

## Health

*“We have two tiers of service, for rich and for poor. It would be helpful if it would be a crime to deprive care to people who need it.”*  
–Survey Comment



### What is the vision of the future for Health?

#### Quality of Healthcare

- Increased integration between providers results in better coordination and improved continuity of care.
- A team approach is used for the transition from pediatric to adult health services.
- There are improved professional standards and accountability for health professionals working with people with disabilities.
- There is better training for health professionals on working with individuals with disabilities and systems that support and incentivize those relationships.
- Health care is individualized, based on an individual’s culture and strengths, with flexibility and adaptations by providers when needed.
- Providers consider the individual, not the individual’s medical coverage, and do not deny care because of a disability.
- Insurance companies allow for choice of providers and more flexibility for time and coordination of care.
- Providers understand that the progression of age for seniors may be causing an issue rather than the disability.

#### Medication

- There is better overall management of medications including less overuse, less dependence, access to both Western and herbal medication, with information for decision-making that is accessible.
- Healthcare providers listen to individuals and their supports related to the effects and dosage of medication to find the best balance.

#### Wellness

- There is more accessible evidence-based preventative information for individuals, parents, and staff on topics like diet/nutrition, exercise, and stress management so all can work toward an environment supporting healthy choices.
- There is increased access to preventative screenings and immunizations/vaccinations.
- There is more community involvement in childcare to provide supports for working parents, including trained childcare providers.

- There are improved supports in rural Alaska for families to stay together in the community using natural supports (e.g., local churches) and technology to access health care providers.
- A holistic and comprehensive approach to health strives to improve overall quality of life through improvements to physical, social (e.g., relationships, intimacy, employment), emotional, and spiritual health.
- Physicians and other health care providers see the individual first and not the stigma of medical conditions.
- Disability is not seen as an illness, it is well known that people can be healthy and have a disability.
- There is more flexibility to use alternative medicine.

### Choice

- Individuals are involved in setting health goals, creating support plans, and making health decisions.
- Individuals and their support teams are more educated with evidence-based information, and they share responsibility for health choices.
- Strong self-advocates that are empowered to have personal control over their health and environment, including the right to learn from mistakes.
- There are more providers doing family practice and lifespan care so that individuals have more choices and are able to build quality relationships with their health care providers.
- Individuals with disabilities have the right to make choices about their healthcare and decisions about their bodies.

### Access

- Health facilities are physically accessible, information is presented in plain language, and transportation to services is readily available.
- There are more providers in key fields like dentistry, vision care, and family medicine to provide care across the lifespan.
- There is increased access to affordable quality healthcare and preventative screening/health maintenance services, where individuals are not treated differently because of disability.

### Policy & Regulations

- Policies support care-driven (not cost-driven) services that include flexibility in how needed services are funded.
- Policies promote integration of healthcare and health promotion (social/emotional/spiritual health).
- Policies support use of standard and holistic medicine, with payment and access to both.

## What are priorities for Health?

The subsection Quality of Healthcare included the main ideas from two themes: 1) Quality of Healthcare and 2) Medication. The top priority is for **coordination and continuity of care among providers** (46%). This is followed by providers are trained to work with individuals with disabilities (42%), and services are individualized and flexible (35%). Table 8 shows the total response.

*Table 8: Priorities in Quality of Healthcare*

Rank	Priority Statement	%Response
1	Coordination and continuity of care among providers	46%
2	Providers are trained to work with individuals with disabilities	42%
3	Services are individualized and flexible	35%
4	No denial of care because of a disability or medical insurance	28%
5	Team approach for transition from child to adult services	26%
6	Insurance allows for choice of providers, flexibility, coordination of care	25%
7	Providers see individuals first, not medical conditions	22%
8	Coordinated medication management	16%
9	Systems support and reward working with people with disabilities	14%
10	Improved professional standards and accountability	14%
11	Providers listen when making medication decisions	12%
12	Individuals are informed and have access to medication choices	10%
<b>Total Respondents: 269</b>		<b>100%</b>

**Note:** The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

The subsection Health & Wellness included the main ideas from two themes: 1) Wellness, and 2) Choice. The top priority is for a **whole person, quality of life approach** (66%). This is followed by a focus on wellness and prevention (54%), and for individuals and teams to share responsibility for choices in health goals, plans, and decisions (35%). Table 9 shows the total response.

**Table 9: Priorities in Health & Wellness**

Rank	Priority Statement	%Response
1	Whole-person, quality of life approach	66%
2	Focus on wellness and prevention	54%
3	Individuals and teams share responsibility for choices in health goals, plans, and decisions	35%
4	Access to meaningful activities	29%
5	Providers understand that people can be healthy and have a disability	27%
6	More flexibility for alternative medicine	25%
7	Right to learn from mistakes	21%
8	Natural and technology supports for families in rural Alaska	19%
9	Community investment in family wellness	17%
Total Respondents: 267		100%

**Note:** The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

The subsection Health Access & Policy included the main ideas from two themes: 1) Access and 2) Policy & Regulations. This was a smaller set of options and respondents were allowed to choose up to two ideas. The top priority is for **affordable quality healthcare** (50%), followed by policy supporting care-driven services (37%). Table 10 shows the total response.

**Table 10: Priorities in Health Access & Policy**

Rank	Priority Statement	%Response
1	Affordable quality healthcare	50%
2	Policy supports care-driven (not cost-driven) services	37%
3	Accessible buildings, information, and transportation	32%
4	More providers in dentistry, vision, and family practice	30%
5	Policy promotes integration of healthcare and health promotion	22%
5	Policy supports payment and access to both standard and alternative medicine	22%
Total Respondents: 266		100%

**Note:** The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

## **What strategies were suggested for Health?**

### **Strategies for Quality of Healthcare**

- Increase education in healthcare provider training programs (e.g., disability, culture, lifespan, sensitivity, myths and stereotypes).
- Provide training to reduce discrimination and improve attitudes toward elders in the healthcare system.
- Allow more flexibility so doctors can take the time they need to work with individuals with disabilities.
- Healthcare providers need to talk to individuals with disabilities about what is going on and include them in decision-making.
- Provide care in the home environment when possible and appropriate.
- Physicians should work as part of team with input from patients and family/team members.
- Increase medical case managers.
- Look for good matches of staff, supports, and doctors who can positively impact health.
- Increase research in disabilities and aging.
- Provide better screening for dementia.
- Increase access to diagnostic equipment.
- Provide cross training for hospice.
- Provide more end-of-life education, as well as grief counseling for staff, families, and peers.

### **Strategies for Medication**

- Improve medication management, including regular centralized review of medications, considering alternatives to medications, interactions, effects, and cost.
- Advocate for less medication use in foster care.
- Healthcare providers can present options, then the individual and their supports can make a team decision.
- Educate the individual, parents, team, and staff on the medications being used, the benefits and side effects, and general health maintenance.
- Provide access to a central database of medications and side effects.
- Develop practical solutions to situations needing nursing support (e.g., insulin injection, anticonvulsants, suppositories).

## Strategies for Wellness

- Utilize Healthy Families America (or similar programs).
- Utilize the Wise Women Program from the Centers for Disease Control & Prevention (CDC) (e.g., prevention/screening for heart disease and stroke for the underinsured).
- Provide parenting classes specific to parents with children with disabilities.
- Create evidence-based wellness programs for parents, staff, and individuals (e.g., nutrition/diet, exercise, stress management).
- Allow people to choose a faith-based approach.
- Support the family unit to meet the needs of children.
- Provide resources for respite.
- Promote volunteering (e.g., Big Brothers/ Big Sisters, Partners programs).
- Use a holistic approach to transition and discharge planning.
- Promote inclusion in sports, clubs, and drama.
- Include mental health as component of total health plan.
- Provide training and information on behavioral supports.
- Provide access to resources to enhance relationships to support social/emotional health.
- Use talking circles to reduce stress and increase mental health, allowing children to feel honored, to learn from peers, and to normalize.
- Provide access to sex education for individuals with disabilities, explain hormones and what it means for the individual.
- Provide developmental appropriate support for life stage transitions.
- Provide education for individuals on how to not be a victim of abuse, neglect, and financial exploitation.
- Ensure meal programs provide healthy choices; consider local produce, fresh and dried fruit.
- Increase access to health clubs.
- Focus more on overall quality of life and individual goals and choices to improve health.

## Strategies for Choice

- Reduce institutionalization by promoting social/physical/emotional wellbeing.
- Make tools available for motivation/education, which explain the health risks and benefits of choices.

- Provide a centralized scientific evidence database on a State website with information on diseases/treatment concerning development disabilities.
- Provide education in healthy choices (e.g., eating right, physical activity, going to the doctor, hygiene), and provide more accessible tools for providers and parents in how to teach these skills.
- Provide access to information on contraceptives, including their benefits and risks.
- Provide training in creating a Personal Wellness Plan.
- Provide access to information and services to manage life-changing issues (e.g., dementia, Alzheimer's).
- Support Health Navigators.
- Include Direct Service Providers and natural supports in planning meetings.
- Liaison to help families communicate (discuss options).
- Encourage transparency of information about choices related to medical procedures.
- Use role models to model healthy choices and healthy decision-making.
- Involve kids early so they understand their own medical needs.
- Provide self-advocacy training.
- Provide education about individual rights.
- Provide information for families and care providers to navigate when choices conflict with safety.
- Use more of a team approach in patient advocacy, where the team decides what is best. Examples
  - Writing letters to insurance companies
  - Making phone calls needed for care
  - Fighting with Medicaid
  - Hospital stays
- Use Assistive technology to increase the ability of individuals to communicate their choices.

### Strategies for Access

- Use technology to increase access (e.g., rural communications)
- Provide interpreters.
- Ensure wheelchair accessibility in health facilities.
- Allow for doctor home visits.
- Fix technology gaps.



- Stop using “rural” as an excuse.
- Make sure people with intellectual and developmental disabilities have access to mental health services.
- Ensure people know where to go to find out about available resources and services (e.g., itinerant specialists).
- Find resources to help make health facilities accessible.
- Ensure bus routes go to commonly used health facilities.

### Strategies for Policy & Regulations

- Promote a national health insurance policy for a tax credit.
- Reimburse physicians for various types of services (i.e., not just for face-to-face visits).
- Redefine disability in policies so that disability doesn’t mean healthcare.
- Mandate pre-natal check-ups for people using publicly funded services.
- Lower eligibility requirements for early intervention.
- Ensure Medicaid/Medicare covers:
  - Dental services
  - Mental health services
  - The cost of nursing services required for medication administration
  - Preventive healthcare
  - Alternative medicine and therapies (e.g., light therapy for Seasonal Affective Disorder)
- Provide better coverage and access for people in rural communities by Medicaid/Medicare (e.g., travel problems, no flights, can’t drive).
- Address Medicaid barriers like service codes.
- Fund a forum for people to talk about and receive training in health promotion.
- Provide for more oversight and support for nursing staff to manage stress and to deal with loss when patients die.
- Provide debt forgiveness programs for providers that make serving individuals with disabilities a priority.
- Increase providers in dentistry, vision, family practice, behavioral health, and other specialties, and provide incentives for them to serve people with disabilities.
- Reduce disincentives and increase incentives for more providers to accept Medicaid/Medicare.
- Ensure insurance compensates providers fairly and in a timely manner.