numerous resources are available to assist states in engaging communities with lived experience with incarceration in implementation of the Medicaid and CHIP reforms.<sup>69</sup>

Development of these partnerships should start early; past initiatives to support healthy transitions have found that bringing the right people to the table and developing strong partnerships early on was critical to the initiatives' success.<sup>70</sup> Investing in partnerships early is particularly important for data sharing between correctional and community systems and state Medicaid agencies for several reasons. First, in many jurisdictions and in part due to the inmate exclusion policy, data sharing between these entities has not occurred systematically in the past. Accordingly, these entities may lack preexisting relationships that would have laid the foundation for further collaboration. Additionally, correctional and community partners may have (at times, substantially) different objectives and approaches to their work. Collaborating early on to build consensus around data sharing will support implementation of the Medicaid and CHIP reforms.<sup>71</sup>

#### Pima County

Pima County, Arizona, has implemented several initiatives to promote access to care during reentry through information sharing, including health information exchange among correctional and community providers and data sharing among agencies to facilitate Medicaid enrollment or reinstatement.<sup>72</sup> In a 2017 review of these initiatives, the Urban Institute found that strong collaborations were essential.<sup>73</sup> Specifically, in addition to partnerships between Medicaid and correctional agencies, the review emphasized the role of community partner organizations.<sup>74</sup> Pima County partnered with a nonprofit organization, the Pima Community Access Program, to support the Medicaid enrollment process for incarcerated people 30-45 days prior to release.<sup>75</sup> An organization with many years of experience connecting low-income residents to coverage,<sup>76</sup> the Pima Community Access Program exemplifies how organizations with histories of community involvement are positioned to lend unique expertise to data sharing initiatives.



## Promoting Interoperability

Working to strengthen partnerships may additionally support efforts to promote interoperability. While achieving interoperability will require development of more sophisticated technology systems for many partners, establishing a shared vocabulary and standards conducive to data exchange will be a key early step.<sup>77</sup>

For necessary advancements in technology systems, CMS has indicated that federal funding opportunities are available to support states sharing data between carceral and community systems. On September 27, 2024, CMS announced an opportunity for state Medicaid and CHIP agencies to apply for grant funding to support implementation of the Medicaid and CHIP reforms, among other reforms in the CAA, 2023.<sup>78</sup> Permissible uses of funding include investment in IT systems to enable bidirectional information sharing to promote care coordination and support healthy transitions during reentry.<sup>79</sup> Additionally, in guidance on Medicaid section 1115 reentry waivers, CMS explains that state Medicaid agency IT system expenditures incurred to support exchange of information across health care, social services, and carceral systems in implementation of section 1115 reentry waivers may be eligible for enhanced Medicaid funding.<sup>80</sup> Specifically, 90/10 enhanced federal matching may be available for states' design, development, and implementation of data systems to promote sharing across state Medicaid agencies, carceral facilities, and correctional agencies.<sup>81</sup> States may also request 75/25 enhanced federal matching for costs related to ongoing operation of CMS-approved systems.<sup>82</sup>


Given that updating technological systems takes time and partners may not be able to develop fully interoperable systems before the Medicaid and CHIP reforms go into effect, partners may benefit from starting with low-tech data sharing practices that, while not necessarily sustainable, enable initial data sharing while systems are being updated. Being open to short-term, flexible solutions may lay the groundwork for larger scale changes and promote access to services for youth in the interim.<sup>83</sup>

### Ohio Medicaid Pre-Release Enrollment Program

Beginning in 2014, the Ohio Medicaid Pre-Release Enrollment Program, a collaboration between the Ohio Department of Medicaid, the Ohio Department of Rehabilitation and Correction, the Mental Health and Addiction Services Department, and Ohio MCOs, worked to enroll soon-to-be-released individuals in Medicaid and to provide care management.<sup>84</sup> This program involves data exchange between the Department of Rehabilitation and Correction, the Department of Medicaid, prisons, and MCOs.<sup>85</sup> At first, this data exchange was manual, with parties communicating via email, phone calls, and a portal for securely sharing files.<sup>86</sup> Over time, the Medicaid Pre-Release Enrollment Program implemented automated data sharing through a centralized secure site.<sup>87</sup> One lesson learned from this program was the value of being flexible with respect to technology systems, for example, leveraging low-tech systems for initial data exchange while working towards interoperability.<sup>88</sup>

## Navigating Legal Frameworks

As noted above, navigating the legal frameworks governing the data of youth involved in the juvenile justice system will be challenging given the complex patchwork of applicable legal requirements. In general, whether a data privacy law limits the use or disclosure of data will depend on the type of data at issue, the party holding the data, and the purpose of the use or disclosure, among other factors. Importantly, while applicable law will likely limit disclosures under certain circumstances, many data privacy laws permit use or disclosure with the consent of the individual who is the subject of the data. Additionally, although some laws may limit sharing of data even with consent, such laws may permit sharing for care



coordination or other purposes that align with the Medicaid and CHIP reforms. In guidance, CMS has accordingly indicated that, while they may establish certain protections and conditions on use and disclosure (e.g., security or consent requirements), laws and regulations including HIPAA, 42 C.F.R. Part 2, and the Medicaid Applicant and Beneficiary Information Safeguards “should not be barriers for health care personnel to coordinate patient care among organizations” in implementation of the Medicaid and CHIP reforms.<sup>89</sup>

The following sections provide high-level summaries of some laws and regulations that are likely to apply to the data of youth who are eligible for services under the Medicaid and CHIP reforms, highlighting considerations specifically pertaining to minors and people who are incarcerated. This list is not comprehensive. Further, it bears noting that laws and regulations constitute the floor of what is required with respect to consent and privacy protections and do not necessarily reflect best practices for data sharing under all circumstances.

### **HIPAA’s Privacy Rule and Incarcerated Minors**

The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that governs individually identifiable health information, referred to as protected health information (PHI).<sup>90</sup> HIPAA applies to covered entities as well as business associates that provide certain services or perform certain functions for or on behalf of covered entities that involve access to PHI.<sup>91</sup> Covered entities include health plans and health care providers that bill electronically,<sup>92</sup> thus many partners involved in implementation of the Medicaid and CHIP reforms are subject to HIPAA’s requirements. A provision of HIPAA known as the Privacy Rule generally prohibits the use or disclosure of an individual’s PHI absent an authorization from the individual granting permission for the use or disclosure.<sup>93</sup> There are numerous exceptions to this general rule. For example, covered entities may use or disclose PHI for treatment, payment, or health care operations without obtaining individual authorization.<sup>94</sup> Additionally, covered entities may use or disclose PHI absent individual authorization to the extent the use or disclosure is required by law.<sup>95</sup>


The Privacy Rule additionally creates exceptions to the authorization requirement specifically for the PHI of people who are incarcerated in correctional facilities. HIPAA provides as follows:

A covered entity may disclose to a correctional institution or a law enforcement official having lawful custody of an inmate or other individual [PHI] about such inmate or individual, if the correctional institution or such law enforcement official represents that such [PHI] is necessary for:

- (A) The provision of health care to such individuals;
- (B) The health and safety of such individuals or other inmates;
- (C) The health and safety of the officers or employees of or others at the correctional institution;
- (D) The health and safety of such individuals and officers or other persons responsible for the transporting of inmates or their transfer from one institution, facility, or setting to another;
- (E) Law enforcement on the premises of the correctional institution; or
- (F) The administration and maintenance of the safety, security, and good order of the correctional institution.<sup>96</sup>

A correctional institution that is a HIPAA covered entity may use the PHI of individuals who are incarcerated for any of the above purposes.<sup>97</sup>





For uses and disclosures that require individual authorization under the Privacy Rule, HIPAA specifies certain elements that must be included for an authorization to be valid, such as a description of the PHI to be used or disclosed, identification of the persons authorized to disclose and receive the PHI, and the purpose of the use or disclosure, among other elements.<sup>98</sup>

In implementation of the Medicaid and CHIP reforms, PHI shared among entities like state Medicaid agencies, community providers, and correctional health care providers will include the PHI of minors. This raises the question of whether the minor, a parent, or someone else is the appropriate party to provide authorization for a use or disclosure under HIPAA. Generally, an individual's authority to make decisions about the use or disclosure of information related to health care that they receive tracks their authority to decide to receive that health care.<sup>99</sup> For most health care received by an unemancipated minor, the minor's parent or guardian has legal authority to make decisions related to the minor's health care. Under HIPAA, a parent, guardian, or other person acting *in loco parentis* with such legal authority generally serves as the minor's "personal representative."<sup>100</sup> Covered entities must treat a personal representative as the "individual" for the purpose of the Privacy Rule,<sup>101</sup> thus, a minor's personal representative can authorize a use or disclosure of the minor's PHI.

There are, however, three circumstances where an unemancipated minor, and not their personal representative, is treated as the "individual" under the Privacy Rule:

- (1) **The minor may be treated as the individual when the minor has legal authority to consent to receive health care, does consent, and no other consent is legally required.**<sup>102</sup> While parents generally have authority to make health care decisions for minors, every state has laws granting minors authority to consent to receive health care under specific circumstances. For example, state law may permit a minor to consent to receive reproductive health care,<sup>103</sup> HIV/STI screening and/or treatment,<sup>104</sup> and other kinds of care.<sup>105</sup> Accordingly, agencies and other entities applying the Privacy Rule will need to consider applicable minor consent laws when determining the appropriate party to provide authorization.
- (2) **The minor may be treated as the individual when the minor may legally obtain a health care service without the consent of a parent, guardian, or other person acting *in loco parentis*, and the minor, a court, or another person authorized by law consents to such health care service.**<sup>106</sup> This is a somewhat narrow provision that most notably applies in states that permit minors to obtain an abortion without parental involvement through a judicial bypass procedure.
- (3) **The minor is treated as the individual when a parent, guardian, or other person acting *in loco parentis* assents to an agreement of confidentiality between the covered entity and the minor with respect to a health care service.**<sup>107</sup>

When a minor consents to health care under circumstances (1) or (2), the scope of the PHI over which the minor has authority corresponds to the scope of health care services to which they have authority to consent.<sup>108</sup> Thus, for example, if a minor is legally authorized to consent to receive mental health care and does consent, they are the individual with respect to the PHI pertaining to that mental health care.

In situations where the minor is *not* treated as the "individual" under the Privacy Rule, HIPAA defers to state and other law governing who may make health care decisions on behalf of a minor to determine who constitutes the personal representative.<sup>109</sup> Thus, agencies should determine whether state law vests this decision-making authority in parties other than parents—such as social workers, foster parents, or courts acting *in loco parentis* on behalf of system-involved youth—and whether such parties have exercised that authority.<sup>110</sup>



## 42 C.F.R. Part 2: Health Information Related to Substance Use Disorders

Certain health information related to SUDs is subject to additional standards in 42 C.F.R. Part 2 (commonly referred to as “Part 2”). The purpose of Part 2 is to encourage people to seek and remain in SUD treatment by protecting confidentiality and ensuring that patients receiving SUD treatment are not made more vulnerable on account of having a SUD treatment record.<sup>111</sup> Part 2 applies to federally assisted substance use programs and lawful holders of Part 2 records.<sup>112</sup> Federally assisted substance use programs receive federal assistance (such as participating in the Medicare or Medicaid programs or holding a DEA permit) and are either (1) a person (other than a general medical facility) that holds itself out as providing and provides SUD diagnosis, treatment, or referral for treatment; (2) an identified unit within a general medical facility that holds itself out as providing and provides SUD diagnosis, treatment, or referral for treatment; or (3) medical personnel or other staff in a general medical facility whose primary function is the provision of SUD diagnosis, treatment, or referral for treatment and who are identified as such providers.<sup>113</sup> These may include community SUD treatment providers as well as SUD treatment clinics located in correctional facilities.<sup>114</sup> A lawful holder of Part 2 records is defined as a person who is subject to Part 2 because they received Part 2 records as a result of a disclosure pursuant to a valid written consent or an exception to the consent requirement.<sup>115</sup>


Part 2 thus applies more narrowly than HIPAA, covering limited subsets of entities and health information, but it provides protections that are more stringent than those found in HIPAA. In most cases, Part 2 requires written individual consent for uses and disclosures of SUD records outside of the Part 2 program, including for treatment.<sup>116</sup> Unlike HIPAA, which makes many exceptions to the Privacy Rule’s authorization requirement, Part 2 contains limited exceptions.<sup>117</sup> And it generally prohibits uses or disclosures in any civil, criminal, administrative, or legislative proceedings absent consent or a court order.<sup>118</sup>

Under Part 2, a valid consent granting permission for a use or disclosure must be in writing and must include certain elements, including the purpose of the use and disclosure, as well as notices to patients.<sup>119</sup> Disclosures under Part 2 must be limited to the information necessary to carry out the stated purpose.<sup>120</sup> Additionally, when disclosed pursuant to a written consent, Part 2 records must be accompanied by a notice informing lawful holders of prohibitions on redisclosure.<sup>121</sup>

As with HIPAA, whether a minor can, acting by themselves, consent to share SUD records covered by Part 2 will depend on the minor’s authority to consent to receive the underlying health care.<sup>122</sup> If state law authorizes a minor acting alone to obtain SUD treatment, written consent may only be given by the minor.<sup>123</sup> If, on the contrary, state law requires that a parent, guardian, or other person consent to the minor’s treatment, a written consent must be given by *both* the minor and the parent, guardian or other person.<sup>124</sup> In this way, HIPAA and Part 2 differ, as HIPAA generally does not require a minor’s authorization where the minor lacks authority to consent to treatment.

## Medicaid Applicant and Beneficiary Information Safeguards

Section 1902(a)(7) of the Social Security Act and its implementing regulations, 42 C.F.R. Part 431, Subpart F, establish confidentiality protections governing state Medicaid agencies’ use and disclosure of Medicaid data.<sup>125</sup> These Medicaid Applicant and Beneficiary Information Safeguards (Medicaid Information Safeguards) require state Medicaid plans to provide, pursuant to state statute, safeguards restricting the use or disclosure of Medicaid data of applicants and beneficiaries.<sup>126</sup> Under 42 C.F.R. § 457.1110, these requirements apply to separate CHIP plans as well.<sup>127</sup> States have some flexibility in determining what information is protected, but the Medicaid Information Safeguards set forth specific types of information that must be protected, such as names and addresses and data on medical conditions and services.<sup>128</sup>



The Medicaid Information Safeguards require states to limit uses and disclosures to purposes directly related to the administration of the state Medicaid (or CHIP) plan, which are defined as:

- (1) establishing eligibility;
- (2) determining the amount of medical assistance;
- (3) providing services for beneficiaries; and
- (4) conducting or assisting an investigation, prosecution, or civil or criminal proceeding related to the administration of the plan.<sup>129</sup>

Additionally, the Medicaid Information Safeguards require that states restrict access of data to persons or agencies subject to standards of confidentiality comparable to those of the state Medicaid agency.<sup>130</sup> And, for certain disclosures, the agency must obtain consent, whenever possible, before responding to a request for information from an outside source.<sup>131</sup> However, even with consent, disclosures are still limited to those for purposes directly related to plan administration.

Application of these safeguards will depend in part on the specifics of the state law implementing them, but CMS commentary on what constitutes a purpose directly related to plan administration can provide guidance on permissible disclosures. In the July 2024 guidance letter on implementation of the Medicaid and CHIP reforms, CMS states that the Medicaid Information Safeguards “should not be barriers for health care personnel to coordinate patient care among organizations or for audit, monitoring, and/or evaluation activities.”<sup>132</sup> This suggests that certain Medicaid and CHIP data sharing involved in provision of screening, diagnostic, and TCM services to youth covered by Medicaid or CHIP would qualify as disclosures directly related to plan administration. Past CMS statements are consistent with this position. For example, CMS has indicated that sharing Medicaid data with health care providers to “better manage a beneficiary’s total care” and for “improved care coordination” would be permissible under certain circumstances.<sup>133</sup>


### **Additional Laws and Regulations**

The Medicaid and CHIP reforms will likely involve exchanges of data that are subject to additional federal and state laws and regulations. In part depending on the health and social needs of a particular youth, the provision of services—particularly TCM services like connecting youth to support, monitoring, and follow-up activities—may entail information exchange with entities subject to other federal laws. For example, the Family Educational Rights and Privacy Act (FERPA),<sup>134</sup> the Homeless Management Information System (HMIS) Privacy and Security Standards,<sup>135</sup> and the confidentiality requirements in Title IV-E of the Social Security Act for child welfare records,<sup>136</sup> among other laws, may apply. Partners should consider the applicability of such laws, as well as state laws implementing them,<sup>137</sup> and ensure that data exchanges comply with any relevant consent requirements and other safeguards.

State laws and regulations will also govern the exchange of data pertaining to youth in the juvenile justice system. Federal privacy laws like HIPAA and Part 2 create a minimum floor of protections and permit states to establish additional protections that are more stringent.<sup>138</sup> It is common for states to establish additional protections (or protections mirroring federal law), particularly for information that is especially sensitive. This includes, for example, data related to HIV status and treatment<sup>139</sup> and behavioral health.<sup>140</sup> States may also have their own general health privacy laws that mirror or differ somewhat from HIPAA.<sup>141</sup> Partners must additionally heed state confidentiality requirements for juvenile justice system records.<sup>142</sup> Such requirements are critical for safeguarding against stigmatization of and discrimination against youth based on their juvenile justice system involvement.

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The laws and regulations referenced here comprise only a portion of the legal requirements that may govern data exchanges needed to implement the Medicaid and CHIP reforms effectively. Other federal, state, and local laws may apply, and partners exchanging data should consult with their legal counsel early and often to ensure compliance with requirements for consent and other data privacy and security safeguards. Numerous resources are available to support



partners and their legal counsel in navigating these legal considerations.<sup>143</sup> To further support partners navigating state-specific legal issues in implementation of the Medicaid and CHIP reforms, states may consider issuing guidance to clarify how state laws will apply.<sup>144</sup>

## Obtaining Informed Consent

Applicable laws and regulations may impose varying requirements around the content, form, and scope of consent. Partners obtaining individual consent to share data must navigate these different requirements, which can be challenging.<sup>145</sup> Moreover, in addition to complying with legal requirements, partners should strive for informed consent practices that promote ethical and equitable (as well as lawful) data sharing. Common practices for obtaining consent often fail to support informed, autonomous decision-making. For example, while they may be legally compliant, consent forms are often inaccessible due to their length, numerosity, and use of legal jargon.<sup>146</sup> As a result, people may not read them and/or may not fully comprehend the purpose, terms, and consequences of sharing data (or not sharing it).<sup>147</sup> Additional accessibility issues may arise for individuals with limited proficiency in English, individuals with limited literacy, and/or individuals with intellectual disabilities. Furthermore, having to go through numerous consent processes can be frustrating, and even retraumatizing, for individuals attempting to navigate fragmented systems of care.<sup>148</sup> These and other factors can lead to disengagement and ultimately impede informed decision-making.

For structural reasons, youth involved in the juvenile justice system (as well as their parents and guardians) may also experience pressure to consent to share data that could call into question whether their consent is given entirely willingly.<sup>149</sup> By way of example, youth in need of services to address critical needs (e.g., behavioral health issues, housing and food insecurity, etc.) may feel that they must share their data or else forego such services. Consent processes must recognize such dynamics and strive to promote power within systems that, at times, undermine individual agency. What follows is an overview of best practices to promote ethical data sharing identified by parties navigating these consent issues in the context of data sharing projects. Throughout the design and use of consent forms and processes, partners should center the voices of community-based organizations and youth and families with lived experience navigating consent systems.

First, consent forms should use plain language and provide specific and concise explanations that account for potential accessibility issues such as language barriers and limited literacy.<sup>150</sup> Consent forms that are lengthy and complex, causing frustration and disengagement, should be avoided.<sup>151</sup> Some states and localities have piloted consent processes, such as streamlined consent forms, that may be useful to states implementing the Medicaid and CHIP reforms. The California Department of Health Care Services' Authorization to Share Confidential Medi-Cal Information, for example, piloted a concise consent form and consent management system aiming to facilitate the cross-sector exchange of data.<sup>152</sup> While concision can promote clarity, consent forms should avoid combining information to the extent that doing so impedes individuals from making informed decisions regarding specific types of data (highly sensitive data, in particular) and the purposes for which such data may be used or disclosed.<sup>153</sup>

In addition to the forms used, the processes involved in obtaining consent can be designed to support informed decision-making. For example, it may be helpful for staff to explain the purpose, terms, and risks of data sharing and to answer questions that arise, rather than simply providing a consent form. Peer support navigators and community health workers with lived experience may be particularly well positioned to provide culturally competent support to youth who are incarcerated in the consent process.<sup>154</sup> Investing in staff training will help to ensure that staff can provide clear information and answer questions about consent, adjust processes as needed, and cultivate environments of dignity and respect.<sup>155</sup> Ensuring that individuals have sufficient time to review information and make a decision will also support informed decision-making.<sup>156</sup> Finally, consent processes should strive to maximize individuals' control over the scope of their consents, for example, ensuring that consent is revocable at any time and that individuals understand the revocation process.<sup>157</sup> Providing more granular consent options (i.e., permitting individuals to choose what data is shared with whom) is another way to increase control over a consent's scope.<sup>158</sup> Partners providing such granular consent options should aim to ensure that the inclusion of more options does not overcomplicate consent forms, frustrating the goal of clear communication.



## Equitable and Empowering Data Governance

While informed consent plays a crucial role in advancing ethical and equitable data sharing, it is only one of several components of an empowering data system. Structural safeguards in policies and data use agreements and decision-making processes that center equity and build power among impacted communities operate to supplement informed consent and ensure that data uses do not perpetuate structural racism and other drivers of health inequities.

Accordingly, agencies and other partners implementing the Medicaid and CHIP reforms must carefully consider their data governance systems—the policies, procedures, and agreements governing what data is collected, how data is used and secured, with whom it is shared, and how and when consent is obtained, among other key decisions—as well as the ways that data governance is designed.<sup>159</sup>

**Data governance that is driven by impacted communities, including youth with lived experience with the juvenile justice system, can support meaningful safeguards and equity-centered decision-making.<sup>160</sup> As those closest to the problem, impacted communities have unique insight into the importance of data sharing, concerns about harmful uses of data, and avenues for addressing those concerns.<sup>161</sup>** Indeed, in California, counties preparing for implementation of section 1115 reentry waivers have emphasized the importance of including people with lived experience of incarceration in governance, given their unique understanding of challenges and potential solutions.<sup>162</sup> Equitable and empowering data sharing centers these insights throughout the data sharing lifecycle, starting from the initial planning stage and continuing as data sharing practices evolve over time.<sup>163</sup> It also ensures that engagement empowers, rather than burdens, community members, for example through fair compensation.<sup>164</sup> Numerous tools are available to guide partners in this work of engaging communities with lived experience with incarceration<sup>165</sup> and centering racial equity in their data governance.<sup>166</sup>

In the context of the Medicaid and CHIP reforms, data governance can establish standards that go above and beyond requirements set forth in law and regulation. These standards may govern the types of data that may be shared to provide the screening, diagnostic, and TCM services; the agencies and other partners with whom data is shared; and the purposes for which data may be disclosed and used. The implicit but critical corollary is also true—these data governance decisions can dictate what types of data are not disclosed, which entities do not receive data or certain kinds of data, and which purposes are prohibited.


Such safeguards dictating which uses and disclosures are permissible can play a crucial role in implementation of the Medicaid and CHIP reforms given the importance of sharing data to provide appropriate, holistic care and the risk that sensitive data will be used to stigmatize and further criminalize youth. For example, safeguards could include a firewall around a correctional health care facility's data system from other parts of the institution; a prohibition on the disclosure of any data to law enforcement unless required by law; mandatory security measures like encryption; and/or a requirement that only the minimum data necessary is shared.<sup>167</sup> While such safeguards may be required by law under certain circumstances, data governance provides an opportunity to design and implement safeguards in cases when they are not legally mandatory.

In addition to protecting against misuses of data, robust data governance that centers health equity and the voices of impacted communities helps to build the trust and buy-in necessary for effective data sharing.<sup>168</sup> By promoting transparency around the data shared and with whom it is shared, as well as how decisions are made, data governance can cultivate this trust.<sup>169</sup> Particularly in light of the disconnects between correctional and community systems and the historic use of data to subjugate, rather than benefit, certain communities, cultivating this trust should be a top priority.

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### Alameda County Social Health Information Exchange

In Alameda County, California, the Social Health Information Exchange (SHIE) supports cross-sector care coordination through collection and integration of individuals' health and social information, including medical, housing, social care, and incarceration data.<sup>170</sup> SHIE data



populates a Community Health Record (CHR) to share relevant information, in accordance with applicable law, with an individual's care providers to support whole-person, coordinated care.<sup>171</sup> To improve access to services for individuals who are returning to their communities from Alameda County jails, the SHIE facilitates collection of individuals' jail release dates from several sources, including county court systems and the Alameda County Sheriff's Office. Alerts with an individual's release date are sent to care providers with whom the individual has previously worked, with the aim of promoting care continuity, improving access to wraparound services during reentry, and reducing recidivism. Organizations that participate in the CHR as end users, such as community health and social services providers, can view data on health and social needs and eligibility for benefits, as necessary to support care coordination and informed care.

Take the following scenario as an example of how the SHIE aims to support individuals returning to their communities from jail. An individual with a mental illness is expected to be released from jail on an upcoming date, they have previously received services from a community behavioral health provider participating in the SHIE, and they have consented to disclosure of their data. The SHIE will send an alert to the behavioral health provider, notifying them of the upcoming release date. The provider will then know to proactively reach out to the individual during the reentry period to ensure access to care and continuity of services. Using the CHR, the provider can view certain data disclosed by other health and social services providers participating in the SHIE that have delivered services to the individual, including jail health services. This way, the behavioral health provider will have information (e.g., diagnoses, medications, past services received) that assists them in providing higher quality services and making referrals.

While data exchanges in implementation of the Medicaid and CHIP reforms will likely involve more expansive sharing than what currently occurs through the SHIE, Alameda's work to improve care continuity for individuals reentering highlights lessons that can inform states' implementation of the Medicaid and CHIP reforms. For one, listening to the voices and experiences of impacted communities in development of the SHIE has been essential. These perspectives help to ensure that the SHIE promotes effective service delivery, rather than simply collecting data for the purpose of identifying—and not effectively addressing—areas of need. Additionally, the SHIE has aimed to ensure that data sharing benefits and empowers individuals by requiring individual consent for all disclosures and limiting data sharing to what is necessary for care coordination. Organizations access data in accordance with a structured privacy framework that determines which records and data types each organization may access.<sup>172</sup> This protects against data sharing practices that impede access to services, result in stigma, or otherwise harm community members.

Negotiating data sharing agreements and navigating real and perceived legal constraints has posed the greatest challenge. But certain steps have helped the SHIE reach consensus with partner organizations. These include bringing partners together, listening to the reasoning behind any resistance to data sharing, and finding points of agreement, even if that means starting small. Furthermore, focusing on a narrow set of data elements and not attempting to collect more data than is necessary for care coordination purposes can build trust and help partners reach agreement. Importantly, this process can be lengthy; partners should be prepared to invest time in achieving data exchange, ultimately working towards holistic and informed support for individuals returning to their communities from incarceration.

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## Conclusion

The pre- and post-release periods present intervention points to support youth returning to their communities and to interrupt drivers of health inequity. As states work to implement Medicaid and CHIP reforms and other policy initiatives to support healthy transitions during reentry, including Medicaid section 1115 reentry waivers, close attention must be paid to data sharing and privacy issues. Challenges may arise related to complex legal frameworks, limited interoperability, the need to protect sensitive data, and medical mistrust. As outlined in this resource, states can navigate these challenges to develop effective and equitable data sharing systems that center the voices of impacted youth, promote care continuity and person-centered support, and protect against harmful misuses of data.

**This document was developed by Emma Kaeser, J.D., Staff Attorney, Mid-States Region. The Network promotes public health and health equity through non-partisan educational resources and technical assistance. These materials provided are provided solely for educational purposes and do not constitute legal advice. The Network’s provision of these materials does not create an attorney-client relationship with you or any other person and is subject to the [Network’s Disclaimer](#).**

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<sup>1</sup> The terms “children,” “youth,” and “young people” are used somewhat inconsistently in research, advocacy, and policy in this area. In line with the Centers for Medicare and Medicaid Services’ guidance on the Medicaid and CHIP reforms, this resource generally uses the term “youth” if not in reference to a specific source that uses a different term (e.g., the Children’s Health Insurance Program’s coverage of low-income children). As explained further below, the Medicaid reforms apply to otherwise eligible individuals who are under the age of 21 or who are under the age of 26 and are former foster care children, and the CHIP reforms apply to otherwise eligible individuals who are under the age of 19.

<sup>2</sup> Paul K. Braverman & Pamela J. Murray, *Health Care for Youth in the Juvenile Justice System*, 128 PEDIATRICS 1219, 1220-24 (2011).

<sup>3</sup> Leanne L. Heaton, *Racial/ethnic Differences of Justice-Involved Youth in Substance-Related Problems and Services Received*, 88 AM. J. ORTHOPSYCHIATRY 363 (2018).

<sup>4</sup> OFF. OF JUV. JUST. & DELINQ. PREVENTION, MODEL PROGRAMS GUIDE LITERATURE REVIEW: INTERSECTION BETWEEN MENTAL HEALTH AND THE JUVENILE JUSTICE SYSTEM 2-3 (2017), <https://ojdp.ojp.gov/sites/g/files/xyckuh176/files/media/document/intersection-mental-health-juvenile-justice.pdf>.

<sup>5</sup> KAREN M. ABRAM, ET AL., SUICIDAL THOUGHTS AND BEHAVIORS AMONG DETAINED YOUTH 4-7 (2014), <https://ojdp.ojp.gov/sites/g/files/xyckuh176/files/pubs/243891.pdf>.

<sup>6</sup> Michael T. Baglivio, et al., *The Prevalence of Adverse Childhood Experiences (ACE) in the Lives of Juvenile Offenders*, 3 J. JUV. JUST. 1, 8 (2014).

<sup>7</sup> JULIA ACKER, ET AL., MASS INCARCERATION THREATENS HEALTH EQUITY IN AMERICA (2018), <https://www.rwjf.org/en/insights/our-research/2019/01/mass-incarceration-threatens-health-equity-in-america.html>.

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- <sup>8</sup> Michael Massoglia & William Alex Pridemore, *Incarceration and Health*, 41 ANN. REV. SOCIO. 291, 299-301 (2015); Jessica Sandoval, *How Solitary Confinement Contributes to the Mental Health Crisis*, NAT'L ALL. ON MENTAL ILLNESS (Mar. 17, 2023), <https://www.nami.org/advocate/how-solitary-confinement-contributes-to-the-mental-health-crisis/>.
- <sup>9</sup> Elizabeth S. Barnert, et al., *How Does Incarcerating Young People Effect Their Adult Health Outcomes?*, 139 PEDIATRICS 1, 4-7 (2017).
- <sup>10</sup> OFF. OF JUV. JUST. & DELINQ. PREVENTION, DETENTION RATES BY RACE/ETHNICITY, [https://ojdp.ojp.gov/statistical-briefing-book/special\\_topics/faqs\\_fairness/qa11802](https://ojdp.ojp.gov/statistical-briefing-book/special_topics/faqs_fairness/qa11802) (last visited October 2, 2024).
- <sup>11</sup> Joshua Rovner, *Black Disparities in Youth Incarceration*, THE SENTENCING PROJECT (Dec. 12, 2023), <https://www.sentencingproject.org/fact-sheet/black-disparities-in-youth-incarceration/>.
- <sup>12</sup> *Intersection of Juvenile Justice and Child Welfare Systems*, OFF. OF JUV. JUST. & DELINQ. PREVENTION (2021), <https://ojdp.ojp.gov/model-programs-guide/literature-reviews/Intersection-Juvenile-Justice-Child-Welfare-Systems#9-0>.
- <sup>13</sup> CHARLES PUZZANCHERA, ET AL., *YOUTH AND THE JUVENILE JUSTICE SYSTEM: 2022 NATIONAL REPORT 7-9* (2022), <https://ojdp.ojp.gov/publications/2022-national-report.pdf>.
- <sup>14</sup> Elizabeth S. Barnert, et al., *Parent and Provider Perspectives on Recently Incarcerated Youths' Access to Healthcare During Community Reentry*, 110 CHILD. & YOUTH SERVS. REV. 1, 11-12 (2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8145947/pdf/nihms-1555801.pdf>.
- <sup>15</sup> *Id.* at 10-11.
- <sup>16</sup> SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., *BEST PRACTICES FOR SUCCESSFUL REENTRY FROM CRIMINAL JUSTICE SETTINGS FOR PEOPLE LIVING WITH MENTAL HEALTH CONDITIONS AND/OR SUBSTANCE USE DISORDERS*, 35-36 (2023), <https://store.samhsa.gov/sites/default/files/pep23-06-06-001.pdf>.
- <sup>17</sup> Elizabeth S. Barnert, et al., *Reducing Medicaid Coverage Gaps for Youth During Reentry*, 28 J. CORR. HEALTH CARE 39, 40 (2022).
- <sup>18</sup> This resource aims to generally use person-first language to avoid dehumanization of people who are incarcerated. "Inmate" is used on occasion when part of a commonly used term or legal definition.
- <sup>19</sup> 42 U.S.C. § 1396d.
- <sup>20</sup> 42 C.F.R. § 457.310(c)(2)(i).
- <sup>21</sup> Barnert et al., *supra* note 14, at 11-12.
- <sup>22</sup> Marguerite Burns & Laura Dague, *In-Kind Welfare Benefits and Reincarceration Risk: Evidence from Medicaid*, NAT'L BUREAU OF ECON. RSCH. 32-44 (June 2023), <https://www.nber.org/papers/w31394>.
- <sup>23</sup> U.S. DEP'T OF HEALTH & HUM. SERVS., OFF. OF THE ASSISTANT SEC. FOR PLAN. & EVALUATION, *REPORT TO CONGRESS, HEALTH CARE TRANSITIONS FOR INDIVIDUALS RETURNING TO THE COMMUNITY FROM A PUBLIC INSTITUTION: PROMISING PRACTICES IDENTIFIED BY THE MEDICAID REENTRY STAKEHOLDER GROUP 17-18* (2023), <https://aspe.hhs.gov/sites/default/files/documents/d48e8a9fdd499029542f0a30aa78bfd1/health-care-reentry-transitions.pdf> (hereinafter, "Report to Congress"); Geoffrey Glowalla & Vignesh Subbian, *Data Sharing Between Jail and Community Health Systems: Missing Links and Lessons for Re-Entry Success*, 290 STUD. HEALTH TECH. & INFORMATICS 47, 49-50 (2022).
- <sup>24</sup> Elizabeth Barnert & Laura S. Abrams, *Reentry Is a Critical Opportunity to Improve Youths' Health: An Overlooked Pediatric Priority*, SPRINGER NATURE 1 (2024).
- <sup>25</sup> See, e.g., U.S. DEP'T OF HEALTH & HUM. SERVS., CTRS. FOR MEDICARE & MEDICAID SERVS., SMD 23-003, *LETTER TO STATE MEDICAID DIRECTORS RE: OPPORTUNITIES TO TEST TRANSITION-RELATED STRATEGIES TO SUPPORT COMMUNITY REENTRY AND IMPROVE CARE TRANSITIONS FOR INDIVIDUALS WHO ARE INCARCERATED* (April 17, 2023) (hereinafter, "SMD 23-003") (providing guidance for demonstration projects under Medicaid section 1115 to support healthy transitions for individuals reentering their communities).
- <sup>26</sup> Consolidated Appropriations Act, 2023, Pub. L. No. 117-328, 136 Stat. 4459 (hereinafter, "CAA, 2023").
- <sup>27</sup> CAA, 2023 § 5121.
- <sup>28</sup> CAA, 2023 § 5121.
- <sup>29</sup> U.S. DEP'T OF HEALTH & HUM. SERVS., CTRS. FOR MEDICARE & MEDICAID SERVS., SHO 24-004, *LETTER TO STATE HEALTH OFFICIALS RE: PROVISION OF MEDICAID AND CHIP SERVICES TO INCARCERATED YOUTH* (July 23, 2024) (hereinafter, "SHO 24-004").
- <sup>30</sup> CMS' July 2024 letter provides additional guidance on provision of these services as well as other changes in the CAA, 2023, including regarding CHIP eligibility. The overview in this resource is not intended to be a full summary of the July 2024 letter.
- <sup>31</sup> SHO 24-004 at 12-18.
- <sup>32</sup> 42 C.F.R. § 440.169(d).
- <sup>33</sup> SHO 24-004 at 12-18.



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<sup>34</sup> *Id.* at 3, 12-13.

<sup>35</sup> *Id.*

<sup>36</sup> *Id.* at 13.

<sup>37</sup> *Id.* 27-28.

<sup>38</sup> *Id.*

<sup>39</sup> 42 U.S.C. § 1315.

<sup>40</sup> SMD 23-003.

<sup>41</sup> HEALTH AND REENTRY PROJECT, MEDICAID'S NEW ROLE IN ADVANCING REENTRY: KEY POLICY CHANGES (2024), <https://healthandreentryproject.org/wp-content/uploads/2024/10/Harp-MedicaidReentry-Oct2024.pdf>.

<sup>42</sup> Report to Congress.

<sup>43</sup> *Id.* at 21-22; CHRISTINE NYE, ET AL., SUPPORTING INCARCERATED INDIVIDUALS TRANSITIONING TO THE COMMUNITY: STATE AND HEALTH PLAN APPROACHES AND LESSONS 5-7 (2018), <https://www.norc.org/content/dam/norc-org/pdfs/Healthcare%20for%20Incarcerated%20Individuals.pdf>.

<sup>44</sup> Report to Congress at 21-22.

<sup>45</sup> Glowalla & Subbian, *supra* note 23 at 49.

<sup>46</sup> ALANA KALINOWSKI, ET AL., COMMUNITY INFORMATION EXCHANGE: LEVERAGING COLLABORATIVE INFRASTRUCTURE TO ASSESS AND ADDRESS ACES 8, 14 (2021), <https://www.acesaware.org/wp-content/uploads/2021/10/ACEs-Aware-CIE-Practice-Paper.pdf>.

<sup>47</sup> See, e.g., LIVE WELL SAN DIEGO, SUPPORTING CARE COORDINATION FOR JUSTICE-INVOLVED INDIVIDUALS THROUGH FUNDING AND INTEGRATED DATA INFRASTRUCTURE: REPORT ON POTENTIAL OPPORTUNITIES AND CHALLENGES IMPACTING DATA SHARING 9-16 (2023), <https://bosagenda.sandiegocounty.gov/cobservice/cosd/cob/content?id=0901127e80fb2a48>.

<sup>48</sup> EVA H. ALLEN, ET AL., DATA SHARING IN CROSS-SECTOR COLLABORATIONS: INSIGHTS FROM INTEGRATED DATA SYSTEMS 5 (2021), [https://www.urban.org/sites/default/files/publication/104548/data-sharing-in-cross-sector-collaborations\\_0.pdf](https://www.urban.org/sites/default/files/publication/104548/data-sharing-in-cross-sector-collaborations_0.pdf).

<sup>49</sup> OFF. OF THE NAT'L COORDINATOR FOR HEALTH INFO. TECH., THE PATH TO INTEROPERABILITY, [https://www.healthit.gov/sites/default/files/factsheets/onc\\_interoperabilityfactsheet.pdf](https://www.healthit.gov/sites/default/files/factsheets/onc_interoperabilityfactsheet.pdf) (last visited Oct. 2, 2024).

<sup>50</sup> Glowalla & Subbian, *supra* note 23 at 48-49.

<sup>51</sup> NYE, ET AL., *supra* note 43 at 4.

<sup>52</sup> LIVE WELL SAN DIEGO, *supra* note 47 at 22-23.

<sup>53</sup> Marina Tolou-Shams, et al., *Substance Use and HIV Among Justice-Involved Youth: Intersecting Risks*, 16 CURRENT HIV/AIDS REP. 37 (2019).

<sup>54</sup> CTRS. FOR DISEASE CONTROL & PREVENTION & CHANGELAB SOLUTIONS, HIV CRIMINALIZATION LEGAL AND POLICY ASSESSMENT TOOL 14 (2022).

<sup>55</sup> *Id.*

<sup>56</sup> U.S. GOV'T ACCOUNTABILITY OFF., GAO-24-106294, K-12 EDUCATION: DIFFERENCES IN STUDENT ARREST RATES WIDEN WHEN RACE, GENDER, AND DISABILITY STATUS OVERLAP 1 (2024).

<sup>57</sup> Priya R. Pathak & Adriana Chou, *Confidential Care for Adolescents in the U.S. Health Care System*, 6 J. PATIENT-CENTERED RSCH. & REVS. 46, 1 (2019) (collecting sources); Marianne Sharko, et al., *State-by-State Variability in Adolescent Privacy Laws*, 149 PEDIATRICS 1, 2 (2022) (collecting sources).

<sup>58</sup> C.A. Ford, et al., *Influence of Physician Confidentiality Assurances on Adolescents' Willingness to Disclose Information and Seek Future Health Care. A Randomized Controlled Trial.*, 278 J. AM. MED. ASSOC. 1029 (1997).

<sup>59</sup> MARY MADDEN, PRIVACY, SECURITY, AND DIGITAL INEQUALITY: HOW TECHNOLOGY EXPERIENCES AND RESOURCES VARY BY SOCIOECONOMIC STATUS, RACE, AND ETHNICITY 2-8 (2017).

<sup>60</sup> PUZZANCHERA, ET AL., *supra* note 13 at 7, 16-17, 192-93.

<sup>61</sup> Ángel Díaz, *Data-Driven Policing's Threat to Our Constitutional Rights*, BROOKINGS (Sept. 13, 2021), <https://www.brookings.edu/articles/data-driven-policings-threat-to-our-constitutional-rights/>.

<sup>62</sup> Martha Hostetter & Sarah Klein, *Understanding and Ameliorating Medical Mistrust Among Black Americans*, THE COMMONWEALTH FUND (Jan. 14, 2021), <https://www.commonwealthfund.org/publications/newsletter-article/2021/jan/medical-mistrust-among-black-americans>.

<sup>63</sup> ALLEN, ET AL., *supra* note 48 at 7.

<sup>64</sup> Díaz, *supra* note 61.

<sup>65</sup> Greta Byrum & Ruha Benjamin, *Disrupting the Gospel of Tech Solutionism to Build Tech Justice*, STANFORD SOCIAL INNOVATION REVIEW (June 16, 2022), [https://ssir.org/articles/entry/disrupting\\_the\\_gospel\\_of\\_tech\\_solutionism\\_to\\_build\\_tech\\_justice](https://ssir.org/articles/entry/disrupting_the_gospel_of_tech_solutionism_to_build_tech_justice).

<sup>66</sup> See NETWORK FOR PUB. HEALTH LAW & DATA ACROSS SECTORS FOR HEALTH, PATHWAYS TO YES: A LEGAL FRAMEWORK FOR ACHIEVING DATA SHARING FOR HEALTH, WELL-BEING, AND EQUITY 3-4 (2022), [https://www.networkforphl.org/wp-content/uploads/2022/10/DASH\\_NPHL-Pathways\\_to\\_Yes-FINAL-PDF.pdf](https://www.networkforphl.org/wp-content/uploads/2022/10/DASH_NPHL-Pathways_to_Yes-FINAL-PDF.pdf).

<sup>67</sup> STATE HEALTH ACCESS DATA ASSISTANCE CENT., ET AL., TARGETING JUSTICE-INVOLVED POPULATIONS THROUGH 1115 MEDICAID WAIVER INITIATIVES: IMPLEMENTATION EXPERIENCES OF THREE STATES 12 (2019).

<sup>68</sup> ALLEN, ET AL., *supra* note 48 at 7.

<sup>69</sup> See, e.g., Hoskins, et al., *FAQ: Engaging People with Lived Experience of Incarceration*, NAT'L ACAD. FOR STATE HEALTH POL'Y (Oct. 21, 2024), <https://nashp.org/faq-engaging-people-with-lived-experience-of-incarceration/>; CSG JUST. CTR., CENTERING LIVED EXPERTISE: HOW TO MEANINGFULLY ELEVATE THE VOICES OF PEOPLE DIRECTLY IMPACTED BY THE CRIMINAL JUSTICE AND BEHAVIORAL HEALTH SYSTEMS (2024), [https://csjusticecenter.org/wp-content/uploads/2024/05/Centering-Lived-Expertise\\_508.pdf](https://csjusticecenter.org/wp-content/uploads/2024/05/Centering-Lived-Expertise_508.pdf).

<sup>70</sup> NYE, ET AL., *supra* note 43 at 4.

<sup>71</sup> NETWORK FOR PUB. HEALTH LAW, *supra* note 66 at 4.

<sup>72</sup> JANE B. WISHNER & KAMALA MALLIK-KANE, INFORMATION SHARING BETWEEN MEDICAID AND CORRECTIONS SYSTEMS TO ENROLL THE JUSTICE-INVOLVED POPULATION: ARIZONA AND WASHINGTON 2 (2017).

<sup>73</sup> *Id.* at 12.

<sup>74</sup> *Id.* at 5.

<sup>75</sup> *Id.*

<sup>76</sup> *Id.* at 5, 7.

<sup>77</sup> NYE, ET AL., *supra* note 43 at 4.

<sup>78</sup> CTRS. FOR MEDICARE & MEDICAID SERVICES, CMS-2T2-25-001, SECTION 206 OF THE CONSOLIDATED APPROPRIATIONS ACT, 2024: STATE PLANNING GRANTS TO PROMOTE CONTINUITY OF CARE FOR MEDICAID AND CHIP BENEFICIARIES FOLLOWING INCARCERATION (2024), <https://www.grants.gov/search-results-detail/356168>.

<sup>79</sup> *Id.* at 13.

<sup>80</sup> SMD 23-003 at 28.

<sup>81</sup> *Id.*

<sup>82</sup> *Id.*

<sup>83</sup> NYE, ET AL., *supra* note 43 at 11; WISHNER & MALLIK-KANE, *supra* note 72 at 7, 12.

<sup>84</sup> *Id.* at 3; OHIO DEP'T OF MEDICAID, 2018 OHIO MEDICAID RELEASED ENROLLEES STUDY: A REPORT FOR THE OHIO DEPARTMENT OF MEDICAID 10 (2020) [https://medicaid.ohio.gov/wps/wcm/connect/gov/0a2a2099-55f8-4d32-b6c2-653f12cfd18b/OMRES-Final-Report.pdf?MOD=AJPERES&CONVERT\\_TO=url&CACHEID=ROOTWORKSPACE.Z18\\_M1HGGIK0N0JO00QO9DDDDM3000-0a2a2099-55f8-4d32-b6c2-653f12cfd18b-nAUVHSW](https://medicaid.ohio.gov/wps/wcm/connect/gov/0a2a2099-55f8-4d32-b6c2-653f12cfd18b/OMRES-Final-Report.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORKSPACE.Z18_M1HGGIK0N0JO00QO9DDDDM3000-0a2a2099-55f8-4d32-b6c2-653f12cfd18b-nAUVHSW).

<sup>85</sup> NYE, ET AL., *supra* note 43 at 5.

<sup>86</sup> *Id.* at 5.

<sup>87</sup> *Id.*

<sup>88</sup> *Id.* at 11.

<sup>89</sup> SHO 24-004 at 20.

<sup>90</sup> 45 C.F.R. § 160.103.

<sup>91</sup> 45 C.F.R. §§ 160.102, 160.103.

<sup>92</sup> 45 C.F.R. § 160.103.

<sup>93</sup> 45 C.F.R. Part 164, Subpart E.

<sup>94</sup> 45 C.F.R. § 164.506.

<sup>95</sup> 45 C.F.R. § 164.512(a).

<sup>96</sup> 45 C.F.R. § 164.512(k)(5)(i).

<sup>97</sup> 45 C.F.R. § 164.512(k)(5)(ii).

<sup>98</sup> 45 C.F.R. § 164.508(c)(1).

<sup>99</sup> 45 C.F.R. § 164.502(g)(3).

<sup>100</sup> 45 C.F.R. § 164.502(g)(3).

<sup>101</sup> 45 C.F.R. §§ 164.502(g)(1), (3).

<sup>102</sup> 45 C.F.R. § 164.502(g)(3)(i)(A).

<sup>103</sup> *An Overview of Consent to Reproductive Health Services by Young People*, GUTTMACHER (August 30, 2023), <https://www.guttmacher.org/state-policy/explore/overview-minors-consent-law>.

<sup>104</sup> *State Laws That Enable a Minor to Provide Informed Consent to Receive HIV and STD Services*, CTRES. FOR DISEASES CONTROL & PREVENTION, <https://www.cdc.gov/hiv/policies/law/states/minors.html#:~:text=Jurisdictions%20have%20different%20types%20of,and%20treatment%2C%20and%20For%20prevention> (last visited Oct. 21, 2024).

<sup>105</sup> See, e.g., Cal. Fam. Code § 6924; Cal. Health & Safety Code § 124260.

<sup>106</sup> 45 C.F.R. § 164.502(g)(3)(i)(B).

<sup>107</sup> 45 C.F.R. § 164.502(g)(3)(i)(C).

<sup>108</sup> 45 C.F.R. § 164.502(g)(3).

<sup>109</sup> *How Does a Covered Entity Identify an Individual's Personal Representative?*, DEP'T OF HEALTH & HUM. SERVS. (Jan. 9, 2023), <https://www.hhs.gov/hipaa/for-professionals/faq/226/how-does-covered-entity-identify-personal-rep/index.html>.

<sup>110</sup> For example, a state law may provide that, under certain circumstances, the parents of a child in the child welfare system do not retain authority to make decisions about the child's health care and another person, such as a social worker or a foster parent, holds that authority. In this situation, the social worker or foster parent may be acting *in loco parentis* under state law and may therefore be the personal representative with respect to PHI related to any health care services to which they consented. 45 C.F.R. § 164.502(g)(3). This analysis is very likely to be relevant to agencies implementing the Medicaid and CHIP reforms given the significant overlap between youth involved in the juvenile justice system and youth in the child welfare system. Likewise, states may have laws granting authority to a court or other entity to make health care decisions on behalf of minors in juvenile justice system custody, and such laws may dictate who should authorize a release of information.

<sup>111</sup> 42 C.F.R. § 2.2(b)(2).

<sup>112</sup> 42 C.F.R. § 2.12.

<sup>113</sup> 42 C.F.R. §§ 2.11, 2.12.

<sup>114</sup> THE CTR. OF EXCELLENCE FOR PROTECTED HEALTH INFO., *PRIVACY CONSIDERATIONS FOR MEDICATION ASSISTED TREATMENT IN JAILS AND PRISONS* (June 2022), <https://coephi.org/resource/privacy-considerations-for-medication-assisted-treatment-in-jails-and-prisons/>.

<sup>115</sup> 42 C.F.R. § 2.11.

<sup>116</sup> 42 C.F.R. § 2.13

<sup>117</sup> 42 C.F.R. Part 2, Subpart D.

<sup>118</sup> 42 C.F.R. § 2.13; 42 U.S.C. § 290dd-2(c).

<sup>119</sup> 42 C.F.R. § 2.31(a).

<sup>120</sup> 42 C.F.R. § 2.13(a).

<sup>121</sup> 42 C.F.R. § 2.32.

<sup>122</sup> 42 C.F.R. § 2.14.

<sup>123</sup> 42 C.F.R. § 2.14(a).

<sup>124</sup> 42 C.F.R. § 2.14(b).

<sup>125</sup> Social Security Act § 1902(a)(7), 42 U.S.C. § 1396a; 42 C.F.R. Part 431, Subpart F.

<sup>126</sup> 42 C.F.R. § 431.301.

<sup>127</sup> 42 C.F.R. § 457.1110.

<sup>128</sup> 42 C.F.R. § 431.305.

<sup>129</sup> 42 C.F.R. § 431.302.

<sup>130</sup> 42 C.F.R. § 431.306(b).

<sup>131</sup> 42 C.F.R. § 431.306(d).

<sup>132</sup> SHO 24-004 at 20.

<sup>133</sup> Interoperability and Prior Authorization Final Rule, 89 Fed. Reg. 8758, 8810, 8850 (Feb. 28, 2024). See also Streamlining Medicaid, Children's Health Insurance Program, and Basic Health Program Final Rule, 89 Fed. Reg. 22780, 22830 (Apr. 2, 2024) ("Some examples of permissible disclosure of applicant and beneficiary information include: . . . sharing information with a beneficiary's enrolled Medicaid or CHIP providers as needed to provide services[] and sharing information with a beneficiary's Medicaid or CHIP managed care plan as needed to provide services.").

<sup>134</sup> 20 U.S.C. § 1232g; 34 C.F.R. Part 99.

<sup>135</sup> Homeless Management Information Systems (HMIS); Data and Technical Standards Final Notice, 69 Fed. Reg. 45888 (July 30, 2004).

<sup>136</sup> Social Security Act Title IV-E, 42 U.S.C. Part E; 45 C.F.R. § 1355.30; 45 C.F.R. § 205.50.

<sup>137</sup> Federal law may require states to establish confidentiality safeguards via state statute, as with the Medicaid Information Safeguards. See, e.g., 45 C.F.R. § 205.50.

<sup>138</sup> See 45 C.F.R. Part 160, Subpart B; 42 C.F.R. § 2.20.

<sup>139</sup> See, e.g., MCL 333.5131.

<sup>140</sup> See, e.g., Pa. Stat. § 1690.108.

<sup>141</sup> See, e.g., N.M.S.A. § 14-6-1.

<sup>142</sup> See, e.g., Cal. Welf. & Inst. Code § 827.

<sup>143</sup> See, e.g., NETWORK FOR PUBLIC HEALTH LAW, *supra* note 66.

<sup>144</sup> See, e.g., CAL. DEP'T OF HEALTH CARE SERVS., CALAIM DATA SHARING AUTHORIZATION GUIDANCE, V 2.0 (2023) (draft for public comment), <https://www.dhcs.ca.gov/Documents/MCQMD/CalAIM-Data-Sharing-Authorization-Guidance-Version-2-Draft-Public-Comment.pdf> (providing guidance on legal issues related to data sharing in implementation of California Medicaid section 1115 reentry waiver).

<sup>145</sup> DANIEL STEIN, ET AL., STEWARDS OF CHANGE INSTITUTE CONSENT LEARNING LAB 11-17 (Aug. 2023), <https://stewardsofchange.org/wp-content/uploads/sites/2/2023/10/SOCI-HIMSS-Consent-Learning-Lab-Report-FINAL54.pdf>.

<sup>146</sup> *Id.*; DEJA KEMP, ET AL., YES, NO, MAYBE? LEGAL & ETHICAL CONSIDERATIONS FOR INFORMED CONSENT IN DATA SHARING AND INTEGRATION 9 (May 2023), <https://aisp.upenn.edu/wp-content/uploads/2023/05/Consent-Brief-Appx.pdf>.

<sup>147</sup> KEMP, ET AL., *supra* note 146 at 9.

<sup>148</sup> STEIN, ET AL., *supra* note 145 at 12.

<sup>149</sup> See KEMP, ET AL., *supra* note 146 at 10.

<sup>150</sup> *Id.* at 14; STEIN, ET AL., *supra* note 145 at 12-15.

<sup>151</sup> STEIN, ET AL., *supra* note 145 at 11-12; KEMP, ET AL., *supra* note 146 at 9, 14.

<sup>152</sup> See *CalAIM ASCMI Pilot*, CAL. DEP'T OF HEALTH CARE SERVS., <https://www.dhcs.ca.gov/CalAIM/Pages/ASCMI-CalAIM.aspx> (last visited Oct. 21, 2024).

<sup>153</sup> CAROL ROBINSON & CINDY THROOP, BEST PRACTICES IN CONSENT MANAGEMENT FOR THE USE AND DISCLOSURE OF SENSITIVE HEALTH-RELATED DATA 4-6 (2024), <https://www.midatohealth.com/whitepaper-best-practices-in-consent-management/>.

<sup>154</sup> Peer support models can promote better health outcomes for individuals reentering. See, Bradley Ray, et al., *Peer Recovery Services for Persons Returning from Prison: Pilot Randomized Clinical Trial Investigation of SUPPORT*, 126 J. SUBSTANCE ABUSE TREATMENT 1 (July 2021); NYE, ET AL., *supra* note 43 at 4-5, 8; *Evidence and Evaluation*, TRANSITIONS CLINIC NETWORK, <https://transitionsclinic.org/evaluation-quality-improvement/> (last visited Oct. 21, 2024).

<sup>155</sup> Manjekah Dunn, et al., *Equitable and Accessible Informed Healthcare Consent Process for People with Intellectual Disability: A Systematic Literature Review*, 33 BMJ QUALITY & SAFETY 328, 332, 335 (Dec. 9, 2023); STEIN, ET AL., *supra* note 145 at 12.

<sup>156</sup> Dunn, et al., *supra* note 155 at 332-35; KEMP, ET AL., *supra* note 146 at 14.

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<sup>157</sup> KEMP, ET AL., *supra* note 146 at 14.

<sup>158</sup> STEIN, ET AL., *supra* note 145 at 13.

<sup>159</sup> LIVE WELL SAN DIEGO, *supra* note 47 at 24.

<sup>160</sup> ALLEN, ET AL., *supra* note 48 at 8.; *See generally* AMY HAWN NELSON, ET AL., A TOOLKIT FOR CENTERING RACIAL EQUITY THROUGHOUT DATA INTEGRATION (2020), [https://aisp.upenn.edu/wp-content/uploads/2022/07/AISP-Toolkit\\_5.27.20.pdf](https://aisp.upenn.edu/wp-content/uploads/2022/07/AISP-Toolkit_5.27.20.pdf).

<sup>161</sup> LIVE WELL SAN DIEGO, *supra* note 47 at 25.

<sup>162</sup> JUSTICE SYSTEM PARTNERS, ET AL., IMPLEMENTING THE MEDICAID REENTRY WAIVER IN CALIFORNIA: KEY POLICY AND OPERATIONAL INSIGHTS FROM 11 COUNTIES 28-29 (2024), <https://safetyandjusticechallenge.org/resources/implementing-the-medicaid-reentry-waiver-in-california/>.

<sup>163</sup> HAWN NELSON, ET AL., *supra* note 160 at 14.

<sup>164</sup> LIVE WELL SAN DIEGO, *supra* note 47 at 18.

<sup>165</sup> *See, e.g.*, Hoskins, et al., *supra* note 69; CSG JUST. CTR., *supra* note 69.

<sup>166</sup> *See, e.g.*, HAWN NELSON, ET AL., *supra* note 160; KELSEY FINCH, ET AL., NOTHING TO HIDE: TOOLS FOR TALKING (AND LISTENING) ABOUT DATA PRIVACY FOR INTEGRATED DATA SYSTEMS (2018), <https://aisp.upenn.edu/resource-article/nothing-to-hide-tools-for-talking-and-listening-about-data-privacy-for-integrated-data-systems/>.

<sup>167</sup> HAWN NELSON, ET AL., *supra* note 160 at 8, 19, 23.

<sup>168</sup> ALLEN, ET AL., *supra* note 48 at 11.

<sup>169</sup> *Id.*

<sup>170</sup> ALAMEDA CNTY. HEALTH CARE SERVS. AGENCY, SOCIAL HEALTH INFORMATION EXCHANGE (2022), <https://accareconnect.org/wp-content/uploads/2022/08/SHIE-One-Pager-FV.pdf>.

<sup>171</sup> *Id.*

<sup>172</sup> ALAMEDA CNTY. HEALTH CARE SERVS. AGENCY, COMMUNITY HEALTH RECORD (2022), <https://accareconnect.org/wp-content/uploads/2022/08/CHR-One-Pager-2022-fv.pdf>.