Spina Bifida Patient Alliance (SBPA)

Adult Autonomy Checklist

A Guide for Achieving Adulthood and Navigating the Adult Healthcare Market

I. Medical Self-Management & Telemetry

- ☐ **Personal Health File:** I maintain a centralized digital folder or physical binder containing my complete medical history, shunt details, and past surgical summaries.
- ☐ **Appointment Control:** I independently call, schedule, and log my medical appointments.
- ☐ **Clinical Communication:** I can clearly explain my primary health concerns, baseline symptoms, and specific needs directly to a doctor without relying on a caregiver to speak for me.
- ☐ **Prescription Management:** I know the names, dosages, generic alternatives, and purposes of all my medications, and I manage my own pharmacy refills.
- ☐ **Skin & Body Telemetry:** I routinely perform daily skin checks and track changes in my physical baseline independently.

II. Insurance Literacy & Systemic Navigation

- ☐ **Policy Awareness:** I carry my insurance card daily and know whether my coverage is through private insurance, Medicaid waivers, or a managed care organization.
- ☐ **Review Tracking:** I know my annual insurance review or re-enrollment dates to avoid any sudden gaps in medical coverage.
- ☐ **Appeals & Denials:** I know how to contact my insurance provider to contest or appeal a denial for supplies, equipment, or therapy.
- ☐ **Co-pay Management:** I understand my plan's out-of-pocket costs, deductibles, and co-pays for specialist visits.

III. Daily Operational Independence

- ☐ **Supplies Logistics:** I track my inventory of daily medical supplies and place reorders at least one week before running out.
- ☐ **Emergency Protocol:** I have a written backup plan for transportation delays, power outages affecting equipment, or sudden equipment failures.
- ☐ **Directing My Care:** I can clearly interview, train, and manage personal care assistants or articulate my physical boundaries to roommates and partners.
- ☐ **Environmental Adjustments:** I can self-advocate for necessary physical modifications in a workspace, dorm room, or apartment.

IV. Local Market & Community Connections

- ☐ **Adult Specialist Mapping:** I have identified and connected with adult urologists, neurologists, and primary care providers within my regional healthcare market.
- ☐ **Vocational & Educational Resources:** I have connected with local vocational rehabilitation offices or campus accessibility centers to secure career/education accommodations.
- ☐ **Peer Networks:** I have joined regional independent living networks or local peer alliances to share lived-experience life hacks.