Introduction

Children with developmental disabilities are living longer due to improved medical technology and healthcare delivery. Consequently, the population of adults with disabilities has increased. Living well into their thirties, forties and sometimes fifties and still having parental caregivers, they have aged out of pediatric care, although ultimately still require specialty care to ensure continued health and basic function. It is common for these individuals to rely on their pediatrician and pediatric physical therapist for services, yet pediatric facilities are not appropriate for adults. The equipment is not tailored to them, they are not surrounded by their peers and the clinical staff is often not skilled in treating their unique, age-specific needs.

Clinical Practice Guidelines

According to the Institute of Medicine (2011), clinical practice guidelines are “recommendations that are intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.”

The Sheltering Arms AWDD CPG addresses the following areas:

- Prevalence and aging process in persons with developmental disabilities;
- Evidence for PT, OT, SLP and PM&R intervention;
- Assessment tools and outcome measures; impairment identification and intervention; ancillary and community-based services.

Clinical Integration

- Use of appropriate outcome measures during assessment
- Identify impairments specific to this population.
- Guide intervention approach and differentiate between adaptive and remedial approaches.

Expansion Goals

- Develop support groups for patients and caregivers.
- Fitness memberships to promote healthy lifestyle and maintain gains attained in therapy.
- Augmentative and Alternative Communication evaluations.
- Interagency collaboration within the community to establish networks that will assist in the lifetime care for these patients.
- Develop guidelines for care transitions to ensure appropriate and timely access to services.
- Research to validate outcome measures for this population.

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How are the guidelines developed?

1. Define intervention
2. Collect evidence
3. Synthesize results
4. Make recommendations
5. Grade strength of recommendations

The CPG Evolution

- Literature review.
- Attendance of national conference.
- Core treatment team established.
- Creation of multi-disciplinary CPG.
- Document continuously monitored and edited by core team to incorporate most recent literature.
- Eventually, use of program outcomes to refine CPG.

References

