Challenges to continuum of care in the autistic population during transition years.

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Background

The prevalence of Autism Spectrum Disorders in children is 11.3 in 1000. Early diagnosis and intervention helps with better outcomes. Access to specialized services, especially in rural areas is limited. Children in rural areas do not have access to well- trained professionals to help with special needs. Rural children are diagnosed later compared to urban children. Caregivers have identified the need for better quality educational and interventional services. Limited literature is available on effective utilization of community services in autism overall and especially in Kentucky. Parent education and skills decreases their anxiety and mental health problems.

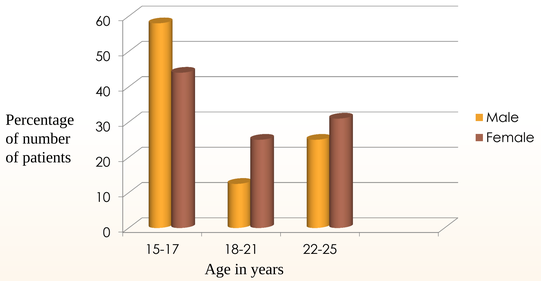
Objectives

1. To look into the differences in availability of community based services between rural and urban areas and identify barriers to accessing them for children with autism.
2. To see if access to services differed between females and males.
3. Recommendations to deal with barriers to care and better utilizing services during transition years.

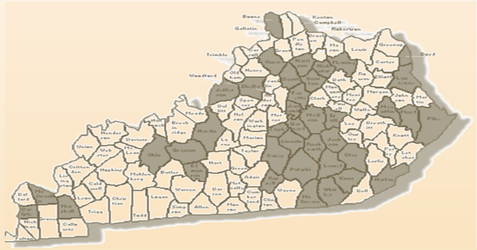
Methods and Materials

Information on 40 patients aged 15 - 25 years diagnosed with autism was collected by provider surveys and retrospective chart reviews in a university based outpatient clinic setting. Special emphasis was placed on availability of school based resources (therapeutic services including speech, occupational therapy, physical therapy, IEP, behavioral accommodations, and vocational rehabilitation). Community services (access to specialized therapists, home based interventions, community integration, assisted living facilities and access to psychiatrists) were assessed. Legal involvement like juvenile arrests for behaviors were also looked into. Fisher's exact test was used to assess statistical significance.

Age Sex Distribution



Patient distribution- KY



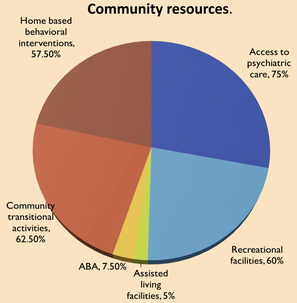
Rural Vs Urban access to services

Services	Rural	Urban
Therapy at schools	38%	47.6%
IEP, Behavioral accommodations	65%	60%
Access to psychiatric care P=0.0005	52.3%	95%
Vocational Rehab	33.3%	25%
Recreational facilities	57%	60%
Assisted Living	4.7%	5%
ABA	4.7%	10%
Community transitional activities	61.9%	60%
Home based behavioral interventions	42.8%	70%

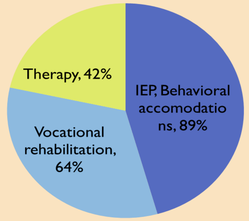
Gender differences in accessing services

Services	Female	Male
Therapy at schools	46%	44%
IEP, Behavioral accommodations	61%	63%
Access to psychiatric care	92.3%	66.6
Vocational Rehab	30.7%	29.6%
Recreational facilities	75%	50%
Assisted Living	7.6%	7.6%
ABA	0	11.1%
Community transitional activities	75%	54%
Home based behavioral interventions	61.5%	55.55%

Community resources.



School Services.



Results

Among the 40 patients, 52.5 % belonged to rural areas and 47.5 % to urban areas. There were 24 males (60%) and 16 (40%) females. Rural population had availability to 39.6% of the studied resources compared to urban population (50.9%). Rural patients had limited access to physician services (p=0.0005). No significant gender differences were noted in access to services. There were less home based behavioral interventions and access to assisted living facilities. Specialized therapeutic services for autism like ABA, community integration services were limited. 12.5 % were school drop outs as they were pulled out because of few school resources especially therapeutic services, and 10% were involved in legal problems.

Conclusions

Overall there was a decreased availability of specialized community resources with significant disparity between rural and urban areas. Specialized school services and community therapeutic services were scarce. Assisted living facilities and vocational rehabilitation services were underutilized leading to more caregiver burden. . Caregivers reported frustrations with accessing services as kids grew older. Most children had access to public education with some behavioral accommodations.

Recommendations

1. Improve provider-school and provider -legal communication and public education.
2. Enhance parent advocacy to better utilize existing resources.
3. Increase awareness about existing resources especially in rural areas.
4. Enhance telepsychiatry opportunities to reach the underserved areas.
5. Increase funding for ancillary services.
6. Community education on handling crisis.

Limitations

1. Small study sample.
2. Non generalizable patient population as they are patients mainly seen in a tertiary care setting.
3. Memory bias.

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References

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