

TASP Comprehensive Healthcare Organizational Self-Assessment

Healthcare Advocacy Focus

You can use this paper version to work on your own or with your team to come up with scores. When completed, you can move on to scoring and reviewing suggested next steps on this paper version, or return to the online survey to input your scores and get a downloadable, printed copy complete with suggested activities.

Estimated time: 45–90 minutes. Rate each item 0–3 or N/A.

Score	Meaning
0	No (Not currently in place)
1	Under Development (Planned or early stages)
2	Partially (Exists but needs improvement)
3	Yes (Fully implemented and effective)
N/A	Not Applicable

Section 1: Healthcare Accessibility and Accommodations

Evaluates how well your facilities, materials, and scheduling practices ensure full physical and communication access for patients with IDD.

#	Item	Score
1.1	Are your healthcare facilities fully physically accessible to individuals with mobility needs (ramps, accessible parking, doorways, bathrooms, exam rooms)?	
1.2	Do you provide communication accommodations (accessible materials, alternative formats, large print, plain-language materials)?	
1.3	What level of interpretation services do you provide?	
1.4	Are assistive technologies available (communication devices, visual aids)?	
1.5	Do exam rooms, scales, and other medical equipment meet accessibility standards (e.g., height-adjustable exam tables, accessible weight scales, and restrooms)?	
1.6	Do you offer flexible appointment scheduling to accommodate support persons and transportation needs (e.g., longer appointment slots, scheduling when a caregiver is available, or telehealth options)?	
1.7	Have you conducted accessibility audits of your healthcare facilities and services (e.g., ADA walk-throughs, accessibility checklists, or patient feedback surveys on facility access)?	

#	Item	Score
1.8	Do you have a means of collecting and addressing accessibility complaints?	

Section 2: Provider Training and Competency

Assesses provider knowledge, attitudes, and skills for delivering respectful, bias-free, and inclusive healthcare to parents with IDD.

#	Item	Score
2.1	Is disability awareness and inclusive communication training included as part of the onboarding process for all new clinical and administrative staff?	
2.2	Do clinical and office staff receive ongoing training on disability awareness and IDD-specific needs (e.g., online or in-person modules, in-service sessions, annual competencies)?	
2.3	Are providers trained to recognize and address unconscious bias about parenting capabilities (e.g., examples of assumptions about fitness to parent)?	
2.4	Do staff receive training on how to communicate effectively with patients with IDD (e.g., plain language, visual supports, breaking down information, allowing extra processing time, reliance on natural/chosen supports, engaging in supported decision-making)?	
2.5	Do staff use plain-language explanations and confirm patient understanding (e.g., teach-back method, visual supports, or repeating key points)?	
2.6	Are providers trained on presumption of capacity and supported decision-making principles (e.g., presuming all patients can make decisions, honoring supported decision-making agreements, providing accessible information before decisions are required)?	
2.7	Do you provide ongoing education to providers about disability culture and respectful interactions (e.g., refresher trainings or community-based learning)?	

Section 3: Informed Consent and Decision-Making Support

Examines policies and practices that uphold informed consent, supported decision-making, and autonomy for patients with IDD.

#	Item	Score
3.1	Do you have protocols for providing accessible informed consent materials (e.g., plain-language consent forms, visual explanations, or reproductive-health information presented without coercion and adequate processing time)?	
3.2	Are staff trained to provide decision-making support without making decisions for patients (e.g., offering explanations, checking for understanding, offering opportunities to discuss with chosen supports)?	
3.3	Do you accommodate support persons in healthcare decision-making processes (e.g., allowing chosen supports to attend appointments)?	
3.4	Are alternative communication methods available for consent processes (e.g., using pictorial forms, assistive devices, or interpreters)?	
3.5	Do you have policies ensuring assumption of capacity for all patients with IDD (e.g., written guidance or staff training)?	

#	Item	Score
3.6	Do staff provide information in multiple ways (spoken, written, visual)?	
3.7	Do staff ensure support persons can assist without limiting patient autonomy?	

Section 4: Legal Rights and Anti-Discrimination

Reviews your organization's compliance with ADA and anti-discrimination laws, patient rights information, and complaint procedures.

#	Item	Score
4.1	Have you reviewed your policies and practices to identify and address unintentional (de facto) discrimination against individuals with IDD, including informal barriers to accessing services (e.g., scheduling systems, intake forms, communication formats, or referral processes that inadvertently exclude people with IDD)?	
4.2	Do you have clear non-discrimination policies that include disability status and parenting (e.g., written policies shared with staff and patients)?	
4.3	Are staff trained on ADA requirements and reasonable accommodations in healthcare (e.g., staff workshops or online compliance modules)?	
4.4	Do you provide patients with plain-language information about their healthcare rights (e.g., rights posters, printed brochures, or digital versions)?	
4.5	Is there a clear, accessible internal grievance process for discrimination or accessibility complaints (e.g., forms, hotline, or contact person)?	
4.6	Do you have partnerships with disability rights organizations for legal or general consultation (e.g., MOUs, referral agreements)?	
4.7	Are privacy and confidentiality policies applied equitably to patients with IDD, including providing assistance without sharing information beyond consent?	
4.8	Are protocols in place for addressing and documenting discrimination incidents (e.g., internal reporting, review, and corrective action steps)?	

Section 5: Outreach and Community Engagement

Evaluates how effectively your organization partners with and listens to parents with IDD to shape equitable healthcare services.

#	Item	Score
5.1	Do you have processes to identify and reach parents with IDD in your service area (e.g., outreach through community partners, plain-language fliers, health navigators, or intake forms that capture parenting status)?	
5.2	Have you surveyed parents with IDD about their healthcare experiences and needs (e.g., using accessible survey formats or interviews)?	
5.3	Do you specifically assess healthcare access barriers faced by parents with IDD (e.g., transportation, communication, accessibility, or provider bias)?	
5.4	Do parents with IDD participate in healthcare service planning and quality improvement (e.g., advisory councils or parent focus groups)?	

#	Item	Score
5.5	Do you partner with community organizations serving parents with IDD (e.g., disability-rights centers, family resource networks)?	

Section 6: Quality Improvement and Outcomes

Looks at how data, feedback, and outcome tracking drive continuous improvement in disability-inclusive healthcare delivery.

#	Item	Score
6.1	Do you track health outcomes for patients with IDD, including parents (e.g., electronic health-record tags or registry data)?	
6.2	Are patient-satisfaction surveys accessible and regularly conducted with parents with IDD (e.g., plain-language, large-print, or digital surveys)?	
6.3	Do you measure the effectiveness of accommodations and accessibility improvements (e.g., tracking utilization or success of adaptive communication tools)?	
6.4	Is there a systematic process for addressing quality concerns raised by patients with IDD (e.g., review meetings, corrective-action logs)?	
6.5	Do you benchmark your services against best practices for serving patients with disabilities (e.g., comparing outcomes to state or national disability-inclusion standards)?	

Section 7: Policy and Systemic Change

Assesses organizational policies and advocacy efforts that influence broader healthcare equity for parents with IDD.

#	Item	Score
7.1	Do you have a process for tracking services and outcomes for individuals with IDD who may not have formally disclosed their disability, using universal design and inclusive intake practices rather than relying solely on self-identification?	
7.2	Are your policies and practices designed to be inclusive for all individuals, regardless of whether they have disclosed a disability (e.g., plain-language materials, flexible communication options, and welcoming intake environments available to everyone)?	
7.3	Do staff understand that disability identification is voluntary, not required, and that patients may not disclose IDD for various reasons including fear of discrimination or loss of parental rights?	
7.4	Does your practice actively create an environment where individuals feel safe and comfortable identifying themselves as having additional needs or requesting accommodations (e.g., clear non-judgment messaging, staff training, accessible intake materials)?	
7.5	Do you collect and report data on parents with IDD served and outcomes achieved (e.g., internal dashboards or reports shared with stakeholders)?	
7.6	Are healthcare policies reviewed regularly for potential discriminatory impact (e.g., annual legal or equity review process)?	
7.7	Do you advocate with insurance companies for coverage of necessary accommodations (e.g., letters of medical necessity or appeals for accessible services)?	

#	Item	Score
7.8	Are care-coordination protocols in place for complex cases involving parents with IDD (e.g., multi-disciplinary case-management teams)?	
7.9	Do you engage in healthcare-system advocacy to improve services for people with disabilities (e.g., policy testimony, coalition participation)?	

Section 8: Leadership and Organizational Commitment

Gauges leadership accountability, resource allocation, and governance practices supporting disability inclusion.

#	Item	Score
8.1	Do parents with IDD participate in leadership and advisory roles in your organization (e.g., serving on boards, committees, or advisory panels)?	
8.2	Has organizational leadership made public commitments to disability inclusion and healthcare equity (e.g., mission statements, press releases, or web content)?	
8.3	Are resources specifically allocated for accessibility improvements and accommodation needs (e.g., budget lines for interpreters, assistive technology, accessible exam rooms and tables)?	
8.4	Does strategic planning include goals related to serving patients with disabilities (e.g., measurable inclusion objectives in annual plans)?	
8.5	Do executives and board members receive training in disability rights and healthcare access (e.g., leadership development sessions or legal briefings)?	

Section 9: Healthcare Advocacy Infrastructure

Measures your organization's legal advocacy capacity, partnerships, and systems for addressing and preventing healthcare discrimination.

#	Item	Score
9.1	Does your organization have legal capacity (staff, consultants, or partnerships) to address healthcare discrimination (e.g., relationship with legal aid or disability-rights attorneys)?	
9.2	Do you provide parents with IDD plain-language know-your-rights materials specifically for healthcare settings (e.g., printed or online plain-language guides)?	
9.3	Have you developed educational materials for other healthcare providers about serving patients with IDD (e.g., training manuals, webinars, or tip sheets)?	
9.4	Do you have established processes for escalating unresolved healthcare discrimination cases to external partners (e.g., legal advocates, protection and advocacy agencies, or oversight bodies)?	
9.5	Does your organization engage in systemic healthcare advocacy and policy development (e.g., legislative comments, task-force participation)?	
9.6	Do you provide direct advocacy support for parents with IDD facing healthcare discrimination (e.g., assisting with complaints, appeals, grievances, or referrals)?	

Section 10: Reproductive and Family Healthcare

Measures equitable access to reproductive, prenatal, and family-related healthcare without coercion or discrimination.

#	Item	Score
10.1	Do you provide or refer patients with IDD to comprehensive sex education (e.g., accessible materials on anatomy, sexual health, relationships, consent, pregnancy prevention, and STI prevention)?	
10.2	Do you provide non-coercive contraceptive counseling and family planning services (e.g., offering options without pressure or assumptions)?	
10.3	Are prenatal and postnatal care services accessible and accommodating to parents with IDD (e.g., extended appointment time, plain-language materials)?	
10.4	Do you provide equitable reproductive and family-related healthcare that supports patient choice, privacy, and accessible communication (e.g., prenatal visits, emergency care, or coordination with pediatric services)?	
10.5	Do you coordinate pediatric care for children of parents with IDD when requested (e.g., helping connect to pediatricians or developmental screening)?	
10.6	Do you have protocols for supporting parents with IDD during medical emergencies involving their children (e.g., accessible communication with emergency staff)?	

How to Score

For each section, add the scores of all answered items and divide by the number of answered items (skip anything marked N/A) to get that section's average, from 0 to 3. Then average your section averages for an overall score. Find your overall score below to see your level and the matching suggested next steps.

Level	Overall Score
Advanced Level	2.5 – 3.0
Developing Level	2.0 – 2.49
Emerging Level	1.0 – 1.99
Beginning Level	0.0 – 0.99

Suggested Next Steps by Level

Advanced Level — Advanced Level (2.5–3.0)

Your organization demonstrates comprehensive healthcare services and accessibility infrastructure. Focus on leadership and innovation.

- Mentor other healthcare organizations in disability inclusion development
- Lead regional policy initiatives for healthcare accessibility
- Conduct research on innovative accommodation and advocacy approaches
- Develop and share best practices with healthcare networks
- Advocate at state/national level for healthcare rights of parents with IDD
- Publish an annual accessibility and equity report tracking outcomes
- Embed disability inclusion into all new staff onboarding processes
- Collaborate with universities or medical associations to promote disability-inclusive healthcare standards
- Refine and expand existing healthcare accessibility tools
- Develop specialized training curricula for other healthcare organizations

Developing Level — Developing Level (2.0–2.4)

Your organization has a good foundation with some gaps to address. Focus on expansion and infrastructure building.

- Enhance legal capacity through partnerships with disability rights organizations
- Develop comprehensive healthcare accommodation protocols
- Expand provider training on disability rights and communication
- Strengthen quality improvement processes for disability inclusion
- Implement systematic outcome measurement for patients with IDD
- Incorporate disability inclusion goals into annual compliance reviews
- Host recurring training series for community providers
- Establish formal healthcare advocacy protocols
- Create patient advisory councils including parents with IDD
- Enhance accessibility features and assistive technology availability
- Offer stipends for parent advisors with lived experience
- Integrate feedback from parents with IDD into policy revisions

Emerging Level — Emerging Level (1.0–1.9)

Your organization is in early stages of building inclusive systems. Focus on capacity building and foundational development.

- Establish basic legal consultation partnerships with disability rights organizations
- Develop foundational provider training on disability awareness
- Conduct comprehensive accessibility audit of facilities and services
- Build relationships with community organizations serving parents with IDD
- Implement basic patient feedback and accommodation request processes
- Identify a staff 'Accessibility Champion' to coordinate initiatives
- Participate in peer learning groups with other healthcare organizations
- Adapt TASP's plain-language materials for internal use
- Assess current barriers to healthcare access for patients with IDD
- Identify potential funding sources for accessibility improvements
- Develop basic non-discrimination policies
- Set achievable short-term goals (one new policy or training per quarter)
- Document inclusion efforts for future funding proposals

Beginning Level — Beginning Level (0–0.9)

Your organization is starting the journey toward disability inclusion. Focus on foundational planning and immediate first steps.

- Conduct comprehensive organizational assessment of disability inclusion readiness
- Develop strategic plan for serving patients with disabilities
- Identify key community stakeholders and potential partners
- Seek technical assistance from advanced-level healthcare organizations
- Apply for grants to support basic accessibility infrastructure
- Reach out to local Centers for Independent Living for consultation
- Hold introductory training using TASP materials
- Designate staff person responsible for disability inclusion initiatives
- Connect with TASP and disability rights organizations for resources
- Attend training on healthcare rights of people with disabilities
- Begin identifying patients with IDD in your service population
- Review current policies for discriminatory language or practices
- Post ADA and accommodation contact information publicly
- Schedule quarterly check-ins to track improvements

General Recommendations for All Organizations

- Provide comprehensive disability awareness training for all healthcare staff
- Establish partnerships with disability rights attorneys and advocacy organizations
- Create patient rights materials in accessible formats
- Develop healthcare self-advocacy toolkits and accommodation request guides
- Conduct healthcare access barrier identification and documentation
- Measure patient satisfaction and outcomes for patients with disabilities
- Provide healthcare navigation assistance and care coordination support
- Co-design accessibility improvements with parents with IDD
- Create advisory councils of parents with IDD for ongoing feedback
- Conduct annual reviews of accessibility and legal compliance initiatives
- Track measurable outcomes to demonstrate progress over time