Demand for national policy for consistent and effective support for children with learning disabilities

DR. FAUZIA KHAN (Maharashtra): Mr. Deputy Chairman, Sir, the children with learning disabilities are not small in number in this nation. Although this momentous population of children with learning disabilities or intellectual disabilities face significant educational barriers and challenges, the National Policy on Education speaks very little about it. This is an area which does not deserve to be neglected, and most developed countries in the world have minutely laid out policies for children with learning disabilities.

In our country, despite their legal recognition under the revised Persons With Disabilities Act, 2016, enormous issues still remain. Major fundamental issue is lack of standardized and consistent assessment tools and diagnostic protocols that leads to imprecise data on the prevalence of learning disabilities. If correct data is received, the sheer numbers of these children could be absolutely astounding. No standardized school-level screening exists. Schools depend on teachers, observations and judgments for referrals. This often results in unidentified children who are mislabled as slow-learners, lazy or having a bad attitude, and thus end up as dropouts and failures in life, and this is criminal. Current diagnostic tools are either inadequate or ill-suited to the Indian environment.

To address these challenges, there is a pressing need for early screening, but regarding early screening, these schemes have limitations. Strengthening learning environments and enhancing teachers' sensitization and teacher training are the vital steps. For training, screening, support, the existing infrastructure of ASHA and Anganwadi workers and teachers are vital steps. A clear referral policy could be made from ASHA and Anganwadi workers and teachers to specialized educators and clinical psychologists. This is important for comprehensive diagnosis. Currently, the absence of a National Policy on Learning Disabilities leads to varied State-level strategies. A national policy would standardize identification, intervention and would support efforts nationwide.

(MR. CHAIRMAN *in the Chair*.)

Professional recommendations and strategies that could be designed for schools are: flexible teaching methods, individualized learning plans, multi-sensory techniques, assisted technologies, like speech-to-text software, digital platforms for

personalized learning, supporting classroom environments with positive reinforcement, peer support programmes and workshops for parents on effective home support. If properly assisted, these are the children who can show light to the world like Albert Einstein, who was also recognized as a child with learning disability. Thank you, Sir.

MR. CHAIRMAN: The following hon. Members associated themselves with the matter raised by Dr. Fauzia Khan: Shri Derek O'Brien (West Bengal), Shrimati Priyanka Chaturvedi (Maharashtra), Shri A.A. Rahim (Kerala), Dr. V. Sivadasan (Kerala), Dr. Sasmit Patra (Odisha), Dr. John Brittas (Kerala), Shri M. Shanmugam (Tamil Nadu), Shrimati Jebi Mather Hisham (Kerala), Shri Jawhar Sircar (West Bengal), Dr. Kanimozhi NVN Somu (Tamil Nadu), Shrimati Mamata Mohanta (Odisha), Shri Niranjan Bishi (Odisha), Shrimati Mahua Maji (Jharkhand), Shri R. Girirajan (Tamil Nadu), Shrimati Jaya Amitabh Bachchan (Uttar Pradesh), Sant Balbir Singh (Punjab), Shri M. Mohamed Abdulla (Tamil Nadu), Ms. Dola Sen (West Bengal) and Shri Jose K. Mani (Kerala).

Concern over children suffering from Spinal Muscular Atrophy (SMA), a rare genetic disease. Shri Sanjay Singh.

Concern over children suffering from Spinal Muscular Atrophy (SMA), a rare genetic disease

श्री संजय सिंह (राष्ट्रीय राजधानी क्षेत्र ,दिल्ली): सभापति जी, आपका बहुत-बहुत धन्यवाद कि आपने मुझे एक अत्यंत गंभीर और संवेदनशील विषय पर अपनी बात कहने का मौका दिया है।

मान्यवर, मैं इस मुद्दे पर माननीय स्वास्थ्य मंत्री जी का और इस सदन का ध्यान आकर्षित करना चाहता हूं कि यह एक ऐसी अत्यंत दुर्लभ और गंभीर बीमारी है, जिससे हिंदुस्तान के करीब-करीब 20-25 हज़ार बच्चे प्रभावित हैं। महोदय, SMA 0,1,2,3,4 के रूप में कई स्टेज की बीमारी होती है। Spinal Muscular Atrophy, जिसमें अगर किसी बच्चे को इंजेक्शन न लगे, तो उसकी 1 साल की अवस्था के नीचे भी मृत्यु हो सकती है, ढाई साल की अवस्था तक भी मृत्यु हो सकती है और 10 साल, 12 साल एवं 15 साल तक पीड़ा में रहकर भी उसकी मृत्यु हो सकती है।

महोदय, यह एक लाइलाज बीमारी है। इस बीमारी का जो इलाज है, वह बहुत महंगा है और इसको कराना किसी गरीब आदमी के लिए संभव नहीं है, किसी सामान्य परिवार के लिए संभव नहीं है। मान्यवर, इसमें 16 करोड़ रुपये का इंजेक्शन लगता है। हमने और बहुत सारे लोगों ने कुछ बच्चों के लिए सामूहिक रूप से प्रयास किया है। हमारे माननीय सांसद संजीव अरोड़ा जी यहाँ बैठे हुए हैं, उन्होने और हम सभी ने मिलकर उनके लिए प्रयास किया है।